

A proposed Health Needs Assessment approach to breast cancer service development in Saudi Arabia: Preparation of a patient-centred tool.

Wafa Nichols¹, Samia M. Al-Amoudi² Hasna Banjar³ Shadia A. Yousuf³

¹FAMS-MLT, King Abdulaziz University Jeddah Saudi Arabia

²Department of Obstetric and Gynecology, Faculty of Medicine King Abdulaziz University Jeddah Saudi Arabia

³Department of Public Health, Faculty of Nursing, King Abdulaziz University Jeddah Saudi Arabia
wnichols@kau.edu.sa

Abstract: Background: Assessing the psychosocial, physical, and informational needs of any population of patients, and their perception on how these needs are being met, is an essential to planning an effective, comprehensive patient-centred cancer support program. However, to our knowledge, no patient-centered community health needs assessment of breast cancer patients has been performed in Saudi Arabia. The aim of this study is to develop a culturally valid, health needs assessment tool for use with the local breast cancer community. **Methods:** Data driven inductive thematic analysis of recorded semi structured interviews of local breast cancer patients was performed. The resulting identified themes were compared to themes present in existing tools and the extent of congruency compared. **Results:** From the shortlist of published needs assessment tools, "Cancer Survivor Unmet Needs" and "Supportive Care Needs Survey- Short Form" have been demonstrated to have a highest degree (8/10) of congruency with the themes identified by the local study group; and the "Cancer Survivor Unmet Needs" assessment tool was the best suited in overall format. **Conclusion:** The selected tool, "Cancer Survivor Unmet Needs", with the suggested modifications, has the necessary overall congruency of content to be developed as a tool for the service needs assessment of Saudi Breast Cancer Patients; establishing content validity helps ensure that the final health needs assessment tool is both comprehensive and culturally appropriate. A large-scale survey, using such a tool, would facilitate a patient centered approach to service development and provide an operational blueprint for possible future breast cancer service development projects in Saudi Arabia.

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1. Introduction

A diagnosis of breast cancer has a major impact on both the patient and her family. Access to the necessary treatment of the cancer and in order to prolong life almost certainly the main concern for most patients, however the provision of services aimed at ensuring quality of life of the breast cancer patient is also of vital importance. In order to maintain a good quality of life holistic support is needed both during the process of diagnosis, the treatment, after the treatment, and during the follow up period. In addition to medical problems directly related to the cancer and side effects of the treatment, patients may have other problems including altered body image (1, 2) and feelings of loss(3), unresolved, these can have profound negative effects on the quality of life of the individual. In order to provide services to meet the needs of the patient, it is logical that those needs be clearly identified. Health needs assessment surveys (HNAS) can help prioritize and facilitate healthcare development and the more effective provision of care plans and facilities, and the use of the HNAS approach is recommended by both the United Kingdom National Centre for Clinical

Excellence (NICE)(4), and the Institute of Medicine (IOM) in the United States(5). It has been demonstrated that when care plans and facilities match the needs of the of the breast cancer patient this helps increase both patient satisfaction and avoid unnecessary unwanted healthcare costs(6). Failing to understand, and not addressing, the patients needs can, conversely, lead to a reduced quality of life, both for the patient and their family(7). Although some needs are shared by all cancer patients, the precise needs have been found to vary with age,(8-10)and with ethnicity(11,12).

Breast cancer is the most frequent cancer occurring in women in Saudi Arabia representing over 21% of all newly diagnosed female cancers(12,13). Breast cancer is therefore a significant problem in Saudi Arabia and modern healthcare facilities exist, both government and private, to diagnose and treat the condition(14). There is however, no published information on the extent that these facilities meet the wider spectrum of service needs required by breast cancer patients to improve their quality of life. The importance of matching needs and services has been fully acknowledged by planners in the Saudi Health

Service(14), however to our knowledge no in depth assessment of the service needs of symptomatic breast cancer patients has been made in our community, and such an assessment would greatly aid future planning.

