

Shared decision making – rhetoric and reality: women’s experiences and perceptions of adjuvant treatment decision-making for breast cancer

Abstract

This interview-based study uses phenomenology as a theoretical framework and thematic analysis to challenge existing explanatory frameworks of shared decision making (SDM); in an exploration of women’s experiences and perceptions of SDM for adjuvant treatment in breast cancer. Three themes emerged: i) women’s desire to participate in SDM, ii) the degree to which SDM is perceived to be shared, and iii) to what extent are women empowered within SDM. Studying breast cancer patients’ subjective experiences of adjuvant treatment decision-making provides a broader perspective on patient participatory role preferences and doctor-patient power dynamics within SDM for breast cancer.

Key words

Breast cancer, shared decision making, patient experience, qualitative methods, phenomenology.

Introduction

Health literature over the past 40 years has reported changes in the ideology and practice of medical decision-making. In between the ‘paternalistic’ and ‘informed patient’ models stands a consumer or ‘shared’ model of decision-making, which in recent years has become more explicit in modern healthcare systems. This cultural shift in decision-making is in response to changes in the ethical notions of patients’ rights to be fully informed and autonomous participants in their treatment decisions (Breitsameter, 2010; Siminoff et al, 2010). Sharing decisions, as opposed to health professionals making decisions on patients’ behalves, has gained prominence in healthcare policy (Department of Health, 2010; O’Connor et al, 2007). “*No decision about me without me*” (Coulter and Collins, 2011; Department of Health, 2010) promotes a more patient-centred healthcare system through the practice of shared decision making (SDM), which is endorsed by UK clinical guidelines (NICE, 2004, 2012). SDM, originally proposed by Charles et al (1997), is defined as an interactional process between the health professional and patient, characterised by mutual engagement and participation, in which information is shared in a context that acknowledges the different values and preferences of both parties (Elwyn et al, 2012; Elwyn and Charles 2001; Towle and Godolphin, 1999).

The concept of SDM has been suggested as the prevailing approach for doctor-patient treatment decision-making in breast cancer (Chewning et al, 2012), and is shown

largely to be associated with adjuvant rather than surgical treatment (Mandleblatt et al, 2006) Women with breast cancer can face several challenging and important preference-sensitive decisions (i.e. when more than one treatment option is available and there is no “best” choice for everyone). Decision-making for adjuvant treatment can often be difficult for breast cancer patients due to the combination of several therapeutic options available (e.g. chemotherapy, radiotherapy, hormone therapy, or no additional therapy). Decision-making can also be complex as the choice depends largely on the estimated risk of relapse. The degree of benefit, in terms of disease-free survival and overall survival, is also uncertain.

A small proportion of breast cancer patients choose either a completely ‘passive’ or completely ‘active’ role in decision-making (Elkin et al, 2007; Say et al, 2006; Vogel et al, 2008). The past decade has seen an increase in breast cancer patients’ preferences for more ‘collaborative’ decision-making roles (Brown et al, 2012; Deber et al 2007; Hubbard et al, 2008; Sabo et al, 2007; Singh et al, 2010; Tariman et al, 2010), with SDM shown to improve breast cancer patients’ quality of life and satisfaction with treatment (Anderson et al, 2009; Ashraf et al 2013; Joosten et al, 2008; Lam et al, 2014; Mandelblatt et al, 2006; Sabo et al, 2007). However, there is a paucity of research about the use of SDM in breast cancer care. Charles et al (2004) reported a cross-sectional study exploring oncologists’ perceived barriers and facilitators to implementing SDM in breast cancer. Key barriers identified were lack of time, information and patient

unwillingness to participate, and facilitators included patients' emotional readiness, support, information and trust in their oncologists. Similarly, Mandelblatt et al (2006) conducted surveys with older women with breast cancer and oncologists to describe determinants of SDM, and to evaluate whether SDM is associated with treatment patterns and outcomes of care. They showed greater association between SDM and adjuvant treatment, and improved patient short-term satisfaction with treatment. While both of these studies are useful in demonstrating the effectiveness and benefits of SDM in breast cancer care, they give a limited view of the SDM experience itself. As SDM is a subjective interaction between two people, more critical approaches and qualitative methods are needed to examine the decision-making processes for women. The missing component within the existing literature on SDM and breast cancer is how women conceptualise SDM, and the extent to which they perceive decision-making as being shared. A unique opportunity exists to highlight SDM processes as experienced and viewed by patients in this clinical speciality. To address this gap, this paper explores women's experiences and perceptions of SDM for adjuvant treatment in breast cancer.

