

CONSTRUCTING UNDERSTANDINGS,  
RENEGOTIATING LIVES:  
WOMEN'S EXPERIENCES OF  
ARM MORBIDITY AFTER  
BREAST CANCER

A Thesis Submitted to the  
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By  
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## ABSTRACT

This research explores women's experiences of arm morbidity after breast cancer. Biomedical knowledge about arm morbidity is limited and often unclear, and there has been even less focus on the health issue from a sociological perspective. While studies do exist about the experiences of arm morbidity, more investigation is required to realize its influence on the daily lives of breast cancer survivors. The purpose of my research is to convey constructed meanings of arm morbidity experiences to indicate the impact it has on women's everyday lives.

Qualitative data were collected via twelve in-depth, semi-structured interviews, as six participants were each interviewed twice. The interviews were focused on a broad range of themes in order to create a comprehensive understanding of the women's experiences of arm morbidity in their daily lives. Phenomenological and feminist approaches were both used to guide the research process and analyze the data, and a range of sociological ideas also informed the analysis, such as chronic illness, disability, gender roles, and embodiment.

The illness narratives produced two broad areas relevant to the women's experiences. The first major topic involves the meanings directly related to experiences of arm morbidity as a health issue, and is divided into four themes: 1) experiencing bodies with arm morbidity, 2) treatment, 3) information and knowledge, and 4) support. The second major topic involves understandings of arm morbidity as it affects the women's lives, in which three themes emerge: 1) changing abilities and adjusting roles, 2) identity and health, and 3) the influence of illness on approaches to life.

As existing research is sparse, the women's narratives present a new level of depth to understandings of arm morbidity experiences that does not exist in current literature. It is evident that more study about arm morbidity is necessary to construct important knowledge and benefit both biological and sociological understandings of this survivorship issue.

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## CHAPTER ONE

### INTRODUCTION: ESTABLISHING THE FOUNDATION

Illness, and especially chronic illness, is precisely that kind of experience where the structures of everyday life and the forms of knowledge which underpin them are disrupted. (Bury, 1982, p. 169)

#### 1.1 Contextualising the Research

As rates of breast cancer incidence remain high, yet medical developments create more positive results in treatment outcomes, there will be an increasing proportion of the population who will have to deal with survivorship issues. It is expected that 22,400 women will be diagnosed with breast cancer in Canada in 2008, and although the expected mortality rate is 24%, breast cancer mortality rates have been decreasing since the mid 1980s (Canadian Cancer Society, 2008). Because of this, more women will be faced with survivorship issues, and more knowledge needs to be constructed to understand the biological and social ramifications that impact women after breast cancer.

##### *1.1.1 Biomedical Perspectives*

My research is focused on the experiences of women with arm morbidity, which is an issue that many breast cancer survivors face as a result of the surgery, lymph node dissection, and radiation involved in treatment (Brorson, 2000; McWayne & Heiney, 2005). Pain, lymphedema, and a limited range of motion can arise in the arm, hand, and upper body following breast cancer treatment. Lymphedema is considered to be the most troublesome result of treatment (Brennan, 2001), and occurs when lymph nodes are removed or damaged (Radina & Armer, 2001). An impaired lymphatic system causes lymphatic fluid to accumulate in the arm or trunk and causes swelling, and this condition can begin at any point following treatment. There is little information about lymphedema prevention, but more extensive treatment, especially surgery and lymph node removal, or having a postoperative infection that requires antibiotics, are risk factors that increase the possibility of lymphedema in breast cancer survivors (Hayes, Janda, Cornish, Battistutta, & Newman, 2008). While lymphedema is considered to be the most severe arm morbidity issue and has been researched qualitatively (e.g., Collins, Nash, Round & Newman, 2004; Johansson et al., 2003), pain and a limited range of motion are also problems that can affect women. There is much variation in estimated rates of arm morbidity after breast cancer, and there is not consensus about effective treatments for

lymphedema or pain (Brennan & Miller, 1998; Marcks, 1997; Stevens, Dibble, & Miaskowski, 1995). In other words, arm morbidity after treatment can be quite serious and have major implications for women's lives, but the knowledge about it is limited and unclear.

### ***1.1.2 Sociological Perspectives***

Health issues have recently received more attention from the discipline of sociology, as they are no longer considered to be solely biomedical concerns. Understandably, there has been some resistance. Biomedical knowledge has traditionally been portrayed and perceived to be truthful and objective, so the social nature of health has been ignored or denied (Fosket, 2000, p. 18). The medical model of health has approached the body in its normal or abnormal state, but does not account for the influence society has on experiences of health, or the reverse. Understandings in sociology suggest that issues of health are socially constructed, ever-changing, and exist long before they are perceived as problematic (Brown, 2000), which indicates that health is relevant to a particular context. Broadly, sociological theory focuses on a number of central issues relevant to health: the meaning of social action; institutional structures and context, as well as their connection to social agency; the problem of social order; and the disruption of social relations and social exchange caused by social processes and circumstances (Turner, 1987, p. 3). This focus on the role of the social world on health and illness frames the issues as public concerns, rather than individual troubles (Weitz, 2004, p. 5). In this sense, we construct ideas of health, create experiences of health, and are all responsible for the implications that follow.

Despite the increasing attention on health in sociology, little research has been conducted about the sociological consequences of arm morbidity in the daily lives of women, so the focus of my study is to construct a broad yet thorough understanding of the experiences of women with arm problems after breast cancer treatment. I use a contemporary phenomenological approach guided by feminist theory to direct analysis of the data, which was collected from two qualitative interviews with six women experiencing arm morbidity issues. In the women's explanations of their health and their lives, two general topics emerge that divided the narratives into those themes that are very clearly specific to their experiences of their health and illness, as the women manage

their changed bodies, and those that are specific to their experiences of their lives, as the women experience their social worlds in changed bodies.

In the breast cancer literature, there is acknowledgement that, while women's experiences are unique, there are also similarities that depict the social nature of the biomedical issue. As Potts (2000) states, "there is a commonality in [breast cancer] narratives, in the stories and the subject positions presented: women's experiences of breast cancer is both personal and private, and collective and connective" (p. 103). This can also be said of the experiences of arm morbidity, and is evident in the themes that emerge in this research. The women's experiences are unique, and their understandings are personal, but there are connections between the narratives. There are a number of sociological themes that are raised in the findings, and the women's knowledge has the potential to further understanding about arm morbidity, the healthcare system, and the social world that we live in. Issues of gender roles, identity, disability, chronic illness, knowledge translation, support, and embodiment are some of the major themes involved in experiences of arm morbidity.

While there has been a "shift towards the inclusion of perspectives expressed by women with breast cancer themselves [in the literature], the emphases still tend to be of the expert opinion bestowed upon the 'ill-informed'" (Potts, 2000, p. 3). In the area of arm morbidity, there has been a lack of attention and information in general, biomedical and otherwise, so my research represents a step towards creating a more thorough picture. Moreover, it is important to hear the experiences of patients themselves and give them a voice, because cancer "is as much a matter of feeling as it is of thought" (McKenzie & Crouch, 2004, p. 141).

The women's experiences are realized in the illness narratives that they conveyed during the interviews. According to Hinchman and Hinchman (1997), a broadly accepted definition of narrative "is a discourse that consists of a sequence of temporally related events connected in a meaningful way for a particular audience in order to make sense of the world and/or people's experiences in it" (p. xvi., cited in Bell, 2000). The women share their experiences of arm morbidity by presenting the meanings they have constructed, and in this way create knowledge about the effects of arm morbidity on daily life.

The gap in research about the experiences of women with arm morbidity after breast cancer suggests that constructing knowledge is absolutely essential to raise awareness and bring understanding to a largely unknown, often misunderstood health issue. There has been little knowledge created about experiences of arm morbidity, and “[w]hile much research has been completed on breast cancer, few researchers have explored women’s experiences of life after breast cancer utilizing feminist and phenomenological approaches” (Thomas-MacLean, 2005, p. 200). Breast cancer incidences remain relatively unchanged, yet survivor rates are improving, so more and more women will experience arm morbidity issues after treatment. However, there is not adequate information to support them. It is important to build understanding about the impact of arm morbidity in the daily lives of women, as the social experiences of health are a major part of the illness experience. By focusing on the narratives of women living with arm morbidity issues, a comprehensive understanding of the complexities of the experiences can be discovered.

Thus, I aim to further the knowledge of arm morbidity experiences by exploring how women’s lives are impacted by the arm problems they encounter after breast cancer treatment. I take a sociological approach to health, and focus on the interconnection of health and illness to experiences of the body and daily life. Through the women’s narratives, their understandings and experiences of arm morbidity are conveyed, and inform the analysis of the research, which is directed by both phenomenology and feminism. The understandings of arm morbidity experiences have been constructed to create more knowledge about health, arm morbidity, and the social world in which we live. The narratives of the women raise taken-for-granted assumptions that we hold about health, the body, and life in society, and present many valuable insights that are important to understanding this specific health issue, and to understanding society in general.

## **1.2 Purpose, Objectives, and Thesis**

My research represents one step towards creating a more thorough and complex understanding of the issues women encounter in experiences of arm morbidity after breast cancer. Relevant sociological domains include disability studies, chronic illness, and experiences of breast cancer, but the literature specific to arm morbidity experiences

is minimal, and leaves many gaps in knowledge. Constructing knowledge about the sociological implications of this survivorship issue pushes health beyond the biomedical field and presents a more comprehensive portrayal of women's experiences after breast cancer treatment. Exploring arm morbidity sociologically uncovers the continuous meaning-making that occurs as individuals interact with their health, in the social world, and this reveals much about the experiences of arm morbidity, as well as the world we live in, including themes of identity, embodiment, gender roles, and knowledge translation in the healthcare system.

The major aim of this research is to explore women's experiences of arm morbidity after breast cancer and create a thorough understanding of the impact it has on their daily lives. I focus on a wide range of areas in daily life to construct an overall understanding of its consequences, including the family, formal and informal work, experiences of the body, knowledge of health, and identity. More specifically, my objectives are:

- To explore what effects arm morbidity has on women in the areas of identity, gender roles, and the family in order to understand the social experiences of disability.
- To explore what knowledge breast cancer patients have about arm morbidity in order to understand what role knowledge and knowledge transfer are playing in the lives of patients, and how they are being managed in the healthcare system.

It became clear, as the research process continued, that the disruption caused by arm morbidity shakes the taken-for-granted assumptions that the women have about their health and their lives prior to the arm problems, which leads them to engage in continuous renegotiation in their daily lives as they manage their health and their lives, experience changed bodies, live with new limitations, and adjust roles and identities.

As a result of this renegotiation of their lives, the women's narratives raise many sociological themes that are related to other areas of study that can benefit from the understandings of arm morbidity experiences, such as areas of disability, chronic illness, gender roles, body image, identity, and experiences of the healthcare system. Gender, identity, social roles, and interactions influence and are influenced by health. These are

not compartmentalized and managed separately, but are interwoven and complex. My research aims to construct knowledge about those complexities in experiences of arm morbidity, as understanding is very much lacking. My work has implications for research, the healthcare system, support systems, and breast cancer patients, and can benefit women who are encountering similar experiences with their health, the healthcare system, and others in their lives. The remainder of the thesis presents the knowledge created from the women's narratives about experiences of arm morbidity.

### **1.3 Outlining the Thesis**

I have introduced the focus of my thesis in Chapter One, as well as its purpose, objectives, and rationale. In Chapter Two, I introduce the relevant literature that supports a thorough understanding of the issues involved in experiences of arm morbidity. Major topics I explore are health and sociology; disability studies; gender, identity, and health; and knowledge and empowerment. The literature in each of these areas is rich and abundant, but the ideas presented are especially relevant to sociological understandings of arm morbidity. I conclude the second chapter by making connections between the major areas of interest, to weave the ideas together in order to establish a foundation for the understandings of the experiences of arm morbidity that follow. In Chapter Three, I discuss the methodology and research methods I used to conduct the research. To thoroughly explain the process, I include a discussion about the methodologies applied to this research; the research design used; an explanation of the selection and recruitment of the participants, including a change in plans that occurred during the process as a result of that recruitment; ethical considerations relevant to this research; the data analysis process; and the focus required to conduct meaningful research. In Chapter Four, I introduce the women who participated in this research and shared their illness narratives with me to create an understanding of the impact of arm morbidity on daily life. In Chapter Five, I present the findings and discussion that result from the exploration of the women's experiences with arm morbidity. The first section of the chapter focuses on the women's experiences of their health, and includes four themes that emerge from the narratives: experiencing bodies with arm morbidity; treatment; information and knowledge; and support. The second section of Chapter Five involves the women's experiences of arm

morbidity as they manage their lives in the social world, and includes three themes that come out of the women's experiences: changing abilities and adjusting roles; identities and health; and understandings of health as they influence approaches to life. Finally, I discuss the implications and conclusions that emerge from the research, to summarize how the women's experiences of arm morbidity address health, disability, embodiment, and life in the social world.

**CHAPTER TWO**  
**BUILDING BLOCKS FOR ARM MORBIDITY RESEARCH:**  
**RELEVANT LITERATURE**

Health is about much more than body parts, their function, and treatment. And women's health is about much more than particular reproductive organs and secondary sex characteristics. Health is about whole people located in specific places, times, and relations. It is defined by, and shaped in, social, psychological, and economic environments and relationships. Bodies and minds, then, cannot be understood apart from their history and culture. This means that health is a social issue and a social contract rather than simply a medical and technical problem to be addressed by experts. (Armstrong, 2001, p. 169).

Breast cancer experiences increasingly involve survivorship issues, as incidence remains high but developments in treatment continue to produce more positive results. Arm morbidity is an issue that impacts the lives of many women after breast cancer treatment, as new physical realities develop. There is discrepancy in the literature as to expected incidence of lymphedema; some suggest 12 to 28% of women will experience lymphedema after breast cancer treatment (Vignes, Arrault, & Dupuy, 2007), but while reports range from 2 to 83%, the accepted incidence rate is approximately 30% (Hayes et al., 2008). In addition to lymphedema, issues of pain and a limited range of motion can also occur post-surgery. Problems arise because of the aggravation to the body caused by surgery (Stanton et al., 2001), and can begin at any point after treatment. This indicates that it is an important issue to study, yet there remains limited knowledge about the condition. There is still a lack of biomedical understanding of lymphedema, creating uncertainties such as the level of activity breast cancer survivors can and should engage in (e.g. Harris & Niesen-Vertommen, 2000), and it is evident that there is a lack of information about arm morbidity in general. The biomedical knowledge is still very ambiguous, and even more unstudied are the experiences of breast cancer survivors living with arm morbidity.

In this review of the literature, I focus on key ideas involved in understanding the social experiences of women with arm morbidity after breast cancer. I draw upon several disciplines, including sociology, psychology, biomedicine, and gender and women's studies. The first issue I discuss is the role of sociology in creating understandings of health, which expands the focus from solely the biomedical to include the social factors involved. The second area I explore is experiences and understandings of disability. I



then turn to ideas about identity, gender, and the roles individuals fill in their lives, as they relate to health. Finally, I review ideas of knowledge and empowerment important to understandings of health. Because context affects health issues, I will look at ideas specific to health in Canada in this literature review.

## **2.1 The Sociological Gaze: Health as a Social Construction**

A review of the literature discussing health and experiences of health indicates a broad range of disciplines and a variety of issues that have been explored. A large proportion of the literature about health, including issues of breast cancer and arm morbidity, is biomedical knowledge: This type of knowledge has traditionally been associated with truth and objectivity, while the social and constructed qualities of knowledge have been downplayed (Fosket, 2000, p. 18). Nonetheless, sociological knowledge about biomedical issues should not be discounted, as the impact of arm morbidity on the daily lives of breast cancer survivors may be as significant as the actual physical impairment. Shifting the focus to include social factors and experiences related to health will not only allow for a more complete, thorough understanding of health, but will also equip individuals and groups to better manage changes in health and the resulting outcomes.

Sociological approaches to health also highlight various aspects of society. For some theorists, health is produced by interactions within society, rather than naturally, and some look at it as a moral status created by those with power who define what is undesirable (for example, Lorber, 1997; Weitz, 2004; White, 1991). Turner (1987) suggests that a theory of health and illness needs to look at 1) the illness experiences of individuals; 2) the social nature of the ideas of health which are created by a professional group and classifies and regulates the population; 3) the organization and positioning of healthcare systems as they relate to other broad social spheres; and 4) the issue of inequality in societies, and among societies (p. 4). Major theoretical perspectives are applied to address those concerns to varying degrees, with each using a different focal point to understand health. Some use a structural approach, which is founded on Parsons's idea of the sick role (Bury, 1982; Turner, 1987; Weitz, 2004), where focus lies on the authority of the medical profession in controlling deviance (White, 1991). Critical

approaches focus on health and medicine in relation to particular factors in society: A Foucauldian perspective focuses on health and medicine in relation to the development of modernity (Turner, 1987; S.J. Williams, 2006); a Marxist analysis takes into account the development of capitalism; and a feminist position focuses on patriarchy (White, 1991). The social constructionist perspective links class, patriarchy and modernity to explore how the interconnection of these elements creates understandings of health (White, 1991, p. 2), while social interactionist approaches focus on how individuals live out their health and illness as they interact in society (Bury, 1982).

Many sociological explanations are constructed relative to the medical model of health, which takes a biological approach that recognizes health as a clearly defined, unbiased state of physical normalcy (see Brown, 2000; Weitz, 2004). Weitz (2004) explains that the basis of the medical model lies in the explanation of illness: that it is a deviation from the norm; straightforward and common; the product of distinctive biological factors; comparable to a machine breaking down; and medically defined and treated using a neutral, scientific procedure (p. 124). The many critiques of the medical model often focus on its narrow view of health (i.e. White, 1991), taking issue with the lack of recognition of social factors that both define and impact health (also see Armstrong, 2001; Brown, 2000; Turner, 1987). Criticisms led to the sociological approach to health, which rejects the idea that definitions of health and illness are fixed and objective (Brown, 2000), and looks rather at the social factors that define health and influence experiences of it within a certain context. This literature clarifies that disease may refer to a clearly defined biological problem (see Bell, 2000; Eisenberg, 1997; Weitz, 2004), but health and illness are social constructions that are subjectively created in a particular society which has defined what healthy is, and what illnesses are (Kleinman, 1988; Lorber, 1997; Weitz, 2004). Health, using this perspective, is considered to be a constructed standard of normalcy, and illness refers to individuals' social experiences that are shaped by the society's ideas of health. As understandings of health continue to be explored, medically and sociologically, Thornton (1998) proposes that we consider a "development of awareness" rather than the duality of health and illness, since illness is simply part of being human, and the constructed nature of health is problematic (p. 120). In this proposed model, health is an open-ended concept that will

continuously evolve as people grow and gain understanding (Thornton, 1998). In the literature, it is clear that ideas of health and illness are not explicit or without tensions, as models and definitions come under scrutiny because of the variety of factors involved in health, and within the sociological model, understandings of health and illness create different foci and accentuate diverse issues, such as inequality.

There are a number of factors that influence inequalities and power imbalances in society. Inequalities are experienced by individuals and groups who do not fit into the ideal of health, and those who experience illnesses defined using standards imposed by powerful groups (Armstrong, 2001). Major areas of focus explaining different rates of health, and the variety of experiences of health and the healthcare system, include research focused on issues such as poverty (e.g., McCally et al., 2000; Ram, 2006); education and the workplace (for example, see Brand, Warren, Carayon, & Hoonakker, 2007; Lipscomb, Loomis, McDonald, Argue, & Wing, 2006; Olafsdottir, 2007); and ethnicity and cultural differences (e.g., Browne, 2007; Kreps, 2006). Gender inequalities that translate into different health experiences have also been explored, and although there is variation from society to society, there is some indication that changes in groups where there has been progress are still not enough to create improvements in health (Backhans, Lundberg, & Mansdotter, 2007).

As a result of the continued gender inequalities, a focus on the impact gender has on health has gained increasing attention in the literature. Medical issues specific to women, such as reproductive health and breast cancer, are areas where a gendered focus has received much attention. However, it is only recently that a gendered approach has been taken beyond the biomedical. For example, the social positioning of women, the availability of and access to resources, particular cultural traditions, hazards people may face, and the roles filled in public and private spheres are some of the characteristics that will affect women's health (Armstrong, 2001; Kabeer, 2004). There is also recognition that the construction of women's health often differs from constructions of men's health (see Armstrong, 2001), and the literature describes issues related to the influence of societal norms and values on the experiences of illness for women: Research includes the study of perceptions and experiences of changing bodies (e.g. Bailey, 2001; Charmaz, 2002; Thomas-MacLean, 2004); the beauty norms in society that relate to health (see

Charmaz, 1995); the impact health and illness have on the social roles people enact in their lives (e.g. Walsh, Manuel, & Avis, 2005; ); and the effect illnesses have on women's relationships (see Bolger, Foster, Vinokur, & Ng, 1996; Ferrell, Smith, Ervin, Itano, & Melanco, 2003.).

Recognition that illness creates disorder in many areas of life has led to research focusing on the consequences it has. Chronic illness is a specific health issue that receives much attention in the literature because, while it may have an impact on life, its permanence does not allow those affected to assume a return to health as it was prior to onset. It “shakes earlier taken-for-granted assumptions about possessing a smoothly functioning body”, so it imposes upon individuals' lives and creates confusion about self and identity (Charmaz, 1995, p. 657). To create an understanding of this effect, Bury (1982) describes chronic illness as a biographical disruption, as it disturbs commonsense ideas and behaviours and creates the need for individuals to reconceptualise their identities. In other words, chronic illness is the sort of event that causes a disruption of the structures of daily life and the forms of knowledge that support them (Bury, 1982, p. 169). He found that biographical disruptions brought on by illness led individuals to reexamine their lives and their understandings of the world in order to maintain a sense of identity (Bury, 2001). This concept has been examined by many, such as S.J. Williams (2000), who discusses biographical disruption and biographical revision, and has been related to many explorations of illness, such as women's experiences of chronic fatigue syndrome and fibromyalgia (Asbring, 2001), and the processes people use to adjust to illness (Sharpe & Curran, 2006).

Illness narratives challenge traditional knowledge models by maintaining that there are multiple truths about a changing world created by socially and historically located knowers (Bell, 2000, p. 131), and individuals' narratives are often constructed when they make meaning of unanticipated or seemingly unrelated events (Bell, 2002). Arthur Frank is one prominent narrative theorist (see, for example, *The Wounded Storyteller*, 1995), whose work creates understanding about “how people go about making something of themselves” (Werner, Isaksen, & Malterud, 2004, p. 1042). This is beneficial as it allows the social nature of health and illness to be explored, from the perspective of those experiencing it, which supports the aim of the sociology of health to

discover social issues that impact people in society. Thomas (2007) states narrative allows patients to create a new sense of identity by incorporating their symptoms, which G. Williams (2000) refers to as the narrative reconstruction. Other individuals have used narratives to approach various health issues, such as the effect of illness on life (e.g. Bell, 2002) and women's experiences of chronic pain (e.g. Bury, 2001; Werner et al., 2004).

A review of the literature indicates how much influence social factors have on issues of health and illness, which demands that we pay attention to the ideas and experiences of individuals and groups as we create further understanding and knowledge. A sociological approach to health allows this to occur, as various perspectives put focus on ideas, relationships, institutions, and power imbalances in society that affect experiences of health. Societal ideas, practices, and inequalities are not separate from health, as it is constructed within a society, so acknowledgement of the distinct experiences of women in society, and in their health, is important when looking at the lives of women who have arm problems after breast cancer. McKenzie and Crouch (2004) recognize that the cancer experience does not end after the cancer is removed from the physical body, which indicates that it is necessary for more research in the area of life after breast cancer, including the issue of arm morbidity. It is a chronic condition that impacts, and is impacted by, the lives of women, and by understanding those experiences it will be possible to create a more complete understanding of women's health, and realities of cancer.

## **2.2 The Interplay of Gender, Identity and Health**

Numerous social factors contribute to the differences and disparities in individual and group experiences. Gender is a factor that greatly affects experiences in society, as constructions of gender create different roles for men and women to fill, different expectations and ideals for each to ascribe to, and different levels of power and acceptance in various areas in society. It assigns identities for men and women that materialize in relation to one another, and those cultural meanings that create normal gendered identities create gendered social actors (Smith, 2004, p. 2). Roles women fill are tied to their being women, so feelings of gender are closely associated with the ability to fulfill roles such as wife, mother, and caregiver.

The literature covers a wide range of topics focusing on identity as it relates to roles and how individuals conceive of themselves. Health and illness influence the ways in which people are able to act out their social roles, and can create hindrances resulting from physical changes or limitations, and from social understandings of health that can stigmatise individuals and create barriers. The impact illness has on abilities and self-concept, including areas of work and the family, indicate that a gendered approach to the relationship between health and identity is important, as women's positioning in various areas within society will be affected by health issues that arise.

Bailey (2001) describes gender as being “composed of a complex web of rules about what can be said and done, by whom, and in what contexts in relation to sexual difference” (p. 110). Gender affects how we live in this world, what we think of ourselves, and what roles we fill. For example, Thomas (2007) found that disabled women, regardless of whether or not they were living lives that followed traditional gender paths, told their stories “with explicit or implicit reference to the public narratives that define ‘what it means to be a woman’” (p. 71). Gender greatly impacts the way individuals create their identities to assist them in navigating in the world.

In the area of identity, Charmaz (1983) looks at the ways a sense of self can be lost, which includes losing independence and individualism through restrictions in life, becoming isolated, experiencing disturbed definitions of self, and feeling like a burden. In other words, when people are unable to live up to the identities that have been constructed, which includes filling the roles we enact based on our gender, there can be a lost sense of self. Some literature approaches gender roles within patriarchal societies by examining inequalities that exist between men and women, but the variety of factors that create different experiences of society and inequality are also considered. The idea of intersectionality is used in some literature to account for the variety of ways in which our experiences are affected by various labels we construct in our identities, personally and as a society, including gender, ethnicity, and socioeconomic status (Moser, 2006). With a focus on disability, Moser's (2006) findings suggest that “different realities and different differences, including those of gender and class, were being made alongside each other, interacting and interfering with one another” (p. 539).

As women's roles have become more complex through shifting interactions between private and public spheres, there has been attention given to the consequences those changes have had in women's lives. There is discussion in the literature about women traditionally being situated in the private sphere, where socially constructed gender and family roles have designated responsibility of care for the family and household work (for example, Balter Blume & Blume, 2003). Traditionally women were situated within the private sphere, where they were responsible for the home and family, but in recent decades women's increased participation in the workforce has compelled a change in responsibilities. There is an understanding in much of the literature, however, that despite the changes in women's roles, men's roles have not appropriately altered, leaving women with increased responsibility and less time. Hochschild extensively looked at couples who both worked outside of the house, focusing on the split of housework, and uncovered what she calls the second shift, which refers to the work done at home on top of the shift in the workforce (1989). She discovered that women were working an extra month of twenty-four hour days every year because of their household responsibilities (Hochschild, 1989). In a later study focusing more on experiences in the workforce, Hochschild found that, while men and women generally had similar emotional states during the week, men described more positive states at home, while women had more positive states at work (1997, p. 40). Partnerships between men and women continue to produce unequal experiences as social norms about gender relations remain strong and there is considerable overlap between the public and private spheres (Mandell, 2001, p. 204): Despite equal rights as the accepted value in gender relations, it is still women who are considered to be responsible for childcare and the care of elderly family members, as well as the housework, and much of this work remains invisible (Beck-Gernsheim, 2002).

The onset of an illness can often be a difficult event for individuals, and there is much recognition that close relationships that offer comfort and support are important to create a positive experience of illness (Bolger et al., 1996; Ferrell et al., 2003; Spira & Kenemore, 2002). However, because illness affects not only those individuals diagnosed, but also those involved in their lives, relationships during illness may be tested. A broad range of literature looks at the impact health has on varying levels of relationships (for

example, Walsh et al., 2005; Weitz, 2004). Depending on the understanding of the illness, there can be stigma attached that will influence social interaction with family and other relationships (Chapple, Ziebland, & McPherson, 2004), and stigma can often lead to shame (Ellis, 1998). The demands placed on those close to ill individuals may become too much of a burden, and experiencing the patient's suffering firsthand may be too much to bear (Bolger et al., 1996). There is also evidence that changes to individuals' self-perceptions transform relationships at varying levels of closeness (Holmber, Scott, Alexy & Fife, 2001). Positive outcomes of relationships in illness include great support from friends, family, and others in the community (Holmber et al., 2001). Studies about the emotions and moods of breast cancer survivors have been approached (e.g., McKenzie & Crouch, 2004), and research indicates both positive and negative themes arise in women's relationships with partners and children, such as increased closeness, emotional distress, and the ending of relationships (Walsh et al., 2005).

In addition to the influence health has on close relationships, illness also affects the ability to work, which is another area women experience uniquely compared to men. Women's experiences of work differ in both the public and private spheres. Some major issues in the literature are the wage gap that still remains between men and women in the workforce, women's increased labour participation, and labour force segregation in particular jobs (e.g. Wilson, 2001). While women may be faced with more stress and responsibility than men when it comes to managing work and family responsibilities, employment has been shown to be beneficial to women's physical and mental well-being because of not only the income, but the social circle as well (Lorber, 2000, p. 62).

The area of identity is often connected to health in the literature, including discussions of disability, chronic illness, and physical changes. Hockey and James (2003) highlight the significance of human agency in creating an understanding of how identity is constructed and how the individual "authors her or himself in the course of everyday life experiences" (p. 10). The onset of illness creates a disruption in those experiences and impacts individuals' identities. As Black (2001) states, "An already-fashioned self comes to the illness... experience with an identity shaped through... [variables of age, class, gender, and race] and woven into a personal and communal history" (p. 294), and therefore requires a new identity to be constructed by incorporating



the limitations (p. 295). Bodies differing from the norm in a society that takes those differences as indication of moral and physical inadequacy can struggle to develop an identity (Weitz, 2004, p. 177). As Ryan states, “Changes in physical, sensory, and/or cognitive abilities, and current and future changes in the ability to manage daily activities, challenge personal identity” (2006, p. 424; also see Asbring, 2001).

The standard of physical appearance is another social construction that is connected to identity in the literature. The expectation that women are to embody beauty, or work towards the ideal (see Wolf, 1991), means that those who are unable to reach the standard of beauty are often scrutinized (Abu-Laban & McDaniel, 2001, p. 120). In research on pregnant women, Bailey (2001) finds that gender is indeed embodied, so changes to the body have repercussions for gendered identity (p. 111), and that some of the women worried that their identities would be reduced to their bodies (p. 125). People who are chronically ill are often found to experience a deterioration of their previous identities without concurrently creating equally valued new ones (Charmaz, 1983). Much of the literature indicates that a change in an individual’s physical condition, whether that comes with an illness or disability, can result in the person feeling as if their sense of self is threatened (see Lindgren, 2004).

Gender is one social situation that influences individuals’ experiences in the lifeworld, including women’s experiences of health and disability relative to that of men’s. An occurrence that affects women’s ability to carry out their roles in the family, at work, or in other areas of society, often creates a disruption of identity. At the same time, the importance of health in the construction of identity, how we live out our roles, and how we are positioned in society, cannot be emphasized enough: “People know themselves, as well as knowing other people and situations, with reference to health” (Frank, 2006, p. 430). In other words, health is a part of the construction of our identities, but at the same time health can shake our identities when illness prevents us to enact our identities as we have constructed them. Women bring the realities of their lives to the experiences of arm morbidity after breast cancer, and as abilities and roles shift in the family, in the workforce, and in other areas of society because of changes in health and new conditions such as disability, identities are challenged.

### 2.3 Disability Studies: Challenging Able-bodiedness

Related to the sociology of health is the concept of disability, because it is often perceived as the absence of a physically normal body – comparable to ideas of illness. Disability is also considered to be a social construction that permeates all areas of society, but the literature suggests that there is a distinction between health and disability. Disability studies has been clearly separated from medical sociology by many in the academic world (Thomas, 2007), and there has been resistance to the association of disability with illness out of concern that the medicalization of disability could lead to perceptions that it is an individual problem rather than a societal issue (Wendell, 2001, p. 17). While there is a physical element involved, disability is a social construction that exists within an able-ist culture (Thomas-MacLean, 2005, p. 201), as the “comparison of bodies is ideological rather than biological” (Garland-Thomson, 2004, p. 77). Because of this, there has been increasing discussion in the literature about the social nature of disability in order to produce more complete understandings.

Taken-for-granted assumptions about the body’s normal state are often discussed in the literature, and as McRuer (2002) states, “able-bodied identity is... even more naturalized than heterosexual identity” (p. 91). In 2001, a reported 3.6 million Canadians, or 12.4% of the population, had activity limitations, with prevalence increasing with age, and adult women in all age groups more likely to have a mobility-related disability (12.2%), or a limitation due to pain or discomfort (11.4%) compared to men (8.6% and 8.8%) (Statistics Canada, 2002). This suggests disability is an issue that will impact many, but despite the prevalence of disability in society, and the likelihood that most people will be affected by it at one point in their lives, disability remains an often hidden issue: As Snyder, Brueggemann and Garland-Thomson (2002) state, “Just as sex was the ubiquitous unspoken subject in the Victorian world, disability – the harbinger of mortality – is the ubiquitous unspoken topic in contemporary culture” (p. 2), which is not conducive to creating an informed and understanding population.

Much of the literature includes a comparison of the sociological model of disability with the medical model, in order to clarify its focus and highlight the social nature of the issue. The sociological model of disability deconstructs or questions the accepted and unspoken assumptions of a society (Fawcett, 2000) and emphasizes the

social forces and public issues involved, while the medical model positions disability entirely in an individual body or mind (Weitz, 2004, p. 149). By presenting the idea that there is a normal state for the body, the medical model creates disability as an abnormality (Daruwalla & Darcy, 2005). The difference between the two models is that disability studies approach disability as an oppressive social construct, while medical studies uses a social deviance perspective (Fawcett, 2000; Thomas, 2007). Ideas about disability permeate all aspects of a society (Garland-Thomson, 2004, p. 76), and as a result there is a broad range of areas and topics covered to understand experiences of disability, including the political sphere (e.g. Siebers, 2002; Swan, 2002; Wendell, 2001); sexuality (e.g. Turner, 1987); beauty (e.g. Weitz, 2004); race and ethnicity (see Cassidy, Lord & Mandell, 2001); and disability and relationships (see Cassidy et al., 2001). Because ideas of disability create a minority group in society, issues such as inequality in the distribution of resources, status and power are also examined to understand the oppression and discrimination involved (for example, Cassidy et al., 2001; Garland-Thomson, 2004; Weitz, 2004).

Mitchell (2002) argues that there has been an abundance of literature about disability, across disciplines, with various perspectives and methods used, but it becomes clear in a review that there are many ambiguities surrounding the issues (see Gronvik, 2007). While there are many sociological understandings of disability, creating disputes about who is considered a disabled person (Fawcett, 2000), disability has been approached as limitations or the lack of ability to carry out activities that result primarily from the reactions in a society towards bodies that do not meet the norm, or from assumptions about the bodily state that have been translated into the social and physical environment (Weitz, 2004, p. 149). The World Health Organization's definition of disability is probably the most widely used (Weitz, 2004), which encompasses impairments, participation restrictions, and activity limitations (World Health Organization, 2008). While Smith's (2004) arguments are most salient to my research, specifically that disability "can suggest a set of practices, kinds of embodiment, interactions with the built environment, an almost limitless array of literary types, frames of mind, and forms of relationships" (p. 1), other scholars have addressed the socio-legal context of disability (e.g., Dale Stone, 2008; Morrow, 2007). In addition to the ambiguity

about definitions of disability, there is also debate about who can write about disability. The concern is that disability materials published by non-disabled individuals may exploit disabled people, may not connect with their perspectives, or may only have relevance in the academic world (Fawcett, 2000, p. 7), so there are various perspectives about entitlement about creating knowledge and understanding on disability.