When selecting a survey tool for a project it is essential that it is valid for the intended purpose and that the responses collected will fully provide the information required. The planned patient service needs survey therefore must be comprehensive, aiming to pose questions about all of the services relevant to the local population. By making detailed semi structured interviews of the service needs of a individuals from our local breast cancer patients, it is possible to optimize overall content validity of a planned survey tool before a large scale community based survey is undertaken. Although some, or even most, of the needs of breast cancer patients in Saudi Arabia will almost certainly be the same as women in other parts of the world, other needs may vary slightly, for demographic, geographic, cultural, and religious reasons. Although within the community of Saudi breast cancer patients it is certain that detailed individual needs will vary, by providing a general care plan and facilities which satisfy comprehensively the most common needs expressed then the majority of all patient needs will be met.

The objective of this research is to identify the range of service needs in the local community of breast cancer patients by means of data driven inductive thematic analysis (ITA). The resulting data will be used to select, and if necessary modify, available needs analysis tools to produce a construct capable of comprehensively assessing the service provision needs of breast cancer patients in Saudi Arabia and ultimately form the basis of a culturally valid, survey tool for the local breast cancer population.

2. Materials and Methods:

Ethical Issues

Formal ethical approval for the project was obtained from the ethics committee King AbdulAziz University Hospital. Subjects were given both a written and verbal explanation of the project and informed consent was obtained from them before the start of the interview. Immediately before the recordings were started the subjects were given the option to reschedule the interview if they did not feel emotionally ready, and the subject was again reminded that they could still stop at any time, have any sections of their recording deleted and simply not answer anything they felt uncomfortable talking about, all without the need of any explanation for their choice. Since subjects were recalling very emotional memories appointments at the centre were available to them following the interview in case they felt the

need for counseling support. Only one of the subjects delayed the interview, she came the following week, and none of the subjects requested post interview counseling support.

Study Design

The methodology used was data driven inductive thematic analysis (ITA) of a small number of interviews from the target community, based on the procedure used in a study of the needs and experiences of gynecologic cancer patients with the New Zealand health service(15). The criteria for participant inclusion were that participants had to be female breast cancer survivors who were at least one-year post diagnosis. For this scoping assessment a convenience sample of participants were approached by telephone from a contact list of breast cancer survivors, held by the breast cancer centre. New participants were called until a data saturation point was met. Data saturation was reached after five patients; eight individuals were contacted but three were unable to attend due to poor health. All interviews were held at the Sheik Al Amoudi Breast Centre, one of the participants requested her mother to be present the others were unaccompanied. The interviews lasted 30-60 minutes, and an audio recording was made of each interview. In addition, the interviewer made brief notes summarizing the points raised by the participant, and these points were read back to the participant at the end of the interview to give them the opportunity to amend, withdraw, or add, any comments.

The interview was split into four sections (diagnosis, treatment, post-treatment, long term); the initial stage of each section was unstructured to enable women to voice their needs and experiences of the health care system. The interviewer had a guide listing the areas of possible patient service needs (administrative, information, support (physical and psychological)) topics covered spontaneously by the patient were noted and by the remaining items on the list were raised briefly by the interviewer, in a neutral manner, to prompt any comments from the patient for example:

“What information needs did you have following diagnosis?”

Followed up by, if not mentioned by the participant “How were these information needs met?”

The interviewer was provided with this guide prior to the interviews.

Needs expressed by the participants were listed categorized according to the basic themes of Administrative, Informational, Support, and an open category “Other needs”.

Themes, and sub themes were then coded from this basic framework. Following each interview the

tree was added to and where necessary new themes and sub themes added.

The additional individuals interviewed until output data saturation point was reached (i.e. no new themes or subthemes were emerging from the analysis). Data was imported and organized using “Nvivo 9” software.

Literature search for published patient needs assessment tools:

In order to identify and obtain copies of recently used published patient needs assessment tools a literature search was performed searching pub med, Ovid, and Google Scholar:

Search criteria: Patient AND needs AND (survey OR tool) + Breast AND/OR Cancer

3. Results:

A summary of the main themes and sub themes identified in a coding tree (Fig 1), and the service elements with description representative topics in the

coding table (Table 1).

Shortlist of tools selected for consideration:

The following nine published patient needs assessment tools were shortlisted as potentially suitable for adoption for our project:

TINQ-BC (16), INQ(17), PNI(18), PNAT(19), Br-CPNQ(20), CaSUN(21), NEQ(22), SCNS-SF34(23), PNPC(24).

