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Healthcare and support needs of women with suspected breast cancer

Mei-Nan Liao, Miin-Fu Chen, Shin-Cheh Chen & Ping-Ling Chen

Correspondence to P.-L. Chen:
e-mail: plchen@tmu.edu.tw

Mei-Nan Liao MSN RN
Doctoral Candidate
Taipei Medical University, Taipei, Taiwan
Manager
Administration Center of Nursing
Department, Chang Gung Memorial
Hospital, Taoyuan, Taiwan

Miin-Fu Chen MD FACS
Professor
Department of Surgery, Chang Gung
Memorial Hospital, Chang Gung University,
Taoyuan, Taiwan

Shin-Cheh Chen MD
Associate Professor
Department of Surgery, Chang Gung
Memorial Hospital, Taoyuan, Taiwan

Ping-Ling Chen PhD MPH RN
Associate Professor
Graduate Institute of Nursing, Taipei
Medical University, Taipei, Taiwan

Abstract

Title. Healthcare and support needs of women with suspected breast cancer

Aim. This paper is a report of a study to investigate changes in the healthcare and support needs during the diagnostic period, and factors that affect these needs in women with suspected breast cancer.

Background. Although the needs of women with breast cancer are well recognized, few studies have examined the needs of women with suspected breast cancer during the diagnostic period.

Method. This longitudinal study used an investigator-developed, self-administered questionnaire to collect data from 127 women in Taiwan on three occasions: notification of need for breast biopsy, before biopsy and after diagnosis. The data were collected from November 2004 to April 2005.

Findings. Participants had high need levels before and after diagnosis, with their top needs in the domains of healthcare services for diagnosis, follow-up and consultation, and information about the disease. They needed disease- and treatment-related information more than emotional support. Need levels were higher ($P < 0.01$) before diagnosis than after, highest before biopsy, and lowest after diagnosis. Furthermore, needs were higher ($P < 0.01$) before than after diagnosis for diagnostic services, disease information, and involvement of family and friends. Higher needs were found in married women with more education and no history of benign tumours. Need level did not differ statistically significantly by age, religious status, degree of social support, family history and breast symptoms.

Conclusion. Need levels of women with suspected breast cancer vary during the diagnostic period, are highest before breast biopsy, and related to personal characteristics and cultural context. Therefore, during this period, nursing staff should provide patients and families with culturally sensitive, individualized, supportive care.

Keywords: diagnostic period, empirical research report, nursing, psychosocial needs, questionnaires, support, suspected breast cancer

Introduction

Breast cancer is the most common cancer in women worldwide. Among all cancers diagnosed in women in 2002, 23·0% were breast cancer (Parkin *et al.* 2005). The incidence of newly diagnosed breast cancer in developed countries is higher than in developing countries: for example, 27·3% in Europe and 31·3% in North America, but 16·3% in southern

Africa. An exception to this pattern is in Japan, where new cases of breast cancer account for only 8·3% of all new cancer diagnoses (Parkin *et al.* 2005). In Taiwan, breast cancer accounts for 8·4% of all female cancers, is the second most common cancer in women, and is the fourth leading cause of death among females with cancer (Department of Health, the Executive Yuan 2005a). The average onset age for breast cancer in Taiwanese women is 5–10 years earlier than for westerners, peaking at 45–49 years of age (Department of Health, the Executive Yuan 2005a).

The needs of female breast cancer patients throughout the course of the disease are mostly related to physical and emotional well-being, social support and the healthcare system. However, these needs change with the disease trajectory (Hoskins & Haber 2000) and are influenced by patient characteristics and environmental factors (Girgis *et al.* 2000, Lindop & Cannon 2001). The regulation of hospital accreditation in Taiwan attaches great importance to patient-centred health care (Department of Health, the Executive Yuan 2006) but, due to the medical reimbursement system, most hospitals pay greatest attention to treating illness and caring for patients with a confirmed diagnosis. Thus, women with suspected breast cancer often do not receive adequate information or emotional care and psychological support during the diagnostic period. Furthermore, no empirical data have identified perceived needs during the diagnostic period for Taiwanese women with suspected breast cancer. Therefore, identifying the healthcare and support needs of this population during the diagnostic period is essential to develop culturally sensitive and accessible healthcare programmes which fulfil the needs of women with suspected breast cancer.

