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The experience of shared decision-making for breast cancer: a qualitative study

By

Neda Mahmoodi

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SUBMISSION OF THESIS FOR A RESEARCH DEGREE**Part I. DECLARATION by the candidate for a research degree. To be bound in the thesis**Degree for which thesis being submitted: **PhD Psychology**Title of thesis: **The experience of shared decision making for breast cancer: a qualitative study**This thesis contains confidential information and is subject to the protocol set down for the submission and examination of such a thesis. **No**Date of submission: **23/09/2014**Original registration date: **21/09/2010**Name of candidate: **Neda Mahmoodi**Research Institute: **Social Sciences**Name of Lead Supervisor: **Dr Sally Sargent**

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Abstract

Shared decision making (SDM) is a collaborative process that allows patients and their providers to make health care decisions together, taking into account scientific evidence and the patient's values and preferences. The thesis shifts the explanatory framework of SDM from current literature, which evaluates the concept of SDM, to a qualitative critical health psychology approach, which explores SDM in terms of its meaning and experiences for individuals. The thesis explores the experience of SDM for the treatment of breast cancer, and theoretically draws on phenomenology (Husserl, 1970) and symbolic interactionism (Blumer, 1969).

The thesis comprises three separate studies to investigate patient experiences of SDM, based on a triangulation of in-depth qualitative methods, which explore patient perceptions and interactions. Study one, a semi-structured interview design with post-treatment patients, identifies themes in accounts of SDM by means of a thematic analysis. Study two, explores SDM further through a thematic analysis on patient interaction within Internet breast cancer support forums. Study three, discusses the experience of SDM through a conversation analysis on doctor-patient interaction during adjuvant treatment consultations.

Results indicate that for most patients, SDM is understood in accordance with the NICE guidelines (2004 & 2012), and is experienced through the characteristics of two-way interaction, information exchange ('sharing information'), and sharing of views and preferences ('sharing decisions'), in respect to individual differences. SDM is also experienced during online interaction. The forums make patients aware of SDM, and encourage it to occur during consultations. However, the construction of power, as a clinical problem, results in problematic experiences of SDM. A perceived discrepancy in clinician-patient roles and discursive practices creates an issue of unbalanced doctor-patient power-relations. This deters patient participation and patients' recognition and response to SDM. The research contributes to qualitative research and critical health psychology. It has implications for medical professionals to understand patient experience of SDM, and to improve doctor-patient communication skills for SDM, for the development of breast cancer services to promote patient good health and well-being.

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Chapter One

Breast cancer and SDM: introducing the research question

Chapter 1

Breast cancer and SDM: introducing the research question

1.1 Introduction

At some point in our lives, we may encounter the task of making a decision. Not so long ago, I was faced with a scenario which involved me talking to a friend who was deliberating about a personal dilemma, regarding health issues. She had to make a confusing decision. My response to her was, “*just decide...it’s not like it’s a matter of life or death*”. This is a phrase we may commonly use after patiently listening to a person describing their problem. We say this, presumably, as a well-intentioned way of encouraging the troubled problem solver to feel a little less anxious, a little more hopeful that life will go on, and that the future will be better. But was I right? Are all health-related decisions really not a matter of life or death? For example, there are many individuals who are diagnosed with life threatening illnesses, and are subsequently faced with the complex dilemma of making an appropriate treatment decision. For some people, the task of decision-making may be non-existent, as they might believe that a treatment choice should be ultimately decided by medical professionals. For others, the responsibility for the decision may be more personal and, perhaps, fuelled by fears of recurrence, feelings of anxiety, distress over side-effects, and the effects on loved ones. All of these are concerns which further add to the complexity of the decision-making task.

It was during my Masters Research project, which involved exploring levels of distress amongst cancer patients, that I became more aware of the heightened emotional distress and decision-making complexities surrounding cancer. Subsequently, this inspired my further research ambitions, which were to take a more focused examination of the decision-making processes, encountered by the cancer patients during treatment. Although much of my previous research had been conducted among patients with a range of cancer types, I decided to focus specifically on breast cancer for the purpose of a PhD thesis. During my Masters, I began to learn about the many difficulties that breast cancer patients face regarding treatment choices, such as worrying about body disfigurement and heightened levels of distress regarding treatment. This became a personal motive for focusing on decision-making relating to breast cancer. With existing collaborations already in place between the Cancer Centre at the University teaching hospital and the School of

Psychology at Keele University, this provided an appropriate opportunity for this research to take place.

At the outset, it is important to gain a better understanding of the disease in question and a clearer scientific rationale for the research project. In order to facilitate a reading of this thesis, a glossary of terms and a dictionary of abbreviations are given in Appendix A.

1.2 Breast cancer

Breast cancer is a disease in which malignant (cancer) cells form in the tissues of the breast. Although the disease occurs amongst men, it is, however, most commonly found in women over the age of 35 (Office for Cancer Statistics, 2007). The precise reasons why women develop breast cancer are still unknown. Neither socio-economic status nor demographics such as age, gender, and ethnicity have been shown to provide a normative basis for causation. It is thought to be a combination of genetic, environmental, and lifestyle factors (National Institute of Environmental Health Science, 2010). The National Health Service (NHS) referral system indicates that all patients, suspected of having breast cancer, must be seen by a hospital specialist within two weeks of an urgent referral by their general practitioner (GP) (Department of Health, DOH, 2010a). The treatment process is under rigid time constraints as, according to guidelines, clinicians have a 31 day timescale from diagnosis to completing treatment (DOH, 2010b). It is during this narrow time frame where information and supportive care is consistently provided by external support groups and educational material, and communicated by medical professionals to guide the patient through queries, emotions, and treatment decision-making.

Effective doctor-patient communication skills are increasingly considered as an important factor in helping patients cope with breast cancer (Cassileth, 1980; Coulter, 1998; Ford, Fallowfield & Lewis, 1995; Fallowfield, Ford & Lewis, 1995; Meredith et al, 1996). Breast cancer patients value effective communication, because they recognise it as central to a therapeutic doctor-patient relationship (Back, Arnold, Tulskey, Baile, Fryer-Edwards, 2003). However, doctor-patient communication in breast cancer care can be particularly challenging, due to fear and stigma associated with the illness, complexity of medical information, and uncertainty about the course of the disease (Siminoff, 1992).

Therefore, clinicians need to acquire the right skills to adapt communication, which takes contextual, cognitive, and emotional barriers into account; and offers patients information and choice (Tattersall, Butow & Clayton, 2002). Regular attendances of communication skills training programmes, which are largely influenced by ideas arising from patient-centred medicine, psychotherapeutic communication, informed consent, and shared decision-making (SDM), are now a necessary part of breast cancer care (Makoul, 2001).

As with most cancers, the key to successful treatment requires early diagnosis. The NHS Breast Screening Programme (NHSBSP, 2009) in the UK allows for the early detection of breast cancer at an early stage, before symptoms or signs develop, such as a lump. The programme invites all women aged between 47 and 73 for screening every 3 years, through the use of mammograms (low-dose x-rays) to each breast. This has shown to lower mortality rates in breast cancer in the 55-69 age group.

Following detection of breast cancer, management and treatment of the diagnosis requires a team effort, provided by a number of specialists, surgeons, oncologists, and breast care nurses. Although there is no single treatment for breast cancer, the treatment path still remains very specific, with options depending on several factors, such as the stage of the tumour (how far it has spread) and whether there is secondary cancer; the receptor status of the breast cancer; the patient's fitness and well-being; and the patient's own wishes regarding treatments. According to the National Institute for Health and Care Excellence (NICE, 2009), the first treatment for most women with breast cancer is usually surgery, and depending on the size of the breast lump, patients will have either a lumpectomy or a mastectomy. With new technologies, it is possible to restore the appearance of the breast with reconstructive surgery during a mastectomy. The advice of the NICE guidelines for early and advanced breast cancer (2009), states that after surgery for breast cancer, all women should be advised to undertake follow-up adjuvant treatments, which consist of either radiotherapy, chemotherapy, hormone treatment, or a combination of all three. These treatments can help to reduce the chance of the cancer cells reoccurring or spreading. The treatment or combination of treatments that patients choose, not only depends on their diagnosis and type of surgery, but could also be influenced by the roles that they and their clinician take during consultations for treatment decision-making. On completion of all treatments, patients are required to undergo regular check-ups and mammograms to monitor the breast and the cancer cells (NHS Breast Screening Program, 2009).

1.3 Breast cancer and medical decision-making

During the diagnosis and treatment for breast cancer, women may often be faced with making complex decisions about surgical and adjuvant treatments. Information describing treatment options can be complex, and the decision comes at an emotionally charged time when communication and thought processing can be difficult to structure. Despite being presented with choices for treatment, many patients believe they have little control over their decisions and find it difficult to manage health decisions (Fallowfield, Baum, & Maguire, 1986; Royak-Schaler, 1991). For example, it can be difficult for some patients to make a decision about something that is very important to them, in respect to the physical side-effects which may come as result of that treatment choice. Patients may feel overwhelmed with all the information given, and possibly feel pressured by the opinions of relatives and friends over their decision. There may also be a degree of uncertainty which comes with the task of making decisions about treatment, as patients could feel anxious, angry, irritable, or frightened about making the right decision. Subsequently, treatment decision-making for breast cancer patients is recognised to be an inherently stressful process (Wainstock, 1991), which can impact patients' psychological well-being (Degner, Kristjanson & Bowman, 1997; Moyer & Salovey, 1998), and result in psychological diagnoses such as distress and anxiety (Akechi, Okuyama, Imoto, Yamawaki & Uchitomi, 2001; Burgess et al, 2005; Grabsch et al, 2006; Okamura, Watanabe, & Narabayashi, 2000). These negative psychological consequences are reportedly severe enough to also affect subsequent quality of life (QOL) (Montazeri, 2008; Skarstein, Aass, Fossa, Skovlund & Dahl 2000), cause poorer adherence to treatment recommendations (Kennard et al, 2004), and result in poorer survival (Steel, Geller, Gamblin, Olek & Carr, 2007).

As a result of such findings on the psychological burden of medical decision-making, research within the field of health psychology has taken a growing interest in exploring the process of decision-making and associated health behaviours. This had led to the development of many normative and descriptive models and theories of decision-making (discussed in Chapter Two), which focus on describing strategies to explain how patients look at choice and decision-making in the medical context. These models have been recognised through an exploration of the patient role and patient levels of participation in decision-making, which illustrate a medical shift from thinking about patient care and treatment decisions in terms of disease and pathology, towards thinking in

terms of people and their problems through established relationships (Emanuel & Emanuel 1992).

Patients are slowly being regarded as consumers, who expect to be involved in their medical care (Coulter & Jenkinson, 2005; Degner et al, 1997; Magee, Davis & Coulter 2003). This is evident in various NHS reports by the DOH on patient centred-care (DOH, 2008 & 2010c), which focus on the need for more active patient participatory roles, without the expense of depleted emotions and psychological well-being. Good doctor-patient communication and accurate information during a consultation, is regarded as highly fundamental to the delivery of high quality cancer care, and an important prerequisite for a successful move towards increased involvement in decision-making (Brennan, 1997; Fallowfield & Jenkins, 1999; Katz, 1984; Scott et al, 2003; Simpson, 1981). As a result, the preferred model of medical decision-making is moving away from approaches which perceive patients as passive spectators in their own healing process (Charles, Gafni & Whelan, 1997), and towards a more shared approach (Elwyn & Charles, 2009). Subsequently, this has given rise to the practice of SDM, which is incorporated into many government policy documents. Such documents highlight SDM as 'standard practice' by all medical practitioners, across all hospitals and GPs in England for all treatments (DOH, 2010; NHS constitution, 2013; NICE, 2004).

SDM is a dynamic process in which patients and doctors influence each other through two-way interaction (Fochsen, Deshpande & Thorson, 2006). SDM involves a partnership between doctor and patient that is based on a division of labour, whereby the clinician provides enough knowledge and information for the patient to make an informed decision (Beaver et al, 1996; Charles et al, 1997; Elwyn & Charles, 2001 cited in Edwards & Elwyn, 2001; Towle & Godolphin, 1999). SDM is increasingly recognised as an ideal model of treatment decision-making in the medical encounter (Brock & Wartman, 1990; Deber, 1994; Emanuel and Emanuel, 1992). Regarding the treatment of breast cancer, this involves 'preference-sensitive' care. The term 'preference-sensitive' care implies that legitimate treatment options exist, and that decisions about these interventions should reflect patients' personal values and preferences, and should be made only after patients have enough information to make an informed choice, in partnership with the clinician. Consequently, as a result of the nature of breast cancer care, the NICE guidelines (2004 & 2012) state that it is essential that decision-making approaches, during treatment choice,

acknowledge patients' informed values and support their involvement in ways which sustain psychological well-being and health outcomes. A review of the literature reveals that SDM has become the preferred approach to treatment decisions for breast cancer, between patients and clinicians (Fallowfield, Hall, Maguire, & Baum, 1990; Gafni, Charles, & Whelan 1998; Guadagnoli & Ward 1998; Moyer, 1997; Silliman, Dukes, Sullivan, & Kaplan, 1998; Street & Voigt, 1997). This will be discussed in more detail in the next section (1.4) of this chapter.

1.4 Breast cancer and SDM: what is already known about research in this area?

There is a substantial amount of existing literature on SDM and breast cancer. This research focuses largely on exploring breast cancer patients' levels of involvement in decision-making (Dominick, Frosch, Robert & Kaplan, 1999; Guadagnoli & Ward, 1998; Hawley et al, 2007; Street, Voigt, Geyer, Manning & Swanson, 1995), and the long-term effects that treatment decision-making can have on women's QOL (Andersen, Bowen, Morea, Stein & Baker, 2008; Katz et al, 2005). These and other studies have highlighted factors which can impact decision-making and patient participation (Degner & Sloan, 1992; Lerman et al, 1990). For instance, one of the main obstacles to patient participation is due to a lack of patient knowledge about their illness (Coulter & Ellins, 2006). Therefore, it has been suggested that the quality of information provided by clinicians, is important in helping women cope with breast cancer (Degner et al, 1997). A second factor suggested by authors is good doctor-patient communication skills during a consultation, as this has been demonstrated to be fundamental to the delivery of high quality cancer care, and in enabling patient involvement in decision-making (Fallowfield & Jenkins, 1999; Katz, 1984; Simpson, 1981). These findings, therefore, suggest the importance of conversation, as a method to further explore health-related decision-making. Finally, there are arguments that support the impact of patients' participatory roles; for example, if they are 'active' or 'passive' in their care, on levels of participation which take place for treatment decision-making (Cahill, 1996; Caress, 1997; Greenfield, Kaplan, & Ware, 1985; Guadagnoli & Ward, 1998; Sutherland, Llewellyn-Thomas, Lockwood, Trichler, & Till, 1989).

Although research illustrates that most patients desire participation in treatment decisions, (Benbassat, Pilpel & Tidhar, 1998; Blanchard, Labrecque, Ruckdeschel, &

Blanchard, 1988; Deber, Kraetschmer & Irvine, 1996; Ende, Kazis, Ash & Moskowitz, 1989; Sutherland et al, 1989), and have shown improved medical outcomes by maintaining an 'active' role in their health care (Frosch & Kaplan, 1999; Kaplan, Greenfield & Ware, 1989; Stewart, 1995; Waterworth & Luker, 1990), a contrary argument is that not everyone wants to participate to the same degree. There are proposed arguments which indicate that patients, with a variety of chronic illnesses, prefer a 'passive' or collaborative role to an 'active' role in making treatment decisions (Arora & McHorney, 2000; Beaver et al, 1996; Blanchard et al, 1988; Degner & Sloan, 1992; Degner et al, 1997; Sutherland et al, 1989). This finding has also been observed in breast cancer patients (Beaver et al, 1996). These findings, therefore, suggest the importance of exploring patient perceptions and views, as a method to further explore health-related decision-making.

In exploring the health literature, in relation to breast cancer and SDM, research demonstrates attempts to provide greater descriptions of SDM between the patient and clinician (Charles et al, 1998; Elwyn, Edwards, Kinnersley, 1999b; Frosch & Kaplan, 1999; Gattellari, Butow, Tattersall, 2001; Towle, 1997). These studies and others, have focused on evaluating the benefits of SDM for breast care patients such as, improved health outcomes (Hack, Degner, Watson & Sihna, 2006; Janz et al, 2004; Mandelblatt, Kreling, Figueiroedo & Feng, 2006; Moyer, 1997; Silliman et al, 1998; Street & Voigt, 1997); adherence to treatment (Desroches, Lapointe & Deschenes, 2011); enhanced coping strategies (Vodermaier et al, 2001); improved patient satisfaction with care (Scheibler, Janssen & Pfaff, 2003; Swanson, Bastani, Rubenstein, Meredith & Ford, 2007); an increase in patient autonomy and confidence (Joosten, De Jong, de Weert-van, Sensky & van der Staak, 2011); and improved satisfaction with care for partners and family members (Zeliadt et al, 2011).

There is also evidence of research which explores barriers and facilitators to implementing SDM within breast cancer care. Such research tends to focus on evaluating specific tools or competencies, such as information aids to help patients and professionals interact more effectively; or structured checklists to support a SDM process (Loh, Simon, Hennig, Harter & Elwyn, 2006; O'Connor, Llewellyn-Thomas, & Flood, 2004). The purpose of such research is to introduce initiatives which can train professionals on their knowledge and practice of SDM, and to try and improve breast cancer services. However, not all research on SDM with breast cancer care is positive, as studies have also revealed barriers to the implementation of SDM in practice. It has been suggested that this is due to

patients lacking adequate information, poor interactive relationships between patients and clinicians, and time/resource pressures (Barry & Edgman-Levitan, 2012; Elwyn, Frosch, Thomson, Joseph-Williams, & Lloyd et al, 2012; Kleeberg, Feyer, Günther, & Behrens, 2008; Légaré, Ratté, Gravel & Graham, 2008; Légaré & Witteman, 2013). These findings, once more, indicate the importance of conversation, as a method to explore health-related decision-making.

The existing literature on SDM and breast cancer, as outlined above, shows that the topic is an explored area of health research. However, these studies often only focus on evaluating and describing characteristics of SDM, through methods which often forget to ask the most basic questions such as, what does the concept of SDM actually mean to the patients, and how is it experienced by patients? We know that every patient has the right to take part in his or her care and the related decision-making (Act on the status and rights of patient 1992), but to what extent is the realisation of this right meaningful, or even known to patients? No existing research has examined this directly in relation to breast cancer care. There is also no literature devoted to exploring the real meaning, role, and process of SDM, through investigation of patients' encounters and perceptions; and through the conversations that patients engage in regarding decision-making for treatment. As discussed above, the existing literature provides awareness of what SDM is and how it operates within breast cancer care. However, to fully understand the processes involved, an enquiry into how SDM is encountered by breast cancer patients, using methods which aim to capture and explore the patients' perspectives, experiences, and interactions across their treatment trajectory, is required. This is an area of research which is limited within the decision-making and breast cancer health literature. With demands for new strategies and increasing guidelines within the cancer care systems, there is a gap in the literature on SDM for breast cancer patients.

1.5 What is the remit of this thesis?

This thesis aims to explore how women with breast cancer experience SDM through their treatment journey. In addition to the general research question, there are additional questions:

- What does the concept of SDM mean to women with breast cancer, and what are the characteristics of SDM?
- How is the experience of SDM influenced (hindered or facilitated) for women with breast cancer?
- Can SDM for breast cancer be explored qualitatively, through examining patient perceptions and conversations?

Patient experience of SDM is explored in two ways: through an exploration of breast cancer patient encounters and perceptions; and an exploration of breast cancer patients' interactions (conversations with clinician, and with other patients). The research questions are explored through a theoretical framework informed by phenomenology and symbolic interactionism (discussed in Chapter Three). Subsequently, this deploys to qualitative research, which is the methodology used throughout the thesis. Figure 1.1 provides an illustration of how the research questions will be explored. The thesis aims to answer the research question through a triangulation of methods, in three distinct qualitative studies. This qualitative method of exploring patient experiences and SDM is the first to be accounted for within the health literature for the treatment of breast cancer. The first study aims to retrospectively explore individual patients' perspectives, understanding, and encounters of SDM within their treatment, through semi-structured interviews. This will provide a comprehensive insight into patient experience of SDM, from the viewpoint of patients who are post-treatment completion. The second study further explores SDM, however, from patient interaction. Through a method of examining the conversations that patients have with other breast cancer patients, during online forum interaction, a thorough insight into patients' experience of SDM will be provided. The final study explores SDM and encounters on part of the patient, through an analysis of the interactions and conversations which take place between doctor and patient, during breast cancer consultations. The exploration of doctor-patient communication will provide additional knowledge about the presence of SDM and how it is displayed through talk. All three of the studies will aim to uncover insight into the additional questions raised about the meaning and characteristics of SDM; and how patient experience of SDM can be influence (hinder or facilitate).

All three of these methods of investigation on the topic of SDM for breast cancer have not been documented in any of the existing literature. Therefore, an overall distinctive

feature of this thesis is that it looks at SDM for the medical treatment of breast cancer, from the patients' experience and interactions. As outlined in the questions above, one of the aims of this thesis is not only to explore the research topic, but to examine how this can be achieved through various qualitative methods and theoretical frameworks. Therefore, the research question is investigated through three different qualitative methods, as shown in Figure 1.1, which focus on exploring SDM from both patient viewpoint and interactions.

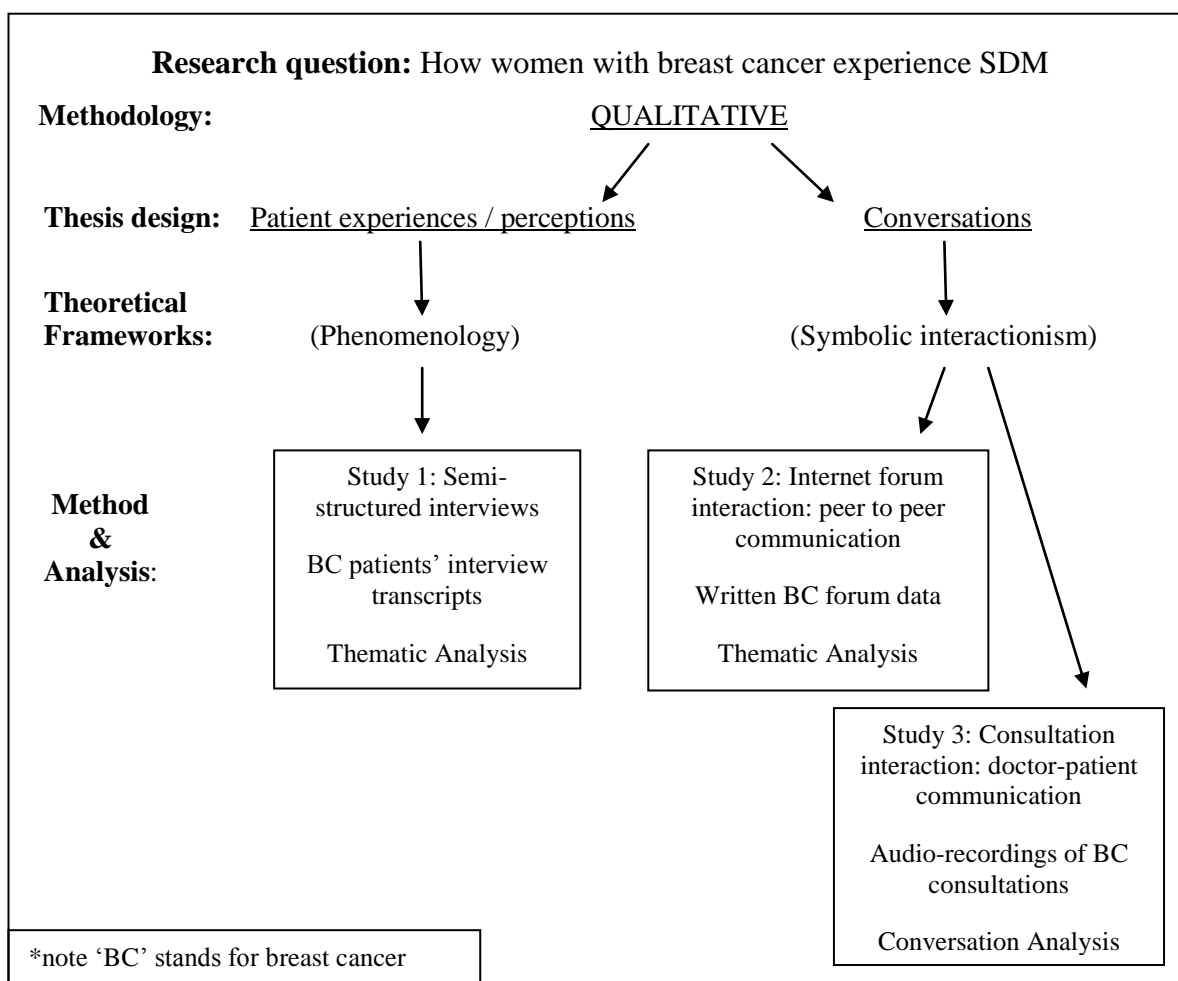


Figure 1.1 Diagram to explain the thesis research questions and how it will be examined

The content of the thesis is as follows:

Chapter Two reviews the literature in health psychology regarding medical decision-making and SDM. The aim of the literature review is to provide an understanding of the concept of SDM in relation to medical models of decision-making.

Chapter Three identifies the theoretical underpinnings of the thesis, and provides a justification for exploring both the general and additional questions raised. Phenomenology and symbolic interactionism are introduced as theoretical frameworks, and discussed in relation to qualitative research and previous literature on SDM, and breast cancer

Chapter Four opens with a literature review which introduces the qualitative method of interviews, as a way to explore patient perceptions and experiences, to further understand about patient experience of SDM. The literature review also provides the rationale for study one. This study aims to explore retrospective accounts of patients' views and experiences of SDM during the course of their treatment for breast cancer. Following the literature review, the chapter describes the methods used for data collection, which consisted of qualitative semi-structured interviews with patients who were two years post-treatment. The interviews offered an opportunity for participants to reflect and to talk about their views and experiences of SDM, and to describe their understanding of SDM. The procedure used for participant recruitment, data collection, and data analysis are described in the chapter. The findings from the interview transcripts are then presented using a thematic analysis (TA). The chapter outlines the key themes derived from the analysis, supported with interview extracts to illustrate them. The chapter concludes with a discussion of the findings.

Chapter Five opens with a literature review which introduces the potential of Internet/ online research, as a way to explore patient conversations, to further understand about patient experience of SDM. The literature review also provides the rationale for study two. This study aims to explore SDM through investigating the interactions that take place between patients, within online breast cancer forums. Following the literature review, the chapter describes the methods used for data collection. Data collection of written posts from online breast cancer support forums, offered an opportunity to explore SDM within an online patient membership community. Exploring interaction within the forums allowed for further insight into how SDM is experienced and understood, in both clinical and non-clinical settings. The findings from the forum discussion threads are then presented using TA. The chapter outlines the key themes derived from the analysis, supported with online forum extracts. The chapter concludes with a discussion of the findings.

Chapter Six opens with a literature review which introduces the potential of doctor-patient communication research and conversation analysis (CA), as a way to explore

patient conversations, to further understand about the concept of SDM. The literature review also provides the rationale for study three. This study aims to explore SDM through investigating the conversations which take place, between patient and clinician, during a breast cancer consultation. Following the literature review, the chapter describes the methods used for data collection which consist of tape recordings of adjuvant treatment consultations. Exploring interaction from the audio-recordings offered an opportunity to gain deeper understanding about the characteristics and presence of SDM, during clinical interactions. This provided an opportunity to explore whether factors, such as conversation techniques and doctor-patient relationships, facilitate or hinder patient encounters of SDM. By means of a CA, the findings from the tape recordings are accounted for in terms of linguistic practices, which impacted upon shared conversations, and are supported by extracts from the recordings. The chapter concludes with a discussion of the findings.

Chapter Seven combines all three studies to discuss how the findings, from all three stages of data collection, can contribute to understanding how SDM is experienced by breast cancer patients. The discussion also reviews the additional questions to answer what the concept of SDM means to patients, and what the characteristics of SDM are; how patient experience of SDM can be influenced (hindered or facilitated); and whether SDM for breast cancer should be explored qualitatively, through examining patient perceptions and conversations. The findings and the use of qualitative research are discussed in relation to their contributions and implications for future health research and cancer care.

This provides an introductory overview of this thesis, but now it is important to consider the questions that have been raised. The first step is to review the literature in more detail to consider what is already known about medical decision-making, and to see what existing literature can contribute to understanding how women with breast cancer experience SDM. The next chapter provides a literature review on the psychology of decision-making and health-related decision-making, in association with SDM.

Chapter Two

Breast cancer and medical decision making: from a paternalistic model to a patient-centred approach

Chapter 2

Breast cancer and medical decision-making: from a paternalistic model to a patient-centred approach

2.1 Introduction

The previous chapter provided an overall introduction to the thesis, and outlined the rationale as to why it is important to further explore SDM within breast cancer care. As emphasised in Chapter One, this thesis is primarily concerned with exploring how women with breast cancer experience SDM during their treatment. As the underlying topic under investigation is associated with health-related decision-making, it is important to explore the literature surrounding the psychology of decision-making. This chapter will explore research on decision-making in the medical setting, in relation to theoretical models of decision making.

2.2 Decision-making theories and models

Decision-making is a process which involves the selection of a preferred option or a course of actions from a set of alternatives (Wang, Wang, Patel & Patel, 2004; Wilson & Keil, 2001). Research on decision-making concentrates on explaining how people make choices, and describes the cognitive processes that underlie the choices. Decision theories and existing research on choice is widely applied in many disciplines such as, computer science, economics, sociology, psychology, political science, and statistics. For the purpose of this thesis and chapter, exploration of the existing research will be based on decision-making in the discipline of health psychology.

Understanding the types of decisions made and the factors that influence an individual's decision-making process, is an important area of exploration. Within the discipline of psychology, strategies have been described to explain the process of decision-making for individuals when faced with having to make a choice between several options.

Decision research has traditionally been categorised across two paradigms: normative and descriptive theories.

2.2.1 Normative models

Normative issues focus on how decisions be made best. It explores theories of formal logic and probability through the implementation of decision analysis, such as cost-effectiveness analysis. This is a particular type of decision analysis in which economic outcomes are analysed in addition to health outcomes, and the cost of achieving those additional health benefits is determined.

There are typical examples of normative theories. One is the *Expected Utility Theory (EUT)* (Bernoulli, 1738) which states that decision-making is achieved through a process of balancing risk versus rewards, using a mathematical function. Another is the *Bayesian Theory* (Bayes, 1763), which provides a mathematical framework for performing inference, or reasoning, using probability. The *Decision Theory* involves mathematical strategies for optimal decision-making between options involving different risks or expectations of gain depending on the outcome. Finally, the *Games Theory* (Von Neumann & Morgenstern, 1947) is a mathematical method of decision-making in a competitive situation, where the outcome of choice crucially depends on other participants' actions. Within these normative theories, the mathematical model of decision-making is highlighted and widely used in determining rational, heuristic, and intuitive selections in complex situations, as well as in daily life procedures.

2.2.2 Descriptive models

Where normative theories consist of rationalistic components that indicate how decisions should be made, the descriptive theories alternatively study the psychological or social processes of decision-making (i.e. how are decisions actually made). The model is based on empirical observation and on experimental studies of choice behaviours. Descriptive models use cognition to explain decision-making, and use decision-making models to illustrate how decision makers analyse a number of possible alternatives from different scenarios before selecting a choice. Stein and Welch (1997) argued that cognitive psychology is useful in that it provides tools for analysing simple rules people use in the

process of reacting to complex dilemmas. As a result, research on cognitive decision-making aims to understand the cognitive processes which underlie human judgment.

Cognitive theories of decision-making are attentive to individual variances and methods of simplification, through which people process information and interpret their surrounding environments. An important approach in cognitive psychology is the *Information Processing Theory* (Miller, 1956). Research in cognitive psychology initially focused on the information processing approach to decision-making, which is primarily concerned with understanding controllable conscious processes. This model of decision-making can be traced back to Simon (1955) and the notion of bounded rationality, that is, humans are constrained by the environment (e.g. information costs), and in the mind (e.g. limited memory); these constraints shape people's behaviour. Over the years, newer cognitive models of decision-making were introduced such as, the *Attribution Theory* (Heider, 1958) which highlights the importance of schemata in determining how people interpret new information based on their pre-existing beliefs. There is also the *Adaptive Decision Maker Framework* (cited in Broder, 2003), which is concerned with preferential choice problems. This framework focuses on how individuals choose between different courses of action, in particular, in choice situations where no single alternative is best for all attributes. The framework argues that preferential choice problems are generally solved through a process of information acquisition and evaluation about the alternatives and their attributes.

Cognitive theories within psychology have also explored the relationship between attitudes and behaviour in the task of decision-making. This has led to the *Theory of Reasoned Action (TRA)* (Ajzen & Fishbein, 1980), which is particularly influential in the field of decision-making regarding health-related behaviour and social influence. This is a model based on behavioural intention, and highlights that the primary determinant of behaviour is the person's intention (as well as attitudes towards the behaviour and perceived social norm regarding the behaviour). Ajzen (1988) proposed an extension of *TRA* which was the *Theory of Planned Behaviour (TPB)*. According to Ajzen, a person's perceived behavioural control (skills, ability, information, and emotions) reflects their beliefs about factors that may inhibit or promote the performance of the behaviour. *TRA* and *TPB* have been applied to a wide range of decisions about health-related behaviours,

for example, smoking initiation, condom use, oral contraception, and participation in exercise.

Similar to normative models of decision-making, an important element of cognitive theories of decision-making is heuristics (Kahneman, Slovic & Tversky, 1982). Cognitive theorists argue that there are ranges of simple strategies (heuristics) that can save on cognitive effort and assist decision-making. According to Gigerenzer (2004), heuristics are simple relative to human capacities; allow fast and frugal judgements; can be easily understood and taught to a novice; and can be generalised to new situations. There are certain models to explain this approach. One is the *Single-Feature Model* or *Lexographic Strategy*, which requires ignoring other variables and focuses purely on a single important attribute. Another is the *Additive Feature Model* (Simon, 1955), which takes all the important features of the possible choices into account, and then systematically evaluates each option to determine which option has the highest rating. Finally, the *Elimination by Aspect Model* (Tversky, 1972), evaluates each option one characteristic at a time, beginning with whatever feature you believe is the most important, until you cross all possible items off and eventually arrive at just one alternative. These models have been suggested to be useful techniques in helping individuals to determine the best option amongst a variety of choices, and minor everyday decisions (Broder, 2000 & 2003; Payne, Bettman & Johnson, 1993). This argument is further supported by Simon (1957) who stated that heuristics are satisfying procedures for making inferences and decisions, and that being satisfied allows for more optimism and higher life satisfaction (Schwartz et al., 2002).

Descriptive theories have explored decision-making in relation to risky and uncertain choices. Risky decisions are those where the probabilities of the various possible outcomes are objective or unknown. Uncertainty occurs when the decision-maker has to estimate the probabilities of the various outcomes happening. The *Prospect Theory* (Kahneman & Tversky, 1979) provides an analysis of probabilistic decision under risk. It is known as a prescriptive approach, as it is concerned with how to get people to act more normatively. This area of work is called decision-analysis. Similar to the *EUT*, the *Prospect Theory* states that people make decisions based on the potential value of losses and gains, using certain heuristics. However, it provides a more accurate description of

decision-making in comparison to the *EUT*, and it tries to model real-life choices rather than optimal decisions.

Many of the existing descriptive models of decision-making, outlined above, assume there is a single system of thought that produces preferences. However, research also signifies that preferences are formed from a dual process/system of reasoning (Damasio, 1994; Sanfey, Loewenstein, McClure & Cohen, 2006). *Dual-process Theory* (Mukherjee, 2010) postulates that there are two fundamentally different systems that can process information. One system is described as automatic, intuitive, fast, and experiential. The other is labelled as deliberative, analytical, slow, and rational. Both systems are identified as having functionally distinct roles that differ according to the type of information encoded, and vary according to the level of expressible knowledge, which results in different responses. Research has shown that dual-process accounts are often more successful at explaining behavioural phenomena than unitary approaches (Kahneman, 2003).

It is therefore apparent that choice represents the core characteristics of decision-making, and that decision-making involves the processes of thinking, reacting, comprehending expectations, and evaluation. Descriptive and normative theories are evident within the health psychology literature, and aim to explain, conceptualise and discuss the meanings of values, beliefs, and behaviours for decision-making amongst individuals. For example, normative theories for cognition aim to tell us how we, ideally, should reason, make judgments, and make decisions. They give us rules to follow that supposedly make our thought rational. Descriptive theories in psychology try to describe how people actually think. Descriptive results, which show that people are out of line with a suggested normative rule, conclude that their thinking is fallacious or biased. The next stage of the chapter discusses decision-making in relation to health-related research and medical decision-making.

2.3 Models of medical decision-making

Within the context of health, decision-making can be a complex and essential part of medical care for both the medical professional and the patient. Medical professionals need to understand what is wrong with the patient, and then suggest the most appropriate form

of treatment. Patients need to decide whether they wish to seek medical care, and to consent to having the treatment the medical expert has recommended. In the context of breast cancer, many treatment recommendations are based on increasingly complicated clinical algorithms. For example, adjuvant treatments are commonly given to women with breast cancer following breast surgery, as results of clinical trials having shown that treatments, such as chemotherapy, decrease cancer recurrence (Abe et al, 2005; Early Breast Cancer Trialists' Collaborative Group-EBCTCG, 2005). For many patients, the decision to opt for such treatment, or to opt out, can possibly be a challenge and may create a dilemma. On the one hand, opting in means that the risk of cancer recurrence may become small; conversely, undergoing adjuvant chemotherapy can have large adverse side-effects on the patient's QOL during treatment (Levine, Gafni, Markham & MacFarelane, 1992; Shapiro & Recht, 2001). In a given scenario like this, there is no right or wrong answer in treatment choice. However, the process of deciding should involve the act of deliberation, similar to the *EUT*, whereby potential morbidity and negative side-effects are weighed up against the potential reduction, in both morbidity and inconvenience (NICE, 2009). Research indicates that patients are often faced with different options and decisions about the type of surgery they receive (Lantz, Janz, Fagerlin, Schwartz & Liu, 2005); the use or avoidance of radiation (Jansen, Otten, van de Velde, Nortier & Stiggelbout, 2004); and the use of follow-up care (Andersen & Urban, 1999).

The burden of involvement in decision-making has been described to likely cause patients to experience decisional conflict. For example, 66% of women with early-stage breast cancer reported feeling uncertain about whether to choose a mastectomy or a lumpectomy with radiation therapy (Collins et al, 2007). Another study indicated that 43% of patients, with advanced breast cancer, were uncertain about whether to receive end-of-life care at home or in a health care institution (Murray, O'Connor, Fiset & Viola, 2003). There are arguments that support patients choosing their own treatments (Longtin et al, 2010); however, a cancer patient's ability to make the appropriate decisions about their treatment choices has arguably been described as limited, due to several factors that contribute to patients' decisional conflict. For example, patients can feel a lack of clinician support for decision-making (Entwistle, Carter, Cribb, & McCaffery, 2010; Leo, 1999); have insufficient knowledge of the likely outcomes of their disease (Renzi et al, 2006); or lack information concerning the effects of alternative strategies on health outcomes (Leo, 1999). Research also supports that some patients may be too ill, or too overwhelmed

emotionally to play a major role in deciding the right therapy (Heyland, Tranmer, O’Callaghan, & Gafni, 2003; Weeks et al, 1998). Furthermore, factors such as past health experience (Juliusson, Karlsson & Garling, 2005); cognitive biases (Stanovich & West, 2008); age and individual differences (Bruin, Parker & Fischhoff, 2007); belief in personal relevance (Acevedo & Krueger, 2004); and an escalation of commitment, can influence what choices people make, and add further difficulty in making decisions. Patients require a lot of time, effort, and mental energy to reach a conclusion.

2.3.1 *The application of normative and descriptive models of medical decision-making*

Across both descriptive and normative theories outlined previously, the components of these theories have provided a number of implications for how we look at choice and decision-making in the medical context. The application of decision-making theories to medical treatment decision-making often requires the measurement of health values (referred to as ‘utilities’) for health outcomes. These measurements have been explored in the medical context through normative methods. For example, the *Game Theory* has been used in research to provide an insight into the possible underlying dynamics of the doctor-patient interaction (Tarrant, Stokes & Colman, 2004). The application of this theory to medical decision-making has provided a supplementary means to explain optimal rational strategies, in situations where the actual outcome depends on the choices of both the patient and the clinician (Diamond, Rozanski & Steuer, 1986).

The use of heuristics has also been applied to health-related decision-making. This allows health research to question the processes by which service users and carers make choices; to explore what important strategies used; and to examine what happens if the strategies used by the patient and professionals differ. For example, Green and Mehr (1997) illustrated the use of heuristics to medical decision-making, by developing the *Fast-and-frugal Tree for treatment allocation of coronary care*. *The resulting heuristic is shown in Figure 2.1 in the form of the fast and frugal decision tree for coronary care*. This method is designed to ignore calculating all probabilities, and instead asks only a few yes-or-no questions to help patients establish mental short cuts in reaching a decision. The model relies on three simple building blocks of heuristics: ordered search for information, a fast stopping rule, and one reason decision-making (Gigerenzer & Goldstein, 1996; Gigerenzer, Todd & the ABC research group, 1999). The model is ‘fast’ because it does

not involve much computation, and ‘frugal’ because it only searches for part of the information. Evaluation of the *Fast-and-frugal Tree* has shown that it is more accurate in classifying and correctly assigning heart disease patients to the appropriate coronary care, than both the clinicians’ intuition and the Heart Disease Predictive Instrument (HDPI) (Gigerenzer & Kurzenhauser, 2005). Furthermore, some medical researchers see the model as a powerful alternative to the prescription of classical *Decision Theory* for patient care (Elwyn, Edwards, Eccles & Rover, 2001). Another model that has been increasingly used to address complex decision-making problems in health care is the *EUT*. Research by both Cohen (1996), and Ubel and Lownstein (1997), identified many strengths of this model in that, it allows for the integration of patient values with medical facts; it uses both information that only a patient possesses and probabilistic information; it closely resembles linear models, which have proven to be successful in judging and prediction; and the model can accommodate two conflicting probabilities by using one piece of information and then the other.

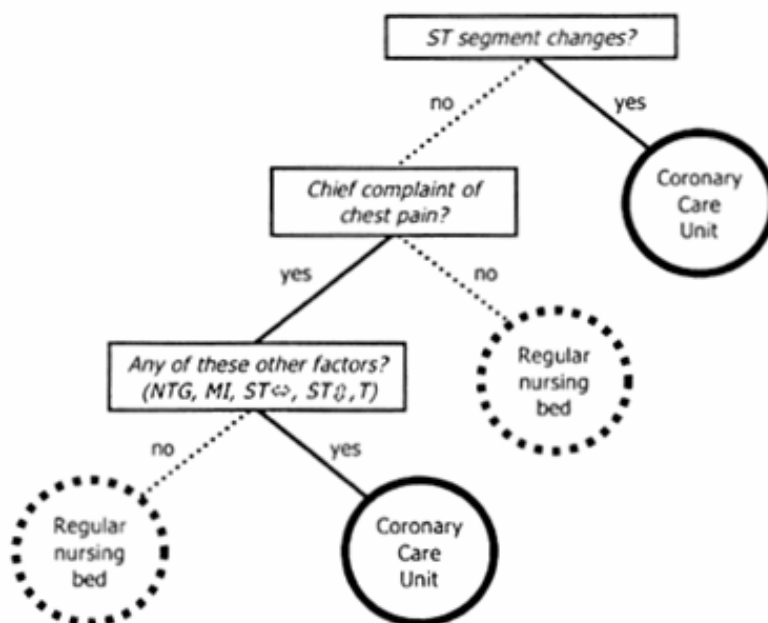


Figure 2.1 *Fast and frugal decision tree for coronary care* (Green & Mehr, 1997). Source: Gigerenzer & Kurzenhauser (2005), page 8

Descriptive models have also been applied to the study of medical decision-making. For example, in a study by Gurmankin and Baron (2005), the *Prospect Theory* was illustrated to explain why subjects are more affected by differences among high probabilities than small ones, with regards to medical risk. Many scholars argue that the

Prospect Theory provides a framework, by which studies have been able to understand how patients assign values to health status, and seemingly make rational or irrational treatment decisions (Treadwell & Lenert, 1999). There are also arguments to support that the *Prospect Theory* is becoming a preferred and more utilised approach, to improve the prescriptive use of *EUT* for medical decision-making under uncertainty and risk (Bleichrodt, Pinto & Wakker, 2001).

The concept of perceived social norms, from the *TRA*, can be seen as relevant to many instances of health-related decision-making, where the attitudes of key people, such as medical professionals, are likely to influence decisions (Ajzen & Fishbein, 2008). Similarly, the *TPB* raises attention to individuals' beliefs, values, and perceived control and explores how these affect choice making (Cote, Gagnon, Houme, Abdeljelil & Gagnon, 2011; Kasper et al, 2012). Consequently, both of these models have, therefore, been shown as relevant to medical decision-making.

Other descriptive theories such as the *Information Processing Theory* and the *Attribution Theory*, which emphasise the role of information in decision-making, may raise issues about access to information in a health setting. For example, the way information is provided and how that may facilitate or hinder a decision; how much information do patients have and actually use in making the decision; and supporting patient involvement in decision-making, by changing the amount of information received and the way it is provided. These areas of enquiry regarding information based from both theories, have subsequently provoked an increase in health research to focus on exploring the impact of information and communication in medical decision-making (Blanchard et al, 1988; Coulter, 1998; Degner et al, 1997; Robinson & Thomson, 2001; Strull, Lo & Charles, 1984;). Finally, the *Dual-processing Model* has also been applied to medical decision-making to shed better understanding of treatment decision-making, and to explain the widespread variation in treatments observed in clinical practice (Djulgovic, Hozo, Beckstead, Tsalatsanis & Pauker, 2012). The model has also been used to identify individual differences in the cognitive processing between doctors that could inform strategies to change practice (Sladek, Phillips & Bond, 2006).

Although the models described provide a normative and descriptive theory for medical decision-making, it is important to note that deviance from these models is very common in medical decision-making. Patients' values may not always conform to a

normative theory. For example, when considering risky options, people may not weigh the possible outcomes exactly according to their respective probabilities. The typical finding in support of this suggestion is that people overestimate low probabilities, and underestimate moderate and high probabilities (Dietrich, 2010). Therefore, measured health values may need to be adjusted prior to inclusion in a normative model. Furthermore, Fischhoff (2006) argued that systematic discrepancies from the normative model can result in biases and, as a result, elicit flawed conclusions about the treatment decision. Similarly, although descriptive models are useful when dealing with uncertainty, heuristics often lead to systematic errors that affect the quality and/or ethics of medical decisions (Thompson & Dowding, 2002). Hastie and Dawes (2001) suggest that good decisions are those in which the process follows the laws of logic and probability theory. Others have argued that it is not possible to identify, assign relative probabilistic weight to, and account for all aspects of risk, particularly in medicine and health care (Hammond, 2000). Attempts to do so provide an analysis that is only valid for one point in time with significant, unrepresented, and unaccounted bias. This has, therefore, led to the criticism of models of decision-making which are based on a fixed universe of possibilities, whereby the 'known' is only considered and focus on expected variations, not on unforeseen events. For example, normative theories of decision-making rely on the quantification of risk in complete and known ways. Thompson and Dowding (2002) argue that this is not always possible, especially in health care decision situations that are characterised by incomplete knowledge of all available alternatives and their consequences; and have limited techniques for measuring patient utility (Thompson & Dowding, 2001). Chapman and Sonnenberg (2000) supports this argument further by suggesting that decision making, through the use of simplifying strategies such as heuristics and decision trees may not fit well in chaotic worlds, uncontrolled environments, or critical situations, and therefore, have an outsized impact during medical decision-making and for significant health-care events which must be considered. This line of argument, called the ludic fallacy, is that there are inevitable imperfections in modelling the real world by particular models, and that unquestioning reliance on models blinds one to their limits.

2.3.2 Models of medical decision-making

With the growth in research aimed at exploring health-related decision-making, a number of medical decision-making models have been identified to describe treatment decision-making. These models were developed through an exploration of doctor-patient relationships and communication. Existing research on patient participatory roles outlines that there is an asymmetry of information between the doctor and the patient (Fudge, Wolfe & McKeivitt, 2008; Woolf et al, 2005). Such studies signify that the clinician can possess technical knowledge about the disease and the expected outcome of each course of action, compared to the patient who does not. As a result of such findings, research in the field of medical decision-making has subsequently focused on identifying a number of theoretical models of decision-making, which describe patient and clinician roles, as well as doctor-patient partnership in medical decision-making. These models of medical decision-making will now be explored individually.

2.3.2.1 Paternalistic model

Historically, it was regarded that medical practitioners were the keepers of medical information and the sole decision makers. Supporting this argument, it has been shown that in many cultures the relationship between the patient and the doctor follows a paternalistic approach (Charles et al, 1997), which looks upon the patient as a passive spectator in his or her own healing process (Emanuel & Emanuel, 1992). This is known as the *paternalistic model* of decision-making, in which the patient passively consents to professional authority by agreeing to the doctor's choice of treatment. Within this model, there are no trade-offs for the patient and no sharing of any of the decision-making steps. This model arguably places the patient in a passive, dependent role, compared to the clinician as the expert. Clinicians are seen as someone who dominates the medical encounter, and using their skills to diagnose and recommend tests and treatments, to restore patients' good health. In the extreme case, "the physician authoritatively informs the patient when the intervention will be initiated" (Emanuel & Emanuel, 1992, p.2221). In a less extreme scenario, the clinician will give the patient selected information, and will encourage the patient to consent to what the physician considers best (Emanuel & Emanuel, 1992). The role of the clinician, depicted in this model, is to act as the patient's guardian and to implement what is best for the patient. Patient involvement is limited to providing consent to the treatment

advocated by the clinician (Emanuel & Emanuel, 1992), and the concept of patient autonomy is patient assent to the clinician's determination of what is best. Table 2.2 describes the *paternalistic model* of medical decision-making.

Table 2.2

The paternalistic model of medical decision-making

Gathering the information	Communicating the information	Understanding and applying the information
-The clinician acquires the scientific information on risks and benefits of different treatment options.	-The clinician in clinical practice communicates the scientific information to the patient.	-Deliberation occurs with clinician alone, with limited or no input from the patient. -The clinician makes the final treatment choice.

The extent to which this approach is currently practised by clinicians is an empirical question. In emergency situations, for example, it may still be widely accepted and might, in practice, be the only feasible model for the task. However, efforts to formulate alternative treatment decision-making models have risen, in reaction to the perceived prevalence of the paternalistic approach, which is viewed as inappropriate for current treatment decision-making contexts (Levine et al, 1992). Subsequently, over the years, there has been a medical shift from thinking about patient care in terms of disease and pathology, towards thinking in terms of people and their problems. With the evolving health care climate, research reveals a shift as patients are slowly becoming regarded as consumers, who are expected to be involved in their medical care (Stacey, Samant, & Bennett, 2008).

Several factors may have contributed to this change. It could be argued that as communities in Western society have become better educated and informed about health care issues, a fundamental shift in society's expectations of the appropriate role for clinicians, and increased emphasis on patient rights, has occurred. This notion is supported by humanist considerations, which state that every human being is endowed with will and with a right to self-determination (Gillon, 1994). Therefore, by participating in the decision-making process, the patient exercises his or her most fundamental rights. It could

also be suggested that such movement has risen as a result of the rapid expansion in medical knowledge and the evolution of improved access to health information for patients. Increased accessibility of the internet has become an influential source for patients to obtain information about medical problems and treatments, alternatives to traditional medicine, as well as to receive social support (Eysenbach, 2000; Hardy, 2001). Such wider availability of information for patients forces clinicians to have to be more comprehensive in discussing available treatment options and, therefore, helps to empower patients (Sharf, 1997). Another proposed argument is that consumerism has contributed to the modification of the patient's role in the treatment process (Kizer, 2001). Like any consumer, patients are beginning to demand and expect quality services (Coulter & Ellins, 2006). By patients continuously evaluating the service, the patient-consumer can improve the health care system (Kizer, 2001), and advocate new patient vision into official medical documents and governmental policies. For example, the Department of Health (1999) recognised the necessity of encouraging an active and participatory role for patients to improve their well-being and increase the efficiency of the health care system.

From the early 1990's research highlights how the terms 'patient participation' and 'patient-centred care' are understood and placed in the context of medical decision-making (Avis, 1994; Biley, 1992; Llewellyn-Thomas, McGreal, & Thiel, 1995; McWhinney, 1989; Siminoff & Fetting, 1991). The concept of patient-centred care is described as an approach where the physician tries to enter the patient's world, to see the illness through the patient's eyes. It is a practice which focuses on ensuring the patient participates by putting their experience foremost, and the practice is at the heart of quality improvement. Table 2.3 describes the core principles and implications of the patient-centred care approach. In today's medical practice, research draws attention to the significance of patient-centred care, as a quality benchmark for establishing increased patient satisfaction by delivering dignified care (Bauman, Fardy & Harris, 2003; Lewin, Skea, Entwistle, Zwarenstein & Dick, 2002). With this new concept taking form, an increased number of health care studies are demonstrating a growth in patient expectations to participate in medical care, and the importance of informed choice in treatment decision-making (Balint, 1996; Charles & DeMaio, 1993; Charles et al, 1997; Feste & Anderson, 1995). Across many different health conditions, research identifies that patients want to be responsible for their health and well-being, and also expect to be well informed and involved in making health decisions (Coulter & Jenkinson, 2005; Degner et al, 1997; Magee et al, 2003).

Table 2.3

The core principles and implications of patient-centred care

Principles	Implications
-Working with patients beliefs and values	
-Providing Holistic Care	- Improves clinical outcomes
-Having sympathetic presence	- Satisfaction with care
-Enabling patients and offering engagement	- Involvement with care
-Shared decision making	- Creating a therapeutic culture
-Offering coordinated care, treatment and support	- People take more responsibility for their own care
-Offering personalised care, treatment and support	- Improves healthcare performance
-Affording people with dignity and respect	
-Power sharing	

Patient-centred care is important for improved patient health outcomes (Crawford, et al, 2002). For example, it allows for greater perceptions of control and self-responsibility (Lerman et al, 1990); less functional disability (Greenfield et al, 1985); increased adherence to medical regimens (Ceichanowski, Katon, Russo & Walker, 2001; DiMatteo, Hays & Sherbourne, 1992; Ley, 1982); and reduced anxiety (Fogerty, Curbow, Wingard, McDonnell, & Somerfield, 1999; Macleod, 1991), and depression (Hack et al, 2006). These improved health outcomes have also shown and to result in good recovery (Selfe, Matthews, & Stones, 1998), and better management of health (Heisler, Bouknight, Hayward, Smith, & Kerr, 2002). More importantly, the impact of patient involvement on improved health outcomes is especially true of breast cancer patients. A mixed method study by Street and Voigt (1997) examined recordings of doctor-patient breast cancer consultations and assessed patient surveys post-operatively. Results illustrated that women who were actively involved in the decision-making process regarding their treatment, tended to be more satisfied with the care they received and had higher overall QOL. These findings are also reflected by Hack et al (2006), who showed similar findings through analysis of breast cancer patient surveys, using the decision role preference scale.

Due to the perceived shortcomings of the *paternalistic model* to patient decision-making, Charles et al (1997) argued the need for a consumer model in health-related decision-making that provided options to patients, and allowed them to make decisions.

Supporting this, Levine et al (1992) suggested that in order to make treatment decisions, which are based on the clinician's knowledge and the patient's preferences, there is a need for a model which combines the two components. To accomplish this, two key treatment decision-making models have been outlined, which originate from recognition of informational asymmetry between patient and clinician. These models are known as the '*physician as the perfect agent model*' and the '*informed decision-making model*'.

2.3.2.2 *Physician as a perfect agent model*

The *physician as a perfect agent* model, also referred to as the interpretative model, aims to elucidate the patient's preferences and values to the clinician. Similar to normative models of decision-making and the *Prospect Theory*, treatment decisions have also been identified in terms of 'trade-offs' of cost versus benefits. In order for a patient to carry out a trade-off, two components are required: first, having full knowledge about the risks, costs, and benefits of each course of action or treatment; and second being able to formulate single measure utility functions (i.e. preferences) for each attribute. However, regarding treatment decision-making, it could be argued that both components are not found in the same person, and often the clinician may have the knowledge while the patient has the preference mapping system. Subsequently, for the clinician to act as a 'perfect agent', the clinician needs to know the patient's values and preferences. To facilitate this process, the clinician provides the patient with the information on the nature of the condition, and the risks and benefits of possible interventions. The clinician then assists the patient in clarifying these values, and determining which medical intervention best supports their values and preferences. According to this model, the patient's preferences are not always fixed, understood, or even known to the patient. To do this, the method of a 'decision tree' type of analysis, at a clinical level, is practiced by the clinician to elicit patient preferences. Through use of a decision tree, similar to one described above by Green and Mehr (1997), the clinician not only offers knowledge, but the patient can also provide preferences in the form of utility scores assigned to various potential outcomes. The clinician can then use the input made by the patient to subsequently refer it back to their knowledge (i.e. the decision tree), and identify the best treatment option in accordance with the patient's perspective and highest score utility. As a result, in this model, the clinician makes the treatment decision, having elicited the patient's preference.

Therefore, both components (information and preferences) reside with the clinician, rather than with the patient, and the former becomes the sole decision maker, while the patient provides informed consent. However, it is important to stress that the clinician does not dictate to the patient or judge the patient's values. They instead help the patient to understand and realise their preferences, by providing them with relevant information, and then use those preferences in the medical situation of decision-making. In accordance to the concept of patient autonomy, this model helps patients to better understand who they are and how the various medical options bear on their identity. Health research shows that this type of doctor-patient interaction, for medical decision-making, is highly recommended by clinicians (Bensing, 2000; Robinson & Thomson, 2001). Table 2.4 provides a description of the *physician as a perfect agent model* of medical decision-making.

Table 2.4

The physician as a perfect agent model of medical decision-making

Gathering the information	Communicating the information	Making the facts personally meaningful	Understanding and applying the information
-The clinician acquires the scientific information on risks and benefits of different treatment options.	-The clinician in clinical practice communicates the scientific information to the patient, with the help of decision aids.	-The patient interprets the information provided and tries to make it meaningful to their preferences. -The patient's preferences/interpretations are influenced by their beliefs and values. - The patient provides the clinician information about their preferences.	-The patient's interpretation of the scientific information is what gives the information personal meaning. -The patient's interpretation and voiced preferences may result in them feeling more informed and participate in decision-making. -The clinician uses the patient's interpretation/preferences to deliberate and make an appropriate decision.

However, some issues about this model have been raised. For example, empirical studies have found that people do not necessarily behave in a manner consistent with their values, and in such cases, the clinician might recommend a treatment option which the

patient sees as inferior (Fishburn, 1988; Karnie & Schmiedler, 1991). Regarding breast cancer care, some critics argue that because there is no optimal treatment for all breast cancer patients this, therefore, disables the process of trade-offs between the clinician and patient (Mooney & Ryan, 1993). Charles et al (1997) elaborated on this notion, explaining that the model is therefore not necessarily one of shared decision-making between the patient and clinician, and that decision-making is still seen as one sided. According to such arguments, by definition, in this model the clinician's treatment preferences are excluded, and the only treatment preferences that matter are those of the patient. Consequently, it can be suggested that although the model might be useful theoretically, it is, however, limited in its use in practice and in particular to decision-making for the treatment of breast cancer.

2.3.2.3 *Informed decision model*

It has been argued that one of the most important preconditions for participation in decision-making is that the patient must have access to adequate and accurate information (Brennan, 1997). Ubel and Lowenstein (1997) emphasised that the provision of information has to be grounded in patients' own values, and that this is crucial in enabling patients to choose the medical option that were most consistent with their values. Since the 1970s, increasing recognition, that patients needed to be better informed about their medical care, led to the introduction of informed consent (General Medical Council, 1999), and alternative models of decision-making, such as the *informed decision-making model*, also referred to as the consumer model. Where the *physician as a perfect agent model* concentrates on the transfer of patients' preferences to the clinician, the *informed decision-making model*, similarly incorporates the idea of information sharing, however, focuses on the transfer of technical knowledge from the clinician to the patient. The aim of the clinician is to provide the patient with all of the relevant information, for the patient to select the medical intervention that they want, and for the clinician to execute the selected intervention. To achieve this, the process involves a partnership between doctor and patient that is based on a division of labour, whereby the clinician provides enough knowledge and information in order for the patient to make an informed decision. This is accomplished by increasing the patient's knowledge of the possible risks of alternative therapeutic options, and about the clinical effectiveness of each treatment option. The *informed decision-making model*, therefore, assumes a clear distinction between facts and values, as the

patient values are well defined and known to the patient, but what the patient lacks is facts. Information transfer is, therefore, seen as key to the decision-making process. According to Hurley, Birch and Eyles (1992), it is a process that allows patients to make decisions that reflect both their preferences and the best scientific knowledge available. Table 2.5 describes the *informed decision making model* of medical decision making.

Table 2.5

The informed decision model of medical decision-making

Gathering the information	Communicating the information	Understanding and applying the information
-The clinician acquires the scientific information on risks and benefits of different treatment options.	-The clinician in clinical practice communicates the scientific information to the patient, with the help of decision aids.	-The patient increases their knowledge of treatment options, and the benefits and risks of each. -The patient feels more ‘informed’ and ‘empowered’. -Deliberation occurs with the patient alone. -The patient increases their involvement in treatment decision-making, and makes the final treatment choice.

This model assumes that the deliberation and decision-making steps are the sole prerogative of the patient. The doctor is accorded no legitimate claim for involvement in these phases, or has any legitimate investment in the treatment decision that the patient makes. It is solely the preference of the patient that counts, and the clinician is consequently a purveyor of technical expertise, providing the patient with the means to exercise control. Charles et al (1997) argued that “the informed model is premised on the assumption that information is an enabling strategy, ‘empowering’ the patient to become a more autonomous decision maker” (p. 683). Therefore, the concept of patient autonomy is control over medical decision-making.

According to Charles, Gafni, and Whelan (2004), such a model of decision-making is in line with the move towards patient-centred care, and towards an ideal in which patient autonomy and appropriate involvement in treatment decision-making is highly valued. This notion is further emphasised by Feste and Anderson (1995), as they argued that the

term ‘informed consent’, which largely rests on the *physician as a perfect agent model*, is slowly becoming revised to ‘informed decision-making’ with this improved model. There are arguments that support such evolved notion of informed consent (Charles, Gafni, & Whelan, 1999b; Emanuel & Emanuel, 1992; Quill & Brody, 1996). These studies illustrate how informed consent, which once essentially demoted the patient’s role to agreeing with the decisions arrived by the doctor, has now moulded into a practice which instead emphasises an open exchange of information and sharing of values and preferences, through patient participation. It can be argued that this model promotes participation in medical decision-making for patients, as it allows patients to possess both components (information and preferences), which are viewed as essential to the task (Levine et al, 1992). Studies have shown that in this model, treatment decision-making control is clearly seen to be in the patient’s hands (Eddy, 1990) and the clinician’s role is limited to that of information exchange and communication of scientific knowledge to the patient (Mooney & Ryan, 1993; Williams, 1988). Consequently, there are arguments that suggest that the model works on the assumption that information is an empowering strategy, which allows the patient to become a more autonomous decision maker and take a more active participatory role (Charles, Whelan, Gafni, Reyno & Redko, 1998; Charles et al, 1999b; Frosch & Kaplan, 1999; Guadagnoli & Ward, 1998).

The *informed decision model* limits the role of the clinician to one of transferring information. In the extreme case, information transfer can be done without the presence of any health care worker, for example, through the use of decision aids. Recently, the issue of transferring adequate information, to enable patients to make an informed treatment choice, has received much attention within health psychology literature. Many different methods to inform patients, known as decision aids, have been systematically reviewed and highlighted as effective in informing patients about available treatment (O’Connor et al, 2009), especially regarding interactive web videos (Deber, 1994; Deber et al, 1996) and decision boards (Levine et al, 1992). Figures 2.6 and 2.7 illustrate an example of an interactive web video and a decision board for breast cancer. These decision aids include a clear description of treatment options, information based on clinical trials, and the associated benefits and risks of recurrence with or without the treatment. They are designed to help patients make specific and deliberative choices, among different options, and to voice their treatment preference.

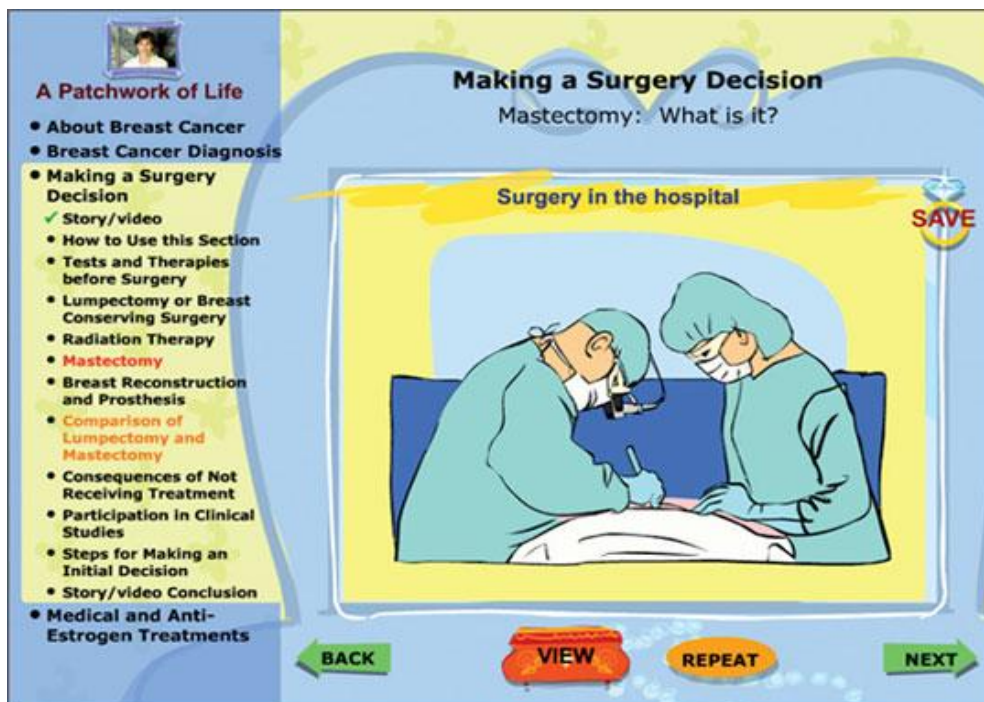


Figure 2.6 Screenshot of an interactive video web-based decision aid for patients diagnosed with early breast cancer, who are about to decide their surgical treatment.

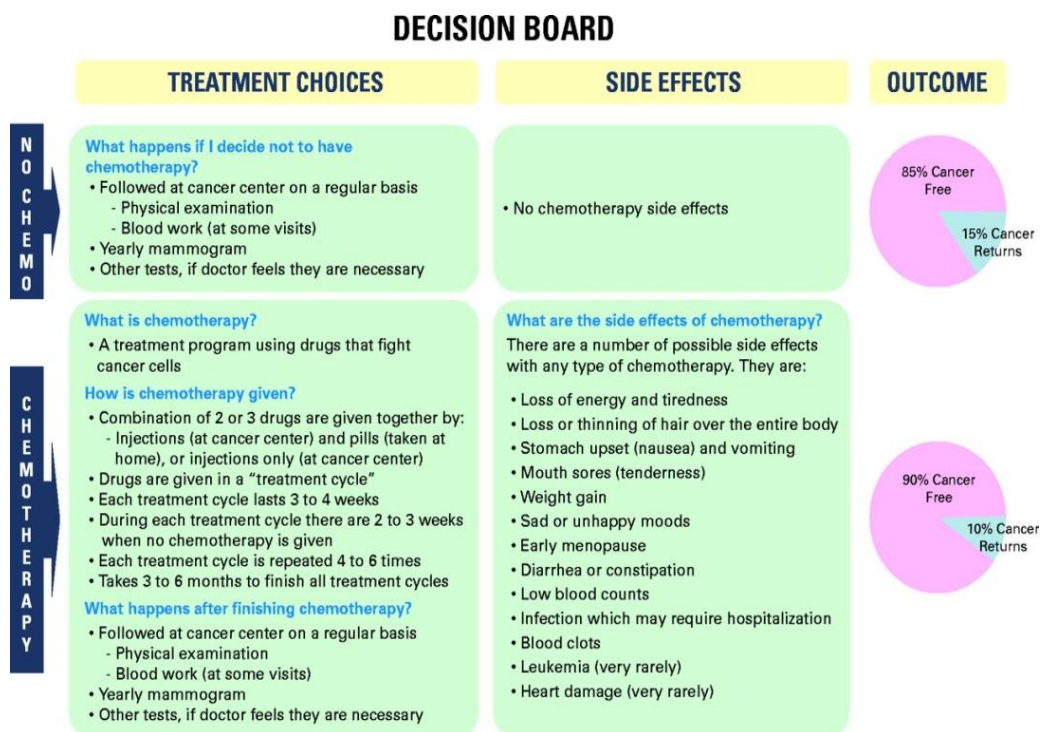


Figure 2.7 A section from the take-home version of the decision board for breast cancer patients, who are having to make adjuvant treatment decisions.

