Participation in treatment decision-making by women with early stage breast cancer

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Abstract

Objective This study aimed to assess the way women treated for early stage breast cancer perceived the treatment selection process. The purpose was to understand more fully patients' experiences of the decision process and their preferences for participation in treatment decisions.

Setting and participants The study informants were 40 women, treated at a teaching hospital in Sydney Australia, who were interviewed face to face 1 year after their first treatment for stage I or stage II breast cancer.

Methods This study used a qualitative approach, based on the analysis of interview transcripts. The main areas covered were how the informants' treatment decisions were made and their preferences for participation in treatment decisions. Content and thematic analyses were conducted with findings presented using verbatim quotations for illustration.

Results and conclusions Many of the informants who preferred not to participate in decisions also failed to recognize the need for value judgements (as well as medical expertise) in the decision-making process. Some informants believed they ought to be responsible for the consequences whilst others did not. Difficulties were identified in patient utilization of medical information for treatment decision-making, and also in establishing preferences for the risks and benefits of treatments where few patients had prior experience of the potential outcomes. The findings indicate that patient participation in treatment decision-making is a more complex issue than simply giving patients information and choices. Ways of enhancing patients' involvement in the treatment selection process are discussed.

Introduction

The two main treatment options currently available for early stage breast cancer (mastectomy or breast conserving surgery with radiotherapy), whilst producing similar survival outcomes,¹ have a different quality of life impact.²⁻⁹ Clinical criteria alone do not favour one treatment, and so patient participation in choice of treatment is frequently advocated.^{10,11} However, the issue of patient participation in decision-making is a complex one.¹² This paper reports a study of treatment decision-making in early stage breast cancer from the patient's perspective. The study uses qualitative methods to examine the experiences of a group of women who had treatment for early stage breast cancer and identifies some important issues for informed patient decision-making.

Studies examining individual preferences for participation in treatment decisions have generally found that most people want to be well informed about their illness and treatment, but have produced varying results with regard to preferences for participation in decisions.¹³⁻²³ Most of the studies failed to specify what was meant by participation in decisions, making their results difficult to interpret. In one study,²⁴ of early stage breast cancer, the main reason given for wanting to participate in the treatment decision was to retain control over body and life, whilst the main reason given for not wanting to participate was faith in medical expertise. This latter reason fails to differentiate between the various aspects of treatment decision-making, and the treatment decision in early stage breast cancer in particular, where value judgements must be made between various potential effects on quality of life (for example the psychological impact of breast loss versus risks of physical side-effects from radiotherapy). Deber *et al.*²¹ separated the elements of the decision into those requiring medical knowledge and expertise, and those requiring knowledge of patient values and preferences for potential outcomes of the alternative treatment plans. This allowed respondents some understanding of what their

potential role in decision-making might be and, whilst few wanted to participate in those aspects of the decision-making which required medical expertise (such as diagnosis and identifying treatment options and their risks and benefits), most wanted to participate in deciding which treatment options to use.

As part of an evaluation of treatment modalities for early stage breast cancer in a setting where patient choice is advocated, it was necessary to evaluate how the treatment decision-making worked in practice from the patient's perspective. As the role an individual plays in a decision depends on many variables related to the interactions between participants and the interpersonal styles of the individuals involved, quantitative methods alone would have been inadequate to provide a sufficiently detailed account of the decision-making process and its context. Qualitative methods were seen as the most appropriate way of identifying patients' perceptions of the role they had played in their decision and what role they would have preferred.

Methods

Individual face to face interviews, using a semi-structured interview schedule,²⁵ were conducted with a consecutive subsample of 40 women participating in a quantitative study of quality of life after treatment for early stage breast cancer at a large teaching hospital in Sydney, Australia. The women were invited to participate in an interview after returning a questionnaire 1 year following primary treatment. The interviews took place in the informants' homes, were audio-tape recorded and later transcribed for analysis. Two of the authors (PK and SC) each carried out interviews with 20 informants. One interviewer was a health services researcher with a background in nursing and public health, whilst the other was an occupational therapist with extensive interviewing experience in both qualitative and quantitative research.

The interview schedule covered three main content areas: how the informant's treatment

decision was made, her preferences for participation in treatment decisions, and the information sources she used. The first question asked how the informant found out that she had breast cancer. In most cases she then told her story with little need for prompting, describing the process of diagnosis, medical referrals, learning about breast cancer treatment, the way the treatment decision was made and the subsequent treatment experience. Probe questions were used to prompt discussion of a topic not covered, for clarification or for further detail.

