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# Distribution and Determinants of Unmet Need for Supportive Care Among Women with Breast Cancer in China

Authors' Contribution:  
Study Design A  
Data Collection B  
Statistical Analysis C  
Data Interpretation D  
Manuscript Preparation E  
Literature Search F  
Funds Collection G

BCDE 1 **Shouhua Wang**  
BC 1 **Yanqing Li**  
CF 2 **Chaozhuo Li**  
ABCDEF 3 **Yijun Qiao**  
AE 4 **Shuling He**

1 Department of Oncology, The Affiliated Hospital of Weifang Medical College, Weifang, Shandong, P.R. China  
2 Department of Clinical Medicine, Xuzhou Medical University, Xuzhou, Jiangsu, P.R. China  
3 Department of Outpatient, Weifang Military Hospital of Shandong Province, Weifang, Shandong, P.R. China  
4 Department of Gynecology and Obstetrics, The People's Hospital of Wulian County, Wulian, Shandong, P.R. China

**Corresponding Author:** Shuling He, e-mail: [gpde4402831@163.com](mailto:gpde4402831@163.com)  
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**Background:** The aim of this study was to determine the need for supportive care among women suffering from breast cancer in China and to identify its potential determinants to inform the development of effective and efficient healthcare services across different settings.





**Material/Methods:** In a tertiary-care hospital in Weifang, China, between July 2015 and January 2016, all women attending the Breast Cancer Clinic for regular physical examinations after treatment for breast cancer were consecutively recruited. The 34-item Supportive Care Needs Survey tool (Chinese version) (SCNS-SF34-C) was used to assess the unmet needs among participants.

**Results:** Among 264 recruited patients, based on at least single-item endorsement, 60.2% had moderate to high level of need for supportive care, while only 13.3% expressed no need. Lack of information regarding health systems was the most common domain with moderate to high unmet needs, more so among rural patients (8 vs. 5 out of 10). In each information-related domain, huge unmet need was observed among all patients irrespective of urban or rural residence. Both overall and individual information-related domain-specific unmet needs were significantly higher among rural patients as opposed to their urban counterparts. Multiple regression analyses revealed a significant rural-urban variation of unmet needs. Moreover, education and post-diagnosis time duration were negatively associated with unmet needs while stage of cancer was positively associated with these unmet needs.

**Conclusions:** There is a huge burden of unmet needs for information on the healthcare system among breast cancer survivors in China. Rural residence, less education, advanced stage of cancer, and shorter duration since diagnosis were the identified determinants requiring targeted intervention.

**MeSH Keywords:** **Breast Neoplasms • Rural Population • Urban Population**

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## Background

Breast cancer (BC) is the most common malignancy among women worldwide. In China in 2011, approximately 248 620 new BC cases were diagnosed and more than 60 000 BC-related annual deaths were recorded [1]. The incidence of BC remained relatively stable in urban areas of the country during the last decade, whereas in rural China, there was a progressive rise, with an annual percentage change (APC) of 8.55 [2]. Although in the recent past, survival among BC patients improved progressively in this country owing to the rapid development in early detection technologies and treatment modalities [3], a major proportion of survivors continued to face myriads of chronic issues, including physical, psychological, sexual, and social disturbances throughout the cancer continuum [4,5]. Thus, there is growing awareness of the need for a multitude of supportive care during the period of survivorship of these patients.

'Unmet need' regarding healthcare services refers to the gap between a person's desire or need for those services and the actual experience of receiving them [6]. During the last decade, numerous studies tried to quantify the need for supportive care among cancer survivors [7–9], providing a better understanding of patients' unmet needs pertaining to focus and coverage of current services and related concerns [10]. Based on this understanding, the existing supportive care system was targeted appropriately to ensure that the available healthcare resources could elicit optimized responses to the needs of the growing population of cancer survivors. However, most of these studies were predominantly from developed countries. It appears somewhat unreasonable to extrapolate those findings to cancer survivors in developing countries, in view of the apparent disparities between healthcare systems among countries and the associated differences in service provision [11,12]. Moreover, most of the aforementioned studies assessed the unmet needs for supportive care among mixed populations of survivors of several different cancers, with women suffering from BC being only a subgroup [13]. Thus, the possibilities that BC survivors could have some specific needs regarding supportive care and were likely to be different from other cancer patients in several ways [14] remained largely unaddressed. Hence, the unmet need for supportive healthcare among women with BC has not been well documented, especially in the developing world.

