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Title: Information needs and decision making preferences of older women offered a choice between surgery and primary endocrine therapy for early breast cancer.

Authors: Maria Burton¹, Karen Kilner¹, Lynda Wyld², Kate Joanna Lifford ³, Frances Gordon¹, Annabel Allison⁴, Malcolm Reed⁵, Karen Anna Collins¹,

Key words:

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Institutional affiliations:

¹ Centre for Health and Social Care Research, Sheffield Hallam University, Collegiate Crescent, Sheffield, UK

² Academic Unit of Surgical Oncology, University of Sheffield, Medical School, Beech Hill, Sheffield, UK

³ Division of Population Medicine, School of Medicine, Cardiff University, Cardiff, UK

⁴ Biostatistics Unit, MRC, Cambridge Institute of Public Health, Cambridge, UK

⁵ Brighton and Sussex Medical School, Falmer, Brighton, BN1 9PX

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Abstract

Objectives: To establish older women's (≥ 75 years) information preferences regarding two breast cancer treatment options: surgery plus adjuvant endocrine therapy versus primary endocrine therapy (PET). To quantify women's preferences for the mode of information presentation and decision making (DM) style.

Methods: This was a UK multi-centre survey of women, ≥ 75 years, who had been offered a choice between PET and surgery at diagnosis of breast cancer. A questionnaire was developed including two validated scales of decision regret and DM preferences.

Results: Questionnaires were sent to 247 women and 101 were returned (response rate 41%). The median age of participants was 82 (range 75 to 99), with 58 having had surgery and 37 having PET. Practical details about the impact, safety and efficacy of treatment were of most interest to participants. Of least interest were cosmetic outcomes after surgery. Information provided verbally by doctors and nurses, supported by booklets, was preferred. There was little interest in technology based sources of information. There was equal preference for a patient-centred or doctor-centred DM style and lower preference for a shared DM style. The majority (74%) experienced their preferred DM style. Levels of decision regret were low (15.73, scale 0-100).

Conclusions: Women strongly preferred face to face information. Written formats were also helpful, but not computer based resources. Information that was found helpful to women in the DM process was identified. The study demonstrates many women achieved their preferred DM style, with a preference for involvement, and expressed low levels of decision regret.

Introduction

A third of new breast cancer diagnoses occur in women aged over 70 years in the UK. Across all age ranges survival rates have improved with a fall in mortality of 37% since 1971 [1]. However, improvement in survival rates in older women (>70 years of age) is lower than in younger women [2]. Older women are less likely to receive standard treatment; with rates of primary surgery, adjuvant radiotherapy and chemotherapy all lower [2-4].

Current UK guidelines [5] state that primary endocrine therapy (PET) should only be offered if “significant comorbidity precludes surgery” and that age alone should not affect the decision [5]. However, PET continues to be widely used in the UK as an alternative to surgery with PET used in up to 40% of women over 70, compared with less than 6% in women under 70 [6]. Increasing age, being deemed too frail or unfit for surgery are cited as reasons for older women receiving non-standard treatment such as PET [3, 4]. Patient choice is also identified as a factor in women receiving PET instead of standard surgical treatment. Oncologic outcomes with PET are acceptable, but rates of local control are inferior to surgery and there may be a small reduction in breast cancer specific survival [7, 8]. This needs to be balanced against short term morbidity associated with surgery. Weighing such ‘trade offs’ is complex, requiring adequate information about each option and its consequences [9].

There is little research investigating information needs of older women or their preferred level of involvement in decision making (DM) about treatment options [10]. Currently, there are no resources to support women faced with a choice between surgery plus adjuvant endocrine therapy (hereafter referred to as 'surgery') and PET for early breast cancer. This study (nested within a current NIHR study 'Bridging the Age Gap' [11]) aimed to identify the information needs and preferences among women age ≥ 75 offered a choice between PET and surgery at diagnosis for breast cancer. Previously reported qualitative findings [9, 12] were used to develop the content of a questionnaire and to illuminate its analysis. The main aim of the questionnaire was to further establish older women's preferences regarding receiving information about breast cancer treatment options (surgery or PET) and quantify issues raised in the interview study [9]. A secondary aim was to quantify women's preferences regarding the presentation of information and establish their preferred DM styles.

Study Design

This was a retrospective, cross-sectional, survey of women aged ≥ 75 years who had been offered a choice between PET and surgery at diagnosis for breast cancer within the previous five years. Those with locally advanced or metastatic breast cancer or who lacked cognitive capacity to consent were excluded.