Experiences of disability in society have received increasing attention since the sociological model took shape, which puts focus on the lives of those whose bodies do not fit the social norm within an able-ist culture. Despite the temporality of the able-bodied state for most individuals (Snyder et al., 2002; Thomas, 2007), it remains the expectation upon which environments are created and ideas are based. The literature indicates that many people argue that the disabilities they experience do not primarily come as a result of their physical differences, but result from the way others react to the differences, and the way the social and physical environment have been constructed (Weitz, 2004, p. 149). In other words, those who are disabled are left out of the able-ist culture not as a result of a physical issue, but because of the socially constructed views about disability. Women and men who are disabled are often kept out of the public sphere, and focus is directed at their need for care rather than their own expectations and understandings about life (Fawcett, 2000, p. 79). There is acknowledgement that disability is disadvantaged in society, and the resulting social oppression impacts an individual's experiences of health, the social world, and various factors involved in it, such as identity (Weitz, 2004), well-being (Lucas, 2007), and work (Cassidy et al., 2001). It also affects relationships of all types, and creates stigma in a variety of contexts (Weitz, 2004). There have been scales and methods created to measure attitudes people have towards disability, both in a general sense and for specific issues (Daruwalla & Darcy, 2005), and more and more research continues to indicate that disability has a lasting impact on the well-being of individuals (Lucas, 2007). While there is recognition of the variety of experiences of disability due to the range of factors that affect and create unique experiences, there is a struggle to establish an identity and move towards creating more rights for the disabled in political, social and cultural forums (Siebers, 2002; Swan, 2002).

In addition to experiences of disability that are quite obviously related to the cultural context, there is also a focus on experiences of the body as individuals engage in their social worlds in disabled bodies. There is increasing attention on the body as it relates to social experiences and ideas, including research of body aesthetics (e.g. Thomas, 2007). Hockey and James (2003), in a discussion about changes in the body over time, suggest that differences in the body become the foundation of policies and practices that establish inequalities (p. 15). In other words, it is our physical differences that create disparity because we accept an ideal of physicality that people are expected to encompass. There has been much research on the idea of embodiment to understand the complex experiences of living in different bodies. The individual body, the social body, and the body politic are all levels of experience and analysis involved in embodiment, which suggests that people have “lived” experiences of their bodies, that bodies are a part of our engagement in the social world, and that experiences of our bodies include power and control (Van Wolputte, 2004, p. 254). There are varying levels of acceptance of embodiment in relation to disability, but the literature on disability indicates that the body is very much linked to our experiences in the social world. However, there is criticism when sole focus is placed on the body. S.J. Williams (2006) argues that “The body, it seems, is everywhere and nowhere today” (p. 6), and suggests that the discussion needs to “go beyond the biological... without leaving it out altogether (p. 13; also see Gronvik, 2007; Mitchell, 2002). What is unusual about disability is the unique understanding of the body that is created through study (Swan, 2002, p. 284), as knowledge about people’s experiences and thoughts about their disabilities could expand upon medical ideas about the normal body and mind (Wendell, 2001, p. 23). Disability theorists, however, did not participate in the rise of the idea of embodiment because their approach has been based on opposition to the belief that disability, and experiences of it, are all about the body (Thomas, 2007, p. 121). Also, there has been little integration of feminist understandings in areas of embodiment or disability, which creates problems with topics such as breast cancer because it ignores the long-term effects treatment can have on the lives of women (Thomas-MacLean & Miedema, 2005, p. 92).

In Canada, over 16 percent of Canadian women consider themselves to be disabled, and experience difficulties in many areas of their lives, including family, work,

and school because of it (Cassidy et al., 2001, p. 91). The unique experiences women have with disability are recognized in the literature, and there is much discussion about the societal perceptions about women with disability, such as ideas that they are asexual, unattractive, overly dependent, unfit to reproduce, and generally unable to fit the ideal standard of femininity (Garland-Thomson, 2004; Weitz, 2004; also see Potts, 2000). The goal of feminism in disability studies “is to augment the terms and confront the limits of the ways we understand human diversity, the materiality of the body, multiculturalism, and the social formations that interpret bodily differences” (Garland-Thomson, 2004, p. 75). However, there are few feminist researchers who have focused on the experiences of women’s daily lives who live with a physical disability in a society with strict social understandings of normalcy (Thomas-MacLean & Miedema, 2005, p. 93).

A review of the literature indicates that discourse about disability is occurring, but there remain many ambiguities, and further knowledge is necessary to create a more thorough understanding of ideas about and the impacts of disability. Disability is a social construction that is enacted in society because the world is organized based on assumptions about normal capabilities and bodily functions. Many people will experience disability during their lifetime, including women with arm morbidity after breast cancer. Realities of pain, swelling, or a limited range of motion can create difficulties when performing tasks or carrying out daily routines, and the chronic condition can mean that those women experience issues related to disability for the remainder of their lives. Understanding society’s institutions and structures, as well as perceptions of disability and impairment, will contribute to the understanding of experiences of arm morbidity.

#### **2.4 Knowledge and Empowerment in Illness Experiences**

As knowledge is constructed about disability, health, and gender issues, it is also important to reflect upon those knowledge systems and foundations of understanding in order to recognize society’s role in that knowledge. There is an important connection between sociology of health and sociology of knowledge (White, 1991), as the sociology of knowledge allows us to understand how our thoughts about health and healthcare are connected to particular social contexts (Annandale, Elston, & Prior, 2004). The difficulty

with knowledge about health lies in the conception that scientific knowledge is universal and constant across time and culture, without influence from the social world, and as a result it not considered to require deconstructing to understand the historical and theoretical influences of the context (Fosket, 2000, p. 18). Much of the information about health is focused on the biomedical, making it quite inaccessible to the majority of the population who lack the expertise to understand the language used and the ideas involved. However, the possibility of survival in many types of cancer has increased and many patients are choosing to become more informed about the disease, and the options they have for treatment (Leigh & Stoval, 2003, p. 382). Information technology is making it easier for the population to acquire that information, and innovations in medical knowledge and medical technologies mean that there are a wide variety of options for individuals to look into in their decision-making process.

A review of the literature indicates many uncertainties and tensions about knowledge and health, with focus on issues such as power of the medical profession, relationships between doctors and patients, and the role of individuals in their own health. The effective and appropriate transfer of quality information is key to empowering patients as they deal with health issues (Henwood, Wyatt, Hart, & Smith, 2003, p. 590), but it appears as if it will not be an easy or natural development of the informed patient in the current structure and relationships of the health care system (p. 605). This suggests that patients are still generally unable to make adequate decisions and attain a sense of empowerment over their own health because the health system does not establish an environment for this to occur.

Much of the literature focuses on interactions between doctors and patients, and the roles each fill in dealing with health and illness (see Lutfey, 2005; May, 2007). Research looks at varying degrees of patient participation in medical care (Flynn, Smith, & Vanness, 2006), and approaches this issue with two models: the physician is considered to be the patient's "perfect agent" who uses expert knowledge to make decisions on behalf of the patient in some scenarios, or the focus is on the patient making an informed decision with the information received from the physician (Gafni, Charles, & Whelan, 1998; also see Entwistle, Skea, & O'Donnell, 2001). Neither of these instances implies a simple process to establishing a common understanding between physicians and

patients (Gafni et al., 1998), and the often ambiguous or complicated relationships between patients and physicians do not assist in creating better understanding: Rees, Knight and Wilkinson's findings indicate that five oppositional metaphors are expressed to describe the patient-doctor relationships, which are war, hierarchy, doctor-centredness, market, and machine, and the one performative metaphor, which is the relationship as theatre (2007).

A review of the literature reveals research aimed at understanding the ways in which patients create knowledge about illness (for example, Fosket, 2000), and there is much discussion about the disjointedness between physician knowledge and patient knowledge. Medical professionals hold the expert knowledge about health while patients construct and interpret daily experiences to create lay knowledge, and perceptions about and uncertainties in each form of knowledge creates tension between patients and professionals (Annandale et al., 2004). Not all knowledge is considered to be equally legitimate, to the patient or to a medical professional, which indicates the presence of a hierarchical classification of knowledge that places superiority in scientific truths (Fosket, 2000). The differences in knowledge and perspectives are problematic, and many sociological theorists propose that doctors need to give more attention to the lay knowledge of their patients, and that patients need to be more vocal in sharing their thoughts with medical professionals (Turner, 1987).

This sharing of information is important in order to allow patients and those providing them with care to create a common understanding, and to ensure that all parties have the information necessary to approach health and illness appropriately. Turner (1987) raises Habermas's theory of communicative action as a way to approach relationships in the healthcare system, where all parties must engage in communication in order to reach a common understanding. The importance of communication between patients and doctors is therefore essential for quality care, but new theories and tools are needed to better the current situation (Epstein et al., 2005). There are many reasons why a gap remains in understandings of both the biomedical discourse and patients' experiences of illness, including: the different languages and perspectives patients and doctors employ creates difficulty in communication (Turner, 1987, p. 50); physicians' ideal outcomes often focus on the removal of the illness to return the body back to its



ideal state, while patients may be more focused on their ability to conduct their lives (Lorber, 1997, p. 4); there is still uncertainty about the level of involvement and choice patients should have in their healthcare (Entwistle, Williams, Skea, MacLennan, & Bhattacharya, 2006); and there is evidence of differences in male and female physicians' approaches to health and relationships with patients (Weisman & Teitelbaum, 1985). The biomedical focus on the body also creates conflict, as physicians may only be listening to patients' bodies for information about health, and speaking with a "voice of medicine", rather than listening to patients' voices, and understanding the "voice of the lifeworld" (Lorber, 1997, p. 40; also see Fosket, 2000; May et al., 2004).

The literature examines the relation between knowledge and power by looking at both the authority and status those in the medical profession have because of their expert knowledge of health, and the control and independence patients can achieve by being more informed about their health (for example, Lorber, 1997; Turner, 1987). If more information about health and illness is a way to empower patients, then it becomes important to consider whether patients feel as if they have adequate information about their health. The idea of partnership roles in healthcare has been gaining more attention, but those in the medical profession continue to maintain a level of physician authority (Lutfey, 2005). For instance, Entwistle et al. (2006) suggest that many women who are faced with a hysterectomy do not feel as if they have adequate information, and most want to know more from their physician about the decisions made and the reasoning for it. However, there is also literature that points to the complications of presenting much information about illnesses, or research that suggests not all patients want to be involved (see Flynn et al., 2006). For example, Potts (2000) argues that, despite the idea that more information would lead to further control of their lives and bodies, women who know that they have a high risk of developing breast cancer are given choices that may not be empowering, but rather makes them confront the possibility of an ill body (p. 8).

There is also discussion, as technology continues to expand and information becomes more accessible to the general public, about a new informed patient that has not been possible in the past. This increased access to health information has received varying levels of support, because it may create a more balanced relationship between patients and their health professionals, allowing for better health decisions, but there is

concern about the quality of information people are accessing (Ziebland, 2004). Research indicates that knowledge about health comes from a variety of places, including our own bodies; personal experiences; interactions and conversations with family, friends or others who have been in similar situations; the media; biomedical information; and expert sources (Fosket, 2000; Ziebland, 2004). The availability of medical information, especially because of technologies such as the internet, is expected to empower patients, but while research indicates that many people do seek out information from a variety of sources, that does not mean that all individuals want the responsibility for their health, or that all individuals are competent to use technology to construct knowledge or to find beneficial information (Henwood et al., 2003). With a focus on health promotion, some research suggests that changes in many institutions in a society need to occur in order to support an individual's attempt to seek out health (Currie & Wiesenberg, 2003), rather than simply a change in patient-doctor relations, or an individual responsibility to acquire information.

This failure of the medical system to empower individuals in health and illness suggests that patients are dealing with a lack of control, which is another social factor that affects experiences of health. When it comes to the well-being of an individual, a "lack of control over one's life is well-known to have adverse effects on emotional states, performance of tasks, subjective well-being, and on actual physiological indicators" (Abu-Laban & McDaniel, 2001, p. 115). This lack of control increases the number of difficulties patients are faced with, if they have health issues but are not given the opportunity to actively engage in their own care. There are many studies that suggest there is a lack of awareness among both breast cancer patients and health care providers of certain conditions that can cause arm morbidity (Thomas-MacLean, Miedema & Tatemichi, 2005), indicating that the individuals involved are missing a sense of empowerment, and therefore have to deal with the issues that go along with a lack of control over their own health, on top of the physical and social difficulties that arise with their illnesses. Deficiencies in current understandings of arm morbidity are evident, as there is a limited amount of knowledge in the biomedical field, and otherwise. The lack of knowledge means that women who experience arm problems after breast cancer have little information to assist them in managing the disability, and people working in the

healthcare system are lacking an accurate understanding of the issue that would allow for better management of the condition, more informed decision-making, and an improved quality of care for the patients.

### **2.5 Connections: Weaving Together Health, Gender, Disability and Knowledge**

Deficiencies in current research are evident, as there is a limited amount of knowledge about arm morbidity, both medically and sociologically. There is some biomedical literature that discusses arm morbidity after breast cancer, within areas such as epidemiology, prevention and control, etiology, pathology, and rehabilitation (for example, see Stanton et al., 2001; Vignes, Arrault, & Dupuy, 2007), and to a lesser degree there is research attempting to understand the experiences of women with arm morbidity (such as Radina & Armer, 2001; Thomas-Maclean & Miedema, 2005). However, available literature is scant, both medically and otherwise. This means that women who experience difficulties with their arms or upper body after breast cancer have little information to assist them with managing the disability, and people working in the healthcare system are lacking an accurate understanding of the issues that would allow for better management of the condition, more informed decision-making, and an improved quality of care for the patients.

An understanding of the issues involved in the sociology of health is an important point to begin understanding arm morbidity, as it extends the focus from the biomedical to include social factors that influence women's experiences. A broad understanding of the sociological model of health is important to explore experiences of health and illness, because the social context and the various factors that impact our lives must be included in our understandings of arm morbidity if we want to create a more thorough understanding of those experiences. The sociological perspective places focus on a range of areas in a society that affect our health and the inequalities that create disparities, which are useful to this research because the women's stories will be impacted by their social contexts, and their own social identities. Gender is one construction that affects experiences within the lifeworld, including that of health and illness, and is central in creating an understanding of the significance of arm morbidity in women's lives. While there is limited knowledge about experiences of arm morbidity, literature focusing on

other chronic illnesses can be applied. The concept of biographical disruption is also informative, and a focus on the illness narratives that come out of those disruptions can help create understanding about the experiences.

Issues of gender and identity are also important to understand within the context of arm morbidity, because health, illness, and physical limitations are closely connected to our experiences in and understandings of the world. Identities are tied to the roles we carry out in our lives, and gender is a major influence in the roles we fulfill and the identities we construct. Women with arm problems after breast cancer will have had constructed identities to include such roles as mothers, wives, friends, and employees. These roles are influenced by the ability to perform those roles, and illness and disability can greatly challenge understandings of gender and identity. This is an important aspect to the research on arm morbidity after breast cancer, because changes in body, new limitations, and the need to adapt because of arm problems are connected to theories of disability.

Knowledge of disability ties in well with an understanding of health, and is especially important to arm morbidity as changes to the body create physical limitations. Expanding from a medical, individual problem to a social issue that is constructed based on an ideal body type developed within an able-ist culture puts focus again on the social world the women's lives are situated in, which is beneficial in exploring the impact physical limitations or difficulties have on the daily lives of women with arm morbidity. The layout of the physical world we create may produce obstacles to performing tasks similar to those described in disability studies research, and the idea of embodiment places focus on experiences of our bodies, but not solely in a biomedical sense. The unique experiences of women with disability – in the various areas of their lives, in their experiences of their bodies, in the limitations they experience – also inform this research, as they create an understanding of the issues women with arm morbidity may face. Literature about disability also helps lay a foundation to begin exploring experiences of arm morbidity, as it discusses issues related to the physical realities that create difficulties due to the way we construct our world, such as those caused by arm problems after breast cancer treatment.

Finally, ideas of knowledge and empowerment are beneficial to this research, as the sociology of knowledge can explain our understandings of health. Issues of power and knowledge lead to a discussion of the power of the medical profession, and the disregard for lay knowledge in health. A number of factors are beneficial to understanding experiences of arm morbidity, including the hierarchy of knowledge in health, communication between patients and physicians, and the idea of the new, informed patient. A lack of control over one's own health, and one's own healthcare, contributes to the illness experience, so ideas of knowledge, empowerment, communication, and power are all useful in understanding my research topic.

Taken together, the sociology of health, gender, disability, and knowledge provide a foundation for understanding the complex, far-reaching experiences of arm morbidity after breast cancer. The sociological ideas and themes discussed above inform and support the exploration of arm morbidity in the lives of breast cancer survivors, but there is need to construct more knowledge specific to arm morbidity after breast cancer.

**CHAPTER THREE**  
**BLUEPRINT TO CONSTRUCTING KNOWLEDGE:**  
**METHODOLOGY AND RESEARCH METHODS**

From a phenomenological point of view, to do research is always to question the way we experience the world, to want to know the world in which we live as human beings. And since to *know* the world is profoundly to *be* in the world in a certain way, the act of researching – questioning – theorizing is the intentional act of attaching ourselves to the world, to become more fully part of it, or better, to become the world. (van Manen, 1990, p. 5)

To create an understanding of the way women with arm morbidity after breast cancer experience the world, I use a phenomenological methodology, guided by feminist theory, for this research. In the first section of this chapter, I discuss the merits of using phenomenology and feminism to understand the impact of arm morbidity in the daily lives of breast cancer survivors. To explain the research process, I then present the design of this study. It incorporates qualitative and quantitative data collection tools, but because of the small sample size, the qualitative data take precedence, while the quantitative is only used to report socio-demographic information and understand basic data of their illness experiences. Following, I explain the recruitment and selection process, which involved a snowball sampling technique to reach my target of six participants, each of whom was interviewed twice. In the fourth section, I then describe the ethical concerns involved in this research and explain how they were accounted for. Next, I present the issues and process involved in the data analysis, discussing themes related to the qualitative data, and the creation of participant profiles using closed-ended questions. I conclude the chapter by discussing credibility as it relates to this study, which is important in order to establish valuable knowledge.

**3.1 Phenomenology and Feminism: Understanding Complexities of the Everyday**

To understand how arm morbidity affects the daily lives of breast cancer survivors requires us to ask how those individuals experience the world as they live their lives, which van Manen (1990) indicates is the essence of phenomenological inquiry. To conduct this research, I use a phenomenological methodology, combined with a feminist perspective. As a methodology, phenomenology offers an alternative to the positivist view of science, and presents a new manner to interpret consciousness and individuals’

involvement in the world (Beck, 1994, p. 499). While there are many strands of phenomenology, I draw upon the work of contemporary phenomenologists such as van Manen and Bentz, because their focus is on creating a depth of understanding about the complexities in experiences of the world (for example, see van Manen, 1997). They draw attention to seemingly mundane things, which allow the stories of individuals' experiences to inform and illuminate understanding. As van Manen (1990) states, phenomenology "aims at gaining a deeper understanding of the nature or meaning of our everyday experiences" (p. 9) by placing emphasis in the consciousness of human beings, as consciousness is the way individuals access the world. Similarly, Bentz (1995) describes phenomenology as "a deeper level of knowing," (p. 45). This is precisely what I aim to achieve in the research: a deep understanding about the meanings women with arm morbidity construct about their everyday experiences. It is important to look at the participants' lives, and the meaning they construct, authentically, and in all of their complexities, as van Manen states this approach is interested in the world "as we find it in all its variegated aspects" (van Manen, 1990, p. 18).

The task in phenomenology, then, is to "empirically study, document and interpret the subjective meanings that individuals employ and construct in the daily round of routine and taken-for-granted activities; society is the aggregation of these individually experienced social worlds or systems" (Thomas, 2007, p. 27). Phenomenology is not used "to interpret the world in terms of methodological assumptions, but to merge the interpretive horizon of the researcher with the image of reality held by a community" (Murphy, 1986, p. 332). An application of this methodology to research, with the attempt to describe and interpret meanings to a high level of depth and richness, demands that the researcher transform the lived experience into text expressing its essence so that "the text is at once a reflexive re-living and a reflective appropriation of something meaningful" (van Manen, 1990, p. 36).

It is then essential to approach experiences thoughtfully, and to meaningfully translate them into text such as this thesis. In phenomenological reflection, the interpretation of meaning is "a process of insightful invention, discovery or disclosure," which involves structuring those experiences to create a thematic understanding by a "free act of 'seeing' meaning," rather than a process involving many rules (van Manen,

1990, p. 79). The research does not lead to a conclusive argument or set of ideas, but “aims to be elusive by orienting the reader reflectively to that region of lived experience where the phenomenon dwells in recognizable form” (van Manen, 2002, p. 238). Unlike other methodologies that aim to construct theories or present answers, the goal of phenomenology is to describe accurately the experiences of the phenomenon being studied (Morse & Field, 1995). van Manen (2002) encourages researchers to approach phenomenological method not as a controlled set of procedures, but rather as “a way toward human understanding,” which may make it more possible for us to be led to understanding, or to be led into understanding (p. 249).

Feminism is an appropriate approach for this research as well, not only because it is a women’s health issue being studied, but in recognition of the extensive impact gender and a number of other factors have on experiences of daily life within a patriarchal society. There is acknowledgement in feminist movements that there are many feminisms (Fawcett, 2000, p. 2000) which involve a variety of definitions, many goals, and numerous agendas (Miles, Rezai-Rashti, & Rundle, 2001). There are also many understandings of what feminist research is (Reinharz, 1992). Dos Ramos (1996) broadly defines feminism “as a moral and ethical struggle based on the extension of basic human rights and fundamental values to all Canadians” (cited in Miles et al., 2001, p. 2). This puts not only gender at the forefront, but other forms of inequality, such as those related to ethnicity and race, sexuality, age, and socioeconomic status, all of which are key concerns within sociology.

A general feminist perspective is used to focus this research, as I draw on ideas that, despite the variation in feminism, are similar among each. According to Jaggar and Rothenberg (1984), there are generally four concerns of feminists: 1) feminists seek to understand the gendered nature of social and institutional relations; 2) they acknowledge that gender relations are constructed as problematic and associated with other inequalities and inconsistencies in life; 3) they believe that gender relations are historical and sociocultural productions, not natural or unchallengeable; and 4) feminist theorists tend to be explicitly political as they advocate for social change (Jaggar & Rothenberg, 1984, cited in Elliot & Mandell, 2001, p. 24). Of primary importance to feminist thought is understanding the socially constructed nature of gender, and how that affects the lives of



both women and men. In differentiating sex from gender, feminist theorists have challenged “causal explanations that assume that sex dictates or necessitates certain social meanings for women’s experience” (Butler, 1988, p. 520).

While feminism is incorporated in much research, it does not imply a particular research design: Harding (1987) argues against the idea that there is a specific feminist method for research, which leaves much flexibility in the way research is conducted. Feminist research incorporates a variety of methods, guiding research that aims to create social change and represent human diversity, and is often directed at establishing social relationships with the individuals involved (Reinharz, 1992, p. 240). In this sense, the most appropriate research design can be applied to the topic, and the feminist approach is incorporated throughout the process. Feminist theory and thought puts lived experience central to inquiry (Denzin & Lincoln, 1998, p. 189), which makes it appropriate for my research. The focus is on the lives of women with arm morbidity in this research, and including a feminist perspective directs attention to the ways in which gender and other circumstances affect those experiences.

My use of feminism along with phenomenology furthers the emphasis on the lifeworld. Many feminist authors look at the gendered experiences by exploring people’s personal, lived experience (Kasper, 1994). My research explores the experiences of women with arm morbidity after breast cancer in order to understand the meaning they have made of the lifeworld. The lifeworld is a concept in phenomenology used to describe the everyday world as people experience it (Dahlberg & Drew, 1997). Merleau-Ponty (1962) describes the idea of the lifeworld in this way:

To return to the things themselves is to return to the world which precedes knowledge, of which knowledge always speaks, and in relation to which every scientific schematization is an abstract and derivative sign-language, as is geography in relation to the countryside in which we have learned beforehand what a forest, a prairie or a river is. (p. ix, cited in Dahlberg & Drew 1997, p. 305)

In other words, before creating knowledge about the experiences of arm morbidity, it is essential to understand the essence of those experiences as they are situated in the everyday world. Because of the emphasis on lived experience and perception, using a phenomenological approach can supply important insights to both our understandings of the experiences of illness and ideas of embodied subjectivity (Lindgren, 2004, p. 147).

Another similarity between feminism and phenomenology is the subjectivity involved when discussing individual meaning and experience. In feminist thought, there is an acknowledgement of the contradiction in the idea that women are all alike in some ways, and different in others (Reinharz, 1992, p. 252). The subjective experience of one woman will differ from the next, so some may not see the validity of understanding individual experience in order to create knowledge. However, as Kasper (1994) states, “[T]he subjective data of each woman’s account do not stand alone as isolated phenomena. Rather the features of the subjective experiences of one woman are frequently shared among other women” (p. 279). This is relevant to phenomenology, as it requires us to expand our understanding of legitimate knowledge and objectives of research. The open-endedness of phenomenological exploration, in the sense that it is a means to lead us towards understanding, rather than the expectation that we are able to produce concrete, factual knowledge, establishes subjective experiences as meaningful knowledge, and of value to research. Phenomenology also pulls out themes in those experiences to indicate the commonalities that make up the shared experiences: It can establish “a point of entry into the exploration of the shared features of a unique experience” (Rehorick, 1986, p. 389). Because of this, we are able to recognize the individuality and uniqueness of each person, but we can also acknowledge that there is shared experience in the world.

To put phenomenology into practice, guided by feminism, it is important to hear the voices of women experiencing arm morbidity in order to allow them to convey the meanings they have constructed as a result of their engagement in the lifeworld. As Thomas-MacLean (2004) states, “[W]omen speaking for themselves, about their own experiences, can contribute much to the knowledge about the complexity of life after breast cancer” (p. 629). When focusing on the women’s voices, it becomes important to pay attention to power dynamics, to minimize the impact of those dynamics as the women convey their understandings, and to connect with the participants rather than asserting control over them (Reinharz, 1992). Because of the subjectivity involved in this phenomenological research, it is also important to be transparent and reflexive throughout the process. As Beck (1994) states, “By repeatedly asking, ‘What am I taking for granted?’ a person can be helped in reflecting on and articulating experiences with the

phenomenon under study” (p. 500-1). Phenomenology is the exploration of taken for granted assumptions in the lifeworld, and that exploration needs to be applied to the researcher’s own understanding in order to conduct valuable research.

Using a critical theory, such as feminism, suggests that the researcher’s ontology is historical realism, the epistemology is transactional and subjectivist, and the methodology is dialogue and dialectical (Guba & Lincoln, 1998, p. 205-6). In other words, our reality is situated in a particular historical context; the way we create understanding is through our interactions, which are influenced by the values of all involved; and the method to do that is by engaging in dialogue to reach a common understanding. Phenomenology converges well with these ideas, as it focuses on the meaning individuals construct from their experiences in the lifeworld, within a particular context; it recognizes that our subjective meanings are valuable knowledge in relation to others’; and the aim of research is to come to an understanding of the essence of a phenomenon, which occurs through communication with others.

The methodologies I selected are important for my research because they establish the value of understanding the lived experience of the participants and provide both direction and flexibility in order to explore subjective meanings. It is an approach that has not often been applied to this area: “few researchers have explored women’s experiences of life after breast cancer utilizing feminist and phenomenological approaches” (Thomas-MacLean, 2005, p. 200). By basing the research within two methodological approaches, the aim is to construct an understanding of the lived experience of women with arm morbidity that will move us towards more knowledge of the complexities and depth involved: “The only way for us to really know what another person experiences is to experience the phenomenon as directly as possible for ourselves” (Patton, 2002, p. 106).

### **3.2 The Research Design: Techniques, Tools, and Follow-Through**

There has been some hesitance from feminist researchers to use surveys and other quantitative methods, with the critique being that quantitative research is unable to provide those involved in the research with the same degree of voice that is possible in qualitative techniques (Shah, 2006, p. 210). But even quantitative research in

conjunction with qualitative research sparks debate, as there has been much discussion about the legitimacy of mixing methods. In support of mixing methods, Onwuegbuzie and Leech indicate that a “false dichotomy” exists between qualitative and quantitative research, and that pragmatic researchers who utilize mixed methodologies within the same inquiry are able to go further into the data to create an understanding and to use one method as verification for the findings from the other method (2005, p. 384). As Sandelowski (2000) states, “Because techniques are tied neither to paradigms nor to methods, combination at the technique level permit innovative uses of a range of techniques for a variety of purposes” (p. 248). Two benefits in using mixed methods, specific to the purposes of this research, include triangulation, where the data collected may be used to corroborate findings, and complementarity, which clarifies or elaborates upon results (Greene, Caracelli, & Graha, 1989, p. 259, cited in Sandelowski, 2000). The participants’ voices will still be heard using the qualitative data, and the quantitative data support and document understandings of issues mainly related to disease and treatment.

To create a thorough understanding of the impact arm morbidity has on the daily lives of breast cancer survivors, I incorporated both qualitative and quantitative methods as data collection tools. I carried out a brief survey with the intention of gathering information about the participants’ health related to breast cancer and arm morbidity, and to ascertain socio-demographic information. However, my focus was primarily on the qualitative interviews that were conducted. There have been many studies in health and illness that include participants’ stories, often conveyed through interviews, as a result of the developing legitimacy of qualitative research (Charmaz, 2002, p. 319). With the interviews, I aimed to create in-depth understanding of the experiences of the participants as they navigate through life with arm morbidity. The focus on exploring the participants’ stories in health research, as told by the participants, places emphasis on understanding the unique experiences of the individual, and gives voice to those who are experiencing the phenomenon. Choosing qualitative interviewing suggests that the ontological perspective of the researcher is that “people’s knowledge, views, understandings, interpretations, experiences, and interactions are meaningful properties of the social reality” that is being explored (Mason, 2002, p. 63). Qualitative interviewing was appropriate as the primary data collection tool because it establishes the importance

of understanding the experiences of the women and allows for their ideas and experiences to be conveyed

The research design included two interviews with each participant, although quantitative data tools were used only during the first meeting. To collect the quantitative data, participants completed a survey (see Appendix D), which incorporated questions from the SIAM (Social Impact of Arm Morbidity) Questionnaire, a Medical Chart Review Form, the DASH (Disabilities of the Arm, Shoulder and Hand) Questionnaire, and the McGill Pain Questionnaire. Except for the SIAM, all surveys are validated questionnaires. The survey included socio-demographic questions, and covered issues focusing on their health and arm problems, including their breast cancer history; the medical care they are receiving for their arm problems; changes made in their lives since experiencing problems with their arm; the physical limitations due to their arm problems; and the pain they have been experiencing. The quantitative data were intended to complement the data collected through the interviews, although because of the small number of respondents, they are only used to construct participant profiles, and provide basic socio-demographic and health information.

I conducted semi-structured interviews so that particular issues would be discussed, but it also permitted each participant to take the discussion in directions that reflected her own experience. Semi-structured interviews allow researchers into participants' "worlds of experience" as the researcher listens to the women speak, comes to understand their membership in certain social systems, and establishes their experiences of the phenomena in a way that is accessible through this type of interviewing (Reinharz, 1992, p. 440). Interview questions for the first interview (see Appendix B) were created with the help of my supervisor. The interview guide incorporated ideas and questions used in her previous research on arm morbidity after breast cancer, including what has been significant in their experiences of their bodies, and what effect arm problems have had in their daily lives in areas such as their daily routine, relationships, and lifestyle. I also included new ideas specific to this research in the interview guide, such as the effect arm problems have on the women's emotions or moods, and any predictions they have for the future about their arm problems and how that would influence their lives. The first interview conducted with the participants

focused on the physical symptoms of their arm problems; the experiences of their changed bodies; the impact arm problems have had in various areas of their lives such as relationships, work, daily routine, lifestyle, and leisure activities; the emotional effects arm problems have had; and any predictions they may have for their lives and their health in the future. The same interview guide was used during each first interview, but the responses of the women created differences in the dialogue that followed, as they focused on the ideas and issues that they felt were important to their experiences. These interviews were audio-recorded and later transcribed.

After the first interview and the survey were completed, I scheduled a follow-up interview with each participant. I created questions from notes taken during and right after the first interview, and in some cases played back the recording of the initial interview. My intention was to clarify or expand on ideas that had been discussed in the initial meeting, and because the questions were based on what each participant had shared, there was no standard structure for the second interview. Follow-up questions focused on issues such as the concerns about others' perceptions of the limitations and health issues, the participant's acceptance of her limitations, and the role of the patient in her own health and treatment. Because there were common ideas or experiences raised during the first interviews, there were similar ideas that were discussed in more than one follow-up interview, including feeling physically uncomfortable in one's own body, experiences as a patient within the healthcare system, and the awareness of the body since treatment. The second interview guide also included two other areas that were discussed with all participants (see Appendix C), which focused on the issue of support, incorporating ideas of physical, emotional, and spiritual support received and required, and experiences of knowledge and information about arm problems since treatment, such as understandings of arm problems following treatment, measures taken to seek out information, and the level of knowledge the women felt they had, and felt they wanted, about their arm problems. The second interviews were also audio-recorded, and then transcribed for analysis.

### **3.3 Recruitment: Finding Participants**

My aim was to find six participants in the city of Saskatoon and its surrounding area, and interested individuals were eligible to participate if they met the study criteria, which were: women who were eighteen years of age or older; had previously had Stage I to Stage III breast cancer; were a minimum of six months post-surgery in their breast cancer treatment; and had experienced or were currently experiencing problems in their arm and/or surrounding area as a result of that treatment, including lymphedema, swelling, pain, or a limited range of motion. Participants had to be willing to share their experiences and be recorded throughout the interview process. There was not a particular demographic group that was the focus of this research, so my goal was to include individuals who had unique histories and who were in different stages of life. There were no established requirements in regards to the women's breast cancer experience, including the type of breast cancer and the time since treatment, and the criteria allowed for variation in the resulting arm problems, such as type of arm problems they were experiencing, and the severity of the arm problems.

I distributed posters in various locations in Saskatoon to advertise for participants, and recruitment was also advanced by snowball sampling, where I relied upon word of mouth to spread information and reach interested individuals. Advertisements were initially distributed at a breast cancer "think tank", as well as various locations in the city that provide support, information, or other services to women with breast cancer, such as the Hope Cancer Help Centre, and a yoga group that had been organized for breast cancer survivors. Those posters led to contact with many individuals who are quite active in the breast cancer community, including women involved in groups such as the Saskatchewan Breast Cancer Network and the Saskatchewan Lymphovenous Learning Association, individuals in the health region such as physiotherapists who work with breast cancer survivors having difficulty with their arm or surrounding area, and breast cancer survivors themselves.