Relatively few studies had ever been conducted to understand the unmet needs among BC survivor women in China. Moreover, given the well-known rural-urban inequalities in the availability of medical resources and resultant healthcare service delivery [2], the unmet needs regarding supportive care were likely to vary across locations and other socio-demographic factors in China. Thus, in light of the dearth of information regarding

the distribution and determinants of the need for supportive care among BC survivor women in China, the present study sought to quantify the aforementioned need, determine its variation across rural and urban settings, and to identify the important determinants of the perceived need.

## Material and Methods

### Study setting and participants

This cross-sectional study was conducted between July 2015 and January 2016 in a tertiary-care hospital serving a population of about 12 million in Weifang, China. All women who attended the Breast Cancer Clinic in this hospital for regular physical examinations after treatment for BC were consecutively recruited. Patients were eligible for this study if they were aged 18 years or more, were aware of their cancer diagnosis, and could communicate in Chinese. We excluded patients diagnosed with secondary breast cancer, those who completed the questionnaire on a prior visit, and those with terminal diseases or any other psychiatric problems that might interfere with communication.

The sample size was estimated based on the assumption that the expected burden of unmet need for supportive care was 60% among rural BC survivors and 40% among urban survivors of BC. To estimate the current burden with a 95% confidence interval along with an absolute precision of 10%, a required sample size of 95 patients was determined using the statistical equation  $n = (Z_{(1-\alpha/2)})^2 p(1-p) / (d)^2$ , where  $n$  = desired sample size,  $p$  = expected proportion in population,  $d$  = absolute precision = 10%, and  $Z_{(1-\alpha/2)}$  = Z score corresponding to 95% confidence level = 1.96. Assuming 10% would decline to participate in the study, 105 eligible female BC survivors were invited to participate in each group. The desired sample size seemed quite feasible because the case register of the study clinic revealed that about 50 BC patients per month attended the clinic.

After a detailed description of the study procedures, written informed consent was obtained from each participant. The study content and procedures were reviewed and approved by the Institutional Ethics Review Board (IERB) of Weifang Medical College.

### Procedures

In the clinic, while waiting to be examined by the physician, patients were approached by trained nurses. After evaluation for eligibility and recruitment in the study, face-to-face interviews were conducted by the nurses. Each participant was asked to complete 2 individual questionnaires during this interview: a structured questionnaire consisting of questions

relating to participants' socio-demographic and disease characteristics, and the Chinese Version of the Supportive Care Needs Survey Short-Form (SCNS-SF34-C). The interviews took approximately 20 minutes each and were administered in a private space near the examination room. A nurse was available to help participants with any difficulty during the surveys. After the completion of the survey, women were clinically examined and the examining physicians were kept blinded regarding the survey results.

SCNS-SF34-C, a 34-item self-administered screening questionnaire [15], was used to investigate the supportive care needs of cancer patients in 5 domains: psychological, health system information, daily living and physical needs, patient care and support, and sexual domains. Each item was scored on a scale of 0 to 5 (1=no need/not applicable, 2=no need/satisfied, 3=low need, 4=moderate need, and 5=high need). Standardized Likert summated values were used to score SCNS-SF34 according to the Supportive Care Needs Survey scoring manual. The score had possible values ranging from 0 to 100, with higher scores indicating more unmet needs. This scale was proven to be reliable and valid in diverse populations, including Chinese [16].

### Data analysis

Statistical analysis was performed using SPSS software 16.0 (SPSS Inc., Chicago, USA). The proportions of survivors who reported either 'no needs' (i.e., selected response option 1 or 2 for all 34 items), 'low needs' (i.e., selected response option 3 for at least one item, but did not select response option 4 or 5 for any of the items), and 'moderate to high needs' (i.e., selected response option 4 or 5 for at least 1 item) were calculated [13]. Categorical variables were described by frequencies and percentages while continuous ones were described through mean  $\pm$  standard deviation (SD). The chi-square test was used to compare categorical variables across groups and the *t* test was employed to examine the difference of mean scores in each domain of SCNS-SF34-C between groups. Ordinal logistic regression analyses were conducted to identify factors associated with unmet needs. Hypotheses tests were all conducted as 2-sided, and a *p*-value of less than 0.05 was considered significant.

