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ORIGINAL ARTICLE

Determining the Unmet Needs Among Breast Cancer Survivors: An Exploratory Sequential Mixed Methods Study

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OBJECTIVE

This study was conducted to characterize the unmet supportive care and factors contributing to the needs among breast cancer survivors in Kuching, Sarawak.

METHODS

It was an exploratory sequential mixed methods study.

RESULTS

In the qualitative exploration phase, nine respondents comprising survivors, healthcare providers, and informal caregivers were interviewed. The need for an additional category of "practical, social, and spiritual support," was indicated in the interviews, which was incorporated into the Short Form 34-item Supportive Care Needs Survey (SCNS-SF34). In the quantitative phase, a total of 259 survivors participated. Regression analysis revealed that shorter duration of survival and younger age were significant factors contributing to greater overall unmet needs. Other significant contributing factors were late stage (Stages III and IV) cancer, undergoing active treatment, being employed, Malays and Sarawak indigenous groups, high education level, and age at diagnosis of <50 years. Marriage was associated with higher needs in the sexuality domain but with lower needs in the physical and daily living domain.

CONCLUSION

The sociodemographic and medical characteristics of survivors were significant factors for the unmet needs. It is crucial to deliver targeted and systematic supportive care according to these factors for improving the quality of life and well-being of breast cancer survivors.

Keywords: Breast cancer survivors; mixed methods study; unmet needs.

Introduction

A diagnosis of cancer alters a patient's perspective on health and eventually life [1] as well as disrupts psychological functioning.[2] For the individual, life after cancer diagnosis is filled with the struggle to find a meaning in life, regain control in activities of daily living, and adjust to the reorientation of values and goals in life.[3] It is a life changing experience that is unique to the individual survivor but also carries a universal similarity, with uncertainties and consequences. Therefore, it is not surprising that the term "quality of life" is often considered when one analyzes the issue of cancer survival. It is no exception that breast cancer survivors experience multiple challenges across various domains, and these challenges are perceived as needs. To address these issues, researchers have developed and proposed the use of an assessment for the needs, which has the advantage of focusing on the issues of both quality of life and care and identifying the area of need and its magnitude.[4] Furthermore, a recent study has revealed that breast cancer survivors

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reported greater unmet needs on an average compared to other cancer survivors.[5] With the growing community of breast cancer survivors worldwide, understanding their unmet needs should be a priority. Failure to identify and address unmet needs would have multiple negative repercussions in various domains of the survivors' lives, including emotional burden, inability for self-care, and incapacitated work and social functioning, which may further worsen the debility left by the primary cancer in a long-lasting manner.[6] Despite the comprehensive cancer care program prepared by the Malaysian government through publicly funded hospitals, recent studies have shown that the unmet needs among cancer survivors still prevail with a rate of about 30%–40%.[4] Meanwhile, studies with local support groups have revealed the prevalence of unmet needs between 14.9% and 34.7%.[7] In addition, the relatively higher prevalence of late stage breast cancers among Malaysian women compared to the developed nations is an area of concern, as the stage at the time of presentation is a crucial prognostic factor among breast cancer survivors.[8,9,10] The stage of cancer also has a direct effect on their subsequent needs and consumption of healthcare resources within the cancer care continuum. Therefore, it is crucial to identify factors that contribute to the unmet needs in bridging the service delivery gap and improving patient satisfaction. The purpose of this study was to determine the factors that contribute to the unmet supportive care needs among breast cancer survivors through a mixed methods research, including a qualitative inquiry method and a quantitative method for sociodemographic and medical characteristics.

Materials and Methods

This was a mixed methods cross-sectional study using an exploratory sequential design approach to seek a clearer understanding of the factors that contributed to unmet needs among breast cancer patients. It involved three consecutive phases: Phase I was the exploration of factors contributing to the unmet needs among breast cancer survivors through qualitative data collection; Phase II involved the development and validation of a questionnaire and a pilot study; Phase III was the application of the instrument, which provided a greater insight into the contributing factors.

The use of mixed methods research in this study was to seek a clearer understanding of the factors which contributed to unmet needs among breast cancer patients. It recognized the diversity of the Malaysian population, its ethnic and cultural background, and aims to better contextualize instruments that measure their unmet needs.

The study was conducted at the breast cancer clinic of the Surgical Outpatient Department of the Sarawak General Hospital (SGH), Kuching, Sarawak. SGH is a tertiary referral center of Sarawak and therefore had a good catchment of breast cancer cases diagnosed within the state, with an approximate 150–170 cases annually.[11]

The inclusion criteria of the qualitative component of the study were (a) Malaysian adult females aged 18 years and above who had a diagnosis of breast cancer (all stages) and were physically and mentally capable of participating in the study; (b) healthcare providers, such as doctors or nurses, who directly provided care to breast cancer patients in the clinic and have worked in the unit for at least 6 months prior to the recruitment; or (c) caregivers (informal), such as spouses or immediate family members, who have been part of the direct care to the survivors for at least 6 months.