As a result of this networking, and because of the very involved, organized and vibrant breast cancer community in the province, fifteen women came forward within a month and expressed interest in participating, and many more offered to contact others who might be eligible. Those women who were willing to participate contacted me for

more information about the study, and after explaining what their participation involved, I ascertained whether the individuals fell within the research criteria, whether they had the time and were physically able to meet with me, and who had backgrounds that would produce a varied group of participants. When six women had agreed to participate, there was an interim of time when it was not possible to schedule interviews because there were some changes in the research design. However, the participants were all willing to accommodate the delay, so once the research directions had been decided upon, I contacted the participants and we established a time to meet at their earliest convenience. While the recruitment process is long over, I continue to receive messages, at the time of writing this thesis, from interested women who come across advertisements that were posted by others and want to participate in research focused on arm problems after breast cancer.

### **3.3a A Change in Plans**

While this research came to involve six participants who met with me twice, there were changes throughout the process that caused a transformation from the original research plan. The objectives of the research remained the same, but the design changed. Initially, the idea was to conduct semi-structured interviews with ten women, using an interview guide from Dr. Roanne Thomas-MacLean's "Charting the Course of Arm Morbidity in Breast Cancer: A Prospective, Longitudinal Follow-up" study. The number of participants originally proposed was ten, but the interview guide was not as extensive, and we would have met only once. Combining the data I collected from my own research with the de-identified transcripts from the forty women interviewed in the larger study would create a sample size of fifty women, and it would have allowed me to compare experiences between women from different areas in Canada.

However, to include the participants' stories from Dr. Thomas-MacLean's research, I needed to maintain the same criteria for participant selection, which presented a problem. The forty participants had been selected with the same criteria I used for the six participants who were involved in this research, but they also had to have had surgery within six to thirty months of the study. I had been in touch with thirteen women willing to participate within a few weeks of commencing recruitment, so there were many



positive responses in a short amount of time, but only two of them fell within that period and were eligible to participate. It became clear that finding ten participants who met those research criteria would take more time than I was able to commit. My supervisor and I discussed the options I had, and we decided that there was another direction I could take and still maintain my original research intent. I chose to move forward with six participants and explore their experiences in further depth by creating a more comprehensive interview guide, and include follow-up interviews. Twelve detailed transcripts resulted from the interviews, along with six surveys, rather than fifty brief transcripts and ten surveys.

### **3.4 Ethical Considerations: Consent, Comfort. And Confidentiality**

While this was a minimal-risk study, there are always a number of ethical considerations that need to be taken into account when the research involves individuals. Prior to beginning the recruitment and data collection process of the research, I received approval from the Behavioural Research Ethics Board (Beh-REB) at the University of Saskatchewan. I submitted an application explaining the intent of my research and outlining how I was going to ensure the ethical treatment of participants throughout my research, as well as materials I would be using, including the interview guide, the survey, the consent form, and the poster for recruitment purposes. It was not realistic to have the ethics board approve the interview guides for both the first and second interviews, as those used in the second were constructed during the interview process. However, the major themes that were pursued in the second interviews were conveyed to the ethics board and received approval. The second interview guides that were created included new questions, but they did not vary greatly from the themes in the initial guide, as questions were assembled based on discussions in the first interview. I did, however, alert the Research Ethics Board of the new research design when I decided to make a change in plans, and sent in the altered consent form for approval.

The women involved in the research made the initial contact to indicate their willingness to participate, but they were also asked to give written and verbal consent. Consent was given prior to the interview and survey, and participants indicated that the researcher is able to use the data collected. The consent form (see Appendix A) specified

that participants had the right to withdraw from the study at any time without explanation, and said that they could choose to have the audio recorder stopped at any point during the interview. They were also informed of the intended uses of the information collected, as well as the steps that were taken to ensure their confidentiality, safety, and anonymity. In consideration for the participants' comfort, as well as ethical issues, participants were free to change their minds and leave the study at any point, and were able to make a request for any information to be kept private, as it is important to allow participants control over the level of exposure they are willing to permit (Sinding & Aronson, 2003, p. 110).

To ensure that participants were comfortable, they were also free to choose the time and location we would meet. The women's well-being was a major consideration as I created plans for the research, in order to ensure a safe, accepting, calm environment during our interactions that allowed them to feel valued, respected, and empowered. As Frank (2001) states, "Research touches ill people. Qualitative researchers pride themselves on their personal encounter with ill people. Remember, how you touch them affects their healing, and your own healing too." (p. 361). I was very conscious of the potential physical burden the interviews could have on the participants, as many were dealing with issues of pain and discomfort. But of equal significance was the need to respect the participants' knowledge of their experiences, and support them in their processes of understanding and dealing with their health issues.

The confidentiality of participants is of primary importance to this research. Participants were willing to share their stories, but sensitivity is required to ensure that they will not feel any negative consequences as a result of their contributions. Involvement in this research would not bring any physical harm, but it was important to treat the participants' private thoughts and experiences with respect. As Punch (1998) states, "The major safeguard to place against the invasion of privacy is the assurance of confidentiality" (p. 175). This was applicable throughout the research process: during the interview stage, as the interviews were being transcribed, throughout the data analysis, and as the findings are presented: I labeled the data with numbers as identifiers rather than names; any identifying names, locations, occupations, and other characteristics were removed during the transcription process; participants were given pseudonyms, which

allows their stories, experiences, and meaning to still be referenced back to a particular individual without disclosing the identity of that person; and other identifying information was altered to make specific information more general, such as profession and location.

However, I was concerned about how much information – even general information – I should disclose in the research, because I discovered that, even in a city with a fairly large population, there were many connections, both close and more distant, between myself and many of the participants, through friends, work, and family. Participants did not confess any major moral or legal transgressions that demanded high degrees of privacy, but I was mindful of the potential issues involved because of the private and sensitive nature of the stories conveyed. I stored consent forms in a different location, and the master list connecting participants to the respective codes, as well as personal information such as phone numbers and addresses, were kept separate and only available to the researcher. Because of the connections within our community, I took extra care when describing the participants, including revealing particular aspects or characteristics of their lives that could potentially reveal identities and cause a breach in trust.

There are many ethical issues to balance when conducting qualitative research. Beck (1994) argues that the ethical part of phenomenology “centers on accurately portraying the reality of the phenomenon under study as it is lived and described by the researcher’s participants” (p. 500). In doing so, the research is true to the participants’ meaning, and conveys credible understanding of the issue. However, along with this requirement to convey accurate understanding, there also needs to be sensitivity towards the participants so as to avoid any harm, embarrassment, or other negative consequences that may come out of their involvement in the research. It was an interesting task to portray the essence of the participants’ stories in a manner that also presented them and their experiences ambiguously enough to keep identities confidential. To deal with any concerns, participants have been encouraged to ask questions about the research throughout the process, and have my contact information if they have questions, concerns, or comments at any time. Toward the end of this research, they will be

supplied with a written report of the findings, to allow them to recognize their contributions.

### **3.5 Data Analysis: Translating Narratives into Sociological Knowledge**

After I met with each participant the first time, preliminary analysis of the interview was done in order to create the second interview guide. In this sense, themes were beginning to develop after the very first interview, and continued to form as more interviews were conducted. To develop the follow-up questions that were specific to each participant, notes that had been taken during the first interview were used, as well as reflections written down following the interview, and, in some cases, a review of the audio recordings was done. This allowed me to understand better the issues that were involved, and began to illuminate themes in the research. At the same time the interviews were being conducted, I was also reading relevant literature, and those ideas were used to inform emerging themes, and were also incorporated into the discussions. It became clear that various experiences and ideas were similar to particular participants, so while the discussions were unique to each woman, there were themes that had become apparent at this point.

The interviews were then transcribed to prepare the data in a manner that would be possible to conduct thorough analysis. Transcription can influence how data are conceptualized, as it is “a powerful act of representation” (Oliver, Serovich, & Mason, 2005, p. 1287). Interpreting the words of other can be difficult, as individuals incorporate their own experiences and ideas as they create meaning, so it is important to ensure that the participants’ voices are preserved throughout the research process. I took much care during the transcription process to include the intricacies of speech in order to maintain the authenticity of the meaning presented by the participants. That made it easier to understand the meaning behind the words, and allowed me to hear the participants’ voices as I read through the transcripts. Transcribing the interviews shed initial light on the themes of the research by giving me a general sense of the issues, and the transcripts were read through multiple times to begin to more concretely organize the data into themes. Another way that the voices of the participants are maintained is to include the voices of the participants in the text (Sprague, 2005), so I used direct

quotations to support ideas as the data were analyzed and presented. Because the quotations express the participants' streams of thought, which reveals the meanings that are constructed as the narratives are conveyed, they may create some challenges for the reader. However, it is important to preserve the women's voices as much as possible.

The abundance of data made it necessary to come up with a functional, understandable way to organize ideas and themes for data analysis. To manage the data, I used cross-sectional organization, where the data are cataloged in a systematic manner based upon particular measures and principles (Mason, 2002, p.150). The transcripts were coded in order to organize themes that came out of the interviews, and to highlight similarities and differences among participants' experiences. The process of coding involves organizing the data into "chunks" before establishing meaning of those "chunks" (Rossman & Rallis, 1998, p. 171, cited in Creswell, 2003, p. 192). Coding the transcripts established themes and subthemes that became the focus of the analysis, and after pulling out these major issues, they were incorporated into a visual model in order to visually depict the importance of and connections between themes. After I had established themes, significant quotations were highlighted and organized to further expand upon themes and clarify ideas. This was all done using hardcopies of the transcripts. The coding process continued until it was possible to present the findings in an organized and clear manner and construct a discussion of themes and ideas.

In addition to the process of organizing the data, the idea of reflexivity is another component required in qualitative research and relevant to the analysis process. Reflexivity involves the process of exposing one's presumptions, and then examining and questioning them to realize the implicit assumptions that they are based upon (Orbe, 2000, p. 611). Research that claims to be value-free does not recognize the impact that claims based on our experiences in the lifeworld have on research, whereas reflexivity places those at the forefront, so it becomes possible for the researcher's reality claims to be united with the participants' to get at the important meaning of the data (Murphy, 1986, p. 333). This is important for qualitative research because the meanings constructed and conveyed incorporate depth and layers of meaning from all of those involved, so researchers must disclose the assumptions that direct their understandings of the world in order to make data analysis as transparent and free from bias as possible. As

Orbe (2000) states, “A researcher’s positioning must be acknowledged and articulated as it functions within the existing social and power structures” (p. 611), which is an important element throughout every stage of phenomenological inquiry. While I was the researcher leading the study, my newness to the research process and the area of breast cancer created an eagerness to learn from and understand the participants. This required me to confront my limited understanding of the issues involved, and consider how my experiences would influence any understanding and assumptions I had as I spoke to the participants. I recognized that my age, my background, my gender, my political views, and a range of other characteristics inform my ideas and experiences of the world, which impact how I understand the participants’ stories. In order to really hear their experiences, it was important for me to recognize those factors, as my own self-awareness would allow me to more fully appreciate other points of view.

While the survey data was originally intended to support the qualitative data collected in the interviews, analysis of the quantitative data became secondary with the change in direction and the smaller number of participants. Socio-demographic information and some information about breast cancer and arm morbidity experiences were extracted from the surveys to create the participant profiles. Particular questions from the survey were also chosen to create tables to convey basic socio-demographic and health information.

To present the analysis of the data, the findings and discussion are included together. This weaves the experiences, ideas, and themes in a manner that conveys the close connection between the participants’ experiences and the understandings created, and allows the analysis to flow out of their stories and establish its basis in the lifeworld.

### **3.6 Meaningful Research**

In order to conduct meaningful research, it is essential that the knowledge created meets particular standards that determine its credibility or authenticity. Qualitative data collected through interaction and conversation with participants demands that the researcher make an effort to produce valid, credible knowledge: “Stories themselves do not replicate experience. Thus, both storytellers and social scientists improvise content, enact stories, and interpret their meanings” (Charmaz, 2002, p. 306). Data collected

through interviews involve interpretations of all individuals involved, and it is necessary for the researcher to understand how individual experiences and biases affect those interactions, and the analysis of data. One cannot eliminate bias in semi-structured interviews, because the interview cannot be separated from the social interactions in which it was produced: facts cannot be separated from contexts, so “[i]t is better to try to understand the complexities of the interaction, and to try to develop a sense of how context and situation work in interview interactions, than to pretend that key dimensions can be controlled for” (Mason, 2002, p. 65).

That awareness of the effect personal biases, experiences, and context have on the data collection process in qualitative research is important in order to ensure that the data is as credible as possible. To do this, I often asked for clarification during the interviews to ensure that my understanding was an accurate representation of the meaning conveyed by the participants. I also approached participants in a manner that would create relationships free of the power imbalances that can occur in research, so as to avoid any distortion of meaning due to the context. Throughout the process, including the analysis and writing stages, I also made sure that I was aware of my own meaning and biases in order to understand my voice in the research, and how that influences my understanding of the participants’ voices. With qualitative data, it is important to include rich description, clarify bias, and present discrepancies in the findings to create and present valuable, trustworthy knowledge (Creswell, 2003). There is much emphasis put on these criteria throughout the research process to ensure that the qualitative data is clear, thorough, and meaningful, and despite the small number of participants, it is possible to establish credible knowledge because of the richness and abundance of qualitative data.

The differences between establishing legitimate qualitative and quantitative data reflect the differences in the nature of the methods, and the small sample size in this research has different implications for the quantitative data collected. The criteria to establish legitimacy in quantitative data differs from qualitative requirements, and due to the small sample size, survey data in this research will not be used to construct knowledge by itself. While it does not create knowledge on its own, I learned valuable information about the participants’ breast cancer histories, the treatment they had and were receiving, and the symptoms they experience with their arm problems. The

quantitative data are used to expand upon the findings, but they are applied primarily for socio-demographic purposes, so there is recognition that this data does not have the validity, reliability, and other quantitative measures that allows for wide sweeping statements about the broader population.

### **3.7 Summary**

I have outlined the research design used in this study, including the methodological approach and the particular steps that had a significant influence on the overall research design. I have presented the connections between a phenomenological methodology and a general feminist theory, and indicated the value of including these in the research. This approach aims to create a description of the phenomenon by focusing on the lived experiences of those involved, and will allow the subjective meanings of the participants to create understanding of arm morbidity in the lifeworld. I then described the methods used to explore the research questions and the value of that design to the research, which helps establish the credibility and legitimacy of the research. Following, I indicated the process of participant recruitment and selection, which raised particular issues that caused a change in the original research plan, which I discussed in the next section. I then explained the ethical issues involved in this research, as well as the steps taken specifically in this research to attempt to produce meaningful research. Following, the elements involved in the data analysis were presented, detailing the steps taken right after the initial interview that eventually led to organized, meaningful findings, including elements such as the transcribing process, coding, and reflexivity. To conclude, I then discussed the idea of credibility as it relates to qualitative research, recognizing the subjective elements in meaning-making and storytelling. The design and process of research are very important in creating valuable knowledge, and I have outlined the steps taken to construct meaningful understanding that arose out of the lived experiences of participants. The goal of my research is to explore the effects of arm morbidity on the daily lives of women after breast cancer, and to understand the knowledge those women have about their health. The research design described above supports the exploration of the issues involved, and informs the remainder of the thesis.



## CHAPTER FOUR

### PARTICIPANT PROFILES: THE WOMEN'S STORIES

Before I discuss the analysis that emerges from the issues, experiences, and meanings that the participants conveyed, it seems appropriate to introduce the six women who are the focus on my research in order to paint a small picture of their lives. This is a way to put some context behind the voices that emerge throughout the discussion, and is intended to bring to life the individuals who have revealed their experiences in the lifeworld for this research.

The make-up of the women's lives – the roles they fill, the stages they are at, the histories that have constructed who they are as women – vary throughout the group. Table 4-1 provides some socio-demographic data of the participants to establish some of this information. In addition, all of the women who participated are Caucasian. In their cancer experiences, all of the women had lymph node dissections, but there is variation in their stories, such as time of diagnosis, type of treatments, and experiences in the healthcare system and in their recoveries. Table 4-2 provides information about the women's breast cancer treatment and arm morbidity. Table 4-3 reveals the women's reporting of pain in their lives, and Table 4-4 illuminates the difficulties the women experience in particular activities they carry out. All women experience some sort of arm problems, but each participant's story is quite unique, as there is variation in areas such as the type of problems, onset, and severity of symptoms; the limitations they experience; the physical changes that have occurred over time; and the care that is used for the arm problems.

***Denise:*** Denise is a fifty year old woman who lives in the city with her husband and their two children, who are in their younger teen years. The first striking thing I noticed when she welcomed me into her home was the abundance of boxes full of pots of dirt and small plants in her kitchen and living room in preparation for the approaching gardening season. That is her passion, and she was looking forward to the nicer weather, which would allow her to be outside and working in her yard. Denise completed a degree at university and became a teacher. She works part time because her health issues make her susceptible to many illnesses throughout the year, and cause her pain in her upper body throughout the day, partly due to her arm morbidity, but also as a result of other health

issues. She was very quick to make me feel welcome, and the ease with which she opened up suggested to me that she is a woman very comfortable with who she is in this world, and has a very independent spirit.

Her cancer experience began at the age of 43. Denise was diagnosed with breast cancer in both of her breasts, and had surgery in July of 2000. Nine lymph nodes were removed on her right side, and eleven on the left, but none were positive. As noted earlier, having more than five lymph nodes removed is a risk factor for developing lymphedema. Chemotherapy was part of her treatment, and she made the decision to have breast implants put in. Denise's story is unique, in that she had a complex experience since diagnosis. Her husband also had a very serious illness shortly after, her family was in the process of moving into a new home, her children were quite young at the time, and she has also had other issues with her health that have been causing her to have pain in her daily life.

Denise indicates that she has had lymphedema since surgery, and has been told by medical professionals that it is a mild case. She is right handed, having problems with lymphedema in her left arm, and cannot go without her compression sleeve for support. But because she had both breasts removed, she has to take caution with both sides of her upper body, and her problems are not limited to just one side. She also mentions that pain and tightness are part of her symptoms, and describes that tightness going up into her shoulder, affecting her shoulder and her neck. As Denise explains, *it's very stiff, it's stiff. It feels like any swollen joint, like if you've sprained an ankle or something, it's stiff. Um, and, and the pain, the uncomfortableness is more in the upper arm and down into the, ah, under the armpit. And, yeah, but you're always still swollen.* She engages in three days of exercise involving her arm per week, on average, but she indicates that she feels as if her problems have been getting worse in the past three years. She said, *Like it just, the pain has accumulated, the pain, the heaviness, the tightness across. I guess any, um, scar tissue is intensified.* As mentioned, Denise also has other physical issues that cause her to experience pain in her daily life, so the limitations in her life cannot be solely connected to her arm problems. In her vulnerable physical state, she is very aware of infections that exist in the air, as she has difficulty, especially in the winter months, because she often gets quite sick.

**Renee:** Upon meeting Renee, it was apparent that she is one of those people who has much fun in life and loves to laugh. She welcomed me into her home, offered me what has now become my favourite tea, and as we talked she was always quick to describe the positives in her experiences. Renee is a fifty year old woman with two grown children living away from home, and it is clear that family is so important to her: her children; her extended family, who are a very significant part of her cancer experience; and the grandchild who was supposed to arrive in a mere couple months, making her a grandmother for the first time. Renee lives alone in the city, having gone through a divorce many years ago, has finished community college, and works full time as an office manager.

Renee was diagnosed with cancer in her right breast, and had surgery in February of 1996. Thirteen lymph nodes were removed, and seven of those turned out to be positive. She had radiation, chemotherapy, and hormonal therapy as part of her treatment. She mentions that there was no history of cancer in her family, so that was the last health issue she was concerned about prior to diagnosis. However, since her experience, there have been other members of her family who have been diagnosed with cancer.

About a year after surgery, Renee noticed swelling on her right side. The swelling was not significant at first, but her arm continued to get bigger, and at this point in time the lymphedema is quite noticeable because of the size of her arm. She has never been hospitalized as a result of infection, but she has been on antibiotics between four to five times. Renee does not have pain or a limited range of motion in her upper body, so her major problem is the lymphedema. As she indicate, *my biggest complaint, in fact, I think my only complaint since, is the swelling in the arm*, although she also indicates that she has recently experienced some numbness in her arm. Renee engages in an average of four days of exercise involving her arm per week, and in this group of women, is probably the least limited in terms of ability.

**Angela:** Angela is a busy woman in her retirement years. She was quick to offer her help, and was willing to be very accommodating, but it was evident that her life is scheduled with many commitments and appointments that keep her busy. At 65 years of age, she lives just outside of the city in a house by herself, with a big yard to take care of.

Her highest level of education completed is high school, and she had been working but is now retired. She is widowed, and her child is grown and lives elsewhere, so she does not have family living in a very close proximity, but she surrounds herself with people through her involvement with social groups and various organizations. She seems to be happy to be a part of the groups, but mentions that it is causing her life to be busier than she wants, as she occupies important positions in a number of them that require her to invest much time and energy.

Angela was diagnosed with breast cancer in 1999, having surgery in her right breast in August of that year. She had twelve lymph nodes removed, and they found one of those to be positive. Her treatment included radiation and hormonal therapy, but no chemotherapy. She is also quick to mention that there was no history of cancer in her family, and is interested in the link between nutrition and cancer.

Angela had problems with her right arm starting about four months after her surgery, which is her dominant side. She has lymphedema in that arm, but while she always carries her arm band with her, she does not use it all the time. On top of the lymphedema, she experiences pain, throbbing, and aching as symptoms. She said, *It was just that it was very tender. I'll lean back and it would hurt.* It is not a constant pain, but when she exerts her arm more than she should, she will suffer the consequences and have more swelling and pain. She does not experience a limited range of motion in her arm, so she is quite capable of doing most things, but it is often afterwards when she will have difficulty with her arm. Her engagement in various organizations is probably what puts the most strain on her arm, because while she can choose to stop or slow down in other areas of her life, those obligations require her to work at certain times.

**Jillian:** Jillian is a 57 year old woman who is quick to make a joke and laugh at her own expense, in order to put everyone else at ease. We met the day before the anniversary date of her cancer diagnosis, nineteen years prior, and while she says she has become less outgoing in those years, she still exudes positive energy and warmth as she engages with people. Jillian lives with her husband outside of the city, and is a mother to two grown children, with four grandchildren. She completed community college when she was younger, and works full time as a library technician. It is evident in her words that the day of diagnosis was the beginning of many changes in herself that she is not happy

about, but she seems to take them in stride and does not want to dwell on those negatives.

Jillian had surgery in April of 1989 after she was diagnosed with breast cancer in her right breast. Nineteen lymph nodes were removed, and three of them were positive. She had no hormonal therapy in her treatment, but she underwent both radiation and chemotherapy. Jillian had a very isolating experience as she was dealing with cancer. She felt as if the care she received was excellent, but she did not feel as though she had much support to navigate through the other issues involved.

Problems on Jillian's right side, which is her dominant side, began right from day one. She had lymphedema from the onset, and while she has never been hospitalized for infections in her arm, she has been on antibiotics eight times as a result of infection. In addition to the swelling, she also experiences pain and has some problems with her range of motion. Jillian does have significant swelling, but as she describes, *Mostly it's the aching, more than anything else*. She experiences that pain primarily in her shoulder, and it is most severe when she has been using her arm too much. She does find herself in many situations where she is unable to avoid aggravating her arm, as her job requires her to work with heavy books, and she is primarily responsible for the work around her home, so she experiences that aching quite often.

**Laura:** The first thing that most people would think about Laura is that she is too young to be participating in a study involving breast cancer survivors. If anybody had seen us talking, they would have probably assumed that we were two friends discussing the normal joys and trials of early adulthood. However, what is not obvious is that Laura had to deal with breast cancer during those years, so her story of early adulthood includes her breast cancer narrative. She is the youngest in the group of women involved, at thirty years of age, and is married with no children. Laura previously completed an undergraduate degree, and is now a graduate student also working part-time as a dietician in the city. What comes across, and is possibly telling of her life both as an academic and within the healthcare system, is that she is very active in seeking out evidence-based information related to her health, as she believes in prevention and wants to live well and be healthy.

Laura found a lump in her breast when she was twenty-six. The doctors told her she was too young for it to be breast cancer, and she said she wanted to be too young, but she had surgery on her left breast in January of 2007. Five lymph nodes were removed, none of them being positive, and she underwent radiation therapy, chemotherapy, and hormonal therapy. She was also the only participant who had experienced a postoperative infection that required antibiotics, which is also a risk factor for lymphedema. All other participants were receiving care from their family physician, but Laura was still under the care of not only her family physician, but also a surgeon, oncologist, and gynecologist.

Laura, who is right-handed, is experiencing problems on the left side of her upper body. She primarily experiences pain and a limited range of motion, which has been the case since surgery. When discussing the postoperative infection, she says,

*that actually, I think, has made me have more pain instead of, having had an infection. Um, and because that's, before that I didn't really have, I mean, I had pain, but it was more, like, I-just-had-surgery pain, and, I don't know, this is kind of different. I don't know how to describe it. But I think it's made me have more pain and more stiffness and more, um, lack of, of range of motions, and things like that than I otherwise would've had.*

She also notes that her symptoms include a strange sensation in her arm, and is concerned because she is just beginning to notice some swelling in her arm and hand. She is very motivated to try avoid lymphedema, so she reads much of the latest information, but between the first and second interview, she experienced a scare when her hand swelled to the point that it was not recognizable.

**Janet:** At sixty-five years old, Janet is a woman who seems to be very self-assured, as she speaks with a confidence that indicates the trust she has in herself – in her ability to make choices, in her right to be the expert of her experiences, and in her capacity to live a life that works for her. Her husband died suddenly many years ago, and she lives alone in the city, with two grown children living nearby with their own families. She completed a graduate degree and had worked in the past, but she is now retired and able to live well enough that she does not need to do many things she feels she is unable to do, or that she does not feel is worth risking her health for. Janet has experienced another quite

traumatic event in her life prior to her cancer diagnosis, when her husband died suddenly, so she already had a support system in place when she learned she had breast cancer.

Janet had breast cancer in both breasts, although this occurred at two separate times. The first surgery she had was in December of 1996, where fourteen lymph nodes were removed, and seven were found to be positive. The second surgery, which led to Janet experiencing more physical difficulty with her upper body, took place in October of 2005. During that time, she had eleven lymph nodes removed, and there were no positive ones found. Janet underwent radiation during one of her breast cancer treatment regimes, and had chemotherapy and hormonal therapy during both. She made the decision to have breast implants put in after surgery. She is under the care of her family physician, but it was only recently that she did not have more health professionals involved in her breast cancer care.

Janet is right handed, but her problems are situated in her chest. She has pain all across her chest, but while lymphedema can occur in the chest wall, and she has had swelling at times, she has not been diagnosed with lymphedema. She has also had problems with her range of motion, although that has improved. What Janet struggles with is what she refers to as chronic discomfort, which she distinguishes from her previous experiences of chronic pain. Explaining her physical symptoms, she states, *when you deal with pain, um, and you're always uncomfortable in your body, chronic pain makes you kind of crazy, and, um, that's what I deal with.* Janet has been working with a physiotherapist to manage the pain in her chest, and a unique part of her story is that she has made much progress in the past few years.

***The Participants:*** The women involved in this research were all extremely generous in their willingness to open up and share their lives and thoughts. They reveal stories of hardship and perseverance, they express the renegotiation and reevaluation in their lives since breast cancer, and the strength in each participant is evident as they find ways to manage their health issues and see positive meaning in difficult situations. The understandings the women construct of their lived experiences of arm morbidity after breast cancer informs the sociological analysis presented in the following chapter.

**Table 4-1 The Women’s Lives: Socio-Demographic Information**

	<i>Marital status</i>	<i>Highest Educational level achieved</i>	<i>Involved in workforce?</i>	<i>Children at home</i>	<i>Age</i>
Denise	Married	University Degree	Part-time	2	50
Renee	Divorced	Community College	Full-time	0	50
Angela	Widowed	High School	Retired	0	65
Jillian	Married	Community College	Full-time	0	57
Laura	Married	University Degree	Part-time	0	30
Janet	Widowed	Graduate Degree	Retired	0	65

**Table 4-2 The Women’s Health: Breast Cancer Treatment and Arm Morbidity**

	<i>Time since surgery in breast cancer treatment</i>	<i>Experiencing lymphedema?</i>	<i>Used antibiotics for an infection in fingers, hand, or arm?</i>	<i>Days per week participating in exercise involving arm?</i>
Denise	8 years	Yes	No	3 days
Renee	12 years	Yes	4-5 times	4 days
Angela	10 years	Yes	No	0 days
Jillian	19 years	Yes	8 times	0 days
Laura	1 year	No	No	2 days
Janet	3 years	No	No	6 days



**Table 4-3 Feeling Bodies: Numbers of Women Reporting Experiences of Pain**

<i>Type of Pain</i>	<i>None</i>	<i>Mild</i>	<i>Moderate</i>	<i>Severe</i>
Throbbing	4	1	1	
Shooting	4	1	1	
Stabbing	6			
Sharp	4	2		
Cramping	3	3		
Gnawing	5		1	
Hot-burning	3	2	1	
Aching	2	1	2	1
Heavy		3	3	
Tender	3	1	2	
Splitting	6			
Tiring- Exhausting	3	1	2	

**Table 4-4 Impacted Abilities: Numbers of Women Reporting Range of Motion Restrictions**

<i>Activity</i>	<i>No Difficult y</i>	<i>Mild Difficult y</i>	<i>Moderat e Difficulty</i>	<i>Severe Difficult y</i>	<i>Unable</i>
Open a tight or new jar.	3		2		
Write.	3	1			1
Turn a key.	4	1	1		
Prepare a meal.	5	1			
Push open a heavy door.	3	2	1		
Place an object on a shelf above your head.	4	1	1		
Do heavy household chores.	1	3	1	1	
Garden or do yard work.	1	3	1		1
Make a bed.	5	1			
Carry a shopping bag or briefcase.	1	3	2		
Carry a heavy object (over 10 lbs).		3		2	1
Change a light bulb overhead.	3	1	2		
Wash or blow dry your hair	3	3			
Wash your back.	4	1	1		
Put on a pullover sweater.	3	2	1		
Recreational activities which require little effort.	4	2			
Recreational activities in which some force or impact is involved.	1	2	1	1	1
Recreational activities in which you move your arm freely.	1	2		2	1
Manage transportation needs.	5	1			

## CHAPTER FIVE

### MAKING MEANING OF ARM MORBIDITY EXPERIENCES

Not only do language and narrative help sustain and create the fabric of everyday life, they feature prominently in the repair and restoring of meaning when they are threatened. Under conditions of adversity, individuals often feel a pressing need to re-examine and re-fashion their personal narratives in an attempt to maintain a sense of identity. (Bury, 2001, p. 264)

In this chapter, I explore the meanings women have constructed of their experiences of arm morbidity after breast cancer. Health impacts how we live in the world, and the social world impacts how we understand, experience, and manage our health. Because of normalized ideas of health and the body, the environment is established in a way that assumes a particular type of body that can function in a standard way (Weitz, 2004), which means that health and ability are major factors in how we are able to live our lives in the social world. The women's narratives of arm morbidity experiences indicate the importance of health and our bodies in our daily lives, and portray the resulting renegotiation in life that occurs as illness and physical limitations influence who we are and how we can be in the social world. Major themes that emerge from the women's narratives make it clear that experiences of our bodies and our health in daily life are complex and interwoven, and there is a continuous process of meaning-making and renegotiation to create understanding and allow us to navigate through life with our health.

In the first major section of this chapter, I focus on the broad idea of Managing Health, related to the meanings the women have created of their physical condition and their medical encounters as they experience their health, live in changed bodies, and grow in their understandings of arm morbidity as a chronic illness. Four primary themes that I present as of primary importance to the women's experiences of dealing with their arm morbidity as a health issue are a) embodiment, b) treatment, c) information and knowledge, and d) support. These four themes raise sociological ideas and understandings about health, illness, and disability, and push experiences of arm morbidity beyond the biomedical field as the social nature of health and healthcare become evident. It is not only an issue of a sick body: It involves the women's explanations of health; how they understand their bodies; how they cope with their

bodies; and how they deal with the realities of chronic illnesses and new disabilities. In other words, the experiences go further than the physical body and incorporate how we navigate through life with our health, in our bodies.

In the following section in this chapter, I discuss the broad idea of Managing Lives, as arm morbidity impacts the participants' interactions and engagement in the social world while they try to carry out their lives, fill particular social roles, and understand their identities with arm problems. Three major themes I discuss related to the women's daily lives are a) changed abilities as they relate to the women's social roles, b) ideas of identity as health changes, and c) understandings of life as they are affected by experiences of health. The women reflect on a wide range of areas in their lives that are important in the experiences of arm morbidity, and a number of themes surface that portray how much health influences our day-to-day lives. The experiences of arm morbidity involve the women's understandings of their changed abilities and resulting limitations, the impact those have on the roles women fill and the interactions they engage in with others, and the effect that health, the body, and ability have on identity.

These themes that have emerged and illustrate new understandings of both health and daily life resulted from my interviews with the participants, as they related their understandings and experiences of arm morbidity to their health, their engagement with the healthcare system, and their social lives. By combining both the findings and analysis in these sections, I present experiences of arm morbidity that weave stories and understandings of health with stories and understandings of daily life. The women place varying levels of emphasis on the issues that we discussed, they have unique stories and experiences of arm morbidity, and all have different ways of creating meaning in their lives. However, each of the participants expressed thoughts, meanings, and experiences that include aspects that fall within the themes presented in the next two sections. Their ideas and words are included in this chapter.

### **5.1 Managing Health: Constructing Understandings in Illness**

The emphasis [in the embodied perspective] is on the moving, thinking, feeling, pulsing body; the lived body as a mindful, intentional site of on-going experience, a spontaneous synthesis of powers, and the very basis of our being-in-the-world. (Merleau-Ponty, 1962, cited in S.J. Williams, 2006, p. 10)

Major themes that emerge from the discussions make it clear that health is a central focus in the participants' lives, and how they manage their health is a major part of the experiences of arm morbidity. Living with, managing and coming to terms with their changed health are important factors as the women experience bodies with arm problems resulting from breast cancer treatment, and four major themes surface from the women's stories, which I will discuss in the following pages. The first theme focuses on the women's experiences of their bodies in their lives, which approaches the idea of embodiment as it is related to arm morbidity. This includes the physical realities the women face during daily life, the heightened self-awareness of the body because of arm morbidity, experiences of a changed body, and the meanings that were made of the symptoms. The second major area involved in managing health is the experience of treatment, which looks at formal treatment and self-care, relationships with healthcare professionals, and experiences in the healthcare system. A third theme that arises is the knowledge and information involved in experiences of arm morbidity, as the women discuss the lack of information they received, the limited expert knowledge that exists, and the inclusion of lay knowledge in their understandings. Finally, I discuss the issue of support, which includes both formal and informal support systems, the benefit of close relationships on experiences of health, and the individual's role in wellness. The meaning and understanding these narratives have to offer sociological thought is in abundance, and suggests that further sociological inquiry about the experiences of arm morbidity would benefit understanding of the social implications of arm morbidity.

### ***5.1.1 Experiencing Bodies with Arm Morbidity***

The emphasis on the lived body, using the concept of embodiment, places focus both on how we experience the world in our bodies, and how we experience our bodies in the world. The biomedical understanding of health does not always incorporate the idea of embodiment, so patients' experiences of their health in daily life are not recognized to the degree that corresponds with the significance those experiences have in patients' lives. The women involved in this research did discuss some of the biomedical understandings of their bodies in the explanations of arm morbidity, but their narratives focus more on their understandings as they experience and feel their bodies. In other words, what is actually happening to the body, from a medical perspective, is a part of the

women's experiences, but what is more significant as they live with arm morbidity is how they experience those medically-defined, physical changes.

