EPIDEMIOLOGY

Trajectories of body image and sexuality during the first year following diagnosis of breast cancer and their relationship to 6 years psychosocial outcomes

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Abstract We examined degree and determinants of change in body image and sexuality over the first year following breast cancer diagnosis to differentiate body image and sexuality trajectories, and then explored if differences in trajectories predicted 6 years' psychosocial outcomes. 363/405 (90%) Chinese women receiving surgery for BC were assessed at 5-days (Baseline), 1-month, 4-months, and 8-months post-surgery. Psychological distress, treatment decision making (TDM) difficulties, satisfaction with treatment outcome, optimism, and self-efficacy were assessed at Baseline. Self-image and sexuality were recorded at each follow-up assessment. Latent growth mixture modeling identified trajectories of self-image and sexuality. Multinominal logistic regression identified factors predicting trajectory patterns. Six years later 211/363 (58%) of the original patients were successfully traced and their psychosocial status assessed. Three distinct trajectories of self-image and sexuality were identified: high-stable, recovery, and high-deteriorating. Most women (64% self-image; 58% sexuality) showed stable levels of self-image and sexuality scores. TDM difficulties, satisfaction with treatment outcomes, physical symptom and psychological distress predicted trajectory patterns. Self-image trajectories over the first year diagnosis predicted 6-years psychosocial outcomes. Women with high-stable level of self-image had the best 6-year self-image and sexuality; women with initial low level of self-image had significantly greater long-term psychological distress. Low TDM difficulties and high treatment outcome satisfaction predicted high and stable self-image and sexuality. Type of surgery showed little impacts on self-image and sexuality. Self-image during acute illness phase predicted long-term outcomes. Interventions should focus on minimizing self-image decrement.

Keywords Body image · Sexuality · Trajectory patterns · Breast cancer · Treatment decision making · 6-Year survivorship · Chinese

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Introduction

The diagnosis and treatment of breast cancer (BC) disrupts patient's lives, affecting the woman's quality of life. Body image and sexuality are two domains particularly sensitive to the effects of BC treatment [1–10]. However, the relationship of treatment type with body image and sexuality is inconsistent. Despite studies showing that women who received breast conserving therapy experience fewer body image and sexuality difficulties compared to women receiving mastectomy or those with mastectomy and breast

reconstruction [1–3, 5, 8, 10], other studies found no significant differences attributable to surgery type [4, 7, 9]. Attempting to resolve this discrepancy, recent longitudinal studies have examined changes in body image and sexuality over time by surgery type [3, 4, 6, 7, 9]. Findings suggested that surgery type predicted body image and psychosexual adjustment in the short-term but not the longer term. These prospective studies indicated that, usually, patients' perceptions of body image and sexuality decrements improve progressively throughout the year following surgery [3, 4]. However, this might not apply to all patients.

Recent evidence suggests that cancer patients show various patterns of change in adjustment over time with distinct trajectories of change in adjustment following a BC diagnosis [11–14]. While most BC patients experienced little functional disruption, some reported persistent chronic disruption of normal functioning and others initial functional disruption that remitted. However, these trajectories focused on psychological morbidity. Existing longitudinal studies of body image and sexuality after BC use averaged data from all patients, thereby obscuring individual patterns of change. We therefore attempted to fill this gap by examining if different patterns of adjustment in body image and sexuality exist over the first year following BC surgery. We also looked for factors that might predict distinct trajectories of adjustment in body image and sexuality. Based on previous research [3, 4, 9], we hypothesized a priori that three sets of factors might differentiate distinct trajectories: (1) perceived treatment decision-making (TDM) difficulties and satisfaction with surgical outcome. Previous studies on TDM mostly examined the impact of decision-making preference on health-related quality of life and found women with greater involvement in TDM reported better quality of life scores [15, 16]. The few studies examining impact of TDM satisfaction on body image and sexuality adjustment suggested women encountering TDM difficulties and who were disappointed with subsequent treatment outcomes reported poor body image and sexuality [3, 17], as well as greater generalized psychological and symptom distress [13]. While surgery type apparently has little impact on body image and sexuality over time [3, 4], TDM difficulties and satisfaction with surgical outcome significantly predict short-term and long-term body image and sexuality adjustment [3]; (2) dispositional optimism and perceived self-efficacy [3]; and (3) physical symptom distress and psychological distress, which also contribute to body image [3] and sexuality adjustment [3, 9] were also included.

Finally, we examined if initial trajectory of body image and sexuality adjustment during the first year following primary BC surgery predicted 6 years psychosocial outcomes.

Methods

Patients and setting

Following institutional ethical approval, all women admitted for BC surgery between October 2001–January 2003 in the six regional Hong Kong public hospitals comprised the sample frame. Inclusion criteria were Chinese women, 18 years or older scheduled for BC surgery. Exclusion criteria were linguistic or intellectual difficulties, or uncontrolled metastatic brain disease. A baseline face-to-face interview assessment was conducted within 5 days after surgery (Baseline). Telephone interview follow-up assessments were conducted at 1-, 4-, and 8-months post-surgery. For the 6-years' follow-up, we attempted to re-contact by telephone all original study participants at between 5 and 6 years following their surgery and invited their participation in a follow-up telephone interview. All women gave fully informed consent to be interviewed and approved access to their medical records.

Measures

Body image and Sexuality were measured using relevant subscales of the Chinese Social Adjustment Scale (Ch-SAS) which was developed and validated by us [18]. The ChSAS incorporates a subscale measuring Self-image (Cronbach's alpha (α) = 0.77) addressing self-consciousness, embarrassment, self-comfort, and felt body integrity, and a subscale measuring Appearance and Sexuality (α = 0.67) addressing intimate appearance and partner intimacy. The ChSAS has good psychometric properties, including convergent, divergent, and clinical validity and acceptable sensitivity [18].

