

The information and decision support needs of older women (>75 yrs) facing treatment choices for breast cancer : a qualitative study

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Title: The information and decision support needs of older women(>75 yrs) facing treatment choices for breast cancer: a qualitative study

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Background

Breast cancer affects 13,000 UK women over age 70 annually and causes the deaths of 6,733 per year [1]. Patients over 70 years of age have seen less than half of the reduction in breast cancer mortality compared to younger women [2].

The standard care for early breast cancer is surgery [3]. However, some older women may be judged too frail or ill to tolerate surgery and may be offered primary endocrine therapy (PET) for oestrogen receptor (ER) positive breast cancer. This is the use of anti-oestrogen tablets, omitting surgery altogether. Approximately 40% of women in the UK, over the age of 70, are treated with PET [4]. Randomised trials have shown that PET has equivalent overall survival rates when compared to surgery (and adjuvant endocrine therapy), although rates of local disease control are inferior and therefore appropriate patient selection is important [5,6].

No guidelines are available to aid clinician or patient choice between surgery and PET in the treatment of older women. The decision is therefore both medically complex and potentially sensitive as it may involve discussion of life expectancy and trade offs of reduced cancer control in return for reduced surgical morbidity (pain, disfigurement, etc.).

There is some published research regarding the information needs of older women with breast cancer. The most important include the likelihood of cure and the risk of metastatic spread [7,8,9,] regardless of patient age. Additionally older women request age-specific treatment and prognostic information [10,11].

Presenting complex material to people who have limited knowledge and possibly declining cognitive function is a challenge. Poor health literacy, reduced word and numeracy fluency [12] and comprehension of written information [13], impaired hearing and eyesight may impact on an older person's ability to access and assimilate information. This in turn may affect their ability to make an informed treatment decision [14]. Two studies have reported that older women undergoing cancer treatment want information in the form of booklets with brief explanations of the risks and benefits of treatment which include clear diagrams and are free of medical terminology [10,15].

There is limited evidence of the preferences for treatment decision making in older women with breast cancer [16,17]. There is a trend for older patients to prefer their clinician to make the final treatment decision and this trend increases with age [18, 19].

A previous study [20] indicated that older women faced with a choice of surgery or PET for the treatment of breast cancer relied heavily on the health care professionals (HCPs) for

treatment information and reported listening for hints from the medical team to detect what treatment was being suggested. The main concerns were disfigurement, the impact on their independence following surgery and a general fear of hospitals and operations. These women demonstrated complete trust in the HCPs recommendations which is likely to be a product of the paternalistic view this generation have of the health service.

Although just under half of older women (>70 years) in the UK are treated with PET [4] there are few resources to aid in making a choice between surgery or PET. Breast Cancer Care, a charity devoted to patient information has no guidance on this choice for older women (<http://www.breastcancercare.org.uk/>). Similarly there are no specific NHS leaflets with information for older women faced with a choice of surgery or PET.

The following multicentre UK study aimed to determine the information needs and preferences for this age group of women relating to the choice between surgery and PET. The ultimate aim being to use this evidence to develop decision support for this underserved group.

Methods

Research ethics approval was obtained from the National Research Ethics Service (12/LO/1722) and research governance approval from 5 UK hospitals. Women were eligible if they were ≥ 75 years, (the lower age at which PET is predominantly used), had been diagnosed with invasive breast cancer in the preceding 60 months and offered an initial treatment choice between PET and surgery (documented in the medical records). Eligible women were invited to take part in semi-structured interviews either when attending clinics or by letter. An interview topic guide was developed from the literature with input from members of the North Trent Cancer Network Consumer Research Panel [21]. Topics included: sources of information they used, desired or would have preferred, factors that influenced their treatment choice, how and who made the treatment decision and their views on computers/the internet/CDs & DVDs in information gathering.

Informed written consent was obtained from all participants. The interviews were digitally-recorded and transcribed verbatim. The Framework approach was used to analyse interview data [22]. Framework analysis involves five steps, familiarisation, theme development, indexing, charting and interpretation analysis and was independently performed by two experienced qualitative researchers (MB/KC) with supplemental analysis by two patient representatives (both former breast cancer patients and members of a recognised patient group (23). Recruitment ceased once data saturation had occurred.

