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# Surgical treatment decision making in breast cancer among Chinese women: participation and satisfaction

## Key Messages

1. Chinese women do not want to make breast cancer treatment decisions alone.
2. Most women left to make a decision with no input from their surgeon feel over-involved.
3. Over-involved women have greater difficulty making decisions and are less confident about their treatment choice.
4. Knowing their surgeon's preferred surgical option is important to Hong Kong Chinese women. Therefore, surgeons should outline the choices then give a recommendation.
5. Once made the woman's choice should be respected.

## Introduction

While patient participation in health care may confer a sense of control, it makes the patient assume responsibility for outcomes, which is stressful. Some women with breast cancer want to leave treatment decision making (TDM) solely to their surgeons, but most prefer to be involved.<sup>1</sup> Participation preferences (PP) in breast cancer TDM are influenced by education<sup>1</sup> and age<sup>2</sup> but are dependant on doctors providing the opportunity to choose. Studies examining the congruence between preferred and actual levels of TDM involvement in breast cancer surgery report that 28 to 50% of women fail to achieve their desired level of involvement.<sup>3</sup> Older women<sup>2,3</sup> and those of lower socio-economic status<sup>4</sup> are less likely to achieve their desired level of TDM involvement. Participation congruence impacts on patient outcomes: more incongruence predicts less satisfaction with a medical consultation. Increasing involvement has little value unless the patient perceives it as preferable and beneficial. Most studies of patient participation in breast cancer TDM have been done on Caucasian women. We examined Hong Kong Chinese women's preferences for, and actual participation in breast cancer TDM, the influences on PP, perceived participation congruence (PPC), and the effect of reported participation incongruence on satisfaction with TDM.

## Methods

### Sample and setting

This study was conducted from October 2000 to June 2003. Between October 2001 and April 2002, 211 Chinese women newly diagnosed with breast cancer underwent surgical treatment in six government-funded hospitals in Hong Kong. Inclusion criteria were age 20 years or older and Cantonese fluency. Exclusion criteria were linguistic or intellectual difficulties, a currently active Axis I psychiatric diagnosis, or uncontrolled metastatic brain disease. Of these 211 women, 22 did not meet the inclusion criteria, and 17 were inaccessible. Therefore, 172 women were invited to participate and 154 agreed, giving a response rate of 89.5%.

### Procedure

Following ethical approval, medical records were reviewed to confirm eligibility. Eligible women were approached and given an explanation of the study and information on: participants' rights, uncontested and unprejudiced withdrawal, and anonymity safeguards. Written informed consent was obtained from each participant. Interviews were conducted in private, by one of three trained interviewers, within 12 days of surgery.

### Measures

#### Perceived involvement in treatment decision making

Three items were used to measure perceived involvement in TDM: "Did your surgeon tell you there were treatment options?" assessed opportunity for surgical choice. "Did you feel you had a choice about which type of surgery to have?" measured perception of control over the treatment choice. A choice of one of the following measured how involved they felt they were in the TDM: "No participation", "Much less than I wanted", "About as much as I wanted", and "I was left to decide everything though I didn't want to". Finally, women indicated whether their surgeons had communicated a preference for a particular type of surgery.

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**Table 1. Women's treatment decision making participation preferences (n=154)**

Education	Participation preference, No. (%)		
	Active	Collaborative	Passive
No formal education	8 (47)	8 (47)	1 (6)
Primary	17 (33)	29 (57)	5 (10)
Secondary	21 (31)	41 (61)	5 (8)
Tertiary	5 (26)	13 (68)	1 (5)
Total	51 (33)	91 (59)	12 (8)
Mean age* (SD) [years]	53.10 (10.19)	50.08 (11.18) <sup>†</sup>	58.83 (11.50) <sup>†</sup>

\* Analysis of variance,  $F=4.01$ ,  $df=2,151$ ,  $P=0.02$

<sup>†</sup> Post hoc Bonferroni mean difference=8.76,  $P=0.029$

### Treatment decision making participation preferences

Women indicated their PP in TDM by choosing one of the following options: active (I wanted it to be fully my decision), collaborative (I wanted it to be partly my decision and partly someone else's), or passive (I wanted someone else to make the decision). Those preferring collaborative or passive roles indicated who they wanted to help them decide. To assess the clarity and content validity of these items they were reviewed by a breast nurse specialist and a breast surgeon and piloted on 10 randomly chosen Hong Kong Chinese women following breast cancer surgery.