Perceived TDM difficulties were measured using the 8-items Perceived TDM Difficulties scale (α = 0.85) [19] on a Likert response scale ranging from "strongly disagree" to "strongly agree". This measure was developed and validated by us previously [19]. Patient satisfaction (disappointment) with surgical outcome was calculated from the congruence between women's expected and perceived outcomes of surgery by adapting the 12-items Breast Cancer Decision Making Questionnaire (BCDMQ) [20, 21] to measure expected (at baseline) (α = 0.78) and perceived (at follow-ups) (α = 0.80) surgical outcome. Higher baseline (expectancy) scores indicated greater negative expectations of later surgical outcome, and higher follow-up scores indicated poorer perceived actual outcome. Follow-up totals subtracted from baseline totals give a discrepancy score reflecting expectancy-outcome incongruence (E-OI), with more extreme scores reflecting greater outcome satisfaction (negative scores) or disappointment (positive scores).

Dispositional optimism was measured with the six-item Chinese revised Life Orientation Test (CLOT-R) ($\alpha = 0.81$) [22]. The CLOT-R is a Hong Kong Chinese population-adapted and validated equivalent of the original LOT-R [22] and has been previously used in this cancer population [19, 23]. General self-efficacy was measured by the 10-item Chinese version of Generalized Self-efficacy scale (GSeS) ($\alpha = 0.90$) [24]. This measure has been validated within a Hong Kong Chinese population including cancer patients [19].

Physical symptom distress was measured by a 14-item checklist ($\alpha = 0.83$) [19] indicating: "I do not have this symptom" (0) or have "mild" (1) through to "very severe" (4) distress arising from this symptom. This measure was derived from our earlier work [17] and other empirical literature. Higher summed sores indicated greater physical symptom distress.

Psychological distress was measured using the 12-item Chinese Health Questionnaire (CHQ-12) ($\alpha = 0.79$) [25]. The CHQ-12 is based on Goldberg's General Health Questionnaire [26] adapted for the slightly different presentation of distress among Chinese and is a validated screening tool for psychological distress in Chinese non-psychiatric populations [25]. The CHQ-12 has been used in previous cancer studies [19, 23]. Higher scores reflect greater psychological distress.

Age, education, marital status, occupation, and disease stage, time since surgery, type of surgery, lymph nodes status and adjuvant therapy status were gathered from patients and medical records, respectively.

ChSAS Self-image and Appearance & Sexuality scales were measured at 1-, 4-, and 8-months post-surgery. TDM difficulties, Expected surgical outcome, GSeS and CHQ-12 were assessed at baseline, whereas CLOT-R and physical symptom distress were measured at 1-month post-surgery.

Psychosocial outcomes at 6 years post-operatively (6-year outcomes) comprised psychological distress, cancer distress, self-image, and sexuality, operationalized as follows: Psychological distress was measured using the 14-item Chinese version of Hospital Anxiety and Depression Scale (HADS) [27]. Because some CHQ12 items address somatic manifestations of distress (e.g., pressure in the chest, palpitations, and headaches), the HADS, which avoids somatic symptoms, was used in the 6-years follow-up study to avoid the possibility of inflated distress due to contamination by physical symptoms. The HADS consists of two subscales measuring anxiety (HAD-A) ($\alpha = 0.84$) and depression (HAD-D) ($\alpha = 0.63$). Higher scores reflect greater anxiety and depression. This measure has been widely used in studies of cancer patients and has excellent validity and reliability [28–30]. ChSAS Self-image, and Appearance and Sexuality scales measured self-image and sexuality [18]. Cancer-related distress was assessed using the 22-item Chinese Impact of Events Scale-revised (CIES-R) [31], a locally validated measure of subjective distress caused by traumatic events including cancer [32]. The CIES-R consists of three subscales measuring intrusive thoughts ($\alpha = 0.85$), avoidant thoughts ($\alpha = 0.70$), and hyperarousal symptoms ($\alpha = 0.68$). In the 6-year follow-up study, data on presence of cancer recurrence and active treatment were gathered from patients.

Data analysis

To examine if participants differ from those refusing or lost to follow-up by demographic and medical factors, we used χ^2 analysis for categorical data and independent t test for continuous data. To examine patterns of body image and sexuality over the first year following BC surgery, we used a latent growth mixture model (LGMM) framework [33], derived using Mplus version 5.21. With longitudinal data LGMM tests whether the population under study comprises two or more discrete classes of individuals with differing profiles of growth (trajectories), with class membership determined by these different growth parameters. After determining the optimal number of component classes, examination of covariates can differentiate determinants or correlates of class membership. Mplus employs a robust full-information maximum-likelihood (FIML) estimation procedure for handling missing data. FIML assumes that missing data are unrelated to the outcome variable (missing at random) [34, 35].