## Results

Out of 305 eligible invited patients, 264 participated in the study. Among participants, 121 (45.8%) lived in rural areas while 143 (54.2%) lived in urban areas. The overall response rate was 86.6%; 80.2% among rural and 88.1% among urban patients. The mean age was 49.5 $\pm$ 9.7 years and about half of the patients were aged below 50 years. More than two-thirds of participants were educated up to junior high school level or less.

Compared to the urban patients, rural patients were less educated, had lower income, and were more likely to have a higher stage of cancer. There were no significant differences across groups in terms of age, marital status, and time since diagnosis. Although more patients in the rural group had undergone mastectomy, radiotherapy, and chemotherapy than their urban counterparts, these differences were not significant (Table 1).

Majority (60.2%, *n*=159) of the participating BC survivor women were found to have 'moderate to high' level of unmet need, while only 13.3% (*n*=35) reported having no such need. 'Moderate to high' level of unmet needs was more commonly reported by rural patients, with more than 75% endorsing such need for at least 1 of the 34 items, which was significant higher than in the urban group (Table 1).

Among rural patients, according to the SCNS-SF-C questionnaire, 8 out of the top 10 most frequently reported 'moderate' or 'high' level of unmet needs was items belonging to the health system information domain, with the rest belonged to psychological and patient care domains. In urban patients, among the most commonly reported items with 'moderate' or 'high' unmet needs, 5 belonged to the health system information domain, 3 were related to psychology, 1 was relevant for physical and daily living, while the rest was related to patient care and support. The reported burden of moderate to high unmet needs ranged between 43.0% and 66.9% among rural patients, while for urban patients it ranged between 35.7% and 47.6%. For BC survivors residing in both urban and rural areas, unmet need was highest for 'being informed about things you can do to help yourself to get well' (Tables 2, 3).

Among all, domain-specific scores for supportive care needs were highest for the health system information domain, both in urban and rural patient groups. The mean score was 68.5 $\pm$ 27.2 in information domain among rural patients, significant higher than 42.7 $\pm$ 29.2 in urban patients (*p*<0.01). Urban patients had higher unmet need scores in psychological domain than their rural counterparts (51.6 $\pm$ 18.8 vs. 40.5 $\pm$ 21.0, *p*<0.01). Although rural patients had higher mean scores than urban patients in physical and daily living as well as patient care and support domains, these differences were not statistically significant. On the other hand, the lowest mean score was observed for sexuality domain in both groups and the 2 groups had similar mean scores in this domain (Table 4).

In the final multivariable model, rural patients showed significantly higher supportive care needs than their urban counterparts (OR=2.19, 95%CI: 1.39–3.44). Similarly, younger patients and women with lower education level showed greater needs than those who were older with higher education level. Moreover, time since diagnosis and stage of cancer were found to be positively associated with supportive care needs, with