Questionnaire development [13] was based on: findings from a literature review [14], expert opinion within the research team, the input of a local patient group [15] and previous qualitative interviews [9]. The questionnaire collected data on the

information women *had* found helpful during their treatment DM, on information they *would ideally prefer*, its preferred format and source, and on the women's preferred and actual DM styles. There were a total of 57 questions split into five sections.

- 1) Patient demographics, (4 items).
- 2) Information needs prior to treatment decision, (30 items).
- 3) The process of treatment DM, including the Control Preferences Scale [16], (7 items).
- 4) Optimal DM, including the Decision Regret Scale [17], (10 items).
- 5) Preferred format, media and presentation of information, (9 items).

A combination of categorical responses and Likert scales were used for the majority of the questions. In addition there were four open response questions.

The questionnaire was piloted by the full study team which included five members of a local cancer patient support group and subsequently adapted according to their feedback to maximise content and face validity, clarity, comprehensibility, acceptability and presentation [18]. Due to the absence of related validated questionnaires, criterion validity was not assessed. As the questionnaire did not measure any abstract concepts, such as pain, construct validity was not assessed.

Sample size

Eligibility criteria included women newly diagnosed with breast cancer within the previous five years who had a treatment choice documented in their medical notes. The study population was drawn from 10 breast cancer units. This was a convenience sample from units which were stratified on the basis of high and low rates of surgery and PET. Each unit has a yearly average of 300 newly diagnosed women. Of these, approximately 25% will be over 75 years, and 85% of these will have ER+ cancers, equating to 64 eligible women per unit per year, or 3200 women in total. Based on this population size, a random sample of 344 enables estimation of proportions to within a maximum of $\pm 5\%$ with 95% confidence.

Ethics Approval

National Research Ethics Committee approval and local research governance approval was obtained.

Recruitment

Eligible women were identified by healthcare professionals (HCPs) in 10 NHS breast units across England and Wales. Women were offered a pack, including a letter inviting participation, an information sheet, a questionnaire and a freepost envelope for return. Consent was implied by the return of the questionnaire. Study recruitment commenced November 2013 and ended 31st January 2015.

Data Analysis

Statistical analysis was completed using SPSS V23 and the 'R' Stats Package. Analysis was primarily descriptive. Categorical data were presented as frequencies and percentages. Fisher's Exact test was used to identify associations between preferences and age, treatment received and level of education. (Only associations with age are reported in this paper.) In line with convention the five statements in the patients' preferred and achieved style DM tool were collapsed into three categories; doctor-centred (passive), shared (collaborative) and patient-centred (active) DM. The decision regret scale score was calculated using the developer's formula [18] (See Table 1). Data were entered by a single person and then checked and cleaned by a second.

Results

Two hundred and forty-seven women were offered a questionnaire and 101 were returned (41% response rate). Twenty-nine (29%) were in the 75-79 age group, 32 (32%) in the 80-84 age group, 22 (22%) in the 85-89 age group, 17 (17%) in the 90+ age group and one unknown (median age 82 years, range 75 – 99 years). Fifty-eight (57%) women received surgery and endocrine therapy, 37 (37%) received PET and six (6%) unknown. Seventy-six (75%) women left school at or before age 16, five (5%) left school at 18, 19 (19%) attended college or university and one unknown.

Information needs to support decision making

Women were asked to identify information that had been helpful in making a treatment decision (Figures 1a & 1b). Across all ages, information about the need for further treatment and how long tablets should be taken for were most frequently cited, 58/73 (79%) and 58/74 (78%) respectively. Items scoring lowest across all ages related to cosmetic outcomes, specifically: how the scar would look after surgery, 7/60 (12%), and whether they would look different after surgery 11/60 (18%). Less than half (28/63, 44%) of the women had found information about post treatment independence helpful. The helpfulness of information about cure rates with PET increased with age (Fisher's Exact $p=.005$). In the 75-79 age group 6/17 (35%) found the information helpful, 5/21 (24%) in those 80-84, 12/17 (71%) in those 85-89 and 9/11 (82%) in those 90+.

Source and format of preferred information

Actual information sources used by women to make treatment decisions

Additional to the information given verbally by doctors and nurses, leaflets and booklets provided by the hospital were considered helpful forms of information (57/101, 56%) by most women. Discussion with the GP (43/101, 43%), and family and friends (37/101, 37%) were also helpful. Only 6/101 (6%) reported using the internet. Sources that required reading information i.e. leaflets, booklets, magazines

and on-line materials, showed a decreasing preference with age (Fisher's Exact $p=.007$). When asked if enough information to make a treatment decision was provided, 79/91 (86%) said it was, whilst a small number, 13/91 (14%) all under 90, would have liked more.

