

## **Mapping the quality of life and unmet needs of urban women with metastatic breast cancer**

S. Aranda, S. P. Schofield, L. Weih, P. Yates, D. Milne, R. Faulkner, & N. Voudouris

Aranda, S. and Schofield, P. and Weih, L. and Yates, P. and Milne, D. and Faulkner, R. and Voudouris, N. (2005) Mapping the quality of life and unmet needs of urban women with metastatic breast cancer.. *European Journal of Cancer Care* 14(3):211-222.

Copyright 2005 Blackwell Publishing

### **ABSTRACT**

Enhancing quality of life and reducing the unmet needs of women are central to the successful management of advanced breast cancer. The objective of this study was to investigate the quality of life and support and information needs of urban women with advanced breast cancer. This study was conducted at four large urban hospitals in Melbourne, Australia. A consecutive sample of 105 women with advanced breast cancer completed a questionnaire that contained the European Organization of Research and Treatment of Cancer Quality of Life Q-C30 and the Supportive Care Needs Survey. Between one quarter and a third of the women reported difficulties with their physical, role and social functioning, and a little over a quarter of the women reported poor global health status. Fatigue was a problem for most women. The highest unmet needs were in the psychological and health information domains. Almost no differences in unmet needs were detected when comparing different demographic and disease characteristics of women. Health care providers should routinely monitor the quality of life and needs of women with advanced breast cancer to ensure that appropriate treatment, information or supportive services are made available.

### **INTRODUCTION**

Breast cancer is the most commonly detected cancer and the most common cause of cancer death amongst women in more economically developed countries (Stewart & Kleihues 2003). Even with early intervention, there is a life-long risk of recurrence even 30 years or more after initial diagnosis of breast cancer (DeVita et al. 2001). Increasingly, advanced breast cancer is being conceptualized as a chronic illness (Brescia et al. 1990). Women can live with the disease for 10 years or more depending upon the location and extent of metastases (DeVita et al. 2001). However, there is evidence that the psychosocial care of women with advanced breast cancer is currently lacking (Parle et al. 2001; Scholten et al. 2001; Cristine et al. 2003). An Australian audit study showed that of the 842 women seen by four breast cancer nurses only 7% were women with advanced disease, despite the fact that this group represented 35% of breast cancer cases in the hospitals where the study was conducted (Aranda et al. 2002). Given the sizeable number of women who are now living with advanced breast cancer (Stewart & Kleihues 2003), it is critical that efforts are directed towards reducing cancer-related morbidity and improving the quality of patient care. Optimal care involves not only the technical or disease management aspects but also meeting the needs of the patient in the psychosocial, supportive care and informational domains (Sackett et al. 1996; AFCOS 1998; Donabedian 1988).

This study investigates the needs of urban women with advanced breast cancer. The results will show the development of interventions designed to meet these needs and enhance these women's quality and length of life.

Quality of life assesses two aspects of experience: the persons' functional status across various domains, such as, physical, occupational and interpersonal, and the persons' appraisal of how their health affects their enjoyment or quality of life (Fayers & Bottomley 2002). However, definitions vary, as do approaches to measurement (Muldoon et al. 1998). Some instruments attempt to measure these dimensions objectively by seeking behavioural information about tasks that can be performed, and others assess quality of life in an inherently subjective way by asking about how the person feels (Muldoon et al. 1998). Concerns have been raised over the validity of commonly used instruments because criterion validation, which is the best method of assessing validity, has not been demonstrated (Muldoon et al. 1998). Also, person characteristics, such as personality, cognitive dysfunction and psychological adaptation to illness may influence how a person responds to the items (Muldoon et al. 1998; Slevin et al. 1988).

Nevertheless, quality of life has been found to be a significant independent predictor of response to treatment and survival time amongst women with advanced breast cancer (Coates et al. 1992; Kramer et al. 2000). Quite apart from potential survival benefits, enhancing quality of life by minimizing the physical and psychological impact of the disease and treatment side effects is an important endpoint in itself and should be the focus of health care for people with metastatic disease. Thus, it is critical for the treatment team to be aware of the impact of the disease and treatment on the quality of life of women with advanced breast cancer.

Recently, it has been argued that quality of life assessments provide an outline of patient concerns or issues but fail to indicate which of the concerns the patients most feel they require assistance (Sanson-Fisher et al. 2000). Similarly, satisfaction measures provide little direction on how to ameliorate patient concerns. Ong and colleagues also question whether creating a 'satisfied' consumer is sufficient given that the purpose of medical care is to optimize the health and well-being of patients (Ong et al. 1995). Moreover, measures of satisfaction are notoriously susceptible to social desirability biases in responses (Ong et al. 1995). Hence, the concept of 'unmet needs' was developed.

Unmet needs are defined as 'the requirement of some action or resource that is necessary, desirable or useful to attain optimal well-being' (Sanson-Fisher et al. 2000). Previous research on the unmet needs of people with cancer has revealed that in general, people with cancer experience the highest levels of unmet needs in the areas of health information, especially in relation to the disease investigatory tests and treatments; psychological/social support concerns; and physical and daily living needs (Foot & Sanson-Fisher 1995; Luker et al. 1995; Bilodeau & Degner 1996; Meredith et al. 1996; Graydon et al. 1997; Newell et al. 1999; Sanson-Fisher et al. 2000; Soothill et al. 2003). In a local Australian study, by far the highest unmet need was in the domain of health information with over 60% of ambulatory patients with cancer expressing this need (McLachlan et al. 2001). However, small variations in findings are noted between studies, probably as a result of different measurement tools and different populations.