The interview transcripts were analysed by their content and themes.^{26,27} The transcripts were coded and sorted using the three main content areas (listed above) as major categories, with subcategories developed from the data in order to identify the primary patterns in the data. The two interviewers independently coded all 40 transcripts. The coded transcripts were then compared, discrepancies discussed and a final coding solution agreed by the two interviewers. The emerging themes were then considered. A sample of eight transcripts was read by another author (SQ), a qualitative researcher with a background in sociology, as a check on the interviewers' interpretation of the data. The thematic categories (and linked issues within these) were further refined through discussion with the remaining author (AS), a health economist familiar with decision-making literature from economics and psychology.

Informants in this qualitative study had similar socio-demographic characteristics and treatment details to participants in the quantitative study. Informants' ages ranged from 25 to 80 years (mean 56 years). Over a third (15) had a post secondary school qualification. Whilst all were English speaking, two spoke a language other than English at home. The breast cancer treatment received was mastectomy for five informants and breast conserving surgery with radiotherapy for the remaining 35. Four informants also received cytotoxic chemotherapy, whilst a further 10 informants received hormone therapy with Tamoxifen. The treatment pathway and medical practitioners involved in the treatment decision-making process varied between

participants. The treatment pathway was initiated through a breast screening unit with a multi-disciplinary approach for 18 informants, and through referral from a general practitioner to a surgeon for the remaining 22.

The issues arising from the interviews for patient participation in treatment decision-making were grouped under the four main themes identified in the analysis: preferred role in treatment decision-making, responsibility for the consequences of the decision, assimilating technical information, and establishing preferences for the risks and benefits of the treatments. The results are presented in terms of these four themes.

Results

Preferred role in decision-making

In order to have a preference regarding participation in treatment decision-making, a patient must have an understanding of what role she might realistically play in that decision. Some informants did not appear to have contemplated the notion of participation in decision-making, and the way they described the selection of breast cancer treatment suggests that some doctors may not have discussed this with their patients. For these informants treatment decision-making involved seeking and following medical advice, as the following quotation illustrates:

I relied on [the surgeon] to tell me. He's the man with the knowledge. And I asked him did he want to remove it? And he said definitely not. There is no need. So I went with [the surgeon]. That was good enough for me. He's the one with the years of experience and that was good enough for me, I didn't challenge that at all.

Several informants did not understand that choice of treatment incorporated an element of value judgement and thought that their lack of medical knowledge and expertise precluded their participation in treatment decision-making. This reliance on medical expertise was also linked to their trust or faith in doctors. The following are examples of responses from these informants

when preferences for participation in treatment decision-making were discussed:

I don't know anything medical... I trust the doctors. Who else can you trust?

Well I feel that, being a layman, I feel that you should first have faith in your doctor. If you're happy with your doctor, then you should ask him which type of treatment would be best for you and just go with his expert opinion.

A further (although not unrelated) reason some informants gave for not wanting to participate in treatment decision-making was their concern that they might make the 'wrong' decision. There were also some informants who, although wanting their doctors to make their treatment decisions, wanted some involvement. The involvement they wanted consisted of either having their views considered or being prepared to question the doctor if necessary.

Many informants thought that they ought to participate in their treatment decision-making. Whilst knowledge of their own preferences was a reason given by some, many also thought it was important to take responsibility for their own bodies. Others thought it necessary to think for themselves because doctors were not infallible and sometimes disagreed with each other. The following quotes illustrate these issues:

Well at least I'd be having treatment that I was agreeable to and not what somebody else wanted me to have.

I think you should be comfortable with your treatment. I find if you ask opinions of this doctor and another doctor, but I think in the end it has to be your decision because, it's your life and if something goes wrong you can't blame anyone but yourself.

I think that the old days of trusting the doctor implicitly are gone... We've got a doctor team here, they both agree to differ. So what do you do? You've obviously got to do a lot of thinking for yourself.

The idea of patient values and preferences, although not raised explicitly, is implied by two of the informants quoted above in terms of having treatment with which they agreed or were

comfortable. This was not mentioned by the informants who did not want to participate in treatment decision-making, unlike the issues of 'trust' and 'responsibility' which were discussed by both groups (those who did and those who did not want to participate in decision-making).

Responsibility for the decision consequences

The idea of blame or responsibility for the consequences of the decision was raised by several informants, both those wanting to participate in treatment decision-making and those who did not. Those wanting to participate in decision-making generally thought that they ought to take responsibility for the outcome of their decision and not blame others should things go wrong, whilst those not wanting to participate in decision-making thought that they might make the wrong decision and felt it was too much responsibility. The following quotes illustrate each viewpoint:

I could say 'No I don't want that' when it could be important. So I just always leave it in the doctor's hands.