For the quantitative component of the study, the inclusion criteria were (a) Malaysian adult females aged 18 years and above; (b) patients diagnosed with breast cancer (all stages); and (c) those physically and mentally capable of participating in the study. Non-Malaysians were excluded from the study.

A purposive sampling was conducted during the qualitative exploration. The sample size for this phase was considered adequate when data saturation was achieved and no new themes emerged.

The Supportive Care Framework by Fitch [12] recognizes that about 20% of cancer patients within the healthcare system have unmet needs. Therefore, to estimate the 20% prevalence of unmet supportive care needs with a confidence interval of 95% and a 5% error margin, an estimated sample size of 246 was required as per the equation $n=(z^2 pq)/(d^2)$ where $z=1.96$, $p=0.2$, $q=1-p$, and $d=0.05$.[13] By factoring in attrition rate of 5%, a total of 259 respondents was required and recruited in this study for the quantitative exploration.

An in-depth face-to-face interview using a semi-structured protocol was conducted within a conducive environment for the qualitative exploration. The responses were recorded in both textual and audio format. Respondents were encouraged to express themselves, and they sought further clarification on certain points during the interview. The information regarding past experiences of the survivors during the qualitative exploration was collected with tact and empathy to ensure that the past traumatic experience or discomfort did not resurface and was kept to a minimum. The participants were encouraged to reveal as much as they were comfortable with, or a subsequent interview was scheduled and conducted to complete the data collection. Each respondent was debriefed and thanked upon the successful completion of the interview. The audio files were then transferred into a computer for re-play and transcribing. The transcribed data files were then loaded into QDA Miner 4 Lite software for analysis. Upon complete transcription and counter checks of the audio files into a textual format, the audio files were deleted from the Dictaphone and computer.

The quantitative phase of this study was conducted solely among breast cancer survivors. Informed and written consent was obtained from the survivors who attended follow-ups at the breast cancer clinic. The respondents were selected via a random sampling of survivors who were scheduled on a clinic day after alphabetically arranging the clinic card. The questionnaire was administered via an interview-assisted survey, wherein the responses were recorded on a one-on-one basis. This approach ensured better response rate, provided the opportunity to clarify any queries on the spot, and therefore eliminated the risk of missing data or an incomplete response. Furthermore, data collection was done while the respondents were waiting for their turn, thus ensuring efficiency by minimizing loss in terms of physical effort and time. The collected responses were again simultaneously checked for the completeness of information and subsequently transferred into the Statistical Package for Social Sciences (SPSS®) program for statistical analysis.

The qualitative data collection involved the use of a semi-structured interview protocol. This approach enabled to directly assess the perception of breast cancer survivors and indirectly assess through the informal caregivers and healthcare providers of the needs during patient care. The interview protocol was formulated after reviewing the barrier framework currently in use [14] as well as articles that discuss the factors of delayed presentation and hurdles of follow-up among breast cancer patients.[15,16]

The quantitative data included the sociodemographic and medical characteristics of the respondents and their unmet supportive care needs. In Part I, items generated from Phase I of the qualitative exploration were used and incorporated in the assessment of unmet needs through the Short Form 34-item Supportive Care Needs Survey (SCNS-SF-34).[17] The SCNS-SF34 developed by Boyes and colleagues is used to perceive the cancer-specific need and covers five domains: psychological (10 items), health system and information (11 items), patient care and support (5 items), physical and daily living (5 items), and sexuality (3 items).[17] In this study, the respondents indicated the extent of help needed within the past 1 month owing to the cancer according to a five-point Likert scale with: 1=no need, not applicable; 2=no need, satisfied; 3=low need; 4=moderate need; and 5=high need. The domain mean score was calculated by adding the responses to each of the items within the domain and dividing the sum by the number of items in the domain. A higher score (maximum 5.00, and minimum 1.00) would indicate a higher perceived need in that domain.

Part II of the questionnaire includes medical characteristics of respondents, duration in years and months since the first diagnosis of breast cancer, cancer stage at the time of diagnosis, and current treatment status of the survivor. Part III of the instrument relates to sociodemographic characteristics, which include age in years, ethnicity, religion, marital status, cohabitation status, formal education, and employment status.

A pilot study of the modified questionnaire, which incorporated items generated from Phase I of the study was conducted among 30 breast cancer survivors. A feedback on the level of acceptance of the survey, time taken to complete, and other arising issues were obtained from these respondents.

For qualitative data analysis, a thematic analysis was conducted using the QDA Miner 4 Lite software. A 6-step approach in the thematic analysis was employed in this study based on Virginia Braun and Clarke study.[18]

The statistical analysis for the quantitative data was carried out using the IBM SPSS statistics program version 22 (SPSS Inc., Chicago, IL, USA). All tests of significance with a p value <0.05 was accepted as the cut off and deemed statistically significant.