Waitzkin (1991) suggested that clinicians, who adopt the paternalistic approach, are unlikely to use such decision aids, as they can help overcome traditional professional dominance over interactions regarding medical treatment decisions. However, the *informed decision model* enables the clinicians to provide patients with decision aids and, therefore, to transfer the medical information and knowledge needed for patients to make a treatment decision.

Decision aids, decision boards in particular, are predominantly used within breast cancer care. Research has shown that within the treatment of cancer, doctor-patient communication is a major problem (Mackillop, Stewart, Ginsberg & Stewart, 1988; Siminoff et al, 1989). As a result of this breakdown, aids, such as decision boards, are being introduced into cancer care to encourage and improve doctor-patient communication. Furthermore, randomised tests have demonstrated that the decision boards improve breast cancer patients' knowledge about their disease and risk of recurrence, and increases their satisfaction and confidence with decision-making (Whelan et al, 2003 & 2004). Whelan et al (1995), for example, reported in a quantitative survey study that 97% of women with breast cancer who were assigned to a group, in which the clinician used a treatment decision board with information about the risks and benefits of breast irradiation following lumpectomy, felt that they were offered a treatment choice compared with 70% of women in the no decision board group. However, Charles et al (1997) stated that a limitation to the *informed decision model* is that there are time costs involved, in the process of transferring information. Moreover, it could be argued that there may be a possibility of bias, as the clinician might present decision aids and the information in a way to convince the patient to choose a treatment that the clinician prefers.

In an ideal world of doctor-patient partnership, where both clinicians and patients share the goal of a treatment decision by transferring both knowledge and preferences to one another, it could be suggested that there should be no difference between the *informed decision-making model* and the *physician as a perfect agent model*. However, in reality, the implementation of each approach is far from perfect and easy. This view is supported by existing research which argues that, while both represent two normative models of treatment decision-making, the patients' actual preferences, for the role they want to play in the decision-making process, are problematic in both models. For example, in the field of cancer care, a high number of quantitative cross sectional survey and questionnaire studies, using instruments and scale which measure patient satisfaction, participatory roles,

and informational needs, have been conducted. These studies suggest that while most patients have high preferences for information about their disease, treatment alternatives, and prognosis, they have low preferences for participation in the treatment decision-making process (Beisecker & Beisecker, 1990; Blanchard et al, 1988; Cassileth, 1980; Deber, 1994; Degner & Sloan, 1992; Ende et al, 1989; Sutherland et al, 1989). In other words, patients may want information about their medical condition and treatment options, without necessarily being responsible for making treatment decisions. There are other arguments that support that patients want to be 'active' in discussing treatment options and receiving information, but ultimately rely on their clinician when it comes to making decisions (Blanchard et al, 1988; Frosch & Kaplan, 1999; Deber, 1994; Quill, 1989; Robinson & Thomson, 2001; Strull et al, 1984). These findings are based on systematic reviews, and utilise self-administered questionnaires to measure the degree of patient participation. Subsequently, what is clear from the findings is that limiting the conceptualisation of clinician-patient treatment decision-making to any one model of decision-making, does not reflect the current realities of clinical practice. This is especially true of breast cancer care; Ong, Haes, Hoos and Lammes (1995) stated, through a systematic review of doctor-patient communication literature, that there is a need for an approach which can amalgamate the process of information exchange and the patient values, beliefs, and preferences in one model that better reflects the current cancer care practice.

In summary, several models of treatment decision-making have been developed, partially in reaction to the *paternalistic model*. A closer examination of each model reveals that none of these explicitly describes a process in which both the clinician and patient share in decision-making, no matter how much information is shared. The notion that information sharing and treatment decision-making are two separate goals, in the medical encounter, is recognised in the literature on doctor-patient communication (Ong et al, 1995). This consequently led to the introduction of the '*shared model*' for treatment decision-making. This suggests that for shared treatment decision-making to occur, there needs to be a two-way exchange, not only of information, but also of treatment preferences, by both the clinician and the patient. The next section describes the concept of medical SDM and the extent to which it is practiced in health care.

2.3.2.4 *The shared model and concept of SDM*

With the NHS cultural shift towards a patient-centred service over the years, treatment decisions should ideally result in the most desirable outcome for the patient. According to Eddy (1990), to meet this goal there is a need for ‘active’ participation and engagement by both the clinician and the patient. Policy guidelines, such as the White Paper Equity, Liberating the NHS: equality and excellence (DOH, 2010c), were established to give everyone a more integrated and equal voice concerning their care and treatment; and to allow for more patient opportunities to make choices, with shared information, and collective support structures. This guideline was enforced as a means of securing appropriate treatment decisions and better health outcomes. None of the models outlined above, explicitly describe a process in which both clinician and patients necessarily share in decision-making, no matter how much information they exchange between themselves. This introduces the third theoretical approach to medical decision-making, between clinicians and patients, which is the *shared model*. The characteristics of this model are grounded in two-way interaction and exchange of information, and involve complex trade-offs between risks and benefits. Table 2.8 describes the *shared model* of medical decision-making. The doctor and patient share all stages of the decision-making process simultaneously. Both the clinician and patient reveal their treatment preferences, and both agree on a chosen treatment plan.

Table 2.8

The shared decision model of medical decision-making

Gathering the information	Communicating the information	Understanding and applying the information
-The clinician acquires the scientific information on risks and benefits of different treatment options.	-The clinician in clinical practice communicates the scientific information to the patient, with the help of decision aids. - The patient provides the clinician information about their preferences.	-The roles in decision-making processes are defined during the task of information exchange. - The clinician and patient deliberate treatment choice together. -Both clinician and patient make the final treatment choice together. .

Wirtz, Cribb and Barber (2006) criticised the *shared model* for being nothing more than an alternative name for the *informed decision model*, or a model of the doctor-patient relationship. However, this critique misses the essence of a shared approach towards decision-making. This approach assumes that both the patient and the clinician have a legitimate investment in the treatment decision; hence, both declare treatment preferences and their rationale, while trying to build a consensus on the appropriate treatment to implement. To achieve this, Brennan (1997) suggested that a sense of trust between the patient and the clinician is required, so that the patient can be assured that the information given is credible and in their best interests. Consequently, it could be argued that there is now an established system which incorporates a combined process of patient participation and informed consent, as well as facilitating an individualised patient-centred approach.

The SDM approach, towards medical treatment decision, has been introduced into NICE medical guidelines (2004 & 2012) and termed as the preferred practice for all treatments, by all medical practitioners across hospitals and GPs. The character of SDM in clinical consultations is co-determined by patients and professionals (Thompson, 2007). Good communication is essential for SDM (Moumjid, Gafni, Brémond & Carrère, 2007). During doctor-patient communication, the acquisition of health information is shown to be important in allowing patients to construct stable beliefs about self-interest, and in helping patients to choose a course of action (Hibbard, Slovic & Jewett, 1997). However, sharing information and sharing decisions are not identical processes, as they are separate goals within the consultation and require different skills (Ong et al, 1995). While it is possible for the sharing of information to occur alone, the process of SDM cannot occur unless preceded by the sharing of information (Ong et al, 1995). Subsequently, the way information is provided by the clinician during interaction, and combined with other skills for SDM, is crucial in assisting patients to construct their preferences and make their decisions.

Elwyn and Charles (2009) explained that to achieve an SDM approach in clinical practice, the model has to encompass three stages, which fundamentally rely on both the patient and clinician playing reciprocal roles. The first stage consists of ‘*information exchange*’, whereby the patient identifies their beliefs, values, and preferences and the clinician informs the patient of their treatment/management options and explains the risks and benefits of each option. The second stage involves ‘*deliberation*’, whereby the pros

and cons of the available treatment options are discussed in light of the evidence and patient preferences. The final stage consists of '*implementation*', whereby both the patient and clinician work together to attempt to achieve a consensus, and the clinician may offer a specific recommendation which contributes to the decision-making.

SDM sits between an authoritarian approach, where clinicians make medical decisions for patients, and a consumer approach, where clinicians provide information to patients to make their own decisions. In comparison with the notion of patient participation, aspects of SDM expanded from a simple concept of patient engagement, towards advocating a more bipartisan approach. SDM has been extensively and systematically reviewed within medical decision-making literature. It has been described as a framework whereby both parties involved are required to communicate and exchange information together, about possible attributes and consequences of options. They should also share their informed preferences for treatment, in order to negotiate a mutually acceptable decision, which respects patient autonomy and is also desired, ethical, and legal (Beaver et al, 1996; Charles et al, 1997; Elwyn & Charles, 2001; Towle & Godolphin, 1999).

Unlike the *paternalistic model* and *informed decision model*, SDM recognises two experts: the clinician is an expert in defining the clinically appropriate options, including the risks and benefits of each option, based on the latest medical evidence; and the patient is an expert in their own values, preferences and concerns. However, SDM is not all about mutual agreement on a matter. There are also arguments, which support the view that it is also suitable for both parties to agree to disagree, as an acceptable outcome of SDM (Elwyn et al, 1999b). It is also important to note that SDM should not be confused with the *informed decision model* or obtaining 'informed consent' from a patient. The historical concept of informed consent can be interpreted as a legal rather than an ethical obligation of doctors, in order to preserve patient sovereignty. Obtaining information of the clinician and informed consent does not necessarily mean that patients are involved in making medical decisions; rather, the signature indicates that they have agreed to the treatment, which may, more or less, have been recommended by their clinician. However, SDM is a process which goes several steps further.

Increasingly, SDM is emphasised for preference-sensitive care. For example, Wennberg (2002) argued that SDM is particularly valuable for decisions about cancer

treatment trajectories, or care situations in which there are two or more treatment options that are medically justified. Research supports this argument by highlighting the concept of SDM as a prevailing approach for patient involvement in breast care decision-making. Hack et al (2006) illustrated this finding in a quantitative study, using the decisional role preference scale and QOL measures. Similarly, in a self-administered survey study by Bruera, Willey, Palmer and Rosales (2002), approximately 89% of women with breast cancer preferred a SDM process during their treatment. Research evaluating the benefits of SDM, through the use of systematic review, illustrate a promotion in both psychological and physical well-being (Joosten, DeFuentes-Merillas, de Weert, Sensky, van der Staak, & de Jong, 2008). Evaluation studies which explore patients' perceived involvement in care, through the use of self-report questionnaires, also demonstrated how SDM provides patients with a greater sense of control over their health care (Adams & Drake, 2006; Joosten et al, 2008). According to a systematic review on SDM and doctor-patient relationships (Charles et al, 1997), the concept of sharing medical decisions is advantageous, as it allows for better data collection on the part of the clinician, as well as the patient; and it forces the clinician to present and consider all treatment alternatives. In later research, Charles et al (1999a) revisit and add elements to their earlier conceptual framework on shared treatment decision-making, by stating that the process of sharing decisions can enhance the quality of decisions made, and increase satisfaction with medical treatment, as patients feel that they have participated in the decision-making process.

Specifically regarding breast cancer, the NICE guidelines (2007) specify that “treatment and care should take into account patients’ needs and preferences” (p.6). Therefore, patients with advanced breast cancer should have the opportunity to participate in making informed decisions about their care and treatment, in collaboration with their healthcare professional. According to the NICE guidelines (2004), due to the complexity of cancer treatment choice, breast care services must allow for substantial patient-centred care through the use of the *shared model*, embedded within its services. A relevant example of this is demonstrated within cancer treatment paths, which aim to join a range of high quality experts in breast cancer diagnosis, surgery, medication, treatment/therapy, and support services. Different health professionals are trained to work together in a single clinic, with the patient being the centre of attention, surrounded by shared information and discussions, to reach a mutual agreement. Importantly, in support of these adjustments, quantitative and mixed method research has also illustrated SDM as a preferred approach

to breast cancer treatment decision-making, and has been linked to positive patient outcomes (Moyer, 1997; Silliman et al, 1998; Street & Voigt, 1997). A number of interventions promoting SDM in breast cancer treatment have been evaluated, all showing that women who have actively been involved in SDM for their treatment, tend to be more satisfied with the care they receive and have a higher overall QOL (Street & Voigt, 1997); show treatment adherence (Sepucha, Belkora, Tripathy & Esserman, 2000); obtain higher physical and social functioning (Whelan et al, 1999); and report fewer side effects (Hack et al, 2006). Concurrently, from these findings, the Registered Nurses' Association (2006) has placed greater emphasis on motivating providers and the health care system within oncology, to increase more 'active' participatory roles for patients, and to include the routine practice of patient involvement in making informed health decisions.

2.3.2.4.1 *To what extent is there a shared approach in medical decision-making?*

A central question about the *shared model* is whether it actually describes what takes place within particular treatment decision-making settings. Several studies have explored this through examinations of certain mediating factors, such as age and educational difference. For example, previous research has found that younger and more educated patients, generally prefer more egalitarian relationships with providers, ask more questions, offer more opinions, and believe more strongly in participating in decision-making than older and less educated patients (Roter, Hall & Katz, 1988; Street, 1991).

Within doctor-patient relationship research, it has been shown that SDM is sparsely implemented and practiced in health care (Holmes-Rovner et al, 2000; Stevenson, Barry, Britten, Barber & Bradley, 2000). Clinicians can lack self-efficacy to implement SDM (Keefe, Thompson & Noel, 2002; Thistlethwaite & van der Vleuten, 2004), and can be reluctant to disclose information relevant to making uncertain choices, especially when these choices involve trade-offs among risk, disability, and death (Eraker & Politser, 1982). There are also arguments outlining why clinicians may discourage patient participation. For example, research has shown that clinicians can show unwillingness to share power between doctor and patient (Ford, Schofield & Hope, 2003). Earlier research supports this (Katz, 1984) and argued that some clinicians may feel threatened by patient empowerment. Other authors suggest that clinicians are reluctant to encourage patient

participation, because either they refuse to delegate power or control, or they are afraid to lose their identity (O'Flynn & Britten, 2006), even though they may not be openly negative about the concept of SDM (O'Flynn & Britten, 2006; Stevenson, 2003).

A primary obstacle to patient participation in decision-making is low health literacy and lack of knowledge on the subject (Coulter & Ellins, 2006). The most common complaints made by cancer patients are about poor communication and inadequate information (Jenkins, Fallowfield & Saul, 2001). Research suggests that clinicians lack the appropriate communications skills to engage patients in the medical SDM process (Auerbach, 2000; Gwyn & Elwyn, 1999; Marvel, Epstein, Flowers & Beckman, 1999). This is further supported by Charles et al (2004), who stated that clinicians lack the necessary communication skills needed to 'share' and 'involve' patients in decision-making. Subsequently, this can inhibit patients from acquiring the knowledge and understanding they need regarding treatment options, to make informed decisions (Fallowfield & Jenkins, 1999; Maquire, 1999). It can also result in patients' lack of awareness and familiarity with SDM (Cabana et al, 1999; Davis et al, 2003).

According to Thorne (1999), problems with staff communication such as their failure to provide all the information the patient needs, or the assumption that the patient is unable to understand medical information, will deter patient participation. This is supported by the earlier work of Waitzkin (1985) who operationalised a multivariate research model, to assess associations between information giving and the characteristics of doctors, patients, and the clinical situations in which they interact. From this study, Waitzkin (1985) argued that patients were more likely to be more responsive when the clinician provided efficient communication which encourages patient participation, and shows interest in the patient's questions, feelings, and beliefs. However, if the patient perceived that the clinician wished to be in charge of the consultation, did most of the talking, and made decisions for treatment, then many patients assumed the traditionally 'passive' role in the encounter. The above studies suggest that the inherently unequal power dynamic within consultations, may prevent a successful provision of information and communication about treatment options and risk (Gafni et al. 1998; Schneider 1998). This, consequently, suggests that SDM probably requires an attitudinal shift by clinicians, as well as the conventional communication skills training currently taught within medical education (Skelton, 2005). The importance of doctor-patient interaction and communication skills on SDM will be explored more thoroughly in Chapter Six.

Historically, research shows another obstacle to patient participation which is an imbalance in the patient-clinician relationship. Studies suggest that an imbalance in perceived roles is created, since the patient is the person who is regarded as sick and the clinician has the expert knowledge to address this issue (Emanuel & Emanuel, 1992; Haug & Lavin, 1981). Studies revealed that for some patients, the aspect of being faced with the life-threatening diseases and having to challenge the psychological emotions, can result in them taking a more 'passive' role (Richards et al, 1995), and leaving treatment decisions to their clinician to make (Degner & Sloan, 1992). As explained by Degner and Sloan (1992), when severely ill patients feel physically vulnerable and distressed, they appear to show a decrease in information seeking, thus allowing for a degree of paternalism by the clinician in decision-making. Research suggests that patients are more likely to be involved in decisions that do not require medical knowledge than those that require clinical expertise (Thompson, Pitts & Schwankovsky, 1993). In a study which explored barriers to patient participation in decision-making, through observations across several hospitals, Lidz et al (1983) reported that although patients want information about treatment, they generally believed that treatment decisions should be primarily left to clinicians, due to their technical expertise and commitment to the best interests of the patients.

To explain such perceived discrepancies in doctor-patient relationships, Henderson (2003) described that certain situations are referred to as '*problem solving situations*' (requiring medical expertise) and, therefore, do not present themselves well to patient participation. In contrast, most '*decision-making situations*' (involving values and preferences) require an analysis of the value (utility) of potential outcomes to the individual, which is something only the patient can determine. Further research on this notion has illustrated, that patients instinctively make the distinction between these two types of decisions, and prefer to be involved in the latter rather than the former (Thompson, Pitts & Schwankovsky, 1993). This is also supported by Deber (1996) who asserted that patients, who do not appear to want to participate, may have simply rejected a role in the '*problem-solving aspect*' and, therefore, would rather pass on elements of responsibility to their clinician. On the other hand, research also shows that some may still participate in the decision-making aspect, by sharing their values and beliefs, and believe that the '*decision-making situation*' should be shared (Frosch, & Kaplan, 1999; Robinson & Thomson, 2001; Strull et al, 1984; Waterworth & Luker, 1990).

A central question to the SDM paradigm is whether patients actually want to participate in medical decision-making and be 'active' in aspects of information seeking. Several studies have addressed this question, and results of these studies have been mixed. For example, the research predominantly reveals, through quantitative questionnaire studies, that most patients desire participation in treatment decisions (Benbassat et al 1998; Blanchard et al, 1988; Cassileth et al, 1989). A qualitative example of this is also demonstrated by Mazur and Hickam (1997), who used structured interviews to examine the extent to which patients desired SDM, when faced with the possibility of an invasive medical procedure such as surgery. The findings showed that most participants (68%) indicated a preference for SDM. However, there are also further quantitative survey studies which propose alternative arguments. These suggest that a proportion of patients do not accept the 'active' patient role, and instead prefer a 'passive' or collaborative role in making treatment decisions (Beaver et al, 1996; Deber et al, 1996; Ende et al, 1989; Lidz et al, 1983; Strull et al 1984). This has been shown to be especially true for patients who are faced with a life-threatening disease (Deber et al, 1996; Ende et al, 1989; Richards et al, 1993).

Regarding the *shared model* and cancer/breast cancer research, the findings within this area of health care also appear to be mixed. For example, a systematic review both for and against patient participation in decision-making by Guadagnoli and Ward (1998), highlighted that patient preference for an 'active' role can range from 48% for women recently diagnosed with breast cancer, to 80% for patients with cancer who had been offered an experimental treatment. Waterworth and Luker (1990), demonstrated through the use of qualitative in-depth interviews with 12 cancer patients, that patients are more concerned about doing what is right, that is, pleasing the medical professional, than participating in decisions concerning care. Yet, in a cross-sectional survey study on treatment decision-making amongst breast cancer patients, it was confirmed that 22% desired to select their own cancer treatment, 44% desired to select their treatment collaboratively with their clinician, and 34% desired to delegate this decision to their clinician (Degner et al, 1997). Within this study, Degner et al (1997) also drew attention to the importance of assessing both the preferred and actual levels of patient participation, as only 42% of women had achieved their desired level of participation in making decisions about their breast surgical treatment. A similar finding was also demonstrated by Keating, Guadagnoli, Landrum, Borbas and Weeks (2002), as only 49% of women reported an

actual role that matched the desired role they had reported. As a result, by the early 1990s, more established arguments grew for the importance of matching patients' preferred level for participation with actual level of participation, as an important outcome for decision researchers (Beaver et al, 1996; Bilodeau & Degner, 1996; Degner & Sloan, 1992).

Schain (1990) proposed that ideal clinician communication with breast cancer patients, should be tailored to the patients' needs or coping styles, to reduce patient distress; and clinicians need to practice achieving a balance between under-informing and overloading the patient. Differentiating strategies to foster patient involvement in treatment decisions have been identified for clinicians' use. For example, Pierce's (1993) study, which described the decision-making process of women facing early stage breast cancer, classified three types of decision makers: 'delayers', who consider at least two options, but their deliberation is perfunctory and they immediately prefer one option; 'deferrers', who accept their doctor's recommendation; and 'deliberators', who weigh the pros and cons of each treatment, and do not make a choice until they have considered the relevant information and have found an alternative that satisfies them. These findings were derived from a qualitative analysis on a convenience sample of 48 women, who completed an open-ended interview while they were making a decision. With these classifications, it is proposed that clinicians should modify their style to accommodate the different types of patients. For example, a paternalistic style with a patient who is a 'deferrer'; a more informative style with a 'delayer' patient; and a shared approach with a patient who is classified as a 'deliberator'. Although such strategy is useful in assessing initial preferences, a limitation to such an approach could be that it assumes that some patients are incapable of participating and, therefore, little is done to encourage those who may be initially reluctant to participate.

The NICE guidelines (2006), advises that clinicians should regularly assess the quality of doctor-patient communication skills, to ensure information quantity and levels of involvement are personalised to suit individuals' needs and preferences. This is supported by Shaller (2007), who suggested that clinicians need to create an atmosphere that is conducive to patients' desired level of participation, which includes making the patients feel that their contributions, preferences, and goals are valued. This argument is further supported by the NICE guidelines (2009), which emphasise the need to achieve higher quality decisions, by balancing patient autonomy with clinician expertise; encouraging open communication and information between patients and their oncology team; and

sharing the responsibility for these decisions. According to Politi, Dizon, Frosch, Kuzemchak and Stigglebout (2013), by endeavouring to engage all patients, according to their desired needs, this can overcome some of the known barriers to SDM (Gravel et al, 2006).

In conclusion, given the findings from the above studies, there are a number of unresolved questions related to the implementation of SDM. It is not clear whether the SDM paradigm is, in fact, feasible for all patients. As discussed above, the evidence regarding breast cancer patients' interest in decision-making is somewhat mixed. While the evidence suggests that many prefer SDM and control over treatment decisions, it remains unclear why some women with breast cancer prefer clinicians to make decisions for them. Moreover, there is currently little known knowledge about patients' lived experience of SDM during treatment for breast cancer.

Empirically measuring if and how patients deliberate over treatment choices, and the process they use to arrive at a decision, is an area within the SDM literature which is heavily dominated by quantitative methods. Observation techniques are frequently used to measure doctor-patient relationships. However, observations have limitations when trying to understand the subjective experiences of patients. A key method, as outlined previously, is to measure patient preferences for participation in treatment decision-making through the use of quantitative self-report questionnaires, Likert scales, and surveys. Such quantitative measures also have limitations, as they simplify and structure the measurement process to such a degree, that little information is gleaned about the dynamics of SDM, encountered experiences, or the interactional processes involved. To answer some of the mixed findings on SDM, particularly within cancer care and breast cancer, it is necessary to undertake more in-depth exploration of these complex processes: how patients think about decision-making and SDM; why patients hold different perspectives and preferences for treatment involvement; and to explore the meanings patients ascribe to views and experiences.

By taking the view that SDM is a subjective interaction between two people, understanding such complex processes is therefore beyond quantitative methods. In order to access patient experience, there is a need to adopt a research method that originates from a person centred paradigm. Therefore, this research moves towards a more critical health psychology perspective, which challenges many mainstream health psychologists'

assumptions and practices that take a 'scientific' approach. In contrast, a critical health approach argues that people are far more complex than just fixed objects that can be studied 'scientifically'. It seeks understanding and insight into human behaviour by means of a more social constructionist position, which assumes that knowledge is variable and a product of the social and cultural context, within which it is located. Subsequently, by taking such a critical health approach, the thesis introduces interests in qualitative research as a method of enquiry to explore breast cancer patients' experiences of SDM; and introduces the theoretical frameworks of phenomenology and symbolic interactionism, which will be discussed thoroughly in the next chapter.

2.3.2.4.2 A qualitative approach towards exploring SDM and breast cancer

It is important to review the existing research to explore the extent to which medical decision-making for breast cancer has been researched qualitatively. The literature review in this chapter has demonstrated that health-related decision-making, amongst women with breast cancer, is an area of research which is predominantly explored by means of quantitative measure, such as surveys and questionnaires. As outlined in this chapter, much of this research devotes attention to interpreting breast cancer patients' attitudes and their preferences towards decision-making, in relation to doctor-patient communication, impact of illness on QOL, and levels of patient participatory roles.

However, research also reveals some evidence of qualitative methods used to explore medical decisions for breast cancer. The qualitative method of inquiry employed in these studies focuses on fully understanding patients' experiences of the decision process, and their preferences for participation in treatment decisions. This is achieved by methods which aim to explore and understand how they interpret their individual worlds, by producing rich and in depth information, and opening clarity and transparency to the dimensions of reality, to both the patient and the researcher. A key study illustrating this is by Hack, Degner and Dyck (1994), who examined relationships between cancer patients' preference for involvement in making treatment decisions, and preferences for information about diagnosis, treatment, side-effects, and prognosis. Semi-structured interviews were conducted with 35 women with stage one and two breast cancer, to provide patients with an opportunity to elaborate on their role preferences and health care experiences. Results

showed that patients who desired an 'active' role in treatment decision-making also desired detailed information and explanations of their diagnosis, treatment alternatives, and treatment procedures. In a similar study, Grunfield et al (2006) used semi-structured interviews on 102 women with advanced breast cancer, who were offered chemotherapy, to examine their perceptions of the information they had received, and their involvement in the decision-making process. Grunfield et al (2006) showed that compassionate and good doctor communication skills about prognosis and likelihood of benefit from treatment, helped to enable patients to make fully informed decisions about palliative chemotherapy.

Yet, qualitative studies have also shown that patient participation in breast cancer treatment decision-making is a more complex issue, than simply giving patients information and choices. This was shown in a study, which aimed to assess how women treated for early stage breast cancer perceived the treatment selection process, using semi-structured interviews and thematically analysing the transcripts (Kenny, Quine, Shiell & Cameron, 1999). Although these qualitative studies shed valuable light on medical decision-making from breast cancer patients' perspectives they, however, are aimed at examining issues which are intrinsic to breast cancer and decision-making, largely at a clinical level. Therefore, it is implied that they only focus on evaluating and assessing (Moyer, 1997; Silliman et al, 1998; Street & Voigt, 1997), rather than describing the meanings and the lived experiences of treatment decision-making.

While every effort has been made by research to qualitatively explore breast cancer patients' accounts of decision-making, the concept of SDM is lacking from a qualitative stand point in the critical health psychology literature. There are some examples of qualitative studies carried out to distinguish the processes of SDM and to evaluate SDM with patients and clinicians, which will be explored in thorough detail in Chapter Four (Davis et al, 2003; Edwards & Glyn, 2006; Stevenson et al, 2000). However, the health psychology literature fails to demonstrate any qualitative research conducted, which is concerned with breast cancer patients' meanings and experiences of SDM.

Currently, the majority of research on SDM has been systematically reviewed amongst patients with wide-ranging chronic illnesses (Charles et al, 1997; Coulter, Entwistle, & Gilbert, 1999; Gwyn & Elwyn, 1999), and has been evaluated and defined amongst breast cancer patients by means of quantitative measures, such as patient questionnaires, self-report surveys, and health scales. Much of these evaluative studies are

far from being able to provide an in-depth understanding of the concept and process of SDM within breast cancer care, from the patients' perspectives, experiences, and actions. An understanding of SDM amongst women with breast cancer is yet to be explored qualitatively and comprehensively. Within the existing breast cancer and SDM literature, there are no studies which have adopted an interpretative approach to exploring cancer patients' experiences of SDM. By employing a phenomenological and symbolic interactionist approach to qualitatively exploring SDM, this would subsequently allow for a more in depth and thorough understanding of concept, from the service users' personal encounters, views, and interactions. It adds to the existing decision-making health literature and fills the gap on SDM research, by providing a qualitative study which explores how SDM is characterised; and examines patients' experiences and meanings of SDM.

2.4 Conclusion

This chapter has taken a broad approach to understanding medical decision-making. It initially reviews several cognitive and psychological theories of decision-making, and then explores these theories in relation to decision-making in the context of health care. Reviews of normative and descriptive theories of decision-making outlined several useful models, which illustrate how decisions are made by individuals, and how they can be made better. Within the health psychology literature, these models of decision-making have also been shown to be applicable and useful in explaining and evaluating medical decision-making by patients and clinicians.

In reviewing health-related decision-making, several approaches to treatment decision-making were highlighted. Importantly, these models illustrate the overall progression in models of medical decision-making, from a paternalistic approach to a method which integrates the patient within the decision-making task. With this move towards patient-centred care, the concept of the *shared model* and SDM was introduced and discussed.

However, the available evidence suggests that participation can mean different things to different people. Although these models are useful in understanding how people make treatment decisions, in the real world of everyday practice, it could also be argued that many clinical decision-making interactions reflect a form of hybrid model. As this

chapter illustrates, it is not always possible to categorise patients into ‘passive’ or ‘active’ participatory types. A review of the extent to which SDM occurs, demonstrated some mixed findings and several mediating factors. It was suggested that given the dynamic, complex, and personal nature of the doctor-patient relationships, the type of decision-making model adopted at the beginning of the consultation may not operate accordingly to the patients’ ideal form. For example, a clinician who favours a *shared model* and takes an SDM approach during consultations, may find, through the course of interaction and information exchange, that the patient has gained enough confidence and gathered enough information to make the decision on his or her own. At this point, the process might shift from a *shared model* to an *informed decision-making model*, as a result of the learning that has occurred in the interaction itself. As a result, research suggests that medical decision-making needs to be modified to reflect the needs of patients. Furthermore, the literature review highlighted the lack of qualitative enquiry and subjective experience concerning SDM for breast cancer patients, and in addition to the issues stated above, cemented the rationale for this thesis.

As outlined in Chapter One, there is no research which has explored SDM through the patients’ experiences, as the health psychology literature remains largely medical, and SDM has been studied largely through examination of patient health outcomes. This, therefore, instigates whether a qualitative enquiry, through exploring patient perspectives and interactions, has more significance in assisting our understanding of SDM. To truly understand the actual processes involved in SDM for the treatment breast cancer, a more comprehensive exploration of the lived experience of the patient is required. To find this undocumented experience and method of enquiry, Chapter Three discusses the theoretical frameworks and research methodology of this thesis.

Chapter Three

Exploring patient experiences: theoretical and methodological framework

Chapter 3

Exploring patient experiences: theoretical and methodological framework

3.1 Introduction

The previous chapters outlined the research questions which this thesis aims to address. They also reviewed the literature on models of decision-making, paying particular attention to decision-making in the context of health care. Chapter One outlined the thesis aim, which is to explore breast cancer patients' experience of SDM, through three distinct studies. The first being a semi-structured interview study, which aims to capture the patients' experience of SDM from their perspectives and encounters. The second study is an online forum study, which explores the patients' experience of SDM from analysis of peer interactions within breast cancer forums. The final study is an audio-recorded study, which seeks and interprets how patients might experience SDM from analysis of the conversations which take place between patients and clinicians during a medical consultation.

To understand why SDM needs to be explored qualitatively through patient experiences, and to understand how an insight into patient experience can be obtained, it is important to outline the chosen methodology and theoretical framework of the thesis as a whole. In this chapter, phenomenology and symbolic interactionism as theoretical frameworks, and qualitative research, are discussed in relation to health psychology and the research questions.

3.2 Theoretical approach

What is decision-making? Although this may sound like a simple question, especially since most people can apparently provide everyday examples of decision-making, the answer, however, is by no means clear. According to Owens (2001) the topics that are studied by health psychologists, such as health behaviours (e.g. decision-making), experience of disease and suffering, and the meaning of illness, "must be open to question and critical examination (p.263). As biomedicine and health psychology are ideological and

ethnocentric in nature (Stainton Rogers, 2002), critical perspectives within health psychology have gathered momentum in the past few years.

The discipline of critical health psychology “aims to analyse how power, economics and macro-social processes influence and/or structure health, health care, health psychology, and society at large” (Mark, 2002a, p. 15). The approach provides diverse and conflicting views about the direction and shape of the field of health and illness (Mark, 2002b). The thesis is situated in the realm of critical health psychology, in an attempt to develop new psychological ways of conceptualising medical SDM for the treatment of breast cancer. It is also in line with the four inter-related areas of the critical health approach, in that it has: 1) *theory* that is typically reflexive, relational, moral and experiential; 2) a focus on *contexts* that take into account social justice and an appreciation of the meanings of culture as transitional; 3) *research methods* that are critical, qualitative and ethical; and 4) *practice* that is enabling, community-based and empowering for participants (Murray, 2004). Critical health psychology research focuses on experience and meaning, and giving a voice to the ill. It also asks questions that bring to the fore issues of power-relations. Such basic principles of critical health psychology are related to the underlying aims of this thesis, which focus on exploring patients’ experiences and understandings on SDM in the medical context of breast cancer. Furthermore critical health psychologists focus on the use of various qualitative research methods, based on social constructionist epistemology, and interpretivist perspectives (e.g. phenomenology and symbolic interactionism) and methodologies (e.g. phenomenological research, discourse/conversation analysis) (Hepworth, 2006). These principles provide greater insight into the experience of health and illness (Chamberlain, Stevenson, Lyons, 1997; Murray & Chamberlain, 1999), which therefore further situates the topic of this thesis and the research questions proposed within the domain of critical health psychology.

The thesis emphasises the underlying philosophical assumptions and methodological approaches of phenomenology and symbolic interactionism, both as useful theoretical frameworks for gaining a deeper understanding surrounding the experience and meaning of SDM, amongst women undergoing treatment for breast cancer. These two methodological frameworks will now be explored more thoroughly.

3.2.1 Phenomenology

Since Strauss and Glaser's (1975) pioneering work on the use of grounded theory to understand the meaning and experience of chronic illness, from both sufferers and their families' own perspectives, interest in studying the meanings and experience of chronic illness has grown (Anderson & Bury 1988; Bury 1991; Williams, 2000). The past decade has brought an increasing focus on understanding how patients experience illness and health care. Arguably, this is due to an increasing growth in the number of people who expect to be involved in their care, and want to be sure that the received services are of the highest quality and safety (Holme, 2009). Patients offer a complementary perspective to that of clinicians, providing unique information and insights into both the humanity of care and the effectiveness of health care. Subsequently, it is suggested that the experiences of patients are a key component of the quality of healthcare, and as a result it is suggested that research should increasingly focus on understanding and improving patient experience (National Clinical Guideline Centre- NCGC, 2012).

Phenomenology, is a field of inquiry which argues that human beings are not passive perceivers of an objective reality, but rather that they come to interpret and understand their world by actively engaging with it (Sokolowski, 2000). The phenomenological perspective assumes that human action depends upon the meanings that people ascribe to their situations and actions. It has been suggested that such a perspective involves the use of detailed description and close analysis of individuals lived experiences, to understand how meaning is created through embodied perception (Sokolowski, 2000). Through close examination of individuals' experiences, phenomenological analysts seek to capture the meaning and common features, or essences, of an experience or event. As a theoretical framework, it is rooted within the principle that the most basic human 'truths', are only accessible through the subjective view of the individual experiencing reality (Merleau-Ponty, 2012). This notion is consistent with a phenomenological life-world approach. According to Schutz (1966), this approach is defined as the world in which we as humans among other fellow humans, experience culture and society, take a stand regarding objects, are influenced by them, and act on them. Drew (1989) argued that the life-world consists of "social, practical, experiential, and taken for granted dimensions" (p.6). Howitt (2010) states that taking a life-world approach, involves a systematic inquiry and understanding of conscious experience from the person experiencing it. Phenomenology is, therefore, argued to be a critical reflection on conscious experience,

rather than subconscious motivation, and is designed to uncover the essential invariant features of that experience (Jopling, 1996).

Researchers suggest that a person's experience is seen as unfixed and enriched with meaning, which only emerges when consciousness engages with it (Crotty, 1998; Raphael, 2000). As the aim of this thesis, as a whole, is to explore patient experience of SDM from the patient's perspective, a phenomenological perspective is employed for the purpose of the first study. This is a semi-structured interview study aimed at exploring patients' encounters and understandings of SDM from their perspectives. This will allow for greater understanding about the concept of SDM, as well as what it means to patients and how it is experienced. In addition, by examining how SDM is perceived, from the point of view of patients having experienced it, this allows for a greater insight into the presence of SDM, and to explore how factors can influence (hinder or facilitate) patient experience of SDM. In order to apply this phenomenological approach to the first study of this thesis, it is important to determine which phenomenological framework is most appropriate.

The two approaches that guide phenomenological investigations are descriptive phenomenology (Husserlian, 1970) and interpretive phenomenology (Heideggerian, 1962). In both the interpretive and descriptive methods, the aim is to capture the descriptions of the lived experiences, as described by the participants. Kleiman (2004) suggested that in the interpretive method, the researcher uses prior knowledge and insights to interpret hidden meanings, with the goal of producing a vivid textual representation of the phenomenon described. This is achieved through interpretative phenomenological analysis (IPA), which is tied to a Heideggerian phenomenological epistemology (Smith, Jarman, & Osborn, 1999; Smith & Osborn, 2003), and is theoretically rooted in critical realism and contextualism (Larkin, Watts & Clifton, 2006). IPA is phenomenological in that it seeks an insider perspective on the lived experiences of individuals (Holloway & Todres, 2003), and interpretative in that it acknowledges the researcher's personal beliefs and standpoint and embraces the view that understanding requires interpretation (McLeod, 2001). In contrast, in descriptive phenomenology, the researcher analyses the descriptions given by participants and divides them into meaning-laden statements, which are essential to the phenomenon being studied. For the purpose of this thesis, a descriptive phenomenological approach is regarded as appropriate for study one and two. By employing a descriptive phenomenological approach, this would allow for deeper exploration of phenomena, at the descriptive semantic level, setting aside any researcher preconceptions or subjectivity.

Therefore, the lived experience itself, as described by patients, is used to provide description of their experiences of SDM.

Descriptive phenomenology is achievable through qualitative data collection, and analysis which focuses on scrutinising the text for ‘meaning units’. These are then synthesised, to provide a general description of the whole central aspect of patient experience of SDM. It is important to note that there are numerous methodological approaches within descriptive phenomenology. The steps consistently outlined as essential in the descriptive phenomenology method of inquiry include: bracketing, analysing, intuiting, and describing (Colaizzi, 1978; Giorgi, 1997). Figure 3.1 illustrates the steps within the process of descriptive phenomenological data analysis, created by Colaizzi (1978).

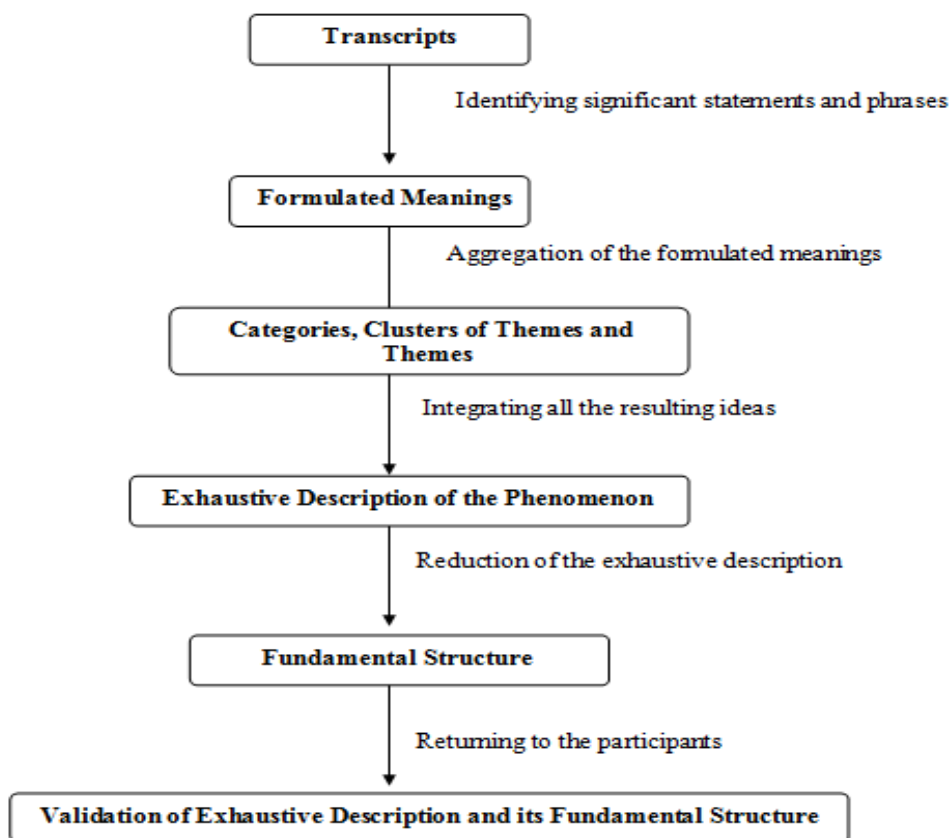


Figure 3.1 A summary of Colaizzi's (1978) strategy for the process of descriptive phenomenological data analysis. Source: Shosha (2012), pg 34

According to Shosha (2012), the accurate application of Colaizzi's process of descriptive phenomenology provides an exhaustive description about human experience, as it includes understanding the data and identifying significant statements, which in turn are converted into formulated meanings. This strategy will be employed within the data analysis of study one and two by means of a thematic analysis (TA). Similar to IPA, TA is characterised by theories such as critical realism and can be underpinned by phenomenology, as its analytical procedures acknowledge the ways individuals make meaning of their experience, and, in turn, the ways the broader social context impinges on those meanings (Willig, 1999). This makes it a useful method of analysis for this thesis, in exploring the how women with breast cancer experience SDM. However, unlike IPA, the hallmark of TA is its theoretical freedom and flexibility, as it can be essentially independent of theory and epistemology, and can be applied across a range of theoretical and epistemological approaches. This makes it a suited analytical method for study one and two, as a phenomenologically-informed TA can be applied to Colaizzi's process of descriptive phenomenology, which also fits both studies epistemological approach of inductive-realism. TA can also be used to provide rich and detailed analysis from a range of qualitative data (e.g. focus groups, diaries, qualitative surveys, secondary sources, and story completion tasks), other than qualitative interviews, which is how IPA ideally collects data (Smith, Flowers & Larkin, 2009), and, therefore, makes it applicable to the online forum data in study two. Moreover, as both studies one and two involve working with larger samples, which do not require IPA's ideographic focus, and focus on the patterning of meaning across participants and the data-set, this, therefore, further supports the use of TA.

The thesis as a whole also deals with exploring SDM through conversations, which requires another theoretical perspective. The second study in this thesis focuses on exploring SDM through the analysis of interactions, between peers, within online breast cancer forums. The third study explores SDM through the conversations that take place between patient and clinician, during medical consultations. Subsequently, this introduces symbolic interactionism as the second theoretical framework deemed appropriate for this thesis.

3.2.2 Symbolic interactionism

The second theoretical framework applicable to this project is symbolic interactionism. Symbolic interactionism is a major framework of sociological theory. It was formulated by Blumer (1969) and its perspective relies on the symbolic meanings that people develop and rely upon in the process of social interaction. For symbolic interactionists, 'meaning' is one of the major elements in understanding human behaviour, interactions and social processes within particular contexts. In this regard, Osborne (1994) stated that symbolic interactionists have much in common with phenomenologists, in their emphasis on the individual's lived experience, the inner world of human behaviour, the notion of meaning perceived by the participant, and understanding a situation from the participant's point of view.

The symbolic interactionist theory consists of three core principles: 'meaning', which states that humans act toward people and situations based upon the meanings they ascribe to those people or situations; 'language', which allows humans to negotiate meaning through symbols during speech with others; and 'thought', which modifies each individual's interpretation of symbols (Griffin, 1997). According to Griffin (1997), these core principles lead to conclusions about the creation of a person's self and socialisation into a larger community. For example, social interactionists state that people behave on the basis of what they believe and not just on what is objectively true. Therefore, society is thought to be socially constructed through human interpretation. People interpret one another's behaviour, and it is these interpretations that form social bonds. Regarding the notion of 'self', social interactionists assert that the person and the world cannot be understood in isolation, because the 'self' is being continually developed through interaction with other human beings and participation in society (Cooley, 1964; Mead, 1933). This process is often referred to as the 'looking-glass self', which means that individuals have the capacity to reflect upon oneself through the process of taking the role of the other, and imagining how they would look to another person (Cooley, 1964). As a result of such skill, it has subsequently been argued that the looking-glass self enables human beings to develop the sense of 'social self' (Morris, 1977).

Symbolic interactionism can be considered as a second theoretical approach in this thesis, suited for studying how breast cancer patients might experience SDM. According to Boden (1990) the ordinary or important talk of people in their everyday world, is the very

sinew of social interaction. Boden (1990) further argues that one way of characterising talk is as ‘language-in-action’, and it is here, as thought becomes action through language, that conversation analysis meets symbolic interaction. Symbolic interactionists have long been concerned with language, thought, meaning, shared symbols, and social acts. These concepts hold relevance to the research question, for example, as this facilitates exploration the subjective experience of SDM constructed through patient interaction, and how language can be interpreted to give meaning to patients’ personal encounters of SDM.

The methodological position for symbolic interactionism proposes that to understand the meaning and experience of SDM, research needs to look into the interpretations and meanings that patients ascribe to their actions, interactions, and situations. This subsequently makes language a central medium for transmitting meaning to such interactions and the object of experience. The meaning of a word is taken to be what it references, corresponds with, or stands for in the real world. This is based on the premise that the essential task of language is to convey information and describe ‘reality’. Therefore, research must be able to see things from a patient’s point of view, and in their natural context. This is of particular relevance to breast cancer research, as the life threatening chronic illness presents and reflects a deeply personal existential crisis (Frank, 1995). Therefore, an approach which offers an insight into the suffering as it is lived during the cancer journey, and narrates the role and range of cancer beliefs and attitudes following life threatening diagnosis, is of importance (Frank, 2000). Subsequently, through exploring the symbolic meanings attached to personal experiences of breast cancer, this helps to construct the realities of breast cancer and decision-making behaviour, through the strategic health-seeking choices and beliefs patients make during social interaction.

According to Charles et al (1999a) decision-making, and SDM in particular, involves some form of partnership and interaction between the patient and significant others (i.e. medical professionals, family, support group member). Therefore, the study of social interactions, and the meanings ascribed to those interactions, becomes important to this thesis. It allows for greater understanding about the concept of SDM, how it is encountered, and what it means to patients. In addition, by examining of how SDM is verbalised or exchanged, this allows for a greater insight into the presence of SDM, to explore how patient experience of SDM can be influenced (hindered or facilitated). Consequently, for the purpose of this thesis, a symbolic interactionist approach is used in

two separate studies: in study two, to explore the social interactions amongst breast cancer patients within online forums; and in study three, to examine interactions between the patient and clinician, during breast cancer consultations. This will produce a deeper understanding of the relationship between breast cancer care, patient experience, and SDM.

In conclusion, as the aim of the thesis is to explore SDM through patients' lived experiences, i.e. their perspectives and interactions, for the purpose of this thesis, symbolic interactionism and phenomenology will serve as the theoretical frameworks to examine breast cancer patients' experience of SDM. The relevance of these two approaches will now be discussed in more detail in relation to the discipline of health psychology, research in the field of cancer, and the existing research on SDM.

3.2.3 The relevance of phenomenology and symbolic interactionism to health psychology

Phenomenology and symbolic interactionism, both as philosophical and methodological approaches, have been used in organisational and consumer research in order to develop an understanding of complex issues that may not be immediately explicit. It has been suggested that both of the theoretical frameworks have particular relevance for health psychology (Smith, Jarman & Osborn, 1999). Health psychology assumes a connection between physical condition, cognition, and verbal response. As research moves away from the biomedical model of disease, where observations of biological processes are seen as predictable illness experiences, there is, therefore, increasing recognition of understanding patients' perceptions and interpretation of their bodily experiences, and the constructed nature of illness (Leventhal, Nerenz & Steele, 1984).

Schutz (1966) argues that chronically ill people experience their constructions ('beliefs') as reality, and their constructions reflect their understandings of their experiences as well as the diverse situations in which they have them. Some patients struggle to make their constructions plausible or negotiable. Others may use their constructions to challenge or contradict medical professionals. What interpretivist approaches, like phenomenology and symbolic interactionism, do is subsequently provide an alternative understanding of patients' beliefs and actions than those readily available in clinical settings. According to Beck (1994), through interacting with patients and focusing on people's interpretations of the meaning of the phenomena they encounter, a deeper

understanding of their perceptions, experiences, and needs is developed. As a result, medical professionals and health care establishments may use these understandings to improve medical communications and to act on problems defined by patients.

There is a significant amount of work in health psychology, which use phenomenology or symbolic interactionism to understand and explore chronic illness (Åsbring & Närvänen, 2002; Fox & Chesla, 2008; Karp, 1996; Ohman, Soderberg & Lundman, 2003; Woodgate, 1998). Studies adopting a phenomenological framework acquire a common goal, which is to understand the complex world of lived experience and the meaning of chronic illness, from the point of view of patients living it. Understanding of the phenomenon is gained through patients' accounts and interpretations of their experiences or actions. Such a phenomenological method of enquiry has been predominantly used to explore topics, such as the impact of chronic illness on QOL (Holmes, Coyle, & Thomson, 1997; Michael, 1996), and health care relationships during chronic illness (Fox & Chesla, 2008; Thorne & Robinson, 1988). Alternatively, studies employing a symbolic interactionist approach are concerned with examining the interaction between the different role players in health and illness. The focus is on how illness and the subjective experience of being sick are constructed through the doctor-patient exchange. The argument here is that health and illness are *social constructions* (Lorber & Moore, 2002). This means that various physical and mental conditions have little or no objective reality, but instead are considered healthy or ill conditions, only if they are defined as such by a society and its members. Clinicians 'manage the situation' to display their authority and medical knowledge. Subsequently, the symbolic interactionist approach informs that health and illness can have a subjective as well as an objective reality. This approach is predominantly present within the nursing and women's health literature to explore patient-nurse interactions (Benzies & Allen, 2000; Shattell, 1997). It is also used to understand topics about stigma attached to illness (Åsbring & Närvänen, 2002; Stevens & Hall, 2007), and the role of illness on body and identity (Charmaz, 1983 & 1995; Thoits, 2013; Waskul & Vannini, 2006).

Consequently, both phenomenology and symbolic interactionism allows research, within the health psychology field, to explore subjective experiences, as a participant's account will provide an entrée to that perceptual process. For both theoretical frameworks, emphasis is on interpretivism and on inductive logic (also known as 'bottom-up' research),

as they seek participants' opinions, subjective accounts, and interpretations to guide the research to understand how illness affects the lived experiences. According to Raimundas and Darulis (2007) in order to provide meaningful evidence-based health research, attention needs to be given to patients' lived experiences; patients' understanding of health-related issues and situations; and the social interactions within which patients gain meaning and insight about their situation and illness.

3.2.3.1 The relevance of phenomenology and symbolic interactionism to cancer research

With specific attention to cancer research within the field of health psychology, phenomenology and symbolic interactionism have been widely used approaches to explore the lived experience of cancer for patients. Topics on the screening, diagnosis, treatment, and survival of cancer have been explored phenomenologically (Lyons, Jacobson, Prescott & Oswalt, 2002; Potter, 2004; Pascal 2010; Phillips & Cohen, 2011). The method used within these phenomenological enquiries consisted of qualitative semi-structured interviews with cancer patients, to acquire an insight into patients' meanings and encounters of their illness. In relation to breast cancer, phenomenology has also been applied to elicit the experience of breast cancer (Cohen, Kahn & Steeves, 1998; Coward, 1990; Luoma & Hakamies-Blomqvist, 2004; Moch, 1990); the meaning of breast cancer (Allen, 2002); breast cancer survival (Cater, 1993; Thibodeau & MacRae, 1997); and doctor-patient working relations (McWilliam, Brown & Stewart, 2000).

More relevantly, phenomenology has also been applied to research aimed at understanding the phenomenon of making decisions during the experience of breast cancer. For example, in a study by Hack et al (1994), semi-structured interviews were conducted with 35 breast cancer patients to examine their preferences for decision-making, based upon their breast care experiences and meanings ascribed to the concept of patient-involvement. In another similar, recent study, in-depth interviews were conducted with 18 breast cancer patients who had completed treatment, to phenomenologically provide an understanding of the broad range of decisions with which women may be faced, and present an interpretation of what the experience of making decisions is like for women diagnosed with breast cancer (Halkett, Arbon, Scutter & Borg, 2007). Phenomenology within both of these studies played a useful role in advancing health researchers and professionals understanding of the decision-making process, from the patients'

perspectives. This in turn enabled medical professionals to improve their therapeutic relationships with patients, and further assisted women as they worked through their experience of breast cancer.

Similarly, research exploring patient experiences of cancer has also been carried out with a symbolic interactionist approach. For example, topics such as the impact of cancer on the self (Fife & Erc, 2000; McClement, 2005; Wilson & Luker, 2006), and relationships between the patient and medical professionals, families members, and group therapy participants (Cline et al, 2006; Rustøen & Hanestad, 1998) have been explored from a symbolic interactionism theoretical framework. These focused on studying patient perceptions of social interaction, and exploring language to access cancer patients' experience and understanding of their illness. Methods used in these studies tended to consist of qualitative recorded observations, conversation analysis (CA), and semi-structured interviews. With specific attention to breast cancer, a symbolic interactionist approach has also been applied to elicit meaning and experience in the context of breast cancer (Chalmer & Thomson, 1996; Ching, Martinson & Wong, 2009; Collie & Long, 2005; Degner, Hack, O'Neil & Kristjanson, 2003; Halstead & Hull, 2001; Suh, 2008; Taleghani, Yekta, Nasrabadi & Käppeli, 2008; Zebrack, 2000), and to explore the lived experience of breast cancer treatments and side-effects (Collins, Nash, Round & Newman, 2004; Halkett, Kristjanson & Lobb, 2008).

A study by Balneaves, Truant, Kelly, Verhoef and Davison (2007), is more relevant to decision-making and breast cancer research, and contained a theoretical assumption of symbolic interactionism, to explore the social and personal processes that breast cancer patients engage in when making treatment decisions. The method of in-depth semi-structured interviews was conducted to explore how decisions are made and the challenges experienced by patients. The role of symbolic interactionism in this study was to access the patients meaning of 'treatment choice' and 'patient involvement', and their interpretations of decision-making situations during their cancer journey. Symbolic interactionism within this study played a useful role in providing a conceptual framework for enhancing future decision support interventions and strategies, needed to ensure breast cancer patients make informed decisions.

In conclusion, the health psychology literature, as outlined above, indicates the growth of interpretative approaches in informing knowledge on diverse subjects, such as

cancer, and breast cancer in particular, within the more general field of health psychology. Subsequently, this promotes attention to an area of health research, where the priority is to understand the patients' subjective experience of health and illness; and the patients' meanings and interpretations of these experiences, from their unique perspectives and interactions with others and the environment. Due to medical treatment being a science, concerned with human responses to actual and potential health problems, medical professionals, therefore, must acquire specialist knowledge which reflects the lived and contextual realities, and the concerns of the patients (Meleis, 1996). Meleis (1996) further stated that it is important for medical scholars to develop knowledge that is culturally relevant, and respectful of the social realities of those living within the situation. Symbolic interactionism and phenomenology, therefore, can play an important role in allowing medical researchers to achieve the specialist knowledge required.

3.2.3.2 Has SDM been previously explored through a phenomenological or symbolic interactionist approach?

The nursing and medical literature reveals little research on SDM within these philosophical approaches. What has been predominantly written about SDM tends to reinforce the biomedical or bio-psychological view of health and illness, which focuses on physical processes that affect and improve health. This, therefore, loses sight of the concept of SDM as a whole process, as the ways in which patients experience illness and SDM, based on environmental and societal factors, are not accounted for. Instead, as outlined in Chapter Two, research on SDM and breast cancer in particular aims to evaluate the process of SDM on improving patient physical and psychological health outcomes. These health studies are frequently conducted through a positivist theoretical framework, with a deductive approach which employs quantitative research methods. These studies evaluate the bio-medical effectiveness of the process of SDM, through the use of surveys and questionnaires, to measure improved patient health (Moyer, 1997; Silliman et al, 1998; Street & Voigt, 1997); higher physical functioning and emotional well-being (Greenfield et al, 1985; Kaplan et al, 1989; Whelan et al, 1999); treatment adherence (Sepucha et al, 2000); and reduced side-effects (Hack et al, 2006).

As a result, there is limited research on SDM which takes an interpretivist approach. Arguably, to be able to thoroughly explore the process and experience of SDM

for cancer patients', a need exists to study the phenomenon from the perspective and interaction of the patient. This thesis subsequently seeks to fill the gap in the literature, by employing theoretical frameworks, based on the interpretivist approaches of phenomenology and symbolic interactionism, to exploring the experience of SDM from the patients' perspective, interaction with peers, and communication with consultations. Its aim is to uncover the nature of SDM, experienced by patients, through listening to the accounts of women with breast cancer, exploring their lived experiences in their conversations with other breast cancer patients, and assessing the interactions which take place for decision-making between patient and clinician.

3.3 Qualitative methods

As with all research endeavours, choosing the method that is best suited to the line of inquiry is vital in obtaining the desired results. A judicious choice of method guides the research toward the intended aims, and helps to ensure that its products are useful and well received. For many social scientists, the choice of a particular research method is also inextricably linked to a particular theoretical perspective. It is important for research to discuss methods in relation to philosophical foundations. For the purpose of this thesis, both of the outlined theoretical frameworks above will now be examined and rationalised in relation to qualitative research.

Qualitative research methods enable the researcher to delve into questions of meaning, examine practices and processes, identify barriers and facilitators to change, and discover the reasons for the success or failure of interventions. Denzin and Lincoln (1994) broadly define qualitative research:

“Qualitative research is multi-method in focus, involving an interpretive, naturalistic approach to its subject matter. This means that qualitative researchers study things in their natural settings, attempting to make sense of, or interpret, phenomena in terms of the meanings people bring to them. Qualitative research involves the studied use and collection of a variety of empirical materials- case study, personal experience, introspective, life story, interview, observational, historical, interactional, and visual texts- that describe routine and problematic moments and meanings in individuals’

lives. Accordingly, qualitative research deploys wide range of interconnected methods, hoping always to get a better fix on the subject matter at hand". (p. 2)

From the quote above, it is understood that qualitative research embraces an ontology and epistemic foundation that values participant's own interpretations of reality and, therefore, assumes that reality is socially constructed by individuals, from within their own unique contextual interpretation. Denzin and Lincoln (2005) suggested that since the qualitative researcher embraces an 'internal reality', qualitative research cannot embrace an objective epistemology and, therefore, knowledge comes from a deep understanding of the meanings people attach to their experiences, and interpretations of the social world. Qualitative methods, therefore, try to interpret social phenomena in terms of the meanings people bring to them, and because of this, it is often referred to as interpretative research. According to Bauman (1990), qualitative research refers to a process of 'de-familiarising', whereby rather than simply accepting the concepts and explanations used in everyday life, qualitative research asks fundamental and searching questions about the nature of social phenomena. Qualitative research, therefore, focuses on studying people in their natural setting and, therefore, largely depends on watching people in their own territory, and interacting with them in their own language.

Due to different theoretical positions, qualitative research is neither unified nor well defined. The distinctions between the various theoretical stances are frequently presented as clear-cut, but in practice the contrasts are often less apparent. Therefore, there is considerable debate about what constitutes the central tenet of qualitative research. For the purpose of this thesis, the choice of method of enquiry and how it is used is informed by the theoretical underpinning of the project.

Both phenomenology and symbolic interactionism fit into the qualitative paradigm and, therefore, this was the method chosen throughout the thesis. It is apparent that the symbolic interactionist's view of meanings, and the notion of socially constructed realities, blends well with the ontological and epistemological assumptions of qualitative research. As discussed above, symbolic interactionists believe that meanings are socially constructed creations, and it is through our interactions with the social world that we create meaning. Similar to symbolic interactionism, phenomenology also embraces an internal ontology, which assumes the only reality that exists is the one we interpret, through our interactions with symbols, culture and ourselves (Lindlof, 1995). Phenomenological methods are

particularly effective at showing the experiences and perceptions of individuals' from their own perspectives and, therefore, effective at challenging structural or normative assumptions. Pure phenomenological research seeks, essentially, to describe rather than explain, and to start from a perspective free from hypotheses or preconceptions (Husserl, 1980). The purpose of the approach is to illuminate the specific, to identify phenomena through how they are perceived by the actors in a situation. In the human sphere this normally translates into gathering 'deep' information and perceptions through inductive methods, such as interviews, focus group discussions, and participant observation, and representing it from the perspective of the research participants. As such, phenomenology embraces qualitative methods.

3.3.1 Qualitative methods and health psychology

With the growth in interpretative approaches to researching health issues, research has seen an increase in the use of qualitative methods to explore phenomenological issues. Rather than more quantitative research of the clinical practice, focus has turned to exploring patients' lived experience during illness, through qualitative approaches. Barbour (1999) stated that the growth of qualitative health research, implies that qualitative research is not only useful as the first stage of quantitative research, as it also has a role to play in validating quantitative research or in providing a different perspective on the same social phenomena. Therefore, it can force a major reinterpretation of quantitative data.

Subsequently, with the development of qualitative methods within health research, the field of health psychology is now beginning to see an expansion in independent qualitative studies, used to uncover a range of health topics and to access areas of health-related quality of life (HRQOL) that are not open or amenable to quantitative research. These topics include constructions of disease, prevention, treatment, and risk (Charmaz, 1990; Pound et al, 2005; Walter, Emery, Braithwaite & Marteau, 2004; Young, Woods, Windridge & Heney, 2002); living with and managing the physical, psychological, and social effects of diseases and their treatments (Murray et al, 2007; Murray et al, 2010; O'Reilly, Finnan, Smith, Allwright & Shlomo, 1996); and factors enhancing or inhibiting quality care, and the promotion of good health (Davis, Jacklin, Savdalis & Vincent, 2007; Hagbaghery, Salsali & Ahmadi, 2004; Shiner, Whitley, Van Citters, Pratt & Bartels, 2008). It has been argued that qualitative methods can be used to considerable effect in evaluating

organisational reforms, and to provide changes to health service provision, from the viewpoint of patients, health professionals, and managers (Pollitt, Harrison, Hunter & Marnoch, 1991).

Many different qualitative methods are available to explore a patient's understanding and experience of illness: these can be heard, seen, read; and/or can be told, performed, or written. Research reveals excellent examples of a variety of qualitative methods used in health psychology research. For example, clinical observations, focus groups, audio/written diaries, conversational data, online written data, and interviews are all used to engage patients in discussing in-depth information about their health experience, their perceptions, opinions, beliefs, and attitudes. Such qualitative methods are often known as a reflective intervention (retrospective methods) in clinical situations, as they can help patients reflect on their experiences, daily activities, and hidden aspects of their thoughts and feelings. Within all these qualitative methods, the pragmatic is that experience is shared and storied, and focus is on talk and action, rather than on number.

The process of either writing or speaking has been suggested to encourage participants to focus on daily activities and reflections that they value; and highlights hidden aspects of their thoughts and feelings (Campbell, 1992; Rancour & Brauer, 2003). As a result, narratives can provide a context that encompasses and inter-relates both the illness event and surrounding life events. In health research, the method of collecting patient stories of their care journey has gained importance in the study of chronic illness. For instance, Williams (1984) stated that chronic illness alters the relationship between the patient's body, self, and surrounding world and, therefore, the reconstruction of a patient's own story of their lived experience is of central importance, and makes it possible to give meaning to events that have occurred during that person's health journey. Subsequently, Williams (1984) suggested that it is through the process of capturing the individuals' story of illness, which enables research to comment on the narrative and to offer new interpretations and suggestions. Further exploration of specific qualitative methods (semi-structured interviews, online written analysis, and CA) in relation to theoretical frameworks of this thesis (phenomenology and symbolic interactionism) and SDM for breast cancer, will be outlined in more detail within the literature review at the start of Chapters Four to Six.

3.4 Conclusion

This chapter outlined the theoretical framework of the thesis. Phenomenology and symbolic interactionism have been discussed in relation to its philosophical assumptions, and has been explored in relation to research within the field of health psychology, cancer research, and breast cancer. The SDM literature also highlights a lack of research which explores SDM through these theoretical approaches. The chapter also introduces the importance of qualitative research to this thesis, and ties it to phenomenology, symbolic interactionism, and medical decision-making in health research. Existing research on SDM reveals a deficiency in qualitative methods to explore the concept and practice of SDM.

This thesis sets out to explore SDM through a phenomenological and symbolic interactionist approach, and considers qualitative research as the appropriate method to conduct such an inquiry. To address the qualitative phenomenological side of the inquiry, a semi-structured interview study will be conducted with post-treatment breast cancer patients (Chapter Four). The study aims to take a phenomenological approach to capture patients' perspectives and lived experiences of SDM, from their personal accounts, during their breast cancer journey. To address the symbolic interactionist framework of the inquiry by means of qualitative research, two additional distinct studies are presented to explore SDM. The first is an online breast cancer forum study (Chapter Five), which aims to explore patients' experiences of SDM, through a study of the interactions which take place between patients online. The second study is an audio-recording study of breast cancer consultations (Chapter Six), which aims to explore the concept and presence of SDM, through the interactions which take place between doctor and patient during a medical consultation.

The next chapter will introduce the first of the three qualitative studies, which is a semi-structured interview study. Within the next chapter, a small literature review will introduce the study, followed by the method, results, and discussion.

Chapter Four

Study 1: retrospective accounts of breast cancer and SDM

Chapter 4

Study 1: retrospective accounts of breast cancer and SDM

4.1 Introduction

The previous chapter explored theoretical frameworks and qualitative methodology, and drew attention to the increased recognition and importance of patients' perceptions, experiences, and interactions within health psychology and research on illness.

The previous chapter also introduced the roles of phenomenology and symbolic interactionism, as two theoretical bases, for an in depth exploration of breast cancer patients' experiences of SDM, as this has been largely ignored in the existing health literature. These frameworks govern the ideology held within qualitative methodology, which is embedded in the three studies of this thesis.

This chapter introduces the first of three qualitative studies, which investigates patients' experience of SDM through semi-structured interviews. In this chapter, a short literature review is provided which focuses on exploring the use of semi-structured interviews within health research, and as a qualitative method to access patients' health experiences. Semi-structured interviews will also be discussed in relation to existing SDM research and their applicability in exploring SDM amongst breast cancer patients. Following the literature review, the method is described. This is then followed by a detailed explanation of the findings achieved through a TA of the interview data. The chapter is finally concluded with a discussion of the findings.