I think it should be a 50-50 decision. He can advise you and then it's up to you... Because then you can't put the blame or anything back onto the doctor or anything because it was your decision.

Some informants raised this issue in the context of the decision-making process they experienced prior to breast cancer treatment. The following statement was made by a 40-year-old woman who was not told about mastectomy as an alternative to radiotherapy until she saw the radiation oncologist, having already had breast conserving surgery in two operations. She opted for radiation rather than another operation. After seeing relatives die following cytotoxic chemotherapy, this informant was reluctant to have it when it was recommended for her. She was eventually persuaded after seeking a second opinion:

Well I must admit I agreed to it all in the end. So, I can't ever blame anything back onto a doctor.

Despite this somewhat tortuous decision-making process, she believed that, by agreeing to

her treatment, the consequences became solely her responsibility.

Another informant who discussed responsibility in the context of her own experience chose mastectomy, to avoid travelling for radiotherapy and to avoid the possibility of further surgery in the future (should the cancer recur). This 79-year-old woman found the decision-making very difficult and, although well informed by doctors, she felt that neither her doctors nor her family would help her to choose. The following quotation illustrates her concerns about the effects of having made the decision, had she been unhappy with the outcome:

...I was quite happy about the decision... If I would be sorry that I had chosen the wrong decision, I wouldn't be so happy probably. I would think, 'Oh if only'... It's too much responsibility.

This theme gives rise to two important points for patient participation in treatment decision-making. One is the notion of shared decision-making and the extent to which the question is structured for patients in terms of the input (and thus the relative responsibility) of medical expertise and patient value judgements. The second is the purpose of encouraging patient participation in treatment decision-making and whether it is for the benefit of patients, or merely to shift the burden of responsibility.

Assimilation of technical information

Information about treatment was important for all informants. Patients who wished to participate in treatment decision-making wanted access to the appropriate information on which to base this decision. Those who did not want to participate in treatment decision-making generally wanted to understand the reasons for the treatment their doctors selected on their behalf. The way informants described their experience of treatment decision-making pointed to some of the difficulties associated with communicating information about treatment options. Whilst some of the informants who said they had been offered a choice of treatment demonstrated a good understanding of the treatment options for early stage breast cancer, others did not. Some

of these informants described the choice they made as between two surgical treatments (mastectomy or lumpectomy) without reference to radiotherapy, as the following quote illustrates:

He explained to me that I could have had a complete mastectomy or a partial. And I said 'What's the difference?' And they explained there was no difference. It's just a matter of choice.

Another informant had not realized that radiotherapy was usually only required for breast conserving treatment:

I somehow thought, maybe it went over my head with all my other worries at the time, that I would still need radiotherapy if I had the breast off.

Both these cases point to the importance of the way the choice is structured when it is presented to the patient. The information should be formulated in terms of the risks and benefits that are being traded when either path is taken. The choice between having a breast with axillary lymph nodes removed and having a lump with axillary lymph nodes removed is clearly a different proposition when the risk of side-effects from radiotherapy is added to the latter option (although radiotherapy may occasionally be indicated after mastectomy, this is not routinely recommended as was the case with lumpectomy in our research setting).

Related to this issue is the importance of understanding, not only which treatments are being traded, but their implications. Some informants, whilst accurately describing the treatment options from which they chose, also described the outcome of the two options as the same. However, whilst mastectomy and breast conserving treatment have similar survival rates in early stage breast cancer, the quality of life outcomes and lifestyle impact are potentially quite different. It is possible that, as with the informant quoted above, this is an issue of absorbing only part of the information. Most informants made their treatment choice soon after learning their diagnosis and it is likely that they were extremely anxious and focusing on survival at this time. Whilst some informants appeared to have been encouraged to decide quickly (some within 24–48 h) by their surgeons'

scheduling, many informants preferred to have their surgery as soon as possible (including women who understood that this was not necessary on clinical grounds).

Another issue in assimilating information is the difficulty of interpreting probabilistic information and the meaning that individuals attach to risk probabilities for themselves. One informant discussed the difficulty of interpreting statistics and the difference made by the way they are framed:

And then the most confusing thing is when they start giving you statistics... But to me statistics always sort of weighed up on how you want to put them across. You can look at it that you know – 20% chance of this and you can reverse it and there's an 80% chance that you won't... It depends I suppose how you want to look negative or positive about it.