Background

Conceptual framework

The needs of cancer patients relate to their physical, psychosocial and spiritual well-being, as well as to their quality of life (Fitch 1994). Understanding these needs in breast cancer patients is the first step in knowing how to support them (Wang *et al.* 1999). Support is usually defined as an attitude or a role that is provided by an interpersonal relationship or intervention for physical–psychological comfort (Byrne & Sebastian 1994). Support would include feeling cared for and loved, self-esteem, and feeling that one's perceptions are valued, all of which can help in coping and improving one's health (Bloom & Spiegel 1984). Support has been confirmed as a positive coping resource for women dealing with the uncertainty of breast cancer during the diagnostic period (O'Mahony 2001).

The supportive care framework used in this study indicates that individuals with cancer experience different needs at different cancer stages, such as the diagnostic, treatment, follow-up and recurrence phases (Fitch 1994). These needs change over time and are influenced by personal and environmental and social factors. Personal factors include demographic characteristics, personal experiences of breast cancer (e.g. breast cancer symptoms, history of breast tumour), family structure, coping resources and social support. Environmental factors include culture and urban or rural location (Fitch 1994), while social support includes the structure of the family, ranging from spouse to families with significant others.

Literature review

Discovering a lump in one's breast is one of the most frightening experiences a woman can face (Hoskins & Haber 2000). While waiting for biopsy results, women may experience considerable suffering and torment (Fridfinnsdottir 1997, Chappy 2004). From the discovery of a breast lump to diagnosis, women have been shown to need emotional and social support, medical care and informational support from their spouses, friends, family and healthcare professionals (Fridfinnsdottir 1997, Northouse *et al.* 1997, Davis *et al.* 2004) to alleviate their distress (Rehnberg *et al.* 2001), help them adapt to the situation (O'Mahony 2001), and make decisions regarding future treatment and possible life changes (Bilodeau & Degner 1996).

To ease the uncertainty during the diagnostic period, women with suspected breast cancer are helped when healthcare professionals shorten the waiting time and contact them as soon as possible (ASAP) to explain the diagnostic results. They also need to be reassured by healthcare professionals that the diagnosis is accurate and to feel respected and cared for during the diagnostic process (O'Mahony 2001). During this period, women with suspected breast cancer also need access to information about check-up procedures and potential progress of disease; however, the most important information needed is diagnosis (Shaw *et al.* 1994, O'Mahony 2001, Chappy 2004). Several factors may influence the information needs of women with breast cancer: age, education, family history and history of benign breast tumour (Bilodeau & Degner 1996, Deane & Degner 1998). Some studies have shown that married women with breast cancer have a greater need for information than single or widowed women (Wang *et al.* 1999, Lindop & Cannon 2001), but others dispute this, suggesting that the information needs of women with breast cancer are not related to age, education or marital status (Graydon *et al.* 1997, Gopal *et al.* 2005).

Although the needs of women with suspected breast cancer during the diagnostic period have been confirmed in many studies, most of these adopted cross-sectional or qualitative designs with a small sample size (Woodward & Webb 2001). Thus, these studies cannot comprehensively depict changes in need at different diagnostic stages. Longitudinal studies are therefore needed to explore women's healthcare and support needs during the diagnostic period, so that individual needs are met and the quality of health care for women with suspected breast cancer improved.

The study

Aim

The aim of our study was to investigate changes in the healthcare and support needs during the diagnostic period, and factors that affect these needs in women with suspected breast cancer.