Our analyses followed three steps [36]: (a) identify a univariate single-class growth model without covariates (the studied predictors); (b) use fit indices to identify the optimal number of distinct trajectories without covariates. To optimize the number of trajectories, the Bayesian (BIC), sample-size adjusted Bayesian (SSBIC), and Aikaike information criteria (AIC), entropy values, the Lo–Mendell–Rubin likelihood test (LRT) and the bootstrap likelihood ratio test [36] fit indices were used. In addition, we examined models in which the growth parameters and associated covariance were constrained to be equivalent across classes, and models in which these constraints were relaxed. We sought a model with lower values for the information criteria indices, higher entropy values, and P values ≤ 0.05 for both the LRT and the BLRT; (c) consistent with recommendations for correct model specification [36], we then extended the LGMM to include covariate predictors of class membership. Because inclusion of too many covariates impairs model convergence, we selected six covariates (perceived TDM difficulties, self-efficacy, optimism, psychological distress, satisfaction with treatment outcomes, and physical symptom distress) postulated to improve class assignment. Then, to examine other covariates (e.g., demographic and medical factors)

not included in the conditional model, we used multi-nominal logistic regression that included all of the proposed predictors and control variables. To determine covariate inclusion in the regression model, we first examined if class memberships differed by any demographic and medical factor using χ^2 analysis for categorical data and independent t test for continuous data.

Lastly, we used stepwise multiple regression to assess the effect of initial trajectories of Self image and Appearance and Sexuality adjustment on 6-year psychosocial outcomes, adjusting for the effects of demographic and medical characteristics. Again, we first determined which demographic and medical factors associated with the 6-year psychosocial outcomes using independent sample t test or analysis of variance (ANOVA). Then variable entry into each regression model was determined by using the stepwise method with a P value for entry of 0.05 and for removal of 0.1. Final models were confirmed using forced entry. Significance was determined if $P < 0.05$. The regression coefficient β (beta coefficient) reflects the magnitude of expected change in dependent variable per standard deviation change in a predictor variable (slope), and indicates the independent contribution of its respective predictor variable to prediction of the dependent variable.

Results

Patient characteristics in the original study

At Baseline, of 443/529 (84%) eligible women, 405 (91%) gave consent, immediately completing a face-to-face interview. Of these, 363 (90%) completed T1, 331 (82%) completed T2, and 338 (84%) completed T3 follow-ups. Women refusing or lost to follow up did not differ by demographic or medical factors.

Here, we report analyses based on data from Baseline, T1, T2, T3, and 6 year follow-up from the 363 participants completing the T1 follow-up, this being the first time point Self-image and Appearance & Sexuality were assessed. Table 1 summarizes the demographic and clinical characteristics of the women.

Self-image trajectories

Unconditional model

Preliminary analyses indicated that the best fitting unconditional models were those in which variance for slope was constrained across classes. For Self image, the AIC, BIC, and SSBIC decreased (better fit) in models up to three classes (Table 2). In addition, LRT indicated a statistically insignificant difference between three-class and four-class models, further suggesting that the four-class model failed to improve fit [36].

Conditional model

Using a three-class solution, as determined above, we included six covariates (perceived TDM difficulties, self-efficacy, optimism, psychological distress, satisfaction with treatment outcomes, and physical symptom distress) to specify a conditional model. Using log-likelihood ratio Chi-square (χ^2) to assess the model fit, the conditional model with six covariates significantly improved model fit ($\chi^2(20) = 533.11$, $P < 0.001$). Table 3 shows growth parameter estimates for the final conditional model. Figure 1 showed the trajectories of Self-image. Most women (63.5%) were assigned to a "high-stable" class having relatively stable, high Self-image scores across assessment points. Women in the second largest group, "high-deteriorating" (19.9%), had high initial Self-image scores but reported steadily decreasing Self-image scores at T2 and T3. Women in the third group, "recovery" (16.7%), started out with the lowest Self-image scores, but showed gradually improving Self-image scores.

Predictors of Self-image trajectories

Compared to the High-stable group (referent), the High-deteriorating and Recovery groups reported greater TDM difficulties ($\beta = 0.134$, standard error (SE) $= 0.051$, $P = 0.009$; $\beta = 0.194$, SE $= 0051$, $P < 0.001$, respectively) and more disappointment with treatment outcomes ($\beta = -0.143$, SE $= 0.052$, $P = 0.006$; $\beta = 0.188$, SE $= 0.052$, $P < 0.001$), respectively). Next, we used multinominal logistic regression to compare TDM difficulties, E-OI, optimism, self-efficacy, type of surgery and physical symptom distress by distinct trajectories of Self-image, adjusted for demographic and medical variables, as well as Baseline psychological distress (Table 4). Perceived TDM difficulties, physical symptom distress, satisfaction with treatment outcomes, psychological distress, and type of surgery significantly predicted Self-image trajectories ($\chi^2(28) = 174.65$, $P < 0.001$), accounting for 40% of variation in class status (Cox and Snell R^2). Compared with the high-stable group, women assigned to High-deteriorating and Recovery groups reported more perceived TDM difficulties (odds ratio (OR) 1.165, 95% confidence interval (CI) 1.076–1.280; OR 1.234, 95% CI 1.124–1.356), respectively), disappointment with treatment outcomes (OR 1.163, 95% CI 1.087–1.244; OR 1.197, 95% CI 1.104–1.297, respectively), and baseline psychological distress (OR 1.065, 95% CI 1.004–1.130; OR 1.084, 95% CI 1.010–1.164, respectively). Compared to the High-