4.2. Literature Review

4.2.1 Accessing patient experience through interviews

Interviews, explained by Britten (1997) are verbal interchanges, where one person, the interviewer, attempts to elicit information from another person, the interviewee. Watt (2011) stresses the importance of the retrospective conduct of qualitative interviews, as this is not only less intrusive, but it also recognises the cognitive and affective dimensions of a patient's experience.

There are three fundamental types of interviews that can be placed along a continuum. Structured interviews are, essentially, verbally administered questionnaires, in which predetermined questions are asked, with little or no variation, and with no scope for follow-up questions to responses that warrant further elaboration. Conversely, unstructured interviews do not reflect any preconceived theories or ideas, and have no obvious organisation to their structure (Silverman, 2010). Semi-structured interviews lie in the middle of this continuum, as they have some predetermined order, but still allow flexibility in the way issues are addressed by the informant. It has been suggested that semi-structured interviews are a key qualitative method of data collection, which account for capturing patients' lived health experiences, as they offer biographical narratives or general opinions (Pavis, Masters & Cunningham-Burley, 1996; Williams, 1984). Centrally, semi-structured interviews consist of open-ended questions to past experiences. This permits the individual to retell their personal story and experiences using their own spontaneous language. The desired minimal influence from the interviewer inhibits the presence of a questions-response-type interview, and instead leans more towards an everyday communicative interaction, namely personal story telling and listening. This allows areas to be explored, and from which the interviewer may divert in order to pursue an idea in more detail, which may not have been possible with more structured questionnaire surveys.

Across all three types of interviews, the key purpose of the research interview is to explore the views, experiences, beliefs and/or motivations of individuals on specific matters. Interviews are believed to provide a deeper understanding of social phenomena (Silverman, 2000). Therefore, they are most appropriate where little is already known about the study phenomenon, or where detailed insights are required from individual participants. They are also particularly appropriate for exploring sensitive topics, where participants may not want to talk about such issues in a group environment. Subsequently, the method has become popular amongst qualitative research and widely used in psychology.

4.2.2 Qualitative interviews as a medium for phenomenology in health research

Health researchers initially led the way for the use of interviews in social action research, particularly to identify problems in clinical practice and to develop potential solutions in order to improve practice (Hart & Bond, 1995). Research on health-related topics

continues to be a major area of interview research today. Medical advances, increasing specialisation, rising patient expectations, and the sheer size and diversity of health service provision mean that today's health professionals work in an increasingly complex arena. The wide range of research questions generated by this complexity has encouraged the search for alternative ways of conducting research, which move away from quantitative research.

As mentioned in the previous chapters, the rapid expansion of research about health and the interest towards participants' own meanings of health and illness, introduced the integration of qualitative methods into clinical research in the 1970s and 1980s. Williams and Popay (1994) suggested that "understanding the nature of lay knowledge requires an approach to data collection that is, in a sense, egalitarian, and most certainly phenomenologically open" (p.123). Therefore, for health researchers with an interest in accessing participants' own meanings, interviews have been suggested to offer a valuable way forward (DiCicco-Bloom & Crabtree, 2006). According to Warren and Karner (2005), the purpose of a qualitative interview is to contribute rich or in depth data to a body of knowledge that is conceptual and theoretical; and is based on the meanings that life experiences hold for the interviewees. Interviews are therefore a major source of data collection for phenomenologist and health research underpinned by phenomenology, and has an established position within critical health psychology, which makes its relevant to the research questions of this thesis.

For health researchers concerned with eliciting meanings, it is argued that qualitative one-to-one interviews are most often the method of choice (O'Connor, Wicker & Germino, 1990). Despite this assertion, some may use questionnaires (Harding & O'Looney, 1984), written accounts (Robinson, 1990), focus groups (Brody, 1990), and scales (Fife, 1995) to explore experience and meaning. However, interviews are most commonly illustrated as an ideal method of data collection, to those researchers concerned with the patients' views, or those approaching health-related research from a theoretical perspective.

The words used to describe what is elicited from interviews can vary across research topics and with the theoretical bent of the researcher. For example, some researchers such as Fielding (1993) suggested that participants' talk provides interviewers with information about their experiences; whereas other researchers use terms such as

‘understandings’ (Rubin & Rubin, 1995), ‘lay representations’ or ‘common sense beliefs’ (Williams & Popay, 1994), and ‘participant’s meanings’ (O’Connor et al, 1990). Regardless of which term used, it is understood from all these terms that the information gathered from interviews, tries to reflect and embody the meanings attributed by the participants themselves to their own experience. Subsequently, for health psychology researchers, the use of qualitative interviews allow for detailed exploration of individuals’ lived experiences of specific disorders and diseases, and the experience of living with chronic illness or disability.

In specific relation to breast cancer, semi-structured interviews are a popular qualitative method used for data collection. Research demonstrates the use of semi structured interviews as a key tool for breast cancer health assessment and service evaluations, through exploring patient experiences of doctor-patient communication (Roberts, Cox, Reintgen, Baile & Gibertini, 2009; Siminoff, Ravdin, Colabianchi & Strum, 2000; Wright, Holcombe & Salmon, 2004), and patient preferences (Degner et al, 1997; Keating et al 2002; Leydon et al, 2000; Simes & Coates, 2001). Semi-structured interviews have also been illustrated as an ideal tool for eliciting breast cancer patients’ meanings and understanding of health, through exploring experiences of psychological distress to cancer (Fallowfield et al, 1986; Fallowfield et al, 1990; Ganz et al, 1996; Spiegel, Kraemer, Bloom, Gottheil, 1989). Other studies have used in-depth interviews to explore patient perceptions of cancer (Woods, 1993), and the meaning of breast cancer on QOL (Luoma & Hakamies-Blomqvist, 2004; Payne, 1992). Topics such as long term survivorship of breast cancer (Carter, 1993; Johnson, 2001) and the impact of breast cancer on relatives (Harrison, Haddad & Maguire, 1995) have also been explored through the method of semi-structured interviews.

It is apparent that qualitative interviews are a method used within research on medical decision-making. Much of this literature focuses on exploring patients’ preferences for involvement in treatment decision-making, through semi-structured interviews (Beaver et al, 2005; Doherty & Doherty, 2005; Ende, Kazis, Ash & Moskowitz, 1989; Ford et al, 2003; Hack et al, 1994; Say, Murtagh, Thomson, 2006); and to determine barriers and facilitators for patient involvement in decision-making (Wetzels et al, 2006; Wirmann & Askham 2006). A more specific literature review on decision-making and breast cancer, also reveals the use of qualitative semi-structured interviews to explore

barriers to patient participation during treatment decision-making (Mills et al, 2006); patient perceptions of decision-making (Grunfeld et al, 2006); and to examine decision-making styles (Harcourt & Rumsey, 2004).

4.2.3 Exploring SDM through interviews

Patients' perspectives and experiences of medical decision-making can be explored through the method of semi-structured interviews, particularly amongst breast cancer patients. Research identifies the benefits of using qualitative methods to investigate patients' experiences of treatment decision-making, and patients' meaning of participation in medical decision-making. However, is this method of investigation also applicable to SDM research?

SDM is an area of research which has been explored by means of qualitative interviews. The focus of these studies was not to explore patients' meanings about the concept, but to describe SDM and to evaluate its effectiveness as a tool in establishing patient involvement and partnership in health care. For example, studies have been carried out to distinguish the definition and processes of SDM through semi-structured interviews, carried out with patients and clinicians (Davis et al, 2003; Edwards & Glyn, 2006; Stevenson et al, 2000). Other qualitative studies have aimed to explore clinicians' attitudes towards sharing decisions, through semi-structured interviews (McGuire, McCullough, Weller & Whitney, 2005; Thistlewait & van der Vleuten, 2004). Research has examined barriers to SDM by means of semi-structured interviews with clinicians (Suurmond & Seeleman 2006). These studies demonstrate that qualitative interviews are a well suited method for acquiring understanding about the concept of SDM, through individuals' views and experiences. However, they fail to demonstrate, through the use of interviews, patients' meanings and experiences of SDM through a theoretical perspective of phenomenology. Furthermore, none of the above qualitative interview studies on SDM have been conducted amongst breast cancer populations. Given the 'preference-sensitive' nature of breast cancer care, which implies that treatment options exist and decisions about interventions should be made by the patient in partnership with their clinician, an opportunity exists to design a qualitative interview study to explore breast cancer patients' understandings of SDM and experiences during their treatment.

There is little doubt that patients' health experiences can be explored through qualitative methods. The literature review has outlined the benefits and use of semi-structured interviews, as a method to capture and explore patients' health experiences, and in relation to decision-making and breast cancer. Although qualitative methods such as semi-structured interviews are shown to have been used to assess and evaluate the concept of SDM, the SDM literature, however, lacks examples of qualitative research which aim to explore the characteristics, meanings, presence, and experience of SDM for patients, through a phenomenological approach (i.e. through their perspectives and encounters). This, therefore, provides a rationale for the first study of this thesis. To elicit breast cancer patients' 'lay knowledge' and 'meanings', the qualitative method of semi-structured interview, retrospectively, captures breast cancer patients' health beliefs and experiences during their cancer journey. The next section of this chapter introduces the first study of this thesis, which, in line with the Heideggerian phenomenology (Heidegger, 1962), utilises a thematic analysis (TA) to provide an in-depth insight about what SDM means to breast cancer patients and how it is encountered.

4.3 Methods

4.3.1 Study design

Semi-structured interviews were selected as a qualitative method of data collection with breast cancer patients, as they are suggested to be well suited for the exploration of the perceptions and opinions of respondents, regarding complex and sometimes sensitive issues; and enable probing for more information and clarification of answers (Barriball & While, 1994). The one to one semi-structured design of the interviews, allowed each participant unrestricted time to thoroughly reflect on their breast cancer journey. It also meant that participants could freely share their personal stories and accounts, with some questions asked by the interviewer to structure the flow and content of the interview. Therefore, it was important that each interview did not restrict the participants in their accounts, and instead allowed participants to share their experiences and perspectives in relation to SDM in more detail.

4.3.2 Pre data collection preparations

Before collecting interview data on breast cancer patients' experiences of SDM, it was important to explore specific aspects of medical assessments for breast cancer. This permitted greater understanding of the participants' accounts of their cancer journey. In order to build a thorough understanding of the terminology and practice of SDM, in the clinical practice for breast cancer, it was essential to find out about the complete medical process and treatments from diagnosis to completion, and post-treatment. This also avoided assumptions about SDM based upon existing literature. While study one aims to explore individuals' personal experiences of SDM relating to their clinical treatment, it is also equally important to become familiar clinical practicalities and situations, to understand more about the practice of breast cancer and the concept of SDM. To achieve this, on-going observation took place at breast cancer clinics and multi-disciplinary team (MDT) meetings. The observations were not intended as an independent observational study, and instead were utilised as an opportunity to become acquainted with medical practices, clinical procedures, and increase awareness of terminology related to breast cancer.

4.3.2.1 Clinic observations: initial diagnosis clinic and post-surgery monitoring clinic

Regular visits were made to two different types of breast cancer clinics for observation. These were an initial diagnosis clinic and a post-surgery monitoring clinic, which were observed weekly, over a four month period. Both clinics took place at the University teaching hospital's Cancer Centre, once a week, by the same clinician who was an oncology surgeon. The aim of the observations was to gain an extensive understanding of breast cancer, and to observe the different types of consultations that take place during a patient's treatment path. Attendance at these clinics provided the first opportunity to see patients talk about their illness, and to perceive the clinician's and patients' roles and duties within the consultations. The observations provided suitable insight into the phraseology, medical terms, procedures, and systems involved during breast cancer care.

The first clinic observed was an initial diagnosis clinic. Patients attended the clinic with a family member, partner, or friend for support. A breast care nurse was also present in the consultation room for additional support. Following a physical examination of the

breast by the clinician, patients were then informed about the outcomes of their test results and the next stages of the treatment process. Little interaction took place during consultation, as patients spent the majority of the consultation time listening to the clinician's suggestions. Dialogue regarding diagnosis and proposed treatment was led by the clinician in terms of description, explanation and justification. Patient involvement was limited to asking the clinician questions about their treatment. The nurse remained inactive during the consultation and during the clinician's interaction with the patient. However, at times when the patients showed emotions, the nurse provided verbal support for them and whoever else had attended the consultation. A more active part of the breast care nurse's role was evident outside of the consultations, during one to one sessions with patients. The session took place immediately after the diagnosis consultation, in a room designed like a home living room. With comfortable sofas, plants, TV, and a kitchenette area for refreshments, the room was designed to give a sense of relaxation and ease. Patients and their partners/family members were invited to come to this room with the breast care nurse, after the initial diagnosis clinic. The time spent there, with the breast care nurse, generally allowed patients some personal time to reflect on their diagnosis and the information given by the clinician, outside of the clinic room. The nurse once more informed them thoroughly about their diagnosis and treatment plan, allowing them another opportunity to express any queries or doubts. This period allowed the nurse time to provide the patient with information packs, and to guide them with reading material.

The second clinic observed was a post-surgery monitoring clinic. On entering the clinic, a physical examination of the patient's breast was conducted by the clinician. Patients were then informed about their progress in their treatment. These consultations were much more patient-led, in that they were focused on reviewing the patients' health, QOL, emotional well-being, and any other concerns or issues with the treatment. Therefore, the clinician asked the patients regular questions and invited them to participate in talk, to check their health status. During the clinician's talk, positive language and reassurance was used throughout the consultation, and adequate time was devoted to describing and explaining the next stages of treatment. More interaction between the clinician and patients took place, with patients frequently asking questions about their health status and treatment plan. A breast care nurse was present during these interactions to take medical notes, but did not interact in order to allow for focussed interaction between the clinician and patient. Upon completion of the examination, patients were taken

to another clinic consultation room, by the breast care nurse who had been present during the consultation, and given the opportunity to ask further questions. Information and treatments outlined by the clinician were once again explained by the nurse, and further support was given to patients.

4.3.2.2 Multi-disciplinary (MDT) team meetings

An opportunity to observe MDT meetings, revealed more details about the diagnosis of breast cancer, and how appropriate treatment choices were discussed by medical professionals. The MDT meetings took place weekly, at the University teaching hospital's Cancer Centre, among all the breast care nurses, oncologists, and oncology surgeons. This was a collaborative period when discussions and confirmations focused on each patient's diagnosis, prognosis, and treatment plan. During this time, it became clear how medical professionals deliberated over the appropriate treatment plan and decided whether, and at which stage of the treatment, SDM is appropriate for each patient. Based on the nature of each patient's illness, decisions about whether surgical treatment was required, and which adjuvant follow-up treatments were of value, and related options were considered based on test results and statistical percentages, devised by scientific measures. Depending on the cancer grade, tumour size, and whether the cancer had travelled to the lymph nodes, the team identified whether a patient required a mastectomy or a lumpectomy, and whether SDM would be suited. Adjuvant treatments, such as chemotherapy, radiotherapy and hormone therapy, were also dependent on the nature of the diagnosis, and decisions relating to whether SDM is appropriate for the adjuvant stages of treatment were discussed. The task of decision-making during these MDT meetings rested heavily on scientific and medical guidelines. The breast care nurses' role during these meetings was to voice patient concerns. As patients do not attend these MDT meetings, the nurses ensured that patients' views and opinions were expressed with respect to their treatment plan. The nurses also used this time to share additional information to the clinicians about the patients' emotional well-being. By the end of the meeting, a consensus on treatment options and the role of SDM was reached by the surgeons, oncologists and breast care nurses for each patient.

Observation of the MDT meetings posed an interesting philosophical point, as it demonstrated that the presence and experience of SDM for each patient is dependent on the

severity and nature of their diagnosis and illness. Decisions as to whether a SDM consultation would be appropriate are made in advance during these MDT meetings. This, therefore, raises an interesting question, which is, do all patients experience SDM and at what point does the process of a *shared model* occur for patients? As a result, the observations of the MDT meetings helped to further rationalise this thesis and show why it is important to further explore the characteristics, meanings, and experiences of SDM from the patients' perspectives and interactions.

The opportunity to observe both initial diagnosis clinics, post-surgical monitoring clinics; and the MDT meetings, provided a better understanding of breast cancer medical terms and stages of treatment, and revealed how a treatment plan is devised and negotiated. Such access to clinical practices and expansion of knowledge subsequently helped to facilitate the development of the study design and methods of data collection.

4.3.3 Participants

Breast cancer is widespread and occurs across different ages, genders, social classes, and races. Fifteen women aged 18 years and above, and diagnosed with breast cancer, were interviewed for the study. The majority (six women) of the participants interviewed were between 60-69 years old. All 15 participants were from a white British ethnic background. Table 4.1 below provides additional information on treatment profiles. Eight of the participants had indicated a family history of breast cancer. In reference to the discovery of the lump, nine participants had found the lump themselves, while the remaining six participants had the lump detected by means of routine mammograms.

All 15 participants had completed all breast cancer treatments two years prior to being recruited into the study. The two year time frame was considered by the outpatient oncology breast surgeon as a suitable length of time for the participant to have adjusted from the emotional distress of the disease, whilst not being too distant from the onset of the disease to prevent recollection of events. This is an important consideration for ethical and data collection purposes. It allowed the women to participate in the interviews at a time of relative physical and emotional stability, rather than soon after diagnosis.

Table 4.1

Participant demographic

P No'	Age	Surgery	Adjuvant treatment	Other conditions	Employment Status	Marital status
1	40-49	L	C	None	Employed	Married
2	50-59	M	C & T	None	Employed	Married
3	60-69	M	C	None	Retired	Married
4	60-69	M	None	None	Unable to work	Married
5	60-69	M	C	Diabetes	Retired	Married
6	70+	M	C	None	Retired	Married
7	60-69	L	R	Diabetes	Retired	Married
8	60-69	L	R & C	None	Retired	Married
9	40-49	M	R, C & T	Depression	Out of work	Married
10	40-49	L	R & C	None	Employed	Married
11	60-69	M	None	None	Retired	Single
12	50-59	L	R & C	None	Employed	Married
13	70+	M	None	Arthritis	Retired	Married
14	40-49	M	C & T	None	Employed	Single
15	50-59	L	R & T	Arthritis	Unable to work	Married

Note: M- Mastectomy, L- Lumpectomy, C- Chemotherapy, R- Radiotherapy, T- Tamoxifen

Patients, who had opted for breast reconstruction following a mastectomy, were not included in the sample criteria. It was advised by the Oncology surgeons, as part of the research team, that reconstructive surgery entails its own dimension of decision-making and, therefore, is arguably a project in its own entity. Focus was maintained on recruiting patients who only had to make surgical and adjuvant treatment decisions that related to the excision and management of disease. Whether individuals had had a specific breast cancer treatment (e.g. having had a mastectomy or a lumpectomy, or undertaking chemotherapy or radiotherapy) was not a criterion of consideration.

4.3.3.1 Participant recruitment

All participants were registered patients of the Oncology Department, at the University teaching hospital outpatient clinic. Following ethical approval and access from the

Research and Development Department (R&D) at the hospital (section 4.3.7), the senior oncology breast surgeon granted access to his patient records. The patient list was filtered to identify patients who met the inclusion criteria. This resulted in 46 individuals, who were all sent a study invitation letter (appendix B) by the clinician to take part in the study, along with a patient information leaflet (appendix C) and an agreement form (appendix D), which indicated their wish for participation. From the purposive sample, 15 responded positively, nine declined, and the remaining 22 did not respond. The sample size of 15 was agreed on and approved upon extensive discussions amongst the research team, taking into account the capacity and detailed nature of the research question. The practical guidelines for interviews recommended for qualitative research (Howitt, 2010; Smith, 2008) was also accounted for.

4.3.4 Interview development

The interview schedule was primarily used to ensure that the wording and sequence of all the questions in the interview were exactly the same for each participant, so that the interviewer can be sure that any differences in the answers are due to differences amongst the respondents, rather than in the questions. It is noteworthy that the interview schedule was to be used to guide the interview only, and not to direct it in any way. According to Patron (2002), the primary aim of a semi-structured interview is to enable participants to talk openly about their views and experiences in their own words. Therefore, considerable flexibility was permitted with the interview schedule during the interviews, to ensure that data collection was largely participant-led. Where the interviewer contributed to the participants talk, they were encouraged to elaborate on their accounts and provide specific examples of their views and experiences through the use of interviewer probes, such as ‘how did that make you feel?’ Such probes were proven to be a valuable tool for ensuring reliability of the data, as they allow for the clarification of interesting and relevant issues raised by the respondents (Hutchinson & Skodal-Wilson 1992). They also provided further opportunities to explore sensitive issues (Nay-Brock 1984, Treece & Treece 1986), and helped respondents recall information for questions involving memory (Smith 1992). The latter was particularly relevant to this sample of participants, as the retrospective nature of the interviews depended on participants’ ability to recall memories of their experiences and perceptions, from two years ago. However, caution was exercised as to the excessive use

of probes, as according to Howitt (2010), this can disrupt participants and create unhelpful diversions.

The focus of the interview schedule was to maintain a balance between disease-related and decision-making material, to allow for an exploration of SDM to take place during the analysis; rather than an analysis of patient experiences and meaning of breast cancer. Therefore, it was important to develop a schedule which was both exploratory in order to elicit abstract concepts, such as perceptions and experiences, and sufficiently standardised to facilitate access to different views of SDM between respondents during analysis. To achieve this, the questions started broadly and then became more detailed. For example, the interviews invited sequential story from self lump discovery, to diagnosis of breast cancer, and then took a more in-depth approach to exploring decision-making. This structure was drawn from the initial clinic observations at the hospital (section 4.3.2.1), and mirrored the structure of a consultation, which starts broadly about the diagnosis and then becomes more detailed about treatment selection. This structure was also based on the guidance of Howitt (2010), who described how it takes time to build up trust and rapport with participants and, therefore, it is important to move slowly towards the main area of interest during an interview.

The interviews started with basic background information questions, such as '*how long ago were you diagnosed?*', and '*what treatment(s) did you undertake?*' These questions were taken from the initial clinic observations made, and were included in the interview schedule to establish a clear account about the participants' medical history, in relation to their breast cancer. The interview then went on to asking participants questions surrounding their knowledge on breast cancer treatments, and whether these changed over time. For example, questions such as, '*can you describe how much you knew about breast cancer and treatments before you were diagnosed?*', were asked, to explore the type and frequency of information and communication style they received, as well as to discuss any information seeking behaviour. These questions were drawn from an engagement with the existing literature on doctor-patient communication and patient participation, to acquire an insight into how patients were informed and whether this had an impact on their decision-making. To avoid the data becoming too disease-orientated, the next stage of the interview schedule focused on specific questions which directed the interview towards the topic of decision-making. For instance, participants were asked questions, such as '*to what extent did you feel involved in choices of treatment /care offered to you?*', so they could recall

aspects of SDM which were experienced during course of their treatment. Such aspects included: their degree of involvement and participation; their levels of control; whether they had treatment choices; their experience of doctor-patient relationship; and finally what their understanding of SDM was. These questions were drawn from both the existing literature on patient participation, and from the observations made at clinics and MDT meetings. These questions were designed to highlight the patients' experience of SDM, their understanding of SDM and its characteristics, and to explore the presence of SDM (i.e. if any factors hindered or facilitated patient encounters of SDM). The final stage of the interview progressed to exploring participants' experience of SDM on their subsequent QOL, post-treatment completion. These questions were drawn from pilot interviews conducted at another University teaching hospital (section 4.3.4.1). Questions such as, '*how would you say your life has changed since completing your treatment?*' were asked, which required participants to describe their current QOL in relation to aspects, such as body image, relationships, social skills, careers, self-control, and emotional well-being. The interview concluded with some short summary questions relating to evaluation of their overall experiences and care received. The full interview schedule can be seen in Appendix E.

4.3.4.1 Pilot interviews

Prior to devising the interview schedule, regular weekly attendance, for a period of three months was made at a breast cancer support group, which took place at a different University teaching hospital to the one where the sample were recruited. Taking part in the support group allowed for an opportunity to talk with some breast cancer patients, and gain insight into their cancer journey. This helped to build a profile of the important issues which could be included in the interview schedule and explored in study one.

According to Barriball and While (1993), the success of the semi-structured interview method, clearly relies upon the skills of each interviewer in making a number of difficult field decisions. Before commencing the main study interviews, three pilot interviews with the designed schedule were conducted with women at the breast cancer support group. These women were post-treatment for breast cancer, or were undergoing treatments at that time. There were two main purposes for the pilot interviews, which were: establishing competent use and understanding of the specific interview schedule being

used in the study; and developing an awareness of the errors or bias which can arise with interview technique. The exercise was extremely useful, as it enabled the practice of interview techniques, such as prompting, language, and listening skills, as well as establishing the appropriate setting and types of questions to consider. The pilot was also a means to build knowledge and gain more familiarity with the specifics of breast cancer. A group discussion took place afterwards with the three women who engaged in the interviews, to gain feedback on the interview schedule and the interviewing skills deployed. All three women were happy with the clarity and type of questions asked, and the manner or sensitivity of the interviewer. Comments were expressed that the interview consisted of questions which were free of technical jargon and leading content or assumptions, which may have led to biased responses. There were no feelings of distress or emotional discomfort reported by the women. Subsequently, no alterations were made to the interview schedule for the main data collection in study one. The audio-tapes of these practice runs were used only by the interviewer, as a self-evaluation tool, so that questions and queries could be raised and discussed with the research team. Identified features from the pilot interviews raised the need for the interviewer to balance flexibility and consistency between each interview, and also highlighted the use of leading questions and inappropriate probing which needed to be eliminated by the interviewer.

4.3.5 Procedure

As mention in section 4.3.3.1 (*'participant recruitment'*), participants who met inclusion requirements were sent a study pack, which included an invitation letter, study information leaflet, and agreement form. Participants, who agreed to take part, signed and sent the agreement form back to the research team, who then contacted them by phone to discuss the next stages of the study. Participants were allocated a convenient interview date and time by the interviewer, and were informed about the interview location. The telephone call also provided an opportunity for participants to ask any questions, and have their queries addressed before the interview day. Once arriving at the hospital, participants were once more issued with the information leaflet to read, and were given another opportunity to ask any questions and to clarify any concerns. They were then asked to sign an interview consent form (appendix F) prior to the interview. Participants were also asked to complete a demographic questionnaire (appendix G), for data collection on participant profiles. On

completion of the interview, participants were fully debriefed and once more given the time to ask any questions or provide any additional comments. This procedure was repeated for all 15 participants, who were interviewed by the same interviewer each time.

4.3.5.1 Interview setting

Given the sensitive nature of the topic, it was seen as appropriate to invite the participant for interview at the teaching hospital's Cancer Centre, which was an area with which they were familiar. With the interview being focused on past events, the choice to conduct the interviews in a clinical environment was also a technique to facilitate the participants' memory and recall experiences of events. The location added extra security and confidentiality to the participants' personal disclosure, with the absence of others. Participants were allowed to bring a companion for support or assistance on the day. However, only the participant who had consented to take part was solely interviewed. This was to allow for an adequate self-reflection by the participant, and also to avoid interference with the structure of the interview and interviewees' relationship with the interviewer.

4.3.5.2 Data collection and transcription

The interviews were recorded on a hand held digital recorder. The use of audio-tapes ensured that an identical replication of the contents of each interview was available for analysis. Audio-recordings provided a detailed insight into the performance of both the respondent and the interviewer, which helped validate the accuracy and completeness of the information collected. Barriball and While (1993) suggested that audio taping also reduces the potential for interviewer error by, for example, recording data incorrectly or cheating by logging an answer to a question that was not asked.

At no point during the interviews was the recorder paused or stopped, until the interview had reached an end, or unless the participant indicated so. There were no time constraints for each interview, as it was important to allow each participant to talk freely for as long as they wanted, and at the required speed. However, on average, each interview lasted approximately 45 minutes. Once all the data had been gathered from the 15 participants, these were reviewed and fully transcribed on a verbatim basis. Each

participant's recording and transcription was listened to and reviewed several times to ensure full understanding and familiarity of content, and accuracy of transcription.

4.3.6 Data analysis

With the first study being underpinned by phenomenology, a TA was considered as the appropriate analytical strategy. TA was regarded as suitable, as it aims to identify, analyse, and report patterns (themes), laterally across an entire data set (Braun & Clark, 2006). It, also, minimally organises and describes the data set in rich detail. Boyatzis (1998) further proposed that TA frequently goes further than this, and interprets various aspects of the research topic. Therefore, it provides a complex account of the data. As a result, TA can be a particularly useful method when investigating an under-researched area (Braun & Clark, 2006), such as SDM and breast cancer, or with participants whose views on the topic are not known. One of the advantages of TA, which made it suited to this study, is that it is theoretically-flexible. This means it does not require the detailed theoretical and technological knowledge of approaches, or connection to any pre-existing theoretical framework. Therefore, it can offer a more accessible form of analysis, and be used within different frameworks to answer different types of research question. TA can be an essentialist or realist method, which interprets and reports individuals' subjective experiences, meanings, and the reality of participants. Therefore, it suits questions related to people's experiences, views, and perceptions, such as 'what are breast cancer patients experience of SDM?'; or it suits questions related to understanding and representation, such as 'how do women with breast cancer understand SDM?' This subsequently made TA, well suited to the phenomenological 'life-world' approach of this thesis, and the first study.

Thematic data analysis was achieved manually without the use of any qualitative data analysis software. In conducting a TA, the procedure and stages described by Braun and Clarke (2006) were followed. First, several readings of each transcript were conducted to achieve familiarity with the data. Specific attention was made to listing patterns of experiences that occurred in the text. Each transcript was systematically examined, line by line, and bits of data embedded within the material were de-contextualised to facilitate a micro analysis of the data. Key points and extracts were highlighted, to indicate potential

patterns. Initial notes were made on the transcript to identify segments of data which appeared to be important or significant, as defined by the researcher, to decision-making, patient participation, views and perceptions, and spoken experiences. Table 4.2 provides an example of notes applied to a short segment of data. Appendix H illustrates a table charting all the notes made across the 15 transcripts.

Table 4.2

Data extract, with initial notes applied

Data Extract	Initial Notes
<i>I didn't want to read anything. I didn't want to absorb any knowledge about it. I just wanted to just do it, get on with it, and forget about it. I still don't think it even hit me then. I just wanted it to go away. (Lucy, lines 74-76)</i>	Block learning/acquiring health information In denial over diagnosis

The second stage involved a process of data reduction and organising the data into meaningful groups. Therefore, all of the talk (initial notes) that fitted under a specific category was identified and placed under an initial code. At this stage, keeping the codes as simple as possible assisted flexibility in the categorisation process, and helped create and re-define the initial themes. A description of what the codes meant and a source of the code were noted. Table 4.3 illustrates an example of how notes were classified into codes.

Table 4.3

How notes were classified into codes

Initial Notes/ Patterns	Lines (name)	Initial Codes
Block learning information	69-77 (Elaine)	Submissive patients
In denial over diagnosis	58-62 (Debbie)	
Fear of increasing knowledge	170-182 (Sarah)	Passive participatory role
Pass responsibility of decision-making	96-99 (Lucy)	
Want no control over health care	101-114 (Debbie)	
View that SDM does not exist	74-81 (Helen)	Hindered experience of SDM
Little awareness of what SDM is	44-50 (Charlotte)	

The next step was to analyse all of the codes, which involved searching for connections, and considering how the different codes combined to form over-arching sub-themes. The focus was on identifying broader patterns in the data and emerging sub-themes, which identified what the data meant. At this stage, visual representations were used to help sort the different codes in to sub-themes. Therefore, each code, with a brief description, was written on a separate piece of paper, and they were played around with until they were organised into sub-theme-piles. The sub-themes were identified by bringing together components or fragments of ideas or experiences (codes), which often were meaningless when viewed alone and, therefore, pieced together to form a comprehensive picture of participants collective experience (proposed sub-theme). Table 4.4 illustrates an example of how this was achieved. At this stage, a number of initial codes had to be abandoned, as upon review there was little original data to support them. Key phrases from the participants' transcripts that supported the sub-themes were also identified at this stage. Appendix H provides a full table of all sub-themes produced from the analysis.

Table 4.4

How codes were combined to form sub-themes

Initial codes	Sub-themes
Involved patient Active participatory role Facilitated experience of SDM	Individual difference
Submissive patient Passive participatory role Hindered experience of SDM	
Varying types of information Clinician's communication skills Quality of information	Learning styles
Knowledge restrictions Quantity of information	
Isolation Self-support Distress management	Coping Strategies
Identification process Support structure Inclusion	

The final stage involved a process whereby sub-themes were examined amongst each other and combined to form main themes. This was the stage of the analysis where the relationship between codes, between sub-themes, and the main overall themes were examined. A provisional name and flexible definition was then created for each emerging theme. Table 4.5 illustrates an example of a final theme with the sub-themes included in that theme. Each theme was then taken separately and re-examined against the original extracts, for each theme, and the entire data set. This was to check the validity of individual themes in relation to the data set; to consider whether they formed a coherent pattern; and to assess what aspects of the data were being captured, and how the theme contributed to understanding the data. This stage of re-contextualisation focused on the underlying meaning of each theme. Each finalised theme was given a name, and illustrated with a few quotations from the original text to help communicate its meaning.

Table 4.5

An example of a final theme and sub-themes within

Provisional named theme	Final theme	Sub-themes
Individualised experiences of SDM- SDM is experienced in different ways by different people	Personalising and adapting SDM	Individual differences
		Learning styles
		Coping strategies

Once the procedure had been carried out for the first transcript, the exact same procedure was carried out for the others. Each transcript was analysed as new. Similar themes between different transcripts were identified, as well as those that were different and exclusive to a particular participant. A final table was constructed containing all of the initial codes, sub-themes, and themes for all of the transcripts (Appendix H).

As a methodological approach, phenomenology and qualitative research acknowledges that the researcher's knowledge, experiences, emotions, and position can influence the research process (Willig, 2001). Therefore, the ongoing completion of

personal reflections, and the adoption of reflexive subjectivity were important during data analysis. Such epistemological reflexivity recognises the importance of the need to continually reflect on the ways in which the researcher may influence the data and analysis, and the ways in which meaning and interpretations are assigned to data (Finlay & Gough 2003). This was undertaken through the use of a reflexive diary, maintained throughout study one, as a measure of quality assurance. Journaling is identified as a good method to use to ensure that the researcher undertakes “an acceptable form of honest self-assessment, and are critically reflective of their performances” (Grbich, 1999, p.89). Therefore, reflexive commentary was maintained during the analytical procedures. The diaries focused on recording key events and habitual practices, what the researcher felt about the data extracts, the reasons for the decisions that were made by the researcher, and the researcher’s thoughts and attitudes towards the research itself and the information that was arising. Any presuppositions, choices, experiences, and actions during the analytical process were included in the diary. An evaluation of the researcher’s performance of a TA was also recorded. In turn, the commentary notes in the diary were an effective way of confronting the researcher’s thoughts and perceptions, and to see whether they influenced the data analysis. The process of reflexivity will be discussed further in the discussion section (section 4.5.1) of this chapter.

4.3.7 Ethical submission

Application for ethical approval was submitted to the local NHS Research Ethics Committee (REC), and to the R&D Department at Keele University (Appendix Ia). Approval was also sought from the R&D Department at the University teaching hospital, from which the participants were recruited (Appendix Ib). The Research Institute for Social Sciences at Keele University, together with the supervisor team in Psychology Department, also certified full peer review of study one and the thesis as a whole. The researcher had clearance from the Disclosure and Barring Services (DBS), and was given access to patients, subject to the award of an honorary contract and research passport by the NHS trust, which was granted by the R&D Department at the University teaching hospital. The research also received full Good Clinical Practice (GCP) training, by the NHS trust, to ensure that research was conducted to ethical and practical standards.

All ethical procedures were adhered to during the conduct, analysis, and write-up of data collection. All of the participants were informed that their participation was completely voluntary, and informed of their rights to withdraw; refusal to answer questions; and ability to stop the recording at any point without giving a reason. All participants provided their written informed consent. Participants were also informed that they could request copies of the transcription, and could also receive a copy of the final report, if they wished. For the purpose of anonymity, participants were given identification numbers only. Where extracts from the transcripts are used within this thesis, participants were given a pseudonym, and no information is displayed to show their identity or to identify any medical professionals.

4.4 Results

The first study aimed to explore breast cancer patients' experiences of SDM, by means of a phenomenological approach to explore patient perceptions. Each transcript was examined in great detail through a TA, before moving on to more nomothetic general claims across all 15 transcripts. The focus of such detailed analysis, aimed to explore the relationships between the individual and the experience of SDM for breast cancer. A narrative account and interpretation of themes that emerged from the analysis follows, encompassing clear illustrative extracts from the participants' transcripts (a false name, interview number and line numbers will be provided for each quote in the parentheses). Whilst these quotes exemplify the theme that is being discussed, the inter-connections between the themes may result in the quotes being illustrative of more than one theme. The interpretative role of the researcher played an integral part in the analysis process and, therefore, it is important that the narrative and description of themes are considered as a product of interpretative engagement with the data. Several sub-themes emerged from the analyses which included: active and/or passive positioning, learning styles, coping strategies, doctor-patient knowledge discrepancy, roles and duties, being informed, information exchange, and two-way processes. Upon clustering these sub-themes together, three key themes were formed which encapsulated the experience of SDM for participants during treatment of breast cancer. These three themes were, 1) *personalising and adapting SDM*, 2) *power imbalance and SDM*, and 3) *features of SDM*. These three themes will now be illustrated and discussed in thorough detail.

4.4.1 Theme one: personalising and adapting SDM

This theme encompassed three sub-themes (*active and/or passive positioning, learning styles, coping strategies*), all associated with how participants are subjected to personal preferences and participatory roles, which influence their decision-making process during their treatment. More specifically, the degree they choose to be involved in their care, and obtain elements of control over their health, negotiated their understanding and experience of SDM. The three sub-themes raised a range of concerns. However, for the purpose of staying close to the research question and ensuring that focus was maintained on exploring patients' understandings and experiences of SDM, the sub-themes *learning styles* and *coping strategies* were chosen not to be reported in the results. The sub-theme *active and/or passive positioning* will be examined in relation to the theme.

This theme is concerned with the impact of patient participatory roles and preferences of involvement, which led to the adoption of modifying behaviours, and resulted in differing encounters (hindered or facilitated) and meanings of SDM, portrayed by participants. For instance, in relation to patient participation in decision-making, some participants demonstrated an enthusiastic attitude towards their treatment decision-making ('active patients'), whereby their involvement and acquired knowledge was essential to their decision-making process. This resulted in a facilitated experience and understanding of SDM, and allowed patients to manage their emotional well-being. Alternatively, some participants showed a defensive approach ('passive patients') towards being informed and participating in decision-making, as a coping strategy, whereby avoidance and disengagement resulted in a hindered understanding and encounters of SDM. Both of these patient characteristics will now be illustrated, through the sub-theme *active and/or passive positioning*, in more detail with extracts, and interpreted in relation to how SDM is experienced and understood.

4.4.1.1 Sub-theme one: active and/or passive positioning

In this sub-theme, the analysis showed that some participants emphasised an active and working role in their health care. Extract one illustrates this personal preference and participatory role, and how it subsequently shapes and facilitates involvement in treatment decision-making.

EXT 1. Judy. Interview 10. Lines 51-58

Oh my goodness. Well after I had had the biopsy and they had told me it was highly unlikely not to be breast cancer, you get on the Internet don't you [LAUGHTER]. I did everything. I did loads of research, looked at all the websites, like McMillan and Breakthrough Breast Cancer, and researched all of those. I looked at some papers and medical journals, but only what was available on the Internet. I also looked at some clinical guidelines because I kind of wanted to be prepared for them to tell me yes it was cancer. I wanted to have a bit more of background knowledge of what to be expected in terms of treatment. So it could make the decision-making process easier for me.

Judy's account exemplifies a participant who is clearly motivated and concerned about their health. Judy's 'active' personality is demonstrated through their eagerness to enhance their knowledge on breast cancer. With the Internet being a common accessible means of information, half of the participants, similar to Judy, who also illustrated 'active' personalities, stated that they utilised the Internet as an immediate reference for further enquires. For older and less computer literate participants, the NHS resource packs and charity leaflets were commonly used to gain further information. It is interesting to note that Judy mentions medical journals and clinical guidelines, which was entirely due to her familiarity through working as a physiotherapist. This was also evident with another participant who practiced as a GP nurse. Therefore, this indicates that demographic factors such as education and employment may facilitate and encourage an 'active' participatory role. For Judy, having an active role in her treatment is seen as vital for preparing her for receiving bad news. In a sense the preparation acts as a shield, to protect her from shock or emotional distress once given the result of her biopsy. However, her 'active' stance also helped to provide her with the ability to organise her thoughts and the capability to confidently participate in the consultation. It also equipped her with enough information to feel educated enough to participate in her treatment decision-making.

For some of the 'active' participants, acquiring information and advancing their knowledge, by means of direct interaction and verbal dialogue with the professionals, was seen as greater advantage to their understanding and decision-making process. All

participants received verbal explanations regarding their diagnosis and treatment. They also all received regular face-to-face or private telephone conversations with the breast care nurse about issues and concerns. The analysis revealed that ‘active’ patients utilised those opportunities, by frequently engaging in decision-making conversations. Extract two illustrates this.

EXT 2. Tina. Interview 13. Lines 43-46

That was a really heavy morning, because you're in bits about your test results. It's a very anxious time, but I still wanted to know all information. So regardless, I was asking loads of questions. It wasn't over whelming for me or exhausting at the end. It was in fact reassuring and made me feel in control. Maybe everyone isn't like that, but it's just that I had those questions to ask and wanted to hear the answers to help me make important decisions.

Much of the doctor-patient communication is standard routine practice, whereby a full patient history is explored and diagnoses of results are outlined. However, in Tina’s case, and those participants who chose to take a more ‘active’ role in their care, the level of discussion and the amount of information exchange was greater. As Tina explains, it was important for her to discuss matters further with the clinician, and to ask questions about uncertain areas. For Tina, not only was this a healing process and one which enabled reassurance, but it also gave her an element of control over her health care and decision-making process. Subsequently, her ‘active’ participatory role was seen to facilitate and contribute towards her decision-making experience.

Patient preferences for being ‘active’ and involved in medical decision-making were not only unique to a medical setting. For many women, as shown in extract three, participation in support groups and discussion, with other breast cancer patients, about their health care and treatment decisions, were also regarded as necessary to their decision-making process. This in turn was interpreted to facilitate their decision-making experience.

Ext 3. Helen. Interview 3. Lines 42-47

I joined this support group, which consisted of this group of old ladies who had all experienced breast cancer in different ways. I enjoyed attending this group, as we would sit down, have discussion and share information and knowledge about

issues or worries. We would ask questions to one another, and try to inform and advise each other. I learnt so many additional things that I didn't know. Things which aren't in the patient hand book, and things that the consultants don't necessarily tell you. This helped to put my mind and distress at ease. So it was another extra source of information to help me make decisions.

Many women like Helen, who preferred to be involved in their health care and decision-making process, also talked about the significance of attending support group sessions. These sessions, brought women with the same problems and issues together, where they could engage in discussions and share experiences or ideas. For Helen, the support groups enabled her to acquire information differently, compared to the standard NHS reading material. Here, Helen could learn from others' personal experiences, and engage in real life material, which she describes as an important facilitator in aiding decision-making, as well as acting as a useful coping strategy. Most importantly, the extract illustrates that for individuals with 'active' characteristics, by participating in discussions with others and sharing knowledge and information, the task of decision-making can also be encountered outside of the clinical setting and with non-medical individuals.

Within this sub-theme, the analysis also revealed some participants who showed opposite traits to involved patient. These participants instead retained 'passive' and submissive behaviours and were, therefore, inert to involvement in their care and did not want to participate in decision-making. Extract four by Debbie illustrates this trait in relation to her treatment for a mastectomy. She highlighted, in her account, that sharing decisions and being involved in her health care was not a priority, and instead preferred to refuse information and decline engagement, due to the fear of increased knowledge about her breast cancer.

EXT 4. Debbie. Interview 4. Lines 47-53

When I got diagnosed I got given a big information booklet, which I didn't look at. I didn't want to read anything. I didn't want to absorb any knowledge about it. I just wanted to just do it, get on with it, and forget about it. I still don't think it even hit me then. I just wanted it to go away. My husband would look up stuff on the laptop to read more about breast cancer. But I rather not, as it's finding out

about what you didn't originally know, that ends up worrying you in your mind. So I preferred to not know [LAUGHTER]. I think you can know too much sometimes, and I didn't want that. I didn't want that emotional weight to have to carry. I wouldn't even watch certain programmes on TV as I wasn't brave enough to deal with some of the cancer related storylines.

Debbie's response demonstrates signs of 'passive' behaviour, which appear to be rooted in her feelings of denial and apprehension to engage in any forms of written information, which might cause further distress. She states that she '*wanted it to go away*' and, therefore, by taking a preventative approach and being avoidant, this became a great way of escaping the issue and realisation of her breast cancer diagnosis. Despite her husband's 'active' role, acquiring knowledge appeared daunting and could expose her to feelings of anxiety and distress. Debbie refers to this as an '*emotional weight*' or burden to have to carry. Therefore, ignorance was regarded as bliss, and by putting up an unconscious barrier or a defence mechanism, which restricted the quantity of information acquired, this stopped her thinking about further health worries and fears. For the other 'passive' participants in the analysis, like Debbie, attaining knowledge was what opened realisation and fear of their cancer and, therefore, many chose to remain in denial by pushing the treatment out of sight and mind, and rejecting all participation in their care. Consequently, the definition of cancer is understood to be labelled as a pessimistic fear, which is fuelled by thoughts of disbelief. As Debbie's interview progressed, a clearer demonstration of how her 'passive' personality and portrayed fear of cancer influenced her involvement in decision-making. Extract five by Debbie, illustrates this further.

EXT 5. Debbie. Interview 4. Lines 24-28

Until this day I still haven't looked at the scar. It's like as if it all never happened, which is why I'm so ignorant towards my treatment. On the day I was diagnosed, we came out of the consultation and went in a room. Then the breast care nurse was trying to tell me things, but it never sank in. I didn't want to know or decide anything. All I could remember at that time was seeing the doctor face and hearing this word 'cancer'. I just couldn't stare at him, it was just that word.

Debbie's second extract shows that a great association is made between the word 'cancer' and fear. For Debbie, such association subsequently resulted in feelings of denial over her diagnosis, and caused her to avoid the disease and its management. For such patients, their encounters of decision-making are almost non-existent and shadowed by their fear of the disease, which subsequently hinders their involvement in any decisions for treatment choice.

In reviewing this sub-theme in relation to this theme, the analysis revealed that these two types of participatory roles appear to impact how SDM is understood and experienced. Extract six illustrates this with a participant who exerts 'active' characteristics.

EXT 6. Judy. Interview 10. Lines 60-66

I think I went prepared to ask them questions, because I had done so much reading. I had a list of questions that I used, taken from things that I had found on the internet, and I wanted to ask them specifically around that. They were very receptive to doing that. I think perhaps they gave me their spiel and then I had time to ask them questions specific to what I wanted to know. Perhaps maybe if I hadn't of asked any questions, then they would think that the information they gave would have been ok or enough. But for me I was keen to have a lot of discussion about the benefits and risks of all the treatments. That's what shared decision-making is. For me I needed to know the evidence behind everything, and it was extremely important that I understood the reasons behind what they were suggesting. I had to understand why I was going through something that was potentially quite a risky procedure, and I needed to understand what the risks and benefits were to make an informed decision. I think it's really important to be involved and how I experienced shared decision-making, I think, is probably due to the way I am.

Judy highlights her continual desire for participation in treatment knowledge and procedures. Her extract is a substantial example of 'active' participation within a consultation, as Judy is keen to form interactive dialogue with the clinician to acquire further information and understanding. For a patient with an 'active' personality, it is

noticeable that being part of the decision-making process is vital for them. We appreciate the importance of open discussions, which entail a two way process of questioning and answering, as this helps to shed light on ambiguities and iron out any anxieties or doubts. What is noteworthy from Judy's account is that she referenced a standard clinical practice. This was defined by Judy as a process which involved the doctor giving '*their spiel*', providing explanations, and then giving the patient an opportunity to ask questions. From Judy's account it is evident that this practice is not sufficient for all patients, especially those who like to play an 'active' role in their care. Therefore, in Judy's case, more sharing of dialogue was encouraged, to enhance her knowledge further, as this was viewed as essential to her ability to make an informed decision, and for her to experience SDM. Judy's extract shows that patient participation is important, and can be achieved by means of an active participatory role. By acquiring an 'active' stance, this can impact the relationship between clinician and patient, the types of conversations within a consultation, and amount of information seeking. As a result, the patient demands and expects more two-way interaction, information, and the opportunity for involvement. This in turn is interpreted and described by Judy to result in the process of SDM to take place, and to be, therefore, experienced during the consultation.

Extract seven below demonstrates that the 'passive' participatory role can also have an impact on how a patient perceives and experiences SDM. The analysis revealed that due to submissive actions towards patient participation, this subsequently resulted in an inactive experience of SDM for some participants.

EXT 7. Lucy. Interview 5. Lines 170-180

I was happy to place a lot of the decision-making in the hands of the doctor. I didn't want any control really because he knew what he was doing, and I just wanted to get on with it. I felt confident with him. He was nice, had a nice manner and he explained everything to me. I got involved as much as I wanted to get involved. I could have had control over my treatment if I wanted to, but I chose to put it one side and give that control to someone else. I was more than happy to pass on that responsibility over to an expert, and put it all to one side of my mind. So I don't really know what shared decision-making is. Even if it did exist or even if I was given the option to have it, I wouldn't want it. Like I said,

I didn't want to know, share, or decide nothing. Just wanted to let the doctor do what was right.

From Lucy's extract, it is understood that her 'passive' personality influenced her experience of decision-making and any encounters of SDM. In her account, she emphasised the need to reject involvement or control over her health care. Arguably, this is because, for a 'passive' patient, responsibility and participation are seen as an emotional weight, as supported by Debbie's extract. Some patients, therefore, preferred not to engage in such complex and emotive task of making a decision. As Lucy states, although she could have been involved and have control over her treatment plan, she felt safer if the clinician, with high expertise, was accountable for the decisions made. Therefore, similar to Debbie, it allowed her to avoid the topic and protected her from any feelings of distress, such as worry or anxiety. The reason why Lucy was able to exercise such passivity is explained and justified through her trust in the clinician, and expectation for him to deliver quality of care. Such confidence and trust is described to be established as a result of the clinician's enhanced knowledge and skills in the field, which subsequently places the clinician at a superior level. Therefore, for a patient like Lucy, there was no personal desire to be in control and involved in decision-making. This was especially due to the clinician being open to explain everything to her, to enable informed consent. As a result of such a 'passive' attitude and behaviour towards decision-making, extract seven shows that SDM appears to be limited. As Lucy explains, she had very little awareness of what the process of SDM is and, therefore, did not encounter it. Due to her personal requirements, this inhibited the process of SDM to occur with the clinician. This was, however, satisfactory for her and in accordance to her needs and personal preferences for involvement.

4.4.2 Theme two: power imbalance and SDM

This theme encompassed two sub-themes, associated with issues which influenced the degree to which participants encountered and experienced SDM. Sub-themes included *doctor-patient knowledge discrepancy*, and *medical professional roles and duties*. Associations between these two sub-themes will be discussed in relation to a perceived discrepancy in power between the clinician and patient, as this appeared to play an influencing role on how and whether SDM was encountered by participants. Interpretation of this theme revealed how and where participants positioned themselves regarding the

SDM process. For example, many participants perceived the clinician's role and expertise at a higher position compared to theirs, and as a result, this allowed the clinician greater control and superiority to make decisions. Subsequently, an experience of SDM became somewhat regulated and hindered by a hierarchal influence and enhanced skills of the clinician. The breast care nurses emerged to play an important role in facilitating patient encounters of SDM, and attempting to find solutions. This theme will now be discussed in more detail in light of each one of the two sub-themes.

4.4.2.1 Sub-theme one: doctor-patient knowledge discrepancy

This sub-theme revealed, that participants described an inconsistency between the clinicians' knowledge and experiences, in comparison to patients'. This in turn was explained to influence patient experience of SDM. Participants argued in their accounts that in order to be able to make appropriate decisions, a certain degree of experience and knowledge in the field of breast cancer is needed. As the clinician is a key individual who is fully experienced and trained, with the relevant skills to handle and manage breast cancer, participants subsequently stated that this helped to raise the clinician's hierarchal status and, therefore, obtain a higher level of control or discretion over treatment decisions, above the patient. Participants agreed that a lack of SDM during consultations is a result of the patient not acquiring high levels of expertise. This discrepancy in professional skill, subsequently, became the product of patient detachment from decision-making and treatment involvement. Extracts eight and nine both illustrate this matter further.

EXT 8. Charlotte. Interview 13. Lines 101-109

I had no control over decision-making. How could I?! How could I say 'no I don't want this, yes I do want that' when I didn't know exactly how the options worked or operated. Even if I was a bit more informed, I don't know how I could have been more in control, because I read and asked about whatever I could at the time. Cancer isn't like a cold, which is an everyday occurrence which you have more control over. Cancer is out of the blue, happens very quickly. Unless you are actually involved in day to day care with people with breast cancer, I don't think you have enough experience to make any big decision yourself. So I guess that can affect the task of

sharing a decision with a clinician, as you don't have the necessary skills to engage in that task with him.

Charlotte's account brings attention to the aspect of patient control within decision-making. In her description, it is demonstrated that control is very much dependent on a level of obtained experience, which is something that she lacked compared to a clinician. She explains that no matter how much she tried to seek involvement in her care, by asking questions or engaging in medical literature, this did not equip her with the same amount of experience required to make a decision, compared to a clinician in the field. She uses the concept of *'having a cold'* as a great example to elaborate on this. For example, a cold is an illness which patients are all capable of independently controlling and managing, as a result of our repeated encounter of the illness over years. However, for many, cancer is an unanticipated illness and one which patients lack experience of, unless their diagnosis is secondary cancer. Therefore, in the face of making a treatment decision, or engaging in SDM, for Charlotte, it felt like she was powerless and unqualified to experience it or take control of such a task. Conversely, she explains that a clinician, through practice and everyday encounters, acquires the appropriate skills and expertise and, therefore, can be viewed as more appropriately suited for such responsibility.

Another similar example which supports this issue of power imbalance, as outlined by Charlotte, is also illustrated in extract nine by Sophie. However, in Sophie's account, she associated the issue of doctor-patient knowledge discrepancy with negative feelings of intimidation and withdrawal, which resulted in a hindered process of SDM.

EXT 9. Sophie. Interview 13. Lines 139-141

I am an ordinary house wife with general academic knowledge. Nothing on their level of skills. So you can feel a little bit that they can be a bit overshadowing and unapproachable because of their professional knowledge. So you choose to not get involved as much. So half of the time you sat there in the consultation thinking, should I say that? Will they think I'm being a bit silly for asking that? So you end up just doing as they say because they know more.

Similar to Charlotte, Sophie's account demonstrates how participants view the clinician on a completely superior level compared to them. However, Sophie's account further shows

how the perceived issue of unequal power between the clinician and patient, can hinder patient experience of SDM. Sophie initially outlines a clear distinction in statuses, as she labels herself as an ordinary housewife who lacks the expertise of a medical professional. It is understood from her account that she felt intimidated and perhaps embarrassed to confront the clinician, due to such a knowledge discrepancy. This distracted her from wanting to get involved in the decision-making process and deterred her from the process of SDM. As a result, she became highly reliant on the clinician, which is evident in her comment *'so you end up doing as they say'*.

Within the next two extracts (extracts 10 and 11), it is observable that the clinician's level of knowledge not only creates a boundary between the patient and clinician, in terms of interaction and decision-making participation, but it also enhances the clinician's position. As a result of such perceived power imbalance, participants indicated that this rationalised for patient compliance and the lack of SDM within a consultation.

EXT 10. Louise. Interview 8. Lines 102-107

Personally, I just left it to the people who knew what they were doing. There was not much control out there for me to have, because if you have a problem that you can't solve, then you go to the doctor who solves it for you. I don't mean that in a derogatory way...I meant it in the sense that your doctor has the knowledge and skills to know what needs to be done, tells you what can be done, and you go ahead with it. So at no point did I feel like I was in control or had to chance to make any decisions.

Some women, similar to Louise, were forced to take a submissive route, as they believed that control, treatment options, and decision-making were out of their hands due to the logicity of the clinician's professional status of knowledge. For Louise, the clinician was seen as an authoritarian figure, due to his assigned role as a medical problem solver. As she truly believed that she was unable to treat herself she, therefore, knew the decision-making task was one which should be in the hands of the experts. As a result of adhering to this mentality, Louise began to show a compliant attitude and behaviour towards the treatment plan, as suggested by the clinician. This consequently left very little room for patient participation and the concept of SDM to operate.

Extract 11 by Katherine illustrates similar findings to Louise's account, however, Katherine account relates the impact of doctor-patient knowledge discrepancy and the issue of power inequality to the experience of SDM further.

EXT 11. Katherine. Interview 1. Lines 160-172

At the end of the day, it was ultimately my decision, but I just really left it to him basically. He's the expert! I use to say to him "you're the expert so you do what you feel the need to do". I don't think you're informed enough to gain that control yourself. Lay people don't have access to the latest medical research. They can only read what they are given, or know from what they see or hear in the media. I'm a believer that if you're the professional then you obviously know your job. Who am I to tell you what you should or shouldn't do? If you think that you can help me by going down that road, then I'm quite happy to go down that road. So I would say decision-making is a 70/30 spilt. The doctor has more power because he is the expert. He would say "right this is the kind of treatment you going to have, this is why we think you should have this treatment, these are the side effects". Then he would finally ask "how do you feel about that?" If it means saving your live, then having less power than the clinician is a small price to pay. So as far as I'm concerned, the clinician is in the driving seat which makes shared decision-making harder to take place.

Although Katherine begins her account by reaffirming patient rights in treatment decision-making she, however, indicates that she chose to discard her entitled involvement. Her rejection of patient participation in decision-making was justified by her understanding that the clinician retains more superior knowledge. This is illustrated by her ability to label the clinician as 'an expert'. However, Katherine showed no dissatisfaction towards there being a chain of command, as she indicated that patients do not have access to the right professional knowledge or resources, to have control over decision-making. What is of interest, further in her account, is that Katherine makes a statement which marks patient inferiority, and raises the issue of a power imbalance between patient and clinician. She expresses 'who am I to tell you', and presents an understanding that the patient is of no impact or importance to have the power and control to make treatment decisions. This,

therefore, reinforces the clinician's position of authority and highlights the impact of imbalanced power-relations. As a result, the participant's concept of SDM is provoked due to the clinician's position of educational superiority. Consequently, the practice of making an equal shared decision is hindered, as the clinician is perceived as a key figure that holds the decision-making power. It is evident in Katherine's account that there is a perceived power imbalance, due to the clinician's position of expertise, which can inhibit a patient's experience of SDM and their participation in the decision-making. However, the presence of such a power imbalance is not frowned upon or protested, as it is explained by participants, similar to Katherine, to be a small sacrifice made for an increase their survival rate.

4.4.2.2 Sub-theme two: roles and duties

This sub-theme highlights an issue raised by participants, which was the issue of the clinician's professional role and duty of care. In examining where the participants positioned themselves in relation to the clinician and their treatment, analysis revealed that the clinician is categorised as a trusted responsible figure, with a duty of care. This view is consistent with traditional concepts which labelled the clinician as a medical healer. For participants who obtained this belief, it subsequently became evident that the idea of participating or challenging the clinician was just not possible. Many women felt that they had to conform and respect the doctor due to his professional role, which they greatly trusted. This subsequently resulted in a heightened issue of imbalanced power-relations between the clinician and patient, which had negative effects on participants' experience of SDM. However, participants displayed no dissatisfaction, as they believed that the presence of a power imbalance and the resulting compliance was normal behaviour, and justified through the trust in which patients have towards the clinicians' role and duty of care. Extract 12 illustrates how levels of patient trust in the clinicians' role, can subsequently facilitate an imbalance in power-relations and submissive behaviours, and result in a hindered encounter of SDM.

EXT 12. Louise. Interview 8. Lines 102-108

I think you don't have control and you can't really participate in decision-making. I mean, how can there really be a shared decision-making process? Because everyone knows that if there is something medically wrong with you, it's the

doctor's role to put you right. I don't think it's an equal weighted relationship or shared process as you know that the cancer could kill you, and you want what is medically appropriate. So you turn to the people who know will do that. Like I say, I was involved as much as I needed to be. Just because I didn't want to be involved or didn't want a shared experience, it doesn't mean that I wasn't fighting it. It just meant that I had a lot of confidence in the people who were dealing with me. It's just putting your trust in other people [LAUGHTER].

The portrayal of the clinician, based upon Louise's account, is one which shows his position of responsibility. Great emphasis is given to the importance of trust within doctor-patient relationship and treatment decision-making. Louise explains that trust is an instinctive response felt, as a result of people's learnt understanding of whom and what a clinician's role is. For example, Louise explains that in the face of health problems, it is natural to initially place your treatment and health in the hands of a doctor, as she/he is regarded as the person to turn to and can give medical advice and care. With the clinician being granted such liability for managing and being responsible for individuals' healthcare, this subsequently meant that participants automatically associated the power and control of decision-making to the clinician. For Louise, control, treatment options, and decision-making was something which was out of her hands due to the logicity of the doctors' role and authoritative position, as a medical problem solver. As a result of Louise's preconception of the clinician's role and duty, she described deferential behaviour towards the clinician and took a submissive route to decision-making. It is understood from Louise's account that her understanding of patient participation was overruled by her deferential position, as she believed that the clinician should be in the driving seat of decision-making due to his given role. Consequently, she had acquired a perception that SDM is not plausible and cannot be experienced by patients. Yet, she states that regardless of choosing to sit in the passenger seat, this did not mean that she felt helpless or disadvantaged in any way, as it was her personal belief to comply with and trust those above her.

Extract 13 is another similar example of how patient perceptions of the clinician's role and responsibility, can impact feelings of compliance and hinder patient participation.

Within Jennifer's account, it is understood that participants' control over decision-making is surrendered as a result of a dominating sense of trust and belief that patients acquire about the clinician's role. An observed disparity in doctor-patient roles was illustrated within the analysis, which subsequently resulted in a lack of understanding about the concept of SDM, and its experience.

EXT 13. Jennifer. Interview 14. Lines 203-215

I don't know what shared decision-making is. I put all the faith and trust I had into the clinician, and had to take away in some respect the control from myself. I believed in these people and what they were doing, and because of my trust, I put the control in somebody else's hands. So by putting my health and life in this person's hand, I was therefore happy to listen and consent to what they said. I believe that they have worked hard to have that role and that why I handed over that control to somebody else who is an expert. I am just an ordinary patient. I remember one day the oncologist said to me "no, you don't have to have chemo, but if you choose not to, then I wouldn't be doing my job properly, especially if you come back to me in three years' time with cancer somewhere else" Then all of a sudden I thought he is right, he has a job to do which is to look after me, and I have to let me carry that out.

Jennifer explains that she had pure faith in the doctors and those who managed her care. As a result of her absolute trust, she believes that it was important for her to owe the responsibility of the decision-making control to the doctors. Subsequently, with the control being passed over to the clinician, it was therefore understood by Jennifer that she had to follow the clinician's advice and suggested treatment plan. To have felt controlled by the doctors was not an issue for Jennifer, as she carried a mind-set which highlighted the clinician as a medically trained professional, who has earned the role to be responsible for the patient and control the patient's health. Further in her account, Jennifer compares this view to her labelled status as an '*ordinary patient*'. Such a term redefines her role and repositions her in relation to the clinician, as someone of less expertise and superiority. As a result of her perceived inferior position, this subsequently helps to justify her behaviour of reliance on and compliance with the clinician. Therefore, the extract demonstrates how

participants were able to hierarchically position themselves, and the clinician, in relation to their treatment and decision-making processes. In Jennifer's case, such positioning involved granting the clinician the power to govern her care. Jennifer provides an example, taken from a conversation she had during a consultation, which further emphasises the difference in patient-doctor roles during decision-making. The scenario she provides raises attention to the issue of job role, and that the clinician has a duty of care to carry out. However, her situation also showed that the patient too has a role, which is to enable the clinician to practice his skills and knowledge, in order to aid the patient. Therefore, a distinct division and discrepancy of roles and positions is demonstrated. The clinician is portrayed as a person with well-defined superior responsibilities in relation to patient health, whereas the patient is perceived as a person who puts their trust into the clinician role and, therefore, hands over control and remains passive to decision-making. As a result of such acquired understanding about roles and discrepancies in roles, the concept and experience of SDM was illustrated to be limited. This is shown in the opening line to Jennifer's extract, as she noticeably states her unfamiliarity to SDM. She is unable to describe knowledge or her experience of SDM, as her decision-making experience is overshadowed by her attitudes towards the clinician's role.

Through exploring the sub-themes '*roles and duties*' and '*doctor-patient knowledge discrepancy*', it became clear that it was not only the clinician's role which impacted on patients' experience of SDM, but that the breast care nurses also played a vital part. Although much reference was made to participants' experience of SDM with the clinician, it was also indicated that SDM can take place with other medical professionals for the treatment of breast cancer. Participants frequently related examples of the emotional care, decision-making support, and information and advice that the breast care nurses provided. They described this as not only beneficial in decreasing patient distress, but also beneficial in facilitating participants with the confidence and ability to engage in decision-making, and encounter an experience of SDM. Extract 14 illustrates how SDM was also experienced between patient and breast care nurse.

EXT 14. Elaine. Interview 9. Lines 92-100

I would see the surgeon and then see the breast care nurse after. The surgeon would advise you what's best, and then the nurse would go over it with you. You see, you don't really

listen in the consultation, due to the shock. It's in one ear and out the other, so the nurse would go over it in simple terms. She would tell me about all the options. She played a big part involving me in the decision-making of my treatment, and helped me make the decisions. The nurse would sit down with me sometimes over an hour, and together we would go over things. You could ask all the questions you wanted to help you decide on your treatment. It was a very reassuring process which helped bring out the positives. That to me is a good example of shared decision-making.

Elaine demonstrates how the breast care nurses played a reinforcing role in encouraging and allowing SDM to be experienced by the patient. She explains that due to shock and emotional responses, much of what is discussed in a consultation about diagnosis and treatment can be distorted. Therefore, the breast care nurses ensured that information and knowledge was attained at all stages of Elaine's treatment, to allow her to make an informed choice. She explains that a large amount of nurse's time is devoted to allowing two-way conversations to take place. This involved a process of information exchange, whereby Elaine was given the opportunity to ask questions and share her queries. This demonstrates that, like clinicians, the nurses reciprocate the process of information exchange by devoting time to explaining and clarifying matters, through sharing of information and their knowledge. This process was highly valued by Elaine, especially since information was delivered in layman terms. For example, material and conversations with the doctor were broken down into simpler terms, which Elaine was able to understand and clearly digest, without feeling over powered or overwhelmed. By having had her knowledge enhanced, had her worries and queries addressed, and become more aware of her treatment options, this type of support subsequently played an important role in Elaine's decision-making. It is observable that the breast care nurses helped Elaine to feel involved in her care and treatment decisions, which resulted in an acquired experience of SDM. The sharing of information and knowledge, along with the interaction and discussions which took place between Elaine and the breast cancer nurses, created a similar encounter of SDM, of that experienced between patient and clinician. This is consistent with the early findings in the chapter (section 4.4.2), which also highlight the importance of information exchange and two-way interaction in facilitating an encounter of SDM.

The breast care nurses not only allowed patients to encounter SDM themselves, but they also played an important role in helping to facilitate SDM between the patient and the clinician. The breast care nurses were seen as the middle person or a bridge that ties the relation between patient and doctor, to allow for SDM to occur. Extract 15 demonstrates how this interconnected process occurs through the breast care nurses' interaction with both the clinician and the patient.

EXT 15. Margaret. Interview 11. Lines 227-232

I see it as a shared decision through a multi disciplinary team because if you have anxieties and queries about decisions and choices, then the nurses are a method of getting your anxieties across to the doctor. Sometimes I didn't even have to come into hospital, and they would just ask the doctor my questions for me, and then ring me back. They could pass information back and forth between me and the doctor. They were like the middle inside people who kept me involved and connected with the medical team. The breast care nurse dealings and efforts to keep my communication with the doctor really helped the decision-making process.

