

# BMJ Open Emotional, informational and instrumental support needs in patients with breast cancer who have undergone surgery: a cross-sectional study

Tingting Cai, Qingmei Huang, Changrong Yuan 

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## ABSTRACT

**Objectives** This study evaluated emotional, informational and instrumental support needs in patients with breast cancer who had undergone surgery, then identified the variables associated with those needs.

**Design** This was a cross-sectional survey study.

**Setting** Questionnaires were distributed in tertiary hospitals in China between January 2018 and July 2020.

**Participants** We recruited 477 eligible patients with breast cancer via convenience sampling. Due to exclusions for response errors, the final analysed sample included 461 participants (mean age of 50.9 years). Each completed a questionnaire consisting of a sociodemographic information component and three short forms from the Patient-Reported Outcome Measurement Information System (social relationships short forms, anxiety short form and depression short form). Subsequent analyses included the  $\chi^2$  test, Pearson correlation and multivariate regression.

**Results** The T scores for informational support were lower than those for the reference group (general population), while those for emotional and informational support were average. Marital status, childbearing history, lifestyle, employment status, anxiety and depression levels were related to the scores for emotional, informational and instrumental support in this population. The regression analysis revealed that emotional support levels, instrumental support levels, marital status, employment status, anxiety and depression outcomes were predictors for informational support levels.

**Conclusions** Informational support should be specifically assessed and promoted among patients with breast cancer in general, while marital status, childbearing history, lifestyle, employment status, anxiety and depression levels should be evaluated when conducting interventions to promote emotional, informational and instrumental support for those who have undergone surgery. Early and regular screenings for high-risk patients will help nurses identify those who are likely to benefit from targeted preventive interventions aimed at emotional, informational and instrumental support issues.

**Trial registration number** ChiCTR2000035439; ClinicalTrials.gov registry.

## Strengths and limitations of this study

- To our knowledge, this was among the few studies to use Patient-Reported Outcome Measurement Information System measures to assess self-reported emotional, informational and instrumental support needs and their predictors among patients with breast cancer who have undergone surgery, especially within the Chinese cancer population.
- Our results will help nurses identify patients who are likely to benefit from targeted preventive interventions aimed at emotional, informational and instrumental support issues.
- We only included patients with breast cancer receiving treatment at tertiary hospitals.
- Our focus was on patients with breast cancer who had undergone surgery, but the sample solely consisted of female patients, most of whom were middle aged.

## INTRODUCTION

Breast cancer is the most frequently occurring type of cancer in women throughout the world.<sup>1</sup> The impacts are also substantial, as both the diagnosis and treatment procedures are often traumatic and life changing. In this context, patients may experience difficulty when attempting to maintain their social networks,<sup>2,3</sup> including the inability to hold stable social relationships with family members, friends, colleagues and other significant individuals. Many patients may also experience unemployment, which can further impact their perception of reduced support while undergoing hardship difficult period.<sup>4,5</sup>

High-level social relationships are known to help patients with chronic diseases cope with their disease.<sup>6,7</sup> However, reports have shown that many of these patients tend to underutilise their support networks and may even receive less support after treatments such as surgery, especially in the first following year.<sup>8</sup> Thus, patients with breast cancer who have undergone surgery



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School of Nursing, Fudan University, Shanghai, China

**Correspondence to**  
Dr Changrong Yuan;  
yuancr@fudan.edu.cn

constitute a vulnerable population with distinct social relationship needs that are associated with psychological well-being.<sup>4</sup> Compared with recently diagnosed patients with breast cancer, those who have undergone surgical treatments tend to experience unique emotional challenges, such as the need to negotiate a changed, unfamiliar body and increased mood disturbances, with many feeling disconnected from their social networks.<sup>4</sup> This is an area of high concern, as patients with insufficient social networks tend to report poor psychological well-being at higher rates, including increased depression and anxiety.<sup>9–11</sup> However, the literature currently shows a lack of research on both the nature of social relationship needs following surgical treatment and the association between social relationships and psychological well-being among patients with breast cancer.