Design

We adopted a descriptive, longitudinal design and collected data using an investigator-developed, self-administered Suspected Breast Cancer Patient's Needs Questionnaire (SBCP-NQ).

Participants

We recruited a purposive sample of women from the general surgery outpatient department at a large teaching hospital in northern Taiwan. Potential participants were women with suspected breast cancer, needing a core needle or surgical breast biopsy as determined by physical or imaging examination. The inclusion criteria were:

- ≥18 years old;
- able to read Mandarin Chinese and speak Chinese or a Taiwanese dialect;
- no previous breast cancer history;
- no history of psychological disorder; and
- currently not receiving psychological treatment or psychotropic medication.

Between November 2004 and April 2005, 153 women consented to join the study. Of these, 23 dropped out because of anxiety and did not finish the questionnaire ($n = 4$), or did not return to hospital for breast biopsy ($n = 19$). Another three participants were excluded because they could not return to the outpatient department on time, thus making their diagnostic period over 40 days, which is extreme value. Thus, the effective sample size was 127. A power calculation showed that this would achieve a medium-size effect with a power of 0·95 and alpha of 0·05 using one-way ANOVA. The majority of participants (78·7%) underwent surgical breast biopsy. Forty-seven women were diagnosed with benign breast tumours and 80 with breast cancer.

Instruments

Suspected Breast Cancer Patient's Needs Questionnaire

To measure the healthcare and support needs of women with suspected breast cancer, we developed the 40-item SBCP-NQ. We began with a 46-item questionnaire based on in-depth interviews with 10 women who had suspected breast cancer and had learned the results of breast biopsy. The content validity of the 46-item SBCP-NQ was evaluated by seven experts in breast cancer or cancer-related issues: two surgeons, one nursing practitioner, one case manager, and three oncology nursing instructors. We then evaluated each item on a 4-point scale for content importance and wording suitability. Based on this evaluation and a criterion for content validity index (CVI) > 0·86, we deleted three items and amended the remaining 43 items as suggested by the experts. The CVIs for content importance and wording suitability of the 43-item SBCP-NQ were 0·91 and 0·89 respectively.

We then examined the reliability and validity of this 43-item SBCP-NQ in a second sample of 215 women with suspected breast cancer. We analysed construct validity by principal components factor analysis and varimax rotation with Kaiser normalization. First-time analysis with the criterion of eigenvalue > 1 indicated nine factors. Scree plot analysis showed no change after the eighth factor, and only two items on the ninth factor, which explained only 3·4% of the variance. Therefore, the ninth factor was deleted, eight factors were kept, and one item with a factor loading < 0·4 was deleted. Thus, our final instrument had 40 items with a factor loading > 0·5.

The eight factors (domains) were information about treatment (eight items), information about disease (seven items), emotional support (six items), healthcare services for diagnosis (five items), follow-up and consultation (four items), involvement of family and friends (four items), companionship (three items) and resources (three items). These eight subscales explained 76·0% of the variance. The internal consistency reliability coefficients (Cronbach's α) for five of the eight subscales were over 0·93, with the exceptions of 0·80 for involvement of family and friends, 0·76 for resources, and 0·66 for companionship, indicating satisfactory reliability and validity of the scale. Cronbach's α of the overall SBCP-NQ was 0·96.

Responses to the self-administered SBCP-NQ are rated on a 4-point Likert scale, where 1 = not needed at all, and 4 = very much needed. The total score ranges from 40 to 160 points, where a higher score indicates a higher need level.

Demographic and disease-related information form

We designed a form to collect participants' demographic and disease-related information: age, marital status, education level, religious status, type and amount of support, family history of breast cancer, family history of benign breast tumour, history of benign breast tumour, and symptoms of breast pain, discharge or other conditions.