Ideal information sources

Face to face discussion with the doctors in the breast clinic was the preferred information source (81/100, 81%) followed by a nurse (37/101, 37%) then a booklet or leaflet (33/101, 33%). Of least interest were DVDs or videos, (6/100, 6%) and internet based information (2/100, 2%). Only 5/100 (5%) did not want any information. Level of access to the internet was generally poor with only 27/93 (29%) patients owning their own computer and having internet access. 23/93 (25%) had no access to the internet, 21/93 (23%) could access the internet via others and 22/93 (24%) said they did not want to use the internet. When asked about the likelihood of future use of internet based information 57/88 (65%) responded that they were '*very unlikely*' or '*somewhat unlikely*' to use it for information related to breast cancer whilst 21/88 (23%) stated they were '*likely*' or '*somewhat likely*' to use it. Ten (11%) were unsure. However, of the 17 surgery related items a median of 3 (range 0-14) were deemed to be useful. Of the seven tablet related items a median of 3 (0-7) were deemed helpful.

Ideal information formats

The preferred format of written information regarding treatment risks and benefits across all ages was a statement in words (e.g. "breast cancer is common in women in the UK") (51/101), followed by proportion e.g. "1 in 8 women in the UK will get breast cancer". There was little interest in visual displays with only 11/101 preferring a pictogram, 10/101 a pie chart, and 9/101 a bar chart.

Preferred support during the decision making process

One eligibility criterion for the study was the women having received a documented treatment choice. However, more than half recalled being offered only one option 52/93 (56%) either only surgery or only PET, and only 40% (37/93) recalled being offered a choice.

Preference for a patient-centred (36/93, 39%) and a doctor-centred DM style (35/93, 38%) was fairly evenly split, with fewer preferring a shared DM style 22/96, (24%). There was a significant association between ideal and actual DM style (Fisher's Exact $p<0.001$) with 69/93 (74.2%) achieving their preferred DM style (Table 2). There was also a strong association between patient-centred actual DM and PET and between doctor-centred DM and surgery (Fisher's Exact, $p>0.001$).

The majority of women stated that ideally their doctor (76/82, 93%) or breast care nurse, (45/55, 82%) would be the person to discuss their treatment decision with. A number of women (41/46, 89%) also felt leaflets would be helpful in making their treatment decision. There was a negative association with age for preference for

written leaflets (Fisher's Exact, $p>0.007$). Friends and family were reported to be helpful for 34/47 women (72%).

Decision regret

The mean score of the Decision Regret Scale was 14.48 (scale 0-100, SD 18.60, range 0-100) demonstrating a low level of regret.

Discussion

This study has identified the information and DM support needs of older women with breast cancer facing a choice between surgery or PET.

The strong preference was for face to face discussion with a doctor (most preferred) or nurse when making a treatment decision. Booklets or leaflets were considered the most useful after the face to face consultations. These findings reflect our previous qualitative findings [9]. In line with the findings from Husain and colleagues it is feasible that the women were not only gaining information from the face to face discussions but also looking for any obvious or subtle clues as to what treatments they felt the doctor was 'recommending'. The women were reluctant to access breast cancer related information via technology, which is in contrast to younger women who increasingly seek information via the internet [19]. Previous studies in this age group have identified feeling too old, fear of technology, lack of skills, no interest in technology and no access to the internet [20, 21] as being potential reasons for this.

Presenting numerical information visually e.g. pie charts, was substantially less preferred than using words, reinforcing the findings of our qualitative study. Visual displays are particularly beneficial to people with lower numeracy skills provided they are able to understand graphical representations [22]. Older people found visual displays less helpful and sometimes confusing for those with low levels of both numeracy and graph literacy [22]. The evidence of a link between declining numeracy, lower literacy [23] and increasing age, and the desire to conserve time and energy, [24] may explain the strong preference for the more familiar use of words. This strong preference is of some concern as it may lead to inaccurate risk perception [25].

The most surprising finding was the limited preference for information regarding the effect of treatment on the women's independence level. This is in contrast to other studies, including our previous interview study [9], that have shown the impact on independence and quality of life were key considerations [16, 26]. However, over a third of respondents (38%) did not answer the two questionnaire items related to these, which could partly explain this finding. It is possible this is as a result of the wording of the questions which states "...after my operation." that led women who received PET to dismiss this question as at the time of completion it seemed irrelevant to them.

The amount of information older women require to make a treatment decision is variable. Some older patients find the type and amount of medical information

overwhelming [27], and are reported to express fewer information needs [28, 29] whilst others want as much information as possible [20].