For Margaret, it becomes apparent that patients cannot always access the clinician outside of consultation appointments. Away from the hospital, she experienced feelings of worry and anxiety, which restricted her decision-making ability at home. However, Margaret explains how the breast care nurses acted as a source of relief to contact any time, as they provide reassurance by verifying matters with the clinician. For Margaret, it was important to have regular contact with the clinician to discuss and address her concerns, and so she could make an informed decision. She believes that the breast care nurses maintained a supportive and encouraging role, by ensuring that the patients' views and queries were persistently voiced and made aware to the clinician. Therefore, the breast care nurses help to maintain the patients' participation and commitment to the SDM process. Margaret states that she was keen to be kept informed at all stages of her treatment and, therefore, saw the breast care nurses as the '*middle inside people*', who could answer her questions and provide feedback from the clinician. This appeared to be a reassuring process for Margaret as it meant that she did not have to wait anxiously for the clinician's availability and appointments. Therefore, because of the breast care nurses' connections between the

clinician and Margaret, her experience of SDM was maintained and further encouraged, through the additional sources of information and shared communication.

4.4.3 Theme three: features of SDM

Through analysis of the patients' accounts, an important theme emerged which encompassed two sub-themes: *information exchange* and *two-way processes*. Both are concerned with the definition and characteristics of SDM from the participants' perspectives. These sub-themes brought awareness to a range of factors which influenced (facilitated) the degree to which SDM was experienced by participants. For participants, these factors were often described in relation to the process of SDM, and more specifically, used to describe what constitutes an experience of SDM. This in turn produced a theme which provided an insight into what characteristics are classified as an experience of SDM, how SDM is perceived by patients, and the meaning of SDM to patients. These two sub-themes will now be explored in more detail.

4.4.3.1 Sub-theme one: information exchange

A predominant feature which stood out in all participants, accounts was the notion of '*being kept in the loop*'. Regardless of the participants' participatory role ('active' or 'passive'), all participants felt that explanation and being informed by the clinician were important parts of their decision-making process. Therefore, to some participants, being given a detailed description of their own individualistic treatment; obtaining clarity over processes; and understanding the reasons grounding their treatment path, produced subsequent feelings of involvement, and for many participants, was described as an experience of SDM. Extract 16 demonstrates how the role of explanation, by the clinician, and the sharing of information were defined as key characteristics, and facilitated a patient's understanding of SDM.

EXT 16. Vicky. Interview 14. Lines 60-72

I saw the oncologist and he explained to me what type of cancer I got, how big the lump was, what I was going to have done. I was happy with that. I didn't have a lot of questions or felt the need to discuss it, because I was explained about

everything I needed to know. I was happy with my involvement. I don't think there was anything else they could have told me. You got a lump, you're going to have it out, you're going to have treatment after, and that's all. For me shared decision-making was the fact that I was being explained what was going to happen. That's what makes it an informed decision. By the doctor sharing all his knowledge with me and allowing me to know all I needed to know, that to me is a shared decision. Even if we don't make the decision together and he does, it's still a shared decision because he has shared everything with me.

Vicky defines what is meant by information exchange to the participant. Her account demonstrates an appreciation of full understanding of diagnosis and how the cancer will be addressed. For Vicky, having a full comprehensive knowledge of her treatment path was necessary before consenting. Therefore, this outlines a clear example of the requirement of informed consent in practice, and the importance of what she refers to as '*informed decision-making*'. Vicky's contentment in her level of involvement is displayed through her ability to acquire understanding. It is recognised, towards the end of her account, that her encounter of SDM is documented through her heightened gratitude towards knowing and being fully informed. Vicky was happy to allow the clinician to outline her appropriate treatment path. However, she still references to an encounter of SDM, which was experienced by means of this method of information and knowledge sharing. Therefore, by the clinician explaining each course of action, this was defined as an SDM process.

Extract 17 below, demonstrates another example of the impact of information exchange on patients' experiences of participation in decision-making.

EXT 17. Helen. Interview 3. Lines 60-65

I wasn't given a choice over surgery, chemo, or radiotherapy. I was told this is what you are going to have to have. I didn't mind being told that, because they said to me that that was the best regime to give me a better prognosis. As long as they explained it to me properly and that I could understand, then I felt involved in my health care and I felt that it wasn't going over my head. The doctors were really

good and I cannot fault their explanations, and how they talked me through what is going to happen to me.

Helen's account displays similarity to Vicky's, whereby the significance of explanation is highlighted. Helen outlines that a matter of choice in treatment decision-making was not always available, due to the type of breast cancer and diagnosis received. This meant that shared discussion over treatment choice, between the clinician and Helen, did not take place. However, this was not seen as problematic to Helen, as she still felt incorporated into the pre-made treatment decision. Her participation in decision-making was experienced through the clinician's ability to explain the decision made. From both Vicky's and Helen's extract, it is understood that as long as participants were aware of what, why, when, and how; and got to acquire knowledge and information from the clinician, then an understanding of patient involvement and participation in decision-making was achieved.

For some participants, the role of information exchange and being informed, did not only offer the clinician an opportunity to share knowledge and information. The process also allowed patients to voice their views and preferences and, therefore, to share information with the clinician about their concerns, queries, and beliefs. Subsequently, such reciprocal process of information exchange partially constituted an SDM experience. Extract 18 below, illustrates the clinician's shared explanations and the given opportunity for the patient to share their views and preferences. It also shows how the process of information exchange, by both the patient and clinician, helped to establish an experience of SDM towards treatment selection. Sarah explains this in relation to her personal experience of having to decide between a lumpectomy and a mastectomy.

EXT 18. Sarah. Interview 2. Lines 135-145

I suppose going to get a second opinion, to discuss the type of surgery I was going to have, is a classic example of a shared decision-making. I was very much in the opinion that I needed a mastectomy, because I just wanted to get rid of it and have the breast tissue taken away, so I completely eliminated the risk of it ever coming back again. That's why I was anxious when I was told I was going to have a lumpectomy. The fact that I was able to have that decision explained to, be told what the outcomes are if I had the lumpectomy, and have explained why a mastectomy was better,

that to me was a perfect example of shared decision-making, and one that I really valued. It allowed me to reflect a little bit more and be more logical about things. It made me feel less distressed, because you can be in such a state and not always thinking logically. So to have that extra time and to be able to have that explanation was handy in enable me to come to a mutual decision with the clinician.

Sarah provides a scenario which demonstrates a difficult time that she faced in having to make the appropriate surgical treatment decision. Primarily, Sarah explains that's she showed resistance towards decision-making, by choosing an immediate mastectomy. In her opinion, the option of a mastectomy eliminated all chances of the cancer returning, whilst increasing her survival chances. This was a reoccurring finding within the data, as all participants stated that when it came to surgical decision-making, patient choice and decision-making was not important. Participants obtained a belief that the clinical route to surgery should be to simply remove the cancer, as the principal aim of recovery is to remove the cells and increase chances of survival. Therefore, a strong attitude of '*just get rid of it*' occupied the data, as illustrated in Sarah's extract. However, to complicate decisions, most women similar to Sarah were encouraged by the clinician to have a lumpectomy, which created a state of dilemma. To ease this process, Sarah makes reference to the importance of explanation during the consultation, as this helped to reassure her confidence on the suggested surgery type. Her doubts over having a lumpectomy soon became diminished through a two-way process of information sharing. For example, by allowing Sarah to participate and share her worries, views, and preferences, through asking questions, this in turn also allowed the clinician to share his knowledge and information to address Sarah's concerns, and inform the patient. For Sarah, this was seen as a healing process which enabled reassurance. Therefore, acquiring an explanation not only enlightened Sarah's knowledge on the benefits of a lumpectomy and gave her a higher degree of optimism, but it also provided justification for the treatment, which she could understand and feel content with. As Sarah explains, the process of reciprocal exchange of information becomes associated with an experience of SDM. Sarah exemplifies high gratitude towards the process of SDM, as it allowed her to make and/or consent to the right decision, with the necessary knowledge in mind. Her experience of SDM also gave her some element of control over her emotions, as the discussions she shared with the clinician

and the information provided to her allowed her to independently rationalise and structure her thoughts and feelings accordingly. Therefore, the role of explanation and interaction here is presented to be more than just a duty in clarification. It activates patient control, and causes a mutual doctor-patient partnership to form, which starts an SDM process which can then be experienced.

4.4.3.2 *Sub-theme two: two-way processes*

Within the analysis, it became apparent that the role of two-way interaction ran very closely with the importance of information exchange. As outlined by Sarah, and by Vicky and Helen, much reference was made by participants about two-way conversations and interaction, and how this facilitated the sharing of information and knowledge; and in turn generated shared participation and constituted experience of SDM. The analysis revealed that two-way processes between the doctor and patient, such as two-way communication and mutual relationships, is an important characteristic of SDM during a consultation. For many participants, their understanding of SDM was shown to be related to their experience of a two-way interaction that occurred between themselves and the clinician. Within the data, much attention was drawn to the participants' experience of doctor-patient communication. Patient experience of SDM became regarded as a collaborative and equal weighted task, by means of doctor-patient conversation. With the clinician ensuring equal interaction during a consultation, the patient was given an opportunity to have a say in their treatment, as opposed to having it imposed on them or being directly instructed. Opening up a two way discussion, invited the patients to work together with the clinician to outline the best route of treatment. Extract 19 demonstrates such notion of two-way interaction, and how this is played a constituting role in a patient's encounter of SDM.

Ext 19. Elaine. Interview 9. Lines 106-111

In my experience of shared decision-making, it was a discussion. I would say a 50/50 process. For example, if the consultant was saying this would be the absolute best route for you to go down, but I was saying I'm actually not so sure about going down that route, then we would have a conversation together to come to an agreement. So decision-making would have to be 50/50 process. I would ask and then

he explains, I would query and then he suggests, and through this back and forth process together we reached a decision.

In Elaine's account, her experience of SDM is shown to be linked to the notion of interactivity. She highlights the importance of conversation in enabling her to engage and take part in the decision-making process. In a hypothetical scenario, she points out in her account, the importance of mutual agreement between the patient and the doctor. She explains that this can be achievable by means of two-way communication, and a 50/50 process. For example, the clinician's purpose is to identify and explain, whilst the patient has a duty to be able to query. Both actions coinciding result in an equal weighted route towards making the decision, and what is defined to be, by Elaine, as an encountered experience of SDM.

In some given situations, participants were told their treatment plan directly, with no element of treatment choice. Yet, participants still made reference to an encounter of SDM, which was as a result of two-way conversations during the consultation. Extract 20 illustrates that SDM is not only experienced or applicable to those patients who are given several treatments to deliberate and choose from. Rachel's extract below, demonstrates that SDM can occur even when there is no choice and little scope for the patient to feel involved. How this alternative is achieved, is through a process of two-way interaction that takes place between the clinician and patient.

EXT 20. Rachel. Interview 7. Lines 103-110

Nothing has ever been totally imposed on me. The clinicians input is more than a suggestion...it is the course of action which is appropriate. I suppose if at any point, for example, if I didn't want the lymph glands out, I could say. But I could see that that was a necessary medical action. I don't think even if there had been a choice it would have made any difference to the decision-making process. I still had everything explain to me regardless of having no choice, which allowed me to see why it was necessary, and why they were doing everything they want to do. So it did feel mutual and shared in that sense. Talking it out together and sharing one another's thoughts and knowledge made it feel like a shared decision.

In this recollection, it is evident that Rachel was offered no choice in her treatment selection. Nonetheless, she highlighted her rights, as a patient, to be able to voice any concerns or preferences. Rachel remained satisfied with the fact that she has no choice over treatment. Her contentment appeared to be due to her encounter of a characteristic of SDM, which was mutual interaction. Through interaction with the clinician about the treatment plan, this enabled Rachel to feel as if her treatment was not imposed. Having that opportunity to talk to the clinician to gain further knowledge, ask questions, and share her emotions, allowed for patient participation during the consultation. Subsequently, as Rachel explains, such involvement, therefore, gave a sense of SDM taking place and having been experienced.

4.5 Discussion

A TA on the semi-structured interview data identified three key themes, which provided valuable information and awareness about the experience of SDM for breast cancer patients, from their personal accounts. The first theme identified that the experience of SDM can mean different things, and be experienced in different ways, for different patients. The second theme emphasised a power imbalance between clinicians and patients, as an influencing factor which can hinder patient experience of SDM. The final theme drew attention to patients' understanding of SDM, and highlighted certain characteristics which define and contribute towards an experience of SDM. This section of the chapter will now discuss how the three identified themes answer the research question- how do women with breast cancer experience SDM? The discussion concludes with the researcher's personal and epistemological reflexivity, to outline certain issues and influences during data analysis and to outline how reflexivity has a place in the findings of this study.

The first theme titled '*personalising and adapting SDM*', highlighted the existence of patient participatory roles. Supporting previous research, patients either displayed an 'active' or a 'passive' participatory role, which influenced their levels of involvement in care and medical decision-making (Chewing & Sleath, 1996; Degner et, 1997; Guadagnoli & Ward). However, the analysis in this study moved away from showing how these traits impact health outcomes and decision-making in general, and instead explored and revealed

how the recognition of varying types of patient participatory roles influence a breast cancer patients' perception, understanding, and experience of SDM.

The findings from the data showed that patient participatory roles are associated with different experiences of SDM. In extracts one to three, the patients' enthusiasm to acquire information and knowledge, and eagerness to be involved in discussions was defined as an experience of SDM. Therefore, for an involved or 'active' patient, SDM was viewed as a process which involves the patient seeking information and knowledge. The task of information seeking is achieved through the patient's own determination to acquire resources (Internet, support groups, and leaflets), and by means of choosing to engage in doctor-patient interaction (Hack et al, 1994). As supported by extract three, the ability to acquire an understanding about their diagnosis and the treatments available, gave patients a sense of control over their health care, and helped to sustain reassurance and comfort. Furthermore, as extracts one and six indicate, the process of seeking information helped to increase patients' knowledge and confidence to engage in conversations with the clinician about decision-making, and to make informed decisions. As a result, the experience of SDM subsequently becomes largely associated with knowledge and the role of information transfer, achieved through a division of labour between the patient and clinician, to inform one another. Therefore, SDM is described as an experience which involves both parties to share valuable information and knowledge with one another, as this will facilitate a shared and mutual route towards informed decision-making. This supports the NICE guidelines (2004 & 2012) on SDM, and the existing literature on the definition of SDM (Beaver et al, 1996; Charles et al, 1997; Elwyn & Charles, 2001; Emanuel & Emanuel, 1992; Towle & Godolphin, 1999).

However, this theme also revealed that clinicians cannot assume that all patients will volunteer to take part in SDM. Not all patients demonstrated acceptance of the new patient role and participated in decision-making. For unresponsive or 'passive' patients responsibility was seen as an unconscious emotional weight to carry and, therefore, acquiring increased knowledge, making choices, or engaging in discussions about breast cancer was prevented. As extracts four and five illustrate, for patients who exemplified such traits, their goal was to maintain good health and emotional well-being. Therefore, being submissive, helped to act as a defensive barrier and coping strategy to protect the individual from feelings of distress and/or anxiety. Subsequently, as extract seven shows, the task of decision-making was passed to the clinician, which resulted in a lack of

understanding and familiarity with the concept of SDM. 'Passive' patients showed an inability to describe their understanding of what SDM is, or to be able to provide any personal examples of their interpretations of an SDM experience. However, this is still an important finding. The fact that 'passive' patients had no accounted experience of SDM implies that SDM must be a process, which is contrary to being 'passive'. This provides support and further intensifies the findings revealed by the 'active' patients, that SDM is a process of information exchange and knowledge acquisition, achieved through a patient's ability to engage in further reading and participate in discussions with the clinician.

The second theme, titled '*power imbalance and SDM*', drew emphasis to factors which can influence a patients' encounter of SDM. These factors included the issue of authority and control between the clinician and patient, and the role of the breast cancer nurses to sustain SDM. The theme captures the view of patients that specific power-relations govern SDM between the clinician and patient which, therefore, creates a hierarchical structure that assigns power and control of decision-making to the clinician (Emanuel & Emanuel, 1992; Haug & Lavin, 1981). Consequently, the issue of unequal power-relations was described as a factor which can hinder or restrict the experience of SDM. However, this theme also drew attention to the role of the breast care nurses, in reversing the power imbalance between patient and clinician. To explain this finding, patients referred to two factors: a perceived discrepancy in knowledge and expertise compared to the clinician; and a perceived issue of power-relations as a result of the clinician's professional roles.

The former factor showed that patients acquired a view that medical expertise, professional knowledge, and medical experience are all skills that clinicians obtain above the patient. This was explained in extract nine, as a key factor which gave patients the feeling that they were inferior compared to the clinicians. Extract nine also shows that for many patients, by not acquiring the right knowledge, skills, and everyday experience of the illness, this resulted in a lack of confidence, belief, and ability to be involved in decision-making (Coulter & Ellins, 2006; Thompson et al, 1993). Due to such inability to be involved, this left many patients stating that they lacked control over their health care, as supported in extracts eight and 10. Similar to the first theme, this highlights that patients' understanding and experience of SDM appears to be rooted in their acquisition of knowledge. Therefore, for SDM to occur, a substantial amount of knowledge is not only

required by the clinician, but by the patient as well. By having that knowledge and information, this allowed patients to feel similarly equivalent to the clinician, and enabled them to confidently participate in discussions and take part in decision-making. However, with the acquired view that *'the clinicians knows best'* and *'is the expert'*, it was understood by patients that, in reality, an experience of SDM cannot take place. Highlighted in extract 11, patients believed that it's not plausible to experience SDM, as automatic behaviour is to adhere to those who know more and are professionals in the field (Gafni et al, 1998; O'Flynn & Britten, 2006). The process of SDM became substituted with deference towards the clinician. Therefore, the meaning of SDM for patients is one which is perceived to be based on equal skills. However, in reality the equal split ratio is distorted and favours the clinician which, therefore, results in patients remaining submissive and compliant, and deters an experience of SDM between the clinician and patient.

The latter factor described by patients, which contributes towards such power imbalance, is the issue of the clinician's professional role and duties. Extract 12 and 13 revealed that patients had a tendency to describe an authoritarian system, which placed the clinician at the top of the ladder and the patient at the bottom, as a result of the clinicians' status and role. Patients made references to the clinician as a responsible figure, with a distinct role as health care manager, and who had a duty of care to improve patient health outcomes. For many women, this belief was subsequently driven as a result of the habitual trust one has in a medical professional when becoming ill. Therefore, the automatic action for many patients was to place the responsibility of decision-making in the hands of the clinician and to comply, as it was perceived to be the clinicians' role and duty to provide appropriate medical assistance. As a result of such attitudes and behaviours, patients became oblivious to the process of SDM and this obstructed their encounter of SDM. Therefore, a patient's experience and awareness of SDM was subsequently overshadowed by this perceived issue of hierarchical status.

However, within this theme it was also revealed that the breast care nurses have an important role to play in a patient's encounter of SDM. Not only did the information and support they provide alleviate patients' feelings of distress and anxiety, but this was described by patients to also allow for an encounter of SDM. Extract 14 shows that the breast care nurses showed substantial commitment in providing patients with the necessary information and knowledge needed to be able to make an informed decision. The nurses acted as a great source for patients to obtain and update their knowledge on treatments and

procedures. Many hours were devoted to the patients, as the nurses sat and engaged in two-way discussion with them, answered their queries, and ensured that they attained understanding about their treatment and/or decision-making options. This process of sharing information to one another, similar to that between the clinician and patient during a consultation, in turn, was perceived by patients as an experience of SDM. This finding is important as it illustrates that SDM is experienced with other member with a breast cancer multi-disciplinary team. Subsequently, this suggests that the concept of SDM is dynamic and applicable to all levels of medical professionals.

Further, it is observable from extract 15 that the breast care nurses not only encouraged the experience of SDM for patients outside of a consultation and with themselves, but they also played a role in facilitating and promoting further experiences of doctor-patient SDM. This was achieved through the nurses' ability to position themselves between the clinician and patients, and, therefore, act as a bridge which passes information to and from one another. The nurses filled in gaps in the doctor-patient relationship outside of a consultation, and this consequently kept an experience of SDM going for the patients. Through the nurses' efforts to maintain interaction between the clinician and patient; ensuring the patients' queries are heard; and providing the patient with information and answers from the clinician, this helped sustain the patients' experience of SDM, as well as encouraging it to take place. Once again, attention is given to the importance of acquisition of knowledge. The breast care nurses were able to facilitate an experience of SDM for the patient, through their ability to provide the patient with knowledge and information, during two-way interaction and discussions which took place between the patient and the breast care nurse; and through the link the nurses provided with the clinician.

The final theme titled '*features of SDM*', raised attention to the patients' understanding and meaning of SDM, through interpretations of their experiences. The theme illustrated the perceived characteristics of SDM for the breast cancer patients. Two key characteristics were perceived by patients, which were described to contribute towards an experience of SDM. The first characteristic which stood out within the data extracts was explanation. The role of verbal explanation was respected as a necessity to the decision-making process, as highlighted in extract 16. Patients valued it as a tool which exploited justification, involvement, and reassurance. Regardless of how much control patients desired over decision-making, the process of explanation was still equally important to them, as it was described as a means to maintain patient involvement in their health care

(Elwyn & Charles, 2009). This is consistent with both of the themes discussed above, which shows that the acquisition knowledge, through a process of information exchange and two-way communication, is valuable to a patient's experience of SDM (Elwyn & Charles, 2009). All patients gave clear accounts, which stated their preference and desire for an explanation and the transfer of information from the clinician; and to be kept informed about procedures. Subsequently, having that knowledge and insight about their treatment, through the clinicians' ability to share information and provide thorough explanations, helped to produce feelings of inclusion. It allowed the patients to feel on par with the clinician and, therefore, informed and confident enough to engage in decision-making conversation (Charles et al, 1999b & 2004; Hack, et al, 2006; Towle, 1997).

As extract 17 illustrates, not all patients were given the privilege of treatment choice, and were instead directed to their course of treatment. However, this was not seen as unethical, as long as an explanation or a rationale was not exempt from their consultations. This theme highlights the importance of doctor-patient relationship, with the role of two-way communication and shared interaction facilitating the relationship (Degner & Sloan, 1992; Frosch & Kaplan, 1999). This relationship is important for patients to establish in order to overcome any asymmetry of information between the doctor and the patient. As extract 18 illustrates, it was important that the clinician provided enough information and knowledge through explanations, as this enabled patients to feel involved and to contribute to the decision-making process. This, subsequently, allowed them to make informed decisions (Ong et al, 1995). As a result, this process of reciprocal information exchange was described by patients to be associated with an experience of SDM. It appeared that participation and feelings of membership in treatment decisions, were being sustained through this method of information exchange. Patients regarded this transfer of knowledge as a 'sharing' process, and one which they defined as an SDM experience. Subsequently, it is understood that the role of information is merely just a description, as it is what patients describe as an important aspect which defines SDM, and an important element which constitutes towards their experience of SDM.

The second characteristic of SDM, which coincides with the first characteristic discussed above, is the importance of equal interaction. The data drew particular relevance to the significance of verbal two-way communication during decision-making, as it allowed for an interaction of information and preferences to be shared between the clinician and patient. This was described as an important ingredient for the experience of

SDM (NICE, 2004 & 2012). As shown by data extracts 19 and 20, the patients' experiences of SDM were defined by means of their cooperative position, alongside the clinician, during discussions which took place within consultations. Unlike reading information, the role of verbal communication allowed patients to develop rapport, and, therefore establish a relationship with the clinician. For the majority of the women, a dual process of information sharing was interpreted as an equal weighted (50/50) route, towards an SDM experience. By opening up a two-way discussion, which operates on a cycle of questions by one person followed by explanations by another person, it invites both the clinician and patient to work together to outline the best route of treatment (Beaver et al, 1996; Charles et al, 1997; Towle & Godolphin, 1999; Elwyn & Charles, 2001). Therefore, the role of two-way interaction presented, by patients, is more than just a process of information exchange, as it contributes towards a *shared model* of decision-making, and subsequently enables participants to experience SDM.

4.5.1 Reflexivity: the researcher's voice

As mention previously in this chapter (section 4.3.6- data analysis), researcher reflection was an integral process throughout the analysis of study, and was maintained by means of a reflexive diary. My intentions in being reflexive were to be transparent and describe my potential influences. In having reached the findings discussed above, it is important to explore how I, the researcher, and inter-subjective elements impinged on, and even transformed, these findings.

I had initially come from Masters Qualification background, on the psychological impact of cancer on patient well-being and QOL. My previous research engagements with cancer patients, prior to starting this PhD, focused on the psycho-social impact of cancer treatments. Therefore, I found myself during the analysis of the interview transcripts, paying significant attention to patients' reported adverse side-effects and how this affected their QOL. I was emotionally interested about the devastating side-effects and horrific emotions, which participants experienced during their treatment trajectory. During the period of analysis, I also knew of a friend who was currently undergoing chemotherapy for breast cancer. Therefore, having spoken to her on several occasions about her treatment and psychological well-being, I was subsequently drawn to certain extracts about patient distress, hair loss, and depression, which focused me to explore decision-making

surrounding these topics. Such interest in the psycho-social well-being of breast cancer patients further fuelled me to want to learn more about the adjuvant treatment side-effects, and to explore whether the prospect of depleted QOL and emotional well-being can impact upon how a patient makes a decision. Subsequently, this encouraged me further to want to explore patient interaction to gain a greater insight into the difficulties and dilemmas during their breast cancer treatments. Such interest therefore provided further basis for me to conduct the second study of this thesis

As I had originally engaged in clinic observations prior to the collection of data, this had therefore equipped me with knowledge and examples of how decision-making occurs between the patients and the clinician. Subsequently, in reviewing the data transcripts, I found myself focusing on trying to find examples and instances, which mirrored what I had witnessed in my observations. During the clinic observations, I noticed a power imbalance between the patient and clinician, as very little patient participation in treatment discussions took place. Such acquired knowledge, therefore swayed me to look for instances within the data which illustrated power differentials during decision-making. My preconceptions about patient experience of SDM, during clinic observations, had resulted in influencing the initial codes and themes I drove from the data.

Having read the NICE guidelines (2004 & 2012) on SDM, I was therefore aware of the clinical procedures and communication skills needed for SDM. This made it very hard for me to examine the data irrespective of this. In exploring how the characteristics of SDM were perceived by participants, I found myself looking for key words such as ‘information-exchange’, ‘patient involvement’, ‘active participation’ and ‘sharing preferences’. Therefore, in some instances I was drawn to data extracts which demonstrated patients’ understanding of SDM in accordance to the guidelines, and not necessarily from their individual perspectives.

My own personal experience of having to make treatment decisions also influenced the way I examined the data. In the first year of my PhD, I was faced with the task of having to make a surgical treatment decision. I recall playing a very ‘active’ role in the decision-making process. I wanted to know lots of information and ensured to do a lot of online research about my illness. To make the right decision, I had questions to ask the clinician, and it was important for me to be able to share my queries, worries and

preferences during the consultation. My personality and individual traits played a key role in my ability to make a decision and, therefore, during the analysis, I was keen to see if patients' individual traits influenced their decision making and/or the process of SDM. Therefore, I was drawn to examples in the data which identified participatory traits, and I looked for examples within the data where individual differences were linked to a particular type of SDM experience.

Throughout the process of reflexivity during this study, I learnt that personal reflexivity can prove useful for evolving the research area. Being reflexive can help illuminate personal research interests, which can pave the way for future projects or additional studies within a project. In my case, by acknowledging my personal interests about the psychological impact of breast cancer on decision-making, this facilitated me to design the second study of this thesis, which would shed more light on the research question. I have also learnt, as a researcher, that during the process of reflexivity, despite what observations have been made previously, or the literature engaged in prior to data collection, it is important to keep the research question at heart of the data analysis. I occasionally had to remind myself what the purpose and aim of my PhD was, to ensure that my engagement with the data extracts, and how analytical themes were drawn, answered the research questions in Chapter One. In conclusion, I am aware that as a researcher that your personal experiences and research experiences can impact on the way you apply meaning and interpretation the data. Therefore, reflexivity should be noted at all stages, in order to provide further justification and clarity to the findings drawn from the data.

4.6 Conclusion

In exploring the research question, through examination of patient perceptions and encounters of SDM during semi-structured interviews, the three identified themes have yielded some important findings about the experience of SDM for breast cancer patients. The findings have demonstrated the impact of individual difference on a patients' experience and meaning of SDM. Therefore, it is understood that SDM is not a uniform process, and can mean different things to different people and/or is experienced in different ways, due to patients' active and/or passive positioning. A patient's experience of SDM is shown to be a variable process, which is self-managed by the patient's preferences for

involvement. This implies that patient encounters of SDM do not automatically occur throughout a patient's treatment path. Instead its occurrence is arguably patient-led and controlled by the patient.

The findings also demonstrated the hindering impact of imbalanced power-relations on patient experience of SDM. As a result of a perceived discrepancy in doctor-patient status and levels of expertise, patients were able to emphasise their understanding and the meaning of SDM, which was described to involve equal acquisition of knowledge and equal involvement in decision-making. However, although the data has revealed signs of a power imbalance between the clinician and patient, which impact upon a patient's ability to experience SDM, the findings also showed that an experience of SDM can take place outside of a consultation with the breast cancer nurses. Therefore, the process of SDM is illustrated to one that is latched within a multi-disciplinary team of breast cancer professionals. This allowed patients to encounter SDM through different people and at various stages of treatment.

Finally, in assessing patients' experiences of SDM, the analysis has opened in depth recognition to meaning of SDM, through a wider knowledge of key characteristics which constitute towards an experience of SDM. Focus is drawn to what is regarded as valuable content with a conversation (i.e. sharing information, preferences, and explanation) and how that content should be delivered (i.e. through two-way interaction). Therefore, the findings elevate attention to the significance of doctor-patient relationships and communication during a consultation, in allowing for two-way information exchange and interaction to occur between clinician and patient, as this works towards a *shared model* of decision-making.

In conclusion, the interview data has revealed substantial awareness around the experience of SDM, from the patients' perspectives. It has also revealed an insight into the additional questions, outlined in Chapter One. For instance, it has informed about what the concept of SDM means to patients, and what characteristics of SDM are. It has provided an insight into the factors which facilitate and hinder patients' encounters of SDM. It has also showed that SDM for breast cancer be explored qualitatively, through an examination of patient perceptions. The main discussion chapter of this thesis (Chapter Seven) will further explore the findings of this study in relation to the implications it has on breast cancer care,

further health research, and qualitative research. Chapter Seven will also further discuss the findings of this study in more detail, in relation to the literature review outlined in Chapters One and Two, and the overall research questions.

The findings from this study have drawn particular attention to patient participatory roles, and issues of a power differential between the patient and clinician. They have also posed questions about the role of two-way interaction and communication within a patient's experience of SDM, specifically about the surrounding discourse and interactions which take place for SDM, and how this further shapes patients' experience. This subsequently warrants further research, underpinned by a symbolic interactionist methodology, which focuses on exploring patients' experiences of SDM through communication and interactions with others. The next chapter introduces the second study of this thesis, which aims to explore patients' experience of SDM, through the interactions they have online with other breast cancer patients.

Chapter Five

Study 2: exploring SDM within online breast cancer forums

Chapter 5

Study 2: exploring SDM within online breast cancer forums

5.1 Introduction

The previous study in Chapter Four took a phenomenological approach and explored SDM from the patients' perspectives by means of semi-structured interviews. Thematic analysis (TA) of the interview transcripts identified three themes: the role of individual differences on a patient's understanding and experience of SDM; the importance of information exchanged and two-way interaction within doctor-patient relationships during SDM; and the impact of imbalanced power-relations between the clinician and patient, which hindered SDM taking place. From these three themes, the role of two-way communication stood out to be an important descriptor within participants' experience of SDM. The study provided a deeper understanding of the experience of SDM, by women with breast cancer. It also provided additional insight about the meaning and characteristics of SDM, as perceived by patients; and brought attention to how the experience of SDM can be influenced (hindered or facilitated) for women with breast cancer

In order to achieve the overall goals of this thesis, a second theoretical approach was introduced in Chapter Three, which focused on exploring the research question by means of a more interpretive perspective, by citing a symbolic interactionist approach. In line with critical health psychology, this theoretical framework focuses on the symbolic meaning that people develop and rely upon, in the process of social interaction. Attention is given to the way that people interact through symbols such as, words, gestures, rules, and roles. Understanding these symbols is important in understanding human behaviour (LaRossa & Reitzes, 1993).

The findings from study one (Chapter Four), which emphasised the importance of two-way communication for SDM, demands an interactionist paradigm to examine the research questions further. This chapter introduces the second of the three qualitative studies, which explores SDM through patient interaction. This is achieved by exploring conversations which take place between patients within online breast cancer forums. In this chapter, a short literature review is provided, which focuses on exploring the use of computer mediated communication as a method of data collection within health research,

and a way to access patients' health experiences. The usage of online forum data will also be discussed in relation to existing SDM research, and its applicability in exploring SDM amongst breast cancer patients. Following the literature review, the method is described. This is then followed by a detailed explanation of the findings achieved through a TA on the online forum data. The chapter concludes with a discussion of the findings.

5.2 Literature review

5.2.1 The Internet as a medium for qualitative research

The Internet, also referred to in research as 'cyberspace' or the 'World Wide Web', is used by many people for daily tasks, such as sending and receiving personal emails, accessing public information, viewing merchandise, making purchases online, and generally for information gathering and transmission. The Internet is also increasingly used as a social space where relationships, communities, and cultures emerge through the exchange of messages and images. Due to the expansion of use in computer mediated communication, over the past decade, the number of studies about the Internet has grown dramatically (Consalvo & Paasonen, 2002; Loader, 1998). It has yielded new opportunity for psychological research, as it lowers the cost of data collection (Gaiser, 1997; Hamman, 1996; Nosek, Banaji & Greenwald, 2002); provides data on varied phenomena (Sproull, 1995); and makes interesting psychological phenomena -which might not exist in traditional settings -visible. (Sproull & Kiesler, 199; Stewart, Eckermann & Zhou, 1998). According to Clark (2000), the accessibility of information for analysis, and the anonymity of the Internet, allows researchers to analyse text and narratives on web sites, to use online groups as global focus groups, and to conduct interviews and surveys via e-mail and chat rooms, all of which are suited to qualitative research.

Qualitative inquiry is grounded in information collected from observation, text, talk, and interviews (Silverman, 1997, 2001). According to Barbour (2000), "qualitative methods seek to acknowledge the existence of and study the interplay of multiple views and voices- including, importantly, lay voices" (p.156). The types of communication and interactions made online, through Internet postings, are suitable for qualitative research. For example, it is possible to determine information needs and preferences of online users,

or to investigate how health-related information can be distributed online and best converted into knowledge (Eysenbach, 2000). As a medium for communication, the Internet provides new channels for people to communicate with each other, and for researchers to communicate with participants. This allows research to capitalise upon emerging discursive forms and practices, to study the way people use communication and interact. Furthermore, as a context of social construction, the Internet is a unique discursive environment that facilitates analysis surrounding the structure of talk; the negotiation of meaning and identity; the development of relationships and communities; and the construction of social structures as these occur discursively. The linguistic and social structures that emerge through online communication, provides the opportunity for researchers to track and analyse how language builds and sustains social reality. Subsequently, the Internet offers qualitative researchers many means of observing and/or interacting with participants, in order to study the complexity of language and interaction. It can be used as a tool for research topics unrelated to the Internet, and/or it can be used as a specific social phenomenon. Regardless of how it used, the Internet is both a tool of qualitative research, and a context worthy of research. This has been demonstrated diversely across relevant literature.

Research reveals three different types of Internet based research methods (Eysenbach & Wyatt, 2000). The first is 'passive analysis', which requires studying information patterns on websites, or interactions on discussion groups, without the researchers actually involving themselves. Previous research examples of this include, the study of content and help seeking within online self-help groups for colorectal cancer (Klemm, Reppert & Visich, 1998), breast cancer (Sharf, 1997), Alzheimer's disease (White & Dorman, 2000), and eating disorders (Winzelberg, 1997). The second type of online research is through 'active analysis', which involves the researcher participating in communications (Seaboldt & Kuiper, 1997). The final type of online research is through a process, which requires the researcher to gather information in the form of online semi-structured interviews, online focus groups, Internet based surveys, or to use the Internet to recruit participants for 'traditional research'. These three methods illustrate the degree of diversity in research that can take place with the Internet, as a research tool.

There are a variety of examples of qualitative research contexts, conducted with the Internet. Examples include the use of chat rooms to examine accounts and conversations about rape (Dibbell, 1993), and how computer-mediated communication (CMC) users

compensated effectively for the absence of non-verbal and paralinguistic elements of conversation (Witmer & Katzman, 1998). In relation to health research, Johnson (2003) used the Internet to explore anorexia, as a lifestyle rather than a disease. The study found that women were actively constructing a global, yet, anonymous community, which provided solidarity and helped to justify their choice to be anorexic. These studies not only demonstrate the usability of the Internet for qualitative research, but also illustrate how the Internet provides new tools for conducting research, and new venues for social research. Online research also provides new means for understanding the way social realities are constructed and reproduced, through discursive behaviours.

5.2.2 Online forums as a medium for health research

The emergence of online support groups in the 1990s has grown into a mass social phenomenon, along with individuals' growing ease in using CMC technology (Walther, 1996). These online groups are providing new opportunities for patients to communicate with health care professionals, and other patients. Online support groups can operate through various Internet applications such as, an email list, a chat room, or a forum (bulletin board). As an online support group differs from a therapy group, this can have certain benefits for users who do not have the desire to attend face-to-face sessions. Some people may find online support groups a more suitable 'venue' in which to discuss a sensitive issue. The anonymity often afforded by the Internet means that messages posted to one another are decontextualised, and free from physical cues to the senders' sex, age, race, disability, and physical appearance. It also allows discussion of potentially embarrassing topics or taboo subjects, whilst minimising the fear of rejection, therefore arguably increasing the possibility of self-disclosure and intimacy, and encouraging honesty (Ferguson, 1997a; Galinsky, Schopler, Abell 1997; Klemm & Nolan, 1998; Madara, 1997). This is particularly useful for patients with breast cancer, as the visible disfiguring effects from surgery and chemotherapy are avoided (Finfgeld, 2000). Many forms of online support groups enable access to information, support, and emotional relief and are an accepted technology, as participants take advantage of their synchronicity, easy access, opportunity for archival search, convenient links, and friendly design (Meier, 2004).

Online support forums exist on many health topics, and have grown in numbers due to the expanding needs of individuals to know more and be more involved about their health conditions. More support forums are providing mutual aid and self-help for people facing chronic disease, life-threatening illness, and dependency issues (Cline, 1999). For those who take part in an online support forum, groups function as accountable sources of help, through which they transmit and obtain information, provide and receive emotional support, socialise and form interpersonal relationships, and experience comradeship with others sharing a similar distress (Bane, Haymaker & Zinchuk, 2005; Cawyer & Smith-Dupre, 1995).

Internet chat rooms and support group bulletin boards provide a rich sample of human behaviour that can be mined for studies of communication (Galegher, Sproull, & Kiesler, 1998; Nardi & Whittaker, 20012). Health-related research has generally focused on studies that evaluate the Internet, and illustrate its impact on health care users, by identifying what patients use the Internet for. For example, Finn (1999) examined 718 messages over a three month period from an online bulletin board. The postings were divided into two realms: socio-emotional messages (expression of feelings, provision of support, casual conversation, friendship, taboo topics; and task-oriented messages (asking for or providing information, problem solving, computer talk or group cohesion). Results indicated that over 50% of postings concerned socio-emotional exchanges. Subjects mostly discussed health and interpersonal relationships, followed by legal and political issues. Similarly, Braithwaite, Waldron, and Finn, (1999) examined one month's messages (1179 postings) to a disability bulletin board and found that the most frequent category of postings concerned emotional support (40%), followed by information (31.7%), esteem support (18.6%), networking (7.1%) and tangible assistance (2.7%). These findings have led further research to explore the impact of Internet use, to examine specific groups of Internet users (e.g. the 'self-helpers'), and to investigate the practices patients deployed from Internet interactions during treatment (Burrows, Nettleton, Pleace, Loader & Muncer, 2000). Studies show that the Internet seems to be used in many different ways by people with serious illnesses, at various stages, and follow-up, to acquire expertise and to display competence in the face of serious illness (Ziebland et al, 2004). This and other studies have found that wider access to medical information is inevitable and likely to encourage a balanced encounter between patient and health professional, to increase the appropriate use of medicine (Grol, 2001). However, others have drawn attention to the dangers of patients

using the Internet for health information, due to the potential for misdiagnosis and exploitation (Eysenbach & Diepgen, 1998; Heathfield, Pitty & Hanka, 1998; Jadad & Gagliardi, 1998). It has also been suggested that Internet use can erode patients' faith in the authority of health-care practitioners (Hardey, 2003).

Other related research has evaluated and assessed the impact of the Internet on patients' health and their treatment. For example, studies have found that an increase in the use of the Internet for health information can result in positive shifts towards more equitable, or even patient-controlled, relationships between practitioners and patients (DOH, 2001b; Graham, Smith, Kamal, Fitzmaurice, & Hamilton, 2000; Hardey 2001; Ferguson, 1997b). Therefore, it is suggested that Internet use may lead to further shifts in the models of doctor-patient interaction, used in health care settings (Gothill & Armstrong, 1999; Little et al, 2001). More specific studies have focused on exploring the health benefits of online support groups for patients. Some have shown benefits such as, enhanced QOL and increased survival time (Cline, 1999; Spiegel, 1994); and reduced depression and cancer related trauma (Housten, Cooper & Ford, 2002; Winzelberg et al, 2003). A questionnaire study showed the significant positive impact that group forums can have on improving decision-making (Spiegel et al, 1989). Other suggested benefits include a sense of power given to forum users, through the process of writing itself, as this activity was argued to enable emotions to be opened and a sense of cognitive order (Pennebaker & Seagal, 1999, Pitts, 2004); improve interpersonal interactions and reduced feelings of isolation, which are established through social relationships (Braithwaite et al, 1999); and enable users to acquire and improve their self-confidence and reassurance (Hoybye, Johansen & Tjornhoj-Thomsen, 2005).

Traditional face-to-face support groups are a usual integral aspect of treatment for patients with cancer (Cella & Yellen, 1993; Spiegel et al, 1989). However, over the years, online groups for cancer support have flourished (Klemm, Hurst, Dearholt, Trone, 1999). Research has found that the Internet is more commonly used, in a health context, by breast cancer patients. Nearly half of women recently diagnosed with breast cancer turn to the Internet for information on health (Satterlund, McCaul, & Sandgren, 2003). The UK has numerous cancer support charities that provide free and accessible online support groups for their members, and all breast cancer patients. Discussion boards within these cancer support groups can vary in content, but are usually categorised according to topics related

to diagnosis, treatment and side-effects, QOL recurrence, and alternative therapy (Weinberg, Schmale, Uken & Wessel, 1996). Several randomised controlled trials, conducted with breast cancer patients, found women used online forums extensively (Gustafson et al, 1993; McTavish et al, 1995; Rolnick et al, 1999; Shaw, McTavish, Hawkins, Gustafson, & Pingree, 2000). Similarly, Weinberg et al (1996) studied an electronic bulletin board established by breast cancer patients, and found during a three month period, that participants used the forum significantly more than face-to-face groups.

Online cancer forums are a popular form of engagement amongst breast cancer patients (Klemm et al, 1999), and research attention has, therefore, turned to explore its uses. Sharf (1997) found that information requests amongst breast cancer forums were the most common interactions, followed by psychological and emotional support, exchanges of personal experiences, and humour. Topics discussed included surgical treatments, side-effects, news items about breast cancer, doctor-patient relationships, and encouragement issues. This is further supported by Klemm et al (1998), who demonstrated that postings on breast cancer support groups could be categorised into eight groups: information giving and seeking (25.4% of the interactions), personal opinions (22%), encouragement and support (17.4%), personal experience (16.4%), thanks (7.7%), humour (4.5%), prayer (2.9%), and miscellaneous (3.2%). Fernsler and Manchester (1997) found that over 85% of the cancer members of a support forum stated that contact with others, who have undergone similar experiences, was the most beneficial aspect of the forum. These studies provide useful knowledge about the function of forums for breast cancer patients, and highlight the “give and take” of information as a key exercise for interaction.

However, this does not apply to all forum users. Not all choose to take a participatory role in interacting and responding, and instead choose to utilise the forums for more passive purposes. Researchers have noted the invisible presence of hundreds, or perhaps thousands, of members who read but do not participate (King & Moreggi, 1998). Subsequently, the phenomenon of ‘lurking’ or reading messages in an online forum without actively sending any messages, has also been identified as a frequent feature of online groups (Brennan, 1996; Brennan & Ripich, 1994; Burrows et al, 2000; Klemm & Nolan, 1998; White & Dorman, 2000). According to Brennan et al (1996), passive online members may select a low level of visibility and participation as their preferred method of functioning in any group situation. Both Winzelberg (1997) and Finfgeld (2000) suggested that shy or reserved members may choose to lurk until they understand the group’s norms

and style. Occasionally patients, who choose to lurk in a group discussion, write to say how valuable the groups are, before returning to lurking (Dickerson, Flaig & Kennedy, 2000).

From the research outlined, it is evident that the Internet mediates interactions, and offers new ways of conducting qualitative research. With more attention being focused on the use of online support groups and forums, these forms of communication and interaction have been shown to be valuable to health research, particularly breast cancer. From research, it is evident that individuals utilise these discussion rooms to seek advice, to improve their QOL and levels of emotional wellbeing during the course of their treatment. These studies generally take an evaluative approach to assessing Internet use and its implications for patient health. However, it is also important to explore whether the Internet can be used as a tool to access patients' lived experiences and perspectives in relation to their health care. As the literature review above has already outlined, the Internet can be used as a medium for qualitative research. There is a need to further explore research that takes a more interpretivist perspective, which is rooted in symbolic interactionism, to further understand the Internet's contribution to qualitative health research. This will be explored next in relation to symbolic interactionism and breast cancer research.

5.2.3 A symbolic interactionist approach to online health research

The Internet has frequently been evaluated within health research, through qualitative methods. According to Jones (1999), "There are no 'traditional' methods for studying or using World Wide Web or anything Internet related" (p. xi). However, the significance of qualitative research practices is growing in online research (Sharf, 1999). Fernback (1999) argued that interpretative methodologies are best suited for studying online communities, as it recognises the importance of language and human interaction as forms of social action (Atkinson & Heritage, 1984; Austin, 1962). With the amount of data already available online this, therefore, highlights the suitability for interpretive methodologies, which aim to analyse social experience in everyday, naturalistic contexts (Gill, 1993; Wetherell & Potter, 1988). To adopt a symbolic interactionist approach, the researcher needs to be actively engaged in the world of the study and, therefore, the Internet has become a good

source in achieving this, through its accessible archives of communication. The basic assumption of symbolic interactionism is that meaning is a social product made possible through social interaction with others (Blumer, 1969). The use of online support groups, therefore make the symbolic interactionist a suited approach to this type of data platform.

Previous work has shown the benefits of online research, which employs a symbolic interactionist approach, in studying social processes, such as personal influence (Cummings, Sproull & Kiesler, 2002), negotiation (Biesenbach-Lucas & Weasenforth, 2002), and identity formation (McKenna & Bargh, 1998). This method of enquiry and theoretical framework is increasingly used in the studying of health and illness. There are examples of research which examine online groups to explore the meaning of health and illness (Crooks, 2001; Heilferty, 2008; Kalichman, Benotsch, Weinhardt, Austin, Luke 2002), and to explore the Internet's role in health information (Eysenbach & Köhler, 2000; Hardey, 2003; Impicciatore, Pandolfini, Casella & Bonati, 1997; Ziebland, 2004).

More specifically in breast cancer research, online studies that are rooted in symbolic interactionism have been reported. These studies aimed to use the Internet to acquire a better understanding of the lived experience of treatment side-effects (Holley, 2001); exploring patient attitudes towards breast cancer (Im, Chee, Lim, Liu & Guevara, 2007); conceptualising the meaning of breast cancer (Høybye, Johansen, & Tjornhoj-Thomsen, 2005; Orgad, 2005); and examining cancer survivors QOL (Zebrack, 2007). A symbolic interactionist approach to exploring decision-making amongst breast cancer patients online has also been demonstrated. This was achieved by Sharf (1997), who explored lived experiences of breast cancer patients, through observing their communication within online groups. Sharf's findings, importantly, demonstrate that an individual's decision-making can be enhanced through discussions which take place within online forums. The discussions which took place between patients online, challenged patients to rethink and reevaluate their prior decisions, attitudes, and courses of action regarding treatment choice. Online interaction, within support groups, helped patients to cope with the emotional, social, and practical difficulties of treatment side-effects. It also enabled patients to gather more information; gain a better understanding of the nature of their distress; and develop ways in the handling of their condition, and feel more confident implementing their decision. Sharf's study also highlighted the importance of interaction in enhancing patient control. Becoming a member of the group offered an approach to

meeting cultural and social needs, which resulted in the experience of personal control, and facilitated decision-making (Braithwaite et al, 1999; Burrows et al, 2000).

With research showing that online support groups can contribute towards a breast cancer patients' experience of treatment decision-making this, therefore, opens suggestions as to whether similar findings can be achieved with SDM. However, there is little research conducted with online forums to explore the concept of SDM and breast cancer patients' experiences and understanding of the concept. For instance, do online forums provide evidence on the extent to which patients discuss the clinical decision-making processes? What meaning does online participation have on patients' experience of SDM? Can the definition of SDM extend beyond patient and clinician, to include others outside the clinical setting? These are all questions that remain unanswered in the existing SDM literature, and in conjunction with the findings established from study one, provide a rationale for exploring SDM online in breast cancer forums. The rest of this chapter will outline the second study of this thesis, which explores SDM within an online community enterprise for breast cancer. Following a description of the study method, the chapter will then outline the results of the analysis, and finally present a discussion on the findings.

5.3 Method

5.3.1 Study design

As interpretive approaches, such as symbolic interactionism, rely heavily on naturalistic methods, breast cancer Internet forums were chosen as a qualitative data source. This material provides an opportunity to explore breast cancer patients' interactions with other patients about their illness and treatment, and their experience and understanding of SDM.

5.3.2. Forum selection criteria

An extensive online search was conducted on UK breast cancer forum websites. Searches were conducted on the 'Google' search engine using key words such as, 'breast cancer', 'forums', 'support groups', and 'discussion boards'. Relevant forum websites were selected on the basis of their topic content (in accordance to Weinberg et al, 1996), and if they mentioned reference to decision-making. From the search process, some of the

websites with these key words were reports, articles, and information pages, which contained no patient discussion. These websites were disregarded. The websites selected for analysis were:

- Breast Cancer Care: www.breastcancercare.org.uk/community/forums/
- Breast Cancer.Org: www.community.breastcancer.org/
- Macmillan Cancer Support:
www.community.macmillan.org.uk/cancertypes/breast-cancer/discussions.aspx

All three websites are UK based organisations that provide information and practical support, campaigns, and bring together patients with breast cancer. Participation in forums requires a private non-fee membership, which subsequently allows members to post their topic for discussion or respond to others. However, these websites are open and accessible to non-forum users, who are able to read members' stories and responses. All of the selected discussion forums were publicly visible and require no membership or subscription to view the online post content. The researcher did not contact members or respond to any of the posts online.

5.3.3 Participants

On the three forum websites and during a two week time frame period, from 15th May 2013 to the 29th May 2013, a total of 571 subscribers posted across the three forums: 162 women posted messages to the Breast Cancer Care website; 189 to the Breast Cancer.org website; and 220 to the Macmillan cancer support website. Amongst those numbers were women who were currently diagnosed with breast cancer; were undergoing surgical treatment; were undergoing adjuvant treatment, and who were post-treatment completion. However, women who used to have breast cancer were the most active subscribers to the three online groups, which represented 83%. (474 women across the three forums). The remaining 17% (97 women across the three forums) were family members, friends, concerned others, and one medical professional (who was not a cancer specialist). Only the 83% were used for data analysis. A total of 332 posts were reviewed across all three websites, and amongst these there were 268 participants (some participants posted within a discussion thread more than once). Participants were all women, aged 37-68 years. This information was directly accessible online, as all the members had their age indicated in brackets next to their name, or they mentioned their age within a post. Different stages of

treatment were evident amongst the 268 participants. However, 72% (193 participants) of the sample represented those who were post-treatment for cancer. Amongst the remaining 28% (75 participants) of the sample, a wide range of treatments were presented, including mastectomy, lumpectomy, hormone therapy, radiotherapy, and chemotherapy. However, chemotherapy constituted 80% (60 participants) of this sample. Information about their stage of treatment plan was identified through examination of the content of their posts online.

For the purpose of consistency with study one's inclusion criteria, participants who had opted for breast reconstruction following a mastectomy were not included in the sample. As reconstructive surgery entails its own dimension of decision-making, focus was therefore maintained on patients who only had to make surgical and adjuvant treatment decisions.

5.3.4 Data collection

Having conducted the search criteria to select the forums for analysis, attention was then given to thoroughly exploring each website, to enable familiarity with each website's structure and content. All three websites displayed posts in written English and, therefore, did not require any translating. Each website was structured in a similar format, as each forum outlined several topic discussion categories, and subcategories existed within each category. Figure 5.1 illustrates an example of the layout, taken from the Breast Cancer Care website, and how categories and subcategories are presented online. Forum users started interaction and discussions threads, by posting their concerns or issues under the relevant website subcategories, which corresponds to the discussion topic they wish to engage in. Across all three websites, it was noticeable that they all contained similar topic categories and subcategory topics. This, therefore, allowed for easier handling of data. All the categories and subcategories across the three websites were initially reviewed, and since all messages were archived, this made it easy to access the posts within each category, on the three websites at any time. However, due to the large number of messages within each website, a decision was made to introduce a data inclusion criterion. The first criteria was that only posts that were relevant to the topic of breast cancer and QOL, breast cancer treatments, and decision-making, were to be included for data analysis. This ruled out non-disease related conversations. For example, the forums were occasionally used by

women for leisure and social purposes, and to talk to others about daily interests such as, books, TV programmes, and films. Another criteria was that only posts, which fell within the two week time frame (between 15th May 2013 and 29th May 2013), were used to ensure that the data was recent and up to date.

Categories

View the latest threads here

<p><u>Welcome to the forum</u></p> <p>New to the forum? Find out how to get started and find support.</p> <p>5 new threads this week</p>	<p><u>Have I got breast cancer?</u></p> <p>Worried about symptoms of breast cancer or a family history?</p> <p>10 new threads this week</p>	<p><u>I am recently diagnosed</u></p> <p>Just been diagnosed? Access information and support here.</p> <p>16 new threads this week</p>
<p><u>Going through treatment</u></p> <p>Talk to other people undergoing treatment for breast cancer.</p> <p>35 new threads this week</p>	<p><u>Living with & beyond breast cancer</u></p> <p>Receive and give support to others no longer in active treatment.</p> <p>6 new threads this week</p>	<p><u>I have secondary breast cancer</u></p> <p>Talk to others with a diagnosis of secondary breast cancer.</p> <p>11 new threads this week</p>
<p><u>Supporting someone with breast cancer</u></p> <p>Connect with others supporting someone with breast cancer.</p> <p>No new thread this week</p>	<p><u>Dedications and remembering others</u></p> <p>Share the memories of those who have been loved and lost.</p> <p>No new thread this week</p>	<p><u>Events, campaigns and meet-ups</u></p> <p>Select your region <input type="text"/> <input type="button" value="Go"/></p> <p>3 new threads this week</p>

Breast Cancer Care Forum / Have I got breast cancer?

Have I got breast cancer?

Are you are concerned about the possible signs of breast cancer? Discuss your concerns and share your symptoms. Talk to others about genetics, scans and screenings. Find out what to expect at appointments and get support whilst waiting for test results.

Boards	Threads	Last Activity
Breast awareness, signs and symptoms	2641	 Mel66 19-07-2014 09:58 AM
Screenings and scans	67	 doucam 21-07-2014 08:23 PM
Family history and genetics	439	 skinnyminx 17-07-2014 01:27 PM
Appointments and waiting for test results	1077	 1852 21-07-2014 05:39 PM

Figure 5.1 An example of the forum categories and subcategories taken from the Breast Cancer Care website

Having met both inclusion criteria, a total of 332 posts were identified across the three websites for the purpose of a TA. Each one of the 332 posts was clearly presented under a title. This title was devised by the thread owner (i.e. the person who initiated the topic of discussion online), and gave the post a form of identity by describing to other forum users what the post, or topic of discussion, was about. A review of all 332 posts revealed that emotive language within women's messages, was expressed through the use of emoticons and capital letters. The 332 posts covered a broad range of categories and subcategories across all three websites. Table 5.2 illustrates the category topics covered, and the content of discussion (subcategories) within those categories. A large number of the 332 posts (N=132) were concerned with psychological issues and treatment decision-making within the category 'going through treatment'.

Table 5.2

Summary of categories and subcategories within the 332 post for data analysis

Categories across the 332 posts	N' of post (%)	Sub-categories across the 332 posts
Have I got breast cancer?	50 (15%)	Signs and symptoms; Screenings and scans; Family history and genetics; Waiting for test results
I am recently diagnosed	103 (31%)	Benign breast cancer; Triple negative; Inflammatory breast cancer; Local recurrence or new primary diagnosis
Going through treatment	132 (40%)	Chemotherapy; Radiotherapy; Hormone; Surgery; Targeted therapies; Lymphoedema
Living with and beyond breast cancer	30 (9%)	Recovering from treatment; Sex and relationships; Work, Finance, Travel; Coping with fear and anxiety; Hope and inspiration
I have secondary breast cancer	17 (5%)	Treatment and medical issues; Living with secondary cancer; Meet-ups; Inspiring news; End of life

5.3.5 Data analysis

With the second study being underpinned by an interpretivist approach, a TA was considered an appropriate analytical strategy. A TA was regarded as suitable, as it aims to identify, analyse, and report patterns (themes), laterally across an entire data set (Braun & Clark, 2006). It also minimally organises and describes the data set in rich detail. Therefore, a TA allowed analysis to remain close and sensitive to the data, and enabled cross comparisons to be made between the three forums, in order to formulate an overall picture of the experiences within the different online support groups. Boyatzis (1998) further added that TA frequently goes further and interprets various aspects of the research topic. Therefore, it provides a complex account of the data. As a result, a TA can be a particularly useful method when investigating an under-researched area (Braun & Clark, 2006), such as SDM and breast cancer forum interaction. A TA can be an essentialist or realist method, which interprets and reports individuals' subjective meanings and realities. This, subsequently, makes a TA well suited to the symbolic interactionist approach of this thesis and the second study.

A TA was achieved manually without the use of any qualitative data analysis software. Similar to Chapter Four, TA was based on guidelines (Braun & Clarke, 2006), and adapted for use with breast cancer forum posts. An inductive approach to a TA was taken, in order to allow themes to emerge from the data, rather than searching for pre-defined themes. Similar to analysis in study one, the analysis comprised four stages. The first stage was to gather descriptions of lived experience; the second and third stage required a process of reduction in reviewing the data to reveal essential themes; and the final stage was to determine the links and associations between the themes, and how they reflected the essence of SDM. These four stages will now be thoroughly described.

First, the 332 posts on each website were read and reviewed several times, in order to gain familiarity with the types of messages posted online. Specific attention was made to listing patterns of experiences that occurred in the post. Each post was systematically examined line by line, and parts of data embedded within the material were de-contextualised to facilitate a micro analysis of the data. In this stage of analysis, statements and phrases pertaining to decision-making and SDM were highlighted and extracted from the 332 posts, to indicate potential patterns. These statements were written on separate sheets and coded based on their post number and line numbers. Table 5.3 provides

examples of the statements which were identified and extracted from the 332 posts across the three websites.

Table 5.3

Example of statements

Significant statement	Post N'	Lines
<i>I have to decide whether the distress of going through chemo and the risk of long term side effects is worth it. I would really like to hear about people's experiences that would help me reach this decision.</i>	126	3-4
<i>I have reconciled with myself that having both removed is the sensible thing but I am scared about having the strength to go through with it and looking at myself in the mirror between surgery and reconstruction. I also worry how it will affect me as a woman and my future self image with my partner. I know there are plenty of others out there who have done this and could give some advice</i>	298	5-8
<i>What have others with similar experiences decided to do about chemo? I'm 55. Would really appreciate some feedback on both points.</i>	72	11-12
<i>After a lot of discussion, thought, and fear of ever dealing with breast cancer again, I have decided that a double mastectomy is the safest choice. My mother thinks I made this decision too quickly. Did I? Am I allowing my fear to dictate this decision, or am I being smart for making sure that I will live a healthy, cancer free life?</i>	312	15-17

After extracting the statements, initial notes were made next to each statement to identify segments of data which appeared to be important or significant, as defined by the researcher, to decision-making, patient participation, views and perceptions, and spoken experiences. Table 5.4 provides an example of notes applied to a significant statement. Appendix J illustrates a table charting all the notes made across the 332 post.

Table 5.4

Significant statement, with initial notes applied

Significant statement	Initial notes/ Patterns
<i>Why are they saying I should have chemo but then also say it's my choice. To me it's either you need it or you don't. I don't know what the right decision is, and it's me that has to decide (post 101, lines 7-9)</i>	Given a choice Treatment decision I have to decide Can't make up my mind

The second stage involved a process of data reduction, and organising the data into meaningful groups. Therefore, all of the talk (initial notes) that fitted under a specific category were identified, and placed under an initial code. At this stage, keeping the codes as simple as possible assisted flexibility in the categorisation process, and helped create and re-define the initial themes. A description of what the codes meant and a source of the code were noted. Table 5.5 illustrates an example of how notes were classified into codes. A full table, charting all codes can be reviewed in appendix J.

Table.5.5

How notes were classified into codes

Initial notes/ Patterns	Lines (post)	Initial codes
Given a choice	5-7 (18)	Treatment decision- making
I have to decide	9-15 (126)	
Hair loss decisions	5-10 (220)	Side-effect decision-making
QOL decisions	13-19 (81)	
Treatment decisions	21-24 (261)	
Cannot make up my mind	11-18 (155)	Problem solving Indecisiveness
Not sure if made right choice	19-249(231)	
	1-14 (190)	

The next step was to analyse all of the codes, which involved searching for connections, and considering how the different codes combined and fitted into categories. The focus was on identifying broader patterns in the data and emerging theme clusters,

which identified what the data means. At this stage, visual representations were used to help sort the different codes in to theme clusters. Therefore, each code, with a brief description, was written on a separate piece of paper, and these were played around with until they were organised into theme cluster piles. The theme clusters were identified by bringing together components or fragments of ideas or experiences (codes). These were subsequently pieced together to form a comprehensive picture of participants' collective experience. Table 5.6 illustrates an example of how this was achieved. Appendix J provides a full table of all sub-themes produced from the analysis.

Table 5.6

How codes were combined to form sub-themes

Initial codes	Theme cluster
Treatment decision-making	Types of decision-making
Side-effect decision-making	
Problem solving	
Indecisiveness	

The final stage involved a process whereby groups of clusters of themes, which reflected a particular vision or issue, were incorporated to form a distinctive theme. This was the stage of the analysis where the relationships between codes, between sub-themes, and the main overall themes, were examined. A provisional name and flexible definition was then created for each emerging theme. Table 5.7 illustrates an example of a final theme with the theme clusters included in that theme. Each theme was then taken separately and re-examined against the original extracts (posts) and the entire data set. This was to check the validity of individual themes, in relation to the data set; to consider whether they formed a coherent pattern; and to assess what aspects of the data were being captured, and how the theme contributed to understanding the data. This stage of re-contextualisation focused closely upon the underlying meaning of each theme. Each finalised theme was given a name, and illustrated with a few quotations from the original post, to help communicate its meaning. A final table was constructed containing all of the

initial codes, theme clusters, and themes for all of the 332 posts in the analysis. (Appendix J).

Table 5.7

An example of a final theme and the theme clusters within

Provisional named theme	Final theme	Theme clusters
Examples of SDM taking place/ experienced online	Experiencing SDM Online	Types of decision-making

For the majority of qualitative researchers, “data gathering involves engaging with other people’s language, the stories they tell and/or the experiences they have” (Shaw, 2010, p.234). Therefore, it was the researcher’s job to make sense of the online stories, interaction, and experiences in a meaningful way, with a view to learn more about breast cancer patients’ encounters of SDM. With this task comes the responsibility of reflexivity. Similar to study one, a reflexive diary was maintained throughout as a measure of quality assurance. The researcher ensured to make reflexive commentary during the analytical procedures of the second study. The diaries focused on recording key events and habitual practices, what the researcher felt about the data extracts, the reasons for the decisions that were made by the researcher, and the researcher’s thoughts and attitudes towards the research itself and the information that was arising. Any presuppositions, choices, experiences, and actions during the analytical process were included in the diary. An evaluation of the researcher’s engagement with the online forum data, and performance of a TA was also recorded. In turn, the commentary notes in the diary were an effective way of confronting the researcher’s thoughts and perceptions, and to see whether they influenced the TA. The process of reflexivity will be discussed further in the discussion section (section 5.5.1) of this chapter.

5.3.6. Ethical Submission

Esyebach (2001) argued, “whether researchers analysing chat room or forum postings enter a ‘public’ place (in which case obtaining informed consent was not necessary), or

whether the space they invade is perceived as ‘private’ (in which case obtaining informed consent is necessary)” (p.131). Different Internet services have different levels of perceived privacy. The three breast cancer forum websites used for analysis were defined as ‘public spaces’, as they had open access and did not require membership to read the messages. Membership was only required to post a message online or reply to a post. As all messages (i.e. the data) on the three websites were publicly available, this meant that informed consent was not necessary. Scholars contend that, although personal, discourses on the Internet are public and are not subject to human subject constraints (Sudweeks & Rafaeli, 1995). In practice, obtaining informed consent for this study was difficult, as it was not possible to post an announcement to the support groups, stating that it would be monitored and analysed for the next few weeks. By doing this, the results could be influenced, and because the mere posting of such a request may disrupt the community, this procedure could be considered unethical.

To overcome any issues of informed consent, a technique developed by Sharf (1997) was used, whereby analysis on communication was conducted retrospectively, and the participants whose comments were to be analysed or quoted, were given a new identity (i.e. a false name). When reporting the results, it was important to ensure that total anonymity of the participants was maintained. The study was presented to Research Review Board at Keele University and was approved. It was outlined by the board that no formal submission to the local NHS Research Ethics Committee (REC) was necessary, as long as the research followed the ethical requirements of participant confidentiality, and the British Psychological Society (BPS) ethics guidelines for Internet mediated research (2007 & 2013), which were reviewed and adhered to thoroughly.

5.4 Results

The second study aimed to take a further exploration of breast cancer patients’ experiences of SDM, by means of a symbolic interactionist approach to explore patient interaction, through examination of the conversations that take place between women within three online breast cancer forums. The focus of a detailed TA was to explore the relationships between patient online interaction and the experience of SDM for breast cancer. A narrative account and interpretation of the three themes that emerged from the analysis

follows, encompassing clear illustrative extracts from the woman's online posts (a false name, post number, and line numbers will be provided for each quote in the parentheses). The interpretative role of the researcher played an integral part in the analysis process and, therefore, it is important that the narrative and description of themes are considered as a product of interpretative engagement with the data. Several theme-clusters emerged from the TA which included: patient involvement, enhancing self-esteem, access to knowledge, identification process, types of decision making, patient authority, and patient participation. Upon clustering these together, three key themes were formed which encapsulated the experience of SDM for participants during treatment of breast cancer. These themes were: 1) *extending the characteristics of SDM to an online peer community*, 2) *experiencing SDM online*, and 3) *ways to enhance SDM*. Some initial descriptive findings were also observed in the analysis. These will be discussed prior to exploration of the three themes.

5.4.1 Initial descriptive findings

Upon provisionally reviewing the data, initial descriptive findings were observed which revealed why and when women used the forums, during their treatment. It appeared that interacting within these forums had distinctive appealing characteristics for women. The interacting appeared to function as way for women to manage their breast cancer, and operated as type of coping strategy to help them through their treatment journey. Many women accessed these forums at various intervals of their treatment, and utilised them for a spectrum of benefits, such as understanding the diagnosis, finding information about treatments, learning about living with cancer, and gaining support from others. Examination of all three websites revealed that women used the forums at six specific times of their treatment, for specific reasons:

Before visiting their doctor- Women came online to engage with other women or to acquire information, to discover the possible meaning of symptoms. This can be regarded as self-diagnosis period, where women try to make sense of their illness by themselves.