Table 1 Demographic and clinical characteristics of participants

Characteristics	Original study	Six year follow-up		
	$N = 363(\%)$	Participants $N = 211(\%)$	Non-Participants $N = 152(\%)$	P value
Demographics				
Age (years) mean ± standard deviation (SD)	50.9 ± 10.1	50.8 ± 9.2	60.0 ± 9.1	0.840
Age at 6 years follow-up (years) mean ± SD	–	56.6 ± 11.2	–	
Marital status at recruitment				0.140
Married/cohabiting	274 (75.5)	167 (79.1)	107 (70.4)	
Single/divorced/separated/widowed	89 (24.5)	44 (20.9)	45 (29.6)	
Marital status at 6 years follow-up				
Married/cohabiting	–	154 (73)	–	
Single/divorced/separated/widowed	–	57 (27)	–	
Education level				0.187
No formal education/primary (up to 6 years formal education)	151 (41.6)	90 (42.7)	61 (40.1)	
Secondary (completed high school)	170 (46.8)	95 (45)	75 (49.3)	
Tertiary (college/university)	42 (11.6)	26 (12.3)	16 (10.5)	
Total monthly household income (HK$)[a]				0.025
<$10,000	124 (36.3)	59 (29.8)	65 (45.1)	
$10,001–20,000	111 (32.5)	75 (37.9)	36 (25)	
$20,001–30,000	48 (14)	26 (12.3)	22 (15.3)	
>30,001	59 (16.3)	38 (18.0)	21 (13.8)	
Occupation				1.000
Full-time/part-time occupation	151 (41.6)	87 (41.2)	64 (42.1)	
Retired	63 (17.4)	37 (17.5)	26 (17.1)	
Housewife	104 (28.7)	61 (28.9)	43 (28.3)	
Unemployed before diagnosis	23 (6.3)	13 (6.2)	10 (6.6)	
Unemployed after diagnosis	22 (6.1)	13 (6.2)	9 (5.9)	
Family history of breast carcinoma	32 (8.8)	21 (10)	11 (7.2)	
Medical information				
Mean (±SD) days since breast carcinoma diagnosis	41.2 (± 56.1)	34.0 (± 34.3)	51.1 (± 75.9)	
Mean (±SD) days since surgery	2.4 (± 1.7)	2.5 (± 1.6)	2.3 (± 1.7)	
Disease stage				0.299
0	44 (12.1)	32 (15.2)	12 (7.9)	
I	92 (25.3)	50 (23.7)	42 (27.6)	
II	180 (49.6)	103 (48.8)	77 (50.7)	
III/IV	27 (7.4)	14 (6.6)	13 (8.6)	
Missing	12 (3.3)	12 (5.7)	8 (5.3)	
Surgery type				0.181
BCT	74 (20.4)	50 (23.7)	24 (15.8)	
MRM	267 (73.6)	149 (70.6)	118 (77.6)	
MRM plus reconstruction	22 (6.1)	12 (5.7)	10 (6.6)	
Adjuvant therapy (8-month post-surgery)				
Chemotherapy	17 (8.6)	7 (5.6)	10 (14.1)	0.041
Radiation therapy	8 (4.1)	4 (3.2)	4 (5.6)	0.401
Hormonal therapy	171 (86.8)	115 (91.3)	56 (78.9)	0.014
Breast cancer recurrence	–	12 (5.7)	–	
Missing	–	2 (0.9)	–	
Adjuvant therapy at 6 years follow-up				

Table 1 continued

Characteristics	Original study	Six year follow-up		P value
	N = 363(%)	Participants N = 211(%)	Non-Participants N = 152(%)	
Hormonal therapy	–	43 (95.6)	–	
Chemotherapy	–	2 (4.4)	–	
Trajectories of self-image				0.699
High-deteriorating	–	45 (21.3)	27 (17.8)	
Recovery	–	35 (16.6)	27 (17.8)	
High-stable	–	131 (62.1)	98 (64.5)	
Trajectories of sexuality				0.985
Recovery	–	62 (29.4)	45 (29.6)	
High-deteriorating	–	28 (13.3)	21 (13.8)	
High-stable	–	121 (57.3)	86 (56.6)	

[a] HK$7.8 = US$1

BCT breast conserving therapy, *MRM* modified radical mastectomy

Table 2 Fit indices determining the number of trajectories (n = 363)

No. of classes	AIC	BIC	SSBIC	Entropy	LRT P value	BLRT P value
Self Image						
1	5115.39	5135.17	5119.30			
2	4729.89	4765.49	4736.93	0.90	<0.001	<0.001
3	4646.50	4697.93	4656.68	0.71	0.05	<0.001
4	4647.93	4703.31	4658.89	0.78	0.39	<0.001
Appearance & Sexuality						
1	4660.44	4692.09	4666.70			
2	4504.59	4540.19	4511.64	0.63	<0.001	<0.001
3	4452.23	4503.65	4462.41	0.71	<0.001	<0.001
4	4458.00	4513.38	4468.96	0.86	0.06	<0.001

AIC Akaike information criterion, *BIC* Bayesian information criterion, *SSBIC* sample size adjusted Bayesian information criterion, *LRT* Lo–Mendell–Rubin test, *BLRT* bootstrap likelihood ratio test

Note: We sought a model with lower values for the information criteria indices, higher entropy values, and significant P values for both the LRT and the BLRT

Table 3 Growth factor parameter estimates for three-class conditional models for Self-image and Appearance & Sexuality (n = 363)

	Intercept			Linear slope		
	Mean	SE	P value	Mean	SE	P value
Self Image						
High-deteriorating	18.62	1.22	<0.001	−0.31	0.275	0.266
Recovery	15.02	1.43	<0.001	0.57	0.27	0.035
High-stable	19.97	1.17	<0.001	0.11	0.22	0.605
Appearance & Sexuality						
High-deteriorating	12.65	0.42	<0.001	−0.36	0.09	<0.001
Recovery	10.46	0.57	<0.001	0.44	0.15	0.003
High-stable	14.39	0.12	<0.001	0.05	0.02	0.02

SE standard error

Fig. 1 Trajectories of self-image following breast cancer surgery

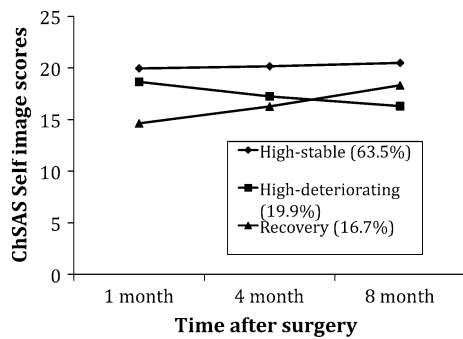Fig. 2 Trajectories of Appearance and Sexuality following breast cancer surgery

stable group, the Recovery group also reported greater physical symptom distress (OR 1.084, 95% CI 1.010–1.164) and were less likely to have undergone breast-conserving therapy (OR 0.084, 95% CI 0.19–0.376).

