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Title: The balance of clinician and patient input into treatment decision-making in older women with operable breast cancer.

Short Title: Decision-making in older women with operable breast cancer.

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Original article.

Abstract:

Objective: Primary endocrine therapy (PET) is an alternative to surgery for oestrogen receptor positive operable breast cancer in some older women. However the decision to offer PET involves complex trade-offs and is influenced by both patient choice and healthcare professional (HCP) preference. This study aimed to compare the views of patients and HCPs about this decision and explore decision making (DM) preferences and whether these are taken into account during consultations.

Methods: This multicentre, UK, mixed methods study had 3 components: (1) questionnaires to older women undergoing counselling about breast cancer treatment options which assessed their DM preferences and realities; (2) qualitative interviews with older women with operable breast cancer offered a choice of either surgery or PET and (3) qualitative interviews with HCPs (both of which focused on DM preferences in this setting).

Results: Thirty-three patients and 34 HCPs were interviewed. A range of opinions about patient involvement in DM were identified. Patients indicated varying preferences for DM involvement which were *variably* taken into account by HCPs. These qualitative findings were broadly supported by the questionnaire results. Most patients (536/729; 73.5%) achieved their preferred DM style, however the remainder felt that their DM preferences had not been taken into consideration.

Conclusions: These results suggest that whilst many older women achieve their desired level of DM engagement, some do not, raising the possibility that they may be making choices which are not concordant with their treatment preferences.

Key words:

Cancer, primary endocrine therapy, oncology, elderly, decision-making.

Background.

Breast cancer in the older population represents a significant problem, with around one third of all new diagnoses occurring in the over 70s in the UK [1]. The “standard” treatment for breast cancer is surgery, but as age increases, so does co-morbidity and frailty, resulting in reduced tolerance to surgery and other breast cancer therapies [2]. Additionally, life-expectancy decreases with age [3] and co-morbidity increases [4] so that other-cause mortality outweighs breast-cancer mortality, thereby decreasing the potential benefit of surgery [5,6]. Consequently, older women with operable breast cancer may be offered alternative treatments, such as Primary Endocrine Therapy (PET) where women with oestrogen receptor positive (ER+) breast cancers are treated with endocrine therapy alone. PET is an effective treatment for some older women, with a Cochrane review demonstrating no difference in overall survival when compared to surgery [7]. However local control rates are superior in surgically treated patients, with disease progression sometimes necessitating a change of management in patients treated with PET [8-10].

There is wide variation in PET use in the UK; rates ranging from 12%-40% in different regions [11]. Whilst some of this may be due to case mix variation, studies have shown that this does not account for all of the variation [12,13] and patient preference for non-surgical therapy is often reported as a major factor in determining PET treatment in older patients [14-16]. However, other studies suggest that patient choice alone is unlikely to be the only cause of lower UK surgery rates [17], with clinician preference and how treatment options are presented also being significant in determining treatment [18].

Shared DM is increasingly considered to be relevant in preference sensitive health care decisions with patients and HCPs working together to make health care decisions that are based on clinical evidence and patients’ informed preferences [19-21]. However there is evidence to suggest that not all older patients want to engage in shared DM, instead preferring to simply receive information [22] and accept a doctor-led DM process [23-26].

Currently little is known about the influence of HCP opinion on DM in older women with operable breast cancer. This study aimed to explore the interaction between HCPs and older patients in the DM process, as well as the concordance between HCP and patient views regarding the process of DM about treatment of operable breast cancer.

Methods:

Study Design:

This study is a convergent mixed methods study with 3 components, where data were collected concurrently and findings were integrated following independent analysis:

1. Questionnaires about DM style administered to a large cohort of older women recruited as part of a multicentre UK cohort study of older women with breast cancer (the Bridging the Age Gap in Breast Cancer study).
2. Interviews with older women previously diagnosed with operable, ER+ breast cancer, to explore their DM preferences about the choice between surgery or PET
3. Interviews with HCPs involved in the care of older women with breast cancer to explore their views about older women's involvement in DM

This type of study design was chosen so the qualitative interviews would provide a more in-depth insight into the quantitative findings obtained from the cohort study.