The illness narratives presented by the women include similar experiences of bodies with arm morbidity, as the women manage pain, lymphedema, a limited range of motion, or a combination of these. Biomedically, the women are in comparable states, as they received the same types of treatments, their bodies have gone through similar ordeals, and their physical conditions now differ from the norm in similar ways. However, sociological thought suggests that, while the women's bodies may differ from the medically-defined healthy body in similar ways, illness experiences move beyond diseased bodies and involve social environments, norms, interactions, and constructions experienced and created in the social world. Both biomedical and social similarities create common experiences in the women's stories, which are evident in some of the words frequently conveyed by the women, including: *stiffness; pressure; swollen; fullness; heavy; throb; pain; uncomfortable; aching; sore; discomfort; tightness; burning; and squeezing*. The discussion of the symptoms reveals commonalities in the physical experiences of arm morbidity, as bodies are in similar biological states and impact the women's experiences of illness in their social contexts.

However, while commonalities exist in the women's experiences, the variations in the women's narratives reveal the multiple truths that Bell (2002) says are present in illness narratives. This suggests that experiences of arm morbidity go beyond the biomedical, as understandings reveal personal and meaningful experiences of the body in the context of the social world, and supports sociological understandings of health and illness. From a biomedical perspective, the women receive the same diagnosis for and explanation about lymphedema, for example, with variation only in the degree of severity in their diagnosis. However, the women's explanations of arm morbidity go beyond the physical body as an uninvolved thing, and incorporate their bodies as involved entities in their experiences of the world. These experiences of embodiment in the arm morbidity narratives create different experiences and truths. Describing the chest pain she experiences, Janet says, *At first it felt like I had a block of wood in my chest that was trying to get out*, while Denise expresses that the lymphedema makes her hand feel *Like you have a tight glove on*. Jillian, who has lymphedema, discusses her most recent

experience of infection in her arm in a similar way, using imagery to describe the effect it has on the way she feels her body:

*I had an, um, an infection in my arm about three weeks ago, and since then I've noticed... it feels like as if I had a wad of Kleenex underneath my arm, and I haven't had that for a long time, but since I had the infection I've noticed that that's been back there again.*

The women feel and experience their arm morbidity in ways that diverge from the biomedical understanding, and it is apparent that they do not simply have arm problems, but they experience arm morbidity and navigate through life with their living, feeling bodies. Laura, who recently noticed swelling in her arm in addition to her pain and limited range of motion, discusses concerns that she has been waking up with her arm and part of her hand *being asleep*, and feels a loss of sensation in her arm: *I hate when people touch me on this arm, because I've lost some of the sensation. I can feel, but it doesn't feel normal.* She feels her body as she interacts in the social world, and is aware of her arm morbidity issues as she feels her body differently. The unique ways each of the women experience her body with arm morbidity presents the complexities and ambiguity in illness that influences experiences, reflecting the social nature of health. The women's understandings suggest that arm morbidity is not straightforward and completely biomedical, which emphasizes the need to construct sociological understandings, because the women's narratives included their unique experiences and meanings of their bodies in the world.

The intensified or different way of feeling bodies due to arm morbidity brings a heightened sense of awareness or consciousness of bodies for the women. The physical realities of arm morbidity, and the impact any sort of strain can have on the severity of symptoms, cause the women to think of their bodies more than they had been. This brings to mind Thornton's (1998) idea of health as a development of awareness, rather than a dichotomy of health and illness, and suggests that those experiencing health issues embody that development of awareness as they gain understanding and continuously, consciously manage their health. Some of the women indicate that this awareness of their bodies is a constant state, and Janet says that the continuous discomfort she experiences in her chest *gets wearing*. Denise, similarly, discusses the constant state of feeling her

arm morbidity issues in relation to what she would consider a healthy body: *[Normal] would be, just being able to not think about it. Not have to, ah you know, to always have it in your thought process and want, and in just some of the decisions you're making.* This statement coincides with the idea that chronic illness disrupts previous taken-for-granted assumptions about having a body that functions smoothly (Charmaz, 1995, p. 657), and van Manen's assertion that "The most common manner of experiencing the body is in the mode of near self-forgetfulness" (1998, p. 11). What would be considered a healthy body, according to Denise, is a body that does not require a person to have to think and experience it all the time, or a body that supports taken-for-granted assumptions. The women's bodies do not encompass the normal ideal, and as a result they are now in a continuous state of experiencing their bodies in their daily lives, which suggests that embodiment is realized or recognized more by individuals outside of the realm of ideal health. This is reminiscent of ideas that suggest disability creates a unique understanding of the body (Swan, 2002), as disability and arm morbidity both cause individuals to continuously think about and negotiate their bodies in the social world, which is structured based on socially constructed ideas of a healthy body. Prior to arm problems, the women had previously been able to avoid thinking about and recognizing how they experienced their bodies, but the changes to their physical states made it more present in their thoughts, and created more awareness and understanding of the relationship of their bodies in their experiences in the lifeworld.

The women also discuss a heightened sense of awareness of their overall health in their illness narratives, indicating that arm morbidity actually impacts the relationship with the whole body. This was apparent in the thoughtful care that each takes to stay healthy, but is also expressed by a number of women who feel more in tune with their bodies, and by the care they take to avoid further illness or strain on their bodies. The women find that a lack of sleep, dehydration, increased body weight, or a lack of attention to nutrition can intensify the pain or swelling, so they are conscious of their overall health to manage their arm morbidity. Participants are also exposed to illnesses more frequently, and many struggle to overcome those illnesses over a longer period of time, meaning that they spend more time living in an ill body than they had previously. Because of this, some of the women indicate they have a high level of awareness of their



bodies in order to manage their arm morbidity and their overall health. As Renee explains:

*Before, you know if you had, um, say, a cut or, even more than that, even like, you know, um, say you got sick, like with a, a cold or a flu or anything like that, you never worried about it, I mean, it was just a cold or flu. But since, um, I pay more attention when I do have something, cuz I'm not prone to colds and flus and stuff like that, so when I do get anything, um, you always have to be aware that, because my body has been compromised.*

While more attention is given to the body to manage arm morbidity, Denise also mentions that her arm acts as an alarm to notify her of impending illnesses: *[T]he more under-the-weather you feel, the more I'm combating something, definitely I will feel it in my arm up in two weeks before any symptoms. So before I have a runny nose, before I have my first sneeze, my arm will swell up.* In a biomedical sense, arm morbidity may be confined to the area of the upper body that is impacted, but to the women, the experience of arm morbidity involves their whole bodies.

The awareness of their bodies also serves as a reminder of the women's experiences of breast cancer as they live with the effects of treatment and experience a changed body. McKenzie and Crouch (2004) indicate that the cancer experience does not end after the cancer is removed, which is apparent as the women weaved their stories of arm morbidity with their experiences of breast cancer. This also coincides with other accounts of breast cancer survivors that suggest experiences of breast cancer are not over simply because acute treatment has ended (Thomas-MacLean, 2004). There was no indication that the women's cancer experiences ended at an obvious point, and their experiences of arm problems began separate from that. Instead, their narratives of arm morbidity are a continuation of their experiences with breast cancer. The reasoning behind this for Laura is the way her body looks and feels since treatment:

*Constant reminder – yeah, and just, you kind of still have moments when you're like, ah, why did this have to happen and, um, so, the physical aspect makes it, I mean, I guess, triggers the mental sort of agony that you went through, and just, um, if that wasn't there, if you didn't have scars and then, I don't know, maybe*

*you wouldn't remember as much, maybe you would, I don't know. But it's definitely a, um, visible reminder.*

Treatment of the cancer may have removed it from their bodies, but the illness experiences went beyond the biological disease, and the women's breast cancer narratives continued after treatment, and persist in the experiences of arm morbidity.

The idea of chronic illness as a biographical disruption (Bury, 1982) is also relevant to the experiences of arm morbidity, as the women are required to adapt to changed bodies. Renee is quite positive in her outlook, and does not see the adjustment to her body with lymphedema as a difficult transition: *I just took it in stride. Yeah, like, you know, okay, this is the way it's going to be, so now try to maintain, try to prevent injury from the arm.* However, most of the women discuss the difficulty they have had, and in many cases continue to feel, about their altered, physical bodies. The women talk about the uncertainty they feel, as arm morbidity makes their bodies unpredictable and more difficult to understand. Laura talks about how she is still bothered by the lack of sensation in her arm, which makes her body feel *foreign*. The women also discuss bad days, anxiety, depression, and thoughts of suicide that are involved during the struggle to understand and manage their bodies. The stories include both positives and negatives along the journey: Laura says, *Ah, it's hard to separate out just the arm problems, um, from everything else, but, ah, I definitely, I, ah, had a lot of anxiety after treatment, depression. Um, yeah, just, I had a lot of ups and downs for sure.* Experiences of arm morbidity include emotional issues that the women struggle with as a result of the changes to their bodies, and they continue to develop in their understandings of those issues as they live with arm morbidity. Janet describes her evolution of dealing with pain issues in this way: *Like, I can have a day of pain and then tomorrow will be a better day, so. When you're right into it, at first, you don't know for sure if there's gonna be a better day, that's the problem.* The women's experiences of arm morbidity involve a continuous adjustment of understanding because of their health, and they construct meaning from their experiences to help them manage their health in their lives.

There is indication of the women's difficulty in reconstructing identities to incorporate the experiences of a body with arm morbidity. The difficulty in reconstructing identities is related to Bury's understanding of the reconceptualisation of

identities involved in chronic illness (1982), and is also relevant to the struggle to develop identity with disability because of its construction as a moral and physical inadequacy in society (Weitz, 2004): The more the women's bodies change, the more different they are from the norm, and the more they are required to construct new meaning and identities to adjust. How the women create new meaning of their bodies seems to rely on how they experience their bodies, including the improvement or deterioration of their arm problems, how intense the symptoms are, and the impact their health has on other areas of their lives. This would presumably be the case because those who are less affected by arm morbidity have to make less of an adjustment to their identities, while the women who are more affected are required to make a bigger adjustment to include the changes.

The adjustment to new bodies illustrates that, in many cases, new ideas of a normal body are created that diverge from social understandings. Angela conveys that she has become comfortable with her new body, comparing it to having Multiple Sclerosis or another chronic illness, but does say that it would be upsetting if her arm problems progressed. Denise explains that her swelling had gone down at one point after undergoing surgery for other health issues, but then it went back to its *normal state*, meaning that she now considers normal to be her arm with lymphedema. However, at the same time, her new understanding of her normal physical body does not mean that she experiences her body normally: *[I]t's all kind of stupid stuff that I feel like I'm talking about, but you're almost fanatical now, because... with lymphedema you feel like you're infested with something. Constantly. And you want to get rid of it. It's, it's, it's weird.* The idea of infestation is interesting, as it suggests that her body has been invaded by something foreign, and implies that there is an intrusion as she interacts with or experiences her body. Denise does not say she feels infected, which would perhaps refer to a more biomedical experience of the body, but indicates that she is dealing with something else besides her self and her body. This is reminiscent of other findings in the area of chronic illness, including Charmaz's understandings about adapting to impairment (1995). A similar idea of illness is presented by Lindgren (2004), who suggests that, because it is often thought of as a foreign agent, and experienced as unfamiliar and alien, illness and disability can both involve feeling as if the body is an other within the self. In this case, it appears as if there is a third entity involved in the experiences of bodies with

lymphedema, as there is something present, and unwanted, that is altering the relationship between the body and the self.

The social nature of health is also revealed in the meanings some of the women create about arm morbidity, as they search for answers about the causes of arm morbidity in their own lives and actions, rather than looking at the biomedical issues. Jillian takes responsibility for the state of her body, as she struggles to manage her health: *I think just, you kind of feel betrayed. You know, like why did, why did it all of a sudden start creating... why did I create this in my body?* This parallels other findings about experiences of women with arm morbidity issues after breast cancer, where women suggest that arm problems are a type of betrayal (Thomas-MacLean et al., 2008). Along the same lines, Denise says, *You know, I never blame God, I always usually blame myself, and I think that's why I'm left with a lot of unanswered questions, because you always think, well, I'm to blame. I think most women do that to themselves. They usually look at themselves for making wrong choices.* The women's narratives of arm morbidity go beyond the biological, as the meanings they construct incorporate social experiences and understandings.

### **5.1.2 Treatment: Continued Care after Breast Cancer**

The treatment of arm morbidity is another central idea in the experiences of the women, as they navigate through their lives and deal with arm morbidity. The women engage in both formal treatment and self-care for their symptoms, and are focused on prevention as they manage their health. They seek out a wide range of professionals for help, including physiotherapists, chiropractors, massage therapists, homeopathic doctors, pain specialists, acupuncturists, counselors, social workers, and personal trainers, and a number of treatments are discussed, including: acupuncture, cortisone injections and other drugs, vitamins, herbs, exercises, arm pumps, and yoga. As Denise says, *You do the gamut.*

The women express both positive and negative experiences with formal treatments for their arm morbidity, and while the progress or failures of those treatments are a part of those understandings, the women are more impacted by the social interactions involved. Janet praises her family physician for the diligence that was put

into finding her proper help from other professionals, and considers her physiotherapist the best person in her treatment:

*The physiotherapist is the person who's given me, ah, a real listening ear, who's explained things, and who's acted like a personal coach to keep me motivated to work on my arm and pain problems, and, ah, you know, the way she explains it to me, ah, it makes a lot of sense, and she, um, she encourages me to keep doing things like swimming.*

While she experiences positive outcomes in the treatment for her arm problems, what she appreciates most is the way those health care professionals engage with her as they work together. This engagement indicates the positive outcomes in collaboration between professionals and patients in experiences of arm morbidity, rather than relationships based on the authority of the physician or expert, which supports arguments that call for partnerships between patients and physicians. Denise indicates the importance of the patient-physician relationship in the experience of arm morbidity when she asked her doctor to keep her in mind when information about treatments for lymphedema arose, saying, *I want... me to be in your thoughts*. This supports Henwood et al. (2003) and Lorber (1997), who indicate that patients' empowerment, control, and independence result from the transfer of quality information. Positive experiences for the women have less to do with the progress of their arm morbidity issues in treatment, and more to do with the encouragement, support and information health care professionals provide, including a level of communication that establishes confidence about their health.

There are also many negative experiences discussed about the formal treatment involved in arm morbidity issues. Most of the women mention a lack of information they received about arm problems after breast cancer treatment, which caused experiences of frustration, uncertainty, discouragement, and distrust. These negative experiences support the argument of Epstein et al. (2005), which is that new theories and tools need to be established in order to improve communication in healthcare. Treatment for arm problems right out of the hospital was not positive for most of the women, as a result of the processes established in the healthcare system: Denise feels as if there had been a mix-up in her experience right after surgery, as she had received a pamphlet about arm problems but did not receive a visit from a physiotherapist, as she had heard others had.

Similarly, Jillian feels as if she *must have fallen through the cracks*, because she did not get attention or information when she left the hospital. This idea corresponds with findings of the experiences of Aboriginal breast cancer survivors, who also felt as if they had fallen into the cracks (Poudrier & Thomas-MacLean, 2008). This reiterates the importance of communication between health care professionals and patients in order to provide quality care. It also supports the notion that a lack of control has negative implications for the experiences of patients in the healthcare system (Abu-Laban & McDaniel, 2001), as the women's negative experiences of treatment are largely due to the feelings of a lack of control and security because of the little attention and information they received about arm morbidity issues.

The women also discuss problems they encounter due to their physicians' lack of knowledge about and treatment for arm morbidity problems. Jillian's doctor recommended that she not use a compression sleeve for her lymphedema when she started having problems, suggesting that it would not help, but many of the women discuss the importance of wearing their sleeves to help with their lymphedema. The physician, in this case, has been asked to assume the role as the perfect agent (Gafni et al., 1998), but was not equipped with the level of expert knowledge to actually be of benefit to the patient. Jillian took it upon herself to make an informed decision, and her understanding, which goes beyond the biomedical knowledge and incorporates experiences from daily life, led her to choose the compression sleeve as part of her care. The physician's misinformation, while not preventing Jillian from wearing a sleeve, compromises his or her ability in this role as perfect agent, and discourages the patient from using something that could potentially benefit her health, which illustrates both the ambiguousness of arm morbidity treatments, and the importance of women making decisions that involve their own understandings of health.

In a similar sense, the lack of knowledge of arm morbidity causes some of the women to question the treatments they receive. Because of the fragile state of her body, Janet says she would be more trusting if a physiotherapist or a massage therapist or other professional was trained specifically to deal with arm problems after breast cancer treatment: *I guess I'm real cautious now, because it costs me big time when I do things I shouldn't*. The gaps in expert knowledge about arm morbidity create hindrances and

frustrations for the women as they try to care for their arm problems, because both misinformation and inaction can potentially cause harm to their arm morbidity issues. Those who fill the role of the perfect agent, in regards to the women's health, do not have the knowledge and understanding necessary to treat their bodies appropriately, which makes the women lose trust in those who act on their behalves. Because of the unique, more comprehensive understandings the women have of their health, their knowledge can in fact inform the professionals and fill some of the gaps in expert knowledge, which would require a shift in the interactions between patient and professional – from the physician as a perfect agent, to more of a partnership, where knowledge is shared and received from both parties. This adjustment supports Turner's (1987) assertion that doctors need to pay more attention to lay knowledge, as those physicians and others involved in treatment could benefit from the women's lay knowledge that they have constructed about arm morbidity issues.

The treatment of arm morbidity is a multi-faceted challenge for the women, as they encounter both physical and financial costs as they manage their health. The lack of knowledge about arm morbidity puts the women at risk of straining their bodies in treatment, getting misguided or harmful treatment, or not receiving treatment at all when there is opportunity or need. In addition to these physical costs, many of the women discuss the financial costs incurred as they seek out treatment. Renee finds that treatment is easy enough to access but is quite expensive, and explains that she has not done more massage and lymphatic drainage with bandaging because it is very costly and is not covered through her healthcare. This indicates that the ability to receive quality healthcare for women with arm morbidity is largely based on socioeconomic status, which is reminiscent of feminist and other critical theories that critique the inequalities involved in health as a result of wealth and power imbalances in society. Denise also discusses the cost in the various treatments she has pursued for her arm problems:

*Like presently I'm going to see, um, a physiotherapist who's just started in January with, ah, facial release, and he has... taken some, um, tightness away from my shoulders. I feel like I'm standing up straighter. But he's very expensive. And I feel good when I go see him four times, you know, once a week, but I don't, can't, I can't keep that up. He's way too expensive.*

The treatment helps her manage her health, and lessens the impact her arm morbidity has in her daily life, but she cannot afford to continuously receive the help that improves her arm problems. This suggests that those who can afford access to treatments for arm morbidity will receive help, but leaves those without the required resources to live in their bodies with more pain, discomfort, and the other problems involved with arm morbidity.

There are many ways the women engage in their own care and treatment in order to try to better their arm problems, including exercise, stretching, self-massage, yoga, cold packs, ibuprofen or Tylenol, staying hydrated, taking hot showers, participating in the Busting for Energy dragon boat team, and sleeping well. Some of the women have gone to workshops to learn how to treat their arms themselves, such as Renee: *I've gone to, um, the Hope Cancer [Help] Centre, and they had, um, a workshop on doing your own massage and your own [lymphatic] draining, and relaxation methods and all kinds of things.* The women also discuss making small changes in their routines to help their arm, including sleeping in different positions to avoid stressing their bodies, elevating their arm when they can, and taking care of their overall health. The self care that the women engage in is another process of developing an awareness of their health and an understanding of their bodies with arm morbidity. As Fosket (2000) and Ziebland (2004) both indicate, knowledge of health comes from many different places and sources, and the women's experiences engaging in their own care supports this: Their knowledge is also acquired through processes of trial and error, as they gain understanding about what their bodies can manage, what to do to care for their bodies, and how they can prevent and alleviate the problems. This lay knowledge of health is important, because while the women were all given the same information about arm morbidity, their bodies respond differently, so they each have unique understandings of the care and treatment that is required.

Two specific treatments for lymphedema that many of the women discuss as a part of their care are the compression sleeve and the arm pump. Denise, who has been told she has mild lymphedema, uses the sleeve to help her alleviate some of her problems: *I can't go without this arm band. I can't even go, at night I have a lighter arm band, cuz I, I'm not comfortable at all, at all, without an arm band.* While most of the women use the sleeve and experience a positive effect on their arm problems, Laura is



skeptical about its benefit: *I'm just not convinced that it's going to prevent anything, cuz they don't have good research for lymphedema.* These experiences indicate that the women look to both lay and expert knowledge in order to construct their understandings of arm morbidity and the care they apply to their bodies, but the deciding factor in their decisions is how they understand their bodies' needs. Similarly, some of the women also use an arm pump in their homes to help with their lymphedema, to varying degrees of consequence and reception, although the effectiveness of arm pumps as a treatment option remains uncertain in the biomedical literature (Brennan & Miller, 1998). Jillian talks about the difficulty of finding time to use it during her day, so she resorts to engaging in the treatment at the end of her day: *I'll fall asleep and then three in the morning I wake up and my arm is so sore because it's been... pumping away for several hours and, yeah, so it's... finding the time to do all of that. Not easy.* Engaging in treatment also means having the time to pursue and receive care, which many women find difficult in their already busy lives. This is another issue of cost related to treatment, as women who could afford the time were able to treat their bodies, but those who were unable to had less opportunity to engage in care to alleviate the pain and discomfort.

The perseverance of the women to manage their health and respond to their arm morbidity is apparent in the measures they take to manage their health, which offsets the lack of power they feel in their experiences of formal treatment. In their formal care, many of the women feel very little power because of the limited understanding of arm morbidity issues, and felt lost in the shuffle as they did not receive the care or attention they required in the past. However, they are simultaneously seizing their own power in order to have control of their healthcare in their social lives. In this sense, they are able to take control and be the authorities of their bodies and health despite the feelings of belittlement, disregard, and powerlessness in the formal system. The reasons for being persistent with their care varies depending on the women's health and social context, and includes hope for improvement, evidence of progress, and avoidance of declining health. Janet, who exercises at her cabin for four months in the summer, says this: *[T]hat's the balancing act. If you're going to be getting better, you have to have such constant perseverance that I was telling you about – going into a cold lake every day – no matter what. You know, that kind of perseverance.* The time each has to commit to treatment

differs, and the funds they have to pursue those options vary, so the lengths the women are able to take to seek out and engage in treatments are impacted by their lives. Nevertheless, all continue to look for ways to combat their arm problems that can work in their own situations, and allows them to be empowered in their own healthcare regardless of the obstacles created in the formal realm.

In addition to treating their symptoms, there is much emphasis on prevention for the women. Concern about infection causes the women to take many preventative measures in their lives in order to avoid falling ill. They talk about avoiding scratching or burning their arms and hands, keeping their hands clean, using antibacterial hand gels and creams, always having tissue nearby, and wiping everything down. The women generally determined that the causes of their infections are due to traumas to the arms and hands – scratches, hang nails, paper cuts, mosquito bites, sunburns – so they are very aware of their surroundings to avoid those agitations to their bodies, and go to great lengths to care for their bodies when they are strained:

*...if I do get a cut I really watch, like I, I use the, ah, the antibacterial wash, um, and, um, I keep any wounds covered, try and keep them covered until they heal, and stuff like that. So yeah, like they said that that's probably what it is, and I have found that every time I have had an infection, I have had a cut or something on my hand. (Renee)*

Similarly, the women also try to prevent further swelling as much as they can by watching how much they stress their arms. Janet has been told that she does not have lymphedema, and Laura is only beginning to experience it, but the awareness that it can occur at any time was a part of their illness experiences, as they watch their arms for signs of swelling, and are cautious about overworking their bodies. This awareness of health leads the women to an awareness of their environments, which affects how they live in their bodies in their surroundings.

Another issue involved in treatment is the effect those measures have on the women's bodies and their arm problems, and the women's understandings of potential progress sheds light on the expectations they have constructed about the impact of arm morbidity in their lives. Janet has been working to alleviate her pain, which she now refers to as discomfort, and feels as if she has made progress and continues to work to

improve her body so she is able to *live a normal life*. She is hopeful that her body will continue to improve, but her primary focus is that her life becomes more reflective of what it had been prior to breast cancer treatment. The women with lymphedema – Denise, Renee, Angela, and Jillian – understand that there is no known cure to treat the swelling, but are more concerned about not letting it progress and affect their lives more. The women’s focus, when discussing progress, is directed more towards attaining the lives they had been living before, rather than curing their bodies. This raises the idea of the disconnect between ideal outcomes of the medical profession and patients, as the medical objective is to return the body to its normal state, while patients are more concerned about returning to what they considered to be a normal life (Lorber, 1997). The women are aware of and hopeful about the progress of their bodies, but are more conscious of the impact that any progress would have on their lives, which is primarily why they engage in the treatments and care they do.

However, while the women rely on treatment for relief, most of them talk about the temporality of the effects of the treatment. Jillian finds that *there’s not a lot that helps, unfortunately. No, just pretty much resting it and not doing anything is, is about the only thing that, um, helps the pain anyway*. The only way that they can really cure their bodies is by adjusting their lives to the point where they feel they are not living, and the only way to live the lives they want is to put more strain on their bodies and exacerbate their health. Reflecting on her experiences with treatment, Denise says,

*Everything’s very temporary. Nothing’s cleared it up, nothing’s long term. And again, I think... for me the long term solution will probably be when I retire and, and I’m not around kids and germs and, and, and probably not using my arm as much. I, I think that’s, for me, the only way that that would be, and I’m not willing to pay that price yet just to have an unswollen arm, I guess. It’s still manageable.*

The women continuously work on their health, to alleviate, to maintain, or to improve, but find it difficult to balance caring for their health with living their lives, because doing one essentially means ignoring the other. Because of this, there is a balancing act that the women are engaged in, as they manage their health in order to limit the consequences of

arm morbidity on their daily lives, but to live their daily live in a manner that allows them to care for their bodies.

### ***5.1.3 Information and Knowledge: Different Languages, Voices, and Perspectives***

A major area of importance to all of the women is their experiences of knowledge and information about arm morbidity. The women receive information from a number of sources, and seek out knowledge themselves through a variety of avenues, but there is a resounding discontentment about the lack of attention to and understanding of their health issues. This discontent is similar to findings in other issues of health, including research looking at women making decisions about hysterectomies (Entwistle et al., 2006), and other studies of lymphedema after breast cancer (Thomas-MacLean et al., 2005). Both medical knowledge and lay knowledge of arm morbidity are discussed as the women convey stories of their experiences in the healthcare system, the development of understandings of symptoms since treatment up to the present, and their own role in their healthcare. It is apparent in the women's narratives that communication about their health is extremely important and beneficial, but that there are major gaps and complications when it comes to arm morbidity, which has many negative implications for the illness experiences.

When managing health and dealing with arm morbidity issues in their bodies, it is clear that the women place immense value on and respect for expert knowledge. They seek out the services and knowledge of those in the medical profession, and search for research findings and informative articles about arm morbidity to help them understand and manage their health. However, a concern raised by the women is the lack of medical knowledge that is known and available about arm morbidity. As sociologists, we understand that physicians are situated as experts of health, and that public trust in the institution of medicine is realized at both micro and macro levels in society (Stevenson & Scambler, 2005), but the women with arm morbidity are left to deal with the knowledge that the experts do not know. They construct lay knowledge of their health based upon their experiences of arm morbidity in the lifeworld to compensate for the gaps in understanding, but are left feeling frustrated, forgotten, and helpless because they are unable to depend on the people who they are told they must depend on. The security and support that the medical field provides to patients with expert knowledge and

understanding does not come through for the women with arm morbidity, and this causes negative experiences with health as they are required to understand their bodies alone, and do not feel confident in their care and management of arm morbidity. The knowledge of biomedical professionals is unclear, contradictory, and often lacking substance in the case of arm morbidity, causing the “voice of medicine” (Lorber, 1997) to be quite incoherent. The uncertainty about causes for problems such as lymphedema, the unreliable and sometimes contradictory information about prevention and treatment, and the lack of solutions for the issues creates frustration for the women. They all feel as if there is more they want to know, including some seemingly basic biomedical information, such as the case of Laura:

*I wish I knew what caused it. And, kind of, you know, doesn't really fit, but I wish there was, there was something that could be done if you did develop severe lymphedema, that they had treatment for that kind of, well they do but they don't. So, um, yeah, something to prevent it. Really prevent it....*

The women want that expert knowledge to manage their health, but the lack of medical knowledge about arm morbidity leads them to experience frustration and uncertainty. These experiences are similar to Fosket's findings of breast cancer patients' experiences, as the women found comfort and hope in biomedicine despite their simultaneous understandings of the problems and social constructedness of biomedical knowledge (2000).

In addition to the lack of medical knowledge that is available about arm morbidity, there is a great deal of frustration about the little information they received after breast cancer treatment. Many of the women were given a pamphlet to tell them about the possibility of lymphedema without an explanation along with it, which means that many of them did not know what was happening to their bodies when symptoms began to appear. Denise did not go to see a physiotherapist until a year after she started experiencing problems, because she did not understand her symptoms; Renee feels as if she would have done more to prevent lymphedema from spreading if she had known more about it; and even when Angela was diagnosed with lymphedema, she was only told that it was a mild case: *So yeah, I would say it wasn't the breast cancer that, that really bothered me so much, it was the unknown of, when they would talk about things but it*

*was just a statement. They didn't say come back and we'll give you some reading material later; didn't say ask our own doctor.* Similarly, Jillian does not feel as if she understood lymphedema as much as she should have after she was diagnosed: *[E]ven after I found out that I did have lymphedema, nobody told me, you know, about being very careful about cuts or, like, I really didn't get a lot of information. Um, it was kind of like trial and error – if you happened to ask the right questions, you got the answer, but nobody, nobody told me about those things.* If effective and appropriate translation of information to the patient is key to empowering individuals (Henwood et al., 2003) as they manage their health, women who receive little information about arm morbidity, and in a manner that does not convey understanding from the medical profession to patients, are not able to participate in their health in a meaningful way. This lack of information does not empower the women to participate in their health with a reasonable understanding of the issues, which can potentially be detrimental to patients' health.

A discussion about the lack of information they received about arm morbidity also led the women to consider the process that occurred when they were first informed about the issues, and the inopportune timing that the information was presented to them. The women's introduction to the possibility of lymphedema came as they left the hospital after breast cancer surgery, and many present the reasons why that is not the appropriate time to receive the information, including: the chaos of the day; dealing with the experience of treatment; and already having so much going on in their minds. As Janet expresses,

*There needs to be follow-up in something like that. You, you can't expect people in the throes of surgery to be thinking straight, and certainly about long-term issues. You need to have somewhere to go where, saying... come and see me at such-and-such a place and we'll talk about this. You know, way down the road.* And when the women did not understand the possibility of arm morbidity as they left the hospital following surgery, it then fell into their hands to find the information about the symptoms when they arose, which some found quite frustrating: As Jillian explains, *I just felt that, at that point, I was probably feeling very sorry for myself, and I felt I had enough to deal with, and, um, I, I didn't feel I had the energy to go into and, and look, try and find out what I wanted to know.* This inopportune timing is also suggested by

another study on women with lymphedema after breast cancer, as Thomas-MacLean et al. (2005) state that the women received information about lymphedema early in their breast cancer treatment when there was an overwhelming amount of medical information to absorb. While communication between the medical professionals and patients is considered to be essential to provide support for the women in their continuing health issues, it is evident that it cannot simply be a transfer of information without consideration of the appropriate timing and manner best suited for the individuals who require the information. The women with arm morbidity express that they feel forgotten by the healthcare system as they were left without much attention and information after treatment, and their illness experiences were not taken into account when treated medically, as the timing did not consider the state of mind or circumstance of the patient.

Despite this, the women are generally appreciative of what their physicians and others involved in their treatment have done for them as they manage their health. Because of the limited medical understanding of arm morbidity, and the difficulty of working within the healthcare system, most of the women feel as if the people assisting them in their treatment did what they could. However, the lack of information they received about arm morbidity, as well as the negative reception some experienced when they relayed their concerns to their doctors, led many of the women to feel as if they do not have the guidance from the health profession in their breast cancer treatment or their arm morbidity issues: *Well, I don't see, um, a lot of patient, um, advocacy, is the word I'm looking for. I don't see a lot of people, in our health system, that help guide people through the maze of serious illness* (Janet). Instead, the women feel as if arm morbidity issues are not given the attention or the importance that they require. Some of the women were told that lymphedema is not a problem, or that it is not serious, or that they should not pursue preventative or treatment measures. After experience with arm problems, however, the women understand that the information from those experts is flawed. Renee was not concerned about lymphedema when it first arose because her doctor was very casual, but in retrospect she wishes she had known the severity of the issue:

*Well, I think if I had been made aware of how, um, that it is more serious than what they made it seem. Then I think I would have been more aware, and I would have probably done more research and more digging and stuff. But, you know,*

*they really glossed over it and said, it's not a big deal, some people get it some people don't, and if you do get it it's not a big deal. But it is a big deal. Yeah, it is.*

Arm morbidity is not commonly life-threatening, so biomedically it may not be of great importance, and the manner in which the health profession deals with it suggests that that is the case. Similar experiences were found in another study of women with breast cancer related lymphedema, where physicians minimized the seriousness of it (Thomas-MacLean et al., 2005). However, the women indicate that it has widespread impact on their lives, making it very important in them, and suggesting that this disconnect between expert understanding and lay understanding is obstructive in the women's experiences with arm morbidity.

These issues – the limited medical understanding, a lack of knowledge, the inopportune timing of information, and the misrepresentation of the seriousness of arm morbidity – contributes to the frustration many of the women feel about their questions that continue to linger about the arm problems. Denise feels as if she always leaves the doctor's office or the physiotherapist with *unanswered questions*, and Angela leaves a question hang in the air as she discusses when she first heard about the possibility of lymphedema: *But going to cancer clinic and that, they never said anything. You know, just, you could. You know, could what though?* This question, in its open-endedness, possibly suggests that while Angela wanted more information, she did not even have enough basic knowledge at that time to ask follow-up questions about lymphedema. The professionals who are equipped with the knowledge did not offer her the information she required, and because she did not have the necessary understanding, she felt as if she was too uninformed to discuss the issue further. Similarly, Jillian talks about not being sure which questions to ask about her arm problems, which makes it difficult for her to get the answers she needs as well: *[I]t just seemed like, if you didn't ask the right questions, nobody told you anything, so it was kind of hit and miss.* The women are left to understand their bodies and manage their health without knowledge about the biomedical conditions they face, and this disconnect between physician and patient knowledge, resulting from poor communication between the parties, does not create a positive experience.