Needs and quality of life issues tend to vary substantially according to the characteristics of the person. Research has shown that women express higher levels of unmet needs than men (Meredith et al. 1996; Sanson-fisher et al. 2000). Needs also change over the course of the disease (Luker et al. 1996; Degner et al. 1997; Frost et al. 2000). In comparison to others, people with advanced disease report higher levels of unmet needs in most domains but especially in the psychological and physical and daily living domains (Foot & Sanson-Fisher 1995; Sanson-fisher et al. 2000; Cossich et al. in press).

The small amount of research focused on people with advanced cancer has shown that they experience unrelieved physical symptoms, especially pain, fatigue, dyspnoea and reduced appetite (Vachon et al. 1995; Stromgren et al. 2001; Wong et al. 2002); high levels of psychological distress, particularly for people who also reported pain (Vachon et al. 1995; Stromgren et al. 2001); and practical service needs, such as help with daily living, housework, financial assistance and transportation (Siegel et al. 1991; Vachon et al. 1995; Wong et al. 2002). Self-care, mobility, physical activity, appetite and sleep were the quality of life issues ranked mostly highly important by women with advanced breast cancer (Sutherland et al. 1990).

Owing to the difficulties inherent in recruiting people with metastatic disease into studies, this tends to be an under-researched group in terms of quality of life research (Kristjanson & Ashcroft 1994; Bottomley & Therasse 2002). The strength of the current study is that a sizeable group of women with metastatic disease from four different urban treatment centres were surveyed using reliable and valid instruments to assess quality of life and unmet needs.

The aims of this study were:

- 1 to identify support and information needs that are commonly experienced by urban women with advanced breast cancer;
- 2 to identify patterns of support and information needs among these women; and
- 3 to evaluate the variation of support and information needs by demographic and disease characteristics among these women.

## **METHODS**

### **Setting**

This study was conducted at four large urban hospitals, three public and one private, in Melbourne, Australia.

### **Sample**

A consecutive sample of 172 women with metastatic breast cancer who were attending an outpatient oncology clinic was screened for inclusion. Inclusion criteria for patients were as follows: a diagnosis of breast cancer that was newly diagnosed at an advanced stage, recurred or progressed in the preceding 12 months; aged 18 years or older; had sufficient English for the study requirements and had access to a

telephone for follow-up. Of these 67 declined to participate for a variety of reasons, including being too tired, involvement in other studies and time commitments. This represents a response rate of 61%. All those who consented completed the baseline questionnaire (n = 105).

### Design and procedure

This study was carried out with ethics committee approval from all study sites. The data reported in this study were collected at baseline for a pilot randomized controlled trial that assessed the effectiveness of an intervention designed to improve patients' quality of life and reduce their unmet needs.

A breast care research nurse at each site reviewed the appointment schedule to identify potentially eligible women and confirmed their suitability with the treating doctor prior to the clinic. The breast care research nurse then placed a screening form on the patient's notes to alert the specialist involved in that woman's care. The doctor provided initial information about the study to the woman. If she was interested in participating, the breast care research nurse provided verbal and written information about the study and obtained written consent. The woman was then asked to complete the baseline questionnaire. The baseline questionnaire contained demographic questions, the European Organization of Research and Treatment of Cancer Quality of Life Q-C30 (EORTC QLQ-30) (version (2.0) (EORTC QLQ-30) and the Supportive Care Needs Questionnaire (SCNQ) and an interactions with health professionals checklist. The breast cancer nurse provided diagnostic and treatment details for each patient based on the patient's medical record.

### Measures

**EORTC QLQ-30** The quality of life questionnaire contains 30 items and was scored according to the algorithm in the EORTC QLC-30 scoring manual. Briefly, the raw score for each scale contained in the questionnaire is an average of the applicable items for that scale. All items for a particular scale are rated on the same range of values (i.e. 14). Raw scores are then linearly transformed to 0100 scales. High scores represent healthy functioning in the functional scales, high quality of life in the global health status quality of life scale and a high level of problems for symptom scales. Scales that were used in this study included the five functional scales, the global health status quality of life scale and the nine symptom scales from the core section of the EORTC QLC-30. It has demonstrated high reliability and concurrent criterion validity (Hjermstad et al. 1995;Kaasa et al. 1995).

**SCNQ** The SCNQ contains 59 items designed to measure patients' perceived needs for help in five core domains: psychologic, health information, physical and daily living, patient care and support and sexuality, and single items assess communication, financial and transport needs. An additional 16 single items assess need for access to services and resources. Patients indicated for each item whether they are experiencing no need, low, moderate or high need for each item. Scores for summary scales are then linearly transformed 0100 average of the items contained in the scale. Higher scores indicate higher level of need. The transformed summary score for each domain and single items were used in the analyses as the primary outcome. As a secondary outcome, for each domain score, each woman was categorized as having a score in

excess of 50 or 50 or below. Women with a score higher than 50 indicated that they have had moderate to high need across the items contained in the domain. It has high internal consistency and demonstrated construct and content validity (Bonevski et al. 2000).

### Statistical analyses

In all analyses, a P-value < 0.05 was considered statistically significant. Analyses were conducted using SPSS. Exact P-values were calculated using StatExact. The methods used to address each of the study aims are as follows. Response frequency for each SCNQ item was tabulated. Then, cluster and discriminant function methods were used to investigate the pattern of support and information needs. Only the five main multi-item SCNQ domains were used in the analysis. This was performed in stages. First, bivariate scatterplots of each domain were examined for evidence of clustering. Then, a hierarchical cluster analysis was used to produce a dendrogram of agglomerative clusters of women with similarity in need. K means cluster analysis was then used to assign individual membership to clusters, with the number of clusters specified as those found in the examination of the dendrogram. Two methods were used to validate this cluster structure. The dendrogram was re-examined for consistency of membership assignment between the two methods of cluster analysis used. Discriminant function analysis was then used to validate the cluster structure.