1. DM preferences questionnaire.

This was a prospective observational cohort study of women aged over 70 years diagnosed with operable primary breast cancer in 43 UK units since February 2013. Recruitment for this trial is ongoing, and results presented here represent an interim analysis of the first 729 patients with available data. Data were collected on patient and tumour characteristics, treatment type, as well as the patients' preferred and actual DM styles for their breast cancer treatment using a widely used validated instrument [27,28] (Table 1). The DM preferences questionnaire was applied within 4 weeks of diagnosis and prior to treatment. DM styles were then classified into three categories: Patient-centred, Shared and Doctor-centred (Table 1).

2. Patient Interviews.

Semi-structured interviews were undertaken with patients across five of the UK breast units recruiting to the Age Gap cohort study to explore opinions on treatment DM styles and preferences between April-December 2013. Eligibility criteria were: age 75 or over with operable breast cancer, diagnosed within the previous 5 years and offered a documented

choice of either surgery or PET at initial diagnosis. Interviews and analysis were undertaken by one of two experienced qualitative researchers (KL/MB). The interview schedule focused on DM preferences and experiences of the DM process. Interviews were digitally recorded and transcribed verbatim. Recruitment ceased once data saturation had occurred.

3. HCP Interviews.

Interviews were undertaken with HCPs (surgeons, nurse specialists or geriatricians working with older breast cancer patients) recruited across 14 of the UK breast units recruiting to the cohort study to explore their opinions on treatment DM styles. Interviews were conducted between January-November 2013, by JM and participants were purposively selected from regions with high and low PET rates according to UK national audit data [11]. Interviews were digitally recorded and transcribed verbatim. Recruitment ceased once data saturation had occurred.

Data Analysis:

Questionnaires:

Statistical analyses were performed using IBM SPSS statistical package, version 21. Concordance between preferred and actual DM preferences was assessed using Kappa, and associations between age, treatment and DM style identified using Chi-squared tests. Statistical significance was taken at $p < 0.05$.

Interviews:

Framework analysis [29], involving five steps of familiarisation, theme development, indexing, charting, and interpretation, was used. Analysis of patient interviews was undertaken by MB/KL with supplemental feedback undertaken by lay patient representatives.

Analysis of HCP interviews was conducted by JM with 10% of transcripts double-coded by MB. Initial DM themes from both sets of interviews were compared and contrasted by two researchers (JM/MB).

Ethics and Research Governance:

The study protocols were approved by the UK National Research Ethics Committee and institutional approvals were granted at each site (12/LO/1808, 12/LO/1722 & SMBRER243). All patients and HCPs gave written informed consent.

Results:

Questionnaires:

Data on DM styles and treatment were available for 729 patients (age range 70-96 years; median 77 years), of whom 594 had undergone surgery and 135 had been treated with PET.

Both preferred and actual DM styles were associated with final treatment type, with surgery being associated with more doctor-centred treatment decisions and PET with more patient-centred decisions ($p < 0.001$ and $p = 0.004$ respectively; Figure 1). There was moderate agreement between patients' preferred and actual DM style (Kappa = 0.60, $p < 0.001$) with 536/729 (73.5%) achieving their preferred DM style (Table 2). Increasing age was also associated with more patient-centred DM styles, both preferred and actual ($p < 0.001$).

Interviews:

Patient interviews were undertaken with 33 older women with breast cancer (median age 83, range 75-94 years), who were a median of 20 months (range 3 to 60) from diagnosis. Twenty-two women received PET and 11 surgery. Interview duration was a median of 57 (range 23 to 85) minutes.