Nevertheless, some qualitative studies have generally reported on the social relationship needs of patients with breast cancer. For example, Martínez *et al* reported that emotional support needs were frequently unmet in patients with breast cancer with emotional distress.<sup>12</sup> Cardoso *et al* investigated patients with advanced breast cancer to better understand their psychosocial, emotional, functional, and support needs,<sup>13</sup> with results showing that approximately half felt isolated and worried, had lower incomes and faced employment changes due to their cancer diagnoses. Furthermore, about half felt they were viewed negatively by society and found it difficult to find similar peers. Although most were satisfied with the support they received from family and friends, this decreased over time, which then increased their feelings of negativity. Halkett *et al* investigated the informational needs of patients with breast cancer undergoing radiotherapy.<sup>14</sup> Healthcare professionals and early stage patients with breast cancer were interviewed via the semistructured methods, with results showing that informational support needs were maximal for patients during their initial radiotherapy appointments. In sum, the literature shows that it is important to assess social relationship needs during routine breast cancer care, with various studies showing that needs may vary based on demographic characteristics. While various types of social relationships have been recognised, only a handful of researchers have explored specific interactions.<sup>3,7</sup> This highlights the need to conduct valid assessments of social relationship needs and interactions, thus ensuring quick and accurate determinations for patients with breast cancer. Such findings will also aid in the selection of appropriate clinical interventions.

As social relationships are subjective experiences, the abovementioned assessments should be conducted from the patient's perspective. In this context, patient-reported outcomes (PROs) are important for revealing many health-related quality-of-life aspects, including symptoms, limitations, well-being and care/treatment preferences. In fact, PROs measurements are considered the best way to obtain subjective information about patient's experience. In this regard, the Patient-Reported Outcome Measurement Information System (PROMIS) project was aimed at advancing PROs measurements in various settings through a range of short-form instruments, with the social relationships

component including concepts of social support and isolation under the PROMIS social health framework.<sup>6</sup> Specifically, the PROMIS social relationships short forms are brief and accurate measures for assessing different types of social relationships among patients with chronic disease.<sup>15</sup> For use in this study, these forms were translated into Chinese versions by our research group.<sup>16</sup> Due to the lack of PROs usage to investigate social relationship needs in patients with breast cancer who have undergone surgery, we believed these measures were optimal research tools for addressing this gap in the literature. As such, this study evaluated emotional, informational and instrumental support needs in patients with breast cancer who had undergone surgery, thus identifying important variables associated with those needs. We used three PROMIS measures, including the social relationships short forms, anxiety short form and depression short form.

## METHODS

### Study design

This study employed a multicenter cross-sectional design.

### Participants and data collection

We used convenience sampling to recruit patients from breast care wards at two tertiary hospitals in mainland China (Shanghai provinces), with eligible participants being enrolled between January 2018 and July 2020. The inclusion criteria were set as follows: breast cancer diagnosis, aged >18 years, undergone surgery within the past 3 months and able to speak and read Mandarin Chinese. On the other hand, patients with psychiatric illness and/or cognitive impairments that would impede effective communication were excluded. This resulted in 477 initial participants, with 16 excluded due to response errors; as such, the final analysed sample consisted of 461 patients. Trained nurse researchers identified and informed eligible patients about the opportunity to participate in this study at the time of hospital admission. A brief study overview was then provided. Candidates were also ensured that confidentiality and anonymity would stringently be maintained. Those who were willing to participate were signed informed consent forms prior to study engagement. All participants completed questionnaires including the sociodemographic information component and three PROMIS short forms, including the social relationships short forms, anxiety short form and depression short form.

## Measurements

### Sociodemographic and clinical information

The sociodemographic questionnaire component asked participants for information on age, marital status, childbearing history, religion, educational background, menstrual status, living style, employment status, monthly family income and health insurance. On the other hand, we directly obtained clinical information about medical treatments from their respective medical records.