Two sets of analyses were conducted to investigate variation in unmet needs by demographic and disease characteristics. The first evaluated variation in demographic and disease characteristics within SCNQ summary scales. The second evaluated variation in demographic and disease characteristics between the clusters identified in the preceding analysis. Pearson chi-square was used to evaluate differences between dichotomous and non-ordered categorical variables. Fisher's exact test of significance was used where contingency tables contained one or more cells with an expected cell count less than five and the Pearson chi-square P-value was < 0.05. The KruskalWallis tests and MannWhitney tests of differences were used to evaluate differences in medians between categorical variables as appropriate.

## RESULTS

### Description of the sample

Table 1 displays demographic details and disease characteristics for the sample. The median age of women was 57 years (range 3485), most were married, over half had adult children and a quarter had at least one child under 18 years. Most women (61%) reported having had previous contact with a breast care nurse; most of this contact had occurred around the time of initial treatment, that is, before surgery, just after surgery or during chemotherapy or radiotherapy. Women also reported having contact with a range of other health professionals. The most commonly seen health professionals were medical oncologists, chemotherapy nurses, general practitioners, radiation oncologists, radiotherapy nurses and surgeons.

		No.	%
Age	Median (range) years	57 (34 85)	
Clinic	Box Hill	19	18%
	Cabrini	29	28%
	Peter MacCallum	37	35%
	The Alfred	20	19%
Marital status	Never married	11	10%
	Married/de facto	67	64%
	Separated/divorced	15	14%
	Widowed	10	10%
	Unknown	2	2%
Highest education	School certificate	30	29%
	Higher school certificate	11	10%
	Certificate/diploma	11	10%
	University degree/diploma	23	22%
	University higher degree	5	5%
	Other	22	21%
	Unknown	3	3%
Children	At least one child < 18 years	25	24%
	Adult children	56	53%
	No children	21	20%
	Unknown	3	3%
Time since primary diagnosis	Median (range) years	5 (< 1 27)	
Time since advanced disease diagnosed	Median (range) years	1 (< 1 14)	
Time between primary diagnosis and diagnosis of advanced cancer	Median (range) years	3 (< 1 24)	
Type of breast cancer	Adenocarcinoma	6	6%
	Ductal carcinoma	43	41%

		No.	%
	Inflammatory breast carcinoma	2	2%
	Lobular	10	10%
	Ductal carcinoma, lobular	2	2%
	No details available	24	23%
	Unknown	18	17%
Number of sites of metastases	0	3	3%
	1	32	30%
	2	35	33%
	3	25	24%
	4	7	7%
	5	2	2%
	Unknown	1	1%
<b>Sites of metastatic disease</b>			
Bone	No	23	22%
	Yes	81	77%
	Unknown	1	1%
Brain	No	94	90%
	Yes	10	10%
	Unknown	1	1%
Liver	No	74	70%
	Yes	29	28%
	Unknown	1	1%
Lung	No	72	69%
	Yes	32	30%
	Unknown	1	1%
Lymph nodes	No	59	56%
	Yes	45	43%
	Unknown	1	1%
Other	No	89	85%
	Yes	15	14%
	Unknown	1	1%

Table 1. Patient and disease characteristics

The median time since primary diagnosis was 5 years (range < 127 years) and median time since diagnosis of advanced disease was 1 year (range < 114 years). The most common breast cancer was ductal carcinoma (41%). The vast majority of patients (87%) had between 1 and 3 metastatic sites: 77% of the women had bone metastases; 43% had lymph node metastases; 30% lung metastases; 28% liver metastases; and 10% brain metastases.

Half the sample was currently receiving chemotherapy; 45% was receiving Aminohydroxypropylidene bisphosphonate (APD) treatment for boney metastatic disease (Pamidronate); 40% was receiving hormonal therapy; 15% radiotherapy; and 5% surgery. Two women were not currently receiving treatment and the current treatment status was unknown for four women.

The quality of life and support and information needs of women with advanced breast cancer

Table 2 displays a summary of the EORTC Quality of Life questionnaire and SCNQ. For the EORTC QLQ-30 functioning scales, 26% of women scored 50 or below, representing worse quality of life, on the global health status scale, and between 27% and 30% of women scored 50 or below on the physical, role and social functioning scales. Only a small proportion of women had scores of 50 or below, on the emotional and cognitive functioning scales (14% and 8%, respectively). For the symptom scales, over half (63%) of women scored over 50 on the fatigue scale, which represents higher symptoms; 30% scored over 50 on the pain scale and 26% scored over 50 on the insomnia scale.