During tests and scans- Women used the Internet to seek reassurance from similar others that their doctors were doing the right tests. They also used this time online to help remove any feelings of distress and to prepare themselves for the test results.

After the diagnosis- During this period of time, women used the forums to gather positive and negative information about the cancer, to make sense of their diagnosis, to interpret information given by health professionals, and to remove any feelings of distress and isolation.

Decision-making about treatments- During this phase, women utilised the forums to acquire information about treatment options and side effects, to gain advice and suggestions on clinical trials and alternative or complementary treatments. Women also used the interaction with other to help them identify and to prepare questions to ask the doctors during decision-making consultations. This stage of Internet use can be regarded as a period of second opinion.

Before treatment- The forums were used by women to find what will happen during treatment, what to expect in terms of side-effects of treatment, and what to expect of recovery.

Short term follow up- Much of the conversations which took place online sought reassurance about symptoms, advice about diet and complementary treatments, and suggestions to help enhance QOL.

Long term follow up- For women who were post-treatment, the forums worked as a space to share experience and give advice, to campaign about the condition, and to establish a network of friends.

From these contexts of use, it can be understood that the forums served different purposes and benefits at each individual's stage of treatment. Due to the voluntary use of forums, this meant that women could access them according to their preferential needs. Therefore, they could use them as much or as little as they wanted, and whenever they wanted. For example, some women only made a one off contribution post, whereas others were regular users who posted and responded every day to the forum members. The foremost reasons for using the forums were to acquire advice, emotional support, and health information

achieved through peer interaction. The motives and rewards of forum use will be explored further in theme one.

5.4.2 Theme one: extending the characteristics of SDM to an online peer community

This theme contained four theme clusters (*patient involvement, enhancing self-esteem, access to knowledge, and identification process*); all associated with what the Internet forums provided to women with breast cancer. Analysis of this theme revealed that the reasons why women engaged in online interaction with peers were similar to the characteristics of SDM in a clinical setting. This subsequently illustrates the presence of SDM characteristics, occurring within an online forum community of breast cancer patients. It also adds to our understanding of the processes involved for SDM. This theme demonstrates that women used the forums for four key reasons. These were to give women a sense of involvement in their cancer care; to acquire assurance, confidence and heightened self-esteem regarding their body, health, and treatment plan; to receive additional information and knowledge about their diagnosis, treatment, and recovery; and to establish social ties, connect, and associate with other women in similar positions. The extracts below illustrate each one of these four motives (theme clusters) and identify its similarity to the characteristics of SDM.

Patient involvement:

EXT 1. Alexandra. Post 100. Lines 1-7

When I was diagnosis I felt like my whole world had collapsed. I found it so overwhelming to sieve through the all the information they gave me in order to make the right choice. But instead I chose to join this group, as it allowed me to be a part of my own cure. I found that chatting on here with others about my treatment choices and plan was cathartic, and certainly made me feel more involved in my health. It helped me to decide, and focused me to engage with my breast cancer and to fight the disease.

Alexandra's message to the forum illustrates how online membership allows women to feel more active and involved in their cancer care. Alexandra's extract shows that

through ‘chatting’ and therefore participating in talk with others about her treatment choices, not only made her feel more involved in her care and treatment decision-making, but also assisted her in having to make a decision. This similarly reflects the characteristics of SDM in a clinical setting. The NICE guidelines (2004 & 2012) define SDM as a process which involves the patient as an active member or partner of the medical team, who can participate in discussions about their cancer care in aid of choosing a preferred course of clinical care. Therefore, it can be interpreted that the forum interaction reflects a process of SDM, and by participating in SDM (i.e. participating in discussions with other forum members) this helps to enhance patient involvement decision-making.

Enhancing self-esteem:

EXT 2. Linda Post 211. Lines 12-19

Don't be sorry for asking loads of questions. I find these forums really useful, as they are a place for me to come and vent, but at the same time received loads of reassurance and hope. I remember feeling insecure about my hair too, but just try your best to hang in there. When we hit rock bottom the only way is up! My advice is just pace yourself and take the first cycle of chemo each day as it comes. Talk with the nurses, your oncologist, and share your worries, doubts, questions. It helped me with the healing process. There is no wrong or right way of dealing with the side-effects, only what is best for you!

From Linda’s extract, it is understood that the forums were a useful place to gain feelings of hope and reassurance about treatment, especially regarding the side-effects of hair loss during chemotherapy. The analysis revealed that positive conversations took place online, which involved motivating women and giving them confidence, comfort, and strength to go through their cancer journey. Therefore, interaction served a purpose, which was to help others increase their self-esteem. This is similar to the characteristic of SDM, as the concept of SDM aims to encourage patients to participate in health discussions and to share their treatment preferences. SDM is described to rely on the patient as well as the clinician, as “the patient is an expert on themselves, their social circumstances,

attitude to illness and risks, values and preferences” (The Health Foundation 2009, p 7). Therefore, the practice of SDM and patient-centred care is to equip patients with confidence to participate in their care, and to give them the self-esteem needed to actively interact with the clinician, and participate in the decision-making process. Interaction within the forums also mirrored these characteristics of SDM, as members shared feelings of self-belief and motivation to be involved in their cancer care.

Access to knowledge:

Ext 3. Sophie. Post 318. Lines 8-11

I originally went into alternative therapies because the evidence for standard of care did not have compelling enough statistical proof. Even the treatment guidelines were fraught with disclaimers. I don't know if anybody here has read them, but I recommend them to those who are stuck with making a treatment decision and are consider rejecting conventional treatments.

Sophie highlights that the forums are used for the purpose of information and knowledge acquisition. Sophie’s post is in response to another forum member’s question, asking if anyone could assist her with the task of making a treatment decision. Sophie’s reply is informative and based on her own personal experiences, views, and opinions. She guides the thread owner towards relevant literature, which may aid in decision-making. The analysis revealed that the forums acted as a useful place to exchange information, receive additional knowledge, and to assist other women with queries (this will be explored more thoroughly in the next theme). However, the process of information exchange was particularly evident online regarding decision-making. Therefore, the forums were predominantly used to acquire information which could assist women in their treatment decision-making dilemma. This similarly reflects the characteristic of SDM. The NICE guidelines (2004 & 2012) for SDM indicate the importance of medical professionals’ roles in giving the patient information, and support needed to make use of the information, in order to promote patient participation in their care. Interaction within the forums represented a similar process to SDM, as members would facilitate knowledge sharing, through a process of information exchange and two-way communication, to facilitate decision-making processes.

*Identification process:*Ext 4. Jenny. Post 285, Lines 20-28

I am replying to your thread because I feel my own situation and diagnosis has a lot of similarity to yours, and I'm also trying to make a similar treatment decision to you. Those feelings you described sound so familiar and I understand your frustration. You're not on your own and you don't have to feel like this, because there are others like you experiencing the same thing and in the same boat. I remember thinking none of my friends are dealing with anything like what I'm going through right now. So I'm finding it good to talk to others on here, because I can relate to them and see what others have been through. Trust me, it's not just the medical information aspect of these forums which are useful. Talking online makes you feel supported and I think it's a great way to make some good friendships.

Jenny's message demonstrates one of the key functions of the forums, which is to provide women the opportunity to form social bonds and interactions with peers in similar situations. As Jenny's account explains, interacting within these forums with women "*in the same boat*", allowed for an experience of self association. By relating and identifying to similar others online, this subsequently created an online environment where everyone was seen as equal. Women were able to self-identify and remove feelings of isolation through the mutual relationships created, and the shared interactions which took place within these forums. This in turn, contributed in helping members to make treatment decisions. This reflects the process of SDM, as it is an approach which requires mutual doctor-patient relationships and shared interaction between the clinician and patient, in face of making treatment decisions (The Health Foundation, 2009). Therefore, during SDM, the patient is made to feel equal to the clinician ('in the same boat'), as both are required to share information and accept responsibility for joint decision-making which, therefore, facilitates treatment decision-making.

5.4.3 Theme two: experiencing SDM online

This theme encompassed a theme cluster (*types of decision-making*), which is associated with the topics of decision-making conversations. As mentioned in the initial descriptive findings and the above theme, women predominantly used the forums to interact over decision-making dilemmas they faced throughout their cancer journey. At a time of diagnosis or whilst undergoing treatments, women may feel vulnerable and/or show an inability to make complex medical and simple everyday decisions. The analysis revealed that during this time of difficulty, common practice for women was to participate in online discussions about the dilemmas they faced; and to engage in the practice of sharing views, knowledge, and experiences, in search for advice and information, and to seek emotional comfort. Participation in online interaction and sharing conversations, subsequently, facilitated women in their ability to solve decision-making problems. In examining the interactions women had about decision-making, analysis revealed more thorough insight about how SDM is experienced in a clinical setting, between the oncologist and patient. It also provided an insight into how the process of SDM can occur between peers within an online community. This theme will now outline the types of decision-making discussed through online interaction, how these relate to SDM, and how it provides an understanding of women's experiences of SDM.

Types of decision-making:

Analysis initially highlighted that women were given a choice and involved by clinicians in the decision-making of treatment choices. Within the forums, women described their choices of surgery- whether to have a mastectomy or a lumpectomy. However, this only occupied a small percentage of decision-making which was detailed online. Instead, the majority of women used the forums to mostly talk about decision-making for adjuvant treatment, and the most frequent topic of discussion was about chemotherapy. Forum members predominantly interacted online to talk about whether they should consent to undertaking chemotherapy. For many, this decision was an important and complex one, which was fuelled by issues surrounding side-effects and hair loss. Therefore, the forums acted as a place for women to share their dilemma with similar others, in aid of receiving advice and support. Women made it very clear within their post about the distress and

emotional impact the decision-making task was having on their ability to function, and to make a rational decision. Extract five illustrates this further.

EXT 5. Susan. Post 126, Lines 9-15

After diagnosed 5 weeks ago with a grade 2 breast cancer, I've had it removed and all seems clear. My nodes have also been checked and are all clear. So I thought I would just be having radiotherapy and hormone treatment since I'm HER2 positive. Yet after seeing the oncologist this week, she told me I should have 8 sets of chemo, followed by 15 + 8 radiotherapy and a minimum of 5 years hormones. The shock of being told I have breast cancer still has not sunk in. Now I'm being told I need FEC chemo. But then I was also told the chemo was my choice to have or not. I have to go back next week and tell them. But what do I say? I have no idea why they are saying chemo, and what will be the long term benefits? If anyone can help set my mind at ease, as I know chemo is not to be taken lightly and there are lots of side-effects right? I don't understand why they are saying I should have it, but it's my choice. To me it's either you need it or you don't.

Susan illustrates an example of decision-making for adjuvant treatment that is discussed in forums. Her post provides an insight into her SDM experience during her consultation with the clinician. From her account, it is understood a conflict of interest between the clinician's role and the role of SDM. For example, Susan has clarified that undergoing chemotherapy is her choice which, therefore, highlights the notion of SDM and patient-centred care. However, from Susan's account, it is also evident that she is "told" by the clinician that she "should have" chemotherapy which, therefore, highlights the clinician's expertise role. This subsequently creates a confusing situation for Susan, whereby the experience of SDM becomes obscured and disorganised due to the clinician's role as a clinical expert. As a result of this confusing predicament, Susan, therefore, turns to the forum for some answers. She poses some questions online, which request advice and suggestions from other forum users. Interestingly, she asks two key questions, "I have no idea why they are saying chemo, and what will be the long term benefits?" and "there are lots of side-effects right?", which signifies the lack of SDM which is experienced within the consultation, between herself and the clinician. For SDM to occur in a clinical setting,

this requires the patients to be actively involved in discussions, and to not only share their preferences but to also share their concerns and queries. Instead of asking the clinician these questions, she decides to share her concerns online with other the forum users. Therefore, a process of SDM is perceived, by the researcher, to be taking place online through two-way interaction. Susan shares her views and concerns with other members, in aid of others sharing their knowledge and experiences. This extract, similar to theme one, highlights the important of sharing information and preferences, and two-way communication, as characteristics of SDM. The extract also further supports the findings displayed in theme one, that those characteristics of SDM can take place within breast cancer forums. It further adds to theme one by showing that for forum members, it seems that SDM extends beyond the clinical setting. It is not simply a phenomenon that occurs between clinician and patient as it is shared in communities beyond that. Extract six further illustrates this finding amongst women who are faced with making decisions about alternative treatment therapy. The forums revealed that many women were issued the additional task to consider and problem solve decisions for alternative therapies, extra complementary treatments, or whether to be part of clinical trials for more targeted treatments. The task of having to make decisions regarding new medicines or different treatment routes was demonstrated to be of a complex task.

EXT 6. Della. Post 231, Lines 19-24

I'm having my second chemo next week. This week my HER2 result finally came back - I'm HER2 positive. The breast care nurse said that usually patients get Herceptin after finishing chemo, but my particular oncologist often likes to start Herceptin alongside chemo. I do personally have a choice. I usually query him and have long conversations with him if I'm feeling anxious about my treatment. But so far he's been on the ball and I'm happy with the treatment path we have chosen together. Yet I'm curious as to what other people's experiences have been - Herceptin with or after chemo? This may help me decide or change my mind.

Della's account exemplifies her struggles in making a decision over the option given to have an alternative treatment path, and draws attention to patient choice. Della describes that she has a good relationship with her oncologist, whereby she is able to engage in discussions and ask questions about her treatment. She illustrates an appropriate example

of her previous experiences of decision-making with the clinician. Her description of a decision-making process is based on her active involvement and sharing of preferences, and a process where decisions are made jointly with the clinician, and therefore is in line with the concept of SDM. However, Della chose not to address her dilemma regarding alternative therapy through the route of SDM with her clinician. Instead she turns to the forum for advice on the options recommended to her. Della states that she is “*curious as to what other people’s experiences have been*”, which indicates that she prefers to make her decisions based upon other women’s personal experiences and views. By engaging in interaction with other women with breast cancer, and participating in the sharing of information and views, based on first-hand encounters, this constitutes towards an online process of SDM, which may aid Della in making a decision about treatment. Della’s extract ends with a direct question she poses to the forum users “*Herceptin with or after chemo?*” This mirrors the type of question she would ask the clinician if she engaged in an SDM consultation. However, she instead poses this question online, in aid of seeking an SDM process to occur between forum members. Similar to Susan’s post, this extract also draws attention to information sharing and knowledge acquisition, as characteristics of SDM. The findings emphasise that SDM is a process which can occur outside of a clinical setting between patients and non-medical professionals.

The forums highlighted that decision-making did not stop at treatment choice for women, but also extended into consideration of side-effects. Analysis revealed that once women had provided consent to their treatment path, a new genre of SDM took place. This includes decisions over the management of hair loss, such as choosing to wearing a wig, scarf, or shave it off; decisions about wearing breast prosthesis or not; and decisions over the management of weight, such as exercise and dieting. Making the right choice was regarded as important for these women, as issues of body image, self-esteem, and QOL were questioned and brought into the equation. The forums, therefore, became a place for women to interact over these dilemmas, by sharing similar stories and offering their experiences and advice. Extracts seven and eight further emphasise that SDM extends into other conceptual as well as interpersonal areas.

EXT 7. Helen. Post 18, Lines 5-9

Today my hair has started to come out, but it isn't noticeable to others yet. I have a wig which I chose with my daughter at the hospital, but I can't imagine me wearing it.

Think I'm more of a scarf or hat person. I'm not sure whether to just shave it off?! Not sure how I'll feel when it's done? But I know it's temporary, and who knows it may come back strawberry blonde with highlights and a gentle perm. Ha! There has to be hope in life.

In Helen's case, and the majority of forum users in the analysis, hair loss was an area of concern, and one which brought a task of decision-making with it. Due to the effects of chemotherapy, hair loss can have devastating effects on a woman's appearance and their confidence. How to manage hair loss was an issue discussed within the forums, as women were keen to read other peoples experiences and methods of adaptation to hair loss. Control over body image and self-esteem was illustrated to be a key concern for women through the forums. From Helen's extract, it is understood that her hair loss causes some dilemma, as she appears to be unsure whether the right decision is to shave it off or wear a scarf, as a wig is not to her preference. Discussions regarding interpersonal issues, such as hair/wig management, may not always be attended to at a clinical level during SDM consultations. Helen's extract demonstrates that by presenting this topic to other forum users, this invites others to share their experiences and offer advice. Similar to Della's post, Helen asks questions to other members online. These are the type of questions which would usually take form during conversation with the clinician, and during the process of SDM. However, by presenting these questions online, this opens an opportunity for a host of members to engage and interact on the topic matter. By reading other people's shared experiences, this in turn allows Helen not only to relate to similar others, but it also equips her with the knowledge and information, as well as the confidence needed, to make a decision which is right for her. This signifies an experience of SDM, which would usually take place in a consultation. This extract emphasises that the forums provide a great opportunity for a process of SDM to take place in circumstances, or on topics, where SDM is not adhered to in a clinical setting.

Extract eight shows a similar example of the possible lack of consideration given to adjunct concerns in breast cancer clinics, and how SDM is a phenomenon in online communities which addresses such interpersonal concerns. The analysis revealed that the treatment of cancer can have an impact on patients' ability to make day to day decisions. For many women the diagnosis, treatments, or side-effects of cancer were demonstrated to cause an inability to make everyday decisions regarding QOL outside of the hospital, and

post-treatment. Women interacted about topics such as, deciding to go back to work, whether to have more children, deciding about marriage, and deciding to go on holiday, in aid of receiving guidance and support.

EXT 8.Charlotte. Post 81, Lines 13-19

I booked a beach holiday before I got diagnosis. I've paid half already. I'm worried that I won't be physically able to keep up with my family. I want to enjoy every second with them, but scared of letting them down. My husband thinks we should cancel the holiday, but I would hate to stomp on my children's' excitement. Has anyone been on holiday whilst undergoing treatment or mid treatment? I just can't seem to decide what the pros and cons are, and what the right decision should be?

Charlotte's post to the forum illustrates her problem over deciding to go ahead with the family holiday or not. As a result of her diagnosis, she is unsure whether the holiday is appropriate, and is torn between upsetting her husband and letting her children down. The decision has left her confused and, therefore, she posts on the forum in aid of addressing her conflict. The extract, similar to Helen's post, once again illustrates that lack of time devoted in clinics to SDM conversations regarding interpersonal decisions. Both Helen's and Charlotte's extract emphasise that the side-effects of cancer treatments can impose on a patient's QOL, and carry the additional task of making decisions as a result of the side-effects. It could be suggested that the process of SDM in a clinical setting only revolves around the topic of treatment decision-making, which subsequently results in many conversations about interpersonal adjunct decisions to occur within these online forums. Subsequently, this raises an opportunity for SDM to occur online, as supported by Charlotte's extract. The experience of SDM is visible when Charlotte states "*I just can't seem to decide what the pros and cons are and what the right decision should be?*" By asking this question, Charlotte is requesting forum members to collectively weigh up 'the pros and cons', and together deliberate over the appropriate decision. In a clinical setting, this would be regarded as SDM between patient and clinician. Therefore, it could be interpreted that the forum members are actively taking up the role of the clinician during online interaction. Consequently, this extract further adds to Susan's, Della's, and Helen's extracts, and to the findings in theme one, by mirroring the characteristics of SDM (i.e.

information exchange, knowledge acquisition, sharing of preferences, and two-way interactions). It supports the previous findings in this theme by showing that SDM extends beyond the clinical setting for patients, and is simply not a phenomenon that occurs between clinician and patient, as it is shared in online communities beyond that.

The analysis revealed that forums were not only used to aid women in making treatment and QOL decisions. Interaction also took place about decisions which had already been made and agreed upon, between patient and clinician in the clinic. For example, some women had already consented and decided upon a treatment with their clinician. However, regardless of the decision already being made, women used the forums to discuss and assess that decision. A process of SDM took place online, in order to assess and decide whether the decision that has been made, during a SDM consultation, is appropriate or not. Extract nine illustrates this further.

EXT 9. Sammy. Post 322, Lines 1-9

Hi all, with my clinician we have decided that mastectomy is right form of treatment for me, given the size of the lump. We sat and thoroughly talked through the options together. However, I'm still not sure if we have made the right decision. I don't really want to lose my breast. He has explained every to me and informed me enough to be able to decide why a mastectomy is the right route. But for some reason I still feel undecided. My breast cancer is a grade 2, but not travelled in my lymph nodes. Has anyone with a similar diagnosis to mine undergone a mastectomy or even a lumpectomy instead? I'm probably just being over cautious and I have made the right decision, but I just can't help but yet question it. What do you think?

Sammy highlights her indecisiveness towards the decision she has made with the clinician. At the start, Sammy describes her previous experiences of SDM with the clinician in the clinic. She makes reference to having “*sat and thoroughly talked through the options together*” with the clinician; and indicates that the clinician has “*informed her enough to be able to decide*” her treatment preference. Although an encounter of SDM took place for Sammy, with the clinician, for making an appropriate treatment decision, she questions her

encounter of SDM. The extract shows that Sammy appears to be unsure about the SDM process she engaged in at the clinic and, therefore, uses the forums for a second opinion. Sammy engages in an online process of SDM with other forum member, by participating in shared discussion to gain supplementary information and advice. This subsequently allows her to clarify and confirm that the treatment chosen, during her clinical encounter of SDM, is optimal. Sammy's extract draws awareness to the degree of trust women have in clinical SDM. Although SDM with a clinician enables women, like Sammy, to make patient-centred decisions; however, as Sammy demonstrates, experience of the concept is still questionable. Therefore, a form of SDM appears to take place online, on a decision which had been formed during a SDM consultation. Women therefore choose to participate further in the forums by interacting with other similar members, as this enables them to gain further information and advice. Such acquired knowledge could supplement the explanations given by the clinician and, therefore, provide verification and reassurance about the decision that has been made. This extract illustrates that engaging in an additional experience of SDM online, is in aid of confirmation and support to carry out the decision. It could be argued that an experience of online SDM coincides and works together with an experience of SDM in a clinical setting, to facilitate and encourage patients to make a decision and adhere to it.

5.4.4 Theme three: ways to enhance SDM

The final theme includes two theme clusters (*patient participation* and *patient authority*), which are associated with how the concept of SDM is brought to awareness and encouraged amongst forum members, through interaction. In examining 'what is said' between forum members, and exploring types of advice or suggestions that are discussed by forum users, it became apparent that type of advice portrayed online was not medically related or aimed at directly providing an answer to the dilemma. Members never told one another what the right or wrong decision is. Instead, they offered advice, which was based upon guiding one another to turn to the clinician to help them with their decision-making dilemmas. Therefore, online interaction served a purpose, which was to facilitate the concept of SDM, and to encourage patient encounters of SDM in a clinical setting. The theme clusters *patient participation* and *patient authority* will be described in thorough detail, with supporting extracts. They will also be examined in relation to how the concept

of SDM, between patient and clinician, is spoken about online, and promoted through online interaction.

Patient participation:

In the process of interacting with other forum users online, and giving advice and suggestions to one another over decision-making topics, analysis of the posts revealed that individuals' posts carried an underlying motive. This motive was to encourage women to participate in their health care by maintaining good doctor-patient relationships and communication, as this facilitated decision-making. Forum users shared their own personal experiences of the type of relationship they acquired with the clinician during decision-making. It appeared that having an established doctor-patient relationship, which is full of rapport, empathy, and understanding, played a facilitating role in decision-making, and patients' experiences of SDM.

EXT 10. Tina. Post 242, lines 8-17

It is so important to maintain a healthy relationship with your oncologist as it makes the decision-making process so much easier. My oncologist was great! He had a good sense of humour, listened to all my concerns and preferences, and took all my values into account. Equally I respected him and took on board all information and suggestions he gave me. We had such a good bond and we worked together, and because of how he was towards me I felt so comfortable to ask him anything. I felt privileged and that was all because I developed a good relationship with him, which was built on mutuality and trust. So my advice to you is to keep liaising with him and build good rapport, as that will get that connection going. Get involved and participate with your oncologist. It did me the world of wonders to have that established relationship during decision-making.

Tina provides an example of how forum users were encouraged, by other members, to develop and sustain a healthy doctor-patient relationship throughout the course of their treatment. To aid decision-making, women were reminded that a strong link with the clinician can overcome the difficulties of decision-making. Tina's account makes strong

reference to the importance of rapport as this helps her to generate trust in the clinician and establish mutual involvement. Arguably, through mutual involvement, both the clinician and the patient will be open to participation, based on the sharing of views, preferences, and information. These features are described by Tina to contribute towards patient participation and, therefore, facilitate the decision-making process. From Tina's extract, it is understood that online interaction can play an important part in defining doctor-patient relationships, and promoting two-way interactions between patient and clinician, within a clinical setting. The extract shows that forums help to inform women about how to encounter such relationships during their treatment, and raise awareness of the benefits surrounding doctor-patient relationships, in respect to decision-making. More importantly, it illustrates awareness of SDM. Tina shows knowledge and experience of SDM in her account, by stating that the clinician "*listened to all my concerns and preferences, and took all my values into account. Equally I respected him and took on board all information and suggestions he gave me*". This signifies a shared process of information exchange, where both the patient and clinician "*working together*". In achieving an encounter of SDM, Tina reinforces the importance of maintaining a good patient relationship with the clinician. Tina's post subsequently shows how online interaction defines the characteristics of SDM, such as mutual doctor-patient relationship, to other forum members. It also demonstrates how forum interaction helps to promote the benefits of SDM, and educates women on how to achieve SDM in a clinical setting. Extract 11 is another example of how forum users enhanced patient awareness and experience of SDM, by encouraging patient participation. However, the extract draws more specific attention to the role of knowledge acquisition in facilitating decision-making, and patients' experiences of SDM.

As mentioned in theme one and two, women entered these forums to access knowledge of their illness, and to seek health information which could facilitate their treatment, or the task of decision-making. Despite of the abundance of information shared online between forum members, the analysis highlighted that peer to peer interaction also took place to encourage and give women the confidence in seeking health information from the medical professionals. Women were reminded that they should take a more 'active' stance in their medical care, and participate in health-related decision-making with the clinician, by engaging in two-way discussions during clinic. It was suggested online that this, therefore, allowed them to develop the relevant knowledge and understanding needed to make informed decisions.

EXT 11. Diana. Post 66, Lines 5-9

I do believe you should get as much information as you can from the oncologist on all of your results, any statistics, facts and figures, and anything that will help you decide. For me, knowing more about the disease and particularly about how it relates to my body, gave me a sense of control. It made me feel like I had more power, and that I played a proactive role in my care.

Diana illustrates how support, through encouragement, is expressed to women online. This was a persistent feature of interaction between the forum users, as women continually championed one another to maintain an ‘active’ role in their treatment plan. As Diana explains, her engagement in conversations with the medical professionals was of valuable assistance to her increased knowledge of the disease. She explains that this in turn helped her with the decision-making process. By taking an ‘active’ stance, this gave Diana the ability to turn the information provided into something more personal to her and her body. Diana suggests that this gave her some elements of “*control*” and “*power*” over the cancer. The extract shows how online interaction encourages women to take decision-making out of the clinician’s hands, and instead turn it into a shared process, which allows them to work alongside the medical team to reach decisions. The level of enthusiasm and commitment, across all three forums, to motivate and give confidence to women to participate in their care was certainly highlighted. Women were reminded about the benefits of acquiring as much possible knowledge from the clinician, as this leads to greater feelings of control, decreased levels of distress, and reduced difficulties in decision-making. Therefore, much time was devoted online to making forum users aware of the characteristics of SDM, such as information acquisition, and encouraging women to engage in these SDM characteristics, in aid of decision-making. Extract 12 is another example of how forums enhanced patient awareness and experience of SDM, by encouraging patient participation. However, the extract draws more specific attention to the importance of two-way conversations between medical professionals and patient in facilitating decision-making, and patients’ experiences of SDM.

EXT 12. Fiona. Post 99, Lines 1-16

You may want to have a consultation with an oncologist to see what the next step is in your treatment plan. I met with my

oncologist a week after I had my lumpectomy and had my preliminary diagnosis. The reason why you should meet with an oncologist is because it will allow you to ask the kind of questions that you are asking on here. My advice to you is to do your homework and prepare the questions you want to ask. Think about the side-effects, benefits, versus risks, and ask questions related to these or other topics of concern. Speak to your breast care nurse and oncologist as much as you can to arrive at a contented decision together. The best approach is for you to think about which treatment is most likely to give YOU the benefit, and a good oncologist can help guide you. You need to make sure your oncologist agrees with YOUR values, and works with you to get a treatment plan that has a reasonably good chance of giving you the best benefit with the lowest risk. That is exactly what I did and it helped me to eventually map out and decide the treatment plan which was right for me.

Fiona starts by steering the thread owner towards interaction and engagement with the oncologist. Her response explains the importance of two-way communication with the oncologist, as this will help to address any concerns and ease the task of making a choice. Therefore, she is primarily enforcing the importance of patient participation. She then continues to elaborate on the role of the oncologist, as a medical professional, who helps with decision-making. This infers that decision-making is assisted by the clinician, not given as an instruction. The process of two-way interaction is defined by Fiona as a process which involves the patient sharing their values and preference, which is then weighed up with the clinician's sharing of medical information. In this instance, Fiona brings awareness to two-way communication, as a process and characteristic of SDM. Fiona indicates that by participating and engaging in discussions, this enables patients to become an expert in their own condition, which can contribute to facilitate decision-making. Therefore, this sustains the need for SDM to be experienced by patients, during a decision-making consultation. The forums illustrated that many members, like Fiona, brought awareness and promoted the practice of a mutual relationship, between the doctor and clinician, which is based on two-way conversations. Through online interactions, members encouraged each other towards a collective approach to problem solving with the medical professional. Subsequently, these findings show that the SDM concept is understood by

forum users, and its characteristics, such as two-way interaction, are acknowledged and experienced by many women in a clinical setting. As a result of the described benefits of SDM in helping women make complex treatment decisions, the forums were utilised as a space for women to inform others about the purpose of SDM, and how it can be achieved during breast cancer care. Extract 13 illustrates another example of how the importance of doctor-patient shared conversations, were emphasised online between members. However, extract 13 develops further to show how forums also informed women about the content and structure of shared discussions they should be having, in order to facilitate encounters of SDM.

The forums served as a place for women to gain some guidance on the content of conversation they should be having with their clinician. Through the interactions which took place online, it appeared that women were presenting one another with the types of concerns that they should be considering and talking about to the clinician, or the type of questions they should be asking during a decision-making consultation. By reading other women's personal breast cancer journeys, it guided members to find the right questions to ask the clinician, and highlighted issues which they may have never previously thought about, prior to forum engagement. It therefore appeared that online interaction helped to direct the women towards the types of conversations and contents of discussions they should be having with clinician, to facilitate decision-making and patient encounters of SDM.

EXT 13. Judy. Post 155, lines 6-14

I would list out the pros and cons of chemotherapy, so you can see what it is that's actually worrying you. Many people here can attest that chemo is doable, but it is not without side-effects that could possibly affect you the rest of your life. Would chemo prevent a recurrence? Maybe, maybe not!? One other thing that many people don't think about is, if it comes back what is left to treat it? That's the crap shoot of it all. It's not a fun decision to have to be making, and one I advise you to share with your clinician by talking about these sorts of concerns and queries. Think about these sorts of questions and make sure to ask them. Don't be afraid to share your views and preferences within your queries. I wish you peace with whatever you decide.

Judy's intention in her post is to guide the owner of the thread towards the type of conversation she should be having with the clinician. Judy suggests for the patient to make a list of advantages and disadvantages, so they become aware of the worries and queries they may potentially want to ask the clinician. Judy's action, of encouraging the patient to ask questions, signifies the importance of patient participation in shared interaction with the clinician, in aid of decision-making. Interestingly, it then appears as if Judy switches roles within her post, and takes on the identity of the thread owner. She begins to pose questions, which a patient would usually ask a clinician during a consultation. By posing these questions, Judy is encouraging the patient to talk with the clinician and to consider asking these sorts of questions, as it could help reach the right decision. The questions that Judy has posed are not just specific to the thread owner, as they could be acknowledged by other forum users who read the post. From this extract, it is understood that the forums can serve as guidance for women, who are unsure about the types of conversation and substance of discussions they should be having with their clinician, during a decision-making consultation. This is reflected in Judy's extract, as she raises awareness to the importance of patient involvement in discussions, sharing of patient views and preferences, and negotiation through questioning and answering, as these are characteristics which define SDM in a clinical setting. Therefore, similar to the posts by Sammy, Tina, Diana, and Fiona, this extract also shows that SDM is a process which is experienced by many women in a clinical setting, and a good understanding of its characteristics are known to breast cancer patients, as demonstrated by Judy. As a result of such awareness and experience of SDM, online interaction ensured to remind women of the importance of SDM, inform them about the characteristics of SDM and how to achieve them, and facilitate patients' encounters of SDM in a clinical setting.

Patient authority:

Within this theme, another underlying intention of forum interaction was illustrated, which was to make forum members feel powerful. Analysis of interaction within the forums showed that much online talk was aimed at making women feel powerful in their status and role to participate in SDM during consultations. As mentioned in theme one, women continually helped one another to raise levels of confidence and self-esteem. They also reminded one another of the rights they had as patients during their treatments. As a result,

the forums appeared to generate a collective authoritarian attitude amongst their members, which focused on patients' ability, influence, and entitlement to participate in their treatment decision-making. Subsequently, this enhanced awareness of the concept of SDM, and facilitated patients' experience of SDM during clinical encounters. Extract 14 shows how forum members reminded one another about the importance of patient control.

EXT 14. Kim. Post 8, Lines 2-6

It's your body, your decision! That's what I kept reminding myself. You have to live with the consequences of hair loss. You have to live with consequences of a losing your breast. You have to live with the weight gain. You have to live with the lack of energy. These are all the things that YOUR body will go through. So it has to be your preferences and views that are taken into account during decision-making. So don't think you just have to go with the flow of what your doctor says.

Kim draws attention to the issue of changes in body image as a result of treatment side-effects. She reminds the thread owner that the decision-making should not be taken lightly, and that they should stay true to their rights and preferences. Her motive is to make the thread owner feel in control and in charge of their body. The extract therefore suggests that women should not take a 'passive' approach towards decision-making, but to 'actively' share their views and preferences, and show interest in involvement for decision-making, as it is ultimately their body that will suffer. Kim's view, subsequently, prompts the thread owner towards SDM. Her encouragement of self-control and 'active' participation supports and enhances SDM to take place in a clinical setting with the clinician, by reminding the thread owner that it is important to voice their preferences and not just "go with the flow" with the clinician. This highlights Kim's awareness to the process of SDM. Extract 15 similarly illustrates how online interaction encourages self-control and patient authority; however, it demonstrates this in respect to how members encourage self-confidence to one another.

EXT 15. Luisa, Post 180, Lines 3-10

My diagnosis was just like yours and I too was told that I had to have a mastectomy. I was so anxious, distress and nervous. But most of all I felt so annoyed that I had no control over

what was happening what so ever. However, I remember my husband sitting me down one night and telling me that I have to try and gain some element of control back, and in doing that, I have to be strong, confident, and positive. That's exactly what I did. It's so important to remain assertive and have self-esteem during your treatment, because it gives you back that control you once thought you loss. I was able to manage and organise my treatment side-effects, and still felt able to talk to my clinician and be involved, despite not have a treatment choice.

Luisa's post draws attention to how the forums have an impact on members' levels of self-esteem and confidence. Luisa explains that it is important to maintain self-belief, as this helps to achieve self-control and feelings of capability. In her case, she was "told" her treatment and, therefore, had no choice or say in decision-making. This subsequently meant that the occurrence of SDM or perceived experience of it was hindered. However, Luisa continues to stress the importance of remaining 'active' and involved in her treatment plan, despite the lack of SDM, as this introduced an element of self-control, and enabled her to self-manage any treatment side-effects. Forum users commonly illustrated this practice of enhancing one another's' confidence, in order to motivate and support each other to remain 'active' in their care, regardless of having "no treatment choice", or no option for SDM to take place. By encouraging women to remain strong and assertive, and by motivating them to raise their confidence, this influenced women to maintain their role and ability to participate in their treatment, alongside the clinician. Therefore, Luisa's extract illustrates that the 'sharing' component of SDM can still be enforced and take place in a clinical setting with the clinician, to manage other areas of the cancer journey; despite the lack of SDM during treatment decision-making. Subsequently, the extract illustrates how SDM is enhanced and maintained during forum interaction. The final extract (extract 16), also illustrates how levels of self-efficacy are enhanced through online interaction. However, it shows more specifically how women are encouraged to exemplify their authority and confidence during decision-making with the clinician, and to remove any false preconceptions about the clinician's role.

EXT 16. Sam. Post 60, Lines 1-8

No-one can advise you what to do. Not the women online or the medical team. It has to be your decision and choice entirely.

Just because the oncologist has offered it to you, doesn't mean you have to take it, and some women don't. Don't be afraid to challenge the oncologist and deliberate over your treatment, as it's your right to find out all the facts and figures. It will help you decide. Good luck with making a decision. Don't feel pressured and don't be shy of voicing your view and opinion during clinic to help make that decision.

Sam's response focuses on reminding women that the decision has to be one that is individual and unpressured. She emphasises the importance of patient authority and patient preferences in decision-making, regardless of what medical professionals say. Therefore, this heightens the concept of patient-centred care. Sam is not only giving the thread owner the confidence needed to make a decision, but she is also injecting the power needed to participate in decision-making, and reminding her of the role she has to play alongside the clinician to help make a decision. Therefore, encouraging and enhancing the importance of SDM. Sam explains that even though the clinician has suggested chemotherapy, this does not mean that the thread owner can no longer challenge the clinician's decision. Therefore, this further brings awareness to importance of sharing patient values and preferences as characteristics of SDM, and enforces it to occur during the clinic. Sam's extract, therefore, aims to diminish any feelings of compliance, and to remove any perceptions of the clinician's status of expertise and professional role. Her motive, primarily, is to remind women of their equal status to the clinician when it comes to treatment decision-making; and of their mutual role in participation for decision-making. Women online were continually reminded by each other that *'the treatment selected should be entirely your choice'* and that *'they should have a say'*. This asserts and preserves women's battle for involvement in treatment choice and SDM. Subsequently, the extract illustrates how SDM is enhanced and maintained during forum interaction

5.5 Discussion

A TA was conducted on three UK breast cancer online forums and identified three key themes, which provide valuable information and awareness about the experience of SDM for breast cancer patients, from the conversations that occur online between patients. The

first theme addressed why women access the forums. The findings revealed that reasons for online peer interaction were similar to the characteristics of SDM. The second theme drew more specific attention to exploring the types of decisions which were discussed online. The findings provided an insight about SDM in a clinical setting, the extent to which it occurs, and about the characteristics of SDM. This theme also revealed that SDM is not only limited to a clinical setting, as it exist between peers during online interactions. The third theme showed that SDM is a concept which is brought to awareness and enhanced through online interactions. Findings revealed that peer to peer interaction aimed at educating women about SDM and to facilitate its occurrence in a clinical setting. Patients were continually motivated to participate in their cancer care, and encouraged to feel in control of their cancer care. The next section of this chapter will discuss how the three identified themes answer the research question- how do women with breast cancer experience SDM? The discussion concludes with the researcher's personal and epistemological reflexivity, to outline certain issues and influences during data analysis and to outline how reflexivity has a place in the findings of this study.

The analysis primarily outlined some initial descriptive findings which supports the existing research on forum use. Within these findings, it was illustrated that women utilise the breast cancer forums during the course of their treatment, to talk about topics related to diagnosis, treatments and side-effects, QOL, recurrence of disease, and alternative therapy (Weinberg et al, 1996). Individuals accessed the forums at various points throughout their entire treatment trajectories, to allow for social and emotional support (Finn, 1999; Braithwaite et al, 1999), and acquisition of health information (Cline, 1999; Satterlund et al, 2003). The forums appeared to provide a space which enabled members to exchange personal experiences (Sharf, 1997), and share similar stories (Bane et al, 2005), in aid of creating a supportive network, which provides it members with the knowledge and advice needed to restore emotional well-being.

The first theme, titled '*extending the characteristics of SDM to an online peer community*', highlighted the reasons for breast cancer forum use in more detail. This theme demonstrated that the forums are an appropriate space and valuable way for women to receive support and information. Patient participation to the forums was largely motivated by the need to be informed and in control of emotional well-being. This finding mirrored the patients' role in a clinical setting, as they primarily expected to be involved in their

health care and feel responsible for their health decisions (Emanuel, 1992). Therefore, the concept of patient-centred care is illustrated to be persistent not only in a clinical setting, but also amongst an online community. The action of posting online allowed women to continue to sustain their 'active' participatory role in their cancer care and, therefore, sustain characteristics of SDM outside of a clinical setting. It is, therefore, suggested that interactions within the forums can further promote aspects of patient-centred care and SDM.

This theme largely drew attention to the underlying characteristics of forums use, which reflect the characteristics of SDM in a clinical setting. SDM represents a framework which focuses on the equal partnership and collaboration between doctors and patients (NICE, 2012). Both parties are required to communicate and exchange information about possible attributes and consequences of options, and share their informed preferences for treatment in order to negotiate a mutually acceptable decision, which respects patient autonomy and is also desired (Charles et al, 1997; Elwyn & Charles, 2001). Similarly, this theme illustrates that the forums also serve a similar process to SDM, as they follow the same characteristics. These are that forums allow for patient participation in treatment discussions; allow women to exchange information and knowledge to one another; allow for equal relationships between peers which, therefore, enhance self-esteem; and enable collaborations to take place between peers. Subsequently, it is understood from this theme that the interactions which take place between forum members, can transfer the characteristics of SDM from a clinical setting to an online community. Therefore, forum members are able to experience similar characteristics of SDM online, through the interactions they establish with other women. As a result, this highlights the importance of two-way or multiple interactions online, similar to a clinical setting, to facilitate the occurrence of SDM. It also highlights that SDM is not just a concept which is experienced in a clinical setting, between patient and medical professional. In exploring this theme, an important question was raised: if the characteristics of SDM are taking place within an online forum community, does this mean that forums members can experience SDM online?

This question was answered in the second theme titled, '*experiencing SDM online*', which emphasised the topics of decision-making discussed online. The forums gave women the opportunity to talk to others about their concerns and difficulties in making medical decisions during their treatment; and to interact about a range of interpersonal

decision, which have to be made as a result of treatment side-effects. For instance, members talked to one another about complex everyday interpersonal decisions that had to be made regarding their treatments. For example, the issue of hair management was a topic of decision-making concern for many, as women suffered great difficulty in deciding how to control and live with their hair loss (e.g. shave it off, wear a scarf, and wear a wig). It can be suggested that due to the private nature of the forums and lack of face-to-face interactions, this allowed patients who were experiencing severe hair loss, the confidence to interact with others comfortably. The forum also appeared to provide an area for patients to interact with other patients about treatment choice. Although some discussions surrounding surgical treatments took place online, the most frequent topic discussed was about decision-making for adjuvant treatments, particularly chemotherapy. The complexity of chemotherapy decision-making was shown to be enhanced as a result of the issue of hair loss, as for many women, the concept of tampering with their body image and playing with their self-confidence was a factor which clouded their ability to make decisions. Subsequently, it can be suggested that decision-making is a topic to be shared and interacted with other breast cancer patients.

Two-way or multiple interactions about decision-making took place online, by members posting their concerns and experiences, and requesting, within their post, for other forum members to offer advice, emotional support, and to share similar experiences (Sharf, 1997). The process of exchanging similar experiences, and telling comparable stories, functioned to establish a commonality and, therefore, promoted relationship development between forum members (Cawyer & Smith-Dupre, 1995). Subsequently, it can be suggested that as a result of such rapport and established relationships online, this can create a united community for breast cancer patients, where decision-making could be shared and the process of SDM could be experienced.

From the interactions that took place about decision-making, a representation of SDM in a clinical setting was documented. It is understood that SDM is a process which is experienced by most women, through two-way communication and joint discussions between the patient and clinicians. Interactions in the forums illustrated substantial reference to patient encounters of SDM with the clinician. However, this theme revealed that SDM in a clinical setting is predominantly only for making treatment decisions, and excludes considerations of adjunct concerns such as interpersonal decisions (e.g. wig use or shaving of hair).

An additional understanding of SDM, acquired from this theme, is that SDM is not a phenomenon which only occurs in a clinical setting between patients and medical professionals. SDM is also experienced in external online communities between peers, and in these circumstances, it took place within Internet breast cancer forums. Interpretation of individuals' posts illustrated a description of how SDM occurred online. Decision-making online was demonstrated to take place through a shared approach, which required one member to share their dilemma and other members to offer advice, views, health information, and personal experiences, in order to facilitate decision-making. This shows that sharing online involves a reciprocal role of information exchange through two-way interactions; and it requires established mutual relationships, which is achieved through the social and emotional support provided (Houston et al, 2002; Winzelberg et al, 2003).

The element of two-way communication, information exchange, and mutual relationships during these forums, facilitate patient decision-making. It can, therefore, be suggested that through the process of two-way interaction and deliberations, and an exchange of information and preferences (patient views), the concept of SDM, which occurs in a clinical setting, is replicated, if not represented online. This is very similar to the concept for SDM which takes place between clinician and patient, as online interaction also involves both parties to communicate and exchange information, and share their preferences about possible attribute and consequences of treatment options (Elwyn & Charles, 2009). This finding is also supported by theme one, which illustrates how the characteristics of SDM in a clinical setting can be extended to an online community. It can therefore be argued that a patients' experience of SDM does not only occur in a clinical setting with medical professionals, but a similar symbolic representation of the concept can also take form through peer to peer interaction. Women are not only emotionally supporting one another to remove psychological distress, but they are also facilitating each other over the tasks of decision-making, by sharing their views, preferences, and knowledge (information) of breast cancer, based on their own personal experiences. It can be argued that a patient's experience of online SDM is particularly useful in instances where interpersonal decisions have to be made, and which are not discussed during clinician/patient SDM consultations. Subsequently, the interactions which take place within online support groups represent traits, which are consistent with the *shared model* of decision-making and the notion of SDM in a clinical setting.

The theme concludes by showing that both the experience of SDM in a clinical setting and SDM experienced online, are important to a patient's decision-making experience. Findings within this second theme showed that despite the practice of SDM in a clinical setting, the decision-making experience was still questioned. For example, women engaged in further interaction online about a decision which had already been confirmed during an SDM consultation with clinician. An additional online encounter of SDM between peers was sometimes needed to further support or facilitate the decision previously made in a clinic. This suggests that SDM in a clinical setting is only a subset of overall SDM behaviours, and should be considered to be incorporated into other SDM programmes outside of a clinical setting, such as SDM amongst breast cancer patients and/or family members.

The final theme titled '*ways to enhance SDM*', examined how women help each other in the face of a decision-making dilemma. The findings revealed that decisions were not, in fact, reached online, as forum members were instead stirred towards an 'active' participatory role for decision-making with the clinician. The analysis revealed that women do not help each other to reach a decision, or tell each other what the right or wrong the decisions are. Instead, through the process of sharing their own personal experiences, their stories carried an underlying suggestion, which was to seek help from the clinician, to ease the decision-making process. Interaction between members online, aimed to offer methods which facilitate patients' encounter of SDM and enhance its occurrence in a clinic.

There were two ways in which forum interactions promoted and enhanced SDM, between patient and clinician. This was through encouragement of patient participation and acquisition of patient authority during breast cancer care. In reviewing the former, women were encouraged to participate in decision-making to encounter an experience of SDM, which could help the decision-making process. Patient participation was encouraged in three ways. First, members encouraged one another to establish a good doctor-patient relationship and rapport with their clinician. To achieve this, attention focused on the importance of equal involvement in which both the clinician and patient shared their views, preferences, and information. Secondly, members encouraged one another to acquire as much information and knowledge as they could from their clinician. To achieve this, focus was given to the importance of two-way interaction and patient participation, which is based on an ability to ask questions and share their views. Thirdly, members encouraged

one another to think rationally about their involvement with the clinician, and the type of conversations they were going to engage in during a consultation. To achieve this, focus was given to the importance of structuring concerns, views, and issues to discuss with the clinician. The benefits of these three techniques were continually reinforced online, as a means to ease decision-making dilemmas. Women advised each other on questions to ask the clinician and tried to boost confidence in those who were hesitant. They continually encouraged one another to become informed participants in their own health care, and taught each other how to be an 'active' patient who is thoroughly aware of their own case history and treatment risk factors. It is important to acknowledge that these three suggestions are bringing awareness to the concept of SDM to members online. Patient participation was described online to be through a process of exchange of information; asking the clinician questions; and sharing patient views and preferences, all of which occurred through an established doctor-patient relationship, built on two-way interaction and rapport. Subsequently, the forums encouraged patients to be involved in their cancer care, to maximise positive shifts towards more equitable, or even patient-controlled, relationships between patient and clinician (DOH, 2001b; Graham et al, 2000; Hardey 2001; Ferguson, 1997b).

As interactions within the forums are leading patients towards doctor-patient interaction in a health care setting (Gothill & Armstrong, 1999; Little et al, 2001), this subsequently heightens attention to the concept of SDM and aims to promote SDM and its occurrence during a treatment consultation. Members encouraged one another to participate in a mutual partnership with their clinician, whereby enough knowledge and information is exchanged through two-way conversations, in order to make an informed decision. This is a described characteristic of SDM (Beaver et al, 1996; Charles et al, 1997 & 1999a; Elwyn & Charles, 2001; Towle & Godolphin, 1999). Therefore, the peer to peer interaction online also encourages and educates its members on how they can experience SDM with their clinician. By describing these three techniques for participation, forum users not only brought awareness about the concept of SDM and promoting its use, but also showed their understanding of the characteristics of SDM, based upon their own personal encounters of it. This suggests that women with breast cancer can and do experience SDM in a clinical setting and do acquire an understanding of what SDM means, which is similar to the NICE guidelines (2004 & 2012) and shared model for medical

decision-making. Moreover, it could be suggested that breast cancer forum interaction can play a contributing part in facilitating patients' experiences of SDM in a clinical setting.

The findings in the third theme also showed that the matter of patient authority emerged through online interactions, to further promote the concept of patient participation and SDM. The forums appeared to illustrate an overall system of support and motivation, which was targeted at improving and sustaining patient control and confidence, to participate in decision-making with the clinician. Feelings of entitlement, control, and power were discussed (Pitts, 2004), by reminding women of their rights and the concept of patient-centred care; encouraging them to remain 'active' in their care in order to gain self-control; and disabling any feeling of disparity between the clinician's and the patient's status and role. Therefore, interaction within an online community does not only raise awareness to patient authority, but it also instructs women how to be authoritative and in control of their health care; and encourages them to remain 'active' and involved in their breast cancer care. It can be suggested that by giving women the self-esteem and power to feel equal to the clinician, this in turn helps to sustain patient participation and draws attention to the importance of SDM in a clinical setting. Subsequently, the forums can act as campaigns for elevating the concept of SDM and enhancing experiences of SDM in a clinical setting.

5.5.1 Reflexivity: the researcher's voice

As mentioned previously in this chapter (section 5.3.5- data analysis), researcher reflection was an integral process throughout this study, and was maintained by means of a reflexive diary. In having reached the findings discussed above, it is important to explore how the themes and interpretations of the extracts were influenced, and even shaped, by the researcher's inter-subjectivity.

During the time of conducting the second study I was personally familiar with the concept and use of Internet forums for health advice. At the time, I had been diagnosed with a herniated spinal disc, and was given the option for surgery or to take the pain management path. I, therefore, turned to the Internet in search of information and advice from similar others. I primarily used online forums to talk to other patients about their similar diagnoses, and to gain an insight into the decisions they had made. For me, the

forums were a positive place to gain health information and advice towards treatment decision-making. This therefore gave me good baseline knowledge of how online forums operated, the type of topics which were interacted, and why patients like me used them. I found that my own personal engagement with online forums, subsequently, made it easier for me to operate the breast cancer forums. However, during data analysis, my own personal motives for using online forums, gave me a set of preconceptions for why breast cancer patients used them. In exploring the data, I asked myself questions such as, ‘why were the forums useful to me?’, ‘how did they help me during decision-making?’, and ‘what topics of interaction did I engage in?’ My answers to these questions, therefore, led me towards examples within the data which were similar to my motives. During the stages of the data collection and analysis, I felt like I could personally relate to the breast cancer forum users, and understood the degree of complexity surrounding making treatment decisions. The forums were a personally valuable tool in helping me overcome some of the decision-making complexities. My biased view and experiences towards online forums resulted in me to over emphasised the benefits of forum interaction for decision-making and SDM. My personal engagement with forums was an empowering experience. During my interaction with members, it became apparent to me that forum users persisted in enhancing my confidence, gave me reassurance, and ensured I voiced my views to the doctor. For me, personally, the forums gave me the encouragement needed to stand up to the doctor and query his treatment preference. Furthermore, with my reading of the research literature on Internet use and patient empowerment, I decided to see if traits of empowerment were visible with the data. I acquired an assumption that if patients could influence each other online to question doctors, then they might encourage one another to engage in SDM with the doctor. This thought, therefore, drew me to extracts which illustrated examples of patient control, ‘active’ patient participatory roles, and the concept of patient-centred care in decision-making.

Whilst analysing the forum data, I was in regular contact with a close friend who is a cancer nurse. We had regular conversations about adjuvant treatment side-effects, breast cancer support, and the decision aids available to patients. This gave me heightened knowledge on topics about hair loss and body disfiguration. She also informed about the benefits of online forums and support groups for breast cancer patients, as a form of support system and coping strategy for such adverse side-effects. This subsequently influenced me to become drawn to data extracts about treatment side-effects above other

extracts. I began to question, ‘if patients come online to talk about their concerns over hair loss, can this impact upon their decision-making?’, and ‘how does gaining advice about adverse side-effects from other patients impact their experience of SDM?’ These questions drew me towards certain aspects of the data, and encouraged me to explore the types of decisions that were articulated online. I was keen to explore whether characteristics of SDM were evident during online interaction about adverse treatment side-effects.

The process of reflexivity during this second study taught me that it is a difficult task to put aside your own personal experiences, in the face of data collection and analysis. My personal experiences allowed me to create certain assumptions about why and how breast cancer patients interacted online, which subsequently stirred me towards certain data extracts. As a qualitative analyst, I have learned that research subjectivity is inevitable, however, must be accounted for and acknowledge during the research process, in order to understand the interpretations that have been made. I have therefore learnt that a researcher cannot completely account for their actions, nor become neutral by being reflexive, but this should not be the intention. Instead, the intention is to be transparent, as a researcher, and to describe the potential influences.

5.6 Conclusion

In exploring the main research question, by means of a symbolic interactionist approach, the three identified themes yielded some important findings about the experience of SDM for breast cancer patients. The findings from this second study have demonstrated that women with breast cancer show knowledge and understanding of the concept of SDM, and about its importance for decision-making. By examining the interactions which take place between peers online, it is understood that women are able to characterise SDM, and show awareness of its meaning. Patients’ understanding of SDM and their perceived characteristics of SDM was shown to be based on individuals’ experiences. Therefore, this signifies that SDM is experienced by breast cancer patients in a clinical setting. The concept of SDM was symbolically characterised as a process which involved ‘active’ patient participation; two-way interaction between the clinician and patient, which entails the sharing of information (view and preferences) and acquisition of knowledge; and equal relationship and division of labour, between the patient and clinician, during decision-making. This indicates that patient understanding of SDM is in accordance with

the NICE guidelines for SDM (2004 & 2012), and the *shared model* of medical decision-making.

The findings show that an experience of SDM is highly valued and favoured by women, which subsequently results in women using the forums to promote, enhance, and educate others about the benefits of SDM during a consultation. Therefore, online support groups play an important role in facilitating breast cancer patients' understanding of SDM, and educate patients on how the concept can be experienced during the treatment of breast cancer. With such awareness and promotion given to the concept of SDM, this helps to facilitate patient experience of SDM in a clinical setting.

The findings from this second study move beyond the experience of SDM in a clinical setting. Results showed that SDM is a concept which can occur outside of a consultation room, and can occur without medical professionals. SDM can be experienced between patients, and Internet forums provide an opportunity for the characteristics of SDM to be experienced online between peers. This, therefore, suggests that decision-making should not only be considered between the patient and clinician, as peer to peer interaction can also facilitate an encounter of SDM and assist decision-making for patients. Similar to an experience of SDM in a clinical setting, the findings show that women highly value and favour an SDM experience online. Subsequently, it can be concluded that research attention to SDM should not be confined to a clinical setting. Although patients showed an understanding of SDM, which corresponded to the clinical characteristics of SDM between patient and clinician, the concept, should be regarded as a transferable process which can be experienced between patients and significant others.

In conclusion, the online forum data has revealed substantial awareness around the experience of SDM, from patient conversations. It has also given insight into the additional research questions outlined in Chapter One. For instance, it has elaborated on the meaning of SDM for patients, and what the characteristics of SDM are. It has provided an insight into the factors which influence (facilitate) patients' encounters of SDM. The main discussion chapter of this thesis (Chapter Seven) will explore the findings of this study in relation to the implications it has on breast cancer care, further health research, and qualitative research. Chapter Seven will also further discuss the findings of this study, in more thorough detail, in relation to the literature review outlined in Chapters One and Two, and the overall research questions.

Similar to study one (Chapter four), the findings from this study assign considerable importance to the role of two-way interaction and doctor-patient communication within a patient's experience of SDM. The findings also highlight the role of mutual doctor-patient relationships, and perceived power-relations in facilitating patients' experience of SDM. These outcomes raising further questions surrounding discourse and interactions which take place for SDM, and how this further shapes patients' experiences. This subsequently warrants further exploration of the conversations which take place during breast cancer consultations. The next chapter introduces the rationale for study three, which investigates the concept and presence of SDM and doctor-patient communication, during breast cancer consultations. This will further examine how SDM is verbalised and exchanged.

Chapter Six

Study 3: the presence of SDM during breast cancer consultations

Chapter 6

Study 3: the presence of SDM during breast cancer consultations

6.1 Introduction

The findings from study one and two provided an insight into patients' experience of SDM, from both the patients' perspective and from the character of online interactions between individuals affected by breast cancer. Both of these studies provided an understanding into the meaning of SDM to breast cancer patients and the understood characteristics of SDM. The studies also provided an insight into and how patient experience of SDM can be influence (hinder or facilitate) by certain factors.

Study one (Chapter Four) highlighted the important of doctor-patient communication and doctor-patient imbalanced power-relations, in influencing a patient's encounter with SDM. Study two (Chapter Five) revealed that characteristics of SDM can be experienced within peer to peer online interaction, outside of a clinical setting. The forums also provided an area for women to enhance their awareness of SDM, and to facilitate patients' experience of SDM in a clinical setting. Subsequently, key thematic findings across both studies highlighted the importance of two-way communication and doctor-patient relationships as integral characteristics of SDM, and factors which influences patients' experiences of SDM. This now warrants further exploration in the third study presented in this chapter.

This chapter focuses on how SDM is discursively formed within a breast cancer consultation. It explores the presence of SDM and how it might be experienced by breast cancer patients, through an examination of doctor-patient interaction to see how SDM is verbalised and exchanged. Specifically this study responds to the identified findings of doctor-patient two-way interaction and the issue of power differential from studies one and two. It maintains the theoretical framework of symbolic interactionism, through a qualitative audio-tape recording design, which examines the character of the conversations that take place during consultations about adjuvant treatment for breast cancer. This provides a thorough examination of how SDM is formulated through talk and how it might be encountered by breast cancer patients. A short literature review is provided which

explores the existing research surrounding doctor-patient communication and SDM, and applicability of using conversation analysis (CA) in exploring SDM amongst breast cancer patients. Following the literature review, the method is described. This is then followed by a detailed explanation of the findings achieved through a CA of the data. The chapter concludes with a discussion of the findings.

6.2. Literature Review

6.2.1 Communication skills for SDM

Medical and health psychology literature increasingly highlights attention to good doctor-patient communication during a consultation, as this is highly valued and fundamental to the delivery of high quality care, as it allows patient involvement in decision-making (Fallowfield & Jenkins, 1999; Katz, 1984; Simpson, 1981). Incorporating accurate and valuable information, by employing communication which provides appropriate description and explanation, has been described as an important prerequisite for a successful move towards increased involvement in decision-making (Brennan, 1997; Scott et al, 2000). Communication that stimulates patient questions has been identified as an important component of decision-making (Post, Cegala & Miser, 2002). Some patients may find it difficult to ask questions, as they feel intimidated, are concerned about using the doctor's time, and fear that assertiveness will jeopardise rapport (Towle, Godolphin, Manklow & Wiesinger, 2003). This causes many patients to attribute the process of question-asking mostly to the doctor. A patient's ability to ask questions is important, as it can offer insight into their views and concerns. Therefore, good communication by the clinician, which comprises a conscientious and judicious search for patient views and preferences, may stimulate questions from the patient and, therefore, lead to better information exchange and more involvement.

Many studies show that patients want far more information than their doctors believe they do (Jenkins, Fallowfield & Saul, 2001). The vast majority of cancer patients want to be thoroughly informed about their illness, to allow for more involvement in their care (Meredith et al, 1996). Patients seek further information that is grounded in their own values, and want to be educated by the clinician during consultations (Greenfield et al, 1985; Kaplan et al, 1989). According to Coulter and Ellins (2006), the delivery of high

quality and appropriately targeted consumer health information is central to the achievement of a patient's health knowledge. Patients need access to adequate information and accurate knowledge given in ways, optimal to their own level of understanding, in order to understand the outcomes of tests and the therapeutic intent of treatments, and most importantly, to participate in management plans and treatment decision-making (Bruera, Sweeney, Calder, Palmer, & Benisch-Tolley, 2001; Buchanan et al, 1996; Coulter & Ellins, 2006). Nutbeam, (2000) argues that patient health knowledge acquisition is not simply a matter of being able to read and make sense of health information, but is also an essential empowerment strategy. Being able to effectively access and use health information is the foundation for individuals to have active and informed involvement in their healthcare and in decision-making relating to this (Beaver et al, 1996; Nutbeam, 2000; Ubel & Lowenstein, 1997). This is particularly important in light of the government's move towards a more formal provision of information within cancer care. According to the DOH (2001b & 2007), the provision of information is a key requirement in current cancer service standards, relating to patient empowerment and patient-centredness in the UK. Young (2004) points out, that being empowered, informed, and confident leads to the most effective self-control. Therefore, by presenting appropriate information, this not only reassures and provides patients with realistic expectations (DOH, 2006), but, importantly, empowers them to actively take control and responsibility for managing their condition, and to make further enquiries (Mettler & Kemper, 2006).

One of the main obstacles to patient participation is due to low acquisition of health information and a lack of knowledge of the subject (Katz, Jacobson, Veledar, & Kripalani, 2007). It has been suggested that complex and poor communication can obscure the patient's understanding of information about the diagnosis and prognosis of the illness (Epstein, Alper, & Quill, 2004); and that clinicians pay little attention to checking how well patients have understood the information told (Maguire & Pitceathly, 2002). The drive to deliver high quality consumer health information is a central component of government policy for the National Health Service (DOH, 1997). As a result of these policies, various organisations have undertaken efforts to address doctor-patient communication issues, by introducing series of information initiatives in aid of enhancing the provision of health information. For example, health professionals are encouraged to improve on their delivery of health information through doctor-patient communication skills training (DOH, 2004). Research demonstrates effectiveness of regular training on clinical practice and improved

patient satisfaction and well-being within cancer care (Fallowfield, Jenkins, Farewell, Saul, & Duffy et al, 2002; Fallowfield, Jenkins, Farewell, & Solis-Trapala, 2003). Other interventions focus on the development of health-related learning material and written information aids for patients (DOH, 2001), which show to have positive outcomes, related to patient anxiety, quality of life, medical knowledge, satisfaction; and on the clinicians communication behaviour and attitudes (Brédart, Bouleuc, & Dolbeault, 2005). For example, a commitment to build on the work of the Calman-Hine Expert Advisory Group (NICE, 2004), includes recent developments and plans for a national information strategy, whereby ‘core information packages’ are established and distributed to all cancer patients. Informed medical decision-making occurs when patients understand both their condition, and the implications of the related clinical care (i.e. benefits, harms, limitations, alternatives, and uncertainties). This is achieved through detailed explanation and information from the clinician and information packs. By acquiring health information, this, therefore, provides patients with the confidence to engage and participate in their health care (Henderson, 2003).

The bulk of research on SDM and doctor-patient communication focuses on outlining the principles and tools required to improve communication skills for SDM, and how to involve patients in decision-making. Helping patients structure their communication through the use of a written tool, may improve the way patients described their health concerns, organise their needs and questions, and be more proactive. As a result, lists of competencies for involving clinicians (Box 6.1, Towle, 1997) and patients (Box 6.2, Towle & Godolphin, 1999) have been proposed to guide the process of SDM. These are stages that medical professionals may use in their discussions with patients, but are areas that are not covered in most communication skill training programmes for SDM (Elwyn et al, 1999b). The competencies listed from Towle’s framework make the process of doctor-patient interaction explicit. The framework should enable clinicians to identify patients’ preferred decision-making styles, at the start of the consultation, and to explore the patient’s preferred role in the decision-making. The framework also highlights the importance of information exchange, achieved through good doctor-patient communication.

Competencies for physicians for SDM

- Develop a partnership with the patient
- Establish or review the patient's preference for information—for example, amount and format
- Establish or review the patient's preferences for role in decision-making
- Ascertain and respond to patient's ideas, concerns, and expectations
- Identify choices and evaluate the evidence from research in relation to the individual patient
- Present (or direct to) evidence, taking into account the above steps, and help the patient reflect on and assess the impact of alternative decisions with regard to his or her values and lifestyle
- Make or negotiate a decision in partnership, manage conflict
- Agree on an action plan and complete arrangements for follow up

*Box 6.1 Towle's competencies involved for clinicians for SDM***Competencies for patients for SDM**

- Define (for oneself) the preferred doctor-patient relationship
- Find a physician and establish, develop, and adapt a partnership
- Articulate (for oneself) health problems, feelings, beliefs, and expectations in an objective and systematic manner
- Communicate with the physician in order to understand and share relevant information (such as from competency 3) clearly and at the appropriate time in the medical interview
- Access information
- Evaluate information
- Negotiate decisions, give feedback, resolve conflict, agree on an action plan

Box 6.2 Towle's competencies involved for patients for SDM

While part of the process of SDM is to establish relationships, as illustrated by Towle (1997), the framework, nonetheless, aims to highlight that the concepts of SDM and two-way interaction are not inseparable. Towle (1997) indicates that if clinicians practice the competencies for SDM, then this should lead to an informed agreed decision, between the clinician and the patient. However, if the patient is not provided with enough information or evidence about options, this can result in a conflict between the clinician and patient, and a solution needs to be negotiated. In the context of SDM, negotiation is referred to as back-and-forth communication which is designed to allow for an agreement, where the

patient and the clinician have some interests that are shared and others that are opposed (Fisher & Ury, 1981).

However, the outlined competencies of doctor-patient communication skills for SDM, has been the subject of debate in the literature on interpersonal communication in health care (Charles, Gafni & Whelan, 1999a; Elwyn, Edwards, Gwyn & Grol, 1997a; Elwyn & Charles, 2001). SDM has been shown to be sparsely implemented and practiced in health care (Holmes-Rovner et al, 2000; Stevenson et al, 2000), and clinicians still lack the appropriate communication skills for SDM (Auerbach, 2000; Gwyn & Elwyn, 1999). There is some uncertainty about whether Towle's framework can be functional in a clinical setting (McKinstry, 2000; Stevenson et al, 2000). There are several proposed explanations for this drawn from previous research. For instance, studies have shown that clinicians trained in some of these competences and communications skills do not devote enough time to two-way interaction, and/or asking the patients questions (Roter et al, 1995; Stewart, Brown & Weston, 1989). Time constraints were the most often cited barriers for implementing SDM in clinical practice. Although dedicating time to the right quantity of communication for an encounter of SDM may take longer, this method has been shown to more efficient because of improved health outcomes (Kinnersley, 1997; Roter & Hall, 1992; Street & Voigt, 1997). According to Howie, Heaney and Maxwell (1997), providing patients with more time and opportunities for communication, helps to develop 'patient enablement', and allows patients to understand and cope with their health problems better. Similarly, Beisecker and Beisecker (1990) found that the degree to which patients sought information, interacted with their doctor, and participated in their health care during the consultation, depended on how long the consultation lasted.