This study was conducted with the approval of the Medical Ethics Committee, Faculty of Medicine and Health Sciences, Universiti Malaysia Sarawak, the Medical Research and Ethics Committee, National Institute of Health, Ministry of Health, Malaysia, and the Director of the Sarawak General Hospital.

Results

Qualitative Component:

A total of nine participants were recruited for the qualitative research component. Details of the participants are presented in Table 1.

Table 2 shows the qualitative analysis of the three groups of respondents, survivors, healthcare providers, and informal caregiver as well as the data derived from the 13 categories.

The qualitative findings in Phase I were compared with the existing SCNS-SF34, and some items within the existing SCNS-SF34 were supported by the qualitative findings. However, 11 items were recommended to be included to supplement the existing questionnaire. The newly generated 11-items were considered unique and domain specific, as it was founded upon and justified by the established theoretical knowledge from the Supportive Care Framework.[12] They were further classified as practical, social, and spiritual support domains. A pilot study of the modified questionnaire was carried out among 30 respondents, and the results of the reliability analysis are presented in Table 3.

Quantitative Component:

The sociodemographic characteristics of all the respondents in this study were analyzed and are presented in Table 4.

Inferential statistics with univariate and multivariate analyses were used to determine the association between independent and dependent variables. Variables with p value<0.20 in the univariate analyses were selected for multiple linear regression.

Overall, the age of respondents and their duration of survival were significant factors contributing to the unmet needs among breast cancer survivors. These two

Table 1 Summary profile of interviewed participants (n=9)

Participant groups	Gender	Age	Duration of survivorship
Breast cancer survivors			
Survivor 01	Female	51	7
Survivor 02	Female	55	8
Survivor 03	Female	46	3
Survivor 04	Female	66	14
Healthcare providers			
Healthcare provider 01	Female	45	-
Healthcare provider 02	Female	56	-
Healthcare provider 03	Female	43	-
Informal caregivers			
Informal caregiver 01	Female	67	-
Informal caregiver 02	Male	28	-

Table 2 Categories and codes as indicated by participant groups (n=9)

Category	Code	Survivors	Healthcare provider	Informal caregiver
Finance (burden)	Financial problems		✓	✓
	Health insurance issues		✓	
	Inability to miss work	✓	✓	✓
Transportation	Transportation issues		✓	✓
	Location to healthcare facility		✓	
Beliefs	Feelings of anguish and helplessness	✓	✓	✓
	Fears of tests, treatment, or death	✓	✓	✓
	Attitudes toward provider	✓	✓	
	Perceptions or beliefs about tests or treatment		✓	
Family and employment issues	Employment issues	✓		
	Childcare issues	✓		
	Lack of social or practical support	✓	✓	✓
Health system	System problems with scheduling care	✓	✓	✓
	Long waiting time	✓		✓
	Carpark facilities	✓		✓
	Inadequate information	✓		
Communication	Communication issues		✓	
Comorbidities	Patient disability	✓	✓	✓
Family support	Support from family or relatives	✓		✓
	Finding strength in surviving for children	✓	✓	✓
Social support	Help from support groups	✓		✓
	Help from friends or colleagues	✓	✓	✓
Financial independence	Health insurance	✓		✓
	Government servant	✓		
Employer support	Supportive employer	✓	✓	
Spiritual support	Spiritual strength	✓		
Others	Other issues			

Table 3 Reliability analysis of domains

Domain	Cronbach’s Alpha
SCNS-SF34 Health system and information (11 items)	0.834
SCNS-SF34 Sexuality (3 items)	0.831
SCNS-SF34 Psychological (10 items)	0.795
SCNS-SF34 Physical and daily living (5 items)	0.748
Practical, social, and spiritual support (11 items)	0.666
SCNS-SF34 Patient care and support (5 items)	0.556

factors were also found to be important determinants across a majority domains (Table 5). In terms of domains with the highest number of contributory factors, sexuality was reported with the most factors that affected the unmet needs and included marital status, race, age at diagnosis, and education level. The summary of significant contributory factors by domains are shown in Table 5.