### PROMIS social relationships short forms

The Chinese versions of the PROMIS social relationships short forms were previously translated by our research group.<sup>16</sup> More specifically, the four-item PROMIS emotional support, informational support and instrumental support short form were used to assess social relationships, as they have been validated for use among patients with chronic disease, including cancer.<sup>7</sup> Responses to each item were given according to a 5-point Likert-type scale ranging from 'never' to 'always'. Total scores for each short form, thus, ranged from 4 to 20, with higher scores corresponding to better social relationships.<sup>6 17</sup> Total raw scores were then converted and reported as T scores (mean=50, SD=10).<sup>18</sup> Cronbach's alpha values ranged from 0.90 to 0.95 for the measures used in this study.

### PROMIS anxiety short form

Anxiety was assessed using the Chinese version of the 8-item PROMIS anxiety short form. All items were rated on a 5-point Likert-type scale ranging from 'never' to 'always' over a 7-day period.<sup>16</sup> Total scores could, thus, range from 8 to 40, with higher scores indicating higher levels of anxiety.<sup>18</sup> Raw scores were then presented via a standard T score metric (mean=50, SD=10).<sup>19</sup> The psychometric properties of this measure were previously verified among Chinese patients with breast cancer.<sup>16</sup> In this study, a Cronbach's alpha of 0.93 was returned.

### PROMIS depression short form

Depression was assessed using the Chinese version of the 8-item PROMIS depression short form. Participants were required to report their experiences with depression over a 7-day period according to a 5-point Likert-type scale.<sup>20</sup> Total raw scores could range from 8 to 40, with a similar scoring procedure to that described in the scoring manual mentioned above. Higher scores represented greater levels of depressive symptom. The Chinese version of the measure was previously shown to be satisfactory for assessing psychometric properties among patients with breast cancer.<sup>16</sup> In this study, a Cronbach's alpha of 0.89 was returned.

### Statistical analysis

All statistical analyses were conducted using IBM SPSS V.23.0 for Windows. Descriptive statistics, such as percentages, numbers, means and SDs, were used to describe demographic and treatment characteristics as well as the item distributions. Item responses were ranked and compared based on mean score values. Sociodemographic and clinical variables that were related to the PROMIS social relationships short form scores were identified via  $\chi^2$  test. The correlations between scores from the social relationships dimensions and those from the anxiety and depression measures were calculated via the Pearson correlation. Based on a purposeful selection of covariates, multivariable regression analyses were then conducted to examine the relative contribution of each

variable in explaining the overall level of informational support among patients, with an entry criterion of  $p < 0.05$ . For all analyses, statistical significance was determined at  $p < 0.05$ .

### Patient and public involvement

No patients or members of the public were involved in the design or planning of this study.

## RESULTS

### Sample characteristics

Table 1 shows descriptive characteristics derived from the sociodemographic and clinical data obtained from participants. As mentioned earlier, 16 of the 477 originally eligible patients were excluded from analysis due to incorrect or incomplete responses. Ultimately, we analysed data from 461 patients with breast cancer. The average participant age was  $50.90 \pm 10.34$  years (range=20–77). Most were married (91.32%), had one or more children (95.23%), were premenopausal (53.58%), were nonreligious (84.16%), had attained secondary school education (35.14%), lived with family (93.28%), were unemployed (43.60%), had family incomes between ¥ 3000 and 9000 per month (51.19%), had employee health insurance (54.66%) and had recently received chemotherapy (58.35%). All participants were women.

### Emotional, informational and instrumental support levels

As shown in table 2, the item score rankings show that the highest scores were returned for PROMIS instrumental support, while the lowest were returned for PROMIS informational support. In other words, participants reported more instrumental support and less informational support. The T scores for PROMIS emotional support, PROMIS informational support and PROMIS instrumental support showed that informational support levels were below average, while other dimensions were simply average.

### Predictors for emotional, informational and instrumental support levels

Demographic variables related to scores derived from the PROMIS social relationships short forms included marital status ( $p < 0.05$ ), childbearing history ( $p < 0.05$  for the instrumental support domain), lifestyle ( $p < 0.05$ ) and employment status ( $p < 0.05$ ) (table 3). For the bivariate analysis, Pearson correlation coefficients confirmed significant negative correlations between the PROMIS social relationships short forms and both the anxiety (ranged from  $-0.30$  to  $-0.38$ ) and depression (ranged from  $-0.43$  to  $-0.51$ ) scores. The correlations were higher for depression than for anxiety.

