

Changing trends in the decision-making preferences of women with early breast cancer

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Background: Previous studies have indicated a predominance of passive decision-making styles among women with early-stage breast cancer in the UK offered a choice between breast-conserving surgery (BCS) and mastectomy. The aim of this study was to determine current decision-making styles and establish their association with operation choice and breast unit mastectomy rate.

Methods: A questionnaire survey was conducted among women from three specialist breast units representing high, medium and low case mix-adjusted mastectomy rates.

Results: Of 697 consecutive patients, 356 (51.1 per cent) completed the questionnaire, a mean of 6.9 (range 1.3–48.6) weeks after surgery. Some 262 women (73.6 per cent) underwent BCS and 94 (26.4 per cent) had a mastectomy. Some 218 patients (61.2 per cent) achieved their preferred decision-making style. The proportions of women achieving an active decision-making style were high, particularly for those choosing mastectomy (83 *versus* 58.0 per cent for BCS; $P < 0.001$) and in the high mastectomy rate unit (79.6 *versus* 53 and 52.2 per cent for medium and low rate units respectively; $P < 0.001$).

Conclusion: More women chose an active decision-making style than in previous UK studies. The provision of greater treatment selection autonomy to women suitable for BCS may not reduce mastectomy rates.

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Introduction

Over the past decade the surgical options available to women with early breast cancer have expanded to include immediate breast reconstruction and therapeutic mammoplasty. However, breast-conserving surgery (BCS) and mastectomy remain the mainstay of surgical treatment for most women. Research has failed to establish the superiority of a particular operation in terms of impact on mortality rates for tumours of up to 4–5 cm in diameter^{1–3}, and on physical and psychological morbidity (except body image)^{4–6}. Providing women with treatment choices is associated with improved short- and long-term psychological recovery^{6–12}, improved satisfaction and reduced regret about the operation undertaken^{11–13}, and improved satisfaction with the

process of care^{11,13}. Thus, providing treatment choices to women with breast cancer has become a recognized priority.

Patients' preferences for involvement in healthcare decision-making vary. Three main patient decision-making styles have been described: active, collaborative and passive, in patients who wish, respectively, to make their own healthcare decisions, share decision-making and defer decision-making to others. Decision-making styles are usually ascertained by adaptations of an instrument designed by Strull and colleagues¹⁴ and popularized by Degner and Sloan¹⁵ (the Control Preferences Scale). Studies conducted in the 1990s reported that women with breast cancer preferred and achieved predominantly passive or collaborative roles in the selection of their surgery,

with 50–70 per cent preferring or achieving a passive role, and 20–30 per cent a collaborative role^{16–18}. More recent studies from North America^{13,19} and Australia²⁰ have suggested a reversal in such patterns, with greater proportions preferring a more active role.

Despite the fact that women with breast cancer are increasingly provided with the opportunity to choose their operation, rates of BCS and mastectomy remain extremely variable, both in the UK^{21,22} and internationally^{23–26}. Case mix does not fully explain this variation²¹. It has been suggested that, if women were provided with greater control in the selection of their surgery, mastectomy rates would fall. Some studies have demonstrated significantly more active decision-making among those choosing BCS^{18,20,27}, whereas others have shown the opposite^{13,28}.

An association has been found between women's satisfaction with their surgery and the process of its selection, both in the role they achieved in the decision-making process^{12,19} and whether they fulfilled that preferred role. Greater satisfaction and less regret were identified among women achieving a more active decision-making style^{7,11,12,19} and in those achieving their preferred decision-making style^{11,13,28,29}.

The first aim of this study was to establish current decision-making strategies among women recently diagnosed with breast cancer in the UK who were offered a choice of operation. The second aim was to establish how frequently women achieved their preferred decision-making style, and to analyse whether differences between preferred and achieved decision-making styles were associated with women's operative choices or with the mastectomy rate in their treating breast unit.

Methods

The study was conducted in three centres from a single large UK region (Trent, population approximately 5 million), after obtaining Multicentre Research Ethics

Committee approval and establishing that case mix and caseload did not account for surgical variation in the region, through an audit of more than 5000 cancers detected by the National Health Service Breast Screening Programme²¹. Consecutive eligible women were invited to participate in the study from each of three breast units reflecting the spectrum of surgical management variation: high, medium and low case mix-adjusted mastectomy rates²¹. Eligibility for inclusion in the study was defined as any woman within 1 month of diagnosis of breast cancer, capable of providing informed consent to participate in a research study, who had been offered a choice of initial therapeutic surgery (BCS or mastectomy) by a specialist surgical consultant or a doctor of longstanding employment (staff grade, associate specialist or general practitioner clinical assistant) in the recruiting breast unit.