Research on communication and SDM has been explored through systematic reviews (Coulter et al, 1999; Elwyn et al, 1999b; Epstein, Alper & Quill, 2004; Godolphin, 2003; Gravel et al, 2006; Stewart, 1995; Towle & Godolphin, 1999). There is also evidence from some qualitative studies, including focus groups studies and semi-structured interviews with patients and clinicians (Edwards & Glyn, 2006; Elwyn et al, 1999a; Elwyn, Edwards, Kinnersley & Grol, 2000; Stevenson et al, 2000). However, understanding the relationship between communication skills and SDM requires new research strategies. Zoppi and Epstein (2002) suggested that investigators should observe communication

behaviours, and concurrently gather participants' objective experiences of the interaction to better understand about doctor-patient communication.

More recent research used alternative methods to examine whether the proposed concepts and practice of SDM for patients and clinicians are utilised, and further promoted SDM training in practice. More specifically, research has taken distinct turn to explore whether communication patterns for SDM can be identified during consultations, through a deeper exploration of routine clinical practice. For example, Saba et al (2006) examined SDM and the subjective experience of interaction, for patients and clinicians in primary care. Direct observations of consultations were made by videotape. Decision moments were coded for objective evidence of SDM, using a structured instrument, and grounded theory was used to identify themes. This was a useful study as it combined direct observation and assessment of the subjective experience of interaction. The findings suggested that communication behaviour did not result in a positive subjective experience of collaboration or partnership, and that attempts to enhance SDM needed to attend to both effective communication style and effective relationship dynamics.

Another similar study is by Elwyn et al (2008) examined the communication strategies of clinicians attempting to involve patients in treatment or decision-making. This was compared with theoretical 'competences' derived for SDM by Towle (1997). Consultations from four purposively selected clinicians, who were experienced in SDM, were tape-recorded and then transcribed and coded by means of CA into skill categories. The focus of analysis was to assess the implementation of SDM, through exploration of the conversations during clinical consultations. The clinical specialities conveyed from this study, were that the empirical data did not match the suggested theoretical framework. Clinicians failed to explore the views of patients about treatment possibilities, and their preferred role in decision-making. Interactions were initiated by a problem-defining phase, and the portrayal of option information was often fused with opportunities to allow patients to question and reflect. Significant proportions of time were shown to be for information exchange and patient interaction. A decision-making stage occurred consistently after approximately 80% of the total consultation duration. This study is useful as it demonstrated that some theoretical competences are not distinguishable in practice, and that the suggested ideal of a SDM interaction will either require more time than currently allocated, or alternative strategies.

Both studies by Saba et al (2006) and Elwyn et al (2008) draw attention to the significance of qualitative methods, in exploring and evaluating the role of communication during SDM. Furthermore, both of these studies are useful as they have found that a criterion for SDM does not ensure that the decision-making process is subjectively collaborative. Relationship dynamics, such as trust and power, may either influence patterns of communication or mediate the perception of collaboration in the decision-making process (Saba et al, 2006). Greater efforts need to be made to enhance doctor-patient communication and relationship dynamics.

6.2.2 Exploring SDM through talk

CA, or as it is sometimes known, the study of ‘talk-in-interaction’ is an “analytical orientated discipline that developed out of ethnomethodology” (Potter, 1996, p.43). Ethnomethodology focuses on providing a rational analysis of the structures, procedures and strategies that people themselves use when they are making sense of their own everyday world, and their actions and interactions within it. Therefore, CA investigates how language is put together and used in interactions. It focuses on the largely verbal communicative practices, which people use in interacting with one another. The analysis centres on first, identifying elements and structures in naturally occurring conversation, and then, through a detailed procedure of micro-analysis, identifying evidence for the models, concepts, and ideas that people use. In a sense, CA is concerned with uncovering the implicit ideas and understandings people possess and use in their everyday interactions. The identification of sequential patterns and the practices, through which these patterns are generated, are distinctive to CA’s approach. In comparison to the somewhat static picture provided by quantitative methods, which produce statistical aggregations, CA aims to identify and describe the specific interactional consequences which follow from given verbal practices (Perakyla, 1997). The novelty and power of a CA approach is the potential for identifying the kinds of choices doctors and patients make, and how they design their turns, utterances, and sequence of talk action. CA can examine talk at various intervals of a consultation, whether during discussions about the patient's history, conducting a physical examination, delivering the diagnosis, or suggesting treatment options.

CA has an established pedigree in psychological research, with specific reference to examining medical communication (Heritage & Maynard, 2006). CA research, in a health setting, compares institutional communication with everyday conversations (Drew & Heritage, 1992), to reveal practices which govern medical consultations. There are many examples of CA research in health settings, which look to explore consultation openings (Gafaranga & Britten, 2003); communication during physical examination (Heritage & Stivers, 1999); and patient explanation of their illnesses (Gill, 1998). CA has also been employed as a useful analytical tool to explore informed decision-making (Braddock, Edwards, Hasenberg, Laidley, & Levinson, 1999; Drew, Chatwin, & Collin, 2008; Pomerantz & Fehr, 1997); patient participation (Greenfield et al, 1985; Kettunen, Poskiparta & Karhila, 2003; McCabe, Health, Burns & Priebe, 2002); and doctor-patient relationships during clinical practice (Greenfield et al, 1988; Maynard & Heritage, 2005).

Regarding research in breast cancer, CA is a method which has been used to explore patient attitudes towards breast cancer (Wilkinson, 2000; Wilkinson & Kitzinger, 2000); their interactions with other patients (Sharf, 1997; Winzelberg et al, 2003), partners and family members (Manne et al, 2006); and patient interaction with medical professionals (Butow, Brown, Cogar, Tattersall & Dunn, 2002; Jarret & Payne, 2000; Pollak et al, 2007; Robinson et al, 2008). Within the context of SDM and CA research, the study outlined above by Elywn et al (2008), is the only documented study. However, SDM and CA research is yet to be explored within breast cancer. There is also no research conducted using CA to examine the meaning of interaction during patient-doctor conversations for decision-making, to explore the concept and presence of SDM with breast cancer care. As CA examines 'talk-as-action' situated in symbolic meanings (Maynard & Heritage, 2005), this makes it valuable to the study of SDM and breast cancer, and relevant to the realm of critical health psychology and the interpretivist perspective of symbolic interactionism, in which this thesis is situated within. By examining the enterprise of people doing the business of 'talk-in-interaction', CA can seek to understand how women with breast cancer make sense of their SDM interactions with the clinician. CA also enables examination of how social structures and social processes, such as the issue of doctor-patient power-relations highlighted in the findings from studies one and two, are reproduced implicitly through interaction and talk. Consequently, CA will help uncover the implicit experience of SDM for patients, which this thesis aims to investigate, through doctor-patient interactions during a breast cancer consultation.

The next study aims to fill the gap in the literature by using CA to add to studies one and two and refine the meanings that can be applied to SDM. Similar to Elwyn, et al (2008), this study will employ a similar method of audio-recordings of clinical consultations and introduces CA as an alternative method to acquire a thorough insight into medical interactions for SDM. However, unlike the previous studies, which use CA to evaluate communication as defined by the acquisition and evaluation of skills, this study utilises CA in exploring doctor-patient communication to examine how breast cancer patients respond to the clinician's talk in context of decision-making, to uncover the meanings behind interaction for SDM, and about the concept and presence of SDM.

6.3 Method

6.3.1 Study design

With the aim to explore the research questions through a symbolic interactionist qualitative approach, Elywn et al's (2008) method of audio-recording consultations was adapted and applied to breast cancer consultations. The study design set to explore SDM during consultations for adjuvant treatment. Exploration of conversations during adjuvant treatment consultations was proposed for the purpose of the third study, over surgical consultations, as a result of the findings from study one (Chapter Four) and study two (Chapter Five). It was highlighted in patient interviews during study one that participants, who had undergone surgical treatments, stated that when it came to surgical decision-making, patient choice and decision-making was not important. Participants obtained a belief that the clinical route to surgical decision-making should be to simply remove the cancer, as the principal aim of recovery is to remove the cells and increase chances of survival. Therefore, a strong attitude of *'just get rid of it'* was found throughout the data, and the concept of SDM was viewed as limited. Similarly, it was revealed in study two, during patient online interaction, that decision-making and patients' encounter of SDM is more important during the adjuvant treatment stage. Due to the side-effects of hair loss and weight gain, which are experienced during adjuvant treatments, patient participation and patient control over decision-making was regarded as essential. Therefore, the concept of SDM was viewed as important within the forums, and experienced largely during adjuvant stages of treatment. Subsequently, for the purpose of the third study, it was decided to explore doctor-patient communication during adjuvant consultations. CA, focused on

examining how SDM is verbalised and exchanged, through interpretations of language and discourse. Transcription used Jefferson conventions (Jefferson, 1985), which observed speech with all characteristics, rather than verbatim. This qualitative method of exploring patients' meaning of SDM interaction is the first to be accounted for within the health literature for the treatment of breast cancer.

6.3.2 Pre data collection preparations

Before collecting audio-recorded data from the consultations, it was important to explore specific aspects of medical assessments during the adjuvant treatment stage for breast cancer. As with study one in reference to diagnosis and surgical discussions, it was essential to find out about the medical process and treatments for breast cancer during the adjuvant stage of treatment. Regular weekly visits were made to oncology clinics and on-going observations took place of adjuvant treatment clinics, over a three month period. The observations were not intended as an independent observational study, and instead were utilised as an opportunity to become familiar with medical practices, clinical procedures, and increase awareness of terminology related to adjuvant treatments for breast cancer.

6.3.2.1 Clinic observation: initial adjuvant clinic and treatment monitoring clinic

Regular visits were made to two different types of adjuvant treatment clinics for breast cancer for observation. These were an initial adjuvant consultation and a treatment monitoring clinic. Both clinics took place at the University teaching hospital Cancer Centre, once a week by the same clinician who was a senior oncologist. The aim of the observations was to gain an extensive understanding of adjuvant treatment knowledge, and to observe the different types of consultations that take place during adjuvant treatments of chemotherapy and radiotherapy. Attendance at these consultations provided an opportunity to see patients talk about their illness, following surgery (either a mastectomy or a lumpectomy), and to perceive the clinician's role and duties during a patient's adjuvant treatment stage. The observations provided suitable insight into the phraseology, medical terms, procedures, and systems involved during post-surgical stages of breast cancer care.

The first clinic observed was an initial adjuvant clinic, which took place weekly for patients who had completed surgical treatment, and were ready to start adjuvant treatments. Patients attended the clinic with a family member, partner, or friend for support. The initial adjuvant consultation began with a physical examination of the breast, and then the content of the consultation comprised of: review of patients' diagnosis and surgical treatment; review of post-surgery test results; review of patients' current health; discussions about why adjuvant treatment was necessary and which treatment was needed for the patient; discussion about procedure and side-effects; and outlining clinician trials which patients could participate in. Dialogue was mostly led by the clinician in terms of description, explanation, and justification. However, patients also showed some involvement by asking questions at the end of the consultation. Following the consultation, the oncologist left the room and a breast care nurse was invited inside, to spend some time with the patient. The nurse once more informed the patient about the treatment plan that was previously discussed by the clinician. This allowed them another opportunity to express any queries or doubts. This period of time allowed the nurse to provide the patient with all information packs and reading material about adjuvant treatments.

The second clinic observed was an adjuvant treatment monitoring clinic. This clinic took place weekly, and was designed for patients currently undergoing treatments of chemotherapy and/or radiotherapy, and/or required follow-up assessments. During these consultations a different structure of conversations took place: a review of patients' adjuvant treatment plans and stages were outlined; the patients' current health was reviewed; discussions about side-effects and how to manage them occurred; and a review of the next stage(s) of treatment was outlined. These consultations were far more patient led, in that they focused on reviewing the patients' health, QOL, emotional distress, and any other concerns or issues with the adjuvant treatment plan. More interaction between the clinician and patient took place, as the patient asked frequent questions about their health status and treatment stages. During these consultations, a breast cancer nurse was present, who took medical notes and contributed to the clinicians talk, by offering further reassurance and health care advice through positive language. At the end of the consultation, patients were once again given the opportunity to spend some time alone with the breast care nurse, to share any queries and questions.

The opportunity to observe both initial adjuvant clinics and adjuvant monitoring clinics, provided a better understanding of some of the medical terms, the post-surgery treatment stages, and how an adjuvant treatment plan is conversed, during the adjuvant stage of breast cancer care. Such access to clinical practices and expansion of knowledge, subsequently, helped to facilitate the development of the study design and methods of data collection in study three. By visually witnessing how adjuvant consultations formulated and operated, the acquired knowledge on medical terminology and the structure of the consultations made listening and analysis of the audio-recordings easier to follow and transcribe.

6.3.3 Audio-recording cassettes

Due the sensitive and confidential nature of accessing first hand clinical observations of breast cancer consultations, it was, therefore, compulsory to ensure a method of data collection was selected which did not breach patient privacy. A technique to overcome direct clinical observations was for the clinician (i.e. the oncologist) to seek consent to record the consultations which took place. As outlined in the literature review above, audio-recording of clinical consultations is now a common practice, which has been used for a variety of health research purposes and CA studies. Of all observing techniques, audio-recording has been recommended as the best method for researching doctor-patient communication because it captures all modalities of the interaction between participants in a consultation (Inui & Carter, 1985). Therefore, it is a method predominantly used to assess patient and medical professional interactions, for teaching and training of communication skills. According to Coleman (2000), the ability to obtain a complete record of both clinicians' and patients' consulting behaviour has enabled researchers to investigate a variety of research questions, which were previously unanswerable. Furthermore, this method within health research has been described as high in internal validity, as the recordings provide a complete record of what actually happened; rather than participants behaving in an 'atypical' manner as a result of the researcher influence, bias, confounding variables, or chance (Gibbs, Friese & Mangabeira, 2002).

For the purpose of this study, audio-recordings, of initial adjuvant treatment consultations, made by the clinician, were used for analysis. The audio-recordings of breast cancer patients' consultations were part of standard institutional practice in the Oncology

Department at the University teaching hospital. The method of recording was used for creating an information tool, which was given to the patient to take home at the end of the consultation. Subsequently, these cassettes acted as a means for patients to receive future clarification and comfort, by listening back to the conversation which took place within the consultation. The recordings were not used for medical or training purposes, nor were they stored at the hospital. As soon as the consultation ended, the tape was handed over to the patient and was, therefore, solely for the patients' possession and future use. The clinician verbally asked patients at the start of the consultation if they agreed to their consultation being recorded, as a source of information for them to then take home. At the end of the consultation, a short self-questionnaire was completed which indicated whether the patient agreed to the tape recorder being switched on. The questionnaire also specified whether the patient decided to take the cassette home. This questionnaire was completed for the clinician's own knowledge and references. For those patients who decided not to take the recorded cassette home, their cassette was subsequently destroyed. In order to use these cassette recordings for research purposes in study three, written informed consent was obtained from the patients, as the cassette was their property and possession.

6.3.4 Participants

Ten women aged 18 years and above, who had completed breast cancer surgery (either a lumpectomy or a mastectomy), consented to releasing their audio-recording cassette of their adjuvant treatment consultation for CA (Table 6.3 illustrates participant profiles). Five of the participants (50% of the sample) were aged between 50-59 years. All 10 participants were from a white British ethnic background. The sample captured all types of adjuvant treatments, thus enabling a broad insight into the conversations which took place between clinician and patient. There was also an equal split of participants who had previously undergone surgical treatments of both a mastectomy and a lumpectomy. However, the surgical type was not an inclusion or exclusion criteria that applied.

Table 6.3

Participant demographics

P No'	Age	Adjuvant treatment	Surgical Treatment	Other conditions	Employment status	Marital status
1	50-59	C & H	M	Mental Health	Unable to work	Single
2	40-49	H	L	None	Employed	Married
3	50-59	C & H	M	None	Self-employed	Married
4	50-59	R & H	L	None	Employed	Divorced
5	60-69	C & R	M	None	Employed	Married
6	50-59	C & H	M	None	Retired	Widowed
7	40-49	R & H	L	Diabetes	Retired	Married
8	60-69	R & H	L	None	Employed	Single
9	50-59	R & H	L	Diabetes	Retired	Married
10	60-69	R, C & H	M	None	Retired	Married

Note: M- Mastectomy, L- Lumpectomy, C- Chemotherapy, R- Radiotherapy, H- Hormone therapy

All women were registered patients of the Oncology Department at the University teaching hospital, and were seen by the same oncologist during their adjuvant treatment stage. All 10 participants had completed their initial adjuvant consultation with their oncologist two months (eight weeks) prior the time of recruitment. The two year time frame was considered by the oncologist as an appropriate length of time for the patient to adjust to their treatment, and to utilise the tape for their personal use. This is an important consideration for ethical purposes. To maintain uniformity with studies one and two, patients who had opted for breast reconstruction following a mastectomy, were not included in the sample criteria. Focus was maintained on only recruiting patients who had received a cassette recording or had agreed for recording of their consultation to take place.

6.3.4.1 Participant recruitment

Following ethical approval and access from the Research and Development (R&D) Department at the University teaching hospital (section 6.3.7), the senior Oncologist granted access to patient records and the cassette questionnaire data from the initial adjuvant clinic. As a log (questionnaire) was kept of patients who consented to the cassette

recording and had taken the cassette home, this meant that participant recruitment could be targeted more specifically. For the purpose of participant recruitment, the questionnaire was used as a means to identify which patients matched the study inclusion criteria. The list was filtered down to patients who had their initial consultation, with the clinician, eight weeks prior to the time of recruitment. Patients from the March 2012 and April 2012 clinic were included for recruitment. April 2012 was also included to allow for enough participants to be contacted and recruited. The initial adjuvant clinic was held weekly, in which four patients were seen during the clinic session. This, therefore, resulted in a total of eight clinic sessions and a total of 32 patients eligible for recruitment. However, two of these patients were male, two did not agree to have their consultation recorded, and one had since died. This left 27 eligible participants who were sent a recruitment pack. This included an invitation letter (appendix K), along with an information leaflet (appendix L) explaining the study, and an agreement form to sign (appendix M). A pre-paid envelope was also included in the pack for the agreement form to be returned. For ethical purposes participants were not contacted until their agreement letter for participation was received. As there was no intention to contact participants prior to acceptance, follow-up of those who did not respond to the initial invitation letter was avoided, and it was assumed that the patient had decided not to take part. From the sample of 27 contacted, 10 positively responded to participate, five declined, and the remaining 12 did not respond.

The sample size was confirmed on three reasons. The first reason pertains to the amount of time and effort that goes into CA text analysis at such a fine level of detail, relative to other qualitative analysis (Guest, Namey, & Mitchell, 2012). For example, compared to the TA, which was conducted in studies one and two, the item of analysis consisted of smaller text and the analytic action was to identify themes within that text segment. In contrast, linguistic-oriented approaches, such as CA, require intricate dissection of words, phrases, sentences, and interaction among speakers; and also take into account tonal inflection during the analysis. Therefore, such linguistic type of analysis requires far more analytic time and effort per page of text, and results in a smaller sample size (Guest, Namey, & Mitchell, 2012). The second consideration is the source of data. Since CA is most interested with naturally occurring language, in-depth interviews or focus groups are not ideal data collection methods (Baker & Edwards, 2012). Therefore, audio-recordings or observations are required to capture the purity of the data. As breast cancer consultations can be arguably regarded as highly emotive or sensitive, recording

doctor-patient interaction during clinic may be viewed as invasive. Subsequently, with the population of breast cancer patients being hard to access, Baker and Edwards (2012) suggested that a small number of consultations or subjects, such as between six and a dozen, may be extremely valuable and represent adequate numbers for a research project. The final consideration is based on Popay, Rodgers and Williams (1998) who stated that, in qualitative work, “randomness and representativeness are of less concern than relevance [...] Does the sample produce the type of knowledge necessary to understand the structure and processes within which the individuals or situations are located?” (p.346). Therefore, the sample size (i.e. number of audio-cassettes) was made on the basis of their ability to provide relevant data on the area under investigation. As each tape recording was extensive in length and in the density of data, this provided many instances for relevant data on decision-making and shared doctor-patient communication to be explored. Subsequently, it is suggested that the number of different speakers or sample is of less relevance, than the number of occasions or instances in which the phenomenon (SDM) can be looked at.

6.3.5 Data collection

The method of data collection required participants to do nothing, other than to consent to their cassette recording being accessed by the researcher and used for research purposes. As mention in section 6.3.4.1 (*‘participant recruitment’*), participants who met inclusion requirements were sent a recruitment study pack, which included an invitation letter, study information, an agreement form, and a pre-paid envelope. Participants were informed that they will be contacted by telephone by the researcher to discuss the next steps only upon accepting to take part, and after returning the agreement form. Upon receiving the agreement form, a telephone conversation took place between a member of the research team and participant. During this telephone conversation, participants were given the opportunity to talk about their participation and ask questions. They were also informed about the next stage of data collection, whereby they were to receive additional documents in the post. Participants were instructed, over the phone, that they were required to sign the informed consent form (appendix N), complete the demographic questionnaire (appendix O), and send both documents back to the research team along with their audio-recorded cassette. A secure postage method was set up to ensure safekeeping and confidentiality of cassettes. This postal service was used by participants to send their cassette to the research

team, and also used by the researcher to send the cassette back to the participant, upon completion of use. Each cassette was only in the researcher's possession, and used for transcription for approximately a week and then returned. Once the cassette had been securely sent back to the participants, they once again received a telephone call from the researcher. The call was to ensure that they received their cassette, and to again allow them to ask further questions. Participants were informed during this second telephone conversation that a summary of findings will be sent to them at a future date.

6.3.6 Data analysis

Each cassette was listened to 5-6 times during transcription. The first listening was of the whole consultation to become familiar with the recording. The second-fourth time entailed micro-detailed transcription of the data, using the Jefferson system (Jefferson, 1985). This meant that the words were not just transcribed verbatim, but were documented as they were heard. The process of Jefferson transcription involves the use of symbols that denote emphasis, pause, inflection/deflection and overlapping speech, amongst other characteristics. Appendix P illustrates an example of the Jefferson system- symbols and their meanings- used during analysis. The process of transcription is often referred to as a 'noticing device', as actually carrying out a transcription, forces the analyst to attend to details of the interaction that would normally escape the attention of the ordinary listener. According to Heath and Luff (1993):

"The process of transcription is an important analytical tool, providing the researcher with an understanding of, and insights into, the participant's conduct. It provides the researcher with a way of noticing, even discovering, particular events and helps focus analytic attention of their socio-interactional organisation". (p. 309).

Transcription involved playing back small sections of a conversation extract repeatedly, and gradually writing out the words and sounds of the conversation according to the symbol outlined in Appendix P. Throughout the transcription process, separate notes were also made about aspects of the conversation which came to attention, such tone linguistic, intonation, tempo, and inflection. Therefore, continuous, careful, yet unmotivated, attention was given to the dynamic and sequential nature of the conversations. This process of transcription subsequently allowed attention to be drawn to aspects of the 'talk-in-

interaction', which usually would not be paid attention to in everyday conversations. The final listening was to ensure certainty that the orthography represented what was heard. CA was conducted using established frameworks and guidelines (Sacks, 1992), which focus on basic content, turn-taking, speech repairs and other communicative devices:

Examining basic content - i.e. what is said. Following this, the analysis turns specifically to what is being done in the conversation.

Turn-taking - locating when the interlocutors know when to take the conversational turn and what contributes to this position, e.g. the construction of turns, pauses, and overlaps.

The sequencing of conversation- how the conversation is distributed and how utterances in talk are sequentially organised, e.g. how utterances are adjacent to each other (adjacency pairs)

Expanding - examines the use of 'filler' words, such as "oh" (e.g. "oh, I'm not sure"), which in a clinical context can be useful to determine the deliberations and reasoning between interlocutors.

Repairs - these look at how people deal with interactional 'trouble' during a conversation. They are common in naturally occurring talk, and are anticipated to be highly prevalent in consultation recordings. An example could be "the procedure will involve a... well mostly it necessitates a cut here" - an active attempt to clarify or emphasise a point once the speech has commenced.

Reliability checks- the research team jointly review drafts of analyses to ensure that the quality of analysis is high and that there is internal consistency in the linguistic and conceptual outcomes.

Throughout the analysis there was a consistent focus on the sequential implications of utterances, to explore relationships between the story and subsequent talk. Therefore, the analysis was guided by regularly asking the question 'why that utterance now?' The

analysis was then interpreted and applied to answer the research question, which is beyond the focus on understanding conversational structure. In contrast to discourse analysis and other language focused qualitative methods, CA has a strong commitment to the idea that interpretations made about the data being analysed, must rest upon identifiable evidence in the conversations themselves. Therefore, during the analysis, specific elements in the talk, which supported the interpretations, were identified and illustrated by supporting extracts.

As mentioned in Chapter Four and Five, the researcher's ability to reflect on their behaviour and thoughts, as well as on the phenomenon being studied, is an important requisite of qualitative research. Richardson (2000) refers to writing as "a method of inquiry, a way of finding out about yourself and your topic" (p. 923). Ellis and Bochner (2000) suggested that the process of written self-assessment should resemble a "personal tale of what went on in the backstage of doing the research" (p. 741). Therefore by keeping a reflexive journal during data analysis, this enabled the researcher to become aware of what allowed and inhibited the research's seeing during analysis, and how the researcher's personal assumptions and behaviour may be impacting the inquiry. The diaries focused on recording key events and habitual practices, what the researcher was feeling about the research, the reasons for the decisions that were made, and the researcher's thoughts and attitudes towards the research itself and the information that was arising. Any presuppositions, choices, experiences, and actions during the research process were included in the diary. An evaluation of the researcher's ability to transcribe the audio-recordings in the Jefferson system, and engagement in CA was also recorded. In turn, the commentary notes in the diary were an effective way of confronting the researcher's thoughts and perceptions, and to see whether they influenced the data collection process and analysis. The process of reflexivity will be discussed further in the discussion section (section 6.5.1) of this chapter

6.3.7 Ethical submissions

A separate ethical application was submitted for study three. Approval was granted from the local NHS Research Ethics Committee (REC) (appendix Qa) and the R&D department at the University teaching hospital (appendix Qb), from which the sample was recruited. The Institute for Social Sciences at Keele University, together with the supervisor team in

the School of Psychology certified full peer review for the study and the project as a whole. The researcher had clearance from the Disclosure and Barring Service (DBS), and was given access to patients, subject to the award of an honorary contract and research passport by the University teaching hospital. This was granted by the R&D Department at the hospital. The research also received up-to-date full Good Clinical Practice (GCP) training, by the NHS trust, to ensure that research was conducted to ethical and practical standards.

All ethical procedures were adhered to during the conduct, analysis, and write-up of data collection. As the cassette recordings were part of routine medical practice at the University teaching hospital, ethical permission to record doctor-patient conversations was not needed, and this was approved by the NHS REC. However, the committee stated that permission was needed of participants to access and use the cassettes for research purposes. Also procedures for safeguarding confidentiality were an issue of ethical concern raised by the committee. The methods of audio-recordings had to be understood with reference to issues of confidentiality, privacy, surveillance, and ownership, which were addressed and made reference to in the patient information leaflet. All participants provided their written informed consent. Participants were also informed that they could request copies of the transcription, and could also receive a copy of the final report, if they wished. All participants and the oncologist remained anonymous, and were only given a number for identity. For the purpose of the thesis, where extracts are used, all participants are given an initial ('P'), and the clinician ('C'), for confidentiality reasons.

6.4 Results

The final third study, in this chapter, took a further exploration of the research questions and the findings raised from studies one and two, by means of a symbolic interactionist. Focus of the study was to gather intelligence on the concept and presence of SDM during breast cancer consultations, through examining of doctor-patient interaction and the meanings situated in actions (i.e. talk). This was subjected to a CA on the audio-recordings. Analysis of the transcripts revealed some initial descriptive outcomes, and outlined three recurrent discursive practices, which took place during doctor-patient interaction. These were: 1) *fragmented conversations*, 2) *territories of knowledge and epistemic markers*, and 3) *extending multi-turn utterances*. The analysis also revealed

'what happens when there is two-way interaction' during an adjuvant treatment consultation. These findings are discussed below, accompanied by illustrative extracts from the audio-recording transcripts (a transcript number and line numbers will be provided for each quote).

6.4.1 Initial descriptive findings

Upon provisionally reviewing the transcripts, there were some trends that appeared prevalent across all of them. The descriptive findings helped to give a general perspective of the audio transcripts and the content and structure of each initial adjuvant treatment consultation. These findings were also important to the rest of the analysis as they initially indicated the types of conversational practices which could be derived from a CA.

There was very little difference in content and topic of conversation which took place between the 10 transcripts. All 10 recordings lasted 40-45 minutes, and had a very strong and rigid structure to the overall consultation, including the following topics:

1. Clinician asks the patient to explain their understanding of their diagnosis, results, and treatment plan
2. Clinician providing a detailed explanation of their diagnosis and treatments carried out.
3. Patient given the opportunity to ask questions about diagnosis.
4. Clinician explaining their current status of health.
5. Clinician explaining why further adjuvant treatment is necessary.
6. Patient given the opportunity to ask questions.
7. Clinician outlining the treatment plan and the processes involved.
8. Clinician describing side-effects of treatments.
9. Patient given the opportunity to ask questions about treatment plan.

This template of conversation, applied to all 10 patients during the consultations. The scripted nature of the consultation and the rigid structure of topics discussed between the clinician and patient, drew attention to the importance of information exchange during doctor-patient interaction. For instance, the descriptive findings showed that the consultation time and structure of conversations were devoted to explaining, justifying, and describing the diagnosis, treatments, and side-effects; and delivering all of the essential

health information. During this time, patients were given the opportunity to share their concern or queries at various stages. However, there was very little patient involvement and interaction in conversation, unless when they were explicitly asked a direct question. This immediately raised questions regarding doctor-patient interaction. If opportunities for information exchange between the clinician and patient are structured to take place, why do patients choose not to contribute to interaction and participate in the conversation? Do patients interact beyond being directly invited and asked ‘do you have any questions?’ And if so, how are two-way discussions structured? These questions helped to guide the rest of the analysis.

The previous studies drew attention to the importance of two-way interaction as a factor which appeared to contribute towards patients’ understandings and experiences of SDM. Therefore, it could be questioned, if doctor-patient interaction is limited during a consultation, does SDM formally take place? In order to acquire a more comprehensive overview about patient conversations for SDM, and to answer the queries raised from the descriptive outcomes, it became important to scrutinise the conversations within the transcripts in more detail. The CA focused on identifying three particular discursive practices which appeared recurrent in structuring dialogue and two-way interaction, such as *fragmented conversation*; *territories of knowledge and epistemic markers*; and *extended multi-turn utterances*. These conversation practices will then be later interpreted in the discussion.

6.4.2 Practice one: fragmented conversations

The data highlighted a strong use of boundary markers and rhetorical questions during sections of talk within consultation, which constrained patient contribution. Extract one illustrates this further.

Ext 1. Transcript 2

- 1 C: The:re’s a good chance you are in remission (.) because
- 2 there is nothing left- (.) and therefore you are cured↑
- 3 (2.9)

4 C: But- there is a sma:ll cha:nce there are micro:scopic cells
5 left* (.) and if we did nothing they will gro:w and the cancer
6 will come back-

7 (2.5)

8 C: If↑ that is the ca:se (.) what can we do n:ow to get rid of
9 them?

10 (3.2)

11 C: >We can't tell< (.) bu:t we try to build up a picture of
12 risk-

13 (2.8)

14 C: S:o (0.2) we think about thre:e areas

15 (1.0)

16 C: We fir:st↑ think about your breast itself (.) >well<
17 following the successful surgery (.) we know that alone is
18 <not enough> (.) >so we want to give you radiotherapy<

19 (2.1)

20 C: We next think about the gland area (.) >well< there is no
21 problem there↑ (.) >so we don't want to do anything more<

22 (2.0)

23 C: Then finally (.) we think about the rest of the body

24 (0.9)

25 C: Could (.) these cells have escaped (.) from the breast(.)
26 and gone elsewhere?

27 (3.4)

28 C: We have n:o answer to that↓ >in which case< we want to give
29 you treat:ment to get rid of it

30 (2.8)

In the opening two lines, the clinician introduces the conversation by talking about the patient's current health status. The use of the word '*cured*', primarily invites the patient into a positive conversation. However, very quickly in line 4, the word '*but*' is used to signify a negotiation. The negotiation is that there is a minute chance, which is illustrated with the use of the word '*microscopic*', of there still being cells left. Nonetheless, the necessity for further adjuvant treatment is rationalised by means of a reminder to the patient that the '*cancer will come back*'. In line 8, a question is posed by the clinician about how these microscopic cells can be removed. The adjacency pair is followed by a long three second pause (line 10), which is heard as attributable to the patient. The silence indicates that the clinician has selected the patient as the next speaker in turn, and allows for a second pair part (SPP). The silence is interpreted as the patient not speaking. This is regarded as interactionally relevant, as the patient is not speaking at a time where she is invited to speak. Subsequently, the lack of interaction from the patient disengages her from the sequential turn-taking of the conversation.

Following on in line 11, the clinician continues the turn of talk as an attempt to repair the silence by providing an answer to the question posed. The question is answered by means of a step by step process of '*building a picture of risk*', through story telling. The story opens in line 14 with a clear boundary marker ('*so*'), which signifies the start of a new section of talk (i.e. the start of the story) and, therefore, instructs the patient to listen. This structural format of the story is achieved through use of time sequence connectives (e.g. '*first*', '*next*', and '*finally*'). Such connectives enable the clinician to maintain control over each turn construction unit (TCU), until the end of the story in line 29. This discourages the patient to participate, which is evident through the lack of interaction during the narrative.

Once again in line 25, another question is posed by the clinician. This again is followed by another extended three second pause (line 27), with no interactional response from the patient. Therefore, the clinician continues and responds to the question posed. In both instances, we can clearly see the use of questioning which does not attain an interaction. In both lines 8 and 25 a figure of speech, in the form of a question, is asked. The action consequence of the question asked is demonstrated to be no interactional response. This practice is arguably regarded as a form of rhetorical questioning. Thus, the question is not necessarily asked in order to seek information from the patient. It is instead

asked as a vehicle for another action, which is, to request to the patient that the clinician provides certain information, and in doing so, this will fill the gap in the patient knowledge or information state. As a result, this will facilitate the decision-making for the patient. There were multiple examples within all 10 transcripts, which demonstrate a systematic practice of rhetorical questioning during the consultations. Extract two demonstrates the same action by the clinician on a different occasion.

Ext 2. Transcript 5

- 1 C: Is there a benefit to chemotherapy
- 2 (2.0)
- 3 C: So- this is your group he:re and they have shown >percentage
4 wise< that there is n:o benefit.
- 5 (0.1)
- 6 C: There m:ay be some detriment (.) >which is the side-effects<
- 7 (3.8)
- 8 C: S:o (.) <ho:w certain> are we of that result
- 9 (2.1)
- 10 C: Well the re:al result is somewhere there↓ (.) it cou:ld be that
11 there is↑ a small benefit
- 12 (0.2)
- 13 C: We thi:nk there is absolutely non-↓
- 14 (2.0)
- 15 C: S:o
- 16 (2.1)
- 17 C: Right(0.8)we have to think what treat:ments do we want to do
- 18 (0.5)

19 C: There are 2 treatments to get rid of it (1.2) first
20 radiotherapy (1.5) secondly (.) to put you on the tablets (.)
21 hormone therapy

Extract two illustrates a new focus to the action of rhetorical questioning. This extract reveals more about the complexity of the action being performed by the clinician. During the conversation, a question is stated by the clinician in line 1, as to whether there are any benefits to chemotherapy. The same effect is achieved, as we see no interaction (response) by the patient. Therefore the next TCU, in line 3, is once again taken up by the clinician. The clinician opens line 3 with 'so', as a boundary marker, which functions as a marker of connection to the question asked, and is used to introduce the answer to the previous unanswered question. It is suggested that there is 'no benefit' to chemotherapy, which is demonstrated further with the use of statistical percentages to support the claim. The clinician strengthens this case further in line 6, by stating that there is a 'detriment', a major loss or damage to the self, as a result of the side-effects of chemotherapy. The patient shows no response or retaliation, which indicates that up that point the clinician has put together a good argument for not having chemotherapy. We can see that the clinician has succeeded in this task and starts the next TCU in line 8 with the boundary marker 'so', which indicates result (at the discursive level of facts). To add to this argument, the clinician assesses the decision by once again asking a question about the certainty of the test results (line 8). The same action by the patient is displayed, as there is no response, and instead the clinician provides an answer. Reiterating in lines 10-11 and using the test results, that the benefit is small. The argument is then finally closed in line 13, as the clinician states, that in fact, the benefit is 'absolutely none'. The consequences of both rhetorical questions, up until this stage of the conversation, enable the clinician to provide step by step information, explanation, and justification in slowly building the presented argument. This process makes transitions of talk harder for the patient, as each suggested line of argument gives the patient no option, but to agree to not have chemotherapy. Although interaction is not picked up by the patient, the action still appears to bear consequences, as it works as an information tool for the patient to understand and consent to why they do not need, and should not have chemotherapy. Furthermore, it works as a technique for reaching a conclusion on a decision together, by speaking for the patient through rhetorical questions.

From line 15 there are another two clear boundary markers, starting with the word 'so'. However, on this occasion, the use of the word, as a stand-alone, acts as an interactional goal to prompt the patient to make the next relevant action. As the two second TCU is not taken up by the patient, the clinician subsequently continues to talk. Talk, in line 17, starts with the word 'right', with raised intonation, which passes up opportunity for further talk to occur on the previous subject matter. Therefore, this informs both the clinician and the patient that all points have been mentioned, and that the argument outlined is now closed, particularly as the patient has shown no interaction. How the clinician chooses to introduce a new topic of conversation, is once more, presented by means of a rhetorical question. In asking the question in line 17, yet again, the same effect of a non-response is shown. Nonetheless, the action consequence of the question is to structure the conversation, and to inform the patient about the next topic of discussion, i.e. we have decided that you are not going to have chemotherapy, so now we are going to talk about and decide which treatments you will need.

Both extracts one and two, draw particular relevance to the use of rhetorical questioning and boundary markers, during doctor-patient interaction. The practice of asking the patient a rhetorical question has shown to have two effects. The first is to enable the clinician to guide the patient towards the next topic discussion and, therefore, structure the content of the consultation. By stating a rhetorical question, the clinician is then able to answer it himself, whilst at the same time, executing their role which is to inform the patient. Therefore, the practice works as a tool to facilitate the patient with appropriate health information needed to make an informed decision. The second effect of rhetorical questioning is to control interaction. In the face of a rhetorical question, the patient's understanding is to listen and not respond. Therefore, the practice allows the clinician to hold the floor of the conversation and maintain turn-taking in dialogue.

The frequent use of boundary markers, during doctor-patient interaction, worked as a way of indicating orientation to what is happening in the discourse, particularly, at transitional points during the consultation. For instance, the clinician made regular use of the word 'so', and used this to signify the start of a new section of talk. This, therefore, instructs the patient to listen. This marker is also commonly used as a way of making a connection to a question just asked, and to mark the transition from the clinicians last TCU to the next. Therefore, although the discourse marker is syntactically independent, its

practice still plays a key role in notifying the patient that the turn-taking belongs to the clinician and, therefore, the patient should still remain inactive in communication. Subsequently, this practice is similar to the use of rhetorical questioning, as it prohibits the patient from engaging in a two-way conversation.

6.4.3 Practice two: territories of knowledge and epistemic markers

The data revealed the importance of expert knowledge and epistemic roles during doctor-patient interaction. Practice one above, has already demonstrated how rhetorical questions are integrated into discussion as a way of informing the patient of the clinician's professional knowledge. However, more significant and reoccurring practices were illustrated throughout the transcripts, which displayed territories of knowledge clearer. The following extracts three and four will examine this closely.

Ext 3. Transcript 1

- 1 C: With it being lobular we see e:very expectation for you to be
2 in that group (.) we would see n:o argument for giving you
3 chemotherapy (.) If you said you wanted it
4 (0.9)
- 5 C: But- it could be that the detriment is as bi:g as that-
6 (2.5)
- 7 C: We are al:most certain the result is in the grey area (1.3) it
8 could ju:st be outside it (.) but (.) we are looking at that
9 (2.3)
- 10 C: >We would< suggest that we don't give you chemo:therapy (.)
11 >and that< we give you hormone the:rapy
12 (1.1)

Extract three demonstrates the use of an epistemic marker to signify doctor-patient roles and levels expertise. The use of word 'we' is predominantly used by the clinician throughout talk. This is especially evident whilst explaining and justifying a treatment

choice, which this extract illustrates. Who is the clinician referring ‘we’ to? It is quite understandable that the patient is not going to obtain expert knowledge on breast cancer, or know what treatments are medically appropriate. Therefore, the term ‘we’ is unlikely to represent the clinician and patient. This therefore informs the patient that the term stands for a collaboration of experts and clinicians and, therefore, represents expert knowledge and professional status. The clinician opens in lines 1-3 by assuring the patient about the accuracy of their test results. The patient is then made aware that despite the test results, she still has choice about having chemotherapy. The element of patient choice, invites the patient into the decision-making interaction. However, the patient is very quickly reminded, in line 5 of the harm and negative effects of chemotherapy. The test results are further reinforced and elaborated in lines 7-8. Once again, reassurance is given to the patient, as the clinician indicates the levels of certainty assigned to the results, which have been further verified and confirmed by all clinicians. Subsequently, this enables the clinician to suggest the appropriate treatment plan needed, and finally bring the conversation of treatment decision making to an end.

The use of words such as, ‘we see’, ‘we would’, and ‘we are’, in the extract, created an understanding of a majority group in which the patient is excluded from. Such group includes members who are professionals and/or experts, who obtain superior knowledge. The clinician self-situates as an expert via membership to the group, and through the use of technical lexicon ‘we’. This, subsequently, creates a scenario where there appears to be clear division of power and roles, for example, the patient (the minority) versus the clinicians (‘the majority’ and ‘the experts’). With the clinician emphasising to the patient that the ‘majority’ (i.e. ‘the experts’) have all agreed with the results, and the right course of treatment, this subsequently constrains patient participation and interaction. This would be expected, as it is very unlikely for a lay person to counter-argue against a ‘majority’ of ‘medical experts’. Extract four demonstrates another epistemic marker used to heighten territories of knowledge during the consultation, and create an imbalance in power-relations between doctor and patient.

Ext 4. Transcript 8

- 1 C: <so yes> we would want to give you some treatment
- 2 (1.0)

3 C: Each treatment improves the chances that we have got rid of it
4 completely (0.1) <if it's gone completely> (.) then you are cured↑
5 (0.9)

6 C: >Of course I don't have a crystal ball< (.) I can't look into
7 the future

8 (1.0)

9 C: The bottom line is that it is <your choice>

10 (3.0)

11 C: I would <very stron:gly> advise you to have bo:th (0.5)It then
12 makes cure the most likely thing↑

13 (4.0)

14 C: <I would be concerned↑ if you didn't take the treatment (0.1)
15 as you would not be giving yourself the most likely chance>

16 (3.8)

17 C: Would there be a reason that you would consider not taking it↑

18 (2.0)

19 P: No (0.2) Reading about the tamoxifen, I know it's rarely rare
20 to get cancer elsewhere as a side-effect.

21 (1.2)

22 C: Yes↑ (.) and I just feel(.)in my view >so to not< take it for
23 that risk (0.9) >so to increase< your risk of it coming back and
24 not being cured<

25 (2.9)

26 C: Is there anything else that concerns you about tamoxifen

27 (1.2)

28 P: N:o (.) >that's it<

Extract four opens, in line 1, with the clinician showing agreement with colleagues ('*we would want*'), to the need for treatment. In contrast to extract three, the use of the word '*we*' is used for an alternative outcome. For example, in lines 1-4 the clinician links '*we would want to give*' to '*we have got rid*' and the word '*cured*'. This creates an imagery that the decisions made by the 'majority' group, lead to positive health outcomes. Therefore, by adhering to what the 'majority' suggest, results in improved health. A lack of response from the patient shifts the interaction back to the clinician, whereby it is mentioned in lines 6-7 that the clinician is not psychic. The action consequence of this is to remind the patient that nothing is a guarantee, which then leads on to reminding the patient that clinician does not obtain special powers and, therefore, patient choice is still equally important. A point is made clear in line 9, that there is a matter of choice, and that it ultimately lies within the patient's hands. Arguably, this can be interpreted as a way in which the clinician tries to promote the task of sharing a decision, and is attempting to invite the patient to participate in the conversation. Yet, the three second silence in line 10 shows that this attempt is unsuccessful, as there remains an interactionally inactive patient.

The patient's role in decision-making becomes further marginalised, and the issue of imbalanced power-relations between the doctor and patient is heightened in line 11. There is an evident shift in positioning, as the clinician starts to detach from the context of '*we*' and the 'group', and instead starts referring to items in person. The clinician's role and expertise becomes isolated from the other professionals through the context of '*I*' which, therefore, enables greater bearing on the importance of the clinician's opinions as a medical expert. By communicating '*I would very strongly advise*', this highlights the clinician's professional duty, as a doctor, to provide expert guidance and recommendations. In line 11, the use of the epistemic marker '*I*', is once again associated to the positive outcome of '*cure*'. Therefore, this links professional status and expertise to improved health and patient reassurance.

Following a lack of patient interaction in line 13, shown by the four second pause, the clinician takes the turn-in-talk by stating concerns for not taking up the treatment. There is nothing to suggest why the clinician is concerned for the patient, as up until this point the patient has shown no interaction or disagreement with the clinician. However, by making a statement of concern, the clinician is, therefore, instigating for a retaliation or response from the patient. Yet, this technique is once again shown unsuccessful in line 16.

This subsequently results in a direct question being asked to the patient in line 17, in order to seek interaction. The question asked displays the method of a preference organisation. It seeks a preference for agreement to the clinician's suggestion of taking the treatment. Thus, the question '*would there be a reason that you would consider not taking it?*' is designed to initiate a 'no' response. This action is achieved in line 19, as the patient agrees with taking the treatment. The patient mentions about the side-effects of the treatment, which she has read about. The clinician displays a positive acknowledging response (lines 22-24) to patient's knowledge, and uses the patient's example of a small risk to further stress the importance of the initial suggestion made. The use of language such as, '*I just feel*', displays the clinician's personal feelings about the patient refusing the treatment plan. Also, the use of terms such as, '*in my view*' further outlines the clinician's beliefs, to help build an argument. These, subsequently, put the clinician in a position that the patient will find difficult arguing against. Especially, as these terms are linked to the negative outcomes of the cancer '*coming back*' and '*not being cured*'. There is no further interaction from the patient within the next TCU (line 25), which results in another direct question being asked to the patient, in line 26, to instigate more patient interaction again. By asking the patient for the second time to disclose any issues or concerns about the given treatment, this helps to achieve verification and approval on the treatment plan, before the topic of decision-making is brought to an end, and the conversation is moved to a new topic of discussion.

Extracts three and four symbolise the clinician's level of authority and expertise. Through the use of epistemic markers such as, '*we*', and '*we think*', display an image of there being a 'majority' of clinicians versus the 'minority' patient. Therefore, this enhances the position and status of the clinician, as the leader in the decision-making process. This practice, subsequently, can make the patient feel excluded from conversations and interaction about decision-making which, therefore, result in 'passive' behaviours and a lack of two-way interaction. The use of epistemic markers such as '*I suggest*', heightens the clinician's intellectual role as a medical expert. This, therefore, signifies to the patient, that the clinician holds key knowledge and skills to make an appropriate decision, and because of that, has a duty of care to practice such acquired medical expertise to ensure good patient health. The patient, therefore, opts to leave the discussion about decision-making in the clinician's hands and control. This creates a perceived imbalance of doctor-patient power-relations, which hinders patient involvement in during the consultation, and

reduces two-way interaction. As a result, it could be suggested that both of these epistemic markers work against the concept of patient participation and a patient-centred care approach, which is designed to allow patient to participate in talk.

6.4.4 Practice three: extended multi-turn utterances

Throughout the previous extracts, references have been made to long gaps or pauses throughout the conversation. These gaps can be seen as transitional spaces, which stretch the talk and, therefore, allow for transitions of turn-talking to take place. Within the data, there was striking evidence of long two-three second TCU's on completion of the clinician's turn. Such lengthened transitional relevant places (TRP) and the role of multi-turn utterances, subsequently, inhibited clear projections of a relevant second pair part (SPP). Therefore, this left a period of silence in the talk. Extract five illustrates this.

Ext 5. Transcript 10

- 1 C: We grade breast cancers into 1 (.) 2 (.) and 3
2 (1.1)
- 3 C: 3 develops quickly and 1 slowly (.) >So 2 tends to be in the
4 middle of the road<
- 5 (3.2)
- 6 C: We took a margin of breast normal tissue and then we did some
7 further test (.) >firstly< to see if it is hormone receptor
8 sensitive or positive
- 9 (1.5)
- 10 C: And indeed it was strongly hormone receptive positive (.)
11 >and that good<
- 12 (2.8)
- 13 C: That tells us hormone therapy (.) and the way tablets can be
14 used for part of the treatment.
- 15 (3.6)

16 C: After that(.) we tested it to see if it is over producing the
17 protein called her2
18 ↓ (Further down the conversation)
19
20 C: An:y questions so far on that- before we move on to any of the
21 treatments
22 (4.8)
23 P: No
24 (1.1)
25 C: S:o
26 (1.2)
27 C: When we are thinking about the breast (.) we think about two
28 areas

In examining extract five, it is understood that silence occurs at the end of the each completed TCU by the clinician. As each one of the clinician's statements is not a clear first pair part (FFP), that signals an SPP response, this suggests that either speaker could legitimately speak. Therefore, the silence is not attributable to any particular speaker. The patient is not supported to contribute at these points of silence, which is it typical of the clinician to continue the turn of talk. A lack of turn-taking can also be described due to signs in the conversation format, which indicate to the patient that the clinician's explanation is not finished yet. The clinician clearly methodically introduces a story by turn-taking, as the patient's diagnosis is described. Indication of storytelling is displayed by the use of sequential timing words (e.g. *'firstly'* in line 7 and *'after that'* in line 16), which suggest a narrative, similar to extract one. The use of extended multi-turn utterances, which do not mark a clear SPP, therefore, indicate to the patient that she cannot take her turn until the story is complete, and, therefore, makes transitions harder.

Once having finished delivering information on a section of talk, the clinician asks the patient a direct question (line 20). As outlined in the initial descriptive findings, a common practice was evident at the end of every topic discussed, whereby the clinician

asked the patients questions and invited them to participate in a questioning and answering session. This subsequently marks the end of a section, and works as a means to ensure that patient understanding and reassurance is gained, before moving the conversation along to the next stage. A long gap of 4.8 seconds is illustrated in line 22, once having completed a TCU. However, unlike the gaps earlier in the conversation, as the four second silence has occurred after the spoken FPP question to the patient this, therefore, creates a TRP which is attributable to the patient, in which a SPP response is expected. As we can see in line 23, this practice is successful, as turn-taking is subsequently taken up by the patient and she responds minimally to the question. This example shows that the clinician's use of direct questioning can generate a desired outcome of interaction from the patient. As shown in extract five and the previous extracts, many TRP markers are left throughout the clinician's talk, in order to allow for turn-taking by the patient. However, the patient fails to recognise these areas of transition, and only when explicitly asked a direct FPP question, is interaction seen. As extracts one to five show, there is no evidence of continuers ('mm hm', 'uh huh', 'yes' or 'right') used by patients whilst the clinician is talking. Such continuers act to bridge TCU's, and if used by the patient, would create opportunities for the patient to interact and "take the floor". However, patients remain inactive, which signifies their understanding of the clinicians' turn-in-process not being complete. As illustrated by extract five, the patient would only speak when directly asked a question at the end of each clinician's topic. Therefore, at this point, the patient is aware that the clinician's discussion has come to an end, making it appropriate for them to interact.

Following the patients minimal response, the clinician in line 25 opens the turn with a stretched boundary marker of 'so'. This functions as a marker of connection to the patient's response. A TCU of 1.2 seconds is provided in line 26, which now deploys a stand-alone 'so'. This is used to prompt the patient to produce the next relevant action response, and perhaps to elaborate on their minimal response of 'no', or to expand further on the original question asked by the clinician in line 20. However, the patient shows no interaction, in which the term 'so' is now used to preface a topic beginner. This, therefore, moves the conversation along to introduce a new topical section, as demonstrated in line 27. The next extract illustrates another example of attempts made to engage patients into the conversation.

Ext 6. Transcript 3

- 1 C: <Do you want> under those circumstances to have chemo:therapy
2 (1.0)
- 3 C: For a small benefit
4 (1.5)
- 5 C: >When we say< there is a li:ttle benefit (.) if there was a 100
6 of yo:u and I gave you all chemotherapy
7 (1.0)
- 8 C: There would b:e (.) a <ve:ry small percentage> (.) >probably
9 less< than a hand full of women it would make a difference
10 (1.0)
- 11 C: A gre:at majority would make n:o difference <what so ever>
12 (3.0)
- 13 C: So in reality (0.1) we got this situation whe:re we got- to
14 make an essential judgement (.) a decision on a <sma:ll benefit>
15 (2.0)
- 16 C: You might say right- I want chemotherapy because I want that
17 small benefit (.)>or you might say< (.) no I DON'T even want to
18 bother as it's <such a small gain>
19 (2.3)
- 20 C: But we will be dealing with philosophy of how you would want to
21 be treat:ed (.) rather than the science
22 (2.0)
- 23 C: But with this onco-type test we can actua:lly now drill down >a
24 little bit< further↑ (0.1) we now move to the science which says
25 that NO ONE WANTS TO do it because there is abs:olutel:y <no
26 point>
27 (2.0)

Extract six opens in line 1 with a direct question asked by the clinician. The question aims to seek information about what the patient wants to do, and to see whether the conditions described earlier in the conversation, have influenced the patients decision. The term '*under those circumstances*', makes it a qualified question, as the question is tied to the technical knowledge, previously given to the patient, about the side-effects of the treatment. Subsequently, with the question being latched on to technical knowledge, this requires an answer which is based on medical judgement, and may cause the patient some difficulty in answering. The one second TRP, indicated in line 2, is attributable to the patient; however, she shows no response. The clinician does not treat the lack of patient interaction as a means to continue the talk, but rather than a problem with the form of turn itself. Therefore, an increment is added in line 3, to scaffold the patient towards what the correct medical knowledge is. This increment subsequently converts the silence to being an intra-turn silence, which in a sense undoes the fact that the patient is not speaking. This is an example of the clinician undoing an interactional problem. By stating '*for a small benefit*', this preference organisation question changes the nature of the initial question, in line 1, as the clinician is now clearly stirring the patient towards the right response, by highlighting a small gain. The clinician then in lines 5-9, begins to expand and spell out what is meant by a '*small benefit*', through statistics. This, subsequently, helps to break up the complexity of medical language, so that the patient is able to digest the information in numerical form, and understand the clinician's explanations of risk versus the benefits.

The long three second TRP, in line 12, indicates that the patient chooses to remain inactive and provide no answer to the clinician's initial question. The clinician follows up the turn in line 13, and transforms numbers into '*reality*', by linking the numerical test results to everyday decision-making. The patient is made aware in line 14 about an '*essential judgement*', which illustrates the importance of the decision to be made. This is then supported with '*we got to make a decision*'. This encourages and informs the patient about what the essence of the consultation is about- the patient and clinician making a decision and weighing up the options. Up until this stage, a '*small benefit*' has been mentioned three times, which again, illustrates a clear stir towards the answer the clinician wants from the patient. Up to this stage of the conversation, a strong argument about what an appropriate treatment decision should be has been presented to the patient. Several attempts have been demonstrated in helping the patient in making that decision. However, no input is shown from the patient.

Due to another lack of response from the patient in line 15, more supportive attempts are presented by the clinician, in lines 16-18, to facilitate decision-making. In order to reduce the struggle and burden of decision-making from the patient, the clinician begins to speak on behalf of the patient. By stating '*you might say*', this provides the patient with an example of the type of answer they could respond with. The patient is made aware that there is no right or wrong answer to the question, as the clinician presents the patient with two types of answers: one which shows disagreement to the question; and another answer which agrees with the question. The action consequence of this is to support patient participation, and illustrate to the patient that they should participate in discussions, despite a consensus or difference in opinion. However, it can also be argued that this practice illustrates to the patient that the clinician can play both roles (i.e. be the doctor and the patient), which creates a perception that the clinician knows what is going on inside the patients head. Therefore, this can have an effect on hindering the patient's role within decision-making.

Regardless of all efforts made, in presenting the patient with technical medical information, and providing example answers, there is still a lack of interaction shown (line 19). Consequently, in lines 20-21, the conversation turns from the concept of '*reality*' to science and evidence-based decision-making, whereby clinical results and numerical statistics are used as a method to aid decision-making. Everything that has been done, up to now, to scaffold and incorporate the patient into the conversation has been unsuccessful. Therefore, the conversation moves toward science and raw findings, to provide the patient with a justifiable answer to the original question asked, back in line 1. The patient is presented with two extreme case formulations in lines 25-26, which state that '*no one wants to*' have chemotherapy, and that there is '*absolutely no point*' in having that treatment. This subsequently reinforces the argument of a '*small benefit*', and, finally, provides the answer to the question, that the clinician was looking for.

Extracts five and six illustrate a lack of patient participation and two-way interaction between the patient and clinician. As shown in extract six, this is particularly evident when a question is asked by clinician, which is attributable to the patient to answer. Both extracts highlight that many instances are presented, with methods incorporated into talk, to encourage patient participation and integrate the patient into the discussion. For example, the use of a long TRP after each TCU, or prompts given by the clinician on how

to respond, are used to facilitate the patient's turn in talk. However, the methods used to scaffold patients into two-way interaction are unrecognised by patients, and do not result in patient participation. As extract five shows, on certain instances, direct FPP questions need to be posed to patient in order to initiate an action. Subsequently, this results in a lack of shared interaction between the patient and clinician during decision-making

6.4.5 What happens when there is two-way interaction?

Not all patients displayed a 'passive' role during their consultation. Regardless of how little or short of a response given by patients, some interaction was evident. Therefore, it became important to look at what happened when the patient attempted to initiate an action, a topic, or secure an extended turn of talk. Extracts seven and eight examine this closely.

Ext 7. Transcript 9:

- 1 C: Any other questions you want to ask about
2 (3.2)
- 3 P: When will I start the radiotherapy
4 (0.2)
- 5 C: Well- you get the two visits beforehand (.) >certainly within
6 the 2 weeks< (.) <maybe next week> (1.0) so we get going pretty
7 quickly-
8 (2.5)
- 9 P: You just want to get on with life don't you
10 (0.2)
- 11 C: Yes- absolutely (.) and you should be able to† (.) NONE of the
12 treatment is going to STOP you doing that.
13 (2.9)
- 14 P: I get people asking me when I am going to be cured

15 (0.2)
16 C: <you're in remission> (.) and with the treatment remission cure
17 can only be said after time.
18 (3.0)
19 P: Am I going to perhaps not be in this position again
20 (0.2)
21 C: I mean (.) the most lik:ely thing is that you are going to be
22 cured (.)that's where we are trying to get everyone as close as to
23 100%...

Extract seven starts in line 1, with the clinician asking a FPP question directly to the patient, to seek information about the patient's concerns. This is followed by a long TRP of three seconds (line2), which instructs the patient to respond. A response is shown in line 3, and in that response, a question is asked on the practical issues. The patient's response is an entirely legitimate question about their treatment plan, which is in the patient's domain. The purpose of the question is to address the patient's concerns. The clinician responds, in lines 5,-7 by means of four separate TCU's, which are devised to address the patients query, and to outline the process of events. The first TCU ('*well you get the two visits beforehand*') is to inform the patient about the process of treatment. In the next TCU, a broad timescale is given ('*certainly within two weeks*'), but then to be more specific and to provide the patient with information, which they see as important to their knowledge, a more defined timescale ('*maybe next week*') is given in the third TCU. The answer, finally, in the fourth TCU is supported with an assessment of the time ('*so we get going pretty quickly*'), which orients to the patient needs of wanting to complete treatment quickly. The patient interacts further in line 9, with a response that acknowledges the clinician's assessment, and informs the clinician about why a quick treatment duration is important. The patient phrases a statement in line 9 which queries her QOL, with a FPP tag question, which acts as a form of indicator that the patient expects a response from the clinician. This question differs from straightforward questions, in that the patient has cued the clinician to the desired response, i.e. that she should be getting on with life. Therefore, the tag question operates similarly to a leading question as it pushes for a certain response. This proves to be effective in lines 11-12, as the clinician shows an agreement with the patient and provides further encouragement. In a similar technique, the clinician's response

to the question is once again split into several TCU's, in which the patient's concerns are addressed, and assessment of the treatment side-effects is provided. Segmenting the answer into sections, helps to display the answer and the information provided accurately, so that it is comprehensible.

The patient remains on the same topic of evaluating her QOL in her next FPP question (line 14). However, the topic of discussion now begins to focus on medical, not practical issues. Once again, the question asked is devised to inform the patient about the treatment timescale. The patient states that she has '*people asking*', which indicates to the clinician the importance of answering this question as there are others, besides herself, who are affected by her cancer. However, use of the word '*people*' is very broad in comparison to mentioning friends or family members. In response, in lines 16-17, the clinician provides no definite time frame, but instead provides a medically termed response ('*remission*'), in which the next TCU expands and elaborates on its meaning, to the patient. The patient is advised that cure is a following result and, therefore, can only be assessed over a period of time. Therefore, this indicates to the patient that treatment process and re-evaluation stages are extensive phases, and cannot be suggested specifically.

It is observable in line 19, that the patient is not convinced with the response she received, regarding her initial question in line 14. Therefore, she rephrases the question in a different way, which will provide her with more reassurance towards being cured. As the clinician's previous response offered little confidence or assessment of her health status, by asking whether there is a chance of her getting cancer again this, therefore, gives way to a less unambiguous evaluation from the clinician. This appears to be successful, as the clinician, in lines 21-23, provides a noteworthy estimation of the patient's health status. Line 21 is opened with '*I mean*', which indicates clarification on the response given in lines 16-17. The term '*I mean*' highlights that remission is a complex point which needs elaborating and, therefore, makes another attempt to explain the patient's initial query from line 14. This signifies that the clinician values speaking clearly, to ensure that the patient fully understands her treatment and health status. Although the patient is still not provided with a precise timescale as to when she will be cured, she can feel more knowledgeable that she will be cured, and can go back and tell the people who were asking. The clinician uses the second TCU during the response (line 22) to add judgement, by informing the patient that cure is on the basis of a percentage, and the degree or percentage to which the

patient will be cured, is subject to further assessment. This informs the patient that although they are almost cured, they are still not 100 percent cancer free.

Extract seven shows an example of doctor-patient interaction, which is achieved through a series of questions and answers. The patient shows a distinct need to be informed about the practical issues which surround her treatment, and about the impact of the treatment on her QOL and future health status. The clinician, very precisely, ensures that the patient's concerns are addressed, and with each answer provided, and uses turns in the conversation to add further information, explanation, and assessment. Following each turn the clinician has in the conversation, long TRP's are provided to inform the patient that they still "hold the floor" of the conversation, and can ask the clinician further questions if they wish. Extract seven illustrates an example of two-way interaction between the patient and clinician, whereby conversation turn-taking is demonstrated to be effective. However, this was not always the case. Extract eight illustrates what happens during a consultation when there is slight overlap in speech, and turn constructions are left uncompleted.

Ext 8. Transcript 7

- 1 P: I'm concerned about work (0.2) The doctors given me another 8
2 weeks of work (0.5) Obviously I:=
- 3 C: =>IF↑ you are< ke:en to work (.) <it
4 may be possible> to work some other time (0.1) But we have to look
5 at the working environment and how big it is.
- 6 (2.0)
- 7 P: >It isn't that big really< (0.8) We work in a cro:w[d]
- 8 C: [>WELL]
9 that's not great<
- 10 (2.2)
- 11 P: I don't think↑ I'm mentally well to go (0.5) I'm [just like-]
- 12 C: [>IT'S quite<]
13 usual not to work (0.9) so if you didn't work during that (.) <I
14 don't think> anyone would batter any eye lid (0.2) why don't you

15 see how it goes↑ (0.1) stay of work at the moment (.) and then we
16 can reassess↓
17 (3.0)
18 P: I think I've prepared myself for the re:s[t].
19 C: [THE] treatment is
20 being done from a <positive view point> (0.1) Though we hope you
21 may already be cur:ed (0.1) the treatment is been given to give a
22 better chance↑ (0.2) >so I think the treatment is the positive
23 thing<

Extract eight illustrates how reducing the transitional space, can cause overlapping in talk with the patient. It is understood from this extract that overlapping, between the clinician and the patient, is problematic and causes a break in the patient's on-going speech. The patient in lines 1-2 opens, by disclosing their concern about not being able to work and taking time off. Before completing a possibility that she does not want that time off, the clinician in line 3 illustrates a collaborative turn construction, and explains a candidate understanding. The patient is advised, in lines 3-5, on the possibility of work at a later date, which is subjected to both of them assessing the workplace first. The purpose of the first overlap is to inform the patient, and also to introduce the notion of evaluating the issue raised. Therefore, this enables the clinician to structure the conversation and direct it towards a discussion which entails problem-solving.

The patient responds in line 7, exclaiming that her workplace '*isn't really big*', followed with a second TCU, which is more specific about the size. As soon as the patient mentions the word '*crowd*', there is an immediate overlap of a reaction response from the clinician (lines 8-9), which is not positive. Following the clinician's negative reaction to the working environment, the patient now shows a change of heart (line 11), and demonstrates agreement with the clinician that perhaps working is not ideal. She draws the clinician's attention to the psychological element of returning to work, in which the clinician, in line 12, overlaps to make a persuasive suggestion, before the patient can finish a turn construction. The clinician opens with a suggestion in line 12-16 by stating that there is absolutely nothing wrong with not working, as this is the norm ('*usual*') amongst most women, adding that this is socially acceptable. The clinician builds on persuasive turn

constructions, by recommending a trial and error scenario, where the patient can stay off work and assess the situation throughout the treatment stages.

The patient stays on her same topic emotional well-being, in line 18, and provides further insight into her psychological health. The clinician, therefore, follows on in line 19 to enlighten the patient that the treatment is a '*positive*' process, and subsequently encourages the patient to engage in an optimistic frame of mind. The overlap in line 19 is unproblematic. The clinician begins to talk slightly before the patient's possible TCU completion, and the overlapping begins mid-word, only two phonemes before possible completion. Therefore, this is not regarded as problematic as the patient's word completion is projectable. The construction of the reduced transitional space is due to timing of the clinician's talk and the modification of rhythm in the word '*rest*', which reduces the transitional space.

Extract eight highlights that subtle overlap in speech is evident during doctor-patient interaction. Such overlap was demonstrated to commonly occur at the end of the patient's talk, and break into the patient's second TCU, not the first. Therefore, the clinician's initiated talk orients to the upcoming completion of talk by the patient. As illustrated in lines 3, 8, 12, and 19, where this happens, the overlap is not resolved by the patient, quickly, reaching a possible completion, but instead the overlap brings the patient's talk to a stop. The purpose of the cut in speech, by the clinician, is regarded as a means to further educate, suggest, and support the patient about their concerns. In the four instances of overlapping made by the clinician, the tone on the first overlapping word is raised, and speed of dialogue is increased. This is to grab the patient's attention, and to ensure the patient's talk has come to a stop. The increase in speed allows the clinician to swiftly get the point across, without further overlap from the patient. However, it is also important to acknowledge from extract eight, that long TRP's are left in between each turn construction, to ensure that turn-taking remains persistent.

Both extracts seven and eight demonstrate that two-way interaction, between the patient and clinician, can take place during a decision-making consultation. These two extracts show that not all patients are 'passive' during the consultation, as some do respond to cues and, therefore, show a more 'active' stance in decision-making discussions with the clinician. The analysis revealed that when interaction did occur; it was not consistently throughout the consultation. Two-way interaction only occurred during a questioning and answering session, which displayed evident FPP questions from the clinician and the patient. The questioning and answering session was allowed to be led by the patient, and required the clinician to provide a thorough answer. This, therefore, symbolises the patient's role as a person who needs to be informed, and the clinician's role as an expert who address concerns through informing and explaining. During this interaction, the clinician provided long TRP's to ensure that the patient maintained their level of interaction and turn-taking. However, when two-way interaction did occur, it was not always as straight forward turn-taking. As extract eight shows, there sometimes appeared to be the practice of overlap in dialogue, by the clinician, through reduced transitional spaces. Yet, it is important to note, that these are small overlaps and not interruptions. The purpose of cutting into the patient's speech, at times, was represented as a means for the clinician to further educate, make suggestions, and offer support to the patient, in order to remove any feeling of distress in relation to the patient's concern. Subsequently, although a flow of interaction appeared to be taking form, it, however, was broken up by the clinician's urgency to respond to a question, before the patient had finished asking it. This in turn, produces what seemed to be an impression of interruption. However, despite the overlap, focus is still maintained on ensuring that the patient's concerns are heard and addressed, and that the patient has continual opportunities to interact and ask more questions. Subsequently, this third practice illustrates that besides the discursive methods shown in practices one and two, which appear to inhibit doctor-patient communication, there are also indications of way in to encourage patient participation and two-way interaction for decision-making and specifically SDM.