### Perceived treatment decision making difficulties

The Perceived Treatment Decision Making Difficulties Scale is a qualitatively and quantitatively derived eight-item instrument that was piloted on 226 Chinese women following breast cancer treatment.<sup>5</sup> This four-point Likert-scored scale comprises two sub-scales: a 'barriers' subscale comprising six items assessing decision making difficulties and a 'facilitators' subscale comprising two items that facilitate treatment decision making. Women also rated their level of confidence in their treatment choice on a 10-cm line marked "0% No chance—100% Completely certain".

### Patient satisfaction with the medical consultation

We used a modified version of the Cognitive and the Affective sub-scales of the Medical Interview Satisfaction Scale<sup>5</sup> to measure satisfaction with the TDM consultation. To minimise the assessment load, only the four most relevant items from each subscale were used. The modified instrument was revalidated on 82 Hong Kong Chinese women following breast cancer treatment. For each of the eight statements, respondents were asked to recall the medical consultation that led to their treatment decision. A total satisfaction score was obtained by combining the two sub-scale scores.

### Demographic and medical information

Information obtained from hospital charts included: cancer stage, time since surgery, type of surgery, and type of adjuvant therapy including radiation therapy, chemotherapy, and hormonal therapy. Demographic information included patient's age, marital status, number of children, income, current household size, education, occupation, residency, and religion.

### Statistical analysis

One-way ANOVA was used to test the effect of age on TDM

PP, and PPC. Kendall's tau was used to test associations between education and both PP and PPC, and associations between TDM PP and PPC. A Chi squared test was used to test differences in PPC by (1) presence or absence of surgeon's expressed preference for surgery type and (2) opportunity to choose between breast conserving treatment (BCT) and modified radical mastectomy (MRM). In those offered a choice between BCT and MRM, the Chi squared test was used to evaluate differences in PPC according to women's perception of control over their treatment choice. Stepwise multiple linear regressions examined the effect of PPC on their TDM satisfaction. The Statistical Package for the Social Sciences (Windows version 10.0; SPSS Inc, Chicago [IL], US) was used.

## Results

### Sample characteristics

The 154 participants, aged 28 to 79 (mean, 51.76; standard deviation [SD], 11.09) years were mostly married (73%), had at least a secondary education (56%), and were employed full-time (37%). The rest were mostly housewives (25%) and retirees (21%). At baseline, 17 (11%) were previously employed and nine (6%) became unemployed after the diagnosis of breast cancer. Of these 154 women, 108 (70%) had MRM, 30 (19%) had BCT, and 13 (8%) had MRM plus breast reconstruction (MRM+R). Two (1%) had BCT followed later by MRM. One had an axillary dissection only. Of the 108 women with known staging information, 19 (18%) had stage 0 cancer, 30 (28%) had stage I, and 53 (49%) stage II. The time since diagnosis ranged from less than 1 month to 10 months (mean, 2.18; median, 2; SD, 1.69 months); 42% had surgery within 1, and 76% within 2 months of diagnosis. Neoadjuvant chemotherapy (given before surgery to shrink the tumour) was associated with more advanced disease ( $\chi^2$  for trend=7.3,  $P<0.001$ ), prompting delays of 4 months or more between diagnosis and surgery ( $\chi^2$  for trend=51.6,  $P<0.001$ ), but referral or hospital source did not affect delay. Women were interviewed between 1 and 12 days (mean, 2.97; SD, 1.87 days) post surgery.