Data collection

To understand the healthcare and support needs of women with suspected breast cancer, we collected data at three significant points during the diagnostic period. The first (time 1) was after the preliminary physical or imaging examination at the general surgery outpatient department had revealed a breast lump and women had been informed about the need for a breast biopsy. The second (time 2) was in the operation waiting room while women were waiting for breast biopsy and likely to experience the greatest uncertainty about diagnosis and need for support. The third time (time 3) was immediately after the biopsy result had been explained to the women in the outpatient department. All participants were asked to complete the questionnaires while in hospital; if they had difficulties with this, the same research assistant helped them to do so. The average period from time 1 to time 3 was 8·65 days (range = 2–31, SE = 0·49), from time 1 to time 2, 4·49 days (SE = 0·39), and from time 2 to time 3, 4·16 days (SE = 0·35).

Ethical considerations

The study was approved by the Institutional Review Board of the hospital where the women were recruited. We explained the study purpose and procedure to all the women before enrolment and assured them that they were free to drop out at any time without their treatment being affected. We also guaranteed that all questionnaires would be processed confidentially and the information would not be used for further studies without permission. All the women signed consent forms.

Data analysis

We analysed the data using the Statistical Package for the Social Sciences/PC + (SPSS for Windows 12·0, Chicago, IL, USA). The women's characteristics were analysed by descriptive statistics. Changes in need levels at the three time points sampled and differences in need according to personal characteristics were analysed by *t*-test, one-way ANOVA, repeated-measures ANOVA and least squares difference.

Results

Participant characteristics

The average age of the women was 48·1 years (range = 22–83, SE = 1·06). Most were married and educated to senior high school level or above (Table 1). Almost all (98·5%) received support from at least one person: spouse (43·3%), children (15·2%), and friends and sisters (13·5%).

Ranking of needs

Our analysis of participants' need scores at the three time points during the diagnostic period showed that the top five needs were in the domains of healthcare services for diagnosis, follow-up and consultation, information about

Table 1 Demographic and disease-related characteristics of participants (*n* = 127)

Variable	*n* (%)
Age (years)	
≤50	76 (59·8)
> 50	51 (40·2)
Education	
Junior high school or under	58 (45·7)
High school and above	69 (54·3)
Religion status	
None	42 (33·1)
Yes	85 (66·9)
Marital status	
Married	107 (84·3)
Never married, separated, divorced, or widowed	20 (15·7)
Number of social supports	
0	2 (1·60)
1	92 (72·4)
≥2	33 (25·9)
Symptoms of breast pain, discharge or other	
No	86 (67·7)
Yes	41 (32·3)
History of benign breast tumour	
No	112 (88·2)
Yes	15 (11·8)
Family history of benign breast tumour	
No	108 (85·0)
Yes	19 (15·0)
Family history of breast cancer	
No	106 (83·5)
Yes	21 (16·5)

Table 2 Ranking of needs among women with suspected breast cancer (*n* = 127)

	Time 1			Time 2			Time 3		
	Mean	SE	Rank	Mean	SE	Rank	Mean	SE	Rank
Overall need (40 items)	3·45	0·04		3·48	0·04		3·32	0·04	
Treatment information (8 items)	3·46	0·07	4	3·48	0·06	4	3·34	0·06	4
Disease information (7 items)	3·54	0·06	3	3·63	0·05	3	3·35	0·06	3
Emotional support (6 items)	3·45	0·05	5	3·42	0·05	5	3·34	0·06	4
Diagnostic services (5 items)	3·89	0·03	1	3·87	0·03	1	3·67	0·05	1
Follow-up and consultation (4 items)	3·73	0·05	2	3·79	0·04	2	3·67	0·05	1
Involvement of family and friends (4 items)	3·34	0·06	6	3·32	0·06	6	3·11	0·07	7
Companionship (3 items)	3·09	0·07	7	3·18	0·06	7	3·13	0·07	6
Resources (3 items)	2·58	0·08	8	2·69	0·07	8	2·61	0·07	8

Overall mean need score = (sum of mean scores for all 40 items)/40 items.