Eligible women were identified before surgery by members of their treating breast team, and invited to participate in the study as soon as possible after the initial therapeutic operation, either in person or by post. Those agreeing to participate completed a consent form and questionnaire employing an adapted version of a validated instrument used widely and internationally among patients with cancer to identify decision-making styles^{14,15} (*Table 1*). By convention, the first two responses are considered active, the third collaborative, and the last two passive. Women were asked to indicate separately which particular statements most accurately described the role they preferred in deciding their breast cancer surgery, and the role they achieved. Additional information was collected on the type of initial therapeutic surgery undertaken, the professional role of the doctor providing information on surgical options, patient age, and date of initial therapeutic surgery.

The data were analysed with SPSS® version 14.0 software (SPSS, Chicago, Illinois, USA), using frequencies, χ^2 statistics (to look for associations between categorical outcomes, for example between decision-making style and

Table 1 Decision-making styles instrument

Preferred	Achieved
I prefer to make the final selection about which treatment I will have	I made the final selection about which treatment I had
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
I prefer that my doctor/nurse and I share 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 prefer that my doctor/nurse makes the final decision about which treatment will be used, but seriously considers my opinion	My doctor/nurse made the final decision about which treatment was used, but seriously considered my opinion
I prefer to leave all decisions regarding my treatment to my doctor/nurse	My doctor/nurse made all the decisions regarding my treatment

operation choice), κ statistics (to assess agreement between achieved and preferred decision-making styles) and one-way ANOVA (to compare mean age at operation between the three decision-making style groups).

The sample size was based on published literature available at the time of study design. Assuming a collaborative decision-making style of 50 per cent at each breast unit, to estimate this proportion within ± 10 per cent (that is, a 95 per cent confidence interval (c.i.) of 40 to 60 per cent) approximately 100 responders per breast unit were required. To gain 100 completed responses per unit, it was estimated that 200 patients from each hospital would need to be approached, allowing for a 50 per cent response rate and a clustering effect, whereby women treated in a specific breast unit are expected to be more similar to other women treated by that breast unit than to women treated by other breast units. If there were ordering across the three (high, medium and low mastectomy rate) breast units with respect to the proportion of collaborative decision-making styles in each unit, then, with a sample size of 100 per unit, a 0.05 two-sided χ^2 test for trend in proportions would have 80 per cent power to detect a difference in proportions characterized by this trend, assuming collaborative decision-making style proportions of 0.39, 0.50 and 0.61 respectively in the three breast units for a mean collaborative decision-making style proportion of 0.50 across the three sites.

Results

Between September 2003 and December 2005, 697 eligible women were identified and approached to participate in the study; 373 agreed and 356 completed questionnaires were received (response rate 51.1 per cent). The mean age of the respondents was 58.5 (range 30.4–89.0) years; 10.7 per cent were aged over 70 years. The mean time between initial therapeutic surgery and return of the completed questionnaire was 6.9 (range 1.3–48.6) weeks, although the majority (352 (98.9 per cent) of the 356 patients) returned the questionnaire within 24 weeks of the operation. Overall, within the three breast units 262 women (73.6 (95 per cent c.i. 68.8 to 77.9) per cent) underwent BCS and 94 women (26 (95 per cent c.i. 22 to 31) per cent) had a mastectomy.

Table 2 shows women's preferred *versus* achieved decision-making styles, and the agreement or concordance between their preferred and achieved styles. Overall, a 61.2 per cent (218 of 356) concordance rate was observed between patients' preferred and achieved decision-making styles ($\kappa = 0.39$, $P < 0.001$). When women failed to achieve their preferred style, they tended to adopt a

more active (105 patients; 29.5 per cent) than passive (33 patients; 9.3 per cent) role. The attainment of patients' preferred decision-making style was associated with the nature of their preferred style, with the greatest concordance being demonstrated among those preferring an active role (131 (91.0 per cent) of 230). Women preferring either a collaborative or a passive role were less likely to achieve their preferred decision-making style: 53.0 per cent of those preferring a collaborative role in the selection of their operation actually had an active role, and 31 per cent of those preferring a passive role had an active role. However, concordance between patients' preferred and achieved style was independent of operation choice ($P = 0.070$) and breast unit mastectomy rate ($P = 0.533$). Table 3 demonstrates patients' preferred *versus* achieved decision-making styles by operation choice, and illustrates a trend towards greater agreement between preferred and achieved style among those choosing mastectomy (67 *versus* 59.2 per cent for BCS), and the achievement of a more passive role than preferred among the BCS group (11.5 *versus* 3 per cent for mastectomy).