A multiple linear regression analysis helped determine predictors for the emotional, informational and instrumental support levels. Since the PROMIS informational support short form scores were lower than those for other subscales, the tool was adopted as the dependent variable.



**Table 1** Sample characteristics (N=461)

Variables	N (%)
Age (mean±SD)	50.90±10.34
18–40	70 (15.18)
41–60	305 (66.16)
61–80	86 (18.66)
Marital status	
Single	11 (2.39)
Married	421 (91.32)
Divorced	9 (1.95)
Widowed	20 (4.34)
Childbearing history	
Yes	439 (95.23)
No	22 (4.77)
Menstrual status	
Premenopausal	247 (53.58)
Postmenopausal	214 (46.42)
Religion	
Yes	73 (15.84)
No	388 (84.16)
Education background	
Primary school or below	139 (30.15)
Secondary school	162 (35.14)
High school	92 (19.96)
University or above	68 (14.75)
Lifestyle	
Living alone	26 (5.64)
Living with family	430 (93.28)
Living with others	5 (1.08)
Employment status	
Employed	92 (19.96)
Medical leave	65 (14.10)
Unemployed	201 (43.60)
Retired	103 (22.34)
Monthly family income	
< ¥3000	212 (45.99)
¥3000 to ¥9000	236 (51.19)
>¥9000	13 (2.82)
Medical insurance	
Free medical insurance	4 (0.87)
Employee health insurance	252 (54.66)
Rural health insurance	173 (37.53)
Without health insurance	32 (6.94)
Medical treatments over the past 7 days	
Postoperative stage	192 (41.65)
Chemotherapy	269 (58.35)

The independent variables varied significantly; these included scores from the PROMIS emotional support short form, the PROMIS instrumental support short form,

marital status, childbearing history, lifestyle, employment status, scores from the PROMIS anxiety short form and scores from the PROMIS depression short form. As shown in table 4, the PROMIS emotional support short form scores, PROMIS instrumental support short form scores, marital status, employment status, PROMIS anxiety short form scores and PROMIS depression short form scores were predictor variables for the PROMIS informational support short form scores ( $R^2=0.62$ ,  $p<0.05$ ).

## DISCUSSION

### Emotional, informational and instrumental support levels

To our knowledge, this was one of the few studies that have used PROMIS measures to assess self-reported emotional, informational and instrumental support needs and their predictors in patients with breast cancer who have undergone surgery, especially in the Chinese cancer population. The results indicated that informational support levels were lower in the study population when compared with the reference group of the general population, while emotional and instrumental support were about average.

Among our study sample, the social relationships dimensions are similar to those reported in previous research, which suggests that informational needs are not routinely met among patients with breast cancer.<sup>21 22</sup> Of further note, the top unmet need for these patients is support from peers and health professionals,<sup>21</sup> specifically including peer support, mammography reminders and professional breast self-examination knowledge, which can be classified as emotional support, instrumental support and informational support, respectively. These results are not contrary to our findings, as our participants reported insufficient levels of emotional, instrumental and informational support. Similarly, Kwok and White explored information needs among Chinese-Australian patients with breast cancer, finding they were in need of culturally and linguistically tailored information about cancer-related side effects and signs of disease recurrence during rehabilitation.<sup>22</sup> This shows that informational support should be customised to fit the unique needs of different patients with breast cancer. Some studies have provided new insights into the informational support needs of patients with breast cancer. For example, Corter *et al* investigated how young patients with breast cancer perceived online information support, thereby suggesting that multifunction online support was a valuable provision.<sup>23</sup> Kemp *et al* similarly demonstrated that an online intervention was a helpful way for health professionals, family members and others to provide informational support.<sup>24</sup> As such, online support might be a good way to provide cancer-related informational support and can even be integrated with traditional interventions.