	Mean	SD	Median†	n < 50	% < 50	Missing Data
<b>EORTC QLQ-30*</b>						
Physical functioning	66	27	60	28	27%	0
Role functioning	62	33	67	31	30%	0
Emotional functioning	71	24	75	15	14%	1
Cognitive functioning	77	24	83	8	8%	0
Social functioning	63	31	67	28	27%	0
Global health status	63	22	67	27	26%	0
<b>Symptom scales</b>						
Fatigue	42	26	33	66	63%	1
Nausea and vomiting	15	23	0	11	10%	0



	Mean	SD	Median†	<i>n</i> < 50	% < 50	Missing Data
Pain	32	31	16	31	30%	0
Dyspnoea	22	24	33	12	11%	0
Insomnia	34	34	33	27	26%	1
Appetite loss	25	32	0	17	16%	0
Constipation	18	28	0	12	11%	0
Diarrhoea	9	19	0	6	6%	2
Financial difficulties	24	32	0	15	14%	0
Supportive Care Needs Questionnaire						
Psychological needs	27	26	18	23	22%	0
Health information needs	26	28	16	23	22%	0
Physical and daily living needs	22	22	14	16	15%	0
Patient care and support needs	9	15	2	3	3%	1
Sexuality needs	26	27	22	15	15%	3
*The EORTC summary scales range from 0 to 100 with a higher score indicating better quality of life on the function scales and a poorer outcome on the symptom scales. The SCNQ scales also range from 0 to 100 with a higher score indicating a higher level of need.						
†All scales had a range from 0 to 100.						

Table 2. European Organization of Research and Treatment of Cancer Quality of Life (EORTC QLQ-30) and Supportive Care Needs Questionnaire (SCNQ) summary scales

For the SCNQ, over one-fifth of women scored over 50 in psychological and health information domains, indicating higher level of need. The proportions were lower for the other domains. This finding was reflected in the results for the individual items (see Fig. 1). Of the top 20 unmet needs, 11 were from the psychological domain, 7 from the health systems domain and 2 from the physical domain. The two items most commonly rated as moderate or high need were 'concerns about the worries of those close to you' (41%) and 'to be informed about things you can do to help yourself get well' (41%). The next most common items related to fears about the future and control over the situation, including being well informed. The items from the physical domain, which were 'pain' and 'not being able to do the things you used to', were ranked below 10 in the list.



Figure 1. Top 20 unmet needs ranked by percentage patients with moderate or high need.

In terms of services and resource needs, the five most commonly reported unmet needs were: 'easy car parking at the hospital or clinic' (33%); monetary allowance for travel, treatment or equipment expenses' (18%), 'drop in counselling services' (17%), '24 h telephone support and cancer advisory service' (17%) and 'relaxation classes' (16%). See Figure 2.

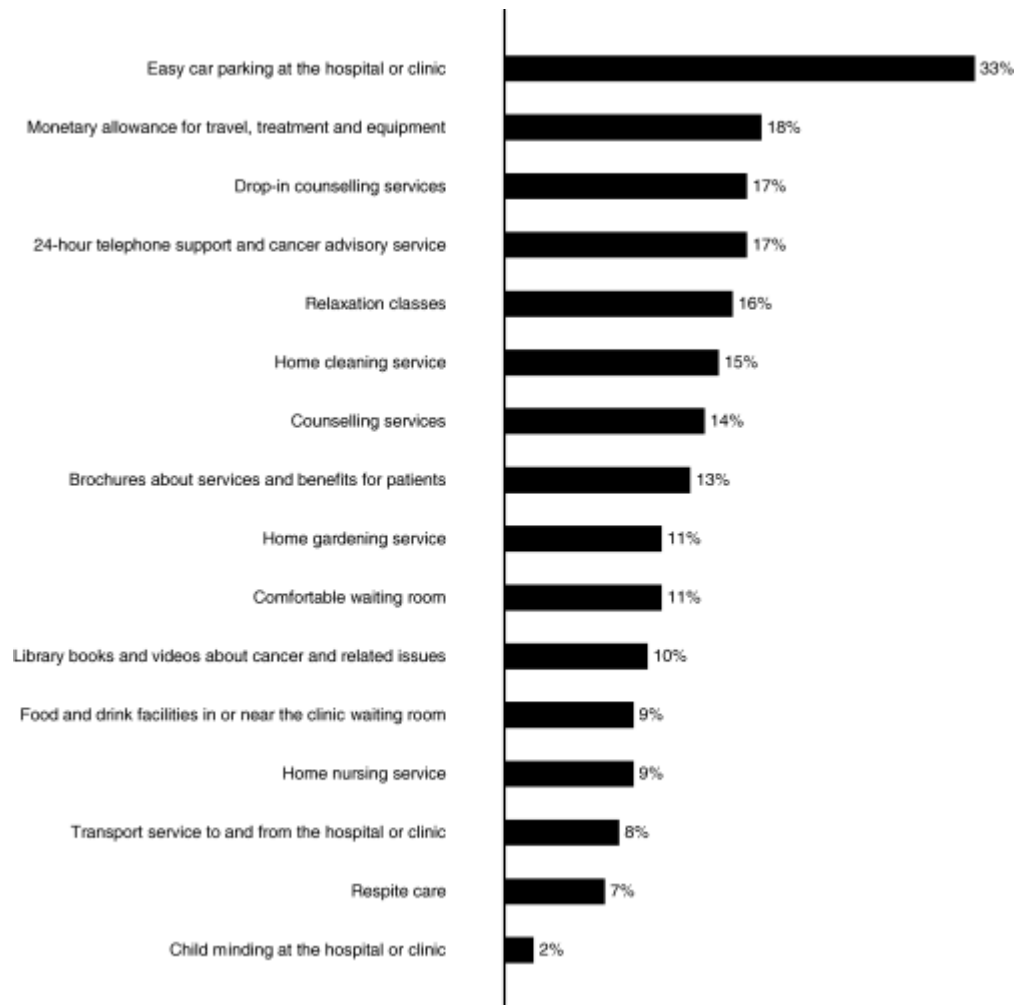


Figure 2. Service and resource needs ranked by percentage patients with moderate or high need.