Each domain's mean need score = (sum of mean scores for all items in that domain)/number of domain items.

disease and treatment, and emotional support (Table 2). However, the domains of involvement of family and friends, companionship and resources were ranked lowest. Further analysis of the need scores for specific items identified participants' most important needs during the diagnostic period (Table 3). These needs included offering tests and treatment ASAP, arranging surgery ASAP if needed, informing patients of the biopsy result ASAP, offering careful examination and accurate diagnosis, providing safety protection during tests and check-ups, helping patients to make the next doctor's appointment, providing information and consultation with specific staff, reminding patients of the next doctor's appointment and providing consultation after check-up tests.

Comparison of need levels at different times

Our analysis of need scores by repeated-measures ANOVA showed that participants had moderate to high levels of needs throughout the diagnostic period, but their overall need before diagnosis was significantly higher ($P < 0.01$) than after diagnosis (Table 4). In fact, the overall need score was statistically highest before biopsy and lowest after receiving the diagnostic result. The domains of healthcare

Table 3 The top 15 needs of women with suspected breast cancer during the diagnostic period (*n* = 127)

	Time 1		Time 2		Time 3		
	Mean	SE	Mean	SE	Mean	SE	
Progress of the disease	3·65	0·06	3·74	0·05	3·49	0·07	Disease
Check-up procedures	3·61	0·06	3·69	0·05	3·43	0·07	Disease
Information about the diagnostic results	3·68	0·06	3·76	0·05	3·46	0·07	Disease
Risk factors for breast cancer			3·60	0·06			Disease
Changes in lifestyle	3·62	0·06			3·53	0·07	Treatment
Family-supported decision-making	3·56	0·06					Emotional support
Post-surgical care	3·56	0·07	3·65	0·06	3·47	0·07	Treatment
Family companionship during surgery			3·62	0·06	3·46	0·07	Companionship
Careful examination and accurate diagnosis	3·89	0·03	3·88	0·03	3·73	0·06	Diagnosis
Tests and treatment offered ASAP	3·91	0·03	3·88	0·03	3·71	0·05	Diagnosis
Information on biopsy result ASAP	3·90	0·03	3·84	0·03	3·61	0·06	Diagnosis
Surgery arranged ASAP, if needed	3·91	0·03	3·88	0·03	3·65	0·06	Diagnosis
Provide safety protection during tests & checkups	3·87	0·04	3·84	0·03	3·66	0·06	Diagnosis
Information and consultation provided by specific staff	3·74	0·06	3·81	0·04	3·71	0·05	Follow-up and consultation
Help patient make the next doctor appointment	3·76	0·06	3·78	0·05	3·68	0·06	Follow-up and consultation
Remind patient of the next doctor appointment	3·71	0·06	3·76	0·05	3·67	0·04	Follow-up and consultation
Provide consultation after check-up tests	3·71	0·06	3·80	0·04	3·64	0·06	Follow-up and consultation

Disease = information about disease; Treatment = information about treatment; Diagnosis = healthcare services for diagnosis; ASAP = as soon as possible.

Table 4 Differences in domains of needs at three times during the diagnostic period (*n* = 127)

	Time 1		Time 2		Time 3			
	Mean	SE	Mean	SE	Mean	SE		
Overall need (40 items)	137·92	1·66	139·20	1·44	132·94	1·79	6·58**	1 > 3
								2 > 3
Treatment information (8 items)	27·68	0·53	27·85	0·49	26·73	0·47	2·02	
Disease information (7 items)	24·80	0·44	25·44	0·35	23·44	0·46	8·09***	1 > 3
								2 > 3
Emotional support (6 items)	20·71	0·33	20·51	0·31	20·06	0·35	1·51	
Diagnostic services (5 items)	19·47	0·14	19·33	0·14	18·35	0·26	14·06***	1 > 3
								2 > 3
Follow-up and consultation (4 items)	14·91	0·21	15·15	0·16	14·69	0·22	1·66	
Involvement of family and friends (4 items)	13·37	0·25	13·30	0·25	12·45	0·27	6·44**	1 > 3
								2 > 3
Companionship (3 items)	9·26	0·20	9·55	0·19	9·39	0·21	1·14	
Resources (3 items)	7·72	0·24	8·06	0·22	7·83	0·23	0·94	