Tool Selection:

A tabulation of the participant identified themes and the themes represented in each of the selected published tools facilitated the analysis for congruency between the two (Table 2).

The CaSUN(21) and SCNS-SF34(23) assessment tools show the greatest overall congruency with the need themes identified by the study participants. Outstanding needs were: Appointments (CaSUN)(21) and religious needs (both CaSUN and SCNS-SF34) (21),(23).

Table 1: Coding table of service elements with description representative topics

Service Elements	Description of Representative Topics
Administrative	Facilities, staffing, protocols and procedures
• Appointments	Frequency, timing, and referrals
• Team	Inter professional treatment plan
• Facilities	Availability of specialized facilities and staff
• Medical Management	Extent of individualized patient centered treatment
Informational	Verbal or written information required
• Medical	Tests, procedures, disease, treatment, side effects and prognosis
• Religious	Religious edicts related to cancer care and treatment
• Practical needs and advice	Availability of prosthesis and clothing. Advice on coping with the physical and emotional challenges of the disease and treatment
Support	All other support systems outside the medical treatment of the disease
• Social	Self help groups, family support, support for family, long term follow up
• Psychological	Professional and trained lay help
• Financial	Money management and monetary support

Table 2: Cross tabulation of the participant identified themes with the themes present in each of the selected published tools

PARTICIPANT THEMES IDENTIFIED	SELECTED PUBLISHED TOOLS									
	CaSUN(21)	Br-CPNQ(20)	PNAT(19)	PNI(18)	INQ(17)	TINQ-BC(16)	PNPC(24)	SCNS-SF34(23)	NEQ(22)	PNQ(2)
ADMINISTRATIVE										
Appointment							√			
Team		√			√					
Facilities		√			√	√				
Management	√	√	√	√	√	√				
INFORMATION										
Medical	√	√	√	√	√	√	√	√	√	√
Religious	√		√	√	√		√	√		
Practical needs and Advice	√	√	√	√	√	√	√	√	√	√
SUPPORT										
Social	√	√	√	√	√	√	√	√	√	√
Psychological	√	√	√	√	√	√	√	√	√	√
Financial	√	√	√	√	√	√	√			

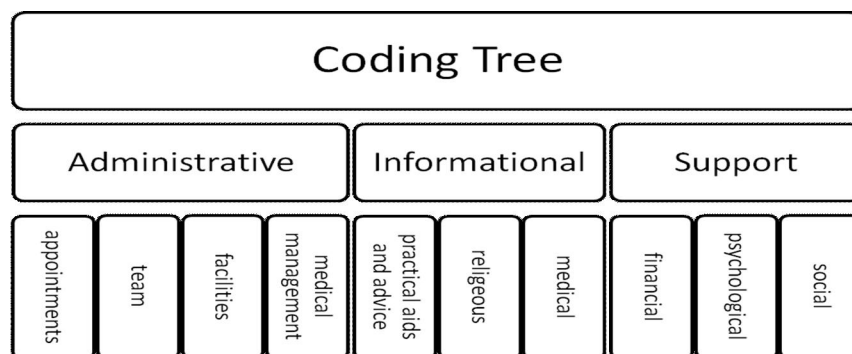


Fig 1: The coding tree shows the main themes and sub themes

4. Discussion

It was decided try and use, with modifications if necessary, an existing tool rather than preparing a new tool from scratch. This approach helps add to the credibility of the tool has the additional advantage making the comparison of any resulting data with previous studies easier.

Data driven inductive thematic analysis (ITA) using a small number of interviews from the target population is a well established approach (27), however it was rather unexpected that we reached data saturation after such a small number of patients. Possible explanations for this are firstly the focused nature of the interview, only themes involving services were included and the framework of the semi-structured interview was designed to real service needs rather than patient experiences in general. Secondly all of our participants were extremely motivated and fully aware of the aim of the project to evaluate service provision for breast cancer patients, in addition to relating their own experiences and needs they also raised the needs of other patients that they had spoken to directly during the course of their treatment.