### Women's perceptions of treatment decision making involvement

Eighty-four (55%) women were offered different surgical options and 43 (51%) indicated that their surgeons expressed a preference for surgery type. Of the 84 women offered a choice, 61 (73%) perceived that they truly had a choice of surgery type, while 23 (27%) perceived that they "really had no choice". Of these, 11 (48%) indicated that their medical condition dictated the decision for them and nine (39%) indicated that their surgeons implied one treatment was superior. Eventually, of the 84 women offered a choice, 50 (60%) chose MRM, 28 (33%) BCT, and six (7%) MRM+R. Forty-one (49%) made an immediate choice, with 27 (66%) choosing MRM, one (2%) MRM+R, and 13 (32%) BCT. Of the women encouraged to delay their decision, 23 (53%) chose MRM, 5 (12%) MRM+R, and 15 (35%) BCT.

**Table 2. Women's perceptions of participation congruence in decision making (n=154)**

	Perceived participation congruence, No. (%)		
	Not allowed/less than desired	As much as desired	More than desired
Education			
No formal education	1 (6)	11 (65)	5 (29)
Primary	5 (10)	39 (76)	7 (14)
Secondary	3 (4)	59 (88)	5 (7)
Tertiary	1 (5)	15 (79)	3 (16)
Surgeon expressed surgical preference <sup>*</sup>			
Yes	9 (8)	91 (83)	10 (9)
No	1 (2)	32 (74)	10 (23)
Treatment choices offered <sup>†</sup>			
Yes	2 (2)	63 (76)	18 (22)
No	8 (11)	61 (86)	2 (3)
Participation preference			
Active	0	46 (90)	5 (10)
Collaborative	8 (9)	68 (75)	15 (16)
Passive	2 (17)	10 (83)	0
Perception of control over treatment choice (n=84)			
Yes	0	48 (79)	13 (21)
No	2 (9)	16 (70)	5 (22)
Total	10 (6)	124 (80)	20 (13)
Mean age (SD) [years]	47.2 (11.5)	52.1 (11.4)	51.6 (8.8)

\*  $\chi^2=6.63$ , df=2, P=0.036†  $\chi^2=15.59$ , df=2, P<0.000**Treatment decision making participation preference**

Fifty-one (33%) women wanted sole responsibility for the decision, 91 (59%) wished to share the decision with someone else, and 12 (8%) wanted to delegate the decision. The surgeon and the spouse were the people most often nominated to share the decision, or delegated to make it. Preferred decision making roles only differed by age ( $F=4.01$ ,  $df=2$ ,  $P=0.02$ ): women preferring a collaborative role were younger (mean age, 50.1 years) than those preferring a passive role (mean age, 58.8 years) [mean difference, 8.8 years;  $P=0.029$  post hoc Bonferroni] (Table 1). The TDM participation preference was neither affected by any delay between diagnosis and treatment nor by immediate versus delayed choice.

**Perceived participation congruence in treatment decision making**

A total of 124 (81%) women felt they had participated as much as they desired, 20 (13%) felt they had participated more than they desired (over-involved), and 10 (6%) felt they were not allowed to participate or had participated less than they desired (not-at-all- or under-involved). The PPC did not differ with age, education, time from diagnosis to treatment, nor by immediate versus delayed choice, however PPC did differ between women whose surgeons had expressed a preference for surgery type and women whose surgeons had not expressed a preference ( $\chi^2=6.63$ ,  $df=2$ ,  $P=0.036$ ). More of those whose surgeons had not expressed a preference (23%) felt that they were over-involved than those whose surgeons had expressed a preference (9%). Differences were also found between PPC and the offer of treatment choice. More of those women not offered treatment choices (11%) felt that they were not-at-all-, or under-involved compared to those offered treatment choices (2%). In contrast, more of those offered treatment choices (22%) felt over-involved than those with no

choices (3%) [ $\chi^2=15.59$ ,  $df=2$ ,  $P<0.000$ ]. These data did not support the hypothesis that PPC is a function of women's perception of control over their treatment choice; in this group PPC was unrelated to the perception that they really had a choice. The PP level and PPC were not significantly correlated (Table 2).