Appearance and sexuality trajectories

Unconditional model

As previously, the best fitting unconditional models were those in which slope variance was constrained across classes. Fit statistics suggested a similar pattern as for Self-image and indicated the best-fitting model for ChSAS Appearance and Sexuality was again a 3-class model (Table 2).

Conditional model

Using log-likelihood ratio χ^2, the conditional model with the same 6 covariates used previously again significantly improved model fit ($\chi^2(24) = 259.46$, $P < 0.001$). Table 3 shows growth parameter estimates for the final conditional
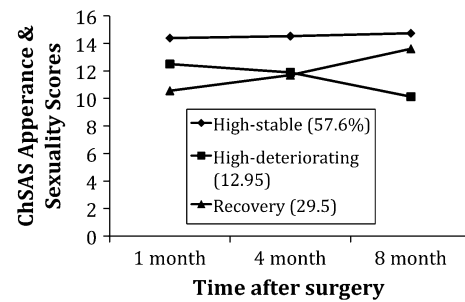
model. Figure 2 shows the Appearance & Sexuality trajectories. Most women (57.6%) were again assigned to a "High-stable" class showing relatively stable, high Appearance & Sexuality scores across assessment points. Women in the second largest "Recovery" group (29.5%) had the poorest Appearance & Sexuality scores at Baseline, but gradually improved over time. Women in the third "High-deteriorating" group (12.9%) had high Appearance & Sexuality scores at T1, which decreased at T2 and T3.

Predictors of Appearance & Sexuality trajectories

Using the High-stable group as the referent, the High-deteriorating group reported more optimistic outlook ($\beta = 0.281$, SE $= 0.120$, $P = 0.019$) but greater psychological distress ($\beta = 0.148$, SE $= 0.058$, $P = 0.011$); the Recovery group reported more TDM difficulties ($\beta = 0.142$, SE $= 0.048$, $P = 0.003$) and disappointment in treatment outcomes ($\beta = 0.106$, SE $= 0.046$, $P = 0.022$). A multinominal logistic regression comparing trajectories against all covariates, with demographic and medical variables, and Baseline psychological distress

Table 4 Multinomial logistic regression of predictors on self-image trajectories (high-stable group as referent) ($n = 363$)

Predictors	Odds ratio (95% CI)	SE	P value
"High-deteriorating" group			
TDM difficulties	1.165 (1.076–1.260)	0.04	<0.001
Disappointment with treatment outcomes	1.163 (1.087–1.244)	0.04	<0.001
Psychological distress	1.065 (1.004–1.130)	0.07	0.036
Physical symptom distress	1.035 (0.981–1.092)	0.03	NS
Type of surgery BCT	.412 (0.167–1.015)	0.06	NS
(MRM as a referent)			
"Recovery" group			
TDM difficulties	1.234 (1.124–1.356)	0.05	<0.001
Disappointment with treatment outcomes	1.197(1.104–1.297)	0.04	<0.001
Psychological distress	1.084 (1.010–1.164)	0.04	0.025
Physical symptom distress	1.077 (1.016–1.142)	0.03	0.013
Type of surgery BCT	0.084 (0.019-0.376)	0.77	0.001
(MRM as a referent)			

95% CI 95% confidence interval, SE standard error, TDM treatment decision making BCT breast conserving therapy, MRM modified radical mastectomy

Table 5 Multinomial logistic regression of predictors on Appearance and Sexuality trajectories (high-stable group as referent) ($n = 363$)

Predictors	Odds ratio (95% CI)	SE	P value
"Recovery" group			
TDM difficulties	1.107 (1.027–1.193)	0.04	0.008
Disappointment with treatment outcomes	1.035 (0.977–1.098)	0.03	NS
Psychological distress	1.207 (1.132–1.287)	0.03	<0.001
Physical symptom distress	1.059 (1.008–1.113)	0.03	0.024
Optimism	1.526 (1.308–1.781)	0.08	<0.001
Non-married	0.831 (0.399–1.729)	0.37	NS
"High-deteriorating" group			
TDM difficulties	1.179 (1.076–1.291)	0.05	<0.001
Disappointment with treatment outcomes	1.126 (1.041–1.217)	0.04	0.003
Psychological distress	1.075 (0.994–1.163)	0.04	NS
Physical symptom distress	1.030 (0.972–1.092)	0.03	NS
Optimism	0.864 (0.724–1.032)	0.09	NS
Non-married	0.268 (0.086–0.843)	0.58	0.024

TDM = Treatment decision making

controlled (Table 5) revealed significant effects for perceived TDM difficulties, physical symptom distress, satisfaction with treatment outcomes, optimism, martial status and psychological distress ($\chi^2(28) = 184.86$, $P < .001$), accounting for 42% of variation in class status (Cox and Snell R^2). Compared with the high-stable group, Recovery group members reported more TDM difficulties (OR 1.107, 95% CI 1.027–1.193), greater physical symptom distress (OR 1.059, 95% CI 1.008–1.113), greater optimistic outlook (OR 1.53, 95% CI 1.308–1.782), and greater psychological distress (OR 1.207, 95% CI 1.132–1.287); High-deteriorating group members reported greater TDM difficulties (OR 1.179, 95% CI 1.076–1.291), greater disappointment with treatment outcomes (OR 1.126, 95% CI 1.041–1.217), and were less likely to be married (OR 0.268, 95% CI 0.086–0.843).