Table 4 summarizes patients' achieved decision-making style by operation choice and case mix-adjusted breast unit mastectomy rate. Overall, 64.6 (95 per cent c.i. 59.5 to 69.4) per cent of the 356 women achieved an active decision-making style. An active style was particularly predominant among women who chose mastectomy (83 per cent) rather than BCS (58.0 per cent) (difference 25 (95 per cent c.i. 14 to 34) per cent; $P < 0.001$), and in women treated in the high mastectomy rate unit (79.6 per cent) compared with those treated in the low (52.2 per cent) and medium (53 per cent) mastectomy rate units ($P < 0.001$). Table 5 illustrates patients' achieved decision-making styles by operation choice within the high, medium and low case mix-adjusted mastectomy rate breast units, highlighting the predominance of the active style among women who chose mastectomy and

Table 2 Preferred *versus* achieved decision-making styles

	Preferred decision-making style			Total
	Active	Collaborative	Passive	
Achieved decision-making style				
Active	131 (91.0)*	80 (53.0)	19 (31)	230 (64.6)
Collaborative	4 (2.8)	51 (33.8)*	6 (10)	61 (17.1)
Passive	9 (6.3)	20 (13.2)	36 (59)*	65 (18.3)
Total	144 (100)	151 (100)	61 (100)	356 (100)

Values in parentheses are percentages. *Perfect agreement between preferred and achieved decision-making styles. κ statistic for agreement = 0.39, $P < 0.001$.

Table 3 Preferred *versus* achieved decision-making styles by operation choice

	Preferred decision-making style			
Operation choice	Active	Collaborative	Passive	Total
Mastectomy				
Achieved decision-making style				
Active	52 (96)*	18 (69)	8 (57)	78 (83)
Collaborative	1 (2)	7 (27)*	2 (14)	10 (11)
Passive	1 (2)	1 (4)	4 (29)*	6 (6)
Total	54 (100)	26 (100)	14 (100)	94 (100)
BCS				
Achieved decision-making style				
Active	79 (88)*	62 (49.6)	11 (23)	152 (58.0)
Collaborative	3 (3)	44 (35.2)*	4 (9)	51 (19.5)
Passive	8 (9)	19 (15.2)	32 (68)*	59 (22.5)
Total	90 (100)	125 (100)	47 (100)	262 (100)

Values in parentheses are percentages. BCS, breast-conserving surgery.

*Perfect agreement between preferred and achieved decision-making styles. $\chi^2 = 8.64$, 4 d.f., $P = 0.070$.

were treated at the high mastectomy rate breast unit. Women choosing mastectomy and those treated in the high mastectomy rate unit also preferred a significantly more active style than women who chose BCS, and those treated in the medium and low mastectomy rate units ($P < 0.001$ and $P = 0.015$ respectively; data not shown).

Although the study was not designed to analyse age as an independent variable, younger women were found to prefer a more active role in decision-making ($P = 0.041$), as illustrated by the mean age of women in the preferred decision-making style groups: active, 57.4 years, collaborative, 58.4 years, and passive, 61.1 years. However, age was not associated with the achieved decision-making style ($P = 0.252$), operation choice ($P = 0.716$) or breast unit mastectomy rate ($P = 0.371$).

Table 5 Achieved decision-making style by operation choice within high, medium and low case mix-adjusted mastectomy rate breast units

	Achieved decision-making style			
Unit mastectomy rate	Active	Collaborative	Passive	Total
Low				
Mastectomy	16 (59)	5 (19)	6 (22)	27 (100)
BCS	43 (50)	21 (24)	22 (26)	86 (100)
Total	59 (52.2)	26 (23.0)	28 (24.8)	113 (100)
Medium				
Mastectomy	26 (90)	3 (10)	0 (0)	29 (100)
BCS	20 (35)	16 (28)	21 (37)	57 (100)
Total	46 (53)	19 (22)	21 (24)	86 (100)
High				
Mastectomy	36 (95)	2 (5)	0 (0)	38 (100)
BCS	89 (74.8)	14 (11.8)	16 (13.4)	119 (100)
Total	125 (79.6)	16 (10.2)	16 (10.2)	157 (100)

Values in parentheses are percentages. BCS, breast-conserving surgery.