Method

Design

Semi-structured interviews were conducted with a purposive, homogeneous sample of women, with resulting transcripts analysed using thematic analysis (Braun and Clark, 2006). The study is informed by descriptive phenomenology (Husserl, 1970) as an ideal theoretical framework and methodology for a deeper understanding and insightful description of the ‘lived’ experience. Phenomenology, as a discipline, 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). In line with a critical health approach, phenomenology is argued to be a reflection on conscious experience rather than subconscious motivation, and is designed to uncover the essential invariant features of that experience (Jopling, 1996). Descriptive phenomenological research places emphasis on the ‘pure’ description of people’s experiences, by describing meanings with depth and richness at the descriptive semantic level. The purpose of this study was to embark on an intense analysis of the descriptions and ‘lived’ experiences of SDM for adjuvant treatment, as provided by women with breast cancer.

Participants and recruitment

Twenty women aged >18 years (mean age 57, range 40-73), who had undergone adjuvant treatment following breast cancer surgery, in a National Health Service (NHS) hospital outpatient breast cancer unit, were recruited. The women had completed all adjuvant treatment two years prior to being approached to participate, to help ensure levels of relative physical and emotional stability following diagnosis. Supplementary file 1 provides additional information on participant treatment profiles and demographics.

Potential participants were identified through screening of patient records by the breast cancer nurse specialists. A sample of 50 women who attended the breast cancer adjuvant treatment follow-up clinic were first told about the study by their oncologist, and invited to take part. Those who agreed received written information about the study and were asked for written consent. Twenty (40%) women agreed to participate, nine (18%) declined, and the remaining 17 (34%) did not respond. The main reasons given for non-participation were time constraints. No further attempts were made to recruit more participants, as the researchers determined that thematic saturation was reached and no additional information or variations of a given theme in the data was forthcoming (Chamberlain, 1999; Miles and Huberman, 1994). Ethical approval was granted by the local NHS Research Ethics Committee, and guidelines prescribed by The

British Psychological Society (2014) were used to inform ethical practice throughout the study.

Interviews

Semi-structured interviews were conducted on a face-to face basis at the outpatient breast unit. All women were aware that the interviewer was an academic researcher rather than a health care professional. Interviews lasted between 45 and 60 minutes, were audio recorded and transcribed verbatim. Pseudonyms were used in all notes, transcripts and analyses. Practical recommendations and guidelines for interviews in qualitative research were observed (Howitt, 2010; Smith, 2008), and best practice regarding data handling was followed (Department of Health, 2005).

A schedule of broad open-ended questions provided a framework to guide discussions about women's experiences and perceptions of breast cancer adjuvant treatment decision-making in general, and more specifically on SDM. Questions about adjuvant treatment for breast cancer assessed women's knowledge about the quality, quantity and sources of information received. The women were also asked about their adjuvant treatment choices and their level of involvement in the decision-making process. Some questions focused specifically on their understanding of SDM, for example, "what does SDM mean to you?" It is important to clarify that the women were never given a definition of SDM; rather, they were asked an open-ended question and given the

opportunity to take the question in any direction they wanted (Clandinin and Connelly, 2000). The women were also asked about their relationship with the oncologists, including experiences of doctor-patient interaction, disagreement and partnership. All questions in the schedule were formulated to facilitate the women's descriptions of their own experiences of decision-making, while exploring in-depth issues related to doctor-patient relationships and communication, patient participation, and the process of SDM.