Self-image and Appearance & Sexuality trajectories relative to 6-year outcomes

We re-contacted these original 363 women and 211(58%) completed the 6-year follow-up interview. From Baseline data women refusing (9%), lost to follow-up (23%) or deceased (9%) at 6 years did not differ by demographic or clinical factors from participants (Table 1).

Multivariate analyses compared both Self-image and Appearance & Sexuality trajectories, with the High-stable group as referent, in predicting 6-year anxiety, depression, cancer distress, Self-image, and Appearance & Sexuality. These analyses controlled for 6-year measures of optimism, self-efficacy, breast symptoms, arm symptoms, age, martial status, occupation, and BC recurrence (Table 6). Appearance & Sexuality trajectories did not predict 6-year outcomes. Self-image trajectories comparing against High-stable group members showed Recovery group members

reported greater anxiety ($\beta = 0.224$, $P < .001$), depression ($\beta = 0.178$, $P = 0.005$), and hyperarousal symptom ($\beta = 0.227$, $p = 0.001$) scores. Women in the Recovery group and those in the High-deteriorating group reported poorer Self-image ($\beta = -0.286$, $P < 0.001$; $\beta = -0.281$, $P = 0.024$, respectively) and Appearance & Sexuality scores ($\beta = -0.321$, $P = .002$; $\beta = -0.216$, $P = 0.002$, respectively), and greater intrusive thoughts ($\beta = 0.241$, $P < 0.001$; $\beta = 0.148$, $P = 0.024$, respectively) than referent group women.

Discussion

We identified three trajectories for Self-image, and Appearance and Sexuality scores among a sample of Chinese women during the 8 months following BC surgery. Whereas previous studies using average-level data showed an initial deterioration in body image and sexuality that gradually resolved [3, 4], our LGMM analyses revealed that only 17 and 30% of our sample showed this pattern for body image and sexuality, respectively. Instead, we found that most study participants did not perceived significant decrements in Self-image and Appearance & Sexuality scores relative to pre-diagnosis. Moreover, a significant proportion of participants perceived deteriorating body image (20%) and sexuality (13%) over time. Our results accord with previous trajectory analyses examining adjustment to demands, supporting the view that most people experienced little or no significant disruption of functioning in response to adverse events [11–14, 37].

We also examined predictors of these different Self-image and Appearance & Sexuality trajectories. Compared with the high-stable group, those in the high-deteriorating and recovery groups for both Self-image and Appearance &

Table 6 Multiple regression modeling of predictors of 6-year psychosocial outcome measures ($n = 211$)

β values	HADS-anxiety	HADS-depression	CIES-R intrusive	CIES-R hyper-arousal	ChSAS self-image	ChSAS Appearance and Sexuality
Self-image trajectory						
High-stable[a]	Referent	Referent	Referent	Referent	Referent	Referent
Recovery[a]	0.22***	0.18**	0.24***	0.22**	−0.29***	−0.32***
High-deteriorating[a]	0.09	0.07	0.15*	0.08	−0.28***	−0.22**
Optimism	−0.27***	−0.34***	−0.17**	–	0.21**	0.24***
Self-efficacy	−0.20**	–	–	−0.14*	–	–
Breast symptoms	0.25***	0.20**	0.21**	0.22**	–	–
Age	−0.14*	–	–	–	–	–
Marital status						
Married	–	–	–	–	–	−.13*
Occupation						
Employed	0.16*	0.19**	.27***	–	–	–
Unemployed	–	–	–	.17**	–	–

This table included only the covariates that were statistically significant in at least on model

HADS Hospital Anxiety and Depression Scale, *CIES-R* Chinese Impact of Events Scale-revised, *ChSAS* Chinese Social Adjustment scale

Distress trajectory: 1–8 months post-surgery. All variable measured concurrently at 6 years, except [a]based on 1–8 months distress trajectory. Significance: * <0.05, ** <0.01, *** <0.001

Sexuality trajectories experienced greater difficulties in making decision about breast cancer surgery. Disappointment with treatment outcomes also differentiated Self-image and Appearance & Sexuality trajectories. Women reporting feeling under- or over-involved in the TDM consultation, perhaps feeling less control, reported more TDM difficulties [3, 38]. These women also reported greater disappointment and more physical and psychological distress, and 6-years later, more hyperarousal and intrusive thoughts. This suggests women experiencing TDM difficulties inaccurately anticipate appearance outcomes, generating disappointment, and impairing self-image and sexuality [38] and also react more to symptoms, experiencing greater distress. These ∼36–42% of patients seemed to have poorer long-term adaptation to breast cancer and carry a disproportionate burden as a consequence. Appearance & Sexuality declines over time were more common in single women those reporting disappointment as well as TDM difficulties. It is possible that single women are more at risk of TDM difficulties, disappointment and Sexuality & Appearance decrements because they lack an intimate relationship to provide reassurance about their appearance and attractiveness.

Another important predictor of Self-image and Appearance & Sexuality trajectories was immediate post-operative psychological distress. Compared to the high-stable group, women in self-image high-deteriorating or recovery groups experienced greater psychological distress immediately following surgery. Psychological distress only differentiated women in the high-stable Appearance & Sexuality group from those in the recovery group. Psychological

distress distorts perception, thereby probably impairing Self-image and Appearance & Sexuality scores [3, 39].