Healthcare professional interviews were undertaken with 34 HCPs (20 surgeons, 13 breast care nurses (BCNs), and 1 geriatrician). Twenty-one (62%) were from high PET rate units, with the remaining 13 (38%) from low PET rate units. Interview duration was a median of 33 (range 16 to 55) minutes.

Combined interview analysis categorised the data into three themes pertaining to the treatment DM of older women with operable breast cancer:

1. Patient involvement in DM
2. Influence of HCP on DM
3. DM processes

Theme 1: Patient involvement in DM

Healthcare professionals varied on their opinions regarding the DM styles of older women; some believing that older patients preferred a more doctor-centred approach whilst others felt

they utilised a more patient-centred DM approach. Patients also tended to fit into one of these categories (Table 3, Subtheme 1b). Patients who had a more patient-centred approach described having already made their mind up about treatment before discussing options with their HCP. Overall, most patients (n=29) were satisfied with their involvement in the DM process.

Patients' preconceived ideas about themselves, breast cancer and cancer treatments were identified by both HCPs and patients as factors that influenced their treatment preference. Particular issues raised included the belief that they were too old for treatment (particularly surgery), the notion that quality of life was prioritised over quantity, and the impact of previous experiences of cancer, either themselves or of family and friends (Table 3, Subtheme 1a).

Theme 2: Influence of HCP on DM

Both HCPs and patients felt that the HCP had significant influence over patient DM when offered a treatment choice (Table 3, Subtheme 2a). Indeed, some women (n=8) described situations where the HCP tried to change their mind regarding their treatment choice (Table 3, Subtheme 2a). Not all HCPs (n=5) felt that patients should be offered a choice of surgery or PET and this was mirrored by some patients (n=7) who felt they had not been given a treatment option (Table 3, Subtheme 2b).

Several patients (n=12) stated that they wanted a recommendation from their HCP about treatment. Willingness to recommend varied, with most (n=25) quite happy to advise patients and others (n=5) feeling very uncomfortable about making recommendations (Table 3, Subtheme 2c).

Theme 3: DM processes

Giving patient's time to reach a treatment decision was viewed as important by HCPs. However, some patients (n=5) felt they had been expected to make a decision quickly, despite HCPs encouraging them to take time to consider their options. Others (n=12) described an internal desire to get the DM process "over with" (Table 3, Subtheme 3a). Both groups felt that the BCNs played a major role in helping patients decide (Table 3, Subtheme 3b).

Interestingly, there was a notion from HCPs that older patients generally did not require or want as much information regarding treatment compared to younger women, and this corresponded to some patients' who felt overwhelmed by the volume of information they were given. A small number of patients (n=4) felt that the HCPs did not want to give them information (Table 3, Subtheme 3c).

Discussion:

Despite the evidence suggesting older patients prefer a more passive, doctor-centred role in treatment DM [23-26], this study identified a range of preferred DM styles among older women with operable breast cancer and demonstrated the complex relationship between patients and their HCPs in the DM process. Vogel and colleagues explored the concordance between HCP and patient preference for DM in breast cancer patients and found that HCP perceptions were often inconsistent with patient preference [22]. Within this study, almost three-quarters of patients achieved their preferred DM style, suggesting that HCPs were utilising a more individualised approach to treatment DM. However, a quarter of patients did not achieve their preferred DM style, raising the possibility that they may be making choices which are not concordant with their treatment preferences.

Treatment received was related to patient DM style, where women choosing PET generally had a more patient-centric DM experience compared to women treated with surgery. This suggests that a significant proportion of women treated with PET chose this treatment as a means of avoiding surgery. This is in line with other similar studies where patient choice is commonly stated as a reason why patients receive PET [14,16,30]. Interestingly, increasing age was also associated with more patient-centred DM styles, with those at the younger end of the age spectrum having more doctor-centred and shared DM styles. This may partly explain the increasing rates of PET in the oldest old, with HCPs perhaps feeling more inclined to stress the importance of surgery in the younger cohort, thus resulting in the perception of a doctor-centred decision. Additionally, some patients treated with PET may have been considered too frail to be offered surgery and so their treatment choice may have been PET vs. no treatment which could partly explain why they felt a patient-centred DM had been used. The findings of the present study are in contrast to findings by Lavelle and colleagues [17] who reported that lower rates of surgical treatment are unlikely to be due to patient choice. This may represent a difference in study population, with the study by Lavelle and colleagues recruiting patients mainly from one region in England in comparison to this study in which patients were recruited from a wider area.