Also reported is variance in the role women wish to play in DM. Some studies report that older women are often passive in the DM process, relying on HCPs to make treatment decisions [30, 31], whilst other studies report that older women want a more active role [12, 32-34].

Four studies examine DM where women are faced with a choice of PET or surgery followed by endocrine therapy [9, 10, 12, 35]. Husain et al [10] reported heavy reliance on expert medical advice when making a treatment choice. In more recent studies [9,12] women were eager to demonstrate their involvement and how *they* made the decision but were also keen to gain approval of their choice demonstrated by statements such as 'the doctor seemed pleased with my choice' [9]. Morgan and Burton et al [35] explored the balance of input of clinicians and patients into the DM process and reported that whilst there was variability in the DM styles, many older women achieved their treatment preferences.

Ensuring women receive the preferred level and amount of information as well as involvement when making treatment decisions can be a challenge for clinicians. Decision support tools of varying length and detail may therefore help patients reach their preferred level of information and involvement in decision making [12]. The findings from this study will contribute to the development of decision support interventions specifically for women ≥ 70 years, faced with a treatment choice of surgery or PET.

A number of women reported not being offered a choice of treatments. This could be a problem of recall or the lack of clarity about what constitutes being offered a choice which has been previously reported [36]. During the consultation it may be that two treatments were discussed which HCPs deemed to be an offer, but that there was an emphasis on one and the other was merely mentioned [12]. It could also mean that having made up their mind about the treatment they wanted prior to the consultation women simply filtered out information they felt was irrelevant.

Where more communication between surgeons and women occurs, choice is perceived to be greater [37]. However, when asked about their involvement in treatment DM the findings from both our interview and questionnaire studies found women consistently reporting involvement [9, 12]. It would seem that women are differentiating between the offer of a choice of treatment and involvement in treatment DM. This could indicate there is a need for HCPs to make the offer of a choice much more overtly.

Study Limitations

The declining cognitive ability and memory function of older people [38] may impact on reliability of findings in a retrospective questionnaire of this kind. However, the diagnosis and treatment for breast cancer is a significant event, and as such is arguably likely to produce strong memories. Time after the event is also a useful

period of reflection and provides a space for making sense of the situation. However, it is acknowledged that for some of the women the time period since breast cancer treatment was significant (up to 5 years) and the details of information received and used, and the DM process, may be difficult to recall.

The achieved sample size was low for statistical representation of the population and the low completion rate further impacted on the validity of the results so the findings should be used with caution. However, despite the sample size not achieving its target, the study provided evidence supporting our interview findings [9]. Previous studies with this population of women have closed early due to inadequate recruitment [39]. Recruitment to this study was reliant on HCPs in NHS breast units with the questionnaires being anonymously completed. The researchers, therefore, had no access to patient details to enable reminders to be sent to non-responders. Although the questionnaire was rigorously developed, it would seem that for some of this older population completion proved to be a challenging process. We can only speculate that the length of the questionnaire and/or the content were issues that contributed to the amount of missing data. The present study has provided a great deal of information about the appropriateness of postal, self-completion questionnaires with women who report a lack of interest in reading.

Conclusion

The findings of this study demonstrate that the majority of women achieved their preferred decision making style and expressed low levels of decision regret. They also challenge the notion that older women prefer a passive role in DM. The findings highlight that the preferred way to receive information is via face to face communication, supplemented by uncomplicated written information and there is a reluctance to engage with technology to obtain information. The development of decision support tools for women with older women facing a treatment choice of surgery or PET may enhance the quality and consistency of the information provided and encourage participation (to individuals' preferred level) in the DM process.

Clinical Implications

Items of information were identified that women found useful in making their decision that will be of value to HCPs in supporting women through the DM process as well as informative in the development of information and breast cancer decision support tools for older women.

The authors have no conflict of interest to declare.