### Predictors of emotional, informational and instrumental support levels

We found that marital status, childbearing history, lifestyle, employment status, anxiety and depression levels were all

**Table 2** Scores from the three PROMIS social relationships short forms

Dimension	Item	Score* (mean±SD)	Rank
PROMIS emotional support	I have someone who will listen to me when I need to talk	4.21±0.86	5
PROMIS emotional support	I have someone to confide in or talk to about myself or my problems	4.11±0.90	7
PROMIS emotional support	I have someone who makes me feel appreciated	3.95±1.05	9
PROMIS emotional support	I have someone to talk with when I have a bad day	4.11±0.92	7
PROMIS informational support	I have someone to give me good advice about a crisis if I need it	4.13±0.88	6
PROMIS informational support	I have someone to turn to for suggestions about how to deal with a problem	4.13±0.88	6
PROMIS informational support	I have someone to give me information if I need it	2.32±1.01	10
PROMIS informational support	I get useful advice about important things in life	4.03±0.93	8
PROMIS instrumental support	Do you have someone to help you if you are confined to bed?	4.29±0.89	3
PROMIS instrumental support	Do you have someone to take you to the doctor if you need it?	4.38±0.82	1
PROMIS instrumental support	Do you have someone to help with your daily chores if you are sick?	4.25±0.88	4
PROMIS instrumental support	Do you have someone to run errands if you need it?	4.32±0.79	2

\*Data are presented in means±SDs.

PROMIS, Patient-Reported Outcome Measurement Information System.

predictors of emotional, informational and instrumental support levels in the study sample. A multiple regression analysis further revealed that emotional support, instrumental support, marital status, employment status, anxiety and depression scores contributed to the prediction of informational support. These findings were similar to the results of a previous study showing that emotional support expression was related to living status of patients with breast cancer.<sup>25</sup> In Chinese traditional culture, women are expected to dedicate themselves to being good wives and devoted mothers.<sup>26 27</sup> For patients with intimate relationships, both the nature of the breast cancer disease and its invasive treatment requirements pose significant challenges in areas pertaining to the family, profession and social life domain. In the context of a positive diagnosis, they are often forced to reconsider their responsibilities and levels of participation in significant life domains. For example, frequent medical treatments and

hospital visits can become overwhelming, especially due to the many side effects and symptoms. Patients may, thus, feel that they are unable to fulfil their roles and are unlikely to participate in social roles and activities as usual.<sup>28 29</sup> Altered employment status is another challenge in this population. In this regards, patients who are treated for breast cancer may face job discrimination, which can impact their perceptions of pre-existing social relationships.<sup>30</sup> Notably, work adjustments are protective factors for professional rehabilitation among patients with breast cancer, thus contributing to financial stability and stable social relationships.<sup>30 31</sup> As employed patients may, therefore, benefit from work adjustments in the long term, they are encouraged to continue working if possible.<sup>32</sup>

While one previous study reported that young patients had more unmet information needs than other age groups,<sup>33</sup> this study found no significant age-related differences. This

**Table 3** Significant demographic variables: PROMIS social relationships short forms

Variables	Emotional support p value	Informational support p value	Instrumental support p value
Age	0.26	0.52	0.20
Marital status	0.00 <sup>†</sup>	0.00 <sup>†</sup>	0.00 <sup>†</sup>
Childbearing history	0.30	0.29	0.04 <sup>†</sup>
Menstrual status	0.71	0.48	0.77
Religion	0.32	0.31	0.61
Education background	0.50	0.25	0.11
Lifestyle	0.00 <sup>†</sup>	0.00 <sup>†</sup>	0.00 <sup>†</sup>
Employment status	0.02 <sup>†</sup>	0.04 <sup>†</sup>	0.04 <sup>†</sup>
Monthly family income	0.14	0.15	0.12
Medical insurance	0.26	0.43	0.70
Medical treatments over the past 7 days	0.17	0.20	0.30

The analysis was performed via  $\chi^2$  test; <sup>†</sup>p-values<0.05.

PROMIS, Patient-Reported Outcome Measurement Information System.