1 = time 1; 2 = time 2; 3 = time 3.
**$P < 0.01$, ***$P < 0.001$.

services for diagnosis, information about disease, and involvement of family and friends received significantly higher scores before diagnosis than after. However, we found no statistically significant differences before and after diagnosis for the domains of information about treatment, emotional support, follow-up and consultation, companionship and resources.

Differences in need levels by demographic characteristics

Analysis of overall need scores at time 1 showed an association with education level and marital status (Table 5). The overall need level of women with at least a senior high school education was significantly greater ($P < 0.05$) than that of women with a junior high school education or below. At time 1, married women also had a greater ($P < 0.05$) overall need level than those who were separated, divorced,

widowed or never married. At time 2, we found no statistically significant differences in overall need scores among women by demographic or disease-related characteristics. At time 3, women without any history of benign breast tumour had a significantly greater overall level of need ($P < 0.05$) than those with this history. At all three times, we found no statistically significant differences in overall need among women by any other characteristics, such as age, religious status, number of social supports, family history of breast cancer, breast pain, discharge or other conditions.

Discussion

Study limitations

Three limitations need to be mentioned. First, more than 20% of the women dropped out of the study because of

Table 5 Differences in overall need levels by demographic and disease-related characteristics before and after diagnosis (*n* = 127)

	Time 1			Time 3		
	Mean	SE	t	Mean	SE	t
Education						
Junior high school or under	133·45	2·57	−2·53*	132·31	2·61	−0·32
High school and above	141·68	2·06		133·48	2·48	
Marital status						
Married	139·57	1·69	2·34*	134·36	1·86	1·84
Never married, separated, divorced, or widowed	129·10	5·00		125·40	5·31	
History of benign breast tumour						
No	139·04	1·66	1·43	134·29	1·81	2·09*
Yes	129·60	6·41		122·87	6·57	

*$P < 0.05$.

anxiety or did not return to see the doctor, which may have led to an under-estimation of need levels. To avoid this problem, future studies could allow women to take the questionnaire home and send it back to increase the return rate. Secondly, we recruited the study sample entirely from the outpatient department of a large teaching hospital; thus, the results may not be generalizable to other populations. We recommend that future studies expand sampling to more than one hospital and increase the sample size to improve generalizability to a larger population. Thirdly, the needs questionnaire used a Likert-type scale, which may lead to ceiling effects. Therefore, the results of the need level should be interpreted with discretion. A high need score does not necessarily mean that a need was not satisfied. In addition, this is the first time that this scale was used, so its psychometric properties may need to be improved by applying it to different samples.

Ranking of needs

Women with suspected breast cancer ranked their top three needs during the diagnostic period in the domains of healthcare services for diagnosis, follow-up and consultation, and information about the disease. Furthermore, the most important need items identified by the women were careful examination and accurate diagnosis, tests and treatment offered ASAP, being informed ASAP of the biopsy and diagnostic results, information about progress of the disease, being provided with safety protection during tests and check-ups, post-surgical care, and information and consultation provided by specific staff. Women also needed the assistance of healthcare staff to make appointments and remind them prior to the next visit, probably because they were worried that they might forget the appointment and delay getting their diagnosis. These results are consistent with previous reports which suggest that, during the diagnostic period, women with suspected breast cancer need to be informed ASAP about the diagnosis, treated with care and have an opportunity to communicate with healthcare providers (O'Mahony 2001, Freedman 2003, Chappy 2004).