The interrelationship between the support and information needs

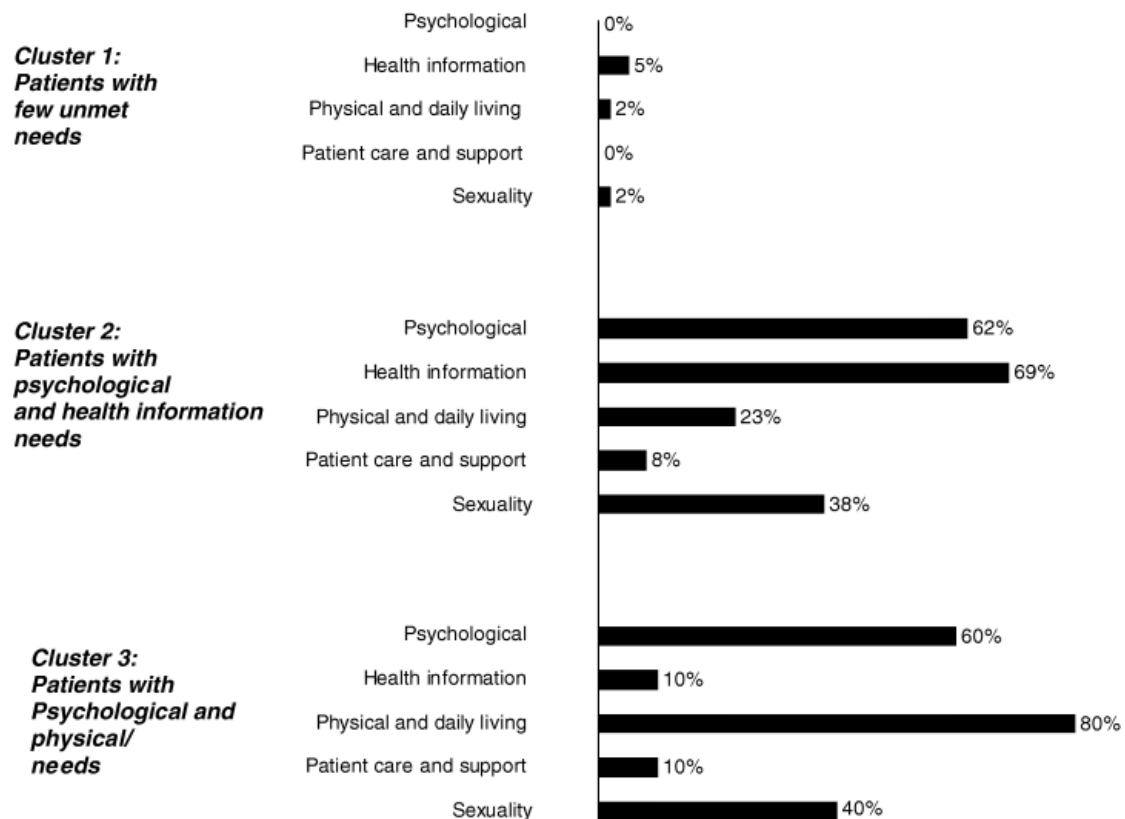


Figure 3. Percentage of women with SCNQ domain score > 50 by cluster.

Cluster analysis suggested that there were three main groups of women with different profiles of need across the five multi-item domains of the SCNQ. Figure 3 displays the percentage of women with SCNQ domain scores of greater than 50 by cluster. The largest group ( $n = 66$ ) was substantially without moderate to high need in any of the SCNQ domains. In the second group ( $n = 26$ ), many women had moderate or high need in the psychological and health information domains, while in the third group ( $n = 10$ ) many women had moderate or high need in the psychological and physical and daily living domains. The mean of each domain varied by cluster ( $F$  d.f. = 2 ranged from 22 to 85,  $P < 0.001$  for all domains). Discriminant function analysis suggested support for the existence of the clusters identified. The discriminant functions generated from this data set effectively separated the members of each cluster (Wilk's = 0.140,  $P < 0.001$ ). However, when compared with the psychological, health information and physical and daily needs domains, the patient care and sexuality needs domains contributed substantially less to the discriminant functions generated. The psychological and health information needs are correlated at 0.70 and 0.58 with function 1 compared with 0.16 or less for the physical and daily living, patient care and support and sexuality needs domains. The second function is most highly correlated with the physical and daily living needs domain, all other correlations below 0.63 (absolute value).

The variation of support and information needs by demographic and disease characteristics

Demographic and medical characteristics by summary supportive care needs questionnaire scales

The primary outcome for this analysis was median SCNQ score for each scale. A secondary analysis to confirm the results of the primary analyses was conducted with the SCNQ scale dichotomized into score  $\leq 50$  or  $> 50$ . Rate of SCNQ score by demographic characteristic was also investigated for the same variables. Of the six medical characteristics examined, only the median SCNQ score for the physical daily living domain varied by current radiotherapy. Women who were currently undergoing radiotherapy experienced comparatively greater physical and daily living needs ( $P = 0.001$ ). The median SCNQ score did not vary in any domain by number of metastatic sites, currently receiving chemotherapy, currently receiving APD treatment, years since breast cancer diagnosed, years since advanced breast cancer diagnosed or years between primary and advanced diagnosis (all  $P > 0.05$ ). Women who had previously seen a breast care nurse were more likely to express unmet needs in the physical and daily living domain ( $P = 0.03$ ). The median SCNQ scores for each of the domains did not vary by the remaining demographic and medical characteristics including age, marital status, education and having children (all  $P > 0.05$ ).