Results

Interviews were undertaken between, April and December 2013, with 33 purposively selected older women (median age 82, range 75-95 years) with breast cancer who had been offered a choice of PET or surgery at diagnosis. These women were between 3-60 months from diagnosis (median, 20 months). Twenty-two women received PET (median age, 83 years, range 76-91) and 11 underwent surgery (median age, 82 years, range 75-94) (9 mastectomy, (Mx) 2 wide local excision, (WLE). Interview duration ranged from 23 to 85 minutes (mean 50 minutes). The Framework analysis categorised the data into three themes:

- Theme 1- The impact of discovering breast cancer
- Theme 2 - Treatment decision making
- Theme 3 - Information – use, preferred content and format

Theme 1: The Impact of discovering breast cancer

The women interviewed either had breast cancer identified as a consequence of investigations for other illnesses or had themselves discovered changes to their breast. Some (n=17) women talked of being shocked, frightened and worried when discovering a breast lump and immediately sought medical advice.

Other women (n=11) appeared less concerned and mentioned breast symptoms only when attending their general practitioner for other reasons. Several women waited until their domestic situation changed e.g. caring for a husband, before seeking medical advice. The possibility of symptoms being breast cancer was the first thought of some women and most were fatalistic about this. As illustrated by these two participants.

'.. I thought, ‘.. I’m going to die with this, so we’ll base it round that’. (85yrs, PET)

'I just thought I have cancer and I wasn’t bothered about it because let sleeping dogs lie. The less you know the less you bother about it,.’ (90yrs PET)

Those who had experienced the death of a friend or family from cancer had distressing memories of the illness and the treatment. These experiences significantly contributed to the treatment decisions they made as seen from this extract,

'I just kept saying, ‘Do what you’ve got to do, do what you’ve got to do’. We lost a daughter-in-law with breast cancer, she was only 26, and that’s 30 years ago.. she would have still been alive if they’d have taken it off.’ (84yrs, WLE)

Theme 2: Treatment decision making

The second theme to emerge was how breast cancer treatment options were considered and decisions made among this group of women. Most (n =22) women said that they had been

given a choice and were pleased with their discussion and involvement in the decision making process.

However, others said they did not wish to make a choice themselves as they feared making the 'wrong' decision. Several women felt that treatment should be decided by the doctors who had specialist knowledge of breast cancer.

A small number of women (n=5) also reported asking the HCP which treatment option they would recommend. This resulted in either, a direct recommendation, a refusal to recommend or a subtle recommendation within the offer of a choice of two options as can be seen from these extracts.

'..you're a bit gobsmacked [when they give you a choice] you don't know what...'
well obviously, he deals with that all day and every day so I just said, 'Well what do you advise?'.I mean what do you see these people for if not to take their advice?' (81 yrs WLE)

'I said 'well I don't know, what would you do?', very diplomatically she [nurse] said 'well if I was advising my mother I would advise her to have the tablets', which I thought was a nice way of putting it without directly telling they advised so that's what I did. ' (80yrs PET)

When asked who made the final decision most women felt they had (n=24). Some had decided based on verbally received information and discussion with the HCP and so this could be seen as a shared decision. Eight women eventually had their decision overtly made for them as four has a medical condition precluding surgery and the other four could not make a decision themselves. Others (n=19) made immediate decisions on preconceived ideas of surgery or cancer often related to previous cancer treatment experience of family or friends.

Fourteen women said that they had thought about what treatment they would want or not want prior to receiving a cancer diagnosis or having a discussion with a HCP. This women was typical of some,

'... I'd already made my mind up because I knew it was cancer...– you know in my own mind and made my mind up that I was having the breast taken off.' (80yrs Mx)

It was common for women who said they had made their own decision to want the approval of the HCP for their decision. As this women said,

'He [Surgeon] seemed pleased with my decision.' (76yrs, Mx)

After arriving at a decision almost all women stated that they were either 'satisfied' or 'happy' with their treatment choice. Only one woman was dissatisfied with her treatment choice and said that in hindsight she would have chosen mastectomy instead of a WLE because she could have avoided travelling for radiotherapy.

It was evident that most women chose PET to avoid surgery. The reasons for this being, their age, feeling physically or mentally unable to withstand surgery, fear of surgery or anaesthesia, impact on independence and for a small number the belief that surgery would stimulate other illnesses. As these women said,

'I was extremely tired,...and I knew I couldn't cope with surgery. I thought if there was any alternative, I would like to go for that.' (80yrs, PET)

'..I decided the years I've got left... I'm not messing about going into hospital...'
(95yrs, PET)

Women talked openly about not being afraid of death. There was an implied assumption and acceptance amongst this group that having PET might result in them dying sooner than if they chosen surgery with many stating that they would have chosen surgery had they been younger. Women who chose PET said it had no negative impact on their lives as most of them already took regular medication so having an extra tablet was not viewed as problematic.