**Table 4** Significant variables from the PROMIS informational support short form scores via multiple linear regression

Variable	B	SD	$\beta$	p
PROMIS emotional support short form scores	0.53	0.32	0.60	0.00*
PROMIS instrumental support short form scores	0.41	0.30	0.55	0.00*
Marital status	0.88	0.28	0.78	0.00*
Childbearing history	0.73	0.23	0.67	0.43
Lifestyle	-0.31	0.57	-0.53	0.59
Employment status	0.81	0.21	0.71	0.00*
PROMIS anxiety short form scores	-0.07	0.13	-0.21	0.01*
PROMIS depression short form scores	-0.11	0.16	-0.32	0.00*
Constant	3.26	1.55		0.00*

\*p-values&lt;0.05.

PROMIS, Patient-Reported Outcome Measurement Information System.

inconsistency may be attributed to the sample characteristics, as patients <40 years of age only comprised 15.18% of our study population, with the majority being middle aged. This highlights the need for additional research aimed at exploring social relationships status among young patients with breast cancer.

Using the focus group interview method, Paladino *et al* identified racial differences of social relationship needs in black and white women with breast cancer who had undergone adjuvant endocrine therapy.<sup>34</sup> All participants noted the importance of informational and emotional support, as provided by friends and family members. On the other hand, white participants reported that support from other patients with breast cancer was crucial, while black women did not regard other patients as important sources of their social networks. Despite these differences, their findings highlighted the general importance of assessing social relationship needs in patients with breast cancer. Our study only included patients with breast cancer in China, in which case we are unable to comment on any racial differences. Future studies should continue to compare race-based differences among patients with breast cancer.

Our bivariate and multivariate analyses showed that emotional, informational and instrumental support levels were associated with depression and anxiety levels, which is consistent with previous studies.<sup>35 36</sup> For example, Cappiello *et al* reported that patients were more likely to experience issues with anxiety and depression if their informational needs about treatment remained unsatisfied.<sup>35</sup> Reportedly, unmet informational needs also predict anxiety in young patients, especially during early survivorship.<sup>36</sup> Indeed, Fong *et al* reported that decreased social support quality was associated with increased depression, stress and negative effects in patients with breast cancer over time.<sup>4</sup>

### Limitations

This study had some limitations. First, our survey only included patients with breast cancer at tertiary hospitals, the results may not be representative of the conditions in other clinical settings. Second, our sample solely consisted of female breast cancer patients, most of whom were middle

aged. In this case, patients of different ages and genders may have different emotional, informational and instrumental support needs.

### CONCLUSIONS

Informational support should be specifically assessed and promoted in patients with breast cancer who have undergone surgery. In this study, marital status, childbearing history, lifestyle, employment status, anxiety and depression levels were related to emotional, informational and instrumental support levels and should, thus, be evaluated when conducting related interventions for patients with breast cancer.

### RELEVANCE FOR CLINICAL PRACTICE

This study provided valuable insight into the nature of the emotional, informational and instrumental support needs of patients with breast cancer who have undergone surgery, especially in regards to what areas may typically be unmet. The early screening of high-risk individuals should help nurses identify those who may benefit from targeted preventive interventions aimed at emotional, informational, and instrumental support issues.

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**Contributors** CY, TC and QH conceived the study. TC and QH were the principal investigators. TC drafted the manuscript. TC and QH was in charge of the statistical analysis. CY, TC and QH contributed to the interpretation of data and intellectual revision of multiple drafts. All authors approved the final version of the manuscript.

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**Competing interests** None declared.

**Patient and public involvement** Patients and/or the public were involved in the design, or conduct, or reporting, or dissemination plans of this research. Refer to the Methods section for further details.

**Patient consent for publication** Not required.

**Ethics approval** Ethical approval was obtained from the Institutional Review Board of Fudan University and all study sites (number: 1810192-22).

**Provenance and peer review** Not commissioned; externally peer reviewed.

**Data availability statement** Data are available upon reasonable request.

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#### ORCID iD

Changrong Yuan <http://orcid.org/0000-0001-8480-2569>

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