#### Demographic and disease characteristics by cluster

The same set of demographic and medical characteristics as used above were included in these analyses. Demographic and disease characteristics did not vary across clusters (all  $P > 0.145$ ). Similarly, there was no significant variation of treatment or metastatic site by cluster membership (all  $P > 0.054$ ).

## DISCUSSION

In terms of quality of life issues, a sizeable minority of women in this sample reported difficulties with their physical, role and social functioning. These difficulties were reflected in an overall assessment of health: over a quarter of the women reported poor global health status. Over half the women reported feeling fatigued. Pain and insomnia also represented difficulties for a sizeable minority of women. These findings broadly reflect previous research on quality of life issues for women with advanced breast cancer; although, it would appear that the level of physical symptoms reported is lower than in previous research (Sutherland et al. 1990; Vachon et al. 1995; Stromgren et al. 2001). This may be because advances in symptom management mean that symptoms are now better controlled than previously. Alternatively, it may be that this sample was captured earlier in the advanced stage of the disease in comparison to samples in previous research. Sub-analyses of median EORTC physical functioning scores and the physical and daily living needs score tend to support the better symptom management explanation. The median scores for both of these scales were comparatively lower for patients receiving APD treatment; however, these trends were not significant. It is a concern that pain and insomnia, which should be able to be controlled with appropriate medication, remain a problem for some women with advanced breast cancer. The reasons underlying this are likely to relate to failure of the health care system to identify and address these symptoms.

In terms of unmet needs, the highest levels of unmet needs were from the psychological and health information domains. This is similar to findings for a heterogeneous sample of mixed cancer types and stages (Sanson-Fisher et al. 2000); however, inspection of rank ordering of individual items reveals that the needs of women with advanced cancer are different from the needs of the general category of people with cancer. In the heterogeneous sample (Sanson-Fisher et al. 2000), the top

three concerns were 'fears about the cancer spreading'; 'fears about the cancer returning'; and 'concerns about the worries of those close to you'; whereas in this group of women with advanced breast cancer the rank order had shifted to 'concerns about the worries of those close to you'; 'to be informed about things you can do to help yourself get well'; and 'uncertainty about the future'. Hence, once the cancer was known to be incurable, fears about it advancing were replaced by self-care and control issues. These are both issues in which women may be assisted by information. In recent years, there have been increased efforts to provide patients with the information that they require (Jefford & Tattersall 2002); clearly there remains a need to develop new strategies for information dissemination. People prefer to receive information in different ways (Jefford & Tattersall 2002), in terms of the level of detail provided, the timing of presentation and the medium in which it is presented. Health systems need to cater for the range of preferences if information provision is to be optimized.

Comparing service and resource needs in women with advanced cancer with the needs of a heterogeneous group (Sanson-Fisher et al. 2000), car parking and financial assistance top the list for both groups. However, compared with the heterogeneous sample, women with advanced breast cancer express greater need for counselling and support services. This is an appropriate response to their circumstances and may also relate to a higher inclination by women to seek emotional support. This finding does highlight the need to ensure that these women have adequate opportunity to access the supportive care services available in hospitals, such as breast care nurses.

Interestingly, there were almost no differences detected in unmet needs in terms of demographic and disease characteristics of the women. This reinforces that no assumptions should be made about the needs of any woman with advanced breast cancer on the basis of her demographic and disease characteristics. This is not to say that women do not differ in their level of unmet needs. These results also suggested that there exists three broad types of women with advanced breast cancer: women with a low level of unmet need in all domains; women with primarily psychological and health information unmet needs; and women with psychological and physical and daily living unmet needs. This was considered an exploratory analysis with the aim of simplifying a complex set of data into a structure that could then be used for future supportive care planning.

Addressing these issues is critical to providing optimal care of women with advanced breast cancer. Hence, the first aspect of care should be regular monitoring of the person's needs and quality of life. This information can then be used to plan or modify treatment regimens and provide the woman with the information or services that she requires. Routine screening questionnaires are increasingly being introduced into clinical practice (Zabora et al. 2003). Recent research has found that touch screen computers are an acceptable way of gathering and disseminating this information to the health care team (Allenby et al. 2002). In the absence of formal mechanisms for obtaining this information, health care teams can just ask the woman about her quality of life and her needs. Use of open-ended questions, active listening, responding with empathy and clarifying perceptions of woman's concerns are all strategies that have been shown to increase the identification of patients' concerns (Ryan et al. in press).

This study provides important information on an under-researched group; however, there are a number of limitations that should be noted. The sample was drawn from four large urban Australian hospitals, three public and one private. The needs of rural women and women who do not speak English are not represented in these findings and may well be different from those of urban, English-speaking women. Also, the consent rate would be generally considered low for survey research. However, considering this group had metastatic disease and they were being asked to consent to a randomized controlled trial involving completing three surveys over a 3-month period, the consent rate may be considered reasonable in this context. Nevertheless, there may be some bias in the sample, especially as one of the reasons given for non-consent was tiredness, which suggests that the views of women with poorer health status may have been missed.

Addressing the quality of life issues and unmet needs of urban women with advanced breast cancer is not only likely to benefit the women and their families but may also reduce their use of the health care system. Patients with unmet psychological needs have higher utilization of medical services, higher medical costs and longer hospital stays than non-depressed patients (Fulop et al. 1987;Levenson et al. 1990;Simon et al. 1995) and therefore place an added burden on the health system. In the face of incurable disease, quality of life outcomes and meeting the patient's needs are the most important outcomes of management. Interventions that have been demonstrated to address these needs are urgently required.