Participants ranked the need for information about treatment below the need for information about disease. This result is consistent with a previous report that women wanted to know the result of breast biopsy rather than treatment options (Shaw *et al.* 1994). However, our study results revealed that before diagnosis, participants ranked the domain of emotional support below the domain of information about treatment. This result is inconsistent with another finding from the same study (Shaw *et al.* 1994) that all women experience emotional distress during this period, and

most want to avoid receiving too much information about treatment to reduce their anxiety. Our finding may be due to the cultural influence of Confucian thought on our sample of women, which means that they tend to perceive an obligation to nurture their families and maintain family harmony even during illness (Kagawa-Singer & Wellisch 2003). Women from Chinese cultures are thus more likely than women from western cultures to remain independent, not seeking support from their families (Kagawa-Singer & Wellisch 2003), and therefore rate treatment-related information from healthcare professionals higher than emotional support. Furthermore, Chinese culture discourages patients and their families from talking openly about being ill. This explanation is supported by a previous report that Chinese husbands whose wives had breast cancer received less support from their family and friends than Israeli husbands (Kadmon *et al.* 2004).

The domain of resources was ranked lowest at all three time points during the diagnostic period, indicating that women paid more attention during the diagnostic period to information about their current situation, and suggesting that, after diagnosis, they would gradually extend their attention to resources such as information on breast cancer genetics. This is consistent with the findings of Luker *et al.* (1996) that women with breast cancer begin to pay more attention to information related to the risk of family history about 21 months after diagnosis. Furthermore, our study revealed that women had a great need for informational support from healthcare professionals, as previously reported (Fridfinnsdottir 1997), a finding which reflects their need for accurate information (Northouse *et al.* 1997).

Need changes during the diagnostic period

The needs of women with suspected breast cancer changed by statistically significant amounts during the diagnostic period, being greater prior to diagnosis. The overall need score and the scores of three domains (healthcare services for diagnosis, information about disease, and involvement of family and friends) were statistically significantly higher before diagnosis than after. These results show that women with suspected breast cancer need reassurance and an efficient healthcare service which can give them their diagnosis ASAP. Furthermore, the results show that women have a greater need for their family's assistance before the diagnosis than after, to help them deal with relevant information and make immediate treatment decisions (Northouse *et al.* 1997). Therefore, healthcare providers should shorten the time that women wait for diagnostic results and take initiatives to provide patients and their families with information regarding the

disease and communication opportunities to discuss diagnostic results.

Participants' overall need level was highest prior to breast biopsy. This result is consistent with previous reports that women with suspected breast cancer need a thorough understanding about breast biopsy procedures, check-up procedures and post-surgical care (Kelly & Winslow 1996, Chappy 2004), as well as family companionship during breast biopsy to reduce their anxiety level. These results highlight the importance of providing women with detailed instructions about breast biopsy procedures.

Women's levels of need for follow-up and consultation remained high throughout the diagnostic period. The majority of outpatients (74%) in Taiwan receive less than 10 minutes with their doctors during a clinic visit (Department of Health, the Executive Yuan 2005b), so doctors often do not have sufficient time to offer detailed information or explanations. Sometimes women with suspected breast cancer may be too anxious to remember the doctor's explanation, or not know what questions to ask about their disease. Therefore, to reduce the risk of emotional distress and uncertainty for patients, it is important to provide access to consultation and designate a specific professional whom patients and their families can contact by phone or in person, to ask questions, share fears or concerns, and clarify discrepancies between their perception of a problem and the facts (Hoskins & Haber 2000, Samarel *et al.* 2002, Palese *et al.* 2005). This recommendation is supported by a report that consultation is extremely helpful to women throughout the diagnostic period (O'Mahony 2001).

Although the women believed that the final diagnostic result was most important in terms of information needs, the need for information about the disease and its treatment also received high scores, with no significant difference in need for information about treatment before and after diagnosis. This result is similar to that found in previous reports: patients need information support to adjust to the possibilities of being diagnosed with breast cancer and coping with life changes after diagnosis (Bilodeau & Degner 1996, Fridfinnsdottir 1997, Leydon *et al.* 2000, Rees & Bath 2001). When informed that they have a benign breast tumour, women needed to know the risk that a malignancy could develop and follow-up details (Deane & Degner 1998). Furthermore, women with newly diagnosed breast cancer needed to know the likely trajectory of the disease and treatment options (Luker *et al.* 1996). Therefore, nursing staff should offer individualized informational support to women after diagnosis.