**Effect of perceived participation congruence on patient treatment decision making satisfaction**

Perceived participation congruence significantly predicted perceived TDM difficulty, adjusting for age. Compared with those who felt they had participated about as much as they desired, women who felt either over-involved ( $\beta=0.21$ ,  $P=0.009$ ) or under-involved ( $\beta=0.16$ ,  $P=0.045$ ) reported significantly greater difficulties making treatment decisions. Decision Barriers and Decision Facilitators sub-scale scores were significantly predicted by PPC. Compared to women who felt they had participated about as much as they desired, women who felt over-involved perceived greater barriers ( $\beta=0.19$ ,  $P=0.021$ ) and fewer facilitators (insufficient time and information) [ $\beta=0.16$ ,  $P=0.04$ ] to making a treatment decision. Compared to women who felt they had participated about as much as they desired, those who felt not-at-all- or under-involved perceived fewer facilitators ( $\beta=0.33$ ,  $P<0.000$ ) when making their treatment decision. Adjusting for the effects of other variables, neither the Medical Interview Satisfaction Scale nor sub-scale scores were predicted by PPC. Overall, women in each of the three PPC categories were satisfied with their medical consultation (mean score, 31.55; SD, 4.22). Perceived participation congruence significantly predicted perceived confidence in having made the right treatment choice. Women who felt over-involved had significantly less confidence ( $\beta=-0.23$ ,  $P=0.005$ ) that they had made the right treatment choice compared with those who felt

they had participated about as much as they desired. There was no significant difference ( $P=0.09$ ) between the under-involved group and the as-much-as-desired group regarding confidence in the right treatment choice.

## Discussion

Breast cancer TDM preferences vary nationally and temporally. Our validated methods are highly relevant to Hong Kong Chinese women. Participants were interviewed after their surgery, permitting bias from cognitive dissonance particularly the post hoc rationalisation of decisional choice. To minimise this, we interviewed women early (mean time, day 3 post surgery). Surgical wounds are usually covered for a few days post-surgery, and anatomical pathology results may not be available for up to 4 weeks hence, participants' responses were unlikely to be contaminated by regret or disappointment over outcomes. There is the possibility that pain, analgesia or in some cases residual anaesthetic effects might have influenced reporting.

Participants preferred to be involved in breast cancer TDM, but two thirds preferred a shared rather than sole responsibility, consistent with earlier reports.<sup>6</sup> However, if the choice is between either the woman or the doctor deciding, then women prefer that their doctor makes the choice, under the assumption that doctors are better informed.<sup>5</sup> Participants preferred a moderated active role if they were asked to choose between active, collaborative, and passive roles. This suggests that most Hong Kong Chinese women want shared responsibility with their doctors when making a treatment decision and do not want to be left to make their decisions alone. Older women preferred a passive role, probably reflecting paternalistic traditions of care.<sup>2,7</sup> In Hong Kong, older women tend to be less formally educated and may lack confidence in their choices. Even so, few women preferred a passive role, which might explain why, unlike previous studies, we found education to be unrelated to PPC.<sup>1</sup> Those women not offered treatment options felt under-involved, finding TDM more difficult. Those feeling over-involved perceived more barriers to their TDM. A similar US study<sup>8</sup> reported PPC rates of 49% congruent, 25% under-involved and 26% over-involved, compared with our rates of 80%, 6% and 13% respectively. Knowing their surgeon's preference for type of surgery is important to Hong Kong Chinese women. Those who did not know this preference felt over-involved. These data indicate complexities in TDM choice roles and have implications for clinical care of Hong Kong Chinese women with breast cancer. If women who prefer shared decision making are left to decide alone, more time and information will not benefit them. Over-involved women face greater difficulties with decision making and have less confidence in their treatment choices, a possible source of unnecessary stress.

This study has several implications for clinicians managing Hong Kong Chinese women with breast cancer.

When discussing treatment options, clinicians should: suggest that decision making be shared but offer the option of either party deciding; ask the woman to express her feelings about being offered a treatment option; respect a preference, once expressed. It is also important to: ensure the woman has enough time to ask questions and to make a treatment decision; encourage the woman to repeat the discussion to ensure she has understood the content; give her time (24-72 hours) to decide and to be available to answer questions; express your own preference for treatment, eg "If you were my sister/wife/mother/daughter..." or "If I were in your position, I'd probably want to have MCM/BCT, etc" and say why.<sup>9</sup>

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