The women value expert knowledge and clearly want biomedical information about their arm morbidity, but they also discuss the role they have in their own health to fill the gaps the biomedical knowledge leave. Part of this is seeking out information themselves in order to become more informed about their health problems and treatments, which is a pattern found to be occurring in patients today (Leigh & Stoval, 2003) as findings suggest that individuals are accessing a range of different sources and media to acquire information (Henwood et al., 2003). The women search for information to varying degrees, but most of the women use the internet to access information about their health, which supports the idea that technology is allowing more patients to become informed about their health issues (Ziebland, 2004). However, the women do raise concern about finding useful and trustworthy information about their health, especially since there is so much uncertainty about arm morbidity issues. Laura, who has most recently begun to deal with arm problems, is most diligent in her search for understanding:

*I'm like hyper-aware of getting the newest information, because that's what I have to do for my own job, so, um, yeah, when I saw that the positions stated, things were, like, printed this year, okay, I know that this is pretty good, and, and, you know, the references are always good information. Um, but yeah, you have to be careful, I think, and I'm suspicious of anything that tells me a long list of things I can't do.*

Because the women do not receive adequate or valuable information about arm morbidity from their physicians, they look to a variety of sources for understanding about their health, but this raises the issue of access to information, as not all people have the access to or knowledge of technology to become informed themselves (Henwood et al., 2003). In this sense, those who have the means to access the information will be better equipped to understand their health, but those who lack the means or the understanding to do so on their own are left to manage their health without the benefit of any expert knowledge whatsoever.

Due to the women's own unique understandings of their bodies, the little amount of time or attention made available in the healthcare system to arm morbidity issues, and the lack of understanding of arm morbidity in the health profession, there is also

reflection about the role they as patients have in the healthcare system. The women talk about the importance of asking questions, raising concerns and being firm with healthcare professionals regardless of the reactions of indifference or suspicion they receive, and having a voice in their own treatment. As Renee says,

*I think you have to really be in charge of your own healthcare. You know, um, I think sometimes you have to push to get the treatment that you want. Um, you have to, you know, it's up to you to decide how you want your treatment and when you want your treatment and stuff like that. um, I don't take what doctors tell me as gospel truth anymore. Yeah. Because I, sometimes they'll have their opinion and that's all they'll tell you... and it's up to you to research in to decide which way you're going to go.*

This reflects Turner's argument that patients must be more vocal with health professionals, as well as the need for doctors to pay more attention to lay knowledge (1987). Sociologically understood, patients bring the "voice of the lifeworld" to the illness, while physicians bring the "voice of medicine" (Lorber, 1997), and because those voices speak different languages and have different perspectives (Turner, 1987), it creates obstacles in the relationship. As communication between the women and the healthcare professionals is either lacking, or lost in translation, in the women's experiences of arm morbidity, they feel responsible to take a more active role and demand respect and recognition for their understandings of their health.

Ultimately, discussions of the patient's role in her healthcare led to ideas of knowledge and experiences of our own bodies that are important in understanding and managing our health. The women's lay knowledge of their health, and their lives, are integral in the care and treatment of arm morbidity from day-to-day, and within the healthcare system. As Entwistle et al. (2001) find, people look at different factors when making choices about health care. The women's experiences with arm morbidity indicate the complexities involved in their health issues, and the various ways they construct meaning and make decisions about their health and care. While biomedical knowledge is important, the women's experiences of their bodies prove to be a major component in their construction of understanding. As Jillian remarks, *[W]e know our bodies better than anybody else does, and, um, ah, so I mean, I guess we have to listen to what our*

*bodies are telling us, and act on that for ourselves.* The experiences suggest that there is a balancing act in managing health, as the women need to weigh the medical knowledge with their own experiences of their bodies, and the context of their lives.

Making those decisions about health, in that balancing act, is difficult because the inadequate medical knowledge about their health in turn limits their knowledge of options, as they have to decide how they will manage their health in a way that allows them to live their lives: *Yeah, well, I know I, I would always want to know. Everything. You know, even, um, like, it's my body, give me all the information that I need to get, to make a decision about how I want to treat it* (Renee). This contests ideas raised by those such as Potts (2000), who suggests that more information about potential health risks could have negative implications, as it makes people confront the possibility of an ill body. It also supports other findings of patients in the healthcare system who want more disclosure from the healthcare professionals (such as Flynn et al, 2006). The women with arm morbidity are desperate for more information about their health and their bodies in order to manage in their daily lives, as they are faced with an ill body every day. And in hindsight, even when arm morbidity issues such as lymphedema are only a potential health problem, most wish that they had known more about it to help them prevent it, even if it never occurred. The suggestion that people can avoid confronting an ill body continues the charade that we can be in a permanent state of health, and withholding information from individuals is not going to protect patients from illness experiences. In addition, keeping potentially valuable information from patients about their health, even in the case of possible future risks, does not empower individuals to be proactive or preventative when dealing with their health. The women want to know as much as possible about their arm morbidity so they can manage in their lives, even if that does make them confront illness, because the alternative, and what they are now faced with, is living with uncertainty, confusion, and frustration in their illness experiences because of the lack of knowledge.

#### ***5.1.4 Support: Care and Healing, Beyond the Physical***

Experiences of support are another part of the women's stories of arm morbidity, and indicate the important role support plays in the construction of experiences of health and bodies. The discussions of treatment detail much of the professional or formal

support the women receive for their arm morbidity issues, but other forms of support are also conveyed in their stories and considered highly valuable as they manage their health. The women present experiences of informal support that comes from an assortment of different people, including family, friends, and coworkers, and in varying ways talk about how they manage to support themselves as they deal with their arm morbidity.

Beyond the medical treatments that the women receive for their physical symptoms, there are emotional issues involved that leads them to pursue other avenues to manage their health. There was discussion of antidepressants to help deal emotionally with the difficulties involved, and many talk about counseling services as an option to navigate through those issues. This need for support beyond the physical further sustains the sociological understanding that health is a multi-faceted issue, as the women experience emotional difficulties as well, and suggests that professionals trained to treat emotional issues are also a part of positive illness experiences. Some of the women mention that they regret not seeking out emotional help from counselors, and others talk about the value they see in individuals or groups intended to lend support and assistance. Janet discusses her experiences with counselors, and reflects on the benefit there would be to have somebody trained to work with women dealing with arm morbidity issues:

*I think it's really important for people to get in touch with counseling services. And again, counseling services, people that specifically know about arm problems with breast cancer – wouldn't that be nice if there was somebody who had that on their résumé up at the cancer clinic?*

As the women experience arm problems and gain understanding about how to manage the range of issues involved, many look to expert knowledge about the emotional problems involved in illness experiences to construct a thorough understanding of their health. Formal support for the emotional impact of arm morbidity is significant in their experiences, and suggests the layers of complexity involved that require the scope of health to include patients' emotional well-being.

Many of the women also discuss the benefits that organizations such as the Hope Cancer Help Centre provide to them as they experienced breast cancer and live with arm morbidity, because they are able to find both information and support as they struggle with health issues. As Angela says,

*Hope [Cancer Help Centre] is my key... I guess I feel more comfortable... most of us that are there are cancer survivors. A lot of us [had] breast cancer. So, and they've been longer on this trail than me, so therefore they have either observed or gone down and suffered some of the side effects that I'm dealing with, so therefore they're good for being able to suggest where to go or what to look for or what to do to ease the, you know, when your arm's bothering you.*

As the women create meaning about their illness experiences, and try to understand their health in their lives, many find comfort in those who have gone through similar experiences and can provide them with information about life after cancer, and understanding about the issues the women are faced with. This commonality does not only benefit the women's search for knowledge about their health, but the comfort in it also relates to the idea of health as a constructed state of normalcy (i.e. Kleinman, 1988; Lorber, 1997). The women, dealing with illness and a disrupted state of normal, look to others who are similar, allowing them to find comfort from that sameness and regain their sense of feeling normal. Illness is experienced socially, in relation to others, and the women's experiences of arm morbidity are benefited by the support of those who have common experiences, both for information and the feeling of solidarity they could provide.

Informal forms of support from people involved in the women's daily lives are discussed at length in the narratives, because of the major importance they place upon informal support in their experiences. The women who feel as if they have great people who were there for them during breast cancer treatment and continue to be in their arm problems continuously stress the value of those support systems in their lives, which reiterates the idea that close relationships that offer comfort and support are important for individuals to have positive illness experiences (Bolger et al., 1996): *Oh, it's so important, to have a good support group around you. Um, and to surround yourself with, with really positive, upbeat people is, it goes such a long way towards helping you heal* (Renee). Healing, in this sense, does not only refer to healing of the physical body. It suggests that healing also involves the betterment of emotional, spiritual, social, and other fractures that occur with illness. The women talk about husbands, friends, children, parents, community groups, neighbours, and co-workers who positively impact their lives

by being there to listen, providing help with physical work when necessary, spending time with them, attending appointments, bringing lunch when they cannot be at work, and providing other forms of moral support during the good and bad days. Four of the participants are divorced or widowed, so as women living alone, they talk about the importance of friends in their lives. Angela, who is involved in many groups to fill her time, considers the members of one to be the most important support in her daily life, and Janet says that *the doing things for me is not so much physical as, ah, just having friends who open the door. Like the door is always open – that's particularly important to a single woman.* Those individuals and groups provide support in varying ways, and to different levels of involvement and results, but most of the women feel as though they have many people to turn to, and value these informal support networks immensely: As Janet says,

*The personal support of friends – I think without that, the situation would be, I, I could hardly relate with, because that's been such a major part of my, my life. Like if one had the professionals but didn't have the other support, I don't know what that would, experience would be like. Because I put my friends right up there, and sometimes even above, the help that I've got from professionals.*

While formal, biomedical treatment is directed at a particular component of the arm morbidity experience, the close relationships in the women's lives provide them with more comprehensive support in the various aspects of their illness experience. This is likely why the support received from those in their lives is considered more beneficial to their health, because those relationships support the physical, emotional, social, and other components that are involved in illness, while the formal treatment they receive is primarily directed at their physical care.

The women overwhelmingly discuss the positive support they receive from the people in their lives, but some do raise feelings of isolation and frustration they experience dealing with their arm morbidity. This variation in perspectives about social support is also found in experiences of ovarian cancer, as responses from the women ranged from tremendously positive to extreme isolation (Ferrell et al., 2003). Some of the women, while receiving particular forms of support in their close relationships, feel as if they are dealing emotionally with their health very much on their own, and that there is

not much understanding about the arm problems and all of the issues that are involved. Jillian, for example, feels very alone as she tries to manage her health:

*[T]hat was maybe part of the isolation, feeling isolated, was because I didn't have that, I didn't have that, um, person to talk to.... So, yeah, that was, it's been hard. Um, people should have somebody they can talk to, but I just never found that person, and when I did they died, so.*

There is a sense of both loss and isolation in her experiences of life after breast cancer treatment, as she does not consistently have somebody who understands and can share in her illness experience. Because of the impact close relationships have on health, the lack of support in Jillian's life creates a tone of isolation that affects the various aspects of her health and well-being. Some of the women also discuss the unsolicited advice that, while it comes with the best of intentions from those in their lives, has the effect of creating frustration. Angela talks about a friend who has a relative with lymphedema: *[S]he drives me crazy about, "Oh, you watch your arm, don't you get out in the sun, don't you do this, don't you do that." I go, "Hey, I'm doing okay. Yes, I will be careful."* Angela wants the recognition that she is the expert of her own health and is capable of taking care of her body, and those who appear to not acknowledge that lead her to feel frustrated, despite the good intentions behind the proffered advice. The women's more negative experiences of support come from a lack of understanding or recognition of their experiences of health from those in their lives, and are realized as they do not receive attention from others, or receive negative attention that does not reflect their own understandings of health and life.

Another common issue in the experiences of the women is the complications that arise in support systems because of the nature of the relationships, which means that particular people offer different types of support. Jillian calls her husband *a fixer*, and that makes it difficult for her to find support from him as she tries to manage her health and deal with lymphedema:

*[Y]ou can't fix it, and he just, he gets frustrated with me when I won't take his suggestions, you know, and well, like I've, you know, been told over the years you treat your arm very gently, you do not, you know, you don't put pressure on your arm and that kind of thing, and, ah, he figured that, you know, if you just squeeze*

*that fluid out of there it's going to go away. Well, it doesn't work that way, so. Yeah, it's not, no, I don't discuss it with any of [my family].*

Her husband's lack of understanding about arm morbidity, as well as the relationship she has with him, prevents her from receiving support in her arm morbidity experiences, and as a result she manages her illness by herself. The women who are mothers also discuss the differences between the support their children give them and the support they receive from parents, spouses or friends. Children cannot provide the same type of support that others can in many cases, because they do not want their mothers to be ill: *I have children, but children, as I learned from my counselor, see you in a whole different role, they desperately want you to be well, and they're certainly, you know, they're helpful, in their way* (Janet). The support from others greatly depends on the relationships that had been established prior to the women's illness experiences, as the relationships are influenced by the women's health and are faced with the adjustment to the new realities the women deal with because of arm morbidity. In other words, support from loved ones does not come equally, due in part to the impact the interactions and relationships have on the ability to provide particular types of support.

Aside from external support that the women receive in their experiences of arm morbidity, there is also discussion about the personal role they have in supporting themselves as they manage their health. Seeking out help from the medical profession, and asking for help from others when necessary, are discussed as ways to actively engage in helping themselves. However, the women mention other ways that they feel responsible for making their experiences with arm morbidity issues positive: *I think, though, the way it impacts, it, it certainly does impact your life, but the manner in which it impacts your life is up to you, I think, to decide* (Renee). The suggestion here is that women are able to take control over their illness experience by choosing how to let it affect their lives. The conscious decision to control the influence of arm morbidity on life is perhaps realized more abstractly, in terms of outlook or perspective about the illness, for example, but in actuality, the ability to decide on the impact is likely dependant on the amount of changes that occur to the women's health and body. Many of the women with arm morbidity cannot avoid making certain changes in their lives because of their health, and as a result do not have the luxury to choose in that respect.



They make decisions about how to adapt and accept the arm problems, but the changes in the body impede many of the women's abilities to carry out life as they had been living.

While the women have less control over the effect the illness has on their physical bodies, most of the women discuss the importance of having a positive outlook in life, regardless of their symptoms. However, most do not suggest that that it is easy to continuously be in that state-of-mind. Laura describes the ongoing process of supporting herself after breast cancer treatment, as she struggles to create a positive experience:

*I've been working with a social worker, um, just to, yeah, work through some stuff from the diagnosis and, so, that as well, just so I can, um, I think I, I need to re-learn how to trust myself after what happened, so, um, I've been working on that, and I know that, I mean, I need to be my own support more than any, anybody else....*

Trust is lost when the previous understandings of health and the self are ruptured, and the more disrupted the women's understandings are, the further they have to go to reestablish new meaning. The women are able to manage their health better as they progress in their new understandings of the body and self, but it is not a process without struggle or setbacks.

Belief systems are also discussed as important to the women's illness experiences, as they are able to find meaning and create understanding of the world, and feel a sense of security as they live with arm morbidity. Some discuss their affiliation with a religious group that provides them with comfort, and attend services and engage in prayer as a part of their self-care. Similarly, accounts of cancer experiences related to wellness also indicate that patients look to religion or some type of spirituality for support (Spira & Kenemore, 2002). However, most of the women focus more on the spirituality or faith that allows them to formulate understanding, rather than organized religious practices. Jillian talks about the support she feels when she walks outside: *[J]ust to see the beauty that we live in and... I'm not a real church-goer... but I think I'm more... just being in, in the beauty of living here, and being alive.* Angela says that faith allows her to *look at things a little different* when she struggles with her health, and Janet mentions that her spiritual outlook helps her overcome the difficulties she faces because of her health issues:

*...connecting myself with all the things in the universe that are positive and work for the good of everybody. Um, connecting with the things in all religions that help us to work better with each other, and to deal with life issues of any kind, like why are we here, and why do we have to die, and all of those kinds of things.*

The meanings the women are able to construct about the world allow them to manage their health and find support that they need to create a better experience of arm morbidity, which indicates the major role meaning has in experiences of health. Faith and belief allow the women to put their trust in something, and as a result they feel supported as they manage their health.

#### ***5.1.5 Managing Health: Narratives Constructing Knowledge***

Treating arm morbidity solely as a biomedical issue does not encompass the full illness experience of the patient, as the women's narratives go beyond the biomedical understandings and include understandings about their health based upon their experiences in the social world. The women feel and experience arm morbidity in their bodies, and the new awareness they have means that the women are continuously, consciously maneuvering with their bodies as they carry out their daily lives in a different state of health. In doing so, they have to negotiate new understandings of themselves that diverge from socially constructed ideas of normal in order to reestablish a sense of self. This meaning-making is essential in the illness narratives, as the women reconstruct understandings of health, life, and themselves after they had been disrupted by illness. There are many obstacles along the way, as the medical knowledge about arm morbidity is full of gaps and contradictions, and the translation of existing knowledge is not conducive to empowering patients to manage their health. But while the women experience frustrations in treatment, as they engage in their care and search for information, they continue to develop in their understandings of arm morbidity by seeking out information and learning from their experiences. The meanings constructed by the women have similarities in understandings and themes, but the narratives indicate the variety of truths that are constructed about health, as they create understandings to navigate through life with arm morbidity that involve the physical, emotional, social, and other components that are a part of the illness experiences.

## **5.2 Managing Lives: Negotiating New Health with Previous Selves**

[When examining narratives,] the new self constructed in the wake of illness is often described not as a distinct, bounded entity entirely separate from the old self but as a fluid configuration in which elements of old and new, self and other, inside and outside, exist concurrently. (Lindgren, 2004, p. 147)

In addition to experiences of the body, the health issues and the physical limitations involved in arm morbidity have major implications on the women's daily lives as they engage and interact. The arm problems that resulted because of biological changes influence the women's abilities to carry out their daily lives, and major themes arise from their illness narratives that are illustrative of the role of health in our participation in society. As the women had previously engaged with a particular health and physicality, they were able to conduct daily life in what they considered to be a normal way. However, the disruption to their health also disrupted this engagement in the social world, suggesting the role of health in our social lives is complex and widespread. In this chapter, I focus on those issues that the women raise in their experiences of arm morbidity as they manage their lives as actors in society. The first major area I look at is the women's experiences of their abilities and the impact those have on the roles they fill in the social world, including their positioning within close relationships, in the household, in the workforce, and in their communities. Following, I discuss the women's perceptions of themselves as social actors, as identity is another major theme that is raised in the women's experiences because of the new limitations, the consequences of arm morbidity on roles, and their changed bodies. Therein, I discuss issues such as the perceptions of their bodies with arm problems, the focus on living as capable women, and the sense of self as understood by the women. Finally, I present the women's new or adapted meanings about the social world that are constructed as they manage their lives, indicating the broad effect experiences of health have on meanings we construct about and apply to our lives.

### ***5.2.1 Changing Abilities, Adjusting Roles?***

The women's arm problems impact many areas of their lives because arm morbidity affects the ability to function the same as they had prior to the problems, and those changes in health and ability influence who the women can be and how they are perceived in relation to others. They raise many limitations or changes in ability in the

narratives as they discuss their daily routines, relationships, housework, paid work, leisure activities, and lifestyle, and it becomes apparent that arm morbidity requires many adjustments to be made in the ways the women conduct their lives. These adjustments, in turn, influence relationships with family and friends, responsibilities at work and in the household, and roles in the community as they engage in the social world. The limitations are a major part of the women's experience of arm morbidity and result in different ways of living in the world, which affects who they can be, and are, to others.

#### *5.2.1.1 Unpaid work: Changed abilities, continued roles, strained bodies*

Arm morbidity issues have an overall impact on the women's ability to carry out their daily routines, as they had to adjust to bodies with limitations or altered capacity and put extra effort into those daily tasks because of the physical changes. Feminist and sociological understandings of gender suggest that individuals are expected to fill normal gendered identities, created from cultural meanings, and this in turn produces gendered social actors (Smith, 2004). Because of traditional gender norms that suggest women are responsible for the menial, daily tasks in the household (Baltes Blume & Blume, 2003), the women's inability to perform that work hinders or prevents them from fulfilling socially acceptable gender roles. The limitations challenge the women's ability to act within the household, and disrupt the entrenched traditional gender norms that suggest those tasks are what the women should do, as women. Many of the participants talk about the extra time that is required to do even simple tasks, such as Denise, who says it can take her two or three minutes to put a glove on her hand. This brings to mind Hochschild's (1989) findings, which suggest that women's time is already in high demand because of traditional gender ideas about household tasks. The changes to the women's ability caused by arm morbidity, then, exacerbate what is likely an already stressed circumstance, and presumably make what we consider simple daily tasks turn into impositions in the women's lives. The women's health imposes upon the time they have during their daily routines, and disrupts the manner in which they are able to carry out the day-to-day tasks prior to their arm problems.

In addition to the time that is required for the daily tasks in the illness narratives, many of the women also detail the planning it takes to carry out parts of their daily routine. Similar to deconstructions and criticisms of the taken-for-granted in feminisms,

the social model of disability, and in phenomenological research, the women's narratives indicate that many of those things that are taken-for-granted in daily life are no longer simple and mindless for them. This increased consciousness of their routines parallels the increased awareness the women have of their health with arm morbidity, as their changed bodies no longer allow them to take for granted the way they had been living in healthy bodies. When asked about her limitations, Angela says,

*I think frustrating at times, because you have to think about how you're going to attack something. And if it's, like, ah, if you're responsible for doing a supper or something like this sometimes, it's not easy to just instantly come up with an idea.*

Acting as social actors who fulfill the normal gender roles does not come as easily to the women, as their physical limitations create obstacles in daily tasks, and they no longer have the ability to act as spontaneously as they had without arm problems, as carrying out seemingly mundane tasks requires more thought and takes more of their time. As a result of arm morbidity, the women lose a certain degree of freedom in their routines to be spontaneous or unscheduled. The ease of ability to perform daily tasks is assumed in an able-bodied society, but in the case of the women, what is taken-for-granted culturally is now disrupted in their lives. The difficulties and limitations they experience no longer allow them to assume that they can fulfill daily tasks without thought, and this, in turn, disrupts the gender roles they were enacting which incorporated the performance of seemingly insignificant work.

The women's arm problems also have implications on the everyday tasks that are involved in their daily routines, which impact the ability to function in various ways. One specific issue that is raised and can have larger implications for the women's lives is the difficulty involved in driving. Some of the women find it arduous to hold their arms up for long periods of time, or experience pain or discomfort turning the steering wheel, which may occur often as the women need to be mobile and cannot necessarily access other methods of transportation easily. If the difficulty becomes more severe, it can disturb the women's mobility and greatly limit their ability to function as they need to. The ability to drive, in a car-based culture, is part of our independence that allows us to conduct our lives and be mobile without reliance on others. However, those who are unable to drive themselves lose the ability to independently have the level of mobility

that is assumed to be the norm today, as engagement across larger spans of distance becomes more typical as commerce, technology, and other things connect communities and expand the contexts of individuals' lives. Instead, they would be required to rely on others to commute, which challenges their ability as able-bodied, independent women to carry out their routines in their lives, including household responsibilities, and roles they perform in the public sphere. We do not encourage dependence on others in adulthood, so the women's physical limitations could prevent them from fulfilling those socially acceptable roles. These issues are related to disability theories, as they critique the socially constructed expectations and ideas about a normal body that assume able-bodied identities and create reactions and social and physical environments that result in disability (Weitz, 2004). The difficulty or inability to drive does not naturally suggest a limitation, but because of the social and physical environments that require the ability to be mobile, and societal expectations of independence and able-bodiedness, the women's arm morbidity creates, or perhaps is, a limitation or disability.

Another issue that has larger implications in daily routines is the impact of arm morbidity on sleep, as many of the women experience a disruption in sleep patterns and feel fatigue during their days as a result. Some of the women take sleeping pills to help them get the amount of rest they need to function during their day, while others struggle during the night as they try to manage the pain and discomfort. In the area of chronic illness, Wendell (2001) argues that one of the most widespread yet misunderstood problems is fatigue. The fatigue the women experience has consequences for moods and temperament, as well as their abilities to function in their daily routines. The changes to the women's dispositions would presumably affect the interactions in their lives and the way they perform the various roles in their routines, as state-of-mind is a contributing factor to the way an individual engages in the social world. However, in a culture that values productivity, the impact of fatigue on the women's ability to function to the fullest potential in their routines is possibly even more problematic. The women experiencing fatigue are further limited, beyond the physical arm problems, as their stamina is not at a normal level that allows them to fill the socially constructed roles that meet understandings and expectations of productivity. It is not just a matter of not sleeping well, but the feeling of fatigue, in turn, affect the women's ability to function well in a

society where we are largely defined by how we perform. As Meadows (2005) states, “Feeling tired is not necessarily a problem, but feeling tired in inappropriate places or whilst trying to function at work is,” (p. 250) because feeling tired and less alert leads to a loss of productivity, unsafe behaviours, and accidents.

In the household, the women experience changes in the ability to carry out chores, both in and around the home, which is a major focus in the narratives of arm morbidity. The women talk about the difficulty they have cleaning around the home, shoveling, grocery shopping, baking, and doing yard work because of their arm problems, which is also expressed in other experiences of women with arm morbidity issues (Thomas-MacLean & Miedema, 2005; Thomas-MacLean et al., 2008). Some of the women discuss their changing expectations about housework to adapt to their limitations, because they are unable to maintain the level of cleanliness they had prior to their arm problems. Denise, discussing her lowered standards, says,

*[My husband] is really good, but he's, is he as neat-freak as I am? Probably not. You know, and so, you know, he tolerated a bit more, I had to tolerate more, and that's what you really, really, you tolerate things being messier.*

As she adjusts to her changing body, she must also change the expectations about household work. While expectations adjusted, a parallel change in roles did not occur, as she continues to take a primary role, in both thought and act, for the household work, as traditional gender roles relegate that to be the responsibility of women. In many instances, the women carry out the work in new ways so as to not strain their affected arm, such as simply not using the affected arm or hand to perform tasks, even if it is their dominant side. The women joke about giving up housework completely, and some mention that they may have to pay others to carry out those tasks, but only Janet has actually hired services that allow her to do less work around the house and avoid straining her body. Instead, the women continue to find ways to manage in spite of their limitations, and make small changes to help them do presumably simple tasks, such as use gadgets to open jars, purchase new lawnmowers that are easier to start, and have steps to stand on in the kitchen to reach into higher cupboards. The women's adaptation around the house is similar to other findings that suggest women with arm morbidity compensated for their limitations in household work (Thomas-MacLean et al., 2008). In

most of the cases, the women try to find ways to perform work around the home in order to maintain the traditional gender role they fill. This is related to similar findings of experiences of women with lymphedema which indicate that women who were unable to perform domestic work experienced a sense of loss in that (Thomas-MacLean & Miedema, 2005), and Hochschild's findings that indicate women feel more responsible for the home and care of the children compared to their husbands (1989). Because the women's roles in the private sphere, in the household and in relation to their families, are so closely associated with the ability to perform domestic work, they continue to take on the responsibilities in the household, rather than hand over that role to others.

The women's responsibilities in the household remain regardless of their physical abilities and limitations, which reveals not only the attachment to that ascribed role for the women, but also the level to which gender roles are embedded in the household. Some of the women live alone and have to manage the household themselves, but those who are married, while receiving help to varying degrees, indicate that they continue to feel responsible for the housework. Laura, for example, suggests that it is primarily her job by saying that her husband *helps*, but also sees room for more equality and better balance with her husband in the household: *I've been trying to change our roles by getting him to do more around the house. So now I have a good excuse.* The women indicate the huge stress housework has on their bodies, but traditional gender roles continue despite the pain it causes, and the risks they take as they strain their bodies. Jillian, who is responsible for the housework, does not see any adjustment whatsoever in response to her limitations: *I don't have any help with any of those kinds of things. No, I've never, and I never have. Like I say, I just, my expectations aren't as great now, so, you know, the bathroom doesn't get done every week, oh well. C'est la vie.* The traditional gender roles remain even though the women's abilities to carry out the work changed, which reflects sociological understandings of the family that suggest despite the accepted ideal of equal rights in gender relations, women are still considered to be responsible for caring for dependents in the home, and perform most of the housework (Beck-Gernsheim, 2002). Instead of shifting roles, the women adjust expectations in order to connect the understandings of the role in the household to their abilities with arm morbidity. Perhaps traditional roles in the household are so entrenched in understandings



of what makes a woman that to remove it would create a role too unrecognizable, which led the women to risk their bodies and lower their expectations rather than change their roles. Perhaps it has less to do with the women's choice, and more to do with others' expectations of the roles the women fill, which did not adjust to coincide with their new physical realities. Or, maybe a combination of these and other social factors led the women to continue in that role. It is interesting, however, that both the women, and those in their lives, are willing to essentially disregard the health issues and physical limitations in order to sustain the roles in the home. This raises the question, then, at what point in the women's physical discomfort, limitation, or potential detriment would that shift occur? Bolger et al. (1996) suggest that the severity of the crisis, which is indicated by the physical impairment, determines when significant others enact support (p. 288), but with a disability that is not necessarily visible, and possibly not considered to be serious, it is unknown when the women's roles would begin to adapt to their needs.

A comparison between the women's experiences in the household and in the formal workplace suggests that the women have more flexibility in their roles in formal work than the informal work they carry out. The women generally find that their roles in the household do not adjust to meet their physical needs, and because the household work is constant and informal, the women are not able to take time off from that work. Just as Hochschild suggests that there is a leisure gap between men and women in the household because of the time women spend working at home (1989), there is perhaps a gap in the time allotted for self-care between men and women, as the women's engagement in housework prevent them from taking care of their bodies as they should. Housework piles up as routines continue, and children need to be cared for, so the women are required to fulfill those responsibilities whether they are healthy and physically able to. It is often monotonous work that requires repetition, and that repetition in tasks, and of tasks, is difficult on the women's bodies and stresses their arm problems. But there is no way to avoid it, as the housework is required to allow them to carry out their routines in and outside of the home. And because the women have the primary role in the household tasks, they have to perform that work whether they are having a good day or bad.

#### *5.2.1.2 Paid work: Flexibility in the formal*

While the women's responsibilities in the household remain rigid and unrelenting, their roles in the formal work environment appear to provide them a greater ability to adjust to their changed health. Regulations in formal work provide employees with particular rights, which allow the women to consider their health as they perform their jobs, and the workplace also provides women with more flexibility in their roles to allow them to make adjustments for their health and limitations. Sick time is beneficial and oftentimes necessary when the women struggle with their arm problems, but the women indicate that they are quite comfortable taking that time off for their health, and feel supported by their workplaces. This accommodation would vary according to the employer, so women engaged in more secure, professional work, such as teachers, psychiatrists, nutritionists, and office managers, would receive more relief in their roles in the workforce than women who engage in part-time, temporary, and service type jobs, such as cashiers, restaurant servers, and other positions involving what is considered unskilled work. However, compared to the constant responsibility in the home, the women are able to find relief from their formal work when they need to take time. When Jillian began having arm problems and required extra help or could not perform certain tasks, she received support from her workplace, and this gave her a sense of freedom to put her health as a priority:

*[T]hey have accommodated me in that way, which has been great. And I've learned that when, you know, when it gets, it gets too uncomfortable, I just take a day or two off work and, and I don't feel bad about it anymore. Because I figure, you got to look after yourself, so, yeah, I take the time that I need, and the work somehow gets done.*

While the roles the women fill in household work are quite rigid, the formal work environment places less demands on the women's bodies, makes adjustments in recognition of their limitations, and allows women the opportunity to take time off because of their health. In addition to the care for their physical health in the workplace, Denise also finds mental relief in her work outside of the home that benefits her: *I've probably mostly gone back to work for sense of well-being.* This has been raised by others who have approached the issue of women's participation in the workforce, such as Lorber (2001) and Hochschild (1997), whose findings show that women's involvement in

formal work is positive not only for financial reasons, but because of the benefit it has on the emotional well-being. Hochschild (1997) even finds that, while the emotional states of men and women are comparable during the week, men experienced more positive emotional states at home, while women's experiences at work were more positive.

In the workplace, the physical environment creates difficulties because of the women's limitations, as they experience problems carrying out certain functions, lifting heavy objects, and even simply sitting in a particular way for a long period of time at desks, or in front of a computer. The women make adjustments by getting carts to push things rather than lift, and change tasks so as not to overwork their arm, but they are required to adjust to a setting that does not support their limitations. Similar experiences are reported by women with arm morbidity issues in other research findings, as the women modified the way they carried out their paid work (Thomas-MacLean et al., 2008). This problematic physical environment, within disability studies, is one of the primary causes of disability, as it is created in a way that reflects socially constructed ideas about normal bodies (Weitz, 2004). Jillian, however, decided to seek out ways to make changes in her environment in the future that would benefit her physically:

*I want to see what they have available as far as, um, you know, chairs, desks, whatever's out there, and to, to help me do my job.... I mean, I take, I take my chair and whatever desk they give me and you just work around it, and I'm thinking, you know, I gotta start doing something for me and saying, look, I can't work here if it's like this.*

It is an interesting observation that, in the workplace, some of the women feel comfortable making demands for changes that benefit their health and limitations, but in the household, they have generally accepted the roles and responsibilities that are in place and settle for physical discomfort and strain because of it.

### *5.2.1.3 Intimate relationships: Roles encompassing old and new*

The women generally do not feel that arm morbidity impacts relationships with others, but most did discuss the changed interactions they experience with others because of their health, including issues they face as mothers managing their lives with arm problems. One issue many discuss is their children's perceptions of them as healthy, capable mothers, and the responsibility they feel to respond accordingly. This

responsibility to their children is likely reminiscent of the traditional gender roles of women that position them as responsible for not only the housework, but for childcare as well. And, similar to housework, the women try to maintain their roles with their children as best they can. In some instances, the women talk about the continuous explanation needed to help their children understand arm morbidity and the limitations involved. Because they have filled the role of caregiver throughout their children's lives, it is a big adjustment for their roles as mother to incorporate limitations and health concerns, which they handle in various ways. Similar experiences are presented in other research findings, as breast cancer causes the need for mothers to shift the roles they fill with their children, and struggle with and accept those changes to varying degrees (Walsh et al., 2005). Janet, for example, talks about her adult children's desire for her to just be well: *[W]ith my family, I, I, I had to train them a bit, because – I have two sons – and they see me as, you know, super competent, and I can do this, and I do, can do that.* In this sense, her children have difficulty adjusting their understandings of her role as an able-bodied mother to a mother who has issues performing the tasks that she had been able to in the past. In other cases, the women feel responsible to protect their children from the concerns of their health and limitations, which leads them to try and maintain the role they filled prior to their limitations. Renee talks about her need to stay positive and not allow her lymphedema affect her life: *I have two kids, and their dad is no longer around, so I'm the only one that they have, and, so, you know, don't let it bring you down and don't let it limit what you can do.* Jillian, whose arm problems involve more severe pain and discomfort than Renee, also mentions that she had kept her health issues private to shield her young children from concerns:

*I didn't want to frighten them more, so a lot of times I didn't let on that, you know, things were bothering me or whatever. I'd just keep that all inside until you were by yourself and then you go down into the basement and yell your head off. But, ah, you didn't want to do that, um, in front of them, or, or, so I tried to be, ah, very upbeat when they were around.*

These women proceeded in the relationships with their children as they had prior to their arm problems, and continue to act as caregiver and protector in order to maintain those roles. This continuation of roles is likely because, as gendered social actors, women are

expected to be nurturers who put others' needs before their own, and while arm morbidity issues make it more difficult for the women to engage with their children the same way they had previously, many hide their health issues, try to overcome them, and feign optimism for their children. The decision to continue in those roles is in part for the sake of the children, but other research also indicates that it may also benefit the women's health, as findings suggest that maintaining roles and relationships in the home has great importance for social well-being in cancer experiences (Ferrell et al., 2003).