Type of surgery did not influence Self-image and Appearance & Sexuality trajectories, except differentiating between high-stable and recovery Self-image trajectories. Compared to women in the high-stable group, women in the recovery group were less likely to have undergone breast-conserving therapy, explaining previous longitudinal studies showing surgery type predicted only short-term body image [3, 4, 6, 7, 9].

No previous studies have related self-image and sexuality trajectories over the year following primary BC surgery to predicting longer term psychosocial outcomes. Low psychological distress and little change in self-image and sexuality among women 6 years following diagnosis [40] prevailed contrary to common belief. It is unclear why only Self-image, but not Appearance & Sexuality trajectories predicted long-term outcomes in this sample. This may reflect cultural beliefs about values surrounding sexuality. Most women had good long-term Self-image and Appearance & Sexuality outcomes, whereas, women showing recovery trajectories during the year following primary surgery reported greater 6-year psychological and cancer distress after adjustment for clinical and demographic factors. Curiously, outcomes among women showing high-deteriorating trajectories were comparable to the high-stable group. During the first year following primary BC surgery, women experiencing recovery trajectories had the lowest initial self-image scores. This suggests that initial response to the diagnosis and treatment impacts on self-image and is a key predictor of longer term

psychological outcomes, possibly reflecting degree of prior investment in appearance-as-identity [41, 42]. Hence, identifying women at risk of immediate poor self-image may help to target support and prevention resources more efficiently.

Our study indicated that TDM and satisfaction with treatment outcomes predict Self-image and Appearance & Sexuality trajectories. Hence, assessing preferred TDM involvement at initial consultation, providing decision-making support throughout, and optimizing communications about treatment outcomes are essential pre-operative interventions to help women establish a realistic expectation of treatment outcome, thereby minimizing threats to perceived self-image and sexuality [3].

Since we were unable to assess Self-image and Appearance & Sexuality at the pre-diagnostic, diagnostic, and the immediate post-operative stages we could not examine if pre-diagnostic factors drive subsequent illness trajectory. Also, omitting assessments in the 4 years from T3 to 6-year follow-up prevented us examining trajectories between the first and the sixth year. Though use of the ChSAS subscales to measure body image and sexuality may limit the cultural generalizability of the study findings the ChSAS item content compares well with other measures, such as the Body Image Scale [41]. For example, both measures assess women's feeling of self-consciousness, satisfaction when wearing tight clothes, and willingness to look at their own body. The 58% follow-up response rate suggests caution in interpreting our findings about long-term outcomes, despite respondents and non-respondents having comparable demographic, medical and trajectory profiles over the first year of this study.

Few decrements in self-image and sexuality over the first year following primary BC surgery were observed in our sample of Chinese women treated for breast cancer. Type of surgery minimally predicted changes of self-image in the first year, while TDM factors and early post-operative psychological distress strongly influence Self-image and Appearance & Sexuality. Finally, Self-image trajectory predicted longer term psychological, self-image, and sexuality outcomes while initial Self-image response following surgery predicted long-term psychological distress.

References

1. Yurek D, Farrar W, Andersen BL (2000) Breast cancer surgery: comparing surgical groups and determining individual differences in postoperative sexuality and body change stress. J Consult Clin Psychol 68:697–709
2. Fobair P, Stewart SL, Chang S, D'Onofrio C, Banks PJ, Bloom JR (2006) Body image and sexual problems in young women with breast cancer. Psycho Oncol 15:579–594
3. Lam WWT, Chan M, Hung WK, Or A, Fielding R (2009) Social adjustment among Chinese women following breast cancer surgery. Psycho Oncol 18:1189–1198
4. Parker PA, Youssef A, Walker S et al (2007) Short-term and long-term psychosocial adjustment and quality of life in women undergoing different surgical procedures for breast cancer. Ann Surg Oncol 14:3078–3089
5. Anagnostopoulos F, Myrgianni S (2009) Body image of Greek breast cancer patients treated with mastectomy or breast conserving surgery. J Clin Psychol Med Settings 16:311–321
6. Collins KK, Schootman M, Aft R, et al (2010) Effects of breast cancer surgery and surgical side effects on body image over time. Breast Can Res Treat. doi:10.1007/s10549-010-1077-7
7. Munshi A, Dutta D, Kakkar S et al (2010) Comparison of early quality of life in patients treated with radiotherapy following mastectomy or breast conserving therapy: a prospective study. Radiother Oncol 97:288–293
8. Han J, Grothuesmann D, Neises M, Hille U, Hillemanns P (2010) Quality of life and satisfaction after breast cancer operation. Arch Gynecol Obstet 282:75–82
9. Den Oubsten BL, Van Heck GL, Van der Steeg AFW, Roukema JA, De Vries J (2010) Clinical factors are not the best predictors of quality of sexual life and sexual functioning in women with early stage breast cancer. Psycho Oncol 19:646–656
10. Falk Dahl CA, Reinertsen KV, Nesovld I, Fossa SD, Dahl AA (2010) A study of body image in long-term breast cancer survivors. Cancer. doi:10.1002/cncr.25251
11. Schain WS, d'Angelo TM, Dunn ME, Lichter AS, Pierce LJ (1994) Mastectomy versus conservative surgery and radiation therapy. Cancer 73:1221–1228
12. Pozo C, Carver CS, Noriega V et al (1992) Effects of mastectomy versus lumpectomy on emotional adjustment to breast cancer: a prospective study of the first year postsurgery. J Clin Oncol 10:1292–1298
13. Lam WWT, Bonanno GA, Mancini AD et al (2010) Trajectories of psychological distress among Chinese women diagnosed with breast cancer. Psycho Oncol 19:1044–1051
14. Henselmans I, Helgeson VS, Seltman H, de Vries J (2010) Identification and prediction of distress trajectories in the first year after a breast cancer diagnosis. Health Psychol 29:160–168
15. Street RL, Voigt B (1997) Patient participation in deciding breast cancer treatment and subsequent quality of life. Med Decis Mak 17:298–306
16. Hack TF, Degner LF, Watson T, Sinha L (2006) Do patients benefit from participating in medical decision making? Longitudinal follow-up of women with breast cancer. Psycho Oncol 15:9–19
17. Lam WWT, Fielding R (2003) The evolving experience of illness for Chinese women with breast cancer: a qualitative study. Psycho Oncol 12:127–140
18. Fielding R, Lam WWT (2004) Measuring social impacts of breast carcinoma treatment in Chinese women: the Chinese Social Adjustment Scale. Cancer 100:2500–2511
19. Lam WWT (2002) Studies of the process of breast cancer treatment decision making and its impacts on short-term adjustment to