Data analysis

Braun and Clarke's (2006) thematic analysis approach was employed to identify themes relating to women's understandings and encounters of SDM. Analysis was inductive, whereby concepts and categories emerge from the data. Transcripts were read several times by NM to gain familiarisation of each individual's account, and initial patterns were noted. The data was subjected to 'open coding', involving a close reading of each transcript and the division of portions of text into specific units of meaning (codes). This involved identifying where and how patterns occur and searching for connections across the data. Following the production of an initial set of codes, a thematic table (supplementary file 2) was produced to present the main themes. Themes were identified by collating components of ideas or experiences (codes) together, which often appear meaningless when viewed alone, to form a more detailed account of the women's experiences and perceptions of SDM. A second review was undertaken by SS

to assist with the contextualisation of the themes, as reflected in the findings, and to cross-examine all themes identified. Themes were then named. Reflexive commentary during the analytical stages was engaged by both authors through the use of a reflexive diary, as a measure of quality assurance (Willig, 2008).

Results

Thematic analysis revealed three main themes across all transcripts: 1) women's desire to participate in SDM, 2) the degree to which SDM is perceived to be shared, and 3) to what extent are women empowered within SDM. These themes provide broader subjective insights about breast cancer patients' experiences and perceptions of SDM for adjuvant treatment.

Theme 1: women's desire to participate in SDM

All of women in the study illustrated an 'active' role, in that they described a sense of personal control or ownership over the extent to which they desired to participate in decision-making. In describing their desired degree of involvement, the women demonstrated contrasting participatory roles preferences. The majority displayed an 'active-collaborative' role, where they preferred to be involved in treatment decision-making and to participate in SDM, whilst a minority illustrated an 'active-passive' role by choosing to disengage from treatment decision-making and the process of SDM.

Most of the women who demonstrated an ‘active-collaborative’ role, wanted to be informed, and were keen to discuss their treatment options and share their opinions. They actively chose to participate in decision-making, and preferred to make their treatment decision in collaboration with the oncologist through the process of SDM:

I wanted to take part in decision-making, have discussions and ask questions about the different treatments so I could better understand my options. But when it actually came down to deciding which treatment was best for me, I decided to share that task with my oncologist. I think it's a difficult one to make on your own and I am happy I decided to make it with my doctor. I felt much supported that way. Choosing to share the responsibility of decision-making made the task so much easier. [Jane]

Jane describes her ‘active’ desire to be involved in treatment decision-making. She explains the importance of information and increased knowledge about her treatment options, which she was able to obtain through her decision to engage in discussions with the oncologist and ask questions. However, she indicates that due to the complexity of decision-making, and in order to make the “best” decision, she personally opted for a ‘collaborative’ and shared approach to decision-making. By choosing to participate in SDM with the oncologist, she was satisfactorily able to share the responsibility of the task, and receive the support needed to make an “easier” decision.

Other women actively choose to remain ‘passive’ in decision-making and showed little interest to participate in SDM:

When I got diagnosed, I was given a big information booklet which I didn't look at. I had so many opportunities to have a say, to discuss the options with my oncologist and be a part of decision-making process, but I didn't want to. I didn't want to absorb any knowledge that could worry me more. [...]I chose not to be involved in decision-making full stop, let alone share decision-making. I totally avoided having those conversations together, and just let him decide. [Charlotte]

Charlotte illustrates an ‘active- passive’ participatory role. She explains that even though she was presented with many opportunities to be involved or to collaborate in treatment decision-making with the oncologist, her ‘active’ preference was to remain ‘passive’. For some women, similar to Charlotte who displayed ‘active-passive’ traits, increased treatment knowledge was regarded as an emotional burden, adding further fear and anxiety. Instead they took a defensive approach to decision-making, where ignorance is bliss. Charlotte demonstrates this further in her account, as she describes how her main goal was to restrict the amount of information acquired, through avoiding shared conversations with the oncologist. She withdrew herself from decision-making and instead situated the oncologist as the decision-maker. Her ‘passive’ participatory role preferences meant that participation in SDM was of no significance or appeal to her.

Theme 2: the degree to which SDM is perceived to be shared

The majority of women showed good understanding of SDM, and identified two characteristics associated with the process: ‘two-way interaction’ and ‘information acquisition’. The process of SDM was often described by some of the women in relation to key subjective terms, such as equal, mutual, and sharing. However, there appeared to be a discrepancy between how they described these SDM particulars, and how they represented the process of SDM in reality.