#### **ACKNOWLEDGEMENTS**

This research was funded by the Inner & Eastern Melbourne BreastCare Consortium, Breast Services Enhancement Program. Dr Penelope Schofield is a National Health and Medical Research Council Post-Doctoral Research Fellow.

#### **REFERENCES**

Allenby A., Matthews J., Beresford J. & McLachlan S.A. (2002) The application of computer touch-screen technology in screening for psychosocial distress in an ambulatory oncology setting. *European Journal of Cancer Care* 11, 245253.

- American Federation of Clinical Oncologic Societies (1998) Access to quality cancer care: consensus statement. *Journal of Clinical Oncology* 16, 16281630.
- Aranda S., Milne D. & Osmond F. (2002) A Breast Care Nurse Database Evaluation Report. Victorian Centre for Nursing Practice Research, Melbourne, Australia.
- Bilodeau B.A. & Degner L.F. (1996) Information needs, sources of information, and decisional roles in women with breast cancer. *Oncology Nursing Forum* 23, 691696.
- Bonevski B., Sanson-Fisher R., Girgis A., Burton L., Cook P. & Boyes A. (2000) Evaluation of an instrument to assess the needs of patients with cancer. *Cancer* 88, 217225.

- Bottomley A. & Therasse P. (2002) Quality of life in patients undergoing systemic therapy for advanced breast cancer. *The Lancet Oncology* 2, 620628.
- Brescia F.J., Adler D., Gray G., Ryan M., Cimino J. & Mantani R. (1990) Hospitalised advanced cancer patients: a profile. *Journal of Pain Symptom Management* 5, 221227.
- Coates A., Gebiski V., Signorini D., Murray P., McNeil D., Byrne M. & Forbes J.F. (1992) Prognostic value of quality of life scores during chemotherapy for advanced breast cancer. Australian and New Zealand Trials Group. *Journal of Clinical Oncology* 10, 18331838.
- Cristine M., Crooks D., Grunfeld E., Stonebridge C. & Christie S. (0000) Caregiving for women with advanced breast cancer. *Psycho-Oncology* 12, 709719.
- Cossich T., Schofield P.E. & MacLachlan S.A. (2003) Validation of the Cancer Needs Questionnaire (CNQ) short form version in an ambulatory cancer setting. *Quality of Life Journal* 13, 12251233.
- Degner L.F., Kristjanson L.J., Bowman D., Sloan J., Carriere K., O'Neil J., Bilodeau B., Watson P. & Mueller B. (1997) Information needs and decisional preferences in women with breast cancer. *Journal of American Medical Association* 277, 14851492.
- DeVita V.T., Hellman S. & Rosenberg S.A. (2001) *Cancer Principles and Practice of Oncology*, 6th edn. Lippincott, Williams, Wilkins, Philadelphia, USA.
- Donabedian A. (1988) The quality of care: how can it be assessed? *Journal of the American Medical Association* 260, 17431748.
- Fayers P. & Bottomley A. (2002) Quality of life research within the EORTC-the EORTC QLQ-C30. European Organisation for Research and Treatment of Cancer. *European Journal of Cancer* 38 (Suppl. 4), S125S133.
- Foot G. & Sanson-Fisher R. (1995) Measuring the unmet needs of people living with cancer. *Cancer Forum* 19, 131135.
- Frost M.H., Suman V.J., Rummans T.A., Dose A.M., Taylor M., Novotny P., Johnson R. & Evans R.E. (2000) Physical, psychological social well-being of women with breast cancer: the influence of disease phase. *Psycho-Oncology* 9, 221231.
- Fulop G., Strain J.J. & Vita J. (1987) Impact of psychiatric comorbidity on length of hospital stay for medical/surgical patients: a preliminary report. *American Journal of Psychiatry* 144, 878882.
- Graydon J., Galloway S., Palmer-Wickham S., Harrison D., Rich-van der Bij L., West P., Burlein-Hall S. & Evans-Boyden B. (1997) Information needs of women during early treatment for breast cancer. *Journal of Advanced Nursing* 26, 5964.