breast cancer in Chinese women. Unpublished Ph.D. Thesis. The University of Hong Kong, Hong Kong

20. Stanton AL, Estes MA, Estes NC et al (1998) Treatment decision making and adjustment to breast cancer: a longitudinal study. J Consult Clin Psychol 66:313–322

21. Lam WWT, Fielding R, Ho EYY, Chan M, Or A (2005) Surgeon's recommendation perceived operative efficacy and age dictate treatment choice by women facing breast cancer surgery. Psycho Oncol 14:585–593

22. Lai JCL, Yue XD (2000) Measuring optimism in Hong Kong and Mainland Chinese with the Revised Life Orientation Test. Pers Individ Differ 28:781–796

23. Lam WWT, Law CC, Fu YT et al (2008) New insights in system assessment: The Chinese version of the Memorial Symptom Assessment Scale Short Form (MSAS-SF) and the Condensed MSAS (CMSAS). J Pain Symptom Manage 36:584–595

24. Schwarzer R (1993) Measuring of self-efficacy: psychometric scales for cross-cultural research. NFER-Nelson, Windsor

25. Chong MY, Wikinson G (1989) Validation of 30- and 12-item version of the Chinese Health Questionnaire (CHQ) in patients admitted for general health screening. Psychol Med 19:495–505

26. Goldberg DP (1978) Manual of the general health questionnaire. NFER-Nelson, Windsor

27. Zigmond AS, Snaith RP (1983) The hospital anxiety and depression scale. Acta Psychiatr Scand 67:361–370

28. Au AHY, Lam WWT, Chan MCM, Or A, Kwong A, Suen D, Wong AL, Juraskova I (2010) Fielding R. Development and pilot-testing of a decision-aid for use among Chinese women facing breast cancer surgery. Health Expect. doi: 10.111/j.1369-7625, 2010.00655.x

29. Lam WWT, Au AHY, Wong JHF, Lehmann C, Koch U, Fielding R, Mehnert A (2011) Unmet support care needs: a cross-cultural comparison between Hong Kong Chinese and German Caucasian women with breast cancer. Breast Cancer Res Treat. doi 10.1007/s10549-011-1592-1

30. Leung CM, Wing YK, Kwong PK, Lo A, Shum K (1999) Validation of the Chinese-Cantonese version of the Hospital Anxiety and Depression scale and comparison with the Hamilton Rating Scale of Depression. Acta Psychiatr Scand 100:456–461

31. Wu KK, Chan SK (2003) The development of the Chinese version of Impact of Event Scale-Revised (CIES-R). Soc Psychiatry Psychiatr Epdiemiol 38:94–98

32. Chan MWC, Ho SMY, Tedeschi RG, Leung CWL (2011) The valence of attentional bias and cancer-related rumination in posttraumatic stress and posttraumatic growth among women with breast cancer. Psycho Oncol 20:544–552

33. Muthen LK, Muthen BO (2002) Mplus user's guide (version 2.14). Muthen & Muthen, Los Angeles

34. Enders CK (2001) The performance of the full information maximum likelihood estimator in multiple regression models with missing data. Educ Psychol Meas 61:713–740

35. Graham JW (2009) Missing data analysis: making it work in the real world. Annu Rev Psychol 60:549–576

36. Jung T, Wickrama KAS (2008) An introduction to latent class growth analysis and growth mixture modeling. Soc Pers Psychol Compass 2:302–317

37. Bonanno GA (2005) Resilience in the face of potential trauma. Curr Dir Psychol Sci 14:135–138

38. Lam WWT, Fielding R, Chan M, Chow L, Ho EYY (2003) Patient participation and satisfaction with treatment decision making in Chinese women with breast cancer. Breast Can Res Treat 80:171–180

39. Beck AT (1983) Cognitive theory of depression: new perspectives. In: Clayton PJ, Barrett JE (eds) Treatment of depression: old controversies and new approaches. Raven Press, New York, pp 265–290

40. Lam WWT, Shing YT, Bonanno GA, Mancini AD, Fielding R (2010) Distress trajectories at the first year diagnosis of breast cancer in relation to 6 years survivorship. Psycho Oncol. doi: 10.1002/pon.1876

41. Hopwood P, Fletcher I, Lee A et al (2001) A body image scale for use with cancer patients. Eur J Cancer 37:189–197

42. Carver CS, Pozo-Kaderman C, Price AA et al (1998) Concern about aspects of body image and adjustment to early stage breast cancer. Psychosom Med 60:168–174