For some of the women who had to decide over several adjuvant treatment options, SDM was largely perceived as a mutual or equal process. They reported that SDM is most feasible through doctor-patient collaboration, which involves sharing of ‘two-way interaction’ and ‘information acquisition’:

For me, shared decision making was a discussion. For example, if the consultant suggests a certain treatment would be the best route for me to go down, but I wasn't sure, then we would have a mutual conversation together to come to an informed agreement or decision. So shared decision making is an equal 50/50 process. I ask, he explains. I query, and he suggests. Through this back and forth process together we shared information and reached a decision. [Judy]

Judy refers to the importance of ‘two-way interaction’ and ‘information acquisition’, in the face of decisional uncertainty. She defines SDM as “50/50”, “equal” and reciprocal

process between doctor-patient, where the oncologist's purpose is to identify and explain information, and the patient's is to query and share their concerns. This perceived "mutual" process of two-way communication and information sharing is viewed by Judy as a seemingly equal weighted route towards decision-making. It appears that although, on the surface, Judy perceives decision-making to be equal, it is far from constructed as a symmetrical process in practice. There is no indication that Judy "explains or suggests", or that the oncologist "asks or queries". There appears to be little "50/50" balance in terms of 'information acquisition' and 'two-way interaction' as far as decision-making.

Understanding of SDM was also evident in some of the women who were not given a choice in their adjuvant treatment course. Most of these women valued having full understanding of their treatment, as determined by the oncologist. They too made a reference to the terms sharing and 'information acquisition' as key components associated with SDM:

I wasn't given a decision to make. I was told I had to have chemotherapy because of my cancer grade. But not having a choice didn't bother me. I was happy because I was well informed, and I think that's really important. [...]When I saw the oncologist, he explained everything to me about the treatment. For me, shared decision making is being explained what is going to happen. By the doctor sharing all his knowledge with

me, and allowing me to know all I needed to know, that's what makes it a shared decision. [Paula]

Paula's treatment was determined by the oncologist due to her cancer type. This was not viewed as problematic, as it appears that the process of explanation maximised her satisfaction with the treatment. Later in her account, Paula defines SDM as a process of 'information acquisition' which involves the oncologist "*sharing*" all available information about her treatment. In Paula's case, the oncologist is therefore sharing everything on a decision that has already been made for her. It appears that although the oncologist is "*allowing*" her to be informed, there is no indication of 'information acquisition' being reciprocated by the oncologist. The process appears to be one-way, with no evidence of Paula being allowed to share information (i.e. her views and values) with the oncologist. With a lack of 'two-way interaction', how would the oncologist know how much information Paula "*needs*" to know? This account reflects a lack of two-way processes and sharing in decision-making.

Theme 3: to what extent are women empowered within SDM

Some of the women's accounts brought insight into the roles and positions that women and oncologists take during SDM. Many held an objective view of a perceived discrepancy in doctor-patient power relations, which appeared to discourage patient empowerment and SDM in practice.

For some of the women their oncologist was viewed and labelled as a problem solver with a duty of care. There was a strong belief that the oncologists had more discretion over decision-making due to their hierarchical status and ascribed role as a medical healer. This expedited an imbalance in doctor-patient power-relations for SDM:

It was hard to share the decision. I always put all my confidence and trust into the doctors. I believe in these people and their role as medical professionals and decision-makers. I mean, everyone knows that if there is something medically wrong with you, it's the doctor's responsibility to put you right. [...] I remember he said to me "It's my job as your doctor to give you the best possible chance of survival". [Sandy]

Sandy's account illustrates the differential roles and power struggles that exist in doctor-patient relationships. She refers to her oncologist as the "decision-maker", and an authoritative "professional" with healthcare responsibilities. On the contrary, she regards herself (i.e. the patient) as a spectator of care and someone who puts trust in their oncologist's role. She defends this view by illustrating it as a societal attitude and expected norm of behaviour. Later in her account, she describes how the oncologist reinforces this normative view and her subjective assessment of the differential roles, by emphasising his "job" as a medical healer, linked to maximising patient "survival". Sandy explains that an objective disparity in doctor-patient roles, arguably, makes SDM difficult to achieve.