One informant, who now regrets her decision to have breast conserving treatment, discussed the problems presented for decision-making by the risk of less common treatment side-effects. She thought that it would not happen to her because she had never heard of anyone having this problem:

He said 'You can get radiotherapy damage. It doesn't happen to many people. But it can affect the lung and the trachea and bones'... I think if they showed you people who had radiotherapy damage. But when you have no evidence, you think 'Oh well, that's okay' and can be quite casual... I wish I'd never had the radiotherapy because I'm now left in this limbo. I don't think, I'd recommend for anyone to have it.

It would be easy to dismiss this as a form of *post hoc* rationalization. However, it does point to two important issues. One is the complexity of treatment decision-making and the strategies people use to simplify the task. The other is the translation of population risk to individual cases and the difficulty faced by clinicians in deciding how much emphasis to place on side-effects with a low probability, although of a severe and long-term nature.

Establishing preferences for risks and benefits

Treatment decision-making frequently involves choosing between therapies with multiple

potential outcomes with different probabilities. Usually patients have little or no previous experience of these outcomes (in themselves or others). Therefore it can not be expected that, by simply informing them of the potential outcomes and their probabilities, they will instantly know what their preferences are. Two main issues were identified in this theme. The first is that an individual may place a high value on more than one of the different aspects of health and well-being which are being traded and may therefore find it difficult to make a choice. The other is the difficulty for individuals to predict how they might adapt to situations of which they have no experience.

The following quote illustrates some of the aspects of health and well-being which are traded when deciding between mastectomy and lumpectomy with radiotherapy. Even with hindsight an individual may have difficulty deciding which is her preferred option. This informant, whilst unhappy about the continuing side-effects of radiotherapy, did not think she would have coped emotionally with breast loss:

I'm pleased I got to keep the breast. Very pleased. I think I would have been more emotionally devastated if I did lose it... When I've looked into it, the ray's more long-term affecting... They did tell me that the ribs could become brittle. But every day you're conscious of it because of a pain or discomfort within the left side. You can't forget it.

Several informants, who initially had fears about mastectomy, felt differently about it after undergoing treatment and meeting other women who were coping with a mastectomy. The following quote is an example:

At that stage just the thought of the mastectomy really, really scared me. I just couldn't live with the thought of it. But now, after going through what I've been through and seeing other women and what they've gone through as well. It's not that bad after all if you really want to live.

This 27-year-old informant pre-empted discussion of her treatment options by telling her doctors she would not have a mastectomy and consequently had breast conservation. She later changed her opinion about mastectomy, illus-

trating the importance of shared experience to enable individuals to identify their preferences.

Discussion

This study of treatment decision-making in early stage breast cancer has identified several important issues for patient participation in treatment decision-making more generally. Whilst some patients preferred not to participate, there was little recognition of the need for value judgements in the decision-making process and whose values ought to be considered. Responsibility (or blame) for the consequences of the decision was discussed, with some informants believing they ought to be responsible and others not wanting this. However, shared responsibility was not mentioned in this context. Difficulties were identified for patient utilization of medical information for treatment decision-making, as well as for establishing preferences for the risks and benefits of treatments where few patients had prior experience of the potential outcomes. Together these indicate that patient participation in treatment decision-making is a more complex issue than simply giving patients information and choices. Much work is still needed to develop appropriate ways to implement this.

Several methodological points should be discussed. Firstly, this is a study of the patient's perspective on the treatment decision-making process and therefore relies solely on informants' recollections of events. The timing of the interviews, 1 year after the initial treatment decision was made, means that memory recall is likely to have decreased over this time. However, this timing means that informants were not in the highly stressed emotional state they might have been at the time of the decision. They will also have recovered from short-term treatment effects which may have been given undue emphasis if interviewed whilst still undergoing treatment, or soon after. The study quality would have been improved by repeated interviews with informants to follow-up specific issues in more detail and to clarify others, but resources were not available for this. The small

number of informants who were treated by mastectomy, whilst similar in proportion to the larger sample from which they were selected, may mean that the full range of issues was not identified. However, this does not detract from the merit of the issues the study did identify, many of which are consistent with the work of other authors.