Hamaker and colleagues [18] suggested that although patient preference or refusal of surgery were often stated as possible reasons for variation in treatment, it may actually reflect clinician preference influencing communication of treatment options and how these are presented to the patient. The present study found that not all patients are offered a choice of

treatment and a significant proportion of treatment decisions were doctor-centred (Table 3). This may reflect current guidelines suggesting PET should not be used unless patients are deemed unfit for surgery, have significantly reduced life-expectancy or refuse surgery [31,32]. However, it is recognised that for some patients, quality of life is more important than quantity [33], and it may be appropriate to offer PET as an alternative to surgical treatment, allowing the patient to decide their preferred treatment option. This principle also fits with the current drive for more shared DM in healthcare, which requires treatment alternatives to be discussed with patients.

For those offered choice, a small number of patients wanted a recommendation from their HCP, and Schonberg and colleagues found this to be the most influential factor affecting older women's breast cancer treatment decisions [25]. However not all HCPs are comfortable recommending a treatment plan, choosing instead to encourage the patient to decide. Encouraging an active role in DM when patients prefer a more passive role may increase anxiety and cause distress [34,35].

Healthcare professionals did not feel that older patients wanted as much information as their younger counterparts, however, for patients this varied, with some appreciating more detailed information on treatment choices. This is in keeping with Elkin and colleagues who found that despite some older people not wishing to take an active role in the DM process, they still wanted to receive information about the treatment option available [36]. Even when patients do not wish to take an active role in decisions they may seek information as a method of coping with and taking control of breast cancer [37,38].

Although most HCPs unsurprisingly felt that patients needed adequate time to consider their treatment options and make decisions, this was in complete contrast to the patients' perception who tended to feel internal pressure to make a decision quickly, this being in line with previous studies [39,40]. Additionally, some patients felt pressured to take a decision quickly as they believed it was expected by the HCPs.

It is acknowledged that retrospective interview studies, particularly involving older people, may be subject to inaccurate recall of events and details. However many themes were common findings between women and HCPs, giving confidence in the data. Combined with the prospectively collected questionnaire data, the mixed methods approach allows the questionnaire data to expand on the qualitative findings, giving a broader overview of this problem.

Our findings support an individualised approach to treatment DM for older women with operable breast cancer, including the discussion of alternative treatment options, which may come with the caveat that one option is considered superior. A decision aid which includes more information on the treatment options and outcomes in this population may be helpful to both patients and HCPs to improve concordance in the DM process. This study also highlights the need for further research on the DM process and its relationship to decision regret in this setting.

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Table 1: Questionnaire options for preferred and actual DM styles [27,28].

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

Table 2: Comparison between patients' preferred and actual decision style.

Preferred decision style	Actual DM style			Total
	Doctor-centred	Shared	Patient-centred	
Doctor-centred	198	28	21	247
Shared	61	178	45	284
Patient-centred	16	22	160	198
Total	275	228	226	729

Agreement = 73.5%; Kappa = 0.60, p<0.001; agreed values in bold

Table 3: Representative quotes from interviews comparing HCP and patients views.