The words 'get rid of it' were frequently associated with women's reasons for choosing surgery. This woman's comment was typical of surgery patients:

'my reaction immediately was '*get rid of it*'...cut it off' (79yrs, Mx)

Some women chose mastectomy and not WLE to avoid further treatment particularly radiotherapy. As one said,

'Right, I said, 'let's *get rid of it*, at my age,' so I went for a full (mastectomy)]. But if I [h]adn't have had a [mastectomy] I'd have to have had radiotherapy...' (75yrs, Mx)

One patient chose surgery as she was not convinced that PET would be effective.

Several women felt they were 'steered' towards a particular treatment i.e. younger women towards surgery and older women towards PET. However, seven women had chosen not to take what they perceived to be the doctors' recommendation.

All the women interviewed stated that the information they received at diagnosis was given verbally by the clinician and for most this was supplemented by a general breast cancer treatment booklet and discussion with a breast care nurse (BCN). Some (n=14) felt they had received enough information, written or verbal, to make a decision. Whilst some reported receiving 'lots of information' in booklet form, others did not recall being given any. The women were divided in whether they read the information. Some decided they would not read it as it was frightening or they trusted the doctors and therefore had no reason to read it. A small number said they read everything (n=7). Only two women at the younger end of the age range sought further information, one bought a book about breast cancer and another used the internet.

In addition to reading the information given, being able to *discuss* treatment options with the HCPs was appreciated. Those women who were asked during the interview if they received

enough written information would respond by saying they would have liked more *discussion*. It was rare to ask for more written information.

When asked by the researcher most women found it difficult to articulate what information they needed to make a treatment decision. It was only with significant prompting and further questioning that they were able to identify items.

Theme 3: Information - use, preferred content and format

Most women, regardless of treatment choice, wanted details about the different treatment options and most importantly their impact on physical function, self-care, and the practicalities of treatment e.g. travel arrangements for appointments, prescription collection and post-op care.

Women wanted targeted information that was personal to them and presented in an uncomplicated jargon free style. As these women said,

'I didn't want to go and talk about somebody else's operation or care because that wasn't mine. I wanted to know about myself ' (87yrs, PET)

'You see if they get big words and things like that... well you lose interest don't you?' (76yrs, Mx)

Some women felt that they did not need additional information other than that received verbally from the HCPs. There was little desire for large volumes of information. As this woman said,

'.. why would you need all the other information? It's only extra worrying.' (81yrs, PET)

There was a general consensus that an information booklet comprising the advantages and disadvantages of each treatment option would have been a helpful adjunct to the understanding the options following the consultation.

During the interviews women were shown various formats of breast cancer information (booklets, option grids, DVDs, CDs, internet). Written information in the form of a booklet and an option grid were the preferred formats.

Option grids are one page tools that summarise information and compare different treatment options in a 'frequently asked questions' format, presented in everyday language (24). The women liked the succinct content and presentation style of these grids.

'.. when you've read about six pages you put it down..... and as you get older them six pages you never get past because you keep reading the same ones. By the next day you've forgotten what's saying. Yeah, that's good that because it gives you all your questions?' (94yrs, Mx)

'... I like this [option grid]. I think it is very clear.' (79yrs, Mx)

Of the women interviewed 10 stated they had access to the internet but only 5 said they used it and this was primarily for shopping or communicating with family and friends. One woman attempted to acquire additional information about treatment options. The large volume and lack of confidence in the credibility of the health information sites were cited as barriers.

When asked about finding breast cancer information this woman said:

I've got it, [internet] but I don't bother about it very much....'No, it would be the last thing I'd do [go to the internet]. (80yrs, PET)

There were also issues around having and retaining the ability to use computers and navigating the internet.

I'm on the internet and I do emails... but I'm not very good at it. (75yrs, Mx)

The CD/DVD format was not favoured by most of the women because they did not own a CD/DVD player or lacked confidence to use.

Women were shown examples of bar charts, pictograms, frequency and percentage displays and asked whether they felt these helped their understanding of the risks and benefits of treatment options. All said they did not add to their understanding and for some they were confusing or frightening.

Photographs of women post-operatively were disliked however, simple diagrams showing post-operative scars were felt to be informative.