**Table 1.** Sociodemographic characteristics and treatment details, by residential areas (N=264).

Variables	Total (n=264)	Rural (n=121)	Urban (n=143)	P value
Age (in years) at survey				0.45
≤50	131 (49.6)	57 (47.1)	74 (51.7)	
>50	133 (50.4)	64 (52.9)	69 (48.3)	
Education level				0.003
Junior high school or lower	196 (72.4)	100 (82.6)	96 (67.1)	
High school or above	68 (27.6)	21 (17.4)	47 (32.9)	
Marital status				0.54
Single/widowed	18 (6.8)	7 (5.9)	11 (7.7)	
Married	246 (93.2)	114 (94.2)	132 (92.3)	
Monthly household income (RMB)				<0.01
Low (≤2,000)	75 (28.4)	55 (45.5)	20 (14.0)	
Medium (200–5,000)	97 (36.7)	37 (30.6)	60 (42.0)	
High (≥5,000)	92 (34.9)	29 (23.9)	63 (44.0)	
Time since diagnosis (years)				0.18
≤1	113 (42.8)	51 (42.1)	62 (43.4)	
1–5	103 (39.0)	53 (43.8)	50 (35.0)	
>5	48 (18.2)	17 (14.1)	31 (21.6)	
Stage of cancer				<0.01
Carcinoma <i>in situ</i> /I	75 (28.4)	23 (19.1)	52 (36.4)	
II	106 (40.2)	47 (38.8)	59 (41.3)	
III	57 (21.6)	32 (26.4)	25 (17.5)	
IV	26 (9.8)	19 (15.7)	7 (4.8)	
Surgery type (at any time)				0.09
Lumpectomy	63 (23.9)	21 (17.4)	42 (29.4)	
Mastectomy	201 (76.1)	100 (82.6)	101 (70.6)	
Non-surgical treatment (during survey)				
Radiotherapy				0.09
Yes	74 (28.0)	40 (33.1)	34 (23.8)	
No	190 (72.0)	81 (66.9)	109 (76.2)	
Chemotherapy				0.06
Yes	191 (72.3)	90 (74.4)	101 (70.6)	
No	73 (27.7)	21 (25.6)	42 (29.4)	
Reported need for supportive care				<0.01
No need	35 (13.3)	7 (5.8)	28 (19.6)	
Low need	63 (23.9)	21 (17.4)	42 (29.4)	
Moderate to high need	166 (62.8)	93 (76.8)	73 (51.0)	

**Table 2.** Ten most prevalent ‘moderate’ or ‘high’ level unmet supportive care needs among rural women with breast cancer (N=121).

Rank	Common unmet supportive care needs	n (%)	Domain
1	Being informed about things you can do to help yourself to get well	81 (66.9)	Health System Information
2	Being given information (written, diagrams, drawings) about aspects of managing your illness and side-effects at home	77 (63.6)	Health System Information
3	Fears about the cancer spreading	70 (57.8)	Psychological
4	Being informed about cancer which is under control or diminishing (i.e., remission)	69 (57.0)	Health System Information
5	Having access to professional counselling	67 (55.4)	Health System Information
6	Being given written information about the important aspects of your care	65 (53.7)	Health System Information
7	Hospital staff acknowledging, and showing sensitivity to, your feelings and emotional needs	59 (48.8)	Health System Information
8	Being adequately informed about the benefits and side-effects of treatments before you choose to have them	58 (47.9)	Health System Information
9	Hospital staff attending promptly to your physical needs	54 (44.6)	Patient care
10	Having one of the hospital staffs with whom you can talk to about all aspects of your health condition, treatment and follow-up	52 (43.0)	Health System Information

**Table 3.** Ten most prevalent ‘moderate’ or ‘high’ level unmet supportive care needs among urban women with breast cancer (N=143).

Rank	Some unmet supportive care needs	n (%)	Domain
1	Being informed about things you can do to help yourself to get well	68 (47.6)	Health System Information
2	Uncertainty about the future	66 (46.2)	Psychological
3	Fears about the cancer spreading	66 (46.2)	Psychological
4	Being informed about cancer which is under control or diminishing (i.e., remission)	65 (45.5)	Health System Information
5	Having access to professional counselling	63 (44.1)	Health System Information
6	Concerns about the worries of those close to you	62 (43.4)	Psychological
7	More choice about which cancer specialists you see	59 (41.3)	Patient Care
8	Being adequately informed about the benefits and side effects	56 (39.1)	Health System Information
9	Hospital staff acknowledging, and showing sensitivity to, your feelings and emotional needs	52 (36.4)	Health System Information
10	Not being able to do the things you used to do	51 (35.7)	Physical

higher scores being observed among patients with longer duration since diagnosis and those at higher cancer stage. In addition, women who had undergone radiotherapy or chemotherapy perceived decreased needs for supportive care (Table 5).

### Discussion

This cross-sectional study was the initial effort to quantify supportive care needs of women with BC in China, revealing

a significant high prevalence of unmet need in this population. The highest levels of need were perceived in the health system information domain. Out of the 10 most frequently reported items with ‘moderate’ to ‘high’ unmet needs, 8 among rural and 5 among urban patients belonged to this domain. In addition, rural patients reported significantly higher unmet needs than their urban counterparts, particularly in the health system information domain. This suggests a substantial rural-urban discrepancy regarding unmet need for supportive care among female BC survivors.