The women, as mothers, are also very aware of the potential burden they could be on their children because of their arm problems, and as a result are not always comfortable receiving support in their lives from them. Feeling like a burden is described in other accounts of chronic illness, such as Charmaz's work that discusses the negative implications that the feeling of being a burden can have on the self, and is another form of suffering (1983). The women had been in the role of caregiver, and it does not appear to be an easy transition to accept help, especially from those they had been responsible for caring for. Angela, as a widower living on her own, discusses the concerns she has about the influence her arm problems could have on her son's life:

*[M]y brother has said, how come [your son] isn't home helping you? I don't expect him... every eight days to come home and, and, ah, help. I've got to do it on my own. I've got to figure out how to do it. Yes, I like to see him. But I know, when [my husband] died, the longer he stayed, the more he thought he could stay. And that's not fair. I can't do that. No matter what, I can't do that. I have to figure out, and if it gets to a point where I really can't do anything outside, then fine, I will have to move.*

The children's lives are central to her thoughts, and the awareness of the implications the women's arm problems can have make many try to avoid upsetting their children's lives as much as possible. This again leads the women to carry out roles with their children more reflective of their lives prior to arm morbidity, which likely has benefits for both the women and their children.

While most of the women discuss concerns about arm problems as they related to the impact it has on relationships and roles with their children, Denise discusses both the benefits and the downfalls of her limitations as they influence her ability to be a mother.

The physical limitations she experiences prevent her from engaging with her kids to the extent that she wants, because she would like to *be doing more kid things*. However, all of the women talk about the benefits their changing health has on their overall outlooks, and Denise relates this explicitly to her ability to be a good mother. She was required to change her expectations and slow her pace because of her health, and she feels as if that molded the type of parent she is:

*I knew the type of mom I wanted to be, from reading those books, and yet I was forced into being, I guess, ah, almost forced into being the type of mom that I wanted to be, I guess. Cuz I think I've found the happy medium.*

Meanings about the role of mother prior to arm morbidity are both maintained and adjusted, which is reminiscent of Lindgren's statement that the new self in illness is a fluid construction of old and new (2004), as some of the women apply their new understandings to previous meaning, and construct new roles that can be applied to their lives with arm morbidity.

Some of the women also discuss relationships with their grandchildren, as the way of being a grandmother has been affected in the experiences of arm problems as their ability to interact changed. The physical limitations the women experience, as well as their need to be aware of the strain they can cause to their bodies, prevent them from interacting with young children in certain ways, especially since those interactions generally require a level of physicality of the adult to provide care. This change in interaction is not necessarily viewed as a negative outcome, but it does shift the role the women filled as grandmothers. As Janet says,

*[A] big one in my life is lifting my grandchild. Ah, and all the things that go with looking after a small baby, like putting him into his diaper when he's squirmy, and things like that. So I'm not much of a babysitter for a little kid.*

This statement encompasses the widespread consequences of arm morbidity in the women's lives, as it reflects changes in relationships, interactions, and roles. Similar findings were discovered in other experiences of women with arm morbidity, where women could not lift grandchildren, and tasks and interactions were affected (Thomas-MacLean et al., 2008). The interactions most would take for granted with young children, such as lifting, carrying, and holding, became difficult as the physical condition

of their bodies limit or prevent the women from engaging as they would have with healthy, able bodies. In this case, Janet is unable to performing seemingly simple tasks necessary for caring for a child. This change in interaction transformed the women's roles in their grandchildren's lives, as they can no longer perform certain tasks that are commonplace for grandparents, such as babysitting. Because of this, their role in the grandchildren's lives cannot be that of caregiver, in the traditional sense, and their role in their adult children's lives adjusts too, as they cannot provide support with childcare. These changes in roles, therefore, affect the relationships the women have with both their children and grandchildren.

There was less focus in the women's narratives on the influence arm morbidity has on the relationships with their husbands, as those with spouses indicate that their arm problems do not have any significant effect on their marriages. However, the discussion of housework suggests that there are both negative and positive effects on these intimate relationships resulting from their changing health, and the experiences do reveal that the health issues have other consequences as well, even if they are not of major importance. The changes in relationships resulting from arm morbidity correspond with findings of Walsh et al. (2005) that suggest breast cancer impacts women's relationships with their partners in a number of positive and negative ways. Somewhat similar to the struggle of children to accept the health problems of their mothers, part of the experiences with spouses includes the husbands' struggles to deal with their wives' arm morbidity. Jillian feels as if her husband wants to fix her, and Laura says, *I don't know, I think he wants me to just be okay*. In addition to the physical implications of arm morbidity on spousal relationships, the narratives also indicate that the individuals' self-concept has consequences for relationships. This connection between self-concept and relationships is similar to the idea of Holmber et al. (2001), who suggest that negative changes in self-perception negatively influenced relationships in women's social world. Jillian discusses her low self-esteem due to her health issues and her body composition, and stresses that it greatly impacts her relationships, including that with her husband: *I guess I've, I just have really pulled away from them*. The self-perceptions the women construct as their bodies change, which is influenced by limitations, health, and appearance, affect relationships with others, and in the case of Jillian, her negative self-concept makes her

withdraw from others, including her husband. Asbring (2001) notes similar experiences in women with chronic fatigue syndrome and fibromyalgia who withdrew from social life as a result of their illnesses. The way the women feel about themselves is central to determining how they interacted with others, and as a result of the adjusted meanings that were created in experiences of arm morbidity, relationships with people changed, and roles shifted.

The women's arm problems also change their ability to engage in leisure activities and hobbies because of the changes to their bodies, which affects their engagement in social activities with friends and other acquaintances. Similar findings are reported in other experiences of arm morbidity, where leisure activities and hobbies were restricted (Thomas-MacLean & Miedema, 2005). Jillian, for example, is no longer able to bowl, but she can play simulated bowling games on a particular electronic gaming system. This indicates that new technologies have the capacity to provide alternatives to those who are physically unable to participate in certain activities, so while they may have to stop participating in physically difficult activities, the virtual counterparts may provide viable substitutes. Renee does not feel as if her lymphedema has stopped her from doing anything she wants, but does say that she had to stop playing ball because of it, and fills her time with new activities because she misses the social aspect of playing. It is not the changes to her ability that bother her, but how those limitations impact her relationships and interactions with others. Similarly, many of the women are conscious of the way their arm problems limit their ability to interact with friends, and do not want to become outsiders because of their health. Denise says that the important thing to her is that her friends do not stop calling her, even if she is less likely to go out because of her health issues:

*I said, just the fact that you always include me, even though I've always, or I've refused more times than I've gone, I said, you know, it's, it's, ah, really big for me. Because if nobody were calling me, I think that would be more threatening.*

Her connection with people, or to a group, is important to maintain as she tries to manage her life with arm morbidity, because those associations with people help her continue to feel normal in spite of her health problems. As she explains further,



*[Y]ou know, even if it is just lymphedema, I think, I've really come to realize that it doesn't matter what you have. You know, even if you just constantly have a cold, it, it just wears you down, physically and mentally I think. And I think when you start feeling different than other people, I guess, you just, you can easily say I'm just not a part of that group.*

Her focus on relationships, and feeling like a part of the group, indicate that her feelings of normalcy in her life are not necessarily attained by having a normal body and normal health, but that her social interactions do not become different, or that she does not feel apart from the regular social group she is involved in. While bodies and health do impact feelings of normalcy, and illness and disability require adjustments, the implication here is that those come secondary to how individuals are accepted in their social worlds, regardless of their bodies and health.

#### *5.2.1.4 Community: Invisible disability and unmet expectations*

More generally, another theme that emerges in the experiences of arm morbidity is the changed role the women experience as active members of the community. Ideals about normal or appropriate participation in the social world assume the expectation of a normal body in order to function in those ways, so a body with limitations or changed abilities does not necessarily allow one to meet those requirements and fill the role. In many instances, the women have decided to pull back from particular activities, as their ability to continue at the pace they had been was no longer realistic. The women limit their involvement in certain activities or groups, such as Angela, who had to withdraw from certain positions in the groups she is involved with, and many discuss that they have to slow down when they engage in activities or work with others, despite the pace that others were able to keep. Laura, talking about her need to change her pace, says,

*I still have moments where I, yeah, start flying around and say, "Nope." Just learning to say no and, and prioritizing what's really important to you. Um, to not worrying about, ah, whatever people think if I don't join this that and the other thing, so, yeah.*

Their ability to engage in the same ways has been compromised because of the physical limitations, and as a result the women are required to draw back from many of the activities, and many of the roles, that they had filled prior to their arm problems. This

proved to be difficult, however, because the women have their own expectations of the roles they feel they should fill in the social world, and because of the expectations of others who have particular ideas about what the women should be doing.

Related to the roles in the broader social world is the reception the women receive in the community with their changing engagement, as some of the women also discuss the changed perceptions in the community that result from their inability to fill particular roles with physical problems that are not necessarily visible to others. The women look healthy to others, but because they are unable to participate or contribute the way they are expected to, oftentimes the women feel as if people have negative perceptions of them because they look as if they are not contributing in an appropriate manner. Janet talks about the reactions she receives from strangers when helping a friend who had broken a shoulder:

*I'm sort of a little bit handicapped myself, so she's got a sling on, she's visibly worse off than I am, but she's got a good left arm. And, you know, I could see a person thinking, like, why is she doing that for you?*

Because she looks healthy to the world, people do not understand the physical limitations she deals with and construct perceptions of her accordingly. In disability studies, there is comparable acknowledgement about social perceptions of the genuineness of disabilities, as the suspicion involved can cause the individual to have to prove the disability, and others to respond with resentment (Wendell, 2001). Similarly, Angela is very conscious of her contributions to a group she is involved with, but worries that the inability to carry out her role as she had done before will have a negative impact, so she risks her health in many cases to avoid disappointing people and failing to meet expectations:

*[I]f you're setting up and carrying eight foot tables and things like that, and they look at you cuz you're one of the younger ones, so hey, you should be able to lift these things. And it's hard to [say no], cuz you look okay. It's not on the surface. And so they expect more from you. And I think with everything, if it's an inner problem, ah, as long as you look healthy on the outside they expect that you can still do what you've always done.*

In this case, Angela does not feel justified to excuse herself, because she is younger and because she looks healthy, so others expect her to be able to perform as any healthy

person would. The invisibility of her arm problems prevent others from gaining a clear understanding of her physical condition, which leads her to strain her body rather than disappoint others' expectations, or have to explain her limitations to others. Visible and invisible disabilities, then, are experienced differently in society, as those with visual disabilities can experience more bias, inequality, and prejudice because of the visual indication of difference, but that visibility also likely allows people to adjust understandings to take into consideration those differences. Invisible disabilities, however, likely do not create the same negative responses because there are no evident differences in the body, but may present individuals with difficulties as they are expected to fulfill roles that require an able body. This idea is found in disability studies, which suggests that, while individuals may avoid stigmatization because of the invisible disability, it may also create unique experiences of rejection, humiliation, and social disapproval (Davis, 2005). Also related to the women's struggle with invisible limitations is the research focused on experiences of uncertain, emergent illnesses, as the lack of definition or understanding proves to be problematic in a society where people are not allowed to have anonymous illnesses (Dumit, 2006; Nettleton, 2006). In the cases of the women with arm morbidity, their abilities to fill roles as contributing members of society change because of their health, and this influences not only how they carry out their lives in their communities, but how they are perceived by others in the community.

#### *5.2.1.5 A balancing act: Listening to bodies and living lives*

The women's experiences of their changing abilities and the impact of arm morbidity in their daily lives led many to discuss the self-awareness of their limitations that emerge as they experience arm morbidity, which allows them to construct understanding about how they can fill roles in their lives with arm problems. It is a work in progress, as the women continuously grow in their understanding of their health to construct lives that incorporate the new limitations. Denise discusses her continuing evolution to understanding and managing her limitations, which takes into consideration the risks involved in stressing her body:

*I'd have to say the first few years I kept saying, I'm going to do this. And then I realized that, you know, why should I be jeopardizing the other arm and, and...*

*it's just stupid of me, like if, I don't want to make myself more sick, or afraid to get worse.*

In this sense, her expectations about what she should be doing in her daily life had at first remained the same, but over time she adjusted her ideas and became comfortable making changes in the roles she performs, in consideration of her health. While the women are all conscious of preventing more strain on their bodies, they also talk about both the cost and benefit that is involved in limiting themselves in their lives. Laura calls her limitations a *moving target*, as her understanding of her changing symptoms grows, and the women talk about the processes of trial and error that they go through to navigate with arm problems in their daily lives. Denise, while cautious, wonders if it is really worth her efforts of staying healthy, saying that it is sometimes a catch twenty-two: *[I]f I overdid it, can I be worse than I already am? Sometimes you ask yourself that, you know? Should I rest or shouldn't I rest?* The women negotiate the roles they fill in their lives as they gain understanding about their arm problems, and incorporate ideas of their health into decisions about their priorities and responsibilities. In doing so, they continuously make decisions about the costs and benefits of prioritizing their health, or prioritizing the lives they wanted to live, in order to decide how to fulfill their roles, and when to put their health first.

While the women are limited in their daily lives to varying degrees, and accept those limitations in a variety of ways, their narratives all include how they cope as they try to navigate with their arm problems and manage their lives. It is evident that they do not want their physical limitations to obstruct their quality of life, which is illustrated by Laura's discussion of the continuous decision-making that is involved in her daily life, in both the big and seemingly mundane:

*I just make a decision each time, similar to with having had cancer, it's just, like, okay, they tell me not to drink alcohol, but, knowing what I know, what I, you know, deciding what I'm comfortable with, or what level of, um, risk, or that kind of, balancing that with living.*

As the women continue to become more aware of their bodies and their limitations, they are more willing to take small risks in order to continue living the way they want, which

allows them to feel more comfortable to not always put their health above everything else. As Angela says,

*I think for the first little while I had found that, um, I think I, I had maybe babied my right arm and thought, oh well I'm not supposed to do that, I'm not supposed to do this, but now I just say, hey, it's gotta work.*

All of the women discuss their need to continue carrying on with their lives, despite the limitations they face, and suggest that they engage in a balancing act between avoiding strain to their bodies and living their lives to the fullest and carrying out the roles they feel are important. Janet talks about making choices that allow her to continue doing those things she values in her life, while letting go of those that are less important in recognition of her limitations: *[Y]ou work on the things that you really enjoy, and, ah, and then, and you get better at them. I've, I save my energy for, for cooking, for example. Or going grocery shopping.* The women's development of understanding of their arm morbidity in their lives allows them to construct new meanings and feel comfortable adjusting their roles and expectations accordingly, as they make meaning as they live in changed bodies.

The women all try to strike a balance appropriate for their circumstances so they can deal with their limitations without conceding their quality of life, but the stage in life they are in, their access to resources, their support systems, and a number of other factors impact the women's ability to make those choices in their lives. This is reflective of feminist and sociological understandings of health that suggest there are various factors that influence our experiences in society, many of which create inequalities or present obstacles in life because of imbalances in power and ideologies that establish hierarchies. Because the women's environments do not always allow them the luxury of listening to their bodies, or because the women resist changing their patterns, many of them talk about overdoing it in their daily lives as they attempt to balance their knowledge of limitations with their need or desire to carry out their lives as they had known them. Most of them admit that, while they know their limitations well, they do not always listen to their bodies. As Renee explains, *[A] lot of the ways that you have to prevent it is to not overexert the arm. Well, if you're gonna live life, you're going to overexert the arm.* Some of the women also talk about the need to carry out and follow through with certain

tasks in their lives, which puts strain on their bodies during the activity, or often afterwards:

*[W]hen you start something, you don't have any idea of how long it's gonna take you, or what, if your arm's not bothering you, you don't think about it. And so, you have a tendency to carry on doing the job, and it's afterwards then you realize you really were doing more than you should've been doing.*

The women's responsibilities to fill roles often lead them to overlook the strain that is put on their bodies, as they try to maintain what they understand to be recognizable and meaningful lives. While they experience their health in their daily routines, the importance they placed on their social roles often makes the women put their roles and interactions ahead of their health, although their arm morbidity and limitations became a part of their experiences of those roles.

### ***5.2.2 Identity and Health: The Self as Health Changes and Understanding Evolves***

The impact of arm morbidity on the women's health, abilities, and social roles affects the women's self-concepts as they have to adjust to their new physical and social realities. This is reflective of many accounts of illness and disability, including Asbring's (2001) findings of women with chronic illnesses that suggest limitations or the inability to carry out previously-performed activities disrupts individuals' definitions of themselves in relation to the past, present, and expected future. The women's change of self-concept raises the theme of identity, which is a major part of the women's experiences of arm morbidity as they manage their daily lives. The women discuss the influence of their health on their self-concept, the relationship of the physical body to confidence and feelings of normalcy, and how their limitations challenge their independence and sense of self. A changed body resulting from arm morbidity causes the women to adjust their identities, and it is apparent that an important part of the women's experiences involves the impact their arm problems have on their sense of self.

The experiences of arm morbidity indicate that health is a big factor in the construction of identities, as the women struggle to accept the consequences the changes to their health have on their previous self-perceptions as healthy women. In various ways, the women discuss the need to reconceptualize their identities, and ideas of their health as they experience arm problems. As Janet says,

*[G]rief is very much involved in this whole issue that you're dealing with because you lose your concept of yourself as a healthy person, as a vigorous person, as a capable, ah, you know, that get-things-done, multi-tasker that I was talking about. And you have to recognize your own limitations and get comfortable with that.*

No longer able to continue living the lives they were prior to arm morbidity, the women had to reconstruct their identities to coincide with their health and new ways of being. The women became engaged in a renegotiation of identity: In this sense, they have to repeatedly adjust their self-concepts as their bodies change and they learn more about their health and physical limitations, and it is not simply deciding upon one understanding of the self or another, but they have to come to a sort of agreement with their bodies that allows their understandings of the self and health to reach a compromise and connect in a meaningful way.

The renegotiation of identities that occurs to incorporate arm morbidity in the women's identities creates positive understanding in many cases, although there is also concern that health will become the primary or sole factor in their identities. As mentioned earlier, Bailey's findings (2001) suggest that changes to the body can sometimes act as a resource that allows women to reconstruct their social positioning, but can also unfold to make women feel reduced to their bodies and therefore become limited in their social lives. In some cases here, the acceptance of a renegotiated identity that included arm morbidity is evident in the women's willingness to be open about their health. As Renee says,

*Like, you know, they'll ask, like I have no trouble, I don't have any trouble with somebody coming up and saying, you know, what's, what happened to your hand, and stuff like that. No, it doesn't bother me at all.*

The experiences of arm morbidity led the women to create understandings of the self that incorporate their new health, and many are comfortable with the implications that has on their new identities in interactions. In other cases, however, the women are concerned that they will be labeled solely based on their health, as an unhealthy person with limitations. Angela discusses the concern that her health will be the basis of how she will be perceived, which could lead to her exclusion from activities and groups: *I think that'd be the big thing, that they may just then not want to ask you to do anything cuz they're,*

*think, you know, well, she's got a health problem, she won't be able to do it.* She does not want her identity to be her health, as the lack of a healthy or functional body does not conform to social understandings of normalcy, and this often has negative implications for people. However, it does appear that, more than her concern about her different health or body, she does not want her identity to incorporate disability or limitation to others, as this will impact her participation in activities or tasks. This is reminiscent of Asbring's findings (2001) of the experiences of women with certain chronic illnesses, where women discuss not feeling needed or counted, suggesting that, as we consider work to be an important part of life, and have not created other ways of occupying oneself, self-esteem suffers. It is evident that, while most of the women are comfortable with their identities that include their health issues, they do not want it to be the sole defining characteristic because people could label them as less competent.

Because social ideals establish a healthy body as a normal body, the women's experiences of arm morbidity also involve constructing new understandings of normal. Bury (2001) suggests that normalisation could mean individuals would attempt to maintain the life and identity they had prior to the illness, or to incorporate the illness into the changed lifestyle to construct an identity, which can also be applied to the experiences of arm morbidity. Frank (1993) also discusses this reformulation of selves in illness narratives, as a combination of the self that the individual has always been, and the self that the individual might become. In this understanding, both selves are new, but the "have been" self is a discovery of the resources already possessed to deal with the illness, while the "might become" self is the discovery of new resources that the person believes did not previously have (Frank, 1993, p. 42). Some of the women discuss their ability to feel normal in a changed body, which suggests that they incorporate their arm problems into their identities. Renee, having accepted that her lymphedema will always be there, explains, *[I]t's a part of me*, and Janet also indicates her ability to feel normal in her changed body: *I mean, um, something bad has happened to my body, but I don't feel any less a person, or any less myself because of this.* However, the arm problems also cause some of the women to feel different in their bodies, and prevent them from feeling normal. Laura, for example, indicates that she still feels the consequences of her health issues on her self perception: *[I]t kind of, I guess, makes me feel a little bit like, not that*



*I'm still sick, but, um, I don't know how to describe it. I, there's still something wrong and stuff.* And similar to the concern about the label of unhealthy, the women discuss the potential to be labeled abnormal because of their health. Janet talks about meeting new people and having to explain her health and limitations, and says, *I'm getting to the point where I'm going to have to somehow deal with my limitations, but I'm not really comfortable with that. I, I don't want to be labeled, and, ah, I don't want to be my disease. I just want to be myself.* This self-disclosure, when dealing with an invisible health issue, is discussed in other literature, and disclosing a physical, unseen abnormality is compared to an individual exposing his or her sexuality (Samuels, 2003). The women are generally comfortable with including the experiences of arm morbidity in their identities, but they are concerned with the idea that they may only be perceived by their health and limitations.

The experiences of arm morbidity also include challenges to identities as capable and independent women, as the limitations affect the way the women are able to carry out their lives. The women, regardless of their arm morbidity issues, and the impact they have on daily life, all valued the level of independence and competency they had prior to breast cancer treatment, and many of the women discuss the shift that arm morbidity causes when they experience limitations. For Angela, it is very important to have her independence, and she is frustrated with her inability to do as much because of her arm problems: *[I]f I'm gonna do something, I'll do it. I don't need you to help me. Like, you're in my way. And, and I guess, now, there's a lot of things I can't do on my own to the same degree.* The loss of her identity as a capable woman is upsetting, as she is no longer able to take for granted her ability to conduct her life on her own. Along similar lines, Charmaz (1983) finds that a form of suffering in experiences of chronic illness is living a restricted life, as identities are challenged, and the independence and individualism that are valued in society increases the difficulties. While Angela has been able to live independently, her arm morbidity issues no longer allow her to be that woman, and results in a change in her self-perception. In other words, the women's needs to care for their bodies and acknowledge their limitations lead them to create new ways of being, and this in turn affects their identities. As Janet says,

*I have been a very active, ah, you know, proactive sort of person. I guess, ah, type A personality, rushing and, you know, multi-tasking, ah, all of those kinds of things that I used to do. And, ah, you know, I've had trouble slowing down. But, I realized if I don't listen to my body, I pay for it.*

While these physical limitations mean that there is a greater need to receive assistance in their daily lives, the difficulty to slow down, or the resistance to ask for help, makes it apparent that the women's able-bodied identities have been a significant part of their self-conceptions. The importance of competence that the women attach to their lives is evident in understandings of chronic illness and disability, as it is "the essential presupposition of membership in a society" (Thomas, 2007, p. 28). In a similar study, a participant suggested that life was now "boring" because she had to slow down her pace in the work world, indicating that her life of work was what made her life interesting (Thomas-MacLean et al., 2008).

The inclusion of the physical limitations of arm morbidity in reconstructed identities is perhaps more significant and difficult than the transition to include the changed body and health, as the women resist changing their lifestyle or responding to their limitations in many ways. Some of the women do convey the importance of asking for help, in order to be mindful of the arm problems, but most of the women indicate that their need to ask was difficult to accept. Angela, similar to most of the women, says, *I have to be real desperate to ask. Real desperate, like I feel frustrated....* In these instances, the women try to maintain their able-bodied identities, and do not concede to the limitations very easily as that independence and capability that are so important to the sense of self is challenged by arm problems. This resistance to the limitations is similar to other research, which indicates that many women with arm morbidity issues "just keep going", raising the need for ideas of disability to include acknowledgement of "the tension between constraints and perseverance" (Thomas-MacLean & Miedema, 2005, p. 98).

While limitations and changes in ability impact identity in the experiences of arm morbidity, the women also discuss the affect their changed bodies have on body image. In disability studies, there is awareness that a disordered body often involves the element of shame, depicted in many accounts of disability such as Toombs (1995), and this is also

the case for some of the women with arm problems as a result of the changes in body composition. Jillian experienced a big change in her body after breast cancer treatment, which has had major consequences for her body image:

*I'm not proud of it, I guess, and I don't want people to look at it, I guess, is what, when I think about it, it's, yeah, I don't want people to. So you kind of dress, or I find that I dress, um, tended to dress not as nicely as I used to. Which can't, doesn't help the self-esteem.*

She indicates the compounding nature of the loss of self-esteem, as her desire to be overlooked leads her to put less effort into her appearance, which further makes her self-esteem fall and negatively affects her identity. Laura also struggles with accepting her changed body, but indicates that she is learning to become comfortable in it, saying,

*I think that's part of, just, the experience I had and, um, getting older and more, um, figure life out, um, a bit. Um, so just a combination of things that, it doesn't matter as much as it used to. Well it matters, but I don't care about it as much, about appearances.*

However, while body image issues are relevant, the women's narratives indicate that they put greater emphasis on their limitations and the feeling of their bodies, which suggests that appearance is less of an issue because of the physical changes and resulting limitations. Findings of pregnant women indicate much focus on sensuality, body shape, and the spatial body (Bailey, 2001), but the women with arm morbidity focus more on the physical limitations and discomfort they experience, which is supported by other research on arm morbidity experiences where women focused on sensation and feeling (Thomas-MacLean & Miedema, 2005). As Denise says, *I never got depressed over having lost both breasts... I never grieved that. I just, I, I guess I was more upset about the tightness.* Similarly, Janet says,

*[I]f I didn't have pain, I might focus on the cosmetic thing. But that part has, it hasn't really, you know, traumatized me that much, other than, you know, at first, naturally. But, um, that part is okay. Like, I'm good with my body image.*

The women's emphasis on their health and ability in their narratives of arm morbidity, above issues of appearances, presumably occurs because of the lesser impact the changes in appearances have on life compared to the changes in ability.

One theme in each of the women's narratives is the problems arm morbidity cause on the area of clothing, which relates to the issue of identity because it is one form of expression in the world. Wendell (1996) suggests that "Clothing one-self shows how embodiment is experienced as actual or even imagined interactions with others" (p. 85, cited in Thomas-MacLean, 2005, p. 205). The women's struggle to find clothes that fit as they live with arm morbidity impacts their ability to feel good in their bodies and express themselves. Similarly, other findings about the experiences of women with arm morbidity indicate that clothing is a major difficulty, in terms of comfort, the meaning of it, appearances, and unwanted attention (Thomas-MacLean, 2005; Thomas-MacLean & Miedema, 2005). All of the women discuss the difficulty they have finding clothes that fit, because of the swelling in their arms, or the stress that the clothes cause to their bodies. By her own account, Renee experiences the least amount of disruption in her experiences with arm morbidity, but does indicate that clothing is one major area that she has struggled with since experiencing lymphedema:

*I'm really limited in, in jackets and stuff cause they're all lined, or most of them are lined. So, um, yeah, and I like clothes. I love clothes. I like clothes shopping, I like new clothes and stuff. So, it's been a bit of a downer, you know, cause you look at a lot of the new styles and, oh, I can't wear that because it won't fit on my arm, and stuff like that. But, I mean, you, you adjust, you, you know, there's not much I can do about it, um, other than to go and have all my clothing made, and that would be very expensive.*

Because bodies with arm morbidity differ from the socially constructed idea of a normal body, the women experience problems finding clothes that fit or are comfortable on their bodies, and their limited options of clothing impact the ability to express themselves.

The women's experiences of arm morbidity are filled with many changes in health, ability, and identity, and with that came a sense of loss in what they had been and no longer were. In some cases, the women discuss small changes in their lives that resulted in subtle or seemingly unimportant changes in their identities. Denise discusses her inability to ride a bike because of her arm problems, which may appear to be insignificant, but is a major change from what she could do, and who she was, before treatment: *I don't do as much bike riding. And yet, up, I didn't have a car until I was 29,*

*and that was my form of transportation before that. And when I had young kids, we always went bike riding.* Biking represented her means of transportation, and an activity she engaged in with her children, and her health issues prevent her from maintaining that in her life, and in her identity. Angela discusses the decision she may have to make to move away from her home in the country, which represents her independence, her activeness, her family, and is a symbol of how she perceives her self. She says, *[I]t's hard to think that after living in a house all your life that you've got to make changes, and you go, you know, where am I gonna go? What do I look for? I don't want to sit in an apartment and just look at four walls.* A potential move because of her arm morbidity does not only mean a change of environment, but also a change in lifestyle, and the loss of those things she associates with her identity. Jillian is the most explicit about the loss of her previous self: *I just look back at pictures, you know, and I think, oh man, whatever happened to that person. Where did she go?* Her arm morbidity has implications for her whole identity, because of the implications her health has on the way she lives her life and perceives herself.

### **5.2.3 Understandings of Health Impacting Approaches to Life**

The experiences of arm morbidity in the women's lives led them to construct new meanings of their bodies, their daily lives, and themselves, which indicates the major role of health in our understandings of the social world. The women also discuss the lessons they have taken away from the experiences of breast cancer and arm morbidity that influence their overall philosophies of and approach to life, which helps them create new ways to manage their lives with arm problems. Their experiences of arm morbidity are a continuous process of learning and making meaning, and that translates into approaches to life in general, and thoughts about the future. Because health is so intertwined with experiences in the social world, the women's experiences of arm morbidity affect ideologies and perspectives overall, indicating the broad scope of the impact illness experiences have on life.

The women discuss the learning involved with arm morbidity, as they recalled the experiences they had since breast cancer treatment, and indicate that their understandings of arm morbidity are constructed in an evolving process to make meanings. The women's perceptions of arm morbidity develop as they experience daily life, and the

meanings constructed allow them to manage their health and lives despite the consequences of the arm problems. Janet discusses how her outlook about her health issues has developed over time: *I would say I've grown in my, ah, my journey to a positive approach.* Similarly, Angela talks about the development of her acceptance of her arm problems:

*It's now something you live with. And you're gonna have good days and you're gonna have bad days, and you deal with the bad days when they show up. That it's not like going and having your appendix out or gall bladder and when it heals you merrily go on your way. It's now something you have to live with, that you have to think about.*

In the same way, Charmaz (1991) discusses the “ebb and flow of time perspectives” involved in chronic illness experiences, (p. ix) that suggests both good days and bad days are a part of the journey. The experiences of arm morbidity include a continuous reconstruction of meaning and understanding that allows the women to manage their lives as they have both positive and negative experiences with their health. The women also apply the meanings they construct to their continuing lives with arm morbidity. As Janet says,

*I believe that, in many cases, it isn't time that heals things, it's what you do in that time. I, I have experience with grief, so I have the same theory about that. Ah, if you don't deal with things, they come back to haunt you, whatever they might be. They just don't go away by themselves. And I feel the same about this. I, it's a, it's my job, I work on this, ah, to get this back to, ah, so I can live a normal life.*

The women's reconstructed meanings that are established as they experience arm morbidity allow them to feel confidence in the understanding of their own lives again, which better equip them to deal with the arm morbidity issues that have become a part of their daily experiences.

While the women apply the new meanings of health and life to their present situations, they also look ahead to the future to understand how arm morbidity will continue to impact their lives. Some of the women discuss concerns they have about the future, as their understandings of arm morbidity lead them to consider the negative

implications they could potentially have. Janet, who does not have lymphedema, is very aware that it can occur at any point, and says that it is *kind of an ominous idea to have in the back of your mind*. Jillian also discusses her concerns about the limitations caused by her arm morbidity, and the affect her health may have on her abilities as she ages. This uncertainty in the experiences of arm morbidity is also raised by Bury (1982) in his findings on chronic illness, as the experiences involve a number of issues that remain unknown for those individuals. However, most of the women are quite optimistic about the future, as they apply the meanings they have constructed of arm morbidity to their lives. This is similar to findings of experiences of cancer survivors as they deal with their emotions, and the relentless optimism that is used, which McKenzie and Crouch suggest is partly because optimism, good humour, and good health are considered to be closely related (2004, p. 151). Comparably, understandings of illness stories have depicted the strength that is included in narratives, and the negative attitudes towards explanations of illness that can be seen as whining or complaining (Werner et al., 2004, p. 1038). In part, the women may feel the need to convey optimism, as it often took some time for them to reveal the difficulties and negatives that are a part of their experiences in their narratives. However, it is not only a response to social expectations, as they do convey very real, positive meanings of their experiences with arm morbidity. Denise, whose health is quite strained by her involvement in the workforce, says,

*I see a, a light at the end of the tunnel. And not necessarily, um, my arm going down. I've kind of given up on the fact that it will ever be normal, to my left arm. Ah, but I know I can, you know, if I had, when it comes that time to retire and I have to make a choice, I will choose something that's not going to aggravate.*

Similarly, Angela, who is retired, talks about the impact her life in the future may have on her arm problems, suggesting that they will improve because of her lighter work load at her home, in the event of a move into a smaller place:

*I would think it would be better for the arm. It's not going to have to work as hard and do heavy things... if it's in a condo situation, well then, you won't have that outside work to worry about. And there won't be as much inside work...*

For these women, it is not the case that they expect their biological problems to improve, but that their lifestyles will slow down and put less stress on their bodies, allowing them to feel healthier.

The development of meaning about arm morbidity translates into the women's perspectives on life, and leads them to challenge previously held assumptions about life and health as they grow in their understanding. The women discuss living a good life, and the understanding of that good life is informed by the meaning they construct as they experience their health. In some instances, the women raise the conflict between ideas and expectations of society with the understandings of they had of their own health. Denise talks about the fast pace of society that people are expected to maintain, and the detriment to health that she considers as she makes decisions in her life:

*I really think people don't realize about how much stress that, ah, the biggest thing I hear from people who are retiring now is they didn't think they were so exhausted. And they didn't realize how much their bodies were going, going, and going, until they stopped. And I think that's really scary for our society.*

While social expectations normalise stress and a fast pace, the experiences of breast cancer and arm morbidity expand Denise's understanding to include considerations of her health as she lives her life. In other instances, the women discuss the conflict that arises because the understandings of health do not coincide with their ideas of a good life. As Laura says,

*... quality of life is such a huge huge thing, and, um, for anybody you don't know how long you have, but, um, you kind of, with cancer, have that extra wake-up call, I guess, that, um, yeah, I mean, I try to live a clean life and follow the rules, but, um, you know, sometimes you just want to do whatever, have a drink or, ah, go for a run, or whatever it is.*

The women decide how they will live their lives by considering not only what is necessary to stay well, or what social norms dictate, but also the meaning they have constructed of their experiences of breast cancer and arm morbidity.

The women also discuss overall changes in their ideas about acceptable ways to live that differ from the beliefs they had ascribed to prior to their health issues. Asbring (2001) discusses similar findings in other experiences of chronic illness, as the reflections



created positive changes to identity as a result of the new understandings they had about their previous lives and life in general. While there is resistance to the limitations imposed because of their arm problems, the women did take away meaning from the need to slow down that translated into ideas about how to manage life. Many of the women discuss the benefit of creating a life with less stress and disorder to live well. As Denise says,

*The more time you have to ponder over it, the more you see that you are either anal about things, or, you know, like, you should let go of things. Simplify your life. Unclutter your life, because if you unclutter it then there's less, ah, to worry about.*

Some of the women also discuss the change in perspective as they approach their lives, as they learn to enjoy and appreciate more. Renee discusses the change in her priorities as life that resulted from her experiences of breast cancer and arm morbidity:

*You realize what's really important, and what's not. Um, I, you tend to live every day to the fullest, you take advantage of, you know, like say, like a nice summer day like yesterday, like, just take the time to enjoy it.*

The women's health imposes upon them the need to slow down in their activities, and they seem to embrace the idea and apply it to their philosophy on life.