	HCP views	Patient views
Theme 1: Patient involvement in DM		
Subtheme 1a: patients' preconceived ideas	<i>"Some ladies will say at 70 'I'm too old to have an operation'."</i> (Female Nurse; High PET unit)	<i>"Well I am too old, 91 to go to a big operation like that."</i> (91yrs; PET)
	<i>"The older woman who lives independently, they'd rather die than lose their independence... their priorities are very different... It's not about survival... thorough treatment of their breast cancer may be something that they're not actually interested in."</i> (Female Surgeon; High PET unit)	<i>"I was feeling okay and I thought if my quality of life is like this at the moment, if I can keep it like this for a couple more years, well, that's okay with me, so that was my decision."</i> (81yrs; PET)
	<i>"Usually when people hold such strong, seemingly irrational, views it's usually because of an experience that they have had or an experience that a member of family or close friend has had."</i> (Male Geriatrician; High PET unit)	<i>"'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... Cancer is the most frightening word."</i> (82yrs; Surgery)
Subtheme 1b: DM styles	<i>"A lot of women in that age group have their own opinions and they can't be changed"</i> (Male Surgeon; Low PET unit)	<i>"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"</i> (81yrs; Surgery)
	<i>"Some women really don't want to make that decision, they think it's the sort of thing that a doctor should do"</i> (Female Surgeon; High PET unit)	<i>"..[Dr] deals with that all day and every day so I just said 'Well what do you advise?' And I mean because he knew about it, I just took his advice."</i> (81yrs; Surgery)
Theme 2: Influence of HCP on DM		
Subtheme 2a: Impact of HCP view on DM	<i>"it's the way you... sell something and personal opinion comes into it... a surgeon might think they know best and patients obviously listen to their doctor"</i> (Female Nurse; Low PET unit)	<i>"I think she [Dr] played a big part, because she put it so clearly that it was easy to make a decision"</i> (89yrs; PET) <i>"I said 'well I'm not taking tablets, I'm going to have my breast off'... he [Dr] said 'but I'm very reluctant' he said 'you're 94 year old'."</i> (94yrs; Surgery).
Subtheme 2b: Offering a choice	<i>"The literature suggests... they should be offered an operation and so that's what I offer them. So I don't give them a choice between surgery and PET"</i> (Male Surgeon; Low PET unit)	<i>"P: I wasn't given a choice, no. I: No, would you have liked a choice? P: I think I would really. I don't know what I would of chosen though thinking about it."</i> (80yrs; PET)

Subtheme 2c: Making recommendations	<i>“If they ask me well what do I think, I will tell them... ‘You choose what is right for you, not what is right for me... I don’t know how I will choose if I was sitting where you’re sitting so it really is your choice’.”</i> (Female Surgeon; High PET unit)	<i>“My son said to him... ‘if it was your wife what would you recommend her to do’ and he said ‘I can’t answer that... it’s your mother’s decision. She has to decide for herself’.”</i> (75yrs; Surgery)
	<i>“I certainly tell them which is the preferable option”</i> (Male Surgeon; High PET unit)	<i>“What would happen if I don’t have treatment? And... the doctor actually did say to me, ‘your other option is to have nothing done... but I wouldn’t recommend that’...”</i> (81yrs; PET)
Theme 3: Processes of DM		
Subtheme 3a: Timing of DM	<i>“Giving them time to think through it, the pros and cons, is very important”</i> (Female Surgeon; Low PET unit)	<i>“Get rid of it. And see you don’t have time, because you want it done there and then. So you don’t have a lot of time to think about it.”</i> (81yrs; PET)
Subtheme 3b: HCP involved in DM process	<i>“She [nurse] does all the decision-making with them. They go into a room with her, I just tell them what it is and what the options are and over to the Breast Care Nurse.”</i> (Male Surgeon; Low PET unit)	<i>“It was when the nurse took us into a separate room away from Dr [name] we thrashed this out”</i> (85yrs; PET)
Subtheme 3c: Information requirements	<i>“A lot of the older population, I feel, don’t want information”</i> (Female Nurse; High PET unit)	<i>“They weren’t very forthcoming with information”</i> (75yrs; PET) <i>“why would you need all the other information? It’s only extra worrying”</i> (81 yrs; PET)