**Table 4.** Residential area-wise distribution of the domain-specific mean scores for Supportive Care Needs (N=264).

Domain	Total (N=264)	Rural (n=121)	Urban (n=143)
Health systems and information	57.0±28.4	68.5±27.2	46.7±29.2
Psychological	37.9±19.1	33.5±21.0	41.6±18.8
Physical and daily living	28.7±15.1	31.8±15.7	26.1±14.6
Patient care and support	37.7±29.8	43.9±31.8	32.4±28.3
Sexuality	19.3±18.2	17.6±15.2	20.7±20.6

**Table 5.** Multivariate logistic regression model for factors associated with supportive care needs (N=264).

Variables	OR	95%CI	Variables	OR	95%CI
<b>Residential area</b>			<b>Stage of cancer</b>		
Urban	1		0-1	1	
Rural	2.19	1.39-3.44	2	1.13	0.58-2.12
<b>Age at survey</b>			3	1.97	1.13-3.45
<50	1.41	0.83-2.12	4	2.46	1.05-5.78
>50	1		<b>Surgery (at any time)</b>		
<b>Education level</b>			Lumpectomy	1.45	0.92-2.26
Junior high school or lower	1.67	1.06-2.61	Mastectomy	1	
High school or above	1		<b>Radiotherapy (at survey)</b>		
<b>Monthly household income (RMB)</b>			Yes	0.58	0.47-0.93
Low (≤2,000)	1.25	0.72-2.18	No	1	
Medium (200-5,000)	0.72	0.43-1.22	<b>Chemotherapy (at survey)</b>		
High (≥5,000)	1		Yes	0.55	0.34-0.92
<b>Time since diagnosis</b>			No	1	
≤1	1				
1-5	0.70	0.37-1.33			
>5	0.47	0.25-0.88			

In the present study, more than 60% of participants reported to have at least 1 item with 'moderate' to 'high' unmet needs. Despite using the same validated instrument and classification of unmet need, the observed burden was clearly higher than most of the previously reported levels. Unlike earlier studies in which the most prevalent items with 'moderate' or 'high' unmet need were usually perceived by 15-40% of participants [17,18], the most commonly reported item with 'moderate' or 'high' unmet need in the present study was endorsed by more than 66% of rural and 47% of urban patients. In a population-based study in Australia, Boyes et al. found that 37% of cancer survivors reported to have need for help with all of the 34 items assessed by SCNS, while almost two-thirds (63%)

reported either no or low level of unmet needs [13]. Similarly, in another population-based survey in Queensland [18], the authors observed that 43% of cancer survivors indicated either a 'moderate' or 'high' level of need for at least 1 item. McDowell et al., in a follow-up study among cancer survivors from a regional cancer treatment center [17] in Australia, revealed that 57.8% of participants expressed 'moderate' to 'high' unmet need at baseline for at least 1 item.

Unlike most reports from western countries, in which highest unmet needs were mostly related to psychological domain [10,19], the present study revealed that the unmet needs were highest in the health system information domain and

the highest mean scores were also observed in the information domain in both groups. Similar findings were also reported in other Asian countries. In a study in Korea [20], 9 out of 10 highest needs rated by BC survivors belonged to the health system information domain. Lam et al. compared the health-care needs between Chinese women in Hong Kong and white German women with breast cancer, and found that the former prioritized needs for information about their disease and treatment, whereas white German women prioritized physical and psychological support [21]. Cultural differences were considered to be instrumental in this disparity, implying that Asian patients might have expressed their psychological concern in the form of practical information and support needs instead of psychological needs [20,21]. This could possibly explain the present findings to some extent. However, given the study setting, it seemed insufficient to comprehensively generalize based on the findings; therefore, further investigation appeared to be necessary to identify specific factors that might have led to this outcome.