In an earlier qualitative study of patient participation in treatment decision-making for breast cancer, Pierce²⁸ developed a model which outlined three decision-making styles: 'deferrer', 'delayer' and 'deliberator'. Deferrers tended to defer to a powerful authority (doctor), delayers opted for the treatment which offered an advantage based on some minimal criteria, whilst deliberators had a strategy and considered many aspects of the differing treatments before finally making a decision. However, simply grouping women based on these three styles does not explain why they use the different approaches to decision-making, or whether any particular approach is more likely to achieve a satisfying outcome. The findings from the current study support the concerns discussed by Guadagnoli and Ward²⁹ that patient typologies (such as that described by Pierce) should not be used to justify a paternalistic decision-making approach for patients who appear reluctant to participate in treatment decisions or who express a desire not to participate. Many of the informants in the current study who did not participate in treatment decision-making, or who expressed a preference not to participate, also made statements which indicated that they were unaware of the need for non-medical judgements in the decision. Not all patients want to participate in treatment decision-making. However, participation is not a meaningful option for those who have no knowledge or expectation of anything but a passive patient role. Thus it is necessary for health care professionals to ensure that patients are made aware of the extent to which the final decision relies on both medical expertise and subjective value judgements.

Charles *et al.*¹² advocated a model of shared treatment decision-making which fits somewhere between the two extremes of a paternalistic

model dominated by the doctor and informed patient choice which gives ultimate control, but also responsibility to the patient. In the current study, some of the informants who wanted to participate in treatment decision-making also thought that they ought to be responsible for the consequences. However, some informants were concerned about this responsibility, feeling that dissatisfaction with the outcome might be more difficult to deal with when they were responsible for their own decisions. According to Bell,³⁰ anticipating and attempting to avoid regret can be an important factor in decision-making under conditions of uncertainty. Prior to the decision, an individual may be prepared to trade-off potential benefits in order to avoid subsequent feelings of regret after the decision outcome is known. It is possible that some patients attempt to avoid regret at making the wrong treatment decision by deferring to the doctor's choice. It is also possible that, whilst not all patients are willing to accept responsibility for the consequences of their treatment decision, some might find this less onerous if both the decision-making and responsibility are explicitly shared (between doctor and patient).

The complexities of patient participation in treatment decision-making go beyond willingness or desire to participate and take responsibility. Even when willing to participate and well informed, patients will not necessarily know their preferences for the risks and benefits of the available treatment options. Problems can arise from the way individuals interpret the probabilistic information necessary for treatment decision-making, as well as from the meaning they attach to risk. According to Gifford,³¹ lay individuals experience risk as personal uncertainty and denial is one way they may attempt to regain control. Thus, they can ignore the risk until some experience causes them to change (makes them believe it could happen). In the current study, one informant felt that she was able to ignore the small risk of rare but severe side-effects because she had never heard of anyone having these. She now regrets her decision. Her concern to see concrete evidence of people with the problem, in order to believe that

it could happen to her, is in keeping with the judgmental heuristic of 'availability' described by Tversky and Kahneman.³² They identified three judgmental heuristics used by individuals to simplify the evaluation of decision components. 'Availability' is when judgements about the probability of uncertain events may be distorted by the ease with which instances of the event can be brought to mind. A slightly different example of 'availability' was identified by Charles *et al.*³³ where women with early stage breast cancer assessed their chances of survival negatively because of knowing others who had died from cancer. Gifford also noted that the translation of epidemiological/scientific knowledge (derived from studies of populations) for individual patient management causes difficulties because of the lack of certainty in predicting the outcome for any particular case. A challenge for doctors is deciding the extent to which less common side-effects should be emphasized in the shared decision-making process.

Lack of experience with the potential outcomes of the treatment options also creates problems for establishing preferences for treatment options. In their discussion of the measurement of the values of individuals, Fischhoff *et al.*³⁴ argued that where the issues are unfamiliar and complex, it is likely that individuals will hold unformulated or conflicting values. For some informants in the current study, the uncertainty about their preferences due to conflicting values appeared to persist 1 year later (as dissatisfaction with the long-term side-effects of radiation therapy, whilst still believing that they would not cope psychologically with mastectomy). Lack of experience of the potential outcomes also makes it difficult for patients to predict how their feelings may change in the future. Redelmeier *et al.*³⁵ argue that people fail to anticipate how their preferences will change over time, because of the uncertainty of human adaptation. Many informants in the current study were extremely fearful of mastectomy prior to their treatment. However, this changed for some of these women, after their own treatment experience and learning about the experiences of mastectomy from women they met at the hospital.

There are several matters arising from this study which point to the need for improvements in the process for making treatment decisions, in order to facilitate patient satisfaction with both the decision-making process and the outcome of treatment. The areas where the process can be enhanced include the way individuals are invited to participate in the process (making the need for value judgements and sharing of responsibility explicit), the extent to which they are assisted to an adequate understanding of the treatment alternatives and their implications, as well as assistance to identify their preferences and to anticipate how these might change over time.

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