As well as perceived discrepancy in roles, some of the women also described an objective discrepancy in medical knowledge and skills between the doctor and patient, which became the product of women's detachment from SDM:

I just have basic knowledge of breast cancer. I'm a believer that if you're the health professional then you obviously know and can decide what is best. Cancer isn't like a cold...it requires medical expertise and skills to treat. So I was in no position to make any big decisions. [...]It's the doctor's call. He's the expert, which made it difficult to share any decision. [Louise]

Louise describes how she felt unqualified to make any important treatment decisions. She heightens the doctor-patient power imbalance by referring to her normative belief that the oncologist is “*the expert*” and the person who “*knows and decides what is best*” for her. This arguably repositions Louise, in relation to the oncologist, as someone of “*no position*” and less power, which further reinforces any perceived role differentials. Towards the end of Louise's account, she explains how such objective disparity in doctor-patient expertise left very little room for SDM to occur.

Discussion

This study confirms previous findings that women with breast cancer can have identifiable participatory role preferences in decision-making (Elkin et al, 2007; Say et al, 2006; Vogel et al, 2008), with the majority preferring a ‘collaborative’ approach (Brown et al, 2012; Deber et al 2007; Hubbard et al, 2008; Sabo et al, 2007; Singh et al, 2010; Tariman et al, 2010). In contrast to these studies, which illustrate ‘active’ and ‘passive’ roles dichotomously, our findings suggest that both of these roles can be presented as two poles of dialectic. For example, choosing to be ‘passive’ was an ‘active’ decision for some of the women in our study. Our findings introduce the terms ‘active-passive’ and ‘active-collaborative’, and is the first to add new knowledge regarding the contribution of these roles to women’s encounters of SDM for adjuvant treatment in breast cancer.

The women all described their participation in decision-making with personal sense of ‘active’ ownership, which is, as one that they felt was right for their participatory role preference. Those who actively chose to remain ‘passive’ in decision-making (‘active-passive’) supported a ‘paternalistic’ model of decision-making, in comparison to the majority of women who actively chose to collaborate and engage in SDM with their oncologist (‘active-collaborative’). This suggests that while a ‘collaborative’ approach to decision-making is popular and may be desirable, it is by no means universally held by all women with breast cancer. The women showed mixed attitudes towards participation

in SDM, and this suggests that SDM is not a fixed preference in this clinical context. Despite the opportunities presented by oncologists for ‘active-passive’ women to engage in SDM, many chose to remain submissive as it took the burden of decision-making away from them. Converging with other evidence, one reason identified was that they wanted to avoid negative information about their prognosis (Kvåle and Bondevik, 2008).

The implications for practice drawn from these findings indicate that even in today’s patient-centred health care climate, it cannot be assumed that all women with breast cancer want to participate in the adjuvant treatment decisions of their breast cancer care. Until further research is conducted and more is known about breast cancer patients’ motivations regarding SDM, oncologists should be sensitive to individual patients’ role preferences, and to assess the extent they desire to be involved in SDM. Oncologists may need training to better conceive patients’ preferences and information needs, and patient-centred communication skills might be useful to meet this task.

Some of the women in this study understood the fundamental principles of SDM, and began to show what is regarded as valuable content within a SDM conversation i.e. ‘information acquisition’, and how it should be managed i.e. through ‘two-way interaction’. These findings suggests that breast cancer patients acquire understandings of SDM that are aligned with UK clinical guidelines (NICE, 2004, 2012), and associated with literature on the frameworks of SDM (Charles et al, 1997; Elwyn et al, 2012; Elwyn and Charles 2001; Towle and Godolphin, 1999). Understanding of SDM

was also apparent for some of the women who were not given treatment choice. This suggests that breast cancer patients' subjective experience of SDM is not dependent on whether there are adjuvant treatment options available.

In describing the two characteristics of SDM, both groups of women (with or without treatment choice) drew particular attention to subjective terms, such as mutual, equal and sharing. Deeper critical interpretation of their subjectivity suggest that what is perceived as a shared process of 'information-acquisition' and 'two-way interaction', constituting towards an encounter of SDM, appears in reality to be a less balanced, asymmetrical and, even for those who are not presented with treatment options, a one-way process. In this clinical context, should the ultimate goal for SDM in breast cancer care be equality? If so, who determines what constitutes a shared or mutual decision-making process? In circumstances where women have no choice, should the oncologists have more say, or should women be supported and empowered in their ability to use the information acquired to contribute to the decision? Our findings draw attention to some of the questions and dilemmas that appear to exist in the process of SDM for adjuvant treatment in breast cancer. To better understand these issues and the mechanics of SDM during adjuvant treatment consultations, it is recommended for future research to take a discursive or symbolic interactionist approach to explore the objective conversations and 'talk-in-interaction' between doctor-patient for SDM, as this is currently omitted from the existing SDM and breast cancer literature.