The women engage in a continuous process of understanding their health and their lives, and the lessons they learn and the meanings they create allow them to continue to make sense of the new realities imposed on their lives as a result of arm morbidity. They acknowledge the struggles that they face along the way, as they are impacted by arm problems, but are all hopeful as they see that a development of understanding will equip them to manage their lives. Janet talks about her effort to maintain a positive outlook along her journey:

*I have a little sign on my, um, on my bedroom mirror where I try to, it says... Acceptance, enjoyment and enthusiasm. And, you know, ah, I, I try to approach the fact that, you know, everybody has grief and tough things to deal with in their life and, um, I have learned from experience that, you know, you keep putting one foot ahead of the other and, and, ah, with the help of a good support system you can manage.*

#### ***5.2.4 Managing Lives: Narratives Constructing Knowledge***

Arm morbidity is a health issue that has many implications for the various aspects of the patient's life, illustrated by the women's experiences that influence the way they carry out their daily routines, the roles they fill in relation to others, the identities they have constructed, and the meanings they create as they engage in the social world. The narratives indicate the unique manner in which individuals experience health, as it is experienced in a particular context, by individuals who draw upon distinctive histories and cultural understandings that are unique to the experiences in their lives. On one hand, the women live in the same culture, and are impacted by the same social norms, gender roles, physical environments, institutions, and other constructions in the social world. But at the same time, the combination of those elements in each woman's makeup is different, and because of that they have a unique perspective into their own arm morbidity narratives as they make meaning and construct understandings with unique combinations of background and understandings. Regardless, it is clear that women's experiences of limitations and roles, identity, and meaning-making in the arm morbidity narratives raise many important sociological themes. The women's arm problems affect their ability to conduct life as they had prior to illness, and that has major implications for both the roles they perform, as well as the identities they construct. This does not imply that all of the roles and identities changed, but it is evident that those things that the women had taken-for-granted before were no longer as simple and straightforward. This continuous renegotiation in their lives, as they live in the social world, creates valuable understanding from meaning-making for the women. The experiences of social roles and identity are greatly influenced by health and ability, and they are all interwoven to construct the women's understandings of arm morbidity in their lives.

## CHAPTER SIX: IMPLICATIONS AND CONCLUSION

The study of 'illness narratives' constitutes a dual process... On the one hand the exploration of chronic illness narratives may throw light on the nature of disrupted experience, its meanings and actions taken to deal with it. On the other hand, the study of such narratives has the potential to reveal a wider set of important issues to do with the links between identity, experience and 'late modern' cultures. (Bury, 2001, p. 264)

In this concluding chapter, I present a number of implications that have come out of the research. The women's experiences of arm morbidity raise a number of sociological and biomedical issues for consideration, and suggest that there are many possibilities for future research focused on arm morbidity that would be of value to pursue. In addition to implications for research, I also present ideas to be considered for the healthcare system, and lessons for the patients, which were constructed from the women's understandings of their health and experiences with arm problems after breast cancer treatment. Finally, I conclude the thesis by presenting the major ideas that were explored in the women's experiences, and explain the importance of this research as we try to gain understanding about life, health, and society.

### **6.1 Implications: Narratives Benefiting Knowledge and Experiences**

As knowledge of arm morbidity is lacking in both sociological and biomedical fields, many implications can be drawn from this research that are of use for the various stakeholders involved, as they relate to women's bodies, health, limitations, and lives. The illness narratives construct understandings that contribute to biomedical and sociological knowledge, and suggest that further study is important in this area as many issues remain relatively unexplored or misunderstood. The meanings the women create also convey a number of lessons for those who make decisions about arm morbidity treatment and who interact with women with arm morbidity issues, as knowledge will help individuals better understand and approach the realities of the health condition. Finally, the women's narratives can translate into lessons for other women in similar circumstances and could benefit from the knowledge and experiences of others.

#### ***6.1.1 For Research and Academia***

The sociological implications arising from this research are extensive, as the impact of arm morbidity on daily life is found to be pervasive and complex. The research

is connected to major sociological themes of gender, identity, embodiment, knowledge translation, social roles, and illness experiences. One primary conclusion significant to the field of sociology is the interconnection of health with experiences in the social world, which suggests that there is continued need to research and understand illness and health from the perspective of patients and those directly involved. This brings to attention the experiences of the physical symptoms, and also illustrates the norms, ideals, and structures of a society as they impact, and are impacted by, illness experiences. The idea of embodiment is also important in the sociological understandings of illness, as the women's experiences of their bodies intertwine with the experiences of their arm morbidity in daily life. While the illness experience cannot be understood solely by the body, and the women do not want to be minimized to their bodies, it is evident that the body is the conduit through which illness and life are experienced. In experiences of health and the body, themes of gender, social roles, and identity are pervasive, and convey the value of understanding the impact of these ideas and experiences on health, and the impact health has on them. Arm morbidity experiences offer much to the sociological understandings of health, the body, and the social world, and as a result, further study of this topic would be beneficial.

The research also has a number of biomedical implications, primarily surrounding the lack of expert knowledge that was clear in the women's experiences of arm morbidity. First and foremost, the women all express the need for more biomedical understanding about arm morbidity issues, as knowledge is incomplete, lacking, or contradictory. The women are left with questions about the causes of arm morbidity, are uncertain what they should or can do to care for their arms and how they are able to carry on with life without straining their bodies, and are frustrated about the lack of options to improve or cure the problems they face. Related, the women's experiences also indicate the need for more recognition about the importance and seriousness of lymphedema and other arm problems as health issues. While they consider arm morbidity to be a serious problem, the amount of valuable information that exists and the treatment of arm problems in the healthcare system do not suggest that the biomedical field approaches arm morbidity with the same level of gravity as the women. The women's experiences of arm morbidity lead them to construct the health issue as serious and problematic, but that

is not validated in the healthcare system. Taking these differences into account, it is also important to expand the biomedical treatment to acknowledge the complexity of the experiences of arm morbidity, by recognizing the patients' understandings of their bodies, their health and their lives, and the social aspects that affect the health issue. Sole, or even predominant, focus on treating the biological problem only accounts for part of the illness experience, so resources and attention to issues beyond the physical body would benefit treating patients as they live with arm morbidity.

The depth and complexity of the women's narratives of arm morbidity suggest a range of directions that are beneficial to pursue in future research in order to construct more understanding of this health issue. While this research covers a number of areas in the women's lives, it is valuable to explore the various areas of life more closely to further understand the impact of arm morbidity in daily life. Raising issues of intimate relationships, sexuality, formal and informal work, identity, routines, support, and other aspects involved in the social world would further the sociological knowledge about the consequences of arm morbidity. It would also be beneficial to explore the experiences of women of different socio-demographic categories to understand how differences such as ethnicity, socio-economic status, marital status, age, and location influence the experiences of arm morbidity. The women in this research vary somewhat in areas such as marital status, age, family make-up, and employment status, but that is primarily due to stage in life rather than differences in social positioning. Future research might also focus on longitudinal studies of women with arm morbidity after breast cancer treatment, to explore how these arm problems affect women's lives over time. This may be especially valuable, as breast cancer affects women at various stages in their lives, and increasing survival rates mean that many survivors may have long lives after treatment.

In addition, understandings of the impact arm morbidity has in daily life can be applied to a number of related topics, such as disability, chronic illness, gender roles, and knowledge translation. In disability studies, there is a problematic relationship understood with the identification of disability as illness, because it is then considered to be an individual problem (Wendell, 2001). However, the sociological model conveys both health and disability as social constructs, and experiences of arm morbidity do not involve disability as illness, or illness as disability, but rather a unique situation of both

disability and illness. And, as the women engage in the world, they perform their roles, construct their identities, and make meaning as gendered social actors. Their understandings of arm morbidity, as a disability and as a chronic illness, indicate the depth of understanding and the broad scope of issues experienced as they manage their health and their lives. These findings may suggest that people with chronic illnesses and disabilities may be better experts than the “real” experts, as the women’s understandings encompass all of the aspects involved with arm morbidity, while the knowledge they receive from professionals is limited, unclear, and not always applicable or relevant to their circumstances. Related to interactions with experts, the research also implies that effective communication between the healthcare professional and the patient may be more primary in the treatment of illness than curing and treating the body itself. In addition, because the roles the women fill in their lives do not always allow for the flexibility that is needed to support their health, the research might also indicate the greater impact that social roles have on health and disability than the physical environment.

### ***6.1.2 For the Healthcare System***

In addition to the relevance of this topic to research, the women’s engagement with the healthcare community also leads to ideas for the healthcare system to consider. The women’s experiences include interactions with healthcare professionals who do not validate their own understandings and experiences of arm morbidity, and their narratives include appeals for those experts engaged in their health and treatment to listen to their concerns, and respect their understandings of their own bodies. Similarly, the women also advocate that healthcare professionals, and the healthcare system in general, give more attention to and concern for arm morbidity issues. The lack of information, the dismissal of arm problems by physicians, the misinformation, and the process by which they were informed of arm morbidity issues do not establish a tone for quality care, and the women indicate that there needs to be more emphasis on and investment in the health issue within the healthcare community.

Another issue that arises when discussing the healthcare system is the process of informing patients about lymphedema after breast cancer treatment, which does not appear to be the most effective process to relay information. Some of the women suggest

that it should occur at the cancer clinic, but that it needs to be made more clear that it can be a problem, and that there needs to be follow-up in order to ensure that women had a clear understanding of lymphedema. This suggestion echoes the work of Thomas-MacLean et al. (2005), who also indicate that there needs to be information about arm morbidity issues transmitted “explicitly, clearly, and most importantly, repeatedly” to patients by their surgeons, oncologists, and family physicians. More broadly, Currie and Weisenberg (2003) also suggest that, in conjunction with the focus that is placed on health promotion, changes in institutions such as the family and the public sphere are needed to support individuals seeking information about their health, as it cannot simply be an individual responsibility.

Also, the women’s narratives indicate the importance of treating their health issues beyond the biological problem, and many suggest or imply that there should be more thought given to the other aspects involved with arm morbidity as they receive formal care, including the emotional and social implications of the health issue. This would expand the team from physicians and other professionals focusing on the body to also encompass social workers, counselors, and others who are qualified and trained to deal with the other aspects of the illness experiences.

Finally, and related to the other implications, some of the women discuss the benefit it would be to have people involved in their care – physicians, massage therapists, counselors, and anybody else contributing to their health – who specialize in dealing with people with arm morbidity issues. This would require more knowledge about and attention given to the health issue, but the women feel that, because of the unique experience of arm morbidity issues after breast cancer treatment, it would benefit their health and their lives if they could deal with professionals who are informed about, and specialized in, issues of pain, a limited range of motion, and lymphedema after breast cancer.

### ***6.1.3 For Women***

Finally, the women’s narratives are rich with meaning and understanding that may benefit patients and others experiencing the same health issues, whether it is with breast cancer, or the arm problems following. First, the women all express the importance of asking questions and taking an active role in treatment, as individuals know their lives

and bodies better than anybody. With this comes a need to feel confident in the knowledge of the body, as lay knowledge is not always recognized or given the value it deserves in the formal context. The understandings of arm morbidity that the women have constructed allow them to manage their health and their lives with the health issue, however, so they are very adamant about seeking information and asking questions to help the process of understanding one's body.

Secondly, aside from seeking out information from medical experts, the women also discuss the importance of seeking out help from other avenues to construct understanding of their health, such as counseling services, and the Hope Cancer Help Centre. These other avenues help the women create understandings of their health beyond the biomedical, and the Hope Cancer Help Centre, for example, not only provides information and opportunities to engage in workshops, but also produces relationships with others who have similar experiences and can offer support and advice about navigating through life after cancer. There are many opportunities to find other support systems beyond the medical profession, and while it does require the effort to seek those out, the women who do make use of those avenues feel as if it benefits their experiences after breast cancer treatment.

Finally, and related to the second recommendation, the women discuss the importance of having a close support system as they experience arm morbidity. It appears as if there is great benefit to having a friend or family member along at appointments throughout the breast cancer experience, to ask questions, take notes, hear information, and be there for support, as it is not necessarily the time when the patient is processing all of the information provided. By having the support system nearby, the women are able to manage as well as they can, considering the obstacles they encounter both in the formal medical system and their lives.

Essentially, these implications and lessons indicate the variety of ways to improve experiences of arm morbidity for the women affected, and the understanding about the condition for all of those involved. There are many contributors to lead to better knowledge about and more positive experiences of, arm morbidity, including patients and physicians, other health care professionals, those involved in the lives of women with arm morbidity, flexible and supportive environments, and the creation and understanding of



valuable, accurate knowledge about arm morbidity and its effects on life. At this point in time, the women have to manage their health and lives with arm morbidity without the benefit of extensive information and understanding for support, and their narratives indicate that there is much room for improvement in the area of arm morbidity after breast cancer.

## **6.2 Conclusions: Understanding Experiences of Arm Morbidity**

The women's experiences with arm morbidity, while constructed by individuals' own subjective meanings of the world, are valuable to understanding experiences of health and arm morbidity, as socially constructed meanings are the way in which we create society. The world is socially constructed, it is the product of human activity, and it is real because we make it real, but it is also historically situated and changeable: "Rational knowledge is open-ended because the world is open-ended" (Sprague, 2005, p. 52). By coming to understand the women's experiences of arm morbidity in their daily lives, knowledge is not only created about the illness experiences of arm morbidity, but the narratives also convey meaning and construct understanding about the broader social world. Arm morbidity after breast cancer clearly has widespread impact in the lives of women, and the narratives raise many themes and issues that are valuable in understandings of health, the body, and life as they are experienced in the social world.

The women's experiences of managing their health with arm morbidity indicate a number of major areas of focus that are involved of the construction of meaning and contribute to experiences in the social world. The women's bodies, changed in composition and feeling, are intertwined with their experiences of illness and in their daily lives throughout the narratives, which suggests the importance of embodiment to experiences of arm morbidity. As G. Williams (2000) states, "The body is not only an object amongst other objects in the world, it is also that through which our consciousness reaches out towards and acts upon the world" (p. 238). It is the experiences of the body that all of the women's daily experiences are based upon, and from which the understandings of their health and their lives are produced. Similar biological experiences create similar feelings of the body, but each of the women conveys truths about her own body that suggest they all have unique interactions with their own living,

feeling bodies. The women's heightened awareness of their bodies, different from "normal" bodies that require no or minimal thinking, indicate the valuable understandings individuals have of their bodies when they are in ill or altered states. And while arm morbidity issues cause biological changes to the upper body region, the women's narratives indicate that it is not simply an issue of the upper body, but that it impacts how they experience their entire bodies, and causes them to be more aware of their overall health. The women's changed bodies require them to engage in a continuous process of readjustment, as previous understandings of their bodies and their lives are disrupted, and they need to construct new meaning of their bodies. Hockey and James (2003) suggest that, as we age, the experience of the self "is produced through direct engagement with the body" (p. 10). This is applicable to health, disability, and illness, as the women with arm morbidity have to create new understandings as a result of their changed engagement with their living, feeling bodies.

As a result, the women are engaged in treating their bodies, formally and informally, in their daily routines, and it is evident that their ideas of treatment, progress, and care differ from what the traditional medical model suggests is appropriate. The women's interactions with professionals in their treatment vary in many ways. It is clear that quality care, to the women, does not solely, or even primarily, depend upon improvement to their bodies, but that it comes from beneficial communication, appropriate information, and positive interactions with their healthcare providers. The misinformation and lack of communication and knowledge from professionals cause the women to lose their trust in those who are acting as perfect agents in their healthcare, because they do not feel confident that professionals will have the information and understanding of bodies with arm morbidity that they require to treat their patients well. The women continue to value expert knowledge in their treatment, but engage in many types of self-care in their lives, and it is evident that, as they balance expert and lay knowledge in their treatment, the understandings of their own bodies' needs are what they look to as they make decisions. That perseverance they exhibit in the informal care of their health counters the lack of power they feel in the formal care of their bodies, as they face costs physically, financially, and on their time. The women's focus in

treatment, while hopeful that their bodies will return to more normal states, is on living more closely to the lives that they had prior to the illness.

The issue of knowledge about arm morbidity is another major component of the experiences of arm morbidity, as the women feel uninformed about their bodies and have feelings of frustration about the translation of knowledge from experts. The huge gaps in expert knowledge about arm morbidity create a lack of trust in the medical profession and leave the women alone in their health, with feelings of frustration and uncertainty. Contrary to ideas in some of the literature that patients do not want or should not receive much information about their health, these participants want the information they need in order to help them make decisions about their health and their lives. In addition to the lack of information, the lack of communication between the healthcare system and the women causes many difficulties in their illness experiences. The assumption behind the empowerment and patient education literature is simply that patients have to be empowered, but this lack of communication indicates a huge gap in the literature, as the patient education literature operates on a major assumption that the professionals are able to educate. In the women's experiences of arm morbidity, this education is not occurring. They have unanswered questions, there is not an adequate transfer of information upon leaving treatment, and the timing when they receive the little information provided is not appropriate to their circumstances. The lack of communication creates a huge disconnect between the healthcare professionals and the patients, as they have different voices to begin with, and then do not share understandings of arm morbidity, so there is discrepancy about the severity of arm morbidity, understandings of the body, and the roles and objectives of the patient and physician in healthcare. The women learned to take a more active role in their healthcare and empower themselves, to compensate for the missing information and the problematic communication they experience that prevents them from participating adequately in their formal healthcare.

The final broad theme raised as the women discuss the experiences with their bodies is support, which materializes in the women's lives in different ways, from different people, but overall has a major impact on the women's illness experiences. Their narratives indicate that healing involves more than just physical improvement, and encompasses a broad understanding of wellness – body, mind, and spirit. The women

find support from many people and in various parts of their lives, but the understanding they receive from others is a key element in their positive experiences. That understanding refers to both the support they receive as they continue to construct knowledge of their health and lives, and the recognition and respect of their circumstances and needs from others. The informal support they receive appears to be more beneficial to their overall well-being, as those people and groups provide a more comprehensive support system than the women find in the healthcare system. These support networks benefit the women as they experience changes to their bodies and lives, and prove to be essential to the management of their health. The roles others can fill in that support system depends on the relationships and interactions they had when the women still had healthy bodies, as adjustments to some relationships are more difficult than others. In addition to the various types of support the women receive from others, they also discuss the importance of trusting the self, having a positive outlook, and the importance of making meaning of life, whether that is referred to as faith or spirituality. Arm morbidity experiences go beyond the physical body, and the women's experiences of support that allow them to heal in their overall wellbeing prove to be very important in their lives.

The experiences of the women as they manage their lives with arm problems suggest the widespread impact ability and health have on the social lives of individuals, and raise a number of major themes that are relevant to sociological thought. The changes in the women's bodies and health, and the resulting transformation of ability and new physical limitations, affect the way the women are able to carry out their daily lives. More time and planning are required for them to carry out seemingly effortless tasks, as they are no longer able to take-for-granted the taken-for-granted aspects of daily life. This, in turn, impacts the ability to function as they had prior to arm morbidity and fill socially acceptable roles. For example, the difficulty in driving can limit a person's ability to function in the world, which has major implications for life, as mobility is necessary to interact and engage in normative ways. Similarly, feelings of fatigue in the arm morbidity experience can also limit an individual's overall ability to fill what is considered to be a productive role in society. What is problematic to the women is that in society, what we do largely defines who we are, as individuals and to others. The ability

to perform certain jobs, and the pace and vigor with which those tasks are approached, changes for the women, so their competence and contributions are sometimes challenged.

Experiences of disability are rooted in both the social and the material (Thomas-MacLean & Miedema, 2005), and because of this, the women's interactions and capabilities are also impacted in the social world. The women's changed abilities create difficulty in maintaining the roles they had filled in many cases, or cause the women to adjust those roles. However, while the women's arm morbidity create more limitations in their lives, there is evidence suggesting that, despite the difficulty those limitations create, the women continue to fill traditional gender roles as much as they can. In both housework and their interactions with their family members, especially with their children, the women generally maintain the roles that are considered to fall within the domain of women. The evidence suggests that it is not a straightforward phenomenon: The women feel responsibility themselves to continue in those roles; there are expectations from others to fill those roles; individuals in those relationships and interactions are not willing to concede their perceptions of the women as capable of filling those roles; and the women themselves may benefit from the traditional arrangement. However, the interaction between limitations and gender roles is interesting, as the women weigh the costs and benefits of those decisions and put their health second to fulfilling those roles. The ideal of gender equality does not equate to the roles in the household, and this, in turn, does not allow the women the opportunity to be in a better state of health. It appears as if the public sphere allows for more adjustment of roles, such as the flexibility the women experience in the workplace. In the private sphere, by contrast, the women's interactions change in many instances, but the performance of their roles remains largely the same.

The roles that the women fill, their abilities to engage in the work in a particular way, and the understandings of their bodies are all part of the identities they have constructed. The changes in the self caused by changes in health creates the women's need to reestablish meaning and reconstruct an identity that incorporates the health issues, which are beneficial to sociology because a patient's self-image and labels say as much about society as they do about the individual (Charmaz & Olesen, 1997). The reconstructed identities, therefore, establish meaningful understanding about the illness

experiences, as well as the social world. The women are in a continuous process of renegotiation, as their bodies continue to change and present new limitations, or simply as the women continue to learn about their own bodies as they carry out their lives. While they are in the process of reconstructing identities that incorporate arm morbidity issues, they continue to struggle with bodies that they are unfamiliar with, and have to adjust to in order to feel normal. Many of the women indicate that, while they are comfortable with their new health and bodies, they do not want to be labeled as ill or less capable. The women's limitations, for example, make it difficult or unrealistic for them to carry out particular tasks, but only one of the women says she is *a little bit handicapped* (Janet), while the others do not label themselves in that way, or directly state that they are not disabled. I want to respect the women's self-understanding and did not label them otherwise, although understandings of disability suggest that arm morbidity does in fact jeopardize the able-bodied state and create disability. In whatever ways the women define themselves, the independence they each enjoy is very important to them, and as a result, they focus on maintaining as much appearance of able-bodiedness as possible in their lives.

These new meanings the women construct, as they experience their bodies, health, and lives, indicate the broad scope of influence that health has in life, as the women apply their understanding not only to their bodies and health, but to their overall perspectives on the way they live and manage their lives. The ebb and flow Charmaz (1991) discusses is apparent in the women's discussions of their health, as they construct meaning to gain understandings of their bodies and the resulting limitations, and experience setbacks when those meanings they negotiated are again disrupted. The idea of ebbs and flows is also relevant to the meanings they make of their lives, as the women see both the positives and negatives that are involved in their illness experiences, and the potential impact their arm morbidity could have for the future. The learning process that accompanies arm morbidity is evident as the women make meaning of those things they had taken for granted in the past, and as they navigate through life, they continue to work out a balancing act, with their health on one side, and their lives on the other.

The women's experiences with arm morbidity after breast cancer treatment indicate the importance of continuing research in this area for the benefit of expert

knowledge, the healthcare community, patients, and those involved in women's lives. The broad impact of arm morbidity on the women's lives indicates the importance of the issue. The lack of information about the biomedical and sociological implications of arm morbidity suggests that more knowledge must be constructed in order to equip professionals, institutions, and patients to deal with this health issue. Understanding the impact of arm morbidity on daily life, based upon the knowledge and expertise of the women themselves as they renegotiate meaning throughout their experiences, portrays the complexities of the illness experience that involves both biomedical and social aspects of health, embodiment, and the social world.

## REFERENCES

- Abu-Laban, S.M., & McDaniel, S.A. (2001). Beauty, status, and aging: Feminist theories. In N. Mandell (Ed.), *Feminist issues: Race, class, and sexuality* (2<sup>nd</sup> ed.) (pp. 108-133). Toronto: Prentice Hall.
- Annandale, E., Elston, M.A., & Prior, L. (2004). Medical work, medical knowledge and health care: Themes and perspectives. In E. Annandale, M. Elston and L. Prior (Eds.), *Medical work, medical knowledge and health care* (pp. 1-18). Malden, MA: Blackwell Publishing.
- Armstrong, P. (2001). Women and health: Not just a matter of care. In N. Mandell (Ed.), *Feminist issues: Race, class, and sexuality* (2<sup>nd</sup> ed.) (pp. 260-278). Toronto: Prentice Hall.
- Asbring, P. (2001). Chronic illness – a disruption in life: Identity-formation among women with chronic fatigue syndrome and fibromyalgia. *Journal of Advanced Nursing*, 34(3), 312-319.
- Backhans, M.C., Lundberg, M., & Mansdotter, A. (2007). Does increased gender equality lead to a convergence of health outcomes for men and women? A study of Swedish municipalities. *Social Science & Medicine*, 64, 1892-1903.
- Bailey, L. (2001). Gender shows: First-time mothers and embodied selves. *Gender & Society*, 15(1), 110-129.
- Balter Blume, L., & Blume, T.W. (2003). Toward a dialectical model of family gender discourse: Body, identity, and sexuality. *Journal of Marriage and Family*, 65(4), 785-794.
- Beck, C.T. (1994). Phenomenology: its use in nursing research. *International Journal of Nursing Studies*, 31(6), 499-510.
- Beck-Gernsheim, E. (2002). *Reinventing the family: In search of new lifestyles*. Malden, MA: Blackwell Publishing.
- Bell, S.E. (2000). Experiences of illness and narrative understandings. In P. Brown (Ed.), *Perspectives in medical sociology* (3<sup>rd</sup> ed.) (pp. 130-145). Prospect Heights, Illinois: Waveland Press.
- Bell, S.E. (2002). Photo images: Joe Spence's narratives of living with illness. *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine*, 6(1), 5-30.
- Bentz, V.M. (1995). Husserl, Schutz, "Paul" and me: Reflections on writing phenomenology. *Human Studies*, 18, 41-62.



- Black, H.K. (2001). Jake's story: A middle-aged, working-class man's physical and spiritual journey toward death. *Qualitative Health Research, 11*(3), 293-307.
- Bolger, N., Foster, M., Vinokur, A.D., & Ng., R. (1996). Close relationships and adjustment to a life crisis: The case of breast cancer. *Journal of Personality and Social Psychology, 70*(2), 283-294.
- Brand, J.E., Warren, J.R., Carayon, P., & Hoonakker, P. (2007). Do job characteristics mediate the relationship between SES and health? Evidence from sibling models. *Social Science Research, 36*(1), 222-253.
- Brennan, M.J. (2001). Pain in the lymphedematous arm following treatment after breast cancer: Evaluation and treatment. Lymphovenous Canada. Retrieved February 10, 2001, from [www.lymphovenous-canada.ca/pain](http://www.lymphovenous-canada.ca/pain).
- Brennan, M.J., & Miller, L.T. (1998). Overview of treatment options and review of the current role and use of compression garments, intermittent pumps, and exercise in the management of lymphedema. *Cancer, 83 Suppl*(12), 2821-2827.
- Brorson, H. (2000). Liposuction gives complete reduction of chronic large arm lymphedema after breast cancer. *Acta Oncologica, 39*, 407-420.
- Brown, P. (2000). Themes and perspectives on health and illness. In P. Brown (Ed.) *Perspectives in medical sociology* (3<sup>rd</sup> ed.) (pp. 71-73). Prospect Heights, Illinois: Waveland Press.
- Browne, A.J. (2007). Clinical encounters between nurses and First Nations women in a Western Canadian hospital. *Social Science & Medicine, 64*(10), 2165-2176.
- Bury, M. (1982). Chronic illness as biographical disruption. *Sociology of Health and Illness, 4*(2), 167-182.
- Bury, M. (2001). Illness narratives: Fact or fiction?. *Sociology of Health & Illness, 23*(3), 263-285.
- Butler, J. (1988). Performative acts and gender constitution: An essay in phenomenology and feminist theory. *Theory Journal, 40*(4), 519-531.
- Canadian Cancer Society (2008). Canadian cancer statistics 2008. Retrieved April 20, 2008, from [www.cancer.ca](http://www.cancer.ca).
- Cassidy, B., Lord, R., & Mandell, N. (2001). Silenced and forgotten women: Race, poverty, and disability. In N. Mandell (Ed.), *Feminist issues: Race, class, and sexuality* (2<sup>nd</sup> ed.) (pp.75-107). Toronto: Prentice Hall.

- Chapple, A., Ziebland, S., & McPherson, A. (2004). Primary care: Stigma, shame, and blame experienced by patients with lung cancer: Qualitative study. *BMJ*, *328*, 1470.
- Charmaz, K. (1983). Loss of self: A fundamental form of suffering in the chronically ill. *Sociology of Health and Illness*, *5*(2), 168-195.
- Charmaz, K. (1991). *Good days, bad days: The self and time in chronic illness*. New Brunswick, NJ: Rutgers University Press.
- Charmaz, K. (1995). The body, identity, and self: Adapting to impairment. *The Sociological Quarterly*, *36*(4), 657-680.
- Charmaz, K. (2002). Stories and silences: Disclosures and self in chronic illness. *Qualitative Inquiry*, *8*, 302-328.
- Charmaz, K., & Olesen, V. (1997). Ethnographic research in medical sociology: Its foci and distinctive contributions. *Sociological Methods & Research*, *25*(4), 452-494.
- Collins, L.G., Nash, R., Round, T., & Newman, B. (2004). Perceptions of upper-body problems during recovery from breast cancer treatment. *Support Care Cancer*, *12*(2), 106-113.
- Creswell, J.W. (2003). *Research design: Qualitative, quantitative, and mixed methods approaches*. Thousand Oaks: Sage Publications.
- Currie, D.H., & Wiesenber, S.E. (2003). Promoting women's health-seeking behavior: Research and the empowerment of women. *Health Care for Women International*, *24*, 880-899.
- Dahlberg, K., & Drew, N. (1997). A lifeworld paradigm for nursing research. *Journal of Holistic Nursing*, *15*(3), 303-317.
- Dale Stone, S. (2008). Resisting an illness label: Disability, impairment, and illness. In P. Moss & K Teghtsoonian (Eds.), *Contesting illness: Processes and practices* (201-217). Toronto: University of Toronto Press.
- Daruwalla, P., & Darcy, S. (2005). Personal and societal attitudes to disability. *Annals of Tourism Research*, *32*(3), 549-570.
- Davis, N.A. (2005). Invisible disability. *Ethics*, *116*, 153-213.
- Denzin, N.K., & Lincoln, Y.S. (1998). *The landscape of qualitative research: Theories and Issues*. Thousand Oaks: Sage Publications.

- Dos Ramos, P. (1996). Dancing with feminism. In B.L. Brown (ED.), *Bringing it home: Women talk about feminism in their lives*. Vancouver: Arsonal Press.
- Dumit, J. (2006). Illnesses you have to fight to get: Facts as forces in uncertain, emergent illnesses. *Social Science & Medicine*, 62, 577-590.
- Eisenberg, L. (1997). Disease and illness: Distinctions between professional and popular ideas of sickness. *Culture, Medicine and Psychiatry*, 1, 9-23.
- Elliot, P., & Mandell, N. (2001). Feminist theories. In N. Mandell (Ed.), *Feminist issues: Race, class, and sexuality* (2<sup>nd</sup> ed.) (pp. 23-48). Toronto: Prentice Hall.
- Ellis, C. (1998). "I hate my voice": Coming to terms with minor bodily stigmas. *The Sociological Quarterly*, 39(4), 517-537.
- Entwistle, V.A., Skea, Z.C., & O'Donnell, M.T. (2001). Decisions about treatment: Interpretations of two measures of control by women having a hysterectomy. *Social Science & Medicine*, 53, 721-732.
- Entwistle, V., Williams, B., Skea, Z., MacLennan, G., & Bhattacharya, S. (2006). Which surgical decisions should patients participate in and how? Reflections on women's recollections of discussions about variants of hysterectomy. *Social Science & Medicine*, 62, 499-509.
- Epstein, R.M., Franks, P., Fiscella, K., Shields, C.G., Meldrum, S.C., Kravitz, R.L., & Duberstein, P.R. (2005). Measuring patient-centered communication in patient-physician consultations: Theoretical and practical issues. *Social Science & Medicine*, 61, 1516-1528.
- Fawcett, B. (2000). *Feminist perspectives of disability*. Toronto, ON: Prentice Hall.
- Ferrell, B.R., Smith, S.L., Ervin, K.S., Itano, J., & Melanco, C. (2003). A qualitative analysis of social concerns of women with ovarian cancer. *Psycho-Oncology*, 12, 647-663.
- Flynn, K.E., Smith, M.A., & Vanness, D. (2006). A typology of preferences for participation in healthcare decision making. *Social Science & Medicine*, 63, 1158-1169.
- Fosket, J. (2000). Problematizing biomedicine: Women's constructions of breast cancer knowledge. In L.K. Potts (Ed.), *Ideologies of breast cancer: Feminist perspectives* (pp. 15-36). New York: St. Martin's Press.
- Frank, A. (1995). *The wounded storyteller: Body, illness, and ethics*. Chicago: University of Chicago Press.

- Frank, A.W. (1993). The rhetoric of self-change: Illness experience as narrative. *Sociological Quarterly*, 34(1), 39-52.
- Frank, A.W. (2001). Can we research suffering? *Qualitative Health Research*, 11(3), 353-362.
- Frank, A. (2006). Health stories as connectors and subjectifiers. *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine*, 10(4), 421-440.
- Gafni, A., Charles, C., & Whelan, T. (1998). The physician-patient encounter: The physician as a perfect agent for the patient versus the informed treatment decision-making model. *Social Science & Medicine*, 47(3), 347-354.
- Garland-Thomson, R. (2004). Integrating disability, transforming feminist theory. In B.G. Smith & B. Hutchison (Eds.), *Gendering disability* (pp. 73-103). New Jersey: Rutgers University Press.
- Greene, J.C., Caracelli, V.J., & Graha, W.F. (1989). Toward a conceptual framework for mixed-method evaluation designs. *Educational Evaluation and Policy Analysis*, 11, 255-274.
- Gronvik, L. (2007). The fuzzy buzz word: Conceptualisations of disability in disability research classics. *Sociology of Health & Illness*, 29(5), 750-766.
- Guba, E.G., & Lincoln, Y.S. (1998). Competing paradigms in qualitative research. In N.K. Denzin & Y.S. Lincoln (Eds.) *The landscape of qualitative research: Theories and issues* (pp. 195-220). Thousand Oaks: Sage.
- Harding, S. (1987). Introduction: Is there a feminist method? In S. Harding (Ed.) *Feminism and methodology* (pp. 1-14), Bloomington, Indiana: Indiana University Press.
- Harris, S.R., & Niesen-Vertommen, S.L. (2000). Challenging the myth of exercise-induced lymphedema following breast cancer: A series of case reports. *Journal of Surgical Oncology*, 74, 95-99.
- Hayes, S.C., Janda, M., Cornish, B., Battistutta, D., & Newman B. (2008). Lymphedema after breast cancer: Incidence, risk factors, and effect on upper body function. *Journal of Clinical Oncology*, 26(21), 3536-3542.
- Henwood, F., Wyatt, S., Hart, A., & Smith, J. (2003). 'Ignorance is bliss sometimes': Constraints on the emergence of the 'informed patient' in the changing landscape of health information. *Sociology of Health and Illness*, 25(6), 589-607.