6.5 Discussion

A CA on audio-recorded data, from breast cancer adjuvant treatment consultations, identified three conversational practices. The first two practices introduced the concepts of

rhetorical questioning, boundary markers, and use of epistemic markers during doctor-patient interactions. The analysis revealed that these practices discouraged patient participation and two-way interaction. The third practice brought attention to the use of multi-turn utterances and extended transitional spaces, which were embedded into doctor-patient interaction, to invite patients to engage and participate in discussions. However, this practice was often not acknowledged by patients, and as a result caused periods of silence during the consultation. The analysis also revealed that not all patients were 'passive' during their consultation with the clinician. Through the process of questioning and answering, a flow of two-way interaction, between the patient and clinician, was generated. At times, however, the flow of conversation between the patient and clinician was segmented, as a result of overlapping in speech. The analysis outlined and assessed the action consequence that these practices had on doctor-patient interaction. This section will discuss how these identified conversational practices relate to SDM to help answer the research question- how do women with breast cancer experience SDM? The discussion concludes with the researcher's personal and epistemological reflexivity, to outline certain issues and influences during data analysis and to outline how reflexivity has a place in the findings of this study.

SDM is described as a division of labour, where there is two-way exchange of information, in which both the doctor and the patient reveal treatment preferences and agree on the treatment decision to implement (Charles et al, 1999a). However, the analysis revealed that this balance, for SDM, was not always sustained at an equal weight during doctor-patient interaction, due to conversational practices which either hindered the process of SDM and/or at other times facilitated it.

The analysis revealed that the process of SDM is not always accounted for during doctor-patient interaction. The concept of SDM focuses on an equal doctor-patient partnership, as both are required to communicate, exchange information, and share their informed preferences for treatment (Thompson, 2007). However, this process did not always take place during a consultation, which limited the presence of SDM during doctor-patient interaction. In reviewing the discourse which took place during adjuvant treatment consultations, it was observed that some linguistic practices were an obstacle that blocked characteristics of SDM and reinforced societal assumptions of healthcare. For instance, the use of epistemic markers (e.g. the words 'we' or 'I') operated as a means to generate

territories of expertise and, therefore, played an interactional significance on the doctor-patient relationship, which has previously been described as a competency for SDM (Towle, 1997). By creating territories of expertise, which heightened a perceived imbalance in power-relations and discrepancies in status and role, between the patient and clinician, this obstructed patient participation in interaction for decision-making. The use of such epistemic markers may have caused patients to feel inferior or inadequate in the decision-making process and, therefore, show little or no effort in turn-taking to negotiate, make suggestions, or present their views and preferences. In turn, the patients took a 'passive' role during the consultation, where the responsibility of decision-making was handed over to the clinician. As a result, by taking a submissive stance, the concept and presence of SDM was restrained, and the patients' experience of sharing decisions was perceived by the research to be deterred. The findings, therefore, suggest that language and discursive practices within doctor-patient interaction can cause patients to perceive a barrier that is based upon unequal power-relations, which subsequently result in a lack of perceived SDM. This is consistent with existing literature which demonstrates that the clinician's unwillingness to share power, between doctor and patient, is a barrier to the implementation of SDM (Brody, 1980; Ford et al, 2003; O'Flynn & Britten, 2006).

The analysis further showed that little opportunity was given for patients to engage in a *shared model* of decision-making. According to Howie et al (1997), by providing patients with more time and opportunities for communication, this helps to develop the concept of 'patient enablement', and allows patients to participate and cope with the task of decision-making better. However, clear markers were displayed during interaction which prohibited involvement, and obstructed the presence of SDM during interaction. This was shown in the use of boundary markers (e.g. 'so' or 'right'), rhetorical questioning, and sequential ordering of words (e.g. 'first', 'then', and 'finally') during the consultation. At times, there was also evidence of overlap in speech prior to the patient finishing speaking. The action of pushing the patient out of the two-way interaction may result in the patient no longer feeling comfortable to participate and, therefore, hinder the patient's ability to share their views, preferences, and queries. These interactional barriers, subsequently, made it difficult for turn-taking between speakers to occur, and often placed the clinician in the driving seat of interaction. Therefore, it is suggested that this resulted in an inadequate process of SDM to taking place between the clinician and patient. This is consistent with existing research, which highlights the lack of characteristics such as,

'sharing' and 'involving' patients, during SDM (Charles et al, 2004). With lack of self-efficiency to enable patient participation, this had have a negative effect on the process of SDM (Keefe et al, 2002; Thistlethwaite & van der Vleuten, 2004), as patients became repressed from the 'sharing' and 'involving' characteristics of SDM, during their adjuvant consultation.

However, in exploring doctor-patient conversations, it was observed that not all interaction was aimed at discouraging patient participation. The analysis also showed some instances where characteristics of SDM were present, and a possibility for doctor-patient SDM to occur.

Previous research argues that a main obstacle to patient participation is low health literacy and lack of subject knowledge (Coulter & Ellins, 2006). For a process of SDM to occur, a key goal for the clinician is to maintain a balance between information, explanation, and patient participation (Elwyn & Charles). The analysis revealed that accurate and detailed health information was an important goal of communication, as patients were thoroughly informed, and conveyed detailed explanations of treatments. This all served a purpose, which was to educate the patient at the level of the clinician, to permit for a two-way exchange of information to occur. This has been described as an important prerequisite for a successful move towards increased involvement in decision-making (Brennan, 1997; Scott et al, 2000), as patients cannot participate in decision-making to their desired extent, unless they have access to adequate and accurate health information (Buchanan et al, 1996). The acquisition of health information has also been described as an essential ingredient for SDM (Moumjid et al, 2007). The analysis, therefore, revealed good practice of providing patients with the information and knowledge needed to participate in SDM. For instance, the use of asking rhetorical questions to the patients was designed to function as an information tool or decision aid. It was also an opportunity to provide the patient with relevant health information, which can facilitate decision-making. Although, a rhetorical question does not lend itself to patient interaction, the action appeared to bear valuable consequences, as it allowed patients to obtain the appropriate explanation, descriptions, and information needed to make an informed decision, or to give informed consent. This represents a process of SDM, and similar characteristics to that of SDM (Beaver et al, 1996; Elwyn & Charles, 2001; Towle & Godolphin, 1999).

According to Buchanan et al (1996), patients can only participate in decision-making if they have access to knowledge given in ways optimal to their own level of understanding. This was evidently reflected during the consultations, as language was broken down through the use of statistics, and elaborated upon through rich and detailed descriptions, so the patients had an accurate and precise understanding of what was being said. At times, where further clarity was required by patients, the use of repairs such as '*I mean*', were used by the clinician to elaborate on complex explanations. It could therefore be suggested that this helped bring the clinician's level of expertise down to the patient's level and, therefore, remove any feelings of patient inferiority. This not only should allow patients to feel more comfortable and at ease to talk to the clinician, but it also means that patients can acquire the right knowledge and understanding needed, to confidently participate in discussions about decision-making (Henerson, 2003). Consequently, the use of uncomplicated language is an example of strategies enforced during doctor-patient interaction, to facilitate patient participation in decision-making, and to promote SDM taking place.

A more direct and evident example of patients being actively encouraged to participate in two-way exchange of information, was shown through a FPP question, directed at patients, '*do you have any questions?*' It has been suggested that communication that stimulates patient questions is signified as an important component to decision-making (Post et al, 2002). Characteristics of SDM, such as two-way information exchange, sharing of views and preferences, knowledge acquisition, and patient participation were mostly illustrated through a reciprocal process of questioning and answering between the patient and clinician. Therefore, by asking patients questions, this can permit them to actively engage in a process of SDM. Many patients showed an 'active' participatory role, in the face of a direct FPP question posed at them. This window of opportunity was grabbed by patients, as they used it as a time to overcome any perceived imbalanced power-relations. It also allowed for an opportunity to actively participate in their care. By engaging in a shared process of questioning and answering, an equal encounter of doctor-patient interaction took place, through a steady turn-taking process where transitional spaces (TRP's) and FFP's were recognised by each member. The importance of reciprocation of dialogue has been described as an important factor for patient participation in SDM (Thompson, 2007). This was evident in the analysis, as the reciprocation of questions and answers, between the patient and clinician, lead to a distinct

process of sharing information, views, preferences, and beliefs, in respect to the adjuvant treatment, by both parties. It was during this time, that discussion about the treatment took place, and the patient was able to share their concerns and views. This exemplifies the characteristics of SDM and, therefore, such discursive practice can facilitate doctor-patient interactions for SDM during this stage of the consultation.

The characteristics of SDM were also observed, at the end of the consultation when the clinician would invite the patient to engage in informal and less structured talk, by asking the patients *'is there anything else you want to talk about?'* During this time, patients showed interaction by asking the clinician questions on topics, which did not require clinical expertise and knowledge such as, going to work, family life, and relationships. This supports Thompson et al's (1993) argument, that patients are more likely to be involved in decision-making that does not necessarily require medical knowledge, than decisions that require clinical expertise. Therefore, this draws attention to this issue of power-relations again, in that, patients rather hand the responsibility of medical decision-making over to the medical expert. Interaction over these topics, subsequently, allowed for a process of information exchange, views, and preferences to be shared between the patient and clinician, to reach a mutual decision. Although this practice in itself is not an experience of SDM for treatment choice, the process exerts characteristics of SDM, and can be a contributing factor, which works towards facilitating the process of SDM during the consultation for a patient to encounter with conversations.

From the analysis, it was understood that opportunities for SDM were created between doctor and patient during a consultation. Much effort was made by the clinician to ensure that two-way conversations took place during the consultation. However, very little acknowledgement to these initiating practices was shown by patients. These cues were not picked up by the patients which, therefore, resulted in a lack of two-way discussion about decision-making, and hindered the presence of SDM during doctor-patient interactions. As discussed above, there were many instances whereby the clinician invited patients to acquire information about their treatment, and to share their concerns, views, and preferences, by asking them a direct FPP questions. The analysis showed that this was a cue that patients recognised as their turn to talk. The findings showed that each time patients were invited to interact with the clinician, in response to a question directed at them, (e.g. *'any questions so far on that?'*), they did respond; however, they showed little

interaction, and only give single word answers (e.g. 'yes'/'no'). Continual attempts were made to invite the patient to share their queries and views at regular intervals. Yet, many patients remained submissive and impassive to the questions asked. In situations where the clinician is anticipating for a response, but yet fails to receive patient interaction, a method of scaffolding was used to try and stimulate patient interaction. This aimed to build an increment to the question asked, in order to provide the patient with further knowledge required, to provide a response. Another method used to push for patient interaction, was to use preference organisation questions. This helped to stir the patient towards the correct response to a topic, which they may have formerly lacked enough knowledge to respond to. However, patients chose not to engage in a sharing process, which involved exchanging any information or preferences to the clinician. According to Towle et al (2003), some patients may find it difficult to ask questions, as they feel intimidated, are concerned about using the doctor's time, and fear that assertiveness will jeopardise rapport. Alternatively, some patients are 'passive' in their participatory style, and choose not to take in decision-making (Levinson, Kao, Kuby & Thisted, 2004). Nonetheless, the findings showed a lack of shared interaction about decision-making taking place. Therefore, this disengaged patients from the process of SDM.

Another example of patients' lack of recognition to cues for SDM is through the lack of recognition shown to transitional spaces. Throughout the consultation, the clinician ensured that considerably long gaps (TRP) were evident at the end of each TCU, to allow invitation of interaction by patients. The period of silence should have been interpreted, by patients, as a sharing opportunity, a time in which the turn of talk is directed to the patient to either ask questions about what was outlined by the clinician, express an opinion or preference, or to share their understanding. The long transitional spaces gave patients enough time to participate and contribute, therefore, creating an opening for the process of SDM to occur. However, this concept of sharing failed to occur, as there was no interaction from some patients, or even a sign of acknowledgement through continuers (e.g. 'mm hm', 'uh huh', 'yes', or 'right'). At times, in order to prompt patients to interact, the clinician used boundary markers, such as the word 'so', as a standalone, at the end of a TCU. The action consequence of this was to prompt patients to make the next relevant action, and to engage in the discussion. Yet the conversational aid, or cue for interaction, was shown to be unrecognised by patients, and in some instances, no interaction took form. Therefore, despite many attempts made within dialogue to try and support characteristics of SDM

within a consultation, such as ‘sharing’ information and preference, and ‘involving’ patients in discussions about decision-making. Patients, nonetheless, were at times unresponsive and failed to recognise such cues. Arguably, there are good indications that the process of SDM should and could occur if these cues were recognised by patients and acted upon.

6.5.1 Reflexivity: the researcher’s voice

As mention previously in this chapter (section 6.3.6- data analysis), researcher reflection was an integral process throughout this study, and was maintained by means of a reflexive diary. The researcher planned at every stage of data analysis to be reflexive and transparent about any potential influences. In having reached the findings discussed above, it is important to explore how the researcher and inter-subjective elements impinged on, and even transformed, these findings.

Besides the clinic observations made prior to data collection for this study, my previous research engagements, prior to the PhD, came from a background on doctor-patient communication. My Masters Qualification required me to assess and evaluate the quality of oncology consultations. Therefore my existing knowledge of the literature and practice of doctor-patient communication within oncology was vast, prior to commencing this third study. I felt strongly that my experiences would play a significant and beneficial role within the third study, and could be used to enhance my understanding of doctor-patient interaction for SDM. As a result, during the analysis, I was significantly aware of clinical barriers which inhibit doctor-patient relationship and interaction. This made me more prone and observant in identifying these barriers within the data. Furthermore, due to my previous research engagements, I found it difficult, as an analyst, to withdraw myself from evaluating SDM during the CA, as oppose to exploring the symbolic meanings of patient interaction. I was mostly drawn to data extracts which highlighted the effectiveness and success of SDM in increasing patient satisfaction and quality of care. However, I had to keep reminding myself of the research question, and kept myself focused to explore patients’ experiences.

I was also drawn to certain extracts within the data as a result of my father’s deteriorated health, during the time of analysis. During this time, my father had had his

third cardiac arrest, and was submitted to stay in hospital for three weeks. The team of cardiologist were trying to decide whether open bi-pass surgery was the best possible treatment option for him. At such a crucial time of decision making, my father had decided to withdraw himself from his treatment options and decision-making, and instead placed his trust in the hands of the multi-disciplinary team of cardiologist. I was deeply furious at my father, as I was aware of the process of SDM. On several occasions, I witnessed the cardiologist talking to my father, on the ward, about treatment decision-making. Within these observations, I perceived the consultant as someone who played a highly specialist role, who exemplified his levels of expertise by means of sharing complex medical information. To me, my father played the role of the question asker, while the consultant played the role of the expert who informs and knows all the answer. My father explained to me that “they know what’s best, and that they know more than he does”. From my own personal engagements with my father’s health, I learnt that patient participation in decision-making is controlled as a result of perceived power-relation, on behalf of the patient. I also understood that the patient and clinician can have distinct roles to play during decision-making, which can eliminate the process of SDM. Subsequently, what I had personally experienced influenced the way I looked at the CA transcripts. By carrying the preconception that SDM fails to occur during doctor-patient interaction, due to imbalanced doctor-patient power-relations, this made it very difficult for me to indentify the presence of SDM during doctor-patient interaction and, therefore, focus instead was on factors which inhibit patient encounters.

To facilitate me in the analysis, I therefore engaged in regular conversation with oncologist at the University teaching hospital, about the practice of SDM. I learnt during these conversations with the oncologists that SDM doesn’t necessarily have to only occur during formal structured talk about the treatment plan. I was informed that it mainly occurs during informal natural talk, for instance, during a questioning and answering session at the end of consultation between the patient and clinician. This reminded me of my father’s experience, when he played the role of the question asker and the clinician was the informer/answerer. From the conversations I had with the oncologists and my father experience, I therefore acquired this belief that the characteristics of information exchange and sharing of views and preferences result in a SDM process, and can facilitate doctor-patient conversations for SDM. This assumption, therefore, stirred me towards instances

within the data extracts, which illustrated these characteristics during doctor-patient interaction.

Whilst undertaking the CA, I found it very difficult to only describe the ‘talk-in-action’, and not make assumptions based upon what was spoken. By attending several CA workshops and seeking aid from CA academics at Keele University, I was able to learn how to solely focus on the talk, and to look for patterns about the phenomena in interaction. Therefore, supervisory discussions were integral to the practice of CA and the data analysis. I was reflexive on a lower level in my diaries and personal reflections, but taken to a higher level of reflexivity when probed by my supervisors, to think about the data or ‘talk’ in different ways.

As a CA analyst, I have learnt that the emotions, experiences, and the thoughts that you carry as a research, do shape and guide your motives and interpretations during analysis. However, it is important that you nonetheless have the appropriate training and supervision, to conduct sensitive analysis accurately. The process of reflexivity, in this third study, has also taught me that my personal emotions and experiences can play a role in the way data is interpreted and understood. Although I could have undertaken this study from a more distanced stand point, I however feel that there would be very little gained, and in fact, believe it would have reduced the depth of the findings. I feel that by utilising my knowledge and experiences, it was possible to make the experience one of being-with, and to become immersed in the worlds of the participants during doctor-patient interaction. I believe that this involvement and being-with, allowed a depth of understanding and comprehension that would not be possible from a more detached standpoint.

6.6 Conclusion

In exploring the research question, through a CA on conversations during breast cancer adjuvant treatment consultations, the findings from the third study have provided valuable insight into doctor-patient communication. It has also brought awareness to the types of discourse which take place during a consultation, which can either inhibit or facilitate the characteristics of SDM, and the presence of SDM during doctor-patient interaction. The audio-recordings have revealed and achieved a level of realism and truth which is, otherwise, difficult to ascertain from participants’ accounts. On the surface when looking

at the data, it is initially noticeable that there was very little two-way dialogue between the patient and clinician about decision-making. Patients appeared to take a 'passive' participatory role, a perceived an issue of imbalanced power-relations between the clinician and patient. This appeared to discourage patient participation and, therefore, patient involvement in discussions about treatment decision-making deterred. This, therefore, paved little way for characteristics of SDM to take form, such as the sharing of information, preferences, and views in making a joint decision together. Subsequently, it can be suggested from these findings that there is limited presence and patient encounters of SDM during adjuvant treatment consultations.

However, once engaging in a deeper CA of the transcript, it became apparent that the process and presence of SDM was not totally excluded during adjuvant consultations. Despite certain conversational practices, which appeared to create interactional barriers and hinder the notion of SDM, there was also evidence of additional practices aimed to promote two-way discussion and patient participation for SDM. The analysis illustrated that there were discursive practice within doctor-patient interaction, tailored to encourage patient participation, and to facilitate the process of SDM. There were opportunities for a *shared model* towards medical decision-making to take place, which involved a reciprocal process of sharing views, preferences, and exchanging information. For some patients, the process of SDM was taken up and encountered during a questioning and answering session between the clinician and patient. Patients actively participated in two-way interaction about their treatment, only when been directly asked to share their views and concerns. During this interaction, characteristics of SDM were displayed, such as the sharing information and preferences, acquisition of knowledge, and patient participation.

However, despite the cues presented, which aimed to facilitate SDM, the findings also revealed that there were patients who failed to recognise the cues for SDM. This subsequently inhibited patients in encountering conversations for SDM with the clinician, despite the facilitators used in language to promote SDM. This, therefore, suggests that the presence of SDM in a consultation is controlled by patient participatory role, i.e. a 'passive' patient will oppress the presence of SDM in comparison to an active patient who will broaden its presence. As a result, clinicians still require appropriate communication skills training with respect to the provision of SDM, to ensure that patient participation in decision-making is maintained, and all cues for SDM are acknowledge. Doctor-patient

interaction needs to be modified to patients' individual differences, to ensure that patient participation in decision-making and SDM is maintained.

In conclusion, the CA data has revealed substantial awareness around the limited presence of SDM, from doctor-patient conversations. It has also revealed an insight into the additional questions, outlined in Chapter One. For instance, it has informed about the characteristics of SDM, and it has provided an insight into the factors which facilitate and hinder the process of SDM for patients. It has also showed that SDM for breast cancer can be explored qualitatively, through examination patient interactions. It is understood from this study that SDM is a process which is characterised by two-way interaction, where both the clinician and patient are required to participate in discussions and share information (i.e. views and preferences). The presence of SDM is understood to be influenced by patient participatory roles ('passive' or 'active') during interaction; and discursive practices, which can create unequal doctor-patient power-relations. This appears to both inhibit and facilitate doctor-patient conversations for SDM.

Similar to study one (Chapter Four) and two (Chapter Five), this final study has also drawn particular attention to the role of doctor-patient communication, patient participatory roles, and the impact of imbalanced doctor-patient power-relations on patients' experience of SDM. The main discussion chapter of this thesis (Chapter Seven) will further explore the findings of this study in relation to the implications it has on breast cancer care, further health research, and qualitative research. Chapter Seven will also discuss the findings of this study in more thorough detail, in relation to the literature review outlined in Chapters One and Two, by exploring all three studies in relation to the research questions proposed in Chapter One. Chapter Seven will also conclude the thesis by outlining the limitations and implications of the research thesis as whole.

Chapter Seven

Advancing the understanding of SDM experience and breast cancer

Chapter 7

Advancing the understanding of SDM experience and breast cancer

7.1 Introduction

At the start of this thesis, the central research question was to find out how women with breast cancer experience SDM through their treatment journey. Additional questions that emerged from this central issue were:

- What does the concept of SDM mean to women with breast cancer, and what are the characteristics of SDM?
- How is the experience of SDM influenced (hindered or facilitated) for women with breast cancer?
- Can SDM for breast cancer be explored qualitatively, through examining patient perceptions and conversations?

Rather than looking at SDM as defined by the clinical guidelines and models of medical decision making (i.e. the *shared model*), the aim was to take a critical and interpretivist approach to exploring the concept of SDM from patients' lived experiences, to gain a more complete and less disease orientated view. The questions above led specifically to look at interpreting the meanings ascribed by patients to their actions (i.e. their perceptions and interactions) and experiences. This was evident in Chapters Four, Five and Six, as three very distinct qualitative studies looked at how SDM is experienced by breast cancer patients, from their own perspectives and interactions/conversations with other patients and the clinician. By taking both theoretical frameworks of phenomenology and symbolic interactionism to explore the research question, the method of semi-structured interviews, online written comments, and audio recordings were used to access patients' lived experience and advance this knowledge. This chapter discusses the main research question in more detail, and the three additional questions posed, using the three previous studies and existing literature. The chapter also discusses the contributions of the thesis, certain limitations, and the prospect of future research in the area within the field of health psychology.

7.2 How do women with breast cancer experience SDM through their treatment journey?

Throughout the data generated across all three studies, two main issues arose that helped to answer this question. The first was the definition of SDM to patients (i.e. the meaning of the concept and perceived characteristics of SDM). The second was the ability to trace SDM in patients' lived experiences. One of the most important developments that this project makes in terms of discovering how breast cancer patients experience SDM, is that it is deliberately explored through a variety of positions within all data (i.e. patient perspectives and interactions).

7.2.1 The meaning of SDM to breast cancer patients

Despite the clinical guidelines outlining a medical definition of SDM by NICE (2004 & 2012) and DOH (2006, 2007, 2010b, 2010c), the actual practice and experience of SDM is a less explored area. The concept of SDM has been previously researched through two main approaches. The first approach is through discussion of medical models of decision-making, as outlined in Chapter Two. Such studies focus on the prototype depiction of each decision-making model and its components. The second approach is through examination of the characteristics of SDM. These studies focus on identifying the necessary criteria for classifying a doctor-patient decision-making interaction as SDM. Research within both of these approaches has explored SDM through examination of patient participatory roles, doctor-patient relationships, and doctor-patient communication. Studies using both qualitative and quantitative methods have revealed much about the explicit behaviours and principles of how to engage in the process of SDM, in the form of instructional guides for patients and clinicians. However, while a checklist approach may resonate with many clinicians, in terms of a clinical framework of SDM, this may not echo within patients' construction of their illness experience. Furthermore, SDM is in some sense a matter of perception and, therefore, may be valued and recognised differently by patients and the clinician. Despite there already being substantial and useful groundwork in place about the definition and classification of SDM, there is a need for further research to explore its meaning from the patient's point of view. The characteristics of SDM and the meaning of those characteristics need to be investigated from the perspectives, interactions, and lived experiences of patients during their health care. Studies one to three achieved this, as each

aimed to explore SDM through an analysis of the interpretations and meanings patients ascribe to their situations (i.e. experiences) and actions (i.e. interactions and perspectives).

Across all three studies a defined meaning of SDM was illustrated, which outlined a process of two-way interaction, between the clinician and patient, whereby information exchange and the sharing of views and preferences took place. In examining the experience of SDM from patients' perspectives (study one, Chapter Four), the interview data revealed that doctor-patient communication, and the sharing of health information and explanations, were important characteristics that played a constituting role towards SDM. For example, the study revealed that clinicians obtained the necessary expertise knowledge about the disease and the expected outcome of each treatment, compared to patients who stated they did not. Establishing a shared relationship, which was based on the exchange of information and knowledge acquisition, was regarded as important to patient participation in decision-making. These findings are similar and consistent with the *informed decision-making model*, which focuses on partnerships between patient and clinician, for the transfer of technical knowledge from the clinician to the patient. Within this decision-making model, the clinician's role is limited to that of providing information and scientific knowledge to the patient (Williams, 1988; Mooney & Ryan, 1993). This understanding of SDM was similarly revealed in study two (Chapter Five), as online interactions, within breast cancer forums, highlighted the clinician as the 'information giver' during consultations. However, participants' accounts in studies one and two also showed that the sharing of information was not a role conducted singularly by the clinician, as it is also important for participants to exchange information that they obtained, such as their views, concerns, and preferences. This finding is consistent with the *physician as a perfect agent model*, which aims to elucidate the patient's preferences and values to the clinician. Both the *informed decision-making model* and the *physician as a perfect agent model*, emphasis the clinician as the person who makes the final decision. However, the findings in both studies one and two revealed that for an encounter of SDM to occur, both the clinician and the patient need to make the final decision together. To achieve this, the findings further showed that there needs to be a process of shared interaction, and an opportunity to share information and knowledge between the clinician and patient. This highlights and supports the movement from the *physician as a perfect agent model* and *informed decision-making model*, to the *shared model* of medical decision-making. Both studies one and two are valuable as they not only explore the

characteristics and meaning of SDM from the patient perspective and interactions, but importantly they show that breast cancer patients show knowledge and awareness of SDM. In exploring patients' lived experiences during their treatment for breast cancer, the findings showed that patients acquired an understanding of the concept of SDM and could talk about what it means to them.

Study three (Chapter Six) supports these findings, through its exploration of doctor-patient interaction during breast cancer consultations. Within this study, interpretation of the conversations revealed that for doctor-patient SDM to occur, there needs to be two-way interaction, whereby both parties equally participate in sharing information and preferences. Within this study, the characteristics of SDM became more definite as the analysis revealed two key aspects, understood by both the clinician and patients: the '*sharing of information*' (knowledge, explanations, descriptions), and the '*sharing of decisions*' (views and preferences). In exploring the barriers and facilitators in talk, which hinder and encourage SDM, it was understood, across all three studies, that SDM is a concept that must include both sharing of *information* and *decisions*, and both aspects must be practiced by both the clinician and patient (Ong et al, 1995).

Further findings about the meaning of SDM emerged across all three studies, which emphasised key characteristics such as '*shared participation*', '*balanced doctor-patient relationship*', and '*mutual interaction*'. It was understood by patients that SDM is an equal approach towards decision-making, whereby both parties are made to feel equal. Importantly, these findings suggest that the meaning of SDM, in the context of breast cancer, is consistent with the existing literature and guidelines, which highlight SDM as a partnership, between doctor and patient, based on a division of labour. Both patient and clinician provide enough knowledge and information, and take steps together to build a consensus about the preferred treatment (Beaver et al, 1996; Charles et al, 1997; Elwyn & Charles, 2001; NICE, 2004 & 2012; Towle & Godolphin, 1999). Breast cancer patients' understanding of SDM is also consistent with the *shared model* of medical decision-making, which implies that SDM fundamentally relies on both the patient and clinician playing a reciprocal role in information exchange, deliberation of pros/cons and preferences, and implementation to the decision-making (Elwyn & Charles, 2009). Finally breast cancer patients' understanding of SDM is consistent with the existing literature on doctor-patient communication, which emphasises competencies for SDM: good doctor-

patient partnership; provide evidence and information; establish preferences and concerns; and develop interaction decisions as a partnership (Towle, 1997).

In addition to determining what SDM means to breast cancer patients, the data also revealed that SDM can mean different things to different patients. This finding was reflected in study one, where a key theme within the analysis highlighted individual difference. In support of existing literature, the interview data illustrated that breast cancer patients exerted two types of participatory roles: 'active' and 'passive'. These impacted on patient participation in medical care (Beaver et al, 1996; Bilodeau & Degner, 1996; Degner & Sloan, 1992; Hack, et al, 2006; Keating et al, 2002; Street & Voigt, 1997). Previous studies have explored how these characteristics can interplay with the efficiency of patient-centred care (Degner & Sloan, 1992; Lerman, et al, 1990). However, there is little context in analysis that tries to examine whether there are personal preconditions that are related to SDM, and whether these can influence a patient's understanding of it. Where these distinct participatory roles have been discovered and assessed in relation to treatment success and satisfaction, nonetheless, very little of this understanding has been made in relation to breast cancer and the notion of SDM. Study one filled this gap in the literature. The findings revealed that an 'active' participant was motivated to take part in their treatment decision-making, through seeking and exchanging information, and discussing treatment options available with the clinician. For these patients, the meaning of SDM was understood to be a two-way operational process, which involves sharing of information, views, and preferences, by both clinician and patient. This supports existing research on the 'active' patient role, which highlights that it is important for patients to work in collaboration with the clinician to reach a mutual and shared decision (Charles et al, 1999b; Degner & Sloan, 1992; Frosch & Kaplan, 1999; Guadagnoli & Ward, 1998). Subsequently, it can be suggested that an 'active' patient participatory role, can facilitate characteristics of SDM between doctor and patient. On the contrary, a 'passive' participant avoided participation, and chose to hand the responsibility of decision-making to the clinician. Therefore, their understanding of SDM was demonstrated to be limited. From study one, it can be suggested that the meaning of SDM is shaped by patients' actions and role preferences, and its meaning is not uniform amongst all breast cancer patients.

Study two showed that the meaning of SDM is something which is discussed amongst patients. Analysis of peer to peer online interaction showed that women with

breast cancer like to inform one another, and share their own understandings of the concept of SDM. The purpose of online interaction was not only to raise awareness of SDM, but to also promote its use in a clinical setting. Therefore, this illustrated that patients' understanding and awareness of SDM is not only beneficial to their own health care, but that the online forums were also valuable tools for informing other patients about the concept of SDM. SDM is shown to be a concept which is spoken about between patients, and highly valued. Great attention is given by patients to support and encourage other patients to encounter SDM, and increase its practice within breast cancer care.

7.2.2 The experience of SDM for breast cancer patients

The literature revealed that a patient experience of SDM is a topic which has been previously investigated, with a focus on evaluating clinician performance. These studies focused on examining the views of medical practitioners and patients, with a range of chronic illnesses, about the use of SDM. They also assessed the feasibility of SDM during medical care. Some studies used qualitative methods, such as semi-structured interviews and focus groups, to explore issues of doctor-patient communication, competencies for SDM, levels of patient involvement, and patient participatory roles (Charles, et al, 1997; Elwyn et al, 1999a, 1999b, 2000; Towle & Godolphin, 1999). However, more advanced research methods were developed to explore patient experience of SDM. This resulted in a growth in research, which used direct observation to assess SDM through the use of video and audio-recordings, to describe doctor-patient relationships/communication (Saba et al, 2006; Elwyn et al, 2008). This highlights a shift in focus and methods, from evaluating competencies for SDM, to evaluating how SDM is experienced by clinicians and patients. Although the health psychology literature is beginning to see research on SDM from patients' perspectives, however, these studies still remain focused on evaluating SDM, by exploring doctor-patient communication or competencies. Therefore, no research has aimed to explore what SDM is like for patients by studying interactions and perspectives, particularly within breast cancer care. Studies one to three addressed this gap in the literature, as each study employed a different qualitative method of enquiry to explore breast cancer patients' experiences of SDM.

All three studies illustrated similar described and interpreted experiences of SDM. Each study revealed that an experience of SDM rested upon an equal doctor-patient relationship which therefore resulted in opportunities to share communication, share information, and share views and preferences. This is similar to the discussion above about the meaning of SDM and implies that patients' understanding (the meaning of SDM) and experiences of SDM are entwined. The findings across all three studies revealed that breast cancer patients' experience of SDM was largely associated with establishing a shared relationship, which depends on doctor-patient knowledge acquisition, and the role of information transfer. This is consistent with the *shared model* of decision-making, as patient encounter of SDM is described as one which is focused on a partnership, between patient and clinician, for the transfer of technical knowledge and treatment preferences. In study one; participants explained that doctor-patient communication, which allowed for mutual discussions and sharing of information and preferences by both the patient and clinician, contributed towards an experience of SDM. In study two; in explaining how SDM can be achieved, forum members made each other aware, during online interaction, about the importance of doctor-patient relationships. This was described to be based on an equal division of roles and information exchange. Finally, in study three; interactions between patients and clinicians revealed that without doctor-patient communication, which permitted equal participation, sharing of preferences, and information exchange by both parties, the presence and process of SDM is non-existent. These findings show that breast cancer patients' encounters of SDM are line with the move towards patient-centred care (Charles et al, 2004) and informed consent (Charles et al, 1997; Fest & Anderson, 1995). It also illustrates and supports the notion of a shift from in medical models of decision-making, as the clinician is no longer the sole person who shares their knowledge and views, and makes the final decision. Similar to the discussion above, these findings once again support the existing guidelines and research about the characteristics of SDM, and support the *shared model* for medical decision-making.

The overall concept of SDM is based around the assumption that all patients prefer or want to receive information on their condition, and wish to participate in the decision-making processes. However, this assumption is not always true, as the literature illustrated that a large proportion of patients do not accept the new patient role, and refused to participate in decision-making (Guadagnoli & Ward, 1998; Levinson et al, 2005; Strull et al, 1984). Therefore, a central question to the SDM paradigm is whether patients actually

want to experience SDM. If patient meaning and experience of SDM are interrelated, it could be assumed that the experience of SDM can be influenced, depending on how SDM is understood by patients. For instance, the discussion above outlines that SDM is understood in accordance to patient participatory roles ('active' and 'passive') and, therefore, the meaning of SDM is not viewed identically across all breast cancer patients. By expanding these findings to how SDM is experienced, it was illustrated that patients' assumptions about SDM resulted in how they encountered it. Therefore, participants would use their 'active' or 'passive' attitudes and behaviours, to account for how they experienced SDM. For example, for an unresponsive or 'passive' participant, responsibility was seen as an unconscious emotional weight to carry (Biley, 1992; Caress, 1997), and, therefore, they acquired limited understanding about the concept or process of SDM. This resulted in them describing their experience of SDM as non-existent. However, an 'active' patient was able to outline characteristics of SDM, such as two-way interaction of information, views, preferences, and described having experienced SDM based on these characteristics. Therefore, the role of the 'active' patient, allows women with breast cancer to increase their participation (Charles et al, 1999b; Guadagnoli & Ward, 1998; Frosch & Kaplan, 1999) towards an experience of SDM. The findings suggest that SDM does not only mean different things to different breast cancer patients, but can also result in varying patient encounters of SDM. Patient experience of SDM is not universal across with breast cancer care, particularly for those who encompass 'passive' traits and choose not to engage in the characteristics of SDM. Therefore, this implies that patient experience of SDM is not static or desired amongst all breast cancer patients.

Further findings about the experience of SDM, revealed it was largely present regarding decision-making for adjuvant treatments, rather than surgical treatments. When initially diagnosed and faced with having to make surgical treatment decisions, women appeared less keen to participate in the decision-making process, and showed more urgency to accept any treatment offered. In light of the psychological implications relating to the discovery of breast cancer (Akechi et al, 2001; Burgess et al, 2005; Grabsch et al, 2006), the findings in study one showed that the concept of SDM was overruled by patients' fear and psychological distress of cancer, as patients' primary concern was to have the cancer removed. Women were not disturbed about the prospect of losing a breast, or concerned about their involvement in the decision-making. However, once the lump or breast had been removed, and patients were then faced with having to make decisions

about adjuvant treatment, the practice of SDM became more. Women wanted to be involved in decisions about treatments which had severe implications on body image (hair loss and weight gain) and QOL. An experience of SDM, therefore, became imperative. Women wanted to voice their views and preferences, and conversely, acquire as much health information and knowledge possible from the clinician. In study one, patients' retrospective reflections of their experiences of SDM were only described in relation to decision-making for adjuvant treatment. This finding was also comparable in study two, as women utilised the forums to share their experiences of decision-making, predominantly regarding adjuvant treatment decisions, such as chemotherapy. Women would also use the forums to talk about decisions regarding the management of adjuvant treatment side-effects, such as hair loss. As a result, both studies showed that there are distinct facets of SDM relating to adjuvant treatment, rather than surgical treatment.

In examining breast cancer patients' experience of SDM, it also became evident that SDM is a process applicable to all conversation in which patients engage in. For instance, study one revealed that SDM is a process which is experienced between breast care nurses and other patients. This experience was described as identical to an experience of SDM encountered with the clinician. The breast care nurse also engaged in a two-way interaction with patients, by '*sharing information*' (knowledge, explanations, and descriptions) with the patients, whilst also offering an opportunity for both the nurse and the patients to '*share decisions*' (their views and preferences). These two characteristics ('*sharing information*' and '*decisions*'), which worked together, were explained by patients to constitute towards their experience of SDM with the nurse. Therefore, this confirms that the concept and practice of SDM is persistent across a multi-disciplinary team of breast cancer specialist (NICE, 2004). Besides conducting the practice of SDM, the breast care nurses also played a facilitating role, in raising awareness and encouraging the importance of SDM between patients and clinicians. Study one revealed that nurses promoted patients to participate in regular discussions with their clinician, to share their views and concerns, and to negotiate about treatments. Therefore, not only were the nurses facilitating SDM during a clinical consultation with the clinicians, but they were also contributing in defining the characteristics of SDM, and informing patients about what an experience of SDM should entail. It could, therefore, be suggested that patients' acquired understanding and experience of SDM, is also shaped by the breast cancer nurses. This is a novel finding in

the literature on SDM, as this is the first illustration of an experience of SDM taking place, between the patient and breast care nurse.

Study two also revealed that an experience of SDM is applicable to all patient conversations, and does not have to solely take place in a clinical setting, with medical professionals. The forums highlighted that patients also experience SDM with other patients, through their interactions online. During online interaction about decision-making, forum members displayed similar characteristics of SDM within their talk, as defined by guidelines (NICE, 2004 & 2012) and existing research (Beaver et al, 1996; Charles et al, 1997; Elwyn & Charles, 2001; Towle & Godolphin, 1999). Women not only used the forums to gain support, and to sustain healthy psychological well-being, but also wanted to talk to other women about their treatment choices. A process of SDM took place as women shared health information and knowledge based on their similar experiences; and shared their personal views and their preferences, in making their own decisions. However, patients' experience of SDM appeared to be less structured during online conversations, compared to SDM in a clinical setting. The forums offered a more automatic and informal approach towards an experience of SDM, where patients naturally experienced the characteristics of SDM through naturally occurring conversations, with no predefined competencies for SDM. From study two, the findings illustrated a representation of SDM taking place online between patients. It could, therefore, be suggested that the forums act as an opportunity for patients to rehearse SDM, before undertaking the concept in a clinical setting, with medical professionals. For those who were 'lurkers' and only used the forums to read other members' posts, by observing other members' interactions, this provided useful insight into how SDM took form. These women could, therefore, acknowledge and learn about how SDM can be experienced with other patients and/or medical professionals.

7.2.3 Implications and contributions of the findings

The discussion above draws much attention to a greater understanding of how SDM is experienced by breast cancer patients, what the concept means to them, and how it is characterised. These findings have implications for breast cancer care which are worth discussing.

First, the findings indicate that breast cancer patients' experiences and understandings of SDM are in line and in accordance with the SDM guidelines (NICE, 2004 & 2012). Women reported informed participation in their treatment decision-making, which aligns with the tenets of patient-centred care for breast cancer (NICE, 2006). The findings raised from all three studies also serve great importance in relation to the changes in medical decision-making models over the years. It is evident that breast cancer patients' understanding and encounters of decision-making is moving away from both the *physician as a perfect agent model*, which concentrates on the transfer of the patients' preference mapping system to the clinician; and the *informed decision-making model*, which is focused on the transfer of technical knowledge from the clinician to the patient. Instead it is moving towards a *shared model* of decision-making, which is grounded in two-way interaction, enabling both the clinician and patient to share all stages of the decision-making process simultaneously; both participate in the exchange of information and preferences, and involve complex trade-offs between risks and benefits; and finally both agree on a chosen treatment plan. This provides reassurance to medical professionals, that the competencies and guidelines outlined for SDM (Towle, 1997; Towle & Godolphin, 1999) are viable in allowing clinicians to practice SDM, and for patients to experience SDM. This is of particular importance, as guidelines for SDM have been associated with patient satisfaction and improved health outcomes (Ashcroft Lenister, Slade, 1985; Deadman, Leinster, Owens, Dewey, Slade 2001; Fallowfield, Hall, Maguire 1989; Kaplan et al, 1989; Laine & Davidoff 1996; Morris & Ingham, 1988).

Secondly, the findings also illustrated that SDM is a process which occurs across a multi-disciplinary team within oncology. With the role of the breast care nurse highlighted in connection to patient experience of SDM, this emphasises the need for further research to evaluate and explore patient experiences of SDM with breast care nurses; an area in the SDM literature which has not been investigated. Moreover, by exploring SDM through patients' experiences, this has provided much useful insight into how the process is perceived and encountered by patients. This suggests the need for further research to devise and evaluate methods, which medical professionals can regularly use to assess and monitor patient experiences of decision-making, for service quality improvements. Acquiring such knowledge would not only offer verification on the decision-making processes, but it would also indicate whether medical professionals need to take additional

relevant training, for services improvement, and to ensure the patient's experiences of SDM is in agreement with medical guidelines and the *shared model* for decision-making.

Thirdly, the findings illustrate that an experience of SDM is not static amongst all breast cancer patients, and does not automatically occur within breast cancer care. SDM was demonstrated to have different meanings, and be encountered in different ways, by patients. The impact of patient participatory roles on patients' experience and understanding of SDM was a novel finding. This is the first time within the health psychology literature, whereby the previously emerged concept of 'passive' and 'active' participatory roles, are brought to attention within breast cancer, and in specific relation to SDM. With the concept of patient-centred care being at the forefront of medical practice, it is important that the issue of individual differences and active and/or passive positioning is incorporated into training and practice. This would ensure that medical professionals are able to recognise the importance of patient participatory roles, and are able to detect and monitor a patient's preferences for involvement. Clinicians need to show the appropriate skills to be able to show flexibility in applying and tailoring SDM, as and when, and in accordance, to the patient's needs and traits (Rowland & Holland, 1989). For instance, the findings showed that 'passive' patients showed little understanding and no experience of SDM. Therefore, medical professionals need to be able to recognise such passivity, and create a mutual atmosphere that is conducive to the patient's desired levels of participation (Coulter & Ellins, 2006; Shaller, 2007), whilst still maintaining a patient-centred approach and *shared model* of decision-making. This could be achieved through patient-focused interventions, which recognise the role of patients in the process of securing appropriate, effective, safe and responsive healthcare. Such interventions include: communication skills training for clinicians; patient surveys to identify role preferences; and patient satisfaction questions to monitor the care performance. These findings have implications for future research to explore how SDM can be classified and adapted to patient individual differences, whilst still being coherent with the *shared model* of decision-making.

However, it could be argued also that it may not be feasible to purely categorise patients within these two participatory roles, as patients may employ a combination of both roles and show differing traits during different stages of the treatment. For example, the findings revealed that some patients remained 'passive' during decision-making for surgical treatments, and were happy to allow the clinician to choose the decision for either

a mastectomy or a lumpectomy; but they showed ‘active’ traits during decisions on the adjuvant treatment stage. Through the *Prospect Theory* framework, it is understood that patients can assign values to health status and seemingly make rational or irrational treatment decisions (Treadwell & Lenert, 1999; Arthur, Werner, Olivier, 2013). Therefore, it could be suggested that patients are not simply assigned to one participatory role type, as their desire for participation, and subsequent experience of SDM, can fluctuate at various stages of the treatment trajectory. Subsequently, inconsistency in patient participatory roles and how this can affect patient experiences of SDM is an area of research, which could be of future interest, within the field of SDM research.

The findings from study two brought much attention to the experience of SDM online, within breast cancer forums. Previous studies have explored patient interaction within online forums for breast cancer (Sharf, 1997), and evaluated its impact on patient health outcomes (Esyenbach, 2001; Winzelberg et al, 2003). No literature has explored SDM for breast cancer online. Study two filled this gap in the literature, and brought valuable insight to the meaning, characteristics, and experience of SDM. Analysis of patient interaction online revealed that SDM is an approach which is applicable to all patient conversations, even outside of a clinical setting. Women were shown to experience SDM online with other breast cancer patients, within the forums. The findings also showed that the forums provided substantial awareness and information about SDM, through members sharing their own personal experiences. Members not only promoted SDM, but they also encouraged women to encounter SDM in a clinical setting, and supported women with advice as to how they could achieve such encounter. The benefits of online support groups in assisting patients’ understanding and experience of SDM, is an area worth further research. There is a long way to go to fully understand the effects and opportunities of SDM and virtual communities on the Internet in facilitating medical decision-making. The findings therefore open opportunities for future research to go beyond pure descriptive studies and, therefore, to develop and evaluate the opportunities and pitfalls of technologically mediated SDM and forum support groups in maximising patients’ experiences of SDM.

Finally, the findings emphasised the importance of patient experience of SDM in relation to decision-making for adjuvant, but not surgical treatment. Previous literature has shown that SDM has been suggested as the preferred approach to treatment decisions for

surgical and adjuvant therapies (NCCN, 2007). However, in exploring patients' experiences of SDM, from their perspectives and interactions, the findings revealed that there are distinct facets of SDM relating to decision-making for adjuvant treatments, and in particular chemotherapy. This links to findings uncovered in study one, which demonstrated that women's initial fear, from having been just diagnosed, led them to believe that full removal of the breast would eliminate risk and increase their survival chances. This acquired view, therefore, left little opportunity for SDM and patient participation in decision-making to take place. Participants explained that they were happy to place decision-making in the clinician's hands, and undergo either a mastectomy or a lumpectomy, as long as it meant that the cancer was removed. However, as study two revealed, in the later stages of treatment, the thought of hair loss was portrayed as very discomforting for women, and this was significantly discussed online in respect to treatment decision-making. Therefore, participation in adjuvant treatment decision-making was of key concern to patients. This is a novel finding, and requires further research to explore SDM, specifically in relation to body image and self-esteem, to understand why patients want more ownership of decision-making for adjuvant treatments, rather than surgical treatment. This will, therefore, open further scope in research to explore patients' experiences of SDM more closely to QOL and psychological well-being. The findings showed that an experience of SDM during decision-making consultations for surgical treatments was deemed less important. Nonetheless, this finding offers a valuable contribution to breast cancer care, as medical professionals can use the findings for assessment, training, and service development purposes, to enhance patient experiences of SDM during consultations with the oncology surgeon.

7.3 How is the experience of SDM influenced (hindered or facilitated) for women with breast cancer?

According to the *shared model* of decision-making, the task of treatment decision-making requires joint involvement from the patient and clinician. The model recognises two experts: the clinician is an expert in defining the clinically appropriate options, including the risks and benefits of each option, based on the latest medical evidence; and the patient is an expert in their own values, preferences and concerns (Emanuel & Emanuel, 1992). Both experts are required to work together to achieve an encounter for SDM (Emanuel &

Emanuel, 1992). Subsequently, this model outlines SDM as a bipartisan approach, which sits between the paternalistic model of decision-making and the consumer model of decision-making (*informed decision-making model*).

However, previous evaluation studies of SDM demonstrate that the concept is not a widely embraced approach, or prevalent in clinical practice (Holmes-Rovner et al, 2000; Stevenson, et al, 2000). These studies focus on assessing and evaluating barriers and facilitators for implementing the process of SDM in clinical practice (*Auerbach, 2000; Butow et al, 2007; Gravel et al, 2006; Gwyn & Elwyn, 1999; Loh et al, 2006;*). These studies of decision-making demonstrate a breakdown in the *shared model*, due to clinicians' inability to share with patients. For example, studies of doctor-patient communication have consistently revealed that the characteristics of SDM, such as sharing information and preferences about the identified problems, and two-way interaction regarding treatment options, rarely occurs (Roter & Hall, 1992; Tuckett D, Boulton, Olson, Williams, 1985). This therefore raises concerns as to whether breast cancer patients' experience of SDM is influenced by factors, which inhibit or facilitate the characteristics of SDM, and their subsequent encounters. This is an area in the health psychology literature which has not been explored.

During the investigation of patient experiences, the findings drew attention to factors which either facilitated or hindered patient encounters of SDM. Findings across all three studies began to raise an issue of a perceived imbalance in power-relations between the patient and clinician, which hindered the process of SDM and patients' experiences of it. The interview data in study one revealed that participants appeared to have certain perceptions about the clinicians' role and duty, which in turn impacted on their doctor-patient relationship, and their subsequent experience of SDM. For many women, the clinician was perceived as a medical expert who attained full knowledge and responsibility for managing patient health, in which they trusted to deliver quality care (Emanuel & Emanuel, 1992). According to Pierce (1993), these patients are referred to as '*deferrers*' in decision-making, as they choose not to deliberate and only accept their doctor's recommendation. An authoritarian view of the clinician meant that patients believed that the clinician was responsible for decision-making and, therefore, an equal relationship was difficult to achieve. This exemplifies an issue of compliance to the clinician and possibly obedience to perceived authority (Milgram, 1963 & 1974). As a result, the finding sustains

the *paternalistic model* in decision-making, in which the patient passively consents to professional authority by agreeing to the doctor's choice of treatment (Charles et al, 1997). With this model of decision-making, there are no trades-off for the patient, no sharing of any of the decision-making steps, and a doctor-patient partnership does not exist (Caress, 1997; Degner & Sloan, 1992).

Such acquired preconceptions about clinicians impacted on the patients' experience of SDM. Many believed that a shared approach to decision-making was difficult to attain, due to the clinician's hierarchical status and role. In support of existing literature, an obstacle to participation was shown to be low health literacy and lack of subject knowledge (Coulter & Ellins, 2006). Women believed they lacked adequate expert knowledge, at the level of the clinician, in being able to share the task of decision-making and, therefore, chose to hand decision-making control over to the clinician. This supports previous literature, showing that participants were less likely to be involved in decision-making that requires clinical expertise (Thompson et al, 1993). The concept of SDM is to empower patients (Charles et al, 1997); however, a perceived discrepancy in doctor-patient power-relations was shown, which made patients feel inferior and inadequate to participate in decision-making. This finding is consistent with existing research which shows that power-relations can obstruct collaboration in the decision-making process (Saba et al, 2006) and, therefore, deter the implementation of SDM (Ford et al, 2003).

Study two strengthened the findings from study one, by also illustrating an impact of unequal doctor-patient power-relations on patients' experience of SDM. In reviewing patients' interactions online, it became apparent that patients believed that they must overcome their preconceptions of the clinician, for an experience of SDM to occur. Women devoted considerable time online to encourage others to maintain their role as a shared partner in decision-making, and to sustain control over their health care. This second study suggests that the issue of power is a matter recognised by breast cancer patients and discussed amongst them. Great focus was illustrated by patients online to challenge this power imbalance, as women want facilitate others in their experience of SDM, in order to preserve patient rights and the concept of patient-centred care. This is consistent with existing research, which shows that support groups can succeed in empowering patients (Pitts, 2004). Time was devoted online by forum members to educate others about the concept and characteristics of SDM, how to encounter them in a clinical setting, and to encourage others about the benefits of SDM in aid of making a treatment

decision. The findings from this study showed that forum patient interaction is important in raising patient awareness about factors, such as imbalanced doctor-patient power-relations, which can hinder patient encounters of SDM in a clinical setting. The findings also illustrate the benefit of online peer interaction, as a way of facilitating breast cancer patients' experience of SDM.

The final study raised the issue of communication skills for SDM, as a factor which can inhibit the presence of SDM, and subsequent patient encounters of it. The findings in this study revealed that the appropriate cues to facilitate the process of SDM to take place, were presented during doctor-patient interaction. However, patients failed to recognise these cues and were unresponsive to them. It could be suggested that the lack of acknowledged cues for SDM are due to poor communication skills for decision-making, which result in a lack of '*sharing of information*' and '*sharing of the decision*' from patients (Roter & Hall, 1992; Tuckett et al, 1985). The clinician showed an ability to share knowledge ('*information sharing*'), and also an ability to share preferences and views ('*sharing of decisions*'). However, for there to be an SDM process between the clinician and patient, the patient must also be able to share both components: '*information*' and '*decisions*' (Ong et al, 1995). Despite substantial efforts made during doctor-patient interaction to encourage both processes, these two characteristics of SDM were not demonstrated by the patients. This supports the literature, that there are still problems with respect to the provision of communication during practice (Avis, 1994; Maquire, 1999; Caress, 1997; Coulter et al, 1999; Fallowfield & Jenkins, 1999; Tierney, Taylor, Closs, 1992). It could be suggested that conversations during breast cancer consultation are not adequately focusing on these two elements, to assist patients in an encounter of SDM.

Analysis of doctor-patient conversations within this study also revealed that SDM is hindered as result of a portrayed issue of power inequality, which inhibits patients from interacting. This is in support of Gafni et al (1998), who suggested that an unequal power dynamic within consultations may prevent a successful provision of information and communication. The findings demonstrated that language and discursive practices were used, at times, during doctor-patient interaction, such as epistemic markers, which enhanced and defined the clinician's authority and level of expertise. Subsequently, a discrepancy in power-relations was established during decision-making conversations, which as a result, inhibited shared participation, and disguised any cues which had been

presented for SDM. This finding is consistent with existing research which has shown how relationship dynamics, such as power, can influence patterns of communication, and mediates the perception of collaboration in the decision-making process (O'Flynn & Britten, 2006). From the findings in study three, it could, therefore, be argued the patients' equal role during SDM, in a consultation, becomes blurred as a result of being overwhelmed by the issue of unequal power-relations, as portrayed and perceived during interaction. The patient's distorted view of their role during decision-making, blinds them to any facilitating efforts in conversation made for SDM to occur and, therefore, hinders patient participation and the process of SDM.

However, this study also showed that conversations for SDM during doctor-patient interaction can be successfully facilitated during consultations. Although patient encounters of SDM was shown to be limited during conversations for decision-making; however, when patients were presented with conversations, which were less structured and informal in topic, patient participation and characteristics of SDM (two-way interaction, information and preference exchange, and patient participation) would occur. Such less structured conversations would take place between the clinician and patient during a questioning and answering session. This was an opportunity for patients to share their concerns, views, and preferences. The informal and less intimidating nature of two-way interaction between the patient and clinician lent itself to SDM. Using Henderson's study (2003) to support and interpret the findings, it could be argued that when patients are faced with '*problem solving situations*', which require medical expertise, they do not present themselves well to patient participation. However, in contrast, in '*decision-making situations*', which involve the patient's values and preferences, patients prefer to be involved in the latter rather than the former (Thompson et al, 1993). Study three showed that women simply rejected the role of '*problem-solving*', and preferred to pass on decision-making to the person with the knowledge and expertise (Deber et al, 1996). Therefore, it could be suggested that conversations for '*problem-solving situations*' are not prone to facilitate patients' experience of SDM. This proposal and the findings from the third study are consistent with the findings drawn from study one and two, which showed that participants displayed an experience of SDM in situations where opportunities arise for them to share their preferences (their views, concerns, and queries). However, as study one demonstrated, an experience of SDM was described as unachievable during situations which require skills and expertise.

7.3.1. Implications and contributions of the findings

The discussion above draws much attention to how SDM is experienced by breast cancer patients, and how a patient's experience of SDM can be influence (facilitate or hinder). These findings bear several contributions and implications to breast cancer care, as they provide useful insight into the views and experiences of breast cancer patients regarding partnership in decision-making. It is suggested that the presence of SDM is one which is conditioned by a perceived power imbalance regarding the clinician's role. This perception is further fuelled during doctor-patient interaction, through language that further enhances the power imbalance. Despite the concept of SDM being designed to empower patients to become more involved in their health care (The Health Foundation, 2009), it appears that breast cancer patients' experience of SDM is one of oppression. This is enhanced by their preconceptions of doctor-patient roles, and through their interactions with the clinician. Patients, subsequently, reduce their participation in decision-making and place greater responsibility for decision-making in the clinician's hands, physically and psychologically.

Despite its theoretical appeal, SDM in the clinical encounter has been shown, in study three, to be not fully translated into practice. Breast cancer patients, in study one and two, show that patients are able to illustrate experiences of SDM and demonstrate an understanding of the concept, in accordance with the *shared model* of medical decision-making. However, in assessing doctor-patient conversations, it is understood that patient experience of decision-making is more inline with a traditional *paternalistic model*, which upholds the practitioner as the ultimate decision maker. This model, therefore, does not offer the opportunities that individuals needs in becoming an 'active' participant in treatment decision-making. If health care professionals remain critical of the rhetoric of unbalanced power-relations, and are not prepared to identify practices that belie a *shared model* to decision-making in breast cancer care, then women with breast cancer will experience unmet expectations and frustration in their interactions to encounter SDM with practitioners. Furthermore, an uncritical adoption of the discourse may lull oncology professionals into a false sense of security that breast cancer patients are able to enter into partnerships with the clinician. Therefore, changes need to occur in the way clinicians communicate to patients, so that discursive cues for SDM are recognised and responded to by patients. Patient participation and SDM will, therefore, remain romanticised until communication and a shared agenda are at the forefront of the health professional-patient encounter. As a result, this project promotes new insights into the development of breast

cancer care and SDM, as it can aid health care professionals to recognise their role in obstructing SDM in the treatment for breast cancer. The findings also suggest the need for further research to revisit the SDM guidelines, and to outline alternative competencies for SDM from those currently outlined in the literature, which may be more equitable and yield more favourable outcomes. More attention needs to be given to assessing and evaluating doctor-patient communication for SDM, from the patient's perspective and told experiences. This will enable more adequate training of communication skills, which is focused on patient-centred care, for the practice and delivery of SDM within breast cancer care.

A crucial element in SDM is the nature of expectations the two people have about their roles, and the congruence and agreement of these role expectations. Patients and medical practitioners should have equal roles to play during SDM. However, breast cancer patients' reality of SDM exists within a perceived issue of power imbalance, which hinders the SDM experience. It is within the doctor-patient interaction that this understanding is constructed, and then further reinforced through peer to peer interaction. Despite the suggestions and encouragement given to patients during online forum interaction, about patient authority and patient participation, an observed power imbalance between the patient and clinician still remains, which conflicts with patient experience of SDM. As shown in study three, it is only when power is shared, and both the clinician and patient participate in an equitable partnership, based on two-way exchange of information and preference, that SDM is established and experienced by patients. The challenge for medical professionals is to empower patients in their individual care and encounters of SDM, as currently the evidence from this thesis suggests that this has not been established. Clinicians need to be proactive in facilitating the process of empowerment in their patients, and showing a commitment in sharing their power, as well as the decisions to be made. By engaging both experts to work together, this can produce an equality of power, only if both roles are acknowledged, clarified, and equally valued. When patients believe they have power, they may feel more comfortable about exercising their right to question clinicians about their care, share their views and preferences, and participate in their treatment choice. All of these aspects have previously been described by participants in the data as characteristics which constitute towards patient experiences of SDM. This is not to say that patients should and will have more power than clinicians, but it is a question of patients acquiring the belief that they are of equal value to the clinician, and entitled to participate

during the decision-making process of treatments. Subsequently, further improvements in breast cancer care are required to reduce any power imbalance, and to ensure that patient roles in SDM are enhanced. Additional training in communication skills is required to remove any patient preconceptions of roles and statuses.

The issue of power featured as a central analytical finding across the three studies. Future research could focus on the power inequalities in doctor-patient consultations for breast cancer, and to investigate the extent to which the issue of power affects patients' experience of SDM. This can be achieved by a review of the literature and a meta-analytic approach to locate, review, synthesise and summarise the findings, methodology, theoretical orientation and interpretation of qualitative research papers. This would ultimately identify the external influences of power on doctor-patient interaction, patient participation, and SDM in healthcare consultations. More training interventions are required to encourage health professionals to implement the *shared model* of decision-making, which aims to share power and induce patient empowerment (Charles et al, 1997; Coulter, 1997; Elwyn et al 1999; Frosch & Kaplan, 1999; The health foundation, 2009). Furthermore, more qualitative research is required to solely explore breast cancer patients' experiences of empowerment during SDM, as this is an unexplored area within the health psychology literature.

The issue of power also featured as an important analytical finding within the breast cancer forum data. The impact of power on patients' active/passive positioning and involvement in decision-making is, therefore, worthy of being furthered explored amongst support groups. Existing literature reveals that online support groups have the potential to create the conditions necessary to empower patients (Sharf, 1997). Study two also revealed that online forum interaction promoted the presence of SDM within a clinical setting, and reminded members about the importance of patient authority and patient participation. It is unknown whether face-to-face support groups could foster the same effects and, therefore, it would be of value for future research to explore this issue of power further amongst cancer support groups, such as Macmillan cancer support or Cancer Research support. This could provide valuable insight as to whether face-to-face interaction, within a support group, should be used as an intervention to remove patients' perceptions of an issue in power, and works towards a better experience of SDM for breast cancer patients. Subsequently the findings from this thesis and recommendations for further research offer

new insights and opportunities for the development of care practices for women faced with breast cancer.

7.4 Can SDM for breast cancer be explored qualitatively, through examination patient perceptions and conversations?

Theoretically, designing a qualitative study which is rooted in phenomenology and symbolic interactionism is a logical step towards answering this question. This project aimed to explore patients' experience of SDM, through methods which provided detailed and in depth meaning and insight into patients' experiences and understanding of SDM. Qualitative research can provide detailed perspectives of individuals' experiences or descriptions of processes, thereby ensuring a more detailed understanding of the phenomenon of interest. As the focus was on patient experience of SDM, experience was to be captured from both theoretical frameworks of phenomenology and symbolic interactionism; and a triangulation of qualitative methods which focused on patients' perspectives and interactions. The triangulation of methods across the three studies meant that patient experience could be explored using a range of qualitative research methods. To tackle patients' perspectives on their experience of SDM, a semi-structured interview study allowed insight into how SDM was experienced during a patients' breast cancer journey, and how SDM was understood as a result of their perceptions and experiences. The second method of capturing experience was to explore patients' interactions, not only with the clinician during a consultation, but with other breast cancer patients. As access to direct observations were limited for ethical purposes, two separate studies took form. One examined patient to patient interaction, through online support forums. The other explored doctor-patient interaction, through audio-recordings of consultations. Both of these studies provided an insight into the experience of SDM, and allowed further exploration of the meaning, characteristics, and presence of SDM. All three studies used qualitative methods, which were considerably different to the traditional methods of exploring SDM, in terms of evaluation studies.

The first study chose semi-structured interviews as a means to explore patients' understanding and experience of SDM from their perspectives. The interviews systematically examined patients' experience of SDM chronologically, from beginning of diagnosis to post treatment completion. This, therefore, provided a spectrum of time points

in which the research questions could be explored. The interviews were personal, but yet collaborative with the interviewee, which made them action orientated. The purpose of this study was to inform what SDM is like for patients during the whole course of their breast cancer journey. The study also operated at an additional level by enabling patients to make private reflections. This, therefore, enabled participants to describe their breast cancer and decision-making experiences, in ways that would not have otherwise been formulated in other SDM-related studies. The semi-structured nature of the interviews meant that women could freely talk about their lived experiences and views, during the course of their breast cancer care. Previous studies of chronic illness and decision-making have often utilised the method of interviews in an inductive way, which depersonalises the lived experience. What this first study has shown, by using semi-structured interviews to explore SDM, is that this method can reveal details of the personal experience of cancer care, whilst simultaneously providing insight into SDM. There was a fine balance which had to be struck in gathering disease related and patient satisfaction issues, and making sure that these were not at the forefront of the enquiry. Details on aspects of the lived experiences that surround SDM were encouraged. The content of these interviews were integrated with the findings of the other two studies, in reaching a more detailed understanding. The interview data meant that the research phenomena and data extracts could be examined laterally, across the whole data set, in an attempt to find general themes. The aim of analysis was not to generalise the findings, but to take an exploratory approach, to document and review individuals' accounts of their experiences of SDM during breast cancer. In addition to the interviews identifying key emergent themes, they also provided a platform from which further research could extend.

The second study chose to explore patients' experience of SDM from the interactions they have with other patients. Peer to peer interaction was examined through online support group forums, as this would provide a personal insight into the conversations which took place for women, during the course of their breast cancer care. The nature and benefits of Internet support groups are that they allow members to come online and share their views, concerns, and experiences. Therefore, this provides valuable data in respect to women's lived experiences and their perspectives. As women talked online about multiple topics in relation to their breast cancer, this enabled SDM to be explored amongst experiences which were not presented in the interview data. The informal nature of online interaction meant that women could comfortably talk at ease,

without feeling embarrassed. Therefore, the online forum data emphasised issues which otherwise might have been too distressing for participants to talk about during an interview. Similar to the interviews, the aim of analysis was not to generalise the findings, but take an exploratory approach, to document and review individuals' accounts of their experiences of SDM during breast cancer. The issues raised in the interviews and the forum data supported the need for further research to explore the conversations that take place during a consultation, to explore the research question further.

The final study adopted a more indirect observational approach to exploring patient encounters of SDM. This was achieved through examination of doctor-patient conversations, during adjuvant treatment consultations. The method was classed as indirect, as direct researcher observations did not take place. Instead, patient experience was explored through an interpretation of the meanings assigned to SDM and doctor-patient interaction through audio-recordings of the consultations. The audio recordings meant that SDM could be explored during every day doctor-patient interaction for breast cancer. The number of recordings or clinicians used for data collection was not important, compared to the number of instances which showed the phenomenon (SDM) occurring during talk. A CA on doctor-patient interaction paid particular attention to symbolic meaning behind doctor-patient interaction, how SDM was verbalised and exchanged, and how the presence of SDM was influenced (hindered or facilitated) through talk. The audio-recording study aimed to document the space between patient perspectives, shown in the interviews; and patient interactions about decision-making shown in the forum data, to provide a comprehensive exploration of SDM. The third study completes the triangulation of methods, as it ensures that SDM has been explored from patients' perspectives, from their interaction with others, and from their interaction with the clinician. Interpretation of the conversations provided an insight into how SDM operates, through talk, and how patients encounter it, through interpretation of discursive practices. By exploring how talk develops between clinician and patient, much is understood about the level of patient participation during decision-making, and the extent to which *shared model* for decision-making is encountered by patients. It is important to note, that the aim within this study was not to evaluate doctor-patient communications skills for SDM, as this has previously been explored in existing literature. Instead the focus was on patients' experiences, and to interpret the meanings ascribed to interactions and actions, which occur between clinicians and patients, for SDM during breast cancer consultations.