- Hjermland M.J., Fossa S.D. & Bjordal K. (1995) Test/retest study of the European Organization for Research and Treatment of Cancer Core Quality-of-Life Questionnaire. *Journal of Clinical Oncology* 13, 1249-1255.
- Jefford M. & Tattersall M.H. (2002) Informing and involving cancer patients in their own care. *Lancet Oncology* 3, 629-637.
- Kaasa S., Bjordal K. & Aaronson N. (1995) The EORTC core quality of life questionnaire (QLQ-C30): validity and reliability when analysed with patients treated with palliative radiotherapy. *European Journal of Cancer* 31A, 2260-2263.
- Kramer J.A., Curran D., Piccart M., de Haes J., Bruning P., Klijn J., Van Hoorebeek I. & Paridaens R. (2000) Identification and interpretation of clinical and quality of life prognostic factors for survival and response to treatment in first-line chemotherapy in advanced breast cancer. *European Journal of Cancer* 36, 1498-1506.
- Kristjanson L.J. & Ashcroft T. (1994) The family's cancer journey: a literature review. *Cancer Nursing* 17, 117.
- Levenson J.L., Hamer R.M. & Rossiter L.F. (1990) Relation of psychopathology in general medical inpatients to use and cost of services. *American Journal of Psychiatry* 147, 1498-1503.
- Luker K.A., Beaver K., Leinster S.J. & Owens R. (1996) Information needs and sources of information for women with breast cancer: a follow-up study. *Journal of Advanced Nursing* 23, 487-495.
- Luker K.A., Beaver K., Leinster S.J., Owens R., Degner L. & Sloan J. (1995) The information needs of women newly diagnosed with breast cancer. *Journal of Advanced Nursing* 22, 134-141.
- McLachlan S., Allenby A., Matthews J., Wirth A., Kissane D., Bishop M., Beresford J. & Zalcberg J. (2001) Randomized trial of co-ordinated psychosocial interventions based on patient self-assessments versus standard care to improve the psychosocial functioning of patients with cancer. *Journal of Clinical Oncology* 19, 4117-4125.
- Meredith C., Symonds P., Webster L., Lamont D., Pyper E., Gillis C. & Fallowfield L. (1996) Information needs of cancer patients in west Scotland: cross sectional survey of patients' views. *British Medical Journal* 313, 724-726.
- Muldoon M.F., Barger S.D., Flory J.D. & Manuck S.B. (1998) What are quality of life measurements measuring? *British Medical Journal* 316, 542-545.
- Newell S., Sanson-Fisher R.W., Girgis A. & Ackland S. (1999) The physical and psycho-social experience of patients an outpatient medical oncology department: a cross-sectional study. *European Journal of Cancer Care* 8, 73-82.
- Ong L.M.L., de Haes J.C.J.M., Hoos A.M. & Lammes F.B. (1995) Doctor-patient communication: a review of the literature. *Social Science and Medicine* 40, 903-918.

- Parle M., Gallagher J., Gray C., Akers G. & Liebert B. (2001) From evidence to practice: factors affecting the specialist breast nurse's detection of psychological morbidity in women with breast cancer. *Psycho-Oncology* 10, 503510.
- Ryan H., Schofield P.E., Cockburn J., Butow P., Girgis A., Tattersall M., Turner J., Bandaranayake D. & Bowman D. (2005) How to recognise psychological distress in cancer patients. *European Journal of Cancer Care* 14, 715.
- Sackett D.L., Rosenberg W.M.C., Gray J.A.M., Haynes R.B. & Richardson W.S. (1996) Evidence based medicine: what it is and what it isn't. *British Medical Journal* 312, 7172.
- Sanson-Fisher R., Girgis A., Boyes A., Bonevski B., Burton L. & Cook P. (2000) The unmet supportive care needs of patients with cancer. *Cancer* 88, 226237.
- Scholten C., Weinlander G., Krainer M., Frischenschlager O. & Zielinski C. (2001) Difference in patient's acceptance of early versus late initiation of psychosocial support in breast cancer. *Supportive Care in Cancer* 9, 459464.
- Siegel K., Raveis V.H., Houts P. & Mor V. (1991) Caregiver burden and unmet patient needs. *Cancer* 68, 11311140.
- Simon G.E., VonKorff M. & Barlow W. (1995) Health care costs of primary care patients with recognized depression. *Archives of General Psychiatry* 52, 850856.
- Slevin M.L., Plant H., Lynch D., Drinkwater J. & Gregory W.M. (1988) Who should measure quality of life, the doctor or the patient? *British Journal of Cancer* 57, 109112.
- Soothill K., Morris S.M., Thomas C., Harman J., Francis B. & McIlmurray M. (2003) The universal, situational, and personal needs of cancer patients and their main carers. *European Journal of Oncology Nursing* 7, 513.
- Stewart B.W. & Kleihues P. (2003) *World Cancer Report*. International Agency for Research on Cancer, Lyon, France.
- Stromgren A.S., Groenvold M., Sorensen A. & Andersen L. (2001) Symptom recognition in advanced cancer. A comparison of nursing records against patient self-rating. *Acta Anaesthesiologica Scandinavica* 45, 10801085.
- Sutherland H.J., Lockwood G.A. & Boyd N.F. (1990) Ratings of the importance of quality of life variables: therapeutic implications for patients with metastatic breast cancer. *Journal of Clinical Epidemiology* 43, 661666.
- Vachon M.L., Kristjanson L. & Higginson I. (1995) Psychosocial issues in palliative care: the patient, the family, and the process and outcome of care. *Journal of Pain and Symptom Management* 10, 142150.

- Wong R.K., Franssen E., Szumacher E., Connolly R., Evans M., Page B., Chow E., Hayter C., Harth T., Andersson L., Pope J. & Danjoux C. (2002) What do patients living with advanced cancer and their carers want to know? a needs assessment. *Supportive Care in Cancer* 10, 408415.
- Zabora J., Diaz I. & Loscalzo M. (2003) Psychosocial screening goes mainstream: a prospective problem-solving system as an essential element of comprehensive cancer care. *Psycho-Oncology* 12, S87 (Abstract)

**S. ARANDA**, phd1,

**P. SCHOFIELD**, bsc (hons), phd1,

**L. WEIH**, phd, msc1,

**P. YATES**, phd2,

**D. MILNE**, rn, mn1,

**R. FAULKNER**, rn, bappsc, med, mha3 &

**N. VOUDOURIS**, bbsc, phd4

1Peter MacCallum Cancer Centre, St Andrews Place, East Melbourne, Victoria, Australia

2School of Nursing, Queensland University of Technology, Queensland, Australia

3School of Nursing, University of Melbourne, Parkville, Victoria, Australia

4School of Psychological Science, Faculty of Science, Technology & Engineering, La Trobe University, Bundoora, Victoria, Australia