- Hinchman, L.P., & Hinchman, S. (1997). *Memory, identity, community: The idea of narrative in the human sciences*. Albany: SUNY Press.
- Hochschild, A.R. (1989). *The second shift*. New York: Avon Books.
- Hochschild, A.R. (1997). *The time bind: When work becomes home and home becomes work*. New York: Henry Holt and Company.
- Hockey, J., & James, A. (2003). *Social identities across the life course*. New York: Palgrave Macmillan.
- Holmber, S.K., Scott, L.L., Alexy, W., & Fife, B.L. (2001). Relationship issues of women with breast cancer. *Cancer Nursing*, 24(1), 53-60.
- Jaggar, A., & Rothenberg, P. (1984). *Feminist frameworks: Alternative theoretical accounts of the relations between women and men* (2<sup>nd</sup> ed.). New York: McGraw-Hill.
- Johansson, K., Holstrom, H., Nilsson, I., Ingvar, C., Albertsson, M., & Ekdahl, C. (2003). Breast cancer patients' experiences with lymphoedema. *Scandinavian Journal of Caring Sciences*. 17(1), 35-42.
- Kabeer, N. (2004). Gender equity and human development outcomes: Enhancing capabilities. In A. Prince and S. Silva-Wayne (Eds.), *Feminisms and womanisms: A woman's studies reader* (pp.525-535). Women's Press: Toronto.
- Kasper, A.S. (1994). A feminist, qualitative methodology: A study of women with breast cancer. *Qualitative Sociology*, 17(3), 263-281.
- Kleinman, A. (1988). *The illness narrative: Suffering, healing & the human condition*. New York: Basic.
- Kreps, G.L. (2006). Communication and racial inequities in health care. *American Behavioral Scientist*, 49(6), 760-774.
- Leigh, S.A. & Stovall, E.L. (2003). Cancer survivorship: Quality of life. In C.R King & P.S. Hinds (Eds.), *Quality of life: From nursing and patient perspectives: Theory, research, practice* (pp. 381-395). Toronto: Jones and Bartlett Publishers.
- Lindgren, K. (2004). Bodies in trouble: Identity, embodiment, and disability. In B.G. Smith & B. Hutchison (Eds.), *Gendering disability* (pp. 145-165). New Jersey: Rutgers University Press.

- Lipscomb, H.J., Loomis, D., McDonald, M.A., Argue, R.A., & Wing, S. (2006). A conceptual model of work and health disparities in the United States. *International Journal of Health Services*, 36(1), 25-50.
- Lorber, J. (1997). *Gender and the social construction of illness*. Thousand Oaks, California: Sage Publications.
- Lorber, J. (2000). Women get sicker, but men die quicker: Gender and health. In P. Brown (Ed.), *Perspectives in medical sociology* (3<sup>rd</sup> ed.) (pp. 40-70). Prospect Heights, Illinois: Waveland Press.
- Lucas, R.E. (2007). Long-term disability is associated with lasting changes in subjective well-being: Evidence from two nationally representative longitudinal studies. *Journal of Personality and Social Psychology*, 92(4), 717-730.
- Lutfe, K. (2005). On practices of 'good doctoring': Reconsidering the relationship between provider roles and patient adherence. *Sociology of Health & Illness*, 27(4), 421-447.
- Mandell, N. (2001). Women, families, and intimate relations. In N. Mandell (Ed.), *Feminist issues: Race, class, and sexuality* (2<sup>nd</sup> ed.) (pp. 193-218). Toronto: Prentice Hall.
- Marcks, P. (1997). Lymphedema: Pathogenesis, prevention and treatment. *Cancer Practice*, 5, 32-38.
- Mason, J. (2002). *Qualitative researching* (2<sup>nd</sup> ed.). Thousand Oaks: Sage.
- May, C., Allison, G., Chapple, A., Chew-Graham, C., Gask, L., Graham, R., Rogers, & A., Roland, M. (2004). Framing the doctor-patient in relationship in chronic illness: A comparative study of general practitioners' accounts. *Sociology of Health & Illness*, 26(2), 135-158.
- May, C. (2007). The clinical encounter and the problem of context. *Sociology*, 41(1), 29-45.
- McCally, M., Haines, A., Fein, O., Addington, W., Lawrence, R.S., & Cassel, C.K. (2000). Poverty and ill health: Physicians can, and should, make a difference. In P. Brown (Ed.), *Perspectives in medical sociology* (3<sup>rd</sup> ed.) (pp. 5-20). Prospect Heights, Illinois: Waveland Press.
- McKenzie, H., & Crouch, M. (2004). Discordant feelings in the lifeworld of cancer survivors. *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine*, 8(2), 139-157.

- McRuer, R. (2002). Compulsory able-bodiedness and queer/disabled existence. In S.L. Snyder, B.J. Brueggeman, and R. Garland-Thomson (Eds.), *Disability studies: Enabling the humanities* (pp. 88-99). New York: The Modern Language Association of America.
- McWayne, J. & Heiney, S. P. (2005). Psychologic and social sequelae of secondary lymphedema: A review. *Cancer*. 104(3), 457-466.
- Meadows, R. (2005). The 'negotiated night': An embodied conceptual framework for the sociological study of sleep. *The Sociological Review*, 53(2), 240-254.
- Merleau-Ponty, M. (1962). *Phenomenology of perception* (C. Smith, Trans.). London: Routledge & Kegan Paul.
- Miles, A., Rezai-Rashti, G., & Rundle, L.B. (2001). Third wave feminism: Antiracists, transnationalists, and young feminists speak out. In N. Mandell (Ed.), *Feminist issues: Race, class, and sexuality* (2<sup>nd</sup> ed.) (pp. 1-22). Toronto: Prentice Hall.
- Mitchell, D.T. (2002). Narrative prosthesis and the materiality of metaphor. In S.L. Snyder, B.J. Brueggeman, and R. Garland-Thomson (Eds.), *Disability studies: Enabling the humanities* (pp. 15-30). New York: The Modern Language Association of America.
- Morrow, M. (2007). 'Our bodies our selves' in context: Reflections on the women's health movement in Canada. In M. Morrow, O. Hankivsky & C. Varcoe (Eds.) *Women's health in Canada: Critical perspectives on theory and policy* (pp. 33-63). Toronto: University of Toronto Press.
- Morse, J.M., & Field, P.A. (1995). *Qualitative research methods for health professionals* (2<sup>nd</sup> ed.). Thousand Oaks: Sage Publications.
- Moser, I. (2006). Sociotechnical practices and difference: On the interfaces between disability, gender, and class. *Science, Technology and Human Values*, 31(5), 537-564.
- Murphy, J.W. (1986). Phenomenological social science: Research in the public interest. *The Social Science Journal*, 23(3), 327-343.
- Nettleton, S. (2006). 'I just want permission to be ill': Towards a sociology of medically unexplained symptoms. *Social Science & Medicine*, 62, 1167-1178.
- Olafsdottir, S. (2007). Fundamental causes of health disparities: Stratification, the welfare state, and health in the United States and Iceland. *Journal of Health and Social Behaviour*, 48(3), 239-253.

- Oliver, D.G., Serovich, J.M., & Mason, T.L. (2005). Constraints and opportunities with interview transcription: Towards reflection in qualitative research. *Social Forces*, 84(2), 1273-1289.
- Onwuegbuzie, A.J., & Leech, N.L. (2005). On becoming a pragmatic researcher: The importance of combining quantitative and qualitative research methodologies. *International Journal of Social Research Methodology*, 8(5), 37-387.
- Orbe, M.P. (2000). Centralizing diverse racial/ethnic voices in scholarly research: the value of phenomenological inquiry. *International Journal of Intercultural Relations*, 24, 603-621.
- Patton, M.Q. (2002). *Qualitative research & evaluation methods* (3<sup>rd</sup> ed.). Thousand Oaks: Sage Publications.
- Potts, L.K. (2000). Introduction: Why ideologies of breast cancer? Why feminist perspectives? In L.K. Potts (Ed.), *Ideologies of breast cancer: Feminist perspectives* (pp. 15-36). New York: St. Martin's Press.
- Poudrier, J., & Thomas-MacLean, R. (2008). "We've fallen into the cracks": A photovoice project with Aboriginal breast cancer survivors. *Nursing Inquiry*, In press.
- Punch, M. (1998). Politics and ethics in qualitative research. In N.K. Denzin & Y.S. Lincoln (Eds.) *The landscape of qualitative research: Theories and issues* (pp. 156-184). Thousand Oaks: Sage.
- Radina, M.E., & Armer, J.M. (2001). Post-breast cancer lymphedema and the family: A qualitative investigation of families coping with chronic illness. *Journal of Family Nursing*, 7(3), 281-299.
- Ram, R. (2006). Further examination of the cross-country association between income inequality and population health. *Social Science & Medicine*, 62(3), 779-791.
- Rees, C.E., Knight, L.V., & Wilkinson, C.E. (2007). Doctors being up there and we being down here: A metaphorical analysis of talk about student/doctor-patient relationships. *Social Science & Medicine*, 65, 725-737.
- Rehorick, D.A. (1986). Shaking the foundations of lifeworld: A phenomenological account of an earthquake experience. *Human Studies*, 9, 379-391.
- Reinharz, S. (1992). *Feminist methods in social research*. New York: Oxford University Press.
- Rossmann, G.B., & Rallis, S.F. (1998). *Learning in the field: An introduction to qualitative research*. Thousand Oaks. Sage.



- Ryan, E.B. (2006). Finding a new voice: Writing through health adversity. *Journal of Language and Social Psychology*, 25(4), 423-436.
- Samuels, E. (2003). My body, my closet: Invisible disability and the limits of coming-out disclosure. *GLQ*, 9(1-2), 233-255.
- Sandelowski, M. (2000). Combining qualitative and quantitative sampling, data collect, and analysis techniques in mixed-method studies. *Research in Nursing & Health*, 23, 246-255.
- Shah, S. (2006). Sharing the world: the researcher and the researched. *Qualitative Research*, 6(2), 207-220.
- Sharpe, L. & Curran, L. (2006). Understanding the process of adjustment to illness. *Social Science & Medicine*, 62, 1153-1166.
- Siebers, T. (2002). Tender organs, narcissism, and identity politics. In S.L. Snyder, B.J. Brueggeman, and R. Garland-Thomson (Eds.), *Disability studies: Enabling the humanities* (pp. 40-55). New York: The Modern Language Association of America.
- Sinding, C., & Aronson, J. (2003). Exposing failures, unsettling accommodations: Tensions in interview practice. *Qualitative Research*, 31(1), 95-117.
- Smith, B.G. (2004). Introduction. In B.G. Smith and B. Hutchison (Eds.), *Gendering disability* (1-6). New Jersey: Rutgers University Press.
- Snyder, S.L., Brueggemann, B.J., & Garland-Thomson, R. (2002). Introduction: Integrating disability into teaching and scholarship. In S.L. Snyder, B.J. Brueggemann, and R. Garland-Thomson (Eds.), *Disability studies: Enabling the humanities* (pp. 1-12). New York: The Modern Language Association of America.
- Sprague, J. (2005). *Feminist methodologies for critical researchers: Bridging differences*. Toronto: Rowan & Littlefield Publishers.
- Spira, M., & Kenemore, E. (2002). Cancer as a life transition: A relational approach to cancer wellness in women. *Clinical Social Work Journal*, 30(2), 173-186.
- Stanton, A.W.B., Svensson, W.E., Mellor, R.H., Peters, A.M., Levick, J.R., & Mortimer, P.S. (2001). Differences in lymph drainage between swollen and non-swollen regions in arms with breast-cancer related lymphoedema. *Clinical Science*, 101, 131-140.

- Statistics Canada (2002). *A profile of disability in Canada, 2001*. Ottawa, ON: Minister of Industry. (Catalogue no. 89-577-XIE)
- Stevens, P.E., Dibble, S.L., & Miaskowski, C. (1995). Prevalence, characteristics and impact of Postmastectomy Pain Syndrome: An investigation of women's experiences. *Pain, 61*(1), 61-68.
- Stevenson, F., & Scambler, G. (2005). The relationship between medicine and the public: the challenge of concordance. *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine, 9*(1), 5-21.
- Swan, J. (2002). Disabilities, bodies, voices. In S.L. Snyder, B.J. Brueggeman, and R. Garland-Thomson (Eds.), *Disability studies: Enabling the humanities* (pp. 283-295). New York: The Modern Language Association of America.
- Thomas, C. (2007). *Sociologies of disability and illness: Contested ideas in disability studies and medical sociology*. New York: Palgrave Macmillan.
- Thomas-MacLean, R. (2004). Memories of treatment: The immediacy of breast cancer. *Qualitative Health Research, 14*(4), 628-643.
- Thomas-MacLean, R. (2005). Beyond dichotomies of health and illness: Life after breast cancer. *Nursing Inquiry, 12*(3), 200-209.
- Thomas-MacLean, R., & Miedema, B. (2005). Feminist understandings of embodiment and disability: A "material-discursive" approach to breast cancer related lymphedema. *Atlantis, 30*(1), 92-103.
- Thomas-MacLean, R., Miedema, B., & Tatemichi, S.R. (2005). Breast cancer-related lymphedema: Women's experiences with an underestimated condition. *Canadian Family Physician, 51*, 246-47.
- Thomas-MacLean, R., Towers, A., Quinlan, E., Hack, T., Kwan, W., Miedema, B., Tilley, A., & Graham, P. (2008). "This is a kind of betrayal": A qualitative study of disability after breast cancer. *Current Oncology*, Under review.
- Thornton, J. (1998). We're all wackos – a new model of health. *International Journal of Sociology and Social Policy, 18*(9), 116-122.
- Toombs, S.K. (1995). The lived experience of disability. *Human Studies, 18*, 9-23.
- Turner, B.S. (1987). *Medial power and social knowledge*. Beverly Hills, CA: Sage Publications.
- van Manen, M. (1990). *Researching lived experience: Human science for an action sensitive pedagogy*. London, ON: The Althouse Press.

- van Manen, M. (1997). From meaning to method [Electronic version]. *Journal of Marriage and the Family*, 45(4), 851-858.
- van Manen, M. (1998). Modalities of body experience in illness and health. *Qualitative Health Research*, 8(1), 7-24.
- van Manen, M. (Ed.). (2002). *Writing in the dark: Phenomenological studies in interpretive inquiry*. London, ON: The Althouse Press.
- Van Wolputte, S. (2004). Hang on to your self: Of bodies, embodiment, and selves. *Annual Review of Anthropology*, 33, 251-269.
- Vignes, S., Arrault, M., & Dupuy, A. (2007). Factors associated with increased breast cancer-related lymphedema volume. *Acta Oncologica*, 46, 1138-1142.
- Walsh, S.R., Manuel, J.C., & Avis, N.E. (2005). The impact of breast cancer on younger women's relationships with their partner and children. *Family, Systems, & Health*, 23(1), 80-93.
- Weitz, R. (2004). *The sociology of health, illness, and health care: A critical approach* (3<sup>rd</sup> ed.). Belmont, CA: Wadsworth Thomson Learning.
- Weisman, C.S., & Teitelbaum, M.A. (1985). Physician gender and physician-patient relationship: Recent evidence and relevant questions. *Social Science & Medicine*, 20(11), 1119-1127.
- Wendell, S. (1996). *The rejected body: Feminist philosophical reflections on disability*. New York: Routledge.
- Wendell, S. (2001). Unhealthy disabled: Treating chronic illness as disability. *Hypatia*, 16(4), 17-33
- Werner, A., Isaksen, L.W., & Malterud, K. (2004). 'I am not the kind of woman who complains of everything': Illness stories on self and shame in women with chronic pain. *Social Science & Medicine*, 59, 1035-1045.
- White, K. (1991). The sociology of health and illness. *Current Sociology*, 39(2), 1-12
- Williams, G. (2000). The genesis of chronic illness: Narrative re-construction. In P. Brown (Ed.), *Perspectives in medical sociology* (3<sup>rd</sup> ed.) (pp. 215-241). Prospect Heights, Illinois: Waveland Press.
- Williams, S.J. (2000). Chronic illness as biographical disruption or biographical disruption as chronic illness? Reflections on a core concept. *Sociology of Health & Illness*, 22(1), 40-67.

- Williams, S.J. (2006). Medical sociology and the biological body: Where are we now and where do we go from here?. *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine*, 10(1), 5-30.
- Wilson, S.J. (2001). Paid work, jobs, and the illusion of economic security. In N. Mandell (Ed.), *Feminist issues: Race, class and sexuality* (2<sup>nd</sup> ed.) (pp. 219-241). Toronto: Prentice Hall.
- Wolf, N. (1991). *The beauty myth*. Toronto, ON: Vintage Books.
- World Health Organization, (2008). *Disabilities*. Retrieved April 20, 2008, from <http://www.who.int/topics/disabilities/en/>
- Ziebland, S. (2004). The importance of being expert: The quest for cancer information on the Internet. *Social Science & Medicine*, 59, 1783-1793.

## APPENDIX A: CONSENT FORM

### **Arm Problems in the Social World: Experiences of Women with Arm Morbidity after Breast Cancer**

**Researchers:**

Kara Schell

Department of Sociology, University of Saskatchewan

Dr. R. Thomas-MacLean

Department of Sociology, University of Saskatchewan

**You are invited** to participate in a study called “Arm Problems in the Social World: Experiences of Women with Arm Morbidity after Breast Cancer”.

**Purpose and Procedure:** The purpose of this study is to understand the experiences of women with pain, a limited range of motion, or lymphedema in their arm and shoulder area after surviving breast cancer. The focus will be on the impact this physical condition has on the daily lives of women, and specific attention will be given to understandings and experiences of gender, identity, and the family as these issues relate to their health. To do this, tape-recorded interviews will be carried out on two separate occasions, and a brief questionnaire will be conducted during the first meeting. The interviews will allow the participants to identify how arm problems after breast cancer have affected their lives. The first interview will last approximately 60 to 90 minutes, and the questionnaire is expected to take no more than ten to fifteen minutes. The second interview is expected to take approximately 60 minutes. The participant will be able to choose the location where the interviews and questionnaire will be conducted.

**Potential Risks and Benefits:** This study poses no known risks or benefits to participants. Being a part of this study may help to further the understanding of women’s experiences of arm mobility problems after breast cancer and the impact it has on daily life. If it becomes necessary or desirable, participants are encouraged to call the Canadian Cancer Society, toll free: 1-877-977-HOPE (4673), or the Hope Cancer Centre (306) 955-4673. Both of these organizations provide support services.

**Storage of Data:** All information that is collected for this study, including contact information, questionnaires, and tapes and transcripts of interviews, will be stored in a locked filing cabinet by Dr. R. Thomas-MacLean at the University of Saskatchewan for a minimum of five years after the study is completed. The master list that will connect participants to the data will be stored separately throughout the study, and will be destroyed once the research is completed.

**Confidentiality:** The findings of this study will be used to produce a Master’s thesis, as well as conference presentations or journal articles. However, your identity will be kept confidential. Direct quotations from the interview will be reported, but you will be given

a pseudonym, and any identifying information (such as family information, locations, etc.) will be removed from the report. After your interview, and before the data is analyzed, you will be provided with a summary of the interview transcript for your review and given the opportunity to add, alter, or delete information as you see fit.

**Right to Withdraw:** Your participation in this study is completely voluntary, and you may withdraw for any reason, at any time, without any consequences. As well, you may refuse to answer any questions which you do not feel comfortable with, or ask to have the audio recorder shut off at any time during the interviews. If you choose to withdraw from the study, the data you have contributed will be destroyed upon your request.

Please feel free to ask any questions you might have concerning the study at any time. You are also welcome to contact the researchers at the numbers provided if you have questions in the future. A written report of the findings will be sent to you when the study is nearing its completion. Please contact the researchers with any of your questions about the research or results.

You can contact either: Dr. R. Thomas-MacLean, Department of Sociology, 9 Campus Drive, University of Saskatchewan, S7N 5A5, Phone: (306) 966-1489 or Kara Schell, Department of Sociology, 9 Campus Drive, University of Saskatchewan, S7N 5A5, Phone: (306) 717-1031. This study has been approved on ethical grounds by the University of Saskatchewan Behavioural Research Ethics Board on January 21<sup>st</sup>, 2008. Any questions regarding your rights as a participant may be addressed to that committee through the Ethics Office (306) 966-2084. Participants from outside of Saskatoon can call the Ethics Office collect.

I have read and understood the description provided above; I have been provided with an opportunity to ask questions and my questions have been answered satisfactorily. I consent to participate in the study described above, understanding that I may withdraw consent at any time. A copy of this consent form has been given to me for my records.

---

(Name of Participant)

---

(Date)

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(Signature of Participant)

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(Signature of Researcher)

## APPENDIX B: FIRST INTERVIEW GUIDE

### *Preamble:*

Introduce myself and describe the study, indicating the purpose of conducting the in-depth interviews and the questionnaire (will be asking about breast cancer, but esp. focusing on arm problems and the impact they have had on life after breast cancer; explain that we'll discuss physical changes to the body, impact arm problems have had on certain areas of life, feelings about arm problems, etc.). Go over the consent form.

### *Questions:*

1. Ask participant to share a bit about herself as an introduction. The questionnaire will cover a lot of basic information, but ask some questions about background and breast cancer experience.

i.e. Are you married? Describe your family. Are you employed?  
What type of breast cancer did you have? When were you diagnosed?  
Is there anything else you would like to share about yourself?

2. What has been most significant for you in terms of your experiences of your body since you were treated for breast cancer?

Probe: Describe how it feels to live in a body that has been changed as a result of surgery.

How do you feel about the changes to your body?

Compare feelings about your body before and after surgery. (body image)

3. What side of your body have you been experiencing arm problems? Is this your dominant hand (or, are you right handed or left handed)?

4. What types of arm problems are you having?

Do you have swelling? Do you have difficulty moving your arm? Can you move the unaffected arm better (or more, not sure what wording you would want to use)? Do you have pain?

Can you please describe in more detail the symptoms you have?

Is there anything that makes the arm problem worse?

Is there anything that makes it better?

Are you getting any sort of treatment to help with these problems?

(physiotherapy, massage, exercise (home vs. organized), pain medication, occupational therapy)

5. What areas of your life have been most affected by your arm problems?

How does your daily routine today compare to before you had arm problems?  
(because of physical limitations; are you experiencing fatigue)

How have your relationships been impacted by your arm problems?

(How did your partner react, other family members, friends, co-workers, others.)

How have your arm problems impacted your ability to work (paid and unpaid)?  
(housework)

How have the problems affected your involvement in leisure activities?  
(crafts, sports, physical activity)

Have you made any changes in your lifestyle because of your arm problems?  
(clothing, diet, sleep, exercise)

Are there any other ways your life has been affected by changes to your arm that you'd like to mention?

5. Describe how you feel about the changes in your life that have occurred because of your arm problems.

Have your feelings about your arm problems changed over time?

Have the problems affected your emotions or moods at all?

6. Do you have any predictions about your arm problems and the impact it may have on your life in the future?

What is your outlook for the future?

Do you expect any further changes in your lifestyle as a result of your arm problems?

7. Do you have anything else you would like to mention that I have not asked you about?



## APPENDIX C: SECOND INTERVIEW GUIDE

### *Follow-up Questions*

#### *Support*

1. Describe the support you receive and seek out when you have problems with your arm? (formal and informal)
  - What physical support do you receive in order to carry out your routines?
  - Where do you receive emotional support?
  - Does spirituality or faith assist you as you manage your health?
  - What support is essential to your health and well-being?

#### *Knowledge*

1. Describe how you first became informed about arm problems after treatment.
  - Where did the information come from? (formal and informal)
  - When did you receive the information?
  - After treatment, how informed did you feel about what to expect in terms of your health? Looking back, how informed do you now feel you were about arm problems at that point?
2. How did the knowledge you received impact your experiences with arm problems after treatment?
  - Did the amount of information you had create a positive or negative experience when your arm problems began?
3. What have you done to seek out information? (internet, magazines, support groups, medical professionals)
  - When did you decide to seek out information?
  - What made you decide to seek out information?
4. Do you feel you know an adequate amount of information about your arm problems today?
  - Who has been most helpful?
  - Are you comfortable with the amount of information you have? Would you like more? Less? Explain.
5. Looking back, what two things do you wish you had learned earlier in the process?

Do you have anything else you would like to mention that I have not asked you about?

## APPENDIX D: QUESTIONNAIRE

**Section I** will incorporate questions from the SIAM (Social Impact of Arm Morbidity) Questionnaire, as well as some medical/demographic questions. Please answer the questions to the best of your ability.

1. Which type of physician(s) is currently providing your breast cancer care?  
(check as many as apply)
  1. Family physician
  2. Surgeon
  3. Oncologist
  4. Other (specify): \_\_\_\_\_
  
2. Have you experienced any severe life events, other than breast cancer, during the last six months? (i.e., negative events such as death in family, divorce, etc.)
  1. No
  2. Yes (specify): \_\_\_\_\_
  
3. Have you had a shoulder/arm problem or injury before you were diagnosed with breast cancer? (i.e., frozen shoulder etc.)
  1. No
  2. Yes, right shoulder/arm (please describe injury) \_\_\_\_\_ Year: \_\_\_\_\_
  3. Yes, left shoulder/arm (please describe injury) \_\_\_\_\_ Year: \_\_\_\_\_
  4. Yes, both shoulders/arms (please describe injury) \_\_\_\_\_ Year: \_\_\_\_\_
  
4. Have you recovered completely from the shoulder/arm problem or injury?
  0. Does not apply
  1. No
  2. Yes
  3. Do not know
  
5. Do you have any children living at home?
  0. Does not apply
  1. No
  2. Yes, (ages) 1: \_\_\_\_\_ 2: \_\_\_\_\_ 3: \_\_\_\_\_ 4: \_\_\_\_\_ 5: \_\_\_\_\_ 6: \_\_\_\_\_
  
6. With which group do you identify the most?
  1. Black (e.g., African, Caribbean etc.)
  2. South Asian (e.g., Indian, Pakistani etc.)
  3. East Asian (e.g., Chinese, Japanese, Korean etc.)
  4. Southeast Asian (e.g., Thai, Filipino, Vietnamese etc.)
  5. West Asian (e.g., Arabian, Iranian etc.)
  6. South or Central American
  7. Aboriginal
  8. Caucasian/White
  9. Other: \_\_\_\_\_

7. Have you ever been hospitalized for infections in your affected fingers, hand or arm since your breast cancer surgery?  
 1. No  
 2. Yes (number of times): \_\_\_\_\_
8. Have you ever had to use antibiotics for an infection in your affected fingers, hand or arm since your breast cancer surgery?  
 1. No  
 2. Yes (number of times): \_\_\_\_\_
9. To what degree have problems with the affected fingers, hand or arm, since your breast cancer surgery, impacted your relationship with the following people:
- |                  | Does not Apply | Worse | Same | Better |
|------------------|----------------|-------|------|--------|
| Husband/ partner | 0              | 1     | 2    | 3      |
| Children         | 0              | 1     | 2    | 3      |
| Grandchildren    | 0              | 1     | 2    | 3      |
10. Have you changed leisure activities because of problems with your affected fingers, hand or arm since breast cancer surgery? (e.g. knitting, crafts, needlepoint, musical instrument etc.)  
 1. No  
 2. Yes (explain:) \_\_\_\_\_
11. How many days per week do you participate in exercise involving your arms since your breast cancer surgery?  
 (e.g. golf, weight training, swimming, physio for shoulder etc. ) \_\_\_\_\_(days)
12. Are you working for pay?  
 1. No  
 2. On paid sick leave  
 3. Part-time  
 4. Full-time  
 5. Retired (year) \_\_\_\_\_
13. What is your occupation?  
 0. Does not apply  
 (List) \_\_\_\_\_
14. Since your breast cancer surgery, have you terminated, reduced hours of work or changed position in your paid workplace due to problems with your affected fingers, hand or arm?  
 0. Does not apply.  
 1. No  
 2. Retired for reasons other than problems in affected fingers, hand or arm  
 3. Yes (explain) \_\_\_\_\_

15. What is your highest level of education?
1. Finished primary or elementary school
  2. Finished junior high school or middle school
  3. Finished high school
  4. Finished community college
  5. Finished undergraduate degree at university
  6. Finished a graduate degree at university
16. Current Marital Status
1. Single
  2. Married
  3. Divorced
  4. Separated
  5. Widowed
  6. Common law relationship
17. What is your age? \_\_\_\_\_ years

**Section II** will use questions from a Medical Chart Review Form. Please answer the questions to the best of your ability.

1. Type of Breast Cancer: \_\_\_\_\_
2. a. Right Breast      b. Left Breast
3. a. Stage I              b. Stage II              c. Stage III
4. Date of Surgery: \_\_\_\_\_
5. Type of Surgery:    a. Radical Mastectomy  
                              b. Modified Radical Mastectomy  
                              c. Partial Mastectomy or Lumpectomy
6. Lymph node dissection: a. No      b. Yes
- Type of Dissection:    0. Does not apply  
                                  1. Sentinel node biopsy without axillary dissection  
                                  2. Sentinel node biopsy with axillary dissection  
                                  3. Axillary dissection without sentinel node biopsy
- Number of lymph nodes removed: \_\_\_\_\_
- Number of positive nodes: \_\_\_\_\_
7. Presence of postoperative infections requiring antibiotics:      1. No              2. Yes

8. Radiation therapy:            1. No            2. Yes
9. Chemotherapy:                1. No            2. Yes
10. Hormonal Therapy:         1. No            2. Yes

Name of Hormonal Therapy Used:

0. Does not apply
1. Tamoxifen
2. Anastrozole (Arimidex)
3. Letrozole (Femara)
4. Exmestane (Aromasin)
5. Other: \_\_\_\_\_

**Section III** will use questions from the DASH (Disabilities of the Arm, Shoulder and Hand) questionnaire.

This questionnaire asks about your symptoms as well as your ability to perform certain activities. Please answer every question, based on your condition in the last week, by circling the appropriate number. If you did not have the opportunity to perform an activity in the past week, please make your best estimate on which response would be the most accurate. It doesn't matter which hand or arm you use to perform the activity; please answer based on your ability regardless of how you perform the task.

Please rate your ability to do the following activities in the last week by circling the number below the appropriate response.

No difficulty=1; Mild difficulty=2; Moderate difficulty=3; Severe difficulty=4; Unable=5

- |  |   |   |   |   |   |
|--|---|---|---|---|---|
| 1. Open a tight or new jar.                    | 1 | 2 | 3 | 4 | 5 |
| 2. Write.                                      | 1 | 2 | 3 | 4 | 5 |
| 3. Turn a key.                                 | 1 | 2 | 3 | 4 | 5 |
| 4. Prepare a meal.                             | 1 | 2 | 3 | 4 | 5 |
| 5. Push open a heavy door.                     | 1 | 2 | 3 | 4 | 5 |
| 6. Place an object on a shelf above your head. | 1 | 2 | 3 | 4 | 5 |
| 7. Do heavy household chores.                  | 1 | 2 | 3 | 4 | 5 |
| 8. Garden or do yard work.                     | 1 | 2 | 3 | 4 | 5 |
| 9. Make a bed.                                 | 1 | 2 | 3 | 4 | 5 |
| 10. Carry a shopping bag or briefcase.         | 1 | 2 | 3 | 4 | 5 |

11. Carry a heavy object (over 10 lbs).	1	2	3	4	5
12. Change a lightbulb overhead.	1	2	3	4	5
13. Wash or blow dry your hair.	1	2	3	4	5
14. Wash your back.	1	2	3	4	5
15. Put on a pullover sweater.	1	2	3	4	5
16. Use a knife to cut food.	1	2	3	4	5
17. Recreational activities which require little effort (e.g., cardplaying, knitting, etc.).	1	2	3	4	5
18. Recreational activities in which you take some force or impact through your arm, shoulder or hand (e.g., golf, hammering, tennis, etc.).	1	2	3	4	5
19. Recreational activities in which you move your arm freely (e.g., playing frisbee, badminton, etc.).	1	2	3	4	5
20. Manage transportation needs (getting from one place to another).	1	2	3	4	5
21. Sexual activities.	1	2	3	4	5

Please check the answer that best applies.

22. During the past week, to what extent has your arm, shoulder or hand problem interfered with your normal social activities with family, friends, neighbours or groups?

Not at all: \_\_\_ Moderately: \_\_\_ Extremely: \_\_\_  
Slightly: \_\_\_ Quite a bit: \_\_\_

23. During the past week, were you limited in your work or other regular daily activities as a result of your arm, shoulder or hand problem?

Not limited at all: \_\_\_ Moderately limited: \_\_\_ Extremely: \_\_\_  
Slightly: \_\_\_ Quite a bit: \_\_\_

24. During the past week, how much difficulty have you had sleeping because of the pain in your arm, shoulder or hand?

No difficulty: \_\_\_ Moderate difficulty: \_\_\_ So much difficulty that I  
Mild difficulty: \_\_\_ Severe difficulty: \_\_\_ can't sleep: \_\_\_

25. I feel less capable, less confident or less useful because of my arm, shoulder or hand problem.

Strongly agree: \_\_\_ Neither agree or disagree: \_\_\_ Strongly Agree: \_\_\_  
Disagree: \_\_\_ Agree: \_\_\_

Please rate the severity of the following symptoms in the last week. (Circle number.)

None=1; Mild=2; Moderate=3; Severe=4; Extreme=5

- |  |   |   |   |   |   |
|--|---|---|---|---|---|
| 26. Arm, shoulder or hand pain.  | 1 | 2 | 3 | 4 | 5 |
| 27. Arm, shoulder or hand pain when you performed any specific activity. | 1 | 2 | 3 | 4 | 5 |
| 28. Tingling (pins and needles) in your arm, shoulder or hand.           | 1 | 2 | 3 | 4 | 5 |
| 29. Weakness in your arm, shoulder or hand.                              | 1 | 2 | 3 | 4 | 5 |
| 30. Stiffness in your arm, shoulder or hand.                             | 1 | 2 | 3 | 4 | 5 |

Please circle the number that best describes your physical ability in the past week.

No difficulty = 1      Mild difficulty = 2      Moderate difficulty = 3

Severe difficulty = 4      Unable = 5

Did you have any difficulty:

- |  |   |   |   |   |   |
|--|---|---|---|---|---|
| 31. using your usual technique for your work?                    | 1 | 2 | 3 | 4 | 5 |
| 32. doing your usual work because of arm, shoulder or hand pain? | 1 | 2 | 3 | 4 | 5 |
| 33. doing your work as well as you would like?                   | 1 | 2 | 3 | 4 | 5 |
| 34. spending your usual amount of time doing your work?          | 1 | 2 | 3 | 4 | 5 |

**Section IV** will incorporate the McGill Pain Questionnaire.

Check None, Mild, Moderate, or Severe to indicate the level of pain you have felt in the past week.

	None	Mild	Moderate	Severe
1. Throbbing	_____	_____	_____	_____
2. Shooting	_____	_____	_____	_____
3. Stabbing	_____	_____	_____	_____
4. Sharp	_____	_____	_____	_____
5. Cramping	_____	_____	_____	_____
6. Gnawing	_____	_____	_____	_____
7. Hot-burning	_____	_____	_____	_____
8. Aching	_____	_____	_____	_____
9. Heavy	_____	_____	_____	_____
10. Tender	_____	_____	_____	_____
11. Splitting	_____	_____	_____	_____
12. Tiring-Exhausting	_____	_____	_____	_____
13. Sickening	_____	_____	_____	_____
14. Fearful	_____	_____	_____	_____

15. Punishing-Cruel

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_