In conclusion, to understand how women with breast cancer experience SDM, the thesis highlights the need for the research question to be understood from patient perspectives and interactions. Much health literature on SDM still remains heavily quantitative in nature, as models of decision-making and patient participation are predominantly explored through evaluations of patient satisfaction and doctor-patient communication. This thesis, however, contributes to qualitative research and raises its profile within health related decision-making research. This thesis has extended beyond the traditional methods of SDM studies, which employ quantitative and qualitative methods for evaluation and assessment of SDM. By examining how women with breast cancer experience SDM, this thesis extended the boundaries of existing decision-making research to allow for greater understanding about the concept of SDM, as it is experienced, in the lived lives of breast cancer patients. A triangulation of qualitative studies has achieved an exploration of how SDM is experienced by breast cancer patients. The methods employed in each study emphasise the importance of a systematic inquiry, and understanding of conscious experience from the person experiencing it. The thesis also extended beyond SDM research, to explore the research question through alternative methods of data collection, such as online forums. It has sought and successfully achieved an insight into breast cancer patients' experience of SDM, from their personal perspectives and their interactions. Finally, it has added to the growing literature on SDM, patient participation, doctor-patient communication, and breast cancer care.

The overall findings make valuable contributions to qualitative critical health psychology research, and provide useful recommendations for future health research. Further research into SDM can benefit from the methods used in this thesis, in particular for investigating SDM amongst other chronic illnesses. Future research could explore the concept of SDM in cancer care, and the identified issue of power within SDM, by means of other qualitative methods. For instance, through the use of participant audio-diaries, this would allow patients to become collaborators in the data collection, thereby shaping their own experience of SDM according to their breast cancer journey. This is a useful consideration for chronic illness and decision-making research, particularly as NHS initiatives aim to integrate patients into research and increase service user involvement. There is a need for more research to move away from focusing on the disease and evaluation of processes and procedures in medical care, and instead focus on experience and interpreted meanings of such experience.

7.5 Project limitations

The self-selecting nature of the sample was a limitation. For example in study one and three, recruitment largely relied on individual women returning the required materials to the researcher, and patient good health. Similarly in study two, recruitment was largely based on subjective self-selection of the researcher's ability to identify online posts, which met the sample inclusion criteria. This resulted in a narrow sample of participants across all three studies. Although the selection of sample produced relevant data to understand the process of SDM and patient experiences of SDM within breast cancer, the diversity of patients with breast cancer was limited. Participant criteria did not discriminate for other chronic illness and cancer diagnoses, which may have influenced patient levels of involvement in decision-making. The experience of younger women with breast cancer was not explored to detail, as the sample across all three studies represented an age of a 40 plus population. All participants described their ethnic origin as White British. The inclusion of participants from other ethnic backgrounds and ages may have elicited different experiences and meanings of SDM, to those raised in this study. This makes the research findings limited to their ability to reflect experiences of SDM for other women with breast cancer in similar situations. There is a need for a greater exploration of the research question with a more diverse sample of patients.

Study one entailed a retrospective design, which allowed for a comprehensive view of patients' perspectives and experiences of SDM from diagnosis to post treatment. However, for a more comprehensive insight of SDM, which does not depend on participant memory, there is the need for a longitudinal design to explore this topic. Such longitudinal exploration would allow for a more in depth review of patient experiences, and allow for transitions, such as from illness to good health, to be uncovered. To assist with this longitudinal design, qualitative methods such as audio-dairies would enable patients' lived experiences to be explored throughout all stages of their illness and life, and outside of the hospital. Therefore, this provides a broader assessment of the issue, and a more global and inclusive insight into patients' views and experiences of SDM, in and out of the hospital, with clinicians, and with others they interact with. By capturing experiences at all intervals of breast cancer treatments, certain questions raised in this thesis could be answered, such as why is there a perceived imbalanced of power-relations during doctor-patient decision making for adjuvant treatments, but not for surgical treatment decisions? Another issue raised within the interview study is that interviewing largely depended upon retrieval of

memories. Recalling a particular distressing time can be a difficult task. Many participants showed difficulty in answering some of the interview questions, which may have been due to poor or repressed memories. This further added to the particular nature of the data collected.

The Internet forum study raises some methodological issues that need to be explored. Despite the advantages of online research such as, reaching a larger pool of potential study participants; increasing access to study sensitive issues and ‘hidden populations’; and decreasing data collection time, there were several methodological issues with online research that became apparent. As well as the sampling issues outlined above, the forums provided some access issues, as many of the British breast cancer support forums required membership as a patient in order to access the posts. This, therefore, limited the scope of online support groups which could be considered for data collection. The forum website arrangements were advanced and based on a categorisation system, exhibited by libraries and archives, which was beneficial to data handling. However, the three forums used for data collection contained large numbers of posts on a variety of topics, which resulted in too much data to handle and refine. The wealth of information available, made it difficult, at times, to not divert from the research question. The filtering process of online forums did not serve as a reliable means of data collection for the research questions, as a ‘top-down’ approach was difficult to obtain due to a large volume of data. Furthermore by creating a data inclusion criteria which electing to seek posts on decision-making, this meant that the data collection was led by the research questions and selected to fit the research, therefore, disabling other general topics and patterns to emerge, which could facilitate the overall research.

The analysis of conversation, through audio-recordings, also showed some limitations. The aim was to capture the interaction which took place between the clinician and patients, which was successfully achieved. However, the interaction data lacked physical cues, facial expressions, and body movements which could add to the analysis and interpretation of talk. There were particular moments of long gaps during conversation, which would infer patient turn-taking to take place. However, patients often failed to take their turn-in-talk and, therefore, it would have been of value to explore what physically occurs during that period of silence. This would have been particularly beneficial in exploring why patients often did not recognise or were unresponsive to verbal cues of

SDM. Video-recordings could have provided a more precise and detailed illustration of both physical and verbal interaction.

7.6 Development and summary of the thesis

From the beginning, this thesis has questioned what it is like for women diagnosed with breast cancer to experience SDM during their treatment. To answer this question, there were additional questions that needed to be asked. These were:

- What does the concept of SDM mean to women with breast cancer, and what are the characteristics of SDM?
- How is the experience of SDM influenced (hindered or facilitated) for women with breast cancer?
- Can SDM for breast cancer be explored qualitatively, through examining patient perceptions and conversations?

From these questions, a subset of issues emerged with the data analysis of three distinct qualitative studies that followed through to the discussion outlined in this chapter. It is useful now to return to the initial research questions raised in Chapter One, to see how far this thesis has answered the main question above. When searching the literature in Chapter Two on SDM and breast cancer, it soon emerged that there was little evidence that documented patients' lived experiences of SDM. It became clear that the literature search needed to be broadened to address medical decision-making as a general concern, to help answer the main research question.

Having consulted the literature regarding methods and methodology, in Chapter Three, and how best to capture patients' experiences of decision-making, a semi-structured interview study was conducted, in Chapter Four, with 15 breast cancer patients, who were two years on from completing all treatments. The literature review at the start of the study drew emphasis to the importance of qualitative interviews, as a means to explore the research topic. This interview data provided a rich source of themes that could be explored further in the thesis. It also provided a valuable insight into participants' views and experiences through their entire treatment trajectory, from diagnosis to post-treatment. Using interviews as a starting point was extremely beneficial, as the content of the data yielded many issues relevant to the experience of SDM for breast cancer patients. These

included, the individual differences in experience of SDM; aspects of doctor-patient interaction which constitute towards an experience of SDM; and barriers between doctor-patient relationship which hinder experiences of SDM. These were striking accounts, not only about how women experienced SDM, but also about their understanding of the characteristics of SDM and the meaning of the concept; and about factors which can enhance and restrict patient encounters of SDM.

To explore patients' experiences of SDM further, an online forum study was carried out and reported in Chapter Five, to capture patients' experiences and understanding of SDM through the interactions they have with other patients. The literature review at the start of the chapter highlighted the value of the Internet as a medium for health research and to capture patients' experiences of SDM; a novel method of exploration in the SDM literature. The Internet data allowed for considerable access to patient experience, and to explore the conversations, dilemmas, and concerns about treatment decision-making patients are faced during their cancer care. Analysis of the interaction yielded valuable insight that supported the interview study, and provided encouragement for further exploration in the thesis. The forum analysis identified many issues relevant to the experience of SDM for breast cancer patients. These included how and when the forums are used by breast cancer patients, and the types of decision-making topics interacted online. Other issues included awareness and encouragement given to the process of SDM to occur in a clinical setting, and educating others about ways to maintain an experience of SDM with clinicians. Considerable insight into breast cancer patients' experiences and understandings of SDM, how SDM is characterised, and the factors which can enhance and restrict patient encounters of SDM, were obtained from this second study.

Both the interview and online forum studies show that these qualitative methods can be successful in terms of accessing patients' experiences of SDM, through capturing patient perspectives and interactions. However, the current practice of SDM during a clinical encounter still needed to be explored to provide a detailed answer to the main research question. To demonstrate how SDM is verbalised and exchanged in a consultation, and to explore how the presence of SDM is hindered or facilitated during doctor-patient interaction, a third study was conducted and reported in Chapter Six. The final study aimed to explore the interactions which took place between patient and clinician during a decision-making consultation for adjuvant treatments. Focus was to

interpret the meanings ascribed to interactions which took place during doctor-patient communication for SDM. As the previous two studies drew awareness to importance of two-way communication in facilitate SDM; and a perceived issue of doctor-patient power discrepancy which inhibited SDM, this third study, therefore, provided an opportunity to further explore this issue. Analysis of conversations yielded valuable findings about how conversations for SDM take place between the patient and clinician. The findings showed that despite great efforts put forward by the clinician to exert SDM and allow for patient participation, there appears to be a lack of acknowledgement and response by patients to these displayed discursive cues. Subsequently, the concept and presence of SDM is demonstrated to be limited by language and conversation practices, which further exaggerate the perceived discrepancy of power-relations between the clinician and patient. The discourse, which maintains the clinician's power, stands above and is acknowledged more than the discourses for SDM. This, therefore, results in a lack of two-way interaction and the exchange of information and preferences between clinician and patient, which allow for SDM to occur. Considerable insight is provided from this third study about patient encounters of SDM, and the factors which influence the presence of SDM during breast cancer consultations.

The question of 'can SDM for breast cancer be explored qualitatively, through examining patient perceptions and conversations?' was raised. Qualitative methods of interviews, online forum, and conversation analysis have shown to be substantial investigative tools. By employing the theoretical perspectives of phenomenology and symbolic interactionism, patient experience of SDM has been captured across all three studies, through examination of patient perspectives and interactions with others and the clinician. The thesis has not only demonstrated research with qualitative methods of interviews and conversation analysis, which have previously been used in existing literature on medical decision-making and patient participation, but it has also taken a novel step forward in utilising these methods in different ways. An example of this was using interviews post-cancer, to capture a comprehensive exploration of patient experiences, through their entire treatment trajectory; and by using audio-recordings to provide detailed insight into conversations for SDM during consultations. The thesis also showcases innovative qualitative methods, such as Internet written data analysis, and shows the applicability of this design to phenomenological and symbolic interactionist research and health psychology research, particularly on medical decision-making.

This thesis has emphasised the importance of qualitative methods in making sense of SDM and understanding how it is experienced by patients. The overall message that this thesis reveals, in terms of how patient experience of SDM can be explored, is that we must study SDM through patients' lived experiences and try to understand the meanings that patients ascribe to those experiences. Attention should be given to how people perceive and interpret their encounters of SDM, and indeed with other chronic illnesses, and not necessarily at exploring competencies which are linked to SDM, or assessing SDM in relation to the disease (patient outcomes). This is because people experience their illnesses in many different contexts and each have personal individual differences, therefore, implying that patients do not always follow a treatment plan that is determined by the disease outcome. Removing the emphasis from evaluating SDM and extending it to other aspects, such as patient experiences, perspectives, and interactions is far more productive in producing rich and detailed data about SDM, which has not been formally documented in this area of research.

The thesis draws on the NICE (2004 & 2012) guidelines for SDM and the *shared model* of medical decision-making, and illustrates its use for the treatment of breast cancer, from the view of the patient's lived experiences. The key development of the research is that it has contributed to the critical health psychology literature, by demonstrating how breast cancer patients experience SDM during their treatment, using qualitative methods and the theoretical perspectives of phenomenology and symbolic interactionism. Most importantly, it has exposed the concept and meaning of SDM from patients' perspectives, interactions, and interpretations of those actions. From all three studies, the thesis has also suggested implications for future research, such as to further explore patient experience of SDM with alternative qualitative methods; to apply the methods and methodological practices from this thesis to explore patient experience of SDM amongst other chronic illnesses; to explore the impact of face-to-face support group interaction on patient experience of SDM; and to further explore the issue of doctor-patient power inequalities and SDM within breast cancer care. It is important to keep exploring patients' lived experiences of SDM to add to the growing health psychology literature on decision-making. Besides the suggestions made for future research, the thesis also offers useful suggestions, at a clinical level, such as, for practitioners to acknowledge patient individual differences and active and/or passive positioning, in order to adapt SDM to patient

preferred participatory roles; communication skills training for improved interaction, which removes discursive barriers and enables patients to recognise cues for SDM and patient participation during doctor-patient interaction; and the development and practice of methods to regularly monitor and assess patient experiences of decision-making for service quality improvement.

The thesis makes an important contribution not only to qualitative critical health psychology and the existing literature on SDM and patient participation, but most importantly to breast cancer care. It signified the relevance and importance of SDM being a requirement in health practice, and emphasises that something that is shared, such as medical decision-making, needs to be understood by all parties. It also helps to advance the knowledge and recognition that health care providers and services have on the concept and practice of SDM. It offers new insights into the development of breast cancer care, as it facilitates health care professionals and organisations with the appropriate knowledge and skills needed to ensure that the concept of SDM is experienced by all patients. The findings on doctor-patient power-relations will help medical professionals develop a greater understanding for establishing and maintaining patient-centred care, and a *shared model* of medical decision-making in the treatment for breast cancer, and for treatment of other cancers. This will advance services and practice to promote breast cancer patients' health and well-being.

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Glossary of breast cancer terms & abbreviations used in this thesis

Absolute risk A measure of the risk of a certain event happening. In cancer research, an example of an 'absolute risk' can include the statistical likelihood that a cancer-free person of a given age will develop that cancer over a certain period of time.

Acute Symptoms or signs that begin and worsen quickly and last for a short time; not chronic.

Adjuvant treatment Treatment given in addition to other treatment, for example chemotherapy or radiotherapy given as well as surgery.

Adverse effect An unexpected medical problem that happens during treatment with a medicine or other therapy. Adverse effects do not have to be caused by the medicine or therapy, and they may be mild, moderate or severe. Also called adverse event.

Axillary clearance An operation to remove all the lymph glands from under the arm (axilla).

Axillary nodes The lymph nodes (also called lymph glands) under the arm (axilla).

Benign Not cancer

Biopsy Removal of tissue to be looked at under a microscope.

Breast care nurse Trained to provide information and support to anyone diagnosed with breast cancer.

Breast-conserving surgery (also known as wide local excision or lumpectomy): the removal of the cancer with a margin (border) of normal breast tissue around it.

Carcinoma The medical term for cancer

Cancer A group of diseases in which malignant cells grow out of control and may spread to other parts of the body.

Cells Tiny structures found in all living organisms

Chemotherapy Treatment aimed at destroying cancer cells using anti-cancer drugs, which are also called cytotoxic drugs.

Chronic An illness, disease or condition that is long lasting and generally slow to progress.

Clinical Observation and treatment of patients.

Clinical trials Research that aims to improve treatment or care for patients.

Complementary therapies A varied group of therapies used alongside conventional medical treatments.

DCIS (ductal carcinoma in situ) or **Intraductal**: An early type of breast cancer where the cells have not yet developed the ability to spread outside the walls of the ducts into surrounding breast tissue or to other parts of the body. Sometimes called a pre-invasive, intraductal or non-invasive cancer.

Drug resistance Reduced effectiveness of a drug on a disease.

Excision Surgical removal

FEC A combination of the chemotherapy drugs 5-fluorouracil (5FU), epirubicin and cyclophosphamide.

FEC-T A combination of the chemotherapy drugs 5-fluorouracil (5FU), epirubicin, cyclophosphamide and Taxotere (docetaxel).

Fibrocystic A benign (not cancer) breast condition when multiple cysts or lumpy areas develop in one or both breasts.

Gene Stores the biological information we inherit from our parents, affecting the way we look and how our bodies work and grow.

Grade The system used to classify cancer cells according to how different they are to normal breast cells and how quickly they are growing (1=low, 2=moderate, 3=high)

HER2 (human epidermal growth factor receptor 2) A protein involved in the growth of cells. Around 20% of breast cancers have higher than normal levels of HER2 (known as HER2 positive) which stimulates them to grow.

Herceptin A targeted therapy used to treat HER2 positive breast cancer, and one of a group of drugs called monoclonal antibodies.

Hereditary Characteristics, conditions or illnesses that can be passed from parent to offspring through genes.

Hormone receptor Involved in the growth of cells. In some breast cancers they bind to hormones within the cells (known as hormone receptor positive) and stimulate the cancer to grow.

Hormones Chemical messengers produced in various organs of the body that regulate growth and reproduction.

Hormone therapy Use of drugs to block the effect of hormones on cancer cells; only used if the breast cancer is hormone receptor positive.

HRT (hormone replacement therapy) Female sex hormones, either oestrogen alone or a combination of oestrogen and progesterone, often used to help reduce menopausal symptoms.

Invasive cancer Has the potential to spread to other parts of the body.

Lobular cancer (in situ/ LCIS) Non invasive cancer that begins in the lobules (milk glands) of the breast

Locally advanced breast cancer Also known as regional recurrence. Breast cancer that has come back and spread to the tissues and lymph nodes around the chest, neck and under the breastbone.

Lumpectomy An operation to remove an area of breast tissue with or without a margin of healthy tissue; in breast cancer may also be called wide local excision or breast-conserving surgery.

Lymph nodes Also known as lymph glands. Small oval-shaped structures found in clusters throughout the lymphatic system, for example under the arm (axilla).

Lymphoedema Swelling of the arm, hand or breast area caused by a build-up of lymph fluid in the surface tissues of the body. It can occur as a result of damage to the lymphatic system, for example because of surgery and/or radiotherapy to the lymph nodes under the arm (axilla) and surrounding area.

Malignant In cancer, uncontrolled growth. Invasive cells that have the potential to spread elsewhere in the body.

Mammogram A breast x-ray.

Mastectomy Removal of all the breast tissue including the nipple area.

MRI (magnetic resonance imaging): a technique whereby a computer linked to a magnet produces images of internal areas of the body

Non Invasive cancer Does not have the potential to spread outside the tissue in which it began

Oncologist A doctor who specialises in cancer (oncology). An oncologist may be a medical oncologist (cancer drugs specialist) or clinical oncologist (radiotherapy and/or cancer drugs specialist).

Oncology: the study or science of cancer

Oncoplastic surgeon A breast cancer surgeon with specific training in plastic surgery

Palliative care Focuses on symptom control and support when an illness cannot be cured; usually involves a team of healthcare professionals such as specialist nurses, doctors, social workers and physiotherapists.

Palliative treatment Aims to control symptoms and slow down the progress of an illness, rather than cure it.

Pathology The branch of medicine that looks at how disease affects the body's cells and tissues. Each time you have tissue removed a report is written by a pathologist (a doctor who examines the tissue).

Plastic surgeon A specialist surgeon trained in plastic surgery techniques such as breast reconstruction.

Primary breast cancer Breast cancer that has not spread beyond the breast or the lymph nodes (lymph glands) under the arm (axilla)

Prognosis The likely outlook of a disease, whether it is likely to be cured and the person's life expectancy.

Prosthesis An artificial breast form used to restore shape when all or part of the breast has been removed.

Psychosocial Oncology Psychosocial Oncology is the formal study, understanding and treatment of the social, psychological, emotional, spiritual, quality of life and functional aspects of cancer across the cancer continuum, from prevention through diagnosis, treatment, survivorship, palliative care and bereavement.

Radiotherapy The use of high energy x-rays to destroy cancer cells.

Radiologist A doctor who specialises in the use of imaging (for example x-rays, ultrasound, CT, PET, MRI) to diagnose and treat disease.

Reconstruction (breast) surgery rebuilds breast shape after all or part of the breast has been removed.

Recurrence When a disease or condition returns. There are several types of breast cancer recurrence.

Local recurrence Breast cancer that has come back in the chest/breast area or in the skin near the original site or scar.

Remission when the signs and symptoms of a disease partly or completely disappear; this may be temporary or permanent.

Risk factor In medicine, something that increases a person's chance of developing an illness such as cancer.

Secondary breast cancer when breast cancer cells spread from the first (primary) tumour in the breast through the lymphatic or blood system to other parts of the body. Also called metastases, advanced breast cancer, secondaries or stage 4 breast cancer.

Sentinel node biopsy (SNB) Identifies whether or not the first lymph node (or nodes) is clear of cancer cells.

Side effect Unwanted effect of treatments

Stage The size of the cancer and how far it has spread.

Surgical margin How close the cancer cells are to the edges of the whole area of tissue removed during surgery.

Systemic treatment Drugs that treat the whole body, for example, chemotherapy, hormone therapy or targeted therapy.

Tamoxifen A hormone therapy drug.

Targeted therapies (also know as biological therapies) A group of drugs that block the growth and spread of cancer by interfering with the biology of the cancer cells. They target specific processes in the cells that cause cancer to grow.

Terminal illness Eventually causing death, often used when someone is approaching the last few weeks or days of life

Tumour An overgrowth of cells forming a lump; may be benign (not cancer) or cancer.

Ultrasound: a test which uses sound waves to create pictures of the tissues and internal organs of the body. It is helpful in determining if a breast lump is solid tissue or contains fluid.

Wide local excision (WLE) Surgery to remove breast cancer with a margin of healthy tissue. Sometimes called breast-conserving surgery or lumpectomy.

X-Ray: Low doses of high energy radiation used to diagnose disease or high doses of radiation used to treat cancer

Abbreviations used in this thesis:

BPS: British Psychological Society

CA: Conversation Analysis

DOH: Department of Health

FPP: First Pair Parts

HRQOL: Health-related Quality of Life

NHS: National Health Service

MDT: Multi-disciplinary Team

NICE: National Institute for Health and Care Excellence

QOL: Quality of Life

SDM: Shared Decision-making

R&D: Research and Development

REC: Research Ethics Committee

TA: Thematic Analysis

TCU: Turn Construction Unit

TRP: Transitional Relevant Place

SPP: Second Pair Parts

IRAS Version 2

Reference 11/H1203/8

2nd March 2011



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- / - / 2011

Dear Patient,

I am writing to inform you about a research project currently taking place at the Cancer Centre at the University Hospital of North Staffordshire. The project aims to explore what are the views and experiences of shared decision making for breast cancer patients during treatment. We would therefore like to invite you to participate in an interview with our research team.

We have enclosed some more information about the project which we would be grateful if you could read. If you are willing to take part in the project, please could you sign, date the invitation form, and return it in the FREEPOST envelope provided.

On consent to your participation, you will be contacted by a member of the research team, Miss Neda Baniamer, who will be happy to arrange to meet you for an interview taking place at the University Hospital of North Staffordshire, at a date and time convenient for you.

Finally, you do not have to take part in the project if you would prefer not to, it will not affect your care in any way.

Yours sincerely,

Mr Sankaran Narayanan

Consultant Onco-plastic Breast Surgeon

IRAS version 1

Reference:

2nd December 2011



University Hospital of North Staffordshire



NHS Trust

K E E L E
UNIVERSITY

Keele University, Staffordshire, ST5 5BG.
Telephone: (01782) 733669

Mr Narayanan
University Hospital of North Staffordshire
City General
Newcastle Road
Stoke-on-Trent
Staffordshire
ST4 6QG

Tel: 01782 679906

Patient Information Sheet

Project Title: Research on the views and experiences of shared decision making for patients during the treatment of breast cancer

You are being invited to take part in a research study. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with friends and relatives if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

*Part 1 Tells you the purpose of this study and what will happen to you if you take part.
Part 2 Gives you more detailed information about the conduct of the study.*

PART 1- The purpose of the study / what will happen if you take part

What is the purpose of the study?

Breast cancer patients often have to face difficult decisions about their treatment. Although cancer management is governed by specific clinical guidelines, many decision making processes remain complex for patients. Even with a choice for treatment, many feel they lack control or involvement in decisions to manage their health. Consequently, medical professionals need to be aware of the important impact of decision making processes and active patient participation.

This research represents the first comprehensive examination of the role of shared decision making in the medical treatment journey and quality of life of woman with breast cancer. The research will help to establish guidelines for acknowledging and maintaining the importance of a patient's role in shared decision making and involvement during their treatment of breast cancer, for use by physicians and other health professionals. Findings from the study will be integrated in an oncology setting and practice, and as a consequence will help physicians and promote breast cancer patients' health and well-being.

Why have I been asked to take part?

All patients who have recently completed surgery for breast cancer treatment in the last month, and who are currently registered under Dr Brunt's care for treatment of radiotherapy or chemotherapy are invited to participate.

Do I have to take part?

No. It is up to you to decide whether or not to take part once you have read this information sheet. If you do, we would like you to sign the invitation form enclosed and send it back in the FREEPOST envelope provided. *You are still free to withdraw at any time, even during or after the study itself, without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care you receive.* If you change your mind after you have sent in your recorded consultation cassette, then please contact a member of the research team within 10 days, and we will remove your data accordingly.

What will happen to me if I agree to take part?

If you agree to take part in the study:

- (1) A member of the research team will contact you to thoroughly go through the information leaflet, give you the opportunity to discuss participation, and answer any questions.
- (2) You will be then sent further documents in the post, in which you will be asked to provide and send back written informed consent to participate, as well as to place your consultation audio cassette recording into the envelop provided.
- (3) The cassette will be comprehensively analysed by a member of the research team.
- (4) You will receive your original cassette recording back to you by post, along with a summary of the findings. This will be accompanied by a call from the research team to ask if you understand the findings, as well as to talk about any questions or feelings you might have regarding your participation.

What do I have to do?

On acceptance of releasing your cassette for research purposes, you are required to send this to the research team, along with full consent. The aim of analysis is to give us a clear picture of the degree of decision making, control, and patient involvement which is evident through the course of your consultation and treatment.

Will I receive any payments or reimbursement of expenses for taking part in this research?

As you are required to send documents and the cassette in the post, it will be ensured that all postage cost is paid for through the use of pre-paid envelopes provided. We cannot make additional payments for participation.

What are the possible disadvantages and risks of taking part?

There are no risks associated with this research. Your participation will not affect the medical care you receive in any way.

What are the possible benefits of taking part?

The research will help to develop a greater understanding for maintaining patient involvement in decision making processes in the treatment for breast cancer, for use by

physicians and other health professionals. Therefore, it can contribute to improving the overall quality of life for women with breast cancer, and increasing patient satisfaction with the level of the care received. As a participant, you will help in achieving those goals

What happens when the research study stops?

When we have collected enough cassette recordings from patient, the research team will transcribe the audio cassettes and read through them carefully. This will be done at Keele University. They will identify key areas which worked particularly well for the patient, and areas which could be done differently to improve the service provided. The results will be presented in the form of a report.

Will my taking part in the study be kept confidential?

Yes. All the information about your participation in this study will be kept confidential. The details are included in Part 2.

This completes Part 1 of the Information Sheet.

If the information in Part 1 has interested you and you are considering participation, please continue to read the additional information in Part 2 before making any decision.

PART 2 - Further information

Is there an independent contact point where I can seek general advice about taking part in research?

The Patient Advice and Liaison Services (PALS) is a hospital service, available to give independent advice on any queries you have about your rights as research subjects or information about being involved as participants in a research study.

What if there is a problem?

If you are unhappy with any aspect of this study, please tell a member of the research team who will contact you with and they will try to rectify the problem. Alternatively, you can contact a member of the research team at any other time who will do their best to answer your questions (see contact information below). If you remain unhappy about the research and/ or wish to raise a complaint about the way you have been approached or treated during the course of the study, please write to Nicola Leighton: Research and Governance Officer, Research and Enterprise Services, Dorothy Hodgkin Building, Keele University, ST5 5BG

Will my taking part in the study be kept confidential?

Several procedures will be carried out to safeguard you and confidentiality. These include:

- (1) Dr Brunt is aware that his patients will be contacted. However he will not know who participates and sends in their cassette recordings for analysis. All information which is collected about you during the course of the research will be kept strictly confidential. Only the research team will have access to hearing the cassette, and no one outside of the research team will have access to any of the information gathered.
- (2) Only the original cassette will be used for analysis. No duplications will be made of the cassette, and the original will be sent back to you.
- (3) Analysis of the cassette will take place in a secure confidential area at Keele University by the research team only.

- (4) The transcript collected from the interview will contain no identifying features. You will be given an identification number only. Where data or direct quotes are used they will be anonymised. Any publication material arising from this research will contain no information identifying patients or medical staff
- (5) Computers which store the data will be password protected, and all data will be kept in a secure environment, at Keele University. The transcription of your cassette will only be read by the research team, not by Dr Brunt or any part of your medical team. After the feedback report has been produced, the transcripts will be kept as secure confidential records for a maximum of 2 years. After this time, all transcripts will be destroyed.

What will happen to the results of the research study?

The research findings will be presented to the oncology staff at the hospital. All participants will be presented with a written summary report, with an opportunity to comment on these results. The work will be submitted in fulfilment of a PhD in Psychology at Keele University. We may use some of the data we collect for publications in academic journals or for presentations at conferences.

Who is organising and funding the research?

The project is being run by Keele University (Institute of Life Course Studies), Psychology Department.

Who has reviewed the study?

The Research and Development Department, The University of North Staffordshire, Dr Darren Clement, Tel: 01782 554334

The Research and Development Department, Keele University, Nicola Leighton, Tel: 01782 733306

Staffordshire Research Ethics Committee, Redditch, Jenny Tyers, Tel: 01527 582535

Contact Details- Research Team

Chief Research Investigator: University Hospital of North Staffordshire, Dr Brunt- Tel: 01782, email: Murray.Brunt@uhns.nhs.uk

Principal Research Investigator: Keele University, Miss Neda Baniamer- email: n.baniamer@ilcs.keele.ac.uk

PhD Academic Supervisor: Keele University, Dr Sally Sargeant- Tel: 01782 583387, email: s.j.e.sargeant@psy.keele.ac.uk.

Thank you for taking the time to read this information sheet. If you think you would like to take part, please sign and return the enclosed invitation form in the FREEPOST envelope provided.

IRAS Version 2

Reference: 11/H1203/8

2nd March 2011



University Hospital of North Staffordshire



NHS Trust

K E E L E
UNIVERSITY

Keele University, Staffordshire,
ST5 5BG. Telephone: (01782)
733669

Mr Narayanan
University Hospital of North Staffordshire
City General
Newcastle Road
Stoke-on-Trent
Staffordshire
ST4 6QG

INVITATION FORM

Title of Project: Research on the views and experiences of shared decision making for patients during the treatment of breast cancer

Name of Principal Investigator: Miss Neda Baniamer

- | | Please tick |
|---|--------------------------|
| 1. I confirm that I have read and understand the information sheet dated 2 nd March 2011 (version 2) for the above study. | <input type="checkbox"/> |
| 2. I have had the opportunity to consider the information, ask questions, and have had these answered satisfactorily. | <input type="checkbox"/> |
| 3. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected. | <input type="checkbox"/> |
| 4. I understand that my participation in this research will have no bearing on my medical treatment and will not be included in my medical notes. | <input type="checkbox"/> |
| 5. I agree to take part in the above study. | <input type="checkbox"/> |
| 6. I agree to be contacted to arrange a convenient time and date for the interview to take place | <input type="checkbox"/> |

Signed:

Date:

Print Name:

.....

Interview schedule

1 Introductions and general information

- a) How long ago were you diagnosed?
- b) What treatment(s) did you undertake?
- c) How long was treatment from initial diagnosis to completion?

(Narrative history of the patients story/background info)

2 Knowledge of breast cancer treatments, information and communication

- Can you describe how much you knew about breast cancer and treatments before you were diagnosed?
 - Friends or family? Media campaigns?
- How did this change shortly after you were diagnosed?
 - Little? Increased your knowledge of a particular area?
 - How did this make you feel?
- What were the main sources of information you received?
 - Written, verbal, nurse, consultant?
 - How did you find this information?
 - How did it make you feel?
- What, if anything, did you do to find out more information for yourself?
 - Online resources, informal discussions with others, NHS Direct?
 - How did this make you feel?

4 Decision-making

- a) To what extent did you feel involved in choices of treatment /care offered to you?
 - How did this make you feel?
- b) If you felt involved, what things do you think assisted this feeling?
 - (What preconditions) give examples – e.g. physical health, courage, personality
 - Other areas of health NHS treatment?
- c) To what extent did you want to be involved in these choices?
- d) How much control did you feel you had about your treatment choices?
 - How did this make you feel?
- e) What is your own concept of shared decision making?
 - Is it a 50/50 relationship?

5 After treatment

- How would you say your life has changed since completing your treatment?
 - Increased confidence/ fear/levels of control/increased wish for involvement on breast cancer research or patient groups?
 - How does this make you feel?
- What specific influence has this experience of breast cancer had on your general decision-making ability? And control?
 - How does this make you feel?
- What specific influence has this experience of breast cancer had on your general levels of control ability?
 - How does this make you feel?

6 Summary questions

- a) Looking back on everything you've been through, is there anything you would have done different or wish you had done/not done?
- b) What, if anything could have improved the overall care you received?
- c) Anything else to add before we conclude?

Key

Numbers: Topic in question

Letters: Questions

○ : Prompts

IRAS Version 2

Reference: 11/1H203/8

2nd March 2011



University Hospital of North Staffordshire



NHS Trust

K E E L E
UNIVERSITY

Keele University, Staffordshire, ST5 5BG.

Telephone: (01782) 733669

Mr Narayanan
University Hospital of North Staffordshire
City General
Newcastle Road
Stoke-on-Trent
Staffordshire
ST4 6QG

Tel: 01782 679906

Patient Identification Number:

CONSENT FORM

Title of Project: Research on the views and experiences of shared decision making for patients during the treatment of breast cancer

Name of Principal Investigator: Miss Neda Baniamer

Today you will be interviewed about views and experiences of your involvement in the decision making processes through the course of your treatment. The interview is confidential and will take approximately 30 minutes. Before participating in the interview, it's important to understand why the research is being conducted and what it will involve for you. So please ensure you have read the information leaflet carefully, and have all questions answered thoroughly. You will be given a copy of this information sheet and your signed form to keep.

If you are interested in being interviewed, please sign below. If you are not interested, this will not affect your treatment in any way.

1. I confirm that I have read and understood the information sheet. I have also had the opportunity to ask questions and have had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected in any way.
3. I understand that my participation in this research will have no bearing on my medical treatment and will not be included in my medical notes.
4. I agree to the interview being audio recorded and transcribed for the researcher's notes.

Demographic Questionnaire

Can you please complete the following demographic information.

1. What is your gender (Please tick)

- Male
- Female

2. What is your age (Please tick)

- Under 22
- 22– 29
- 30 – 39
- 40 – 49
- 50 – 59
- 60 – 69
- 70 and over

3. To which one of these ethnic groups would you say you belong? (Please tick ONE box only)

a. WHITE

- British
- Irish
- Any other White background

b. MIXED

- White and Black Caribbean
- White and Black African
- White and Asian
- Any other Mixed background

c. ASIAN OR ASIAN BRITISH

- Indian
- Pakistani
- Bangladeshi
- Any other Asian background

d. BLACK OR BLACK BRITISH

- Caribbean
- African
- Any other Black background

e. CHINESE OR OTHER ETHNIC GROUP

- Chinese
 - Any other ethnic group
4. Do you have any of the following long standing conditions? (Please tick all that apply)
- Deafness or severe hearing impairment
 - Blindness or partially sighted
 - A Longstanding physical disability
 - A learning disability
 - A mental health condition
 - A long standing illness such as HIV, diabetes, chronic heart disease or epilepsy
 - No, I do not have any other medical condition
5. What is your marital status (Please tick)
- Married
 - Divorced
 - Widowed
 - Separated
 - Never been married
 - A member of a unmarried couple
6. What is your employment status (Please tick)
- Employed
 - Self-employed
 - Out of work
 - A homemaker
 - A student
 - Retired
 - Unable to work

THANK YOU FOR YOUR HELP TODAY

Initial Notes/ Patterns	Lines (name)	Codes	Sub- Themes	Provisional name	Final Theme
Engage in literature Ask the clinician questions Participate in discussion Want to be in control of health care Talking to other patients/support groups Must be involved in decision Experience SDM Patient involvement leads to SDM	149-156 (Sarah) 51-66, 121-124 (Judy) 72-78, 155-156 (Elaine) 125-139 (Katherine) 51-58, 60-66 (Judy) 120-132 (Sarah) 173-185 (Katherine)	Involved patient Active participatory role Facilitated experience of SDM	Active and/or passive positioning	Individualised experiences of SDM	Personalising and adapting SDM
Block learning information In denial over diagnosis Fear of increasing knowledge Pass responsibility of decision making Want no control over health care View that SDM doesn't exist Little awareness of what SDM is	69-77 (Elaine) 24-26, 86-90, 96-99 (Debbie) 58-62 (Sarah) 170-182 (Lucy) 96-99, 101-114 (Debbie) 74-81, 92-97 (Helen)	Submissive patient Passive participatory role Hindered experience of SDM			
Written information Verbal information Friendly, relaxed communication by doctor	74-86 (Judy) 60-65 (Claire) 65-66, 137-141 (Saran) 38-45 (Katherine)	Varying types of information Communication skills Quality of information	Learning styles		
Only want to know relevant information Must know everything and all options Negative information= anxiety Knowing everything= little distress	45-47 (Debbie) 47-52, 56-61 (Louise) 64-71, 77-79 (Lucy) 36-42, 169-171 (Helen) 71-74, 76-83, 112-116 (Sarah)	Knowledge restrictions Quantity of information			

Do want to talk to friends/family Avoid talking about with other patients Avoid hearing negative stories Do want to take anti-depressant Self manage own mental health	117-126, 225-233 (Debbie) 66-105 (Helen) 127-138 (Rachel) 95-100, 200-226 (Sarah)	Isolation Self-support Distress management	Coping strategies	Negative factors influencing SDM	Power imbalance and SDM
Talking to breast care nurses help Important to create social bond Good to relate to others patients Share stories, experiences, remedies Receive support, guidance, advice	137-144 (Helen) 72-79 (Claire) 57-61 (Debbie) 199-122 (Katherine)	Identification process Support structure Inclusion			
Motivational preaching, positive QOL	255-260 (14) 148-156 (4)	Enhancing self esteem			
Lack of patient knowledge Patients have no medical skills Patients lack experiences of illness Doctor is the expert in the field Doctor is medically trained and knows what is medically appropriate Cant challenge doctors expertise Intimidated to ask questions Doctor knows best Doctor is of a higher status	104-107 (Rachel) 106-118, 120-124, 139-147(Claire) 126-131, 171-184 (Lucy) 92-94 (Debbie) 94-97 (Helen) 162-171, 198-201 (Katherine) 100-109 (Charlotte) 102-108 (Louise) 138-154 (Lucy) 187-196 (Katherine)	Patient Inferiority Clinician superior Academic discrepancy Obedience to doctor Social influence Conformity Hierarchal positions	Doctor-patient knowledge discrepancy		
The doctor has a duty of care The doctor is seen as a problem solver Patients innate trust in doctor	186-194, 203-216 (Vicky) 89-95, 169-179 (Louise) 162-169 (Lucy) 102-106 (Sarah)	Doctor-patient roles Levels of responsibility Faith Assurance giver	Roles and duties		

Appendix H
Thematic codes and themes

	84-90 (Claire)				
Patient have rights Patient centred care SDM sustains the patients roles	157-163 (Sarah) 221-236 (Judy) 92-100 (Elaine) 34-38(Rachel)	Patient participation Patient centre of decision making Patient role in care			
Breast care nurses role, multidisciplinary team	34-39, 264-270 (Lucy) 78-84 (Debbie) 201-218 (Katherine)	Solution maker Balancing doctor patient roles Maintaining patient involvement			
Husbands role, children's influence	57-74 (L)	Family Proximity			
Explaining treatment options Justifying treatment choice informed consent Informed decision making Enhancing patient knowledge Being kept in the loop Doctor provides information and patient queries and consents	198-204 (Sarah) 97-102 (Margaret) 126-130, 135-145 (Judy) 66-72 74-79 (Louise) 90-93 (Lucy) 153-158 (Katherine) 101-104,106-114 (Debbie)	Clarification of details Rationalising treatment plans Involved in decisions Educating the patient Sharing information	Information exchange	Patient concept of SDM	Features of SDM

Appendix H
Thematic codes and themes

Two-way conversation Doctor-patient discussions mutual feedback Question/answering sessions 50/50 process Equal partnership/process	96-107, 147-160 (Judy) 106-111 (Elaine) 160-162 (Katherine) 105-115 (Judy) 99-100 (Rachel) 103-111, 114-118 (Helen) 121-135 (Sarah)	Mutual doctor-patient relationship Communication skills Sharing talk Equal control Patient involvement	Two-way processes		
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Key



Codes excluded and not clustered into themes due to lack of substantial extracts and data



Staffordshire Research Ethics Committee

Prospect House
Fishing Line Road
Redditch
Worcestershire
B97 6EW

Telephone: 01527 582535

23 March 2011

Mr Sankaran Narayanan
Consultant Onco plastic Breast surgeon
The University Hospital of North Staffordshire
Central Outpatients
Hartshill Road
Stoke on Trent
ST4 7PA

Dear Mr Narayanan

Study title: The decision making processes in breast cancer patients: A Retrospective Study
REC reference: 11/H1203/8

Thank you for your letter of 03 March 2011, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

The Participant Information Sheet should be corrected under the heading 'What do I have to do' as there is a typographical error. The first two sentences need rewriting to make better sense. The font size varies, this should be consistent if possible.

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Protocol	1.0	05 January 2011
Response to Request for Further Information		03 March 2011
Letter of invitation to participant	v2	02 March 2011
REC application	3.1	05 January 2011
cv academic supervisor		06 January 2011
Expenses claim forms		
Participant Information Sheet	V2	02 March 2011
Interview Schedules/Topic Guides		05 January 2011
Evidence of insurance or indemnity		28 July 2010
Investigator CV		18 September 2009
Participant Consent Form: Initial Consent	V2	02 March 2011
Participant Consent Form: Interview Consent	v2	02 March 2011
Covering Letter		05 January 2011
cv of student Neda Baniamer		05 January 2011

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Now that you have completed the application process please visit the National Research Ethics Service website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

The attached document "*After ethical review – guidance for researchers*" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

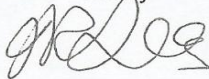
We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nres.npsa.nhs.uk.

11/H1203/8

Please quote this number on all correspondence

With the Committee's best wishes for the success of this project

Yours sincerely



Jenny Tyers (Mrs) for and on behalf of
Dr Kathryn Kinmond
Chair

Email: jenny.tyers@westmidlands.nhs.uk

Enclosures: "After ethical review – guidance for researchers"

Copy to:

Mrs Nicola Leighton
Research and Enterprise Services
Keele University
Staffordshire
ST5 5BG

Miss Neda Benaimer
Room 0.66 Dorothy Hodgkin Building
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University Hospital of North Staffordshire 

NHS Trust

RESEARCH AND DEVELOPMENT DEPARTMENT

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Email: darren.clement@uhns.nhs.uk
karen.rhodes@uhns.nhs.uk

Ref: DC/kr

6 June 2011

Miss Neda Baniamer
PhD Psychology Research Student
Room 0.66
Dorothy Hodgkin Building
Keele University
Keele
Staffs

Dear Miss Baniamer

Re: The decision making processes in breast cancer patients: A Retrospective Study

Chief Investigator: Mr Sanakaran Narayanan

Sponsor: Keele University

I can confirm that the above project has been given NHS Permission for Research by the Research & Development Department for the University Hospital of North Staffordshire NHS Trust and the details entered on to the R&D database.

I note that this research project has been approved by Staffordshire Research Ethics Committee – 11/H1203/8

NHS permission for the above research has been granted on the basis described in the application form, protocol and supporting documentation. The documents reviewed were:

Document	Version Number	Date
Protocol	1	05.01.2011
Patient Information Sheet	2	02.03.2011
Consent Form – Initial	2	02.03.2011
Consent Form – Interview	2	02.03.2011
Contract/Agreement	n/a	

REDA ID:5083 REC REF:11/H1203/8

The research sponsor or the Chief Investigator, or the local Principal Investigator at a research site, may take appropriate urgent safety measures in order to protect research participants against any immediate hazard to their health or safety. The R&D office should be notified that such measures have been taken. The notification should also include the reasons why the measures were taken and the plan for further action. The R&D office should be notified within the same time frame of notifying the REC and any other regulatory bodies.

Approval by the R&D Dept therefore assumes that you have read, understand and agree to comply with the:

- ❖ Research Governance Framework (www.doh.gov.uk/research)
- ❖ Data Protection Act
- ❖ Health and Safety Act
- ❖ ICH Guidelines on good clinical practice
- ❖ All applicable Trust policies & procedures

In line with these requirements may I draw your attention to the need for you to provide the following documentation/notifications to the R&D Department throughout the course of the study and that all amendments (including changes to the local research team) need to be submitted to R&D in accordance with guidance in IRAS:-

- ❖ Annual Progress Report Form (sent to you by this department)
- ❖ End of Study Declaration Form (available on IRAS website)
- ❖ Changes to study start and end dates
- ❖ Changes in study personnel

Please note that the NHS organisation is required to monitor research to ensure compliance with the Research Governance Framework and other legal and regulatory requirements. This will be achieved by random audit by our department.

I would like to take this opportunity to wish you well with your research. If you need any further advice or guidance please do not hesitate to contact us.

Yours sincerely



Dr Darren Clement
R&D Manager – University Hospital of North Staffordshire NHS Trust

Cc Mr Sankaran Narayanan, Chief Investigator
Dr Andrew Stewart, Clinical Director
Catherine Warwick, Information Governance Manager

Initial Notes/Patterns	Lines (post N')	Initial Codes	Theme Cluster	Provisional name	Theme
Feel involved	1-20 (17), 2-10 (90)	Active participation	Patient involvement	How the processes and characteristics of SDM are visible online, between patients	Extending the characteristics of SDM to an online peer community
Participating in the group	1-9 (30), 1-6 (100)	Patient control			
Give confidence	3-12 (41), 7-9 (2)	Scaffolding	Enhancing self-esteem		
Comfort and support	5-16 (176), 8-12 (130)	Reassurance			
Motivational preaching	12-19 (211), 1-3 (199)	Hope			
Feeling distressed	3-12 (164)				
Positive feedback					
Providing knowledge	4-19 (301), 1-4 (200)	Informing			
Views and opinions	8-11 (318), 1-14 (12)	Perceptions	Access to knowledge		
Help and advice	1-7 (252), 5-17 (70)	Experiences			
Personal Stories		Science-based decisions			
Evidence based information					
In the same position	5-19 (77), 6-16 (1)				
Your case is similar to mine	1-14 (33), 4-10 (112)	Proximity	Identification process		
Relate to other patients	19-21 (200), 16-20 (3)	Self association			
Not embarrassed to talk to others	20-28 (285)	Mutual agreement			
Consensus in views	12-18 (152)	Social interaction			
multi-way conversation		Social bonds			
Social connection					
Given a choice	5-9 (18), 9-15 (126)	Treatment decision-making	Types of decision-making	Examples of SDM taking place/ experienced online	Experiencing SDM online
I have to decide	5-10 (220), 13-19 (81)				
Treatment decisions					
Hair loss decisions	21-24 (261), 11-18(1)	Side-effect decision-making			
QOL decisions	19-249(231), 1-14 (16)				
Can't make up my mind					
Not sure if I have made the right choice	15-12 (67), 1-9 (322) 7-19 (290), 4-16 (141)	Indecisiveness Problem solving			

It is entirely your choice	1-12 (19), 3-10 (180)	Battle for control Patient influence Patient-centred care	Patient authority	How awareness to SDM and its process are promoted online	Ways to enhance SDM
You can challenge the doctor					
Patient centred care					
Patient rights					
It's your body	1-16 (99), 1-21 (144)	Patient involvement Two-way process	Patient participation		
Good doctor-patient relationship					
Ask questions					
Two-way communication					
Engage to increase knowledge					

IRAS Version 1

Reference: 12/NW/0140

2nd December 2011



University Hospital of North Staffordshire



NHS Trust

K E E L E
UNIVERSITY

Keele University, Staffordshire, ST5 5BG.
Telephone: (01782) 733669

Dr M Brunt
University Hospital of North Staffordshire
City General
Newcastle Road
Stoke-on-Trent
Staffordshire
ST4 6QG

Tel: 01782 672565

- / - /2011

Dear.....,

I am writing to inform you about a research project at the Cancer Centre of the University Hospital of North Staffordshire. The project aims to explore the experience of shared decision making during initial consultation with me. This will be achieved by examining the tape recordings that are part of the initial consultation with me. We would therefore like to invite you to participate in our research.

We have enclosed some more information about the project and we would be grateful if you could read it. If you are willing to take part in the project, please could you sign and date the invitation form, and return it in the FREEPOST envelope provided.

On agreeing to take part in the study, you will be contacted by a member of the research team, Miss Neda Baniamer, who will thoroughly go through the information leaflet and give you the opportunity to discuss participation and answer any questions. If you are willing to participate by lending us your cassette tape we will send out further documentation.

Finally, you do not have to take part in the project if you would prefer not to, it will not affect your care in any way.

Yours sincerely,

Dr M Brunt MBBS, FRCP, FRCR

Consultant Clinical Oncologist

IRAS Version 2

Reference: 12/NW/0140

18th March 2012



University Hospital of North Staffordshire **NHS**
NHS Trust

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Dr M Brunt

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ST4 6QG

Tel: 01782 679906

Patient Information Sheet

Project Title: Examining the process of shared decision making between patients and a clinician in initial breast cancer consultations.

You are being invited to take part in a research study. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with friends and relatives if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Part 1 Tells you the purpose of this study and what will happen to you if you take part.

Part 2 Gives you more detailed information about the conduct of the study.

PART 1- The purpose of the study / what will happen if you take part

What is the purpose of the study?

Patients who have surgery following a diagnosis of breast cancer often have to face difficult decisions about their further treatment. Although cancer management is governed by specific clinical guidelines, many decision making processes remain complex for patients. Even with a choice of treatment, many feel they lack control or involvement in decisions to manage their health. Consequently, medical professionals need to be aware of the important impact of decision making processes and active patient participation.

This research represents the first comprehensive examination of the role of shared decision making during a clinical consultation in the management of patients diagnosed with breast cancer. The research will help by providing information on the importance of a patient's role in shared decision making and involvement during the management of their breast cancer, for use by physicians and other health professionals. Findings from the study will be integrated into clinical practice and as a consequence will help physicians and promote breast cancer patients' health and well-being.

Why have I been asked to take part?

Some patients selected randomly who have recently seen Dr Brunt to discuss management of breast cancer are invited to participate.

Do I have to take part?

No. It is up to you to decide whether or not to take part once you have read this information sheet. If you do, we would like you to sign the invitation form enclosed and send it back in the FREEPOST envelope provided. *You are still free to withdraw at any time, even during or after the study itself, without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care you receive.* If you change your mind after you have sent in your recorded consultation cassette, then please contact a member of the research team within 10 days, and we will remove your data accordingly.

What will happen to me if I agree to take part?

If you agree to take part in the study:

- (5) A member of the research team (Neda Baniamer) will contact you to go through the information leaflet, give you the opportunity to discuss participation, and answer any questions that you may have.
- (2) You will be then sent further documents in the post which ask you to provide and send back written informed consent to participate. Also we ask you for your consultation audio cassette recording which you would need to put into the self addressed envelope provided.
 - *Nothing else is expected from your participation (i.e. you will not need to travel anywhere, will not actively take part in an interview/questionnaire, and will not be observed during consultations)
- (3) The cassette will be analysed by the research team.
- (4) In approximately 4-6 weeks you will receive your original cassette recording back to you by post once the research team have completed with its transcription. A summary of the research findings will be sent to you when available. This will be accompanied by a call from the research team to ask if you understand the findings, as well as to talk about any questions or feelings you might have regarding your participation.

What do I have to do?

On acceptance of releasing your cassette for research purposes, you are required to send this to the research team, along with full consent. The aim of analysis is to give us a clear picture of the degree of decision making, control and patient involvement which occurs during the consultation.

Will I receive any payments or reimbursement of expenses for taking part in this research?

As you are required to send documents and the cassette in the post, it will be ensured that all postage cost is paid for through the use of pre-paid envelopes provided. You receive no payment for taking part in the research.

What are the possible disadvantages and risks of taking part?

There are no risks associated with this research. Your participation will not affect the medical care you receive in any way. Though it is unlikely, your audio-cassette could be lost e.g. in the post.

What are the possible benefits of taking part?

The research will help to develop a greater understanding of patient involvement in decision making processes in the treatment for breast cancer, for use by physicians and other health professionals. Therefore, it can contribute to improving the overall quality of life for women with breast cancer, and increasing patient satisfaction with the level of the care received. As a participant, you will help in achieving those goals

What happens when the research study stops?

When we have collected enough cassette recordings from patients, the research team will transcribe the audio cassettes and read through them carefully. This will be done at Keele University. We will identify key areas which worked particularly well for the patient, and areas which could be done differently to improve the service provided. The results will be presented in the form of a report.

Will my taking part in the study be kept confidential?

Yes. All the information about your participation in this study will be kept confidential. The details are included in Part 2.

This completes Part 1 of the Information Sheet.

If the information in Part 1 has interested you and you are considering participation, please continue to read the additional information in Part 2 before making any decision.

PART 2 - Further information

Is there an independent contact point where I can seek general advice about taking part in research?

The Patient Advice and Liaison Services (PALS) is a hospital service, available to give independent advice on any queries you have about your rights as research subjects or information about being involved as participants in a research study.

What if there is a problem?

If you are unhappy with any aspect of this study, please tell a member of the research team who will contact you and try to rectify the problem. Alternatively, you can contact a member of the research team at any other time who will do their best to answer your questions (see contact information below). If you remain unhappy about the research and/or wish to raise a complaint about the way you have been approached or treated during the course of the study, please write to Nicola Leighton: Research and Governance Officer, Research and Enterprise Services, Dorothy Hodgkin Building, Keele University, ST5 5BG. Tel:01782 733306, Email: n.leighton@uso.keele.ac.uk

Will my taking part in the study be kept confidential?

Several procedures will be carried out to safeguard you and confidentiality. These include:

- (6) Dr Brunt is aware that some of his patients will be contacted. However he will not know who participates and sends in their cassette recordings for analysis. All information which is collected about you during the course of the research will be kept strictly confidential. Only the research team at Keele University will have access to the cassette and listen to it, and no one outside of the research team will have access to any of the information gathered except the report.
- (7) Only the original cassette will be used for analysis. No copies will be made of the cassette, and the original will be sent back to you.

- (8) Analysis of the cassette will take place in a secure confidential area at Keele University by the research team only.
- (9) The transcript collected will contain no identifying features. You will be given an identification number only. Where data or direct quotes are used they will be anonymised. Any publication material arising from this research will contain no information identifying patients or medical staff, besides Dr Brunt as a named author.
- (10) Computers which store the data will be password protected, and all data will be kept in a secure environment, at Keele University. The transcription of your cassette will only be read by the research team and by Dr Brunt (though he will be unaware of which patients through anonymisation), not by or any other member of your medical team. After the feedback report has been produced, the transcripts will be kept as secure confidential records for a maximum of 3 years. After this time, all transcripts will be destroyed.

What will happen to the results of the research study?

The research findings will be presented to the oncology staff at the University Hospital of North Staffordshire. All participants will be presented with a written summary report, with an opportunity to comment on these results. The work will be submitted in fulfilment of a PhD in Psychology at Keele University. We intend to publish in academic journals and presentations at conferences.

Who is organising and funding the research?

The project is being run by Keele University: Research Institute for Social Sciences, Centre for Psychological Research

Who has reviewed the study?

The Research and Development Department, The University of North Staffordshire, Dr Darren Clement, Tel: 01782 554334

The Research and Development Department, Keele University, Nicola Leighton, Tel: 01782 733306

North West (Greater Manchester East) Research Ethics Committee, Elaine Hutchings, Tel: 0161 6257820

Contact Details- Research Team

Chief Research Investigator: University Hospital of North Staffordshire, Dr Brunt- Tel: 01782 672565.

Principal Research Investigator: Keele University, Miss Neda Baniamer- Tel: 07743450239, email: n.baniamer@ilcs.keele.ac.uk

PhD Academic Supervisor: Keele University, Dr Sally Sargeant- Tel: 01782 733289, email: s.j.e.sargeant@psy.keele.ac.uk.

Thank you for taking the time to read this information sheet. If you think you would like to take part, please sign and return the enclosed invitation form in the FREEPOST envelope provided.

IRAS Version 1

Reference 12/NW/0140

2nd December 2011



University Hospital of North Staffordshire



NHS Trust

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INVITATION FORM

Title of Project: Examining the process of shared decision making between patients and a clinician in initial breast cancer consultations

Name of Principal Investigator: Miss Neda Baniamer

Please initial each statement

1. I confirm that I have read and understand the information sheet dated 2nd December 2011 (version 1) for the above study.
2. I have had the opportunity to consider the information, ask questions if needed and have had these answered satisfactorily.
3. I understand that my participation to release my recording is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.
4. I agree to be contacted to arrange for my recording tape to be sent for research anal

Signed:..... **Date:**.....

Print Name:
.....



Patient Identification Number:

CONSENT FORM

Title of Project: Examining the process of shared decision making between patients and a clinician in initial breast cancer consultations

Name of Principal Investigator: Miss Neda Baniamer

Your clinical consultation recording cassette will be analysed by the research team, examining your views and experiences of your involvement in the decision making processes through the course of your treatment. Before consenting to send in your cassette, it's important to understand why the research is being conducted and what it will involve for you. So please ensure you have read the information leaflet carefully, and have all questions answered thoroughly. You will be given a copy of this information sheet and your signed form to keep.

If you are interested in participating to release your cassette for research purposes, **please initial next to each statement and sign below**. If you are not interested, this will not affect your treatment in any way.

1. I confirm that I have read and understood the information sheet. I have also had the opportunity to ask questions and have had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected in any way.
3. I understand that my participation in this research will have no bearing on my medical treatment and will not be included in my medical notes.

4. I agree to my cassette being transcribed and analysed for the researcher's notes.
5. I understand that my cassette and transcription based from it is confidential, to be seen/heard only by the research team.
6. I understand that relevant sections of any of my medical notes and data collected during the study, may be looked at by responsible authorities and individuals from the research team, where it is relevant to my taking part in this research. I give permission for these individuals and authorities to have access to my records.
7. I agree to allow anonymised direct quotes to be included in the research write up. I understand that all data collected about me during this study will be anonymised before it is submitted for publication.
8. I agree to take part in this study

_____	_____	_____
Name of Patient	Date	Signature

_____	_____	_____
Name of Person taking consent (If different from patient)	Date	Signature

_____	_____	_____
Researcher	Date	Signature

When completed, 1 for patient; 1 for research file

Demographic Questionnaire

Can you please complete the following demographic information.

1. What is your gender (Please tick)

- Male
- Female

2. What is your age (Please tick)

- Under 22
- 22– 29
- 30 – 39
- 40 – 49
- 50 – 59
- 60 – 69
- 70 and over

3. To which one of these ethnic groups would you say you belong? (Please tick ONE box only)

a. WHITE

- British
- Irish
- Any other White background

b. MIXED

- White and Black Caribbean
- White and Black African
- White and Asian
- Any other Mixed background

c. ASIAN OR ASIAN BRITISH

- Indian
- Pakistani
- Bangladeshi
- Any other Asian background

d. BLACK OR BLACK BRITISH

- Caribbean
- African
- Any other Black background

e. CHINESE OR OTHER ETHNIC GROUP

- Chinese
 - Any other ethnic group
4. Do you have any of the following long standing conditions? (Please tick all that apply)
- Deafness or severe hearing impairment
 - Blindness or partially sighted
 - A Longstanding physical disability
 - A learning disability
 - A mental health condition
 - A long standing illness such as HIV, diabetes, chronic heart disease or epilepsy
 - No, I do not have any other medical condition
5. What is your marital status (Please tick)
- Married
 - Divorced
 - Widowed
 - Separated
 - Never been married
 - A member of a unmarried couple
6. What is your employment status (Please tick)
- Employed
 - Self-employed
 - Out of work
 - A homemaker
 - A student
 - Retired
 - Unable to work

THANK YOU FOR YOUR HELP TODAY

Jefferson transcription symbols

Transcription Element	Meaning	Transcription Element	Meaning
□ or □	Marked rise (or fall) in intonation	:::	Sounds that are stretched or drawn out (number of :: indicates the length of stretching)
<u>Underlining</u>	Used for emphasis (parts of the utterance that are stressed)	[]	Overlaps, cases of simultaneous speech or interruptions.
UPPER-CASE LETTERS	Indicate increased volume (note this can be combined with underlining)	□ word □	Shown when a passage of talk is noticeably quieter than the surrounding talk
.hhh	A row of h's with a dot in front of it indicates an in breath. Without the dot an out breath	=	When there is nearly no gap at all between one utterance and another
(comment)	Analyst's comment about something going on in the talk	(.)	Small pauses
> word <	Noticeably faster speech.	<word>	Noticeable slower speech
?	Rising intonation at the end of an utterance	(1.4)	Silences (time in secs)
'	Continuing intonation	•	Closing or stopping Intonation
-	Sharp cut off		



Health Research Authority

NRES Committee North West - Greater Manchester East

3rd Floor, Barlow House
4 Minshull Street
Manchester
M1 3DZ

24 February 2012

Telephone: 0161 625 7820
Facsimile: 0161 625 7299

Dr Adrian Murray Brunt, Consultant Clinical Oncologist
The University Hospital of North Staffordshire
City General Hospital, Cancer Centre
Newcastle Road
Stoke on Trent
ST4 6QG

Dear Dr Brunt

Study title: Examining the process of shared decision making
between patients and a clinician in initial breast cancer
consultations

REC reference: 12/NW/0140

The Research Ethics Committee reviewed the above application at the meeting held on 21 February 2012 and would like to thank Miss Baniamer for attending the meeting to discuss the study.

Discussion

Miss Neda Baniamer was asked about the statement that the study is prospective and, following discussion, acknowledged that it should correctly be described as retrospective.

Concerns about your position in the study as you will, in effect, be both a participant and key collaborator and your consultation style could impact on the study. Miss Baniamer said that as a safeguard, you will not be named as co-author of the report on the study. She was asked to be vigilant about the potential for bias in the study and to take all possible measures to counteract this.

The answer in the application form regarding arrangements for non-English speaking participants was questioned. Miss Baniamer said that as participants had already had a consultation with Dr Brunt, they were known to be competent in English. This point was accepted, but Miss Baniamer was asked to be aware of the possibility of a need for a translator and discuss this further with you to ensure fair treatment of potential participants.

The use of cassettes was queried since these will be provided to participants but as cassettes are no longer in general use, it is anticipated that few people will have means of listening to them. The possibility of digitally recording every consultation and then selecting from these recordings was mooted. The recordings could then be provided to participants in a more secure manner than is proposed in the application. Miss Baniamer was asked to raise this with you for further consideration.

Ethical opinion

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, **subject to** the conditions specified below.

Ethical review of research sites

NHS Sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study:

Standard condition

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations.

Additional conditions

Information sheet

- i. This should give the correct name of the reviewing Research Ethics Committee under the heading 'Who has reviewed the study?'
- ii. The contact details for complaints should include a telephone number and e-mail address.

Consent form

- i. Point 6 should include 'authorities' as well as individuals from the research team in line with the standard paragraph.
- ii. It should have a final point: 'I agree to take part in this study'.

SUGGESTIONS

It is strongly recommended that you give consideration to the following:

- a. When providing the results of the study to participants, it needs to be ensured that these are presented in an understandable way.

- b. Care should be taken that any participants who may need a translator are provided with appropriate assistance so that all participants are treated fairly.
- c. Consideration should be given to using a more accessible means of recording the consultation since few people are likely to have access to means of playing a cassette recording.
- d. If cassettes are to be used, security should be improved for example by using recorded delivery or courier services rather than standard post.
- e. Care should be taken to ensure that there is no bias in the study, in view of the fact that Dr Brunt is in effect a participant and a key collaborator in the study.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Please notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. Confirmation should also be provided to host organisations together with relevant documentation.

Approved documents

The documents reviewed and approved at the meeting were:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Covering Letter		02 February 2012
Evidence of insurance or indemnity		21 July 2011
Investigator CV	Dr A Brunt	
Investigator CV	Dr S Sargeant	
Investigator CV	Miss N Baniamer	
Letter of invitation to participant	1	02 December 2011
Other: Invitation form	1	02 December 2011
Protocol	1	05 December 2011
REC application	3.4	
Referees or other scientific critique report		25 October 2011

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

12/NW/0140

Please quote this number on all correspondence

With the Committee's best wishes for the success of this project

Yours sincerely




Mr Francis Chan
Chair

Email: elaine.hutchings@northwest.nhs.uk

Enclosures: List of names and professions of members present at the meeting
"After ethical review – guidance for researchers"

Copy to: Nicola Leighton, Research & Enterprise Services, Keele University
Dr Darren Clement, R&D, The University Hospital of North Staffordshire

University Hospital of North Staffordshire 
NHS Trust

RESEARCH AND DEVELOPMENT DEPARTMENT

North Staffordshire Medical Institute
Hartshill Road
Hartshill
Stoke-on-Trent
ST4 7NY

Telephone: 01782 554334
Fax: 01782 554610

Email: Darren.Clement@uhns.nhs.uk
research.governance@uhns.nhs.uk

Ref: DC/hr

04 July 2012

Miss Neda Baniamer
School of Psychology
Dorothy Hodgkin Building
Keele University
ST5 5BG

Dear Miss Baniamer

Re: Examining the process of shared decision making between patients and a clinician in initial breast cancer consultations

Chief Investigator: Dr Murray Brunt

Sponsor/Co-sponsor: Keele University

I can confirm that the above project has been given NHS Permission for Research by the Research & Development Department for the University Hospital of North Staffordshire NHS Trust and the details entered on to the R&D database.

I note that this research project has been approved by NRES Committee North West – Greater Manchester East – 12/NW/0140

NHS permission for the above research has been granted on the basis described in the application form, protocol and supporting documentation. The documents reviewed were:

Document	Version Number	Date
Protocol	1	05 December 2011
Patient Information Sheet	2	18 March 2012
Consent Form	2	18 March 2012
Contract/Agreement	N/A	N/A

REDA ID: 5163 UKCRN ID: N/A CSP ID: N/A REC REF: 12/NW/0140

The research sponsor or the Chief Investigator, or the local Principal Investigator at a research site, may take appropriate urgent safety measures in order to protect research participants against any immediate hazard to their health or safety. The R&D office should be notified that such measures have been taken. The notification should also include the reasons why the measures were taken and the plan for further action. The R&D office should be notified within the same time frame of notifying the REC and any other regulatory bodies.

Approval by the R&D Dept therefore assumes that you have read, understand and agree to comply with the:

- ❖ Research Governance Framework (www.doh.gov.uk/research)
- ❖ Data Protection Act
- ❖ Health and Safety Act
- ❖ ICH Guidelines on good clinical practice
- ❖ All applicable Trust policies & procedures


In line with these requirements may I draw your attention to the need for you to provide the following documentation/notifications to the R&D Department throughout the course of the study and that all amendments (including changes to the local research team) need to be submitted to R&D in accordance with guidance in IRAS:-

- ❖ Annual Progress Report Form (sent to you by this department)
- ❖ End of Study Declaration Form (available on IRAS website)
- ❖ Changes to study start and end dates
- ❖ Changes in study personnel

Please note that the NHS organisation is required to monitor research to ensure compliance with the Research Governance Framework and other legal and regulatory requirements. This will be achieved by random audit by our department.

I would like to take this opportunity to wish you well with your research. If you need any further advice or guidance please do not hesitate to contact us.

Yours sincerely



Dr Darren Clement
R&D Manager – University Hospital of North Staffordshire NHS Trust

Cc Chief Investigator: Dr Murray Brunt
Sponsor: Professor Ann Hughes, Keele University
Clinical Director: Dr Andrew Stewart
Catherine Warwick, Information Governance Manager

REDA ID: 5163 UKCRN ID: N/A CSP ID: N/A REC REF: 12/NW/0140