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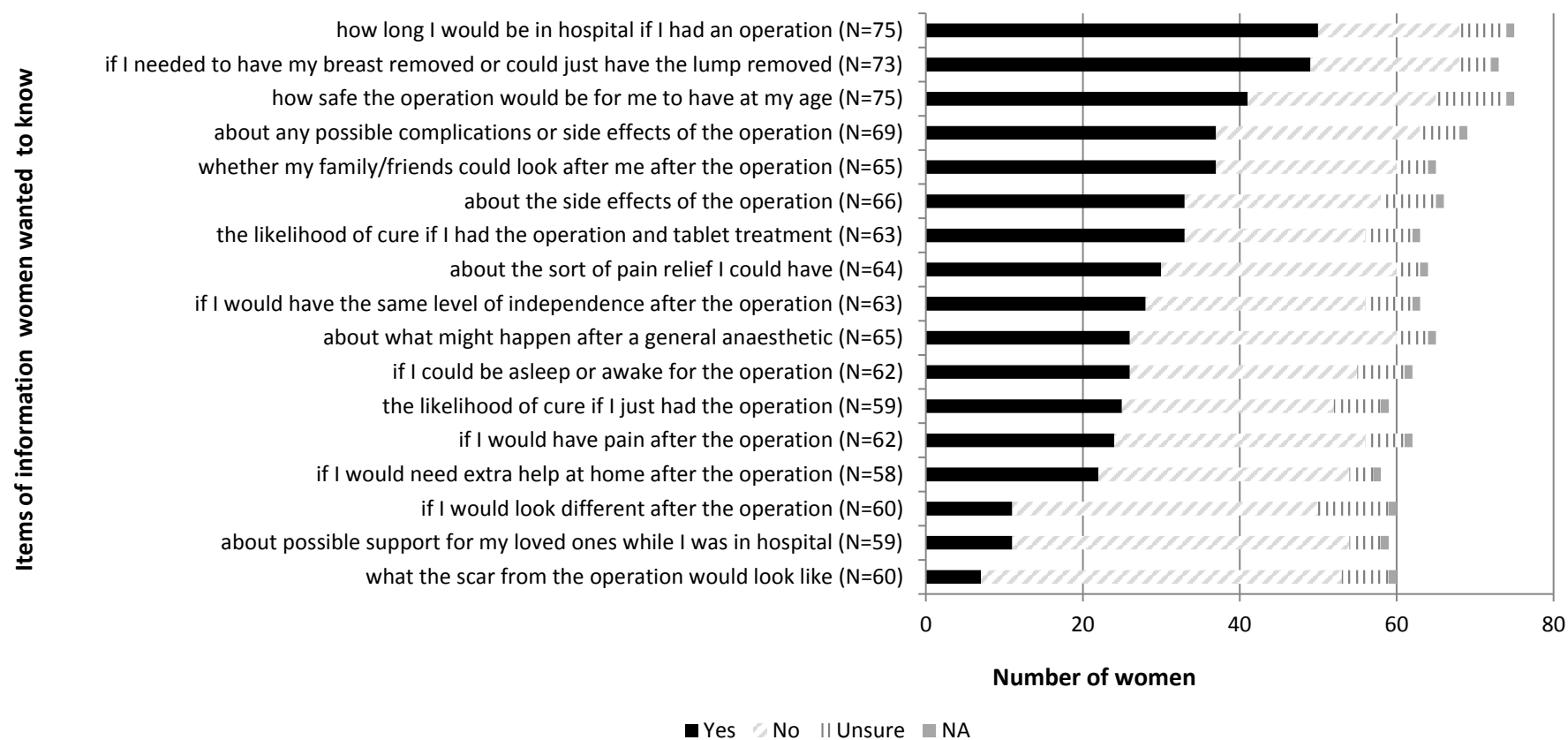
Table 1

	Preferred Decision-Making Style	Actual Decision-Making Style	DM Classification
1	I prefer to make the final decision about which treatment I have	I made the final selection about which treatment I had	<i>Patient-centred DM</i>
2	I prefer to make the final selection of my treatment after seriously considering my doctor/nurse's opinion	I made the final selection of my treatment after I had seriously considered my doctor/nurse's opinion	
3	I prefer that my doctor/nurse and I share the responsibility for deciding which treatment is best for me	My doctor/nurse and I shared the responsibility for deciding which treatment was best for me	<i>Shared DM</i>
4	I prefer that my doctor/nurse makes the final decision about which treatment will be used, but seriously consider my opinion	My doctor/nurse made the final decision about which treatment was used, but seriously considered my opinion	<i>Doctor-centred DM</i>
5	I prefer to leave all the decisions regarding my treatment to my doctor/nurse	My doctor/nurse made all the decisions regarding my treatment	

Table 2. **Congruence between women's preferred and actual decision making style**

No. of patients	Actual DM Style			
Preferred DM Style	Doctor-centred	Shared	Patient-centred	Total
Doctor-centred	31	1	3	35
Shared	7	9	6	22
Patient-centred	4	3	29	36
Total	42	13	38	93

**Figure 1a. Information women found helpful when deciding between PET and surgery
(Surgery information)**



**Figure 1b Information women found helpful when deciding between PET and surgery
(Tablet information)**

Items of information women wanted to know