Discussion

This study has provided up-to-date information on the decision-making styles of women in the UK recently diagnosed with breast cancer who were given a surgical choice for initial therapeutic management. There was a significant change in the roles preferred and achieved by participating women, from the predominantly collaborative and passive roles demonstrated in previous studies^{16–18,28,30} to a more active role. These findings are consistent with trends reported by more recent international studies^{13,19,20}. The change in decision-making styles between the time points is likely to represent a more generally observed cultural shift toward greater autonomy in both expectation and behaviour.

The division of decision-making styles between the two operation groups of patients with breast cancer

Table 4 Summary of achieved decision-making style by operation choice and case mix-adjusted breast unit mastectomy rate

	n	Achieved decision-making style			P*
		Active	Collaborative	Passive	
Overall	356	230 (64.6)	61 (17.1)	65 (18.3)	0.001
Operation choice					< 0.001
BCS	262	152 (58.0)	51 (19.5)	59 (22.5)	
Mastectomy	94	78 (83)	10 (11)	6 (6)	
Breast unit mastectomy rate					< 0.001
Low	113	59 (52.2)	26 (23.0)	28 (24.8)	
Medium	86	46 (53)	19 (22)	21 (24)	
High	157	125 (79.6)	16 (10.2)	16 (10.2)	

Values in parentheses are percentages. BCS, breast-conserving surgery. * χ^2 test.

was particularly interesting, with a predominance of active decision-making in the mastectomy group. Most studies reporting associations between operation type and decision-making style have shown that patients choosing BCS preferred and/or achieved proportionately more active decision-making^{18,20,27}. Studies conducted more recently (including the present one) have indicated that this may be changing¹³. These findings may reflect an underlying change in healthcare professionals' preferences or a wider cultural shift towards BCS, resulting in this surgical option being portrayed and perceived as the 'norm'. In such an environment, women preferring BCS might classify themselves as collaborative decision-makers and this option would predominate in the passive decision-making group, whereas those preferring mastectomy may adopt, or perceive themselves to have adopted, and achieved, a more active role.

The differences in decision-making styles observed between the different mastectomy rate units were unexpected. One possible explanation may be that the high mastectomy rate breast service actively promoted more active decision-making (preferred and achieved) among their patients. This would have resulted in their patients' decision-making style being closer to that generally reported within a healthy population, compared with styles usually reported among those with cancer¹⁵. This supposition would be supported by the results of a randomized clinical trial published in 2002, which demonstrated a significantly more active preferred decision-making style among women newly diagnosed with breast cancer who were encouraged to evaluate their own style before consultation with a surgeon³⁰.

The recruitment methodology adopted in the present study was similar to that of the previous UK study¹⁶ conducted a decade ago; therefore, the results almost certainly reflect a genuine change in women in the UK. Similar trends reported from other countries add weight to this argument. The 51.1 per cent response rate, however, may affect the extent to which these results can be extrapolated. Unfortunately, for ethical reasons, no data are available on the characteristics of the survey's non-responders. Certain patient subgroups may be over- or under-represented within the sample. As with all studies of this nature, the findings may be characteristic only of those patients choosing to participate in the research.

A limitation of this type of study is the administration of the questionnaire after the decision-making episode. As only patients offered a choice of surgery were recruited, in the context of the UK healthcare system it was inevitable that recruitment would have to follow the consultation where both diagnosis and surgical management options

were discussed. This is common to the majority of similar studies.

The attainment of the preferred role in choosing their surgery is a strong indicator of a woman's satisfaction with the treatment^{11,13,28,29} and there is evidence to suggest that this benefit extends to those achieving an active role in decision-making^{7,11,12,19}. Most women in the study achieved the role in decision-making they preferred, or a more active role in the process; only 9.3 per cent achieved a more passive role than preferred. The high rates of concordance identified between the preferred and achieved decision-making style among women preferring an active role may reflect a move away from the traditional paternalistic model of healthcare decision-making. However, the finding that those preferring a collaborative or passive style were far less likely to achieve their preferred role in treatment selection, with patients preferring a passive style being directed towards a more active role and those preferring a collaborative style being directed towards either a more active or a more passive role, may indicate that healthcare professionals are still adopting a directive role. Greater awareness of decision-making styles³⁰ and communication skills training, together with patients' use of decision aids³¹⁻³⁴, may help to improve communication within consultations and the quality of decision-making.

The provision of surgical choices to women with breast cancer is frequently described as a priority in breast cancer services, and it is assumed that this will result in a reduced mastectomy rate. Evidence from this study and others^{13,28} suggests that providing women with greater autonomy in surgical treatment selection may not result in a fall in mastectomy rates among women suitable for BCS.

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