The search undertaken for published survey tools is not comprehensive in that it does not identify every survey tool used for analysis of breast cancer patient needs. However the objective of the search was to identify widely used tools upon which to develop a survey too suitable for the local population, rather than produce a review of all tools. The fact that all of the tools discussed in the report of Richardson *et al.* (28) for the National Health Service (NHS) and in the study by Wen and Gustafson in (6) were located in addition to some others (Br-CPNQ (20), CaSUN (21), INQ (17), SCNS-SF34 (23), SCNS-LF59(29)) reflects the success of the search procedure followed.

After detailed comparison, of the themes and content of the nine selected published tools with the themes derived from the local interviews, the

following assessment of suitability was reached for each:

PNAT(19) and PNI(18): were found to be concerned primarily with the assessment of the psychological, physical, and social situation and needs of the individual, rather than the service needs, so neither of these were considered as suitable framework on which to develop our survey tool.

Of the remaining seven survey tools NEQ(22): Although most of the themes identified during the face to face interviews were covered the emphasis was more of information + the quality of care with only 3 related to an actual service (spiritual, self help, psychologist) also designed for “during hospitalization”.

Br-CPNQ(20): Designed specifically for use with breast cancer patients this is generally quite comprehensive but missing some areas such as clinical team and the appointment and referral systems. The items related to practical advice services were particularly well expressed (e.g. Prosthesis, lymphodema, respite etc). Although BR-CNPQ(20) was not selected to form the foundation of the survey tool for the assessment of local service needs of breast cancer patients, some of the elements of the practical advice services were noted for possible incorporation into the tool at a later stage.

TINQ-BC(16) and INQ(17)(which is derived from TINQ-BC(16)) are rather limited in scope concentrating on information needs, the only service needs considered are the need to have someone to call and the need for self help groups. For this reason neither TINQ-BC(16) nor INQ(17) were selected.

PNPC(24): Combines the assessment of the psychological, physical, and social situation and problems of the individual and the survey design enables the patient to indicate if more help is needed. However services are not referred to directly and factors related to the domain of administration, as described in table 2, were not included, in addition all

information needs were placed in one general question. For these reasons, PNPC(24) was also found not suitable for our needs.

SCNS: There are two main formats the original long form (29) containing 59 questions and the short form(23) which has 34 questions; both were assessed.

SCNS-LF59(29): A large proportion concentrates on about psychological concerns (22/57) (e.g. Fears about pain, keeping a positive outlook etc) all of which can be summarised as the need for a psychological support service. Generally the list is comprehensive and sufficient to fulfill the topics raised by our study group, except the need for religious information. In SCNS-SF34(23) however the section on psychological concerns is reduced from 22 to 11, without any overall change in the number of relevant questions related to support management and information; the big advantage of the short form therefore is the smaller number of questions.

SCNS-SF34(23) and CaSUN(21) appear to be the two best candidate tools for use as a basis of a needs assessment tool for our local breast cancer population, as shown in table 2 they have the highest level of congruency with the needs identified by our study group (8/10). In addition the stated objectives of CaSUN(21) as a tool closely resemble those of this project (i.e.to help assess the service needs of cancer survivors and to help ensure appropriate development and expansion of services) and the presentation of the questions reflects this.

CaSUN(21) was chosen as the most suitable published tool on which to develop a tool to assess the needs of our local breast cancer population. However since CaSUN(21) does not present items related specifically to administrative and religious needs the tool will need to be modified by addition of these categories in order to optimise the relevance of the finalized needs assessment tool to the needs of the local community.

Conclusion:

The selected tool, with the suggested modifications, has the necessary congruency of content to be developed as a tool for the service needs assessment of Saudi Breast Cancer Patients.

Further development and utilization of such a tool, in a large representative survey, would provide the data to enable a patient centered approach to breast cancer service development. The application of needs assessment as the initial step in establishing a patient centered program, as described in this paper, could act as an operational blueprint to guide future health service support projects in Saudi Arabia.

Corresponding Author:

Dr Wafa Nichols

Faculty of Applied Medical Sciences, King Abdul Aziz University P.O. Box 80324, Jeddah
Email: wnichols@kau.edu.sa

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