Health system information domain is directly related to service provision and access to professional assistance [22]. According to its operational description, it includes information regarding side effects of treatment, drugs, treatment regimens, care processes, and other services during the cancer trajectory. In China, however, partially due to the limited medical resources, priority of management of life-threatening diseases has long been focused on primary treatment rather than survivorship care [23]. Similarly, physicians, including oncologists caring for women with BC, often paid more attention to recovering from cancer and ensuring their survival as opposed to survivorship care in routine clinical practice. Although general practitioners and/or community nurses were officially responsible for providing this supportive care to the BC patients, it was just included as one of the chronic diseases in the routine care delivery and their services could not be specifically customized for BC survivors. Therefore, insufficient health care provision and less access to professional care services might also be the probable reasons underlying this result.

A few studies addressing the potential difference in supportive care between rural and urban patients presented inconsistent results. In a study in Scotland, Gill et al. reported that the most prevalent unmet needs were not specific to rural women, but were applicable for women with BC irrespective of where they live [24]. However, a recent review involving 23 relevant studies indicated that rural cancer patients faced distinctive social disruptions and unmet supportive care needs compared to their urban counterparts [25]. Consistent with this observation, the present study also identified a significantly higher proportion of rural patients reporting 'moderate' to 'high' unmet needs and having higher mean scores in information domain when compared to their urban counterparts, suggesting

a considerable rural-urban disparity. This was not surprising considering the well-known huge rural-urban inequalities in health care system development in China, where rural residents constituted 80% of China's population, but received only 20% of total available health resources [2]. This inequality was likely to lead to a disproportional allocation of medical resources culminating in a favorable situation for those living in urban regions, while creating additional obstacles for rural patients because of their rural location. Moreover, the general practitioners or community nurses in rural regions usually had relatively poorer educational background and less opportunity to receive optimum training on patient care, and therefore were not likely to be capable of providing the same quality of services for rural survivors of BC as their urban counterparts.

Contrary to most reports from western countries [7,24], in the present study, unmet needs in sexuality domain were not among the top 10 perceived priorities, and both urban and rural BC survivors had lowest scores in this domain. These observations were consistent with most studies in Asian countries [20,26]. However, the findings, as previous studies indicated, might not reflect the actual situation, warranting further exploration in the conservative society of China where, in the social environment governed by the orthodox cultural values, talking about sexuality is perceived as embarrassing.

In multivariable analysis, the results confirmed the significant rural-urban disparities regarding unmet needs. Additionally, we found that lower education level, higher stages of cancer, and shorter duration since diagnosis were associated with higher levels of unmet needs. This was consistent with previous reports and might also be the probable reason underlying the rural-urban disparities observed in the present study, considering the disproportional distribution of these factors across the 2 groups. In addition, we observed that patients who had received radiotherapy or chemotherapy at the time of the survey expressed decreased unmet needs. This might be because they mitigated their supportive care needs through consultation during treatment [27–29].

Some limitations of this study must be noted. First, the study involved a hospital-based cohort of BC survivors instead of a population-based one. The patients were recruited through consecutive universal sampling, which might have introduced some sampling bias, which in turn could have affected the generalizability of the findings to any super-population. Hence, any effort to extrapolate the interpretation of the findings beyond the study sample should be made with caution. Second, due to the cultural barriers mentioned above, self-reported unmet needs for supportive care might have suffered from some social desirability issues in case of sensitive items, which might have generated some potential for information bias. Third, the interviews were conducted in the hospital and implemented by

nurses; thus, some patients might have overstated their unmet needs to receive more attention. Thus, some amount of social expectation bias was likely. Finally, we did not assess the mortality of participants after this survey. Thus, we could not analyze the unmet needs in the subgroup of dead participants.

## Conclusions

We found a high level of unmet need for supportive care among BC survivors in China. Among these, lack of information regarding the healthcare system was predominant both among urban and rural patients. Rural BC survivor women

faced additional challenges related to service provision because of their resource-poor residential location. Efforts should be made to incorporate supportive care into routine follow-up for the management of women with breast cancer. Specific attention is required to ensure continuity of care by improving the skill and knowledge of general practitioners and/or community nurses to recognize and respond to the multitude of needs of these patients, along with enhancing their access to specific services and informational support.

## Conflict of interest

None.

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