Discussion

In line with previous studies [10,11] there was a general consensus regarding the information women required when considering different treatment options for breast cancer. Information of greatest importance was the impact of treatment on self-care and physical function. Additionally information on the timelines for treatment events e.g. dates of surgery, length of hospital stay, and the practicalities of treatment e.g. would they need care after surgery, where would they get their medication, were of high importance.

The current literature is contradictory with regard to the amount of information older women desire to facilitate treatment decisions. Some studies report that older people want less information [25], others that their information needs are similar to younger women [26]. This study found the level and amount of information desired was variable but tended towards limited amounts which was received verbally and supported by written text. In line with the findings of Jing-Wen Jong and colleagues [10] this study found women who reported having *discussed* the information they received were also likely to state that they played an active or shared role in treatment decision making. The opportunity to discuss treatment options was also associated with women expressing high levels of satisfaction with the quality of their care.

Previous studies point to older patients being more passive in decision making [4,20, 27] with a tendency to delegate responsibility to their doctors, family and friends [28,29,30]. Many of the women in this study stated that they made the final treatment decision but also reported the need for reassurance or approval for their decision from the HCPs. It is possible that their view of the decision making process represents the lack of an imposed treatment by the doctor but may still reflect the preference of the doctors or other HCP [31]. The impact of patients' choice on surgical rates in older women was investigated by Lavelle and colleagues [32] who conclude that actively opting out of surgery is unlikely to be the reason fewer older women undergo surgery. This study found older women wish to be active decision makers with women frequently reporting making an instant decision about their treatment choice either before a confirmed diagnosis or immediately after. Making a decision quickly was something that many women either felt was expected by the HCP or was a personal need to have a plan to deal with the threat and uncertainty of breast cancer [33].

Information is a pre-requisite for informed decision making [9,34,35]. Although there is a large amount of literature to inform younger women faced with treatment choices in early breast cancer there is little that addresses the specific needs of older women. All women interviewed said they had received enough information, and in line with other studies did not seek further information [7,30] but for some the written information was sometimes overwhelming (31) with much of the content not of interest to them. Faced with large amounts of unfamiliar and complex information or where decisions require high levels of cognitive processing (e.g. trade-offs), short-cuts in decision making are made [36]. To reduce the cognitive load a familiar, concrete item becomes the focus of the decision making at the expense of possibly more beneficial items being included in the decision. In this study women focussed heavily on the practicalities of treatment e.g. the need to travel for

radiotherapy, who would care for them after surgery, the need to care for a husband and ignored important factors such as the benefits of the other options-

To capitalise on the experiential style of decision making used by this group of women (36, 37,38), it is necessary to identify the most effective format, content and presentation of information. Making information more familiar and accessible by using clear, jargon-free language with the addition of uncomplicated diagrams will enhance the women's ability to make informed choices.

Simply reducing the amount of information given, making the unfamiliar more inviting, and 'tailoring' the information to the individual can help to increase patient understanding and aid in decision making. Hawkins and colleagues [19] identified the need for more specific information for older people with cancer and suggests that risk should be tailored to the individual as general statistics do not provide the desired information. However, identifying the most effective way to describe risk and benefit is difficult since the literature is conflicting. Graham et al (2009) [38] support the use of words with quantification whilst Fausset & Rogers (2012) [13] suggest percentages best communicate risk and benefit, particularly for people with a lower numeracy level, a category into which many older people are said to fall (39). In this study there is some evidence that words are preferred to numbers but the women were largely uninterested in this type of information. For most women statistics and / or graphs were not regarded as helpful, meaningful, or of interest and occasionally thought to be confusing and frightening.

It is acknowledged that a retrospective study, particularly one involving older people, will always be subject to inaccurate recall of events and details However despite this there is confidence in the data collected as many of the items raised were common amongst the women. The time lapse and the significance of the event also adds strength to the findings. The seriousness of breast cancer will make this a prominent issue in their lives and one which they appear to think of often. The time lapse also provides time to reflect on and evaluate the handling of the cancer and how it has affected their life since leading to more measured responses.

Conclusions

The findings indicate that women want clear, succinct, tailored information in a format that is familiar and easy to use. Booklets, free of medical terminology, with careful use of graphical representations and simple diagrams are required. Most importantly women want the opportunity to discuss the information with an HCP.

This qualitative study has provided a rich description of the information needs of older women faced with a choice of surgery or PET for breast cancer and provides the foundation for further studies. The information will provide the basis for the design of decision support tools for older women faced with this choice in the future.

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