Need scores for the domains of emotional support and companionship were high and not significantly different before and after diagnosis, showing that waiting to find out the test result was a highly stressful experience. These results are consistent with reports that women needed continuous emotional support and care from their families, friends and healthcare professionals even when the test results showed no breast cancer (Fridfinnsdottir 1997, Deane & Degner 1998, Davis *et al.* 2004).

Factors influencing women's needs

Overall need levels were statistically significantly different at specific times during the diagnostic period according to some personal characteristics (i.e. education level, marital status and history of benign breast tumour). This suggests that the needs of women with suspected breast cancer are not universal, but based on individual characteristics. The women in our sample had higher need levels before biopsy if they were married and had a high school education or above than if they were unmarried or had less education. These results are consistent with previous reports and may be explained by married women being more concerned about the impact of the disease on their families (Wang *et al.* 1999, Lindop & Cannon 2001), and more educated women needing more information to become actively engaged in decision-making (Deane & Degner 1998). Women with lower education levels may not have sufficient capability and social support to get relevant information and resources; therefore, they may adopt a strategy of cognitive defence to adjust to events of stress such as suspected breast cancer (Drageset & Lindstrom 2005). The family is an important primary social support resource for women during the diagnostic period (Fridfinnsdottir 1997), and the single women in our sample may not have had sufficient support from their families when needed; therefore, they had to act independently when seeking diagnosis.

The overall need level after diagnosis was higher among women without any history of benign breast tumour than among those with this history. This result, which echoes previous reports, may be associated with uncertainty about the development of malignancy (Deane & Degner 1998) or progress of the disease and treatment options (Luker *et al.* 1996). However, we found that the overall need level did not differ significantly in participants by number of social supports, as found in a previous study (Seckel & Birney 1996). Our result might be explained by the sample being skewed to higher numbers of support sources, reflecting a Confucian influence on strong relationships in most Chinese families (Kagawa-Singer & Wellisch 2003). Taken together, these results suggest that healthcare professionals should consider the influence of personal and cultural characteristics on the healthcare and support needs of women with

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What is already known about this topic

- Women with breast cancer have different healthcare and support needs at different stages of their disease.
- Most women need emotional support to face the stress of events associated with suspected breast cancer during the diagnostic period.
- Women need to learn their diagnosis as soon as possible, but their disease-related information needs differ individually.

What this paper adds

- Taiwanese women's needs for disease- and treatment-related information were greater than their need for emotional support during the diagnostic period, a likely influence of Chinese culture.
- Both before and after diagnosis, women's need for follow-up and consultation remained high.
- Married women with more education and no previous history of tumours had higher need levels than those who were single, less educated and with any history of tumours.

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suspected breast cancer. Our findings are consistent with the supportive care framework (Fitch 1994), which indicates that the needs of cancer patients vary across cancer stages and are influenced by personal and environmental factors.

Conclusion

Women with suspected breast cancer need healthcare professionals to provide reassuring care and a prompt, careful diagnosis. After diagnosis, they need access to professional caregivers to discuss the diagnostic results. Furthermore, women need access to consultation throughout the diagnostic process as well as information and emotional support from professional caregivers and their own social networks. However, the extent and intensity of women's needs may vary individually, be influenced by cultural values, and change over time. Healthcare providers should be aware of these changes in needs. This understanding could be used to develop educational materials related to information support and emotional coping for women with suspected breast cancer and their families. Finally, these women and their families need established consultation channels with specific people to clarify doubts and express concern, thus helping them cope with psychological distress during the diagnostic period.

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