Discussions about the power dynamic involved in SDM remained at the periphery of the process for some of the women in this study. They cited the value of equality in SDM, but also alluded to the reality of the intrinsic power dynamics during SDM (Frosch et al, 2012; Joseph-Williams et al 2014). The concept of SDM is designed to empower patients to become more involved in their healthcare (The Health Foundation, 2013). However, the findings from this study suggest that SDM for adjuvant treatment in breast cancer does not match this ideology. Inequality and power imbalance within SDM was shown to be a result of the objective discrepancy in medical expertise and roles between the doctor and patient. This finding adds an important dimension to theoretical constructions of SDM for breast cancer, as there currently appears to be a misalignment between the goals of oncologists and the rhetoric regarding women's empowerment during adjuvant treatment decision-making. This provides momentum for further research to examine the relatively unexplored area of patient empowerment and SDM for breast cancer, as this critical aspect is often omitted in the SDM literature. It is a worthy recommendation for future research to explore women's empowerment by applying a feminist perspective that takes power differentials in gender into account. The women in this study all referred to the oncologists as a male, with no mention of female oncologists. It would therefore be of further interest to qualitatively explore the impact of gender on doctor-patient relationship and SDM for breast cancer. Until more knowledge arises in this area, the challenge remains to promote attitudinal change and

self-efficacy in women. Professional education in communication skills and training interventions are recommended to encourage oncologists to empower women within SDM. Patient education regarding doctor-patient collaborative working and patient-centred care would also be of value. The Department of Health's (2001) "Expert Patient" programme, based on the work of Lorig et al (2001) is one example of such an initiative.

Limitations should be acknowledged. All women included in this study were white British and over the age of 40. It is recognised that women from different races, ethnic backgrounds and ages, especially younger women, may have different perceptions and experiences of SDM, or expectations of their care. The interview schedule may have been directive, with women probed to say the words "SDM" in describing their decision-making experience. The questions asked could also be criticised for being myopic, as the interview schedule only yielded positive evaluations of SDM and did not explore patients' negative experiences or suggestions for improving the SDM process. This study, however, contributes to an emerging body of literature on SDM in breast cancer care, and is among the first to examine SDM through the theoretical framework of phenomenology. It provides valuable insights into women's experiences and perceptions of SDM for breast cancer adjuvant treatment. More qualitative research, using critical approaches, will positively contribute to advance the knowledge and recognition that patients and healthcare providers have on SDM for breast cancer. As

this paper only focuses on the adjuvant treatment stage of breast cancer, it is recommended for future research to explore patients' experience of the SDM process for breast surgical and reconstructive treatment. A social constructionist perspective would be of value for a better understanding of the broader and critical issues surrounding societal attitudes towards women's bodies and breast removal, which may be pertinent to women's experiences of SDM.

Conclusion

From this sample of women, the findings suggest that breast cancer patients are readily able to identify their preferred level of involvement in SDM. SDM was not a fixed preference, as desire to participate was greatest among those who displayed an 'active-collaborative' participatory role, than those who were 'active-passive'.

The majority of women showed understanding of SDM in line with clinical guidelines and existing frameworks of SDM. They described characteristics and terms associated with SDM, such as 'information acquisition', equal, and 'two-way interaction'.

However, their subjectivity did not equate to a 'shared' decision-making encounter in reality. Many also described an unequal power imbalance within SDM due to an objective discrepancy in doctor-patient knowledge and role expectations. For SDM to become more of a reality in the adjuvant treatment phase of breast cancer practice, future implementation attempts should consider these patient-reported experiences. To

further advance understanding of SDM for breast cancer, more qualitative research with critical approaches is needed to explore SDM across the whole breast cancer treatment trajectory, and to examine the objective process of SDM.

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