Discussion

Generally, the survivors who participated in this study were less than 60 years old, with a mean (standard deviation [SD]) age of 56.2 (10.29) years, mainly Chinese,

Table 4 Socio-demographic and Medical characteristics of respondents (n=259)

Sociodemographic characteristics	n	%	Mean (SD)
Age (years)			56.2(10.29)
Below 60	163	62.9	
60 and above	96	37.1	
Ethnicity	129	49.8	
Chinese	69	26.6	
Malay	61	23.6	
Sarawak indigenous groups			
Religion			
Practices religion	249	96.1	
Does not practice any religion	10	3.9	
Marital status			
Married	220	84.9	
Never married/ widowed/ divorced/ permanently separated	39	15.1	
Cohabitation status			
Lives alone	8	3.1	
Lives with others	251	96.9	
Education level			
Informal or primary education	109	42.1	
Secondary or tertiary education	150	57.9	
Employment status			
Unemployed[a]	185	71.4	
Employed[b]	74	28.6	
Age at diagnosis (years)			51.2(10.33)
Less than 50	120	46.3	
50 and older	139	53.7	
Duration of survival (years)			5.1(4.77)
Up to 5 years	170	65.6	
More than 5 years	89	34.4	
Cancer stage at time of diagnosis			
Early stage (Stages I and II)	183	70.7	
Later stage (Stages III and IV)	76	29.3	
Current treatment status			
No current active treatment	107	41.3	
Undergoing active treatment	152	58.7	

[a] unemployed: housewife/homemaker, retired, unemployed
[b] employed: government/private employee, self-employed.

Table 5 Summary table of significant contributory factors by domains (n=259)

	Domains with corresponding significant B coefficients						
Contributory factors	**Overall**	**Physical and daily living**	**Health system and information**	**Psychological**	**Patient care and support**	**Practical, social, and spiritual support**	**Sexuality**
Age of respondents (years, ref: Below 60)	-0.142 (60 and above)	-	-0.134 (60 and above)	-0.117 (60 and above)	-	-0.129 (60 and above)	-
Duration of survivorship (ref: Up to 5 years)	-0.206 (More than 5 years)	-0.449 (More than 5 years)	-	-0.260 (More than 5 years)	-0.098 (More than 5 years)	-0.139 (More than 5 years)	-
Cancer stage (ref: Early stage)	-	0.264 (Later Stage)	-	-	-	-	-
Marital status (ref: Never married /widowed/divorced /permanently separated)	-	-0.252 (Married)	-	-	-	-	0.750 (Married)
Treatment status (ref: No current active treatment)	-	-	0.197 (Undergoing active treatment)	-	-	-	-
Employment status (ref: Unemployed)	-	-	-	-	-	0.169 (Employed)	-
Race (ref: Chinese)	-	-	-	-	-	-	0.214 (Malays and Sarawak indigenous groups)
Age at diagnosis (years ref: Less than 50)	-	-	-	-	-	-	-0.165 (50 and older)
Education level (ref: Informal and primary education)	-	-	-	-	-	-	0.148 (Secondary and tertiary education)

Only significant ($p<0.05$) contributory factors indicated

religion followers, married, living with others, educated to the secondary or tertiary levels, and unemployed. The predominance of having more survivors being less than 60 years old corresponds to other studies conducted within Malaysia [8] as well as a recent study conducted among breast cancer survivors from a community-based support group within Kuching, Sarawak.[7] The ethnic composition of the study participants was in congruence with the studies involving over 4000 databases of Malaysian and Singaporean survivors [19] as well as a study conducted within Sarawak [7] in which majority of survivors were Chinese. Further, the marital status and employment status were in congruence with the studies conducted within Malaysia, i.e., majority were married [7,20] and unemployed.[20,21] Compared to the recent local studies among survivors from a community-based support group, the parameters for the practice of religion, cohabitation status, and education level were similar.[7]

The present study revealed that the mean (SD) age at diagnosis for breast cancer among survivors was 51.2 (10.33) years, with a majority of them being diagnosed at the age of 50 years and older; the mean (SD) duration of survivorship was 5.1 (4.77) years, wherein a majority who survived up to 5 years presented with the early stage of the disease (Stages I and II) and were undergoing active treatment. The mean age at diagnosis in a retrospective cohort study using a breast cancer registry and medical records of a major tertiary public hospital was reported as 51.6 (SD=11.54) years, which was closely similar to that in the present study.[21] A recent review of a breast cancer research in Malaysia reported that on an average, Malaysian women presented at an earlier age compared to their Western counterparts, citing two main factors that led to the following observations: (i) Malaysia has a younger population demographic, and (ii) the current older population in Malaysia has low-risk lifestyle factors, which led to a lower post-menopausal breast cancer risk.[8]

On an average, the mean duration of survivorship in this study (5.1 years) was longer than the data reported from another tertiary center in the country (4.5 years), [21] while it appeared shorter in the survival duration when compared against data reported from a university hospital in the country (6.7 years) [22] and community based support group survivors (8.2 years). [7] This variation in survival duration can be attributed to the differences in having a greater number of late stage cases recruited from hospital records in tertiary centers, [21] leading to a shorter average survival duration. In contrast, the longer survival duration reported from the university hospital [22] and the community-based support group [7] compared to the current study could be because of the greater number of early stage cancer survivors recruited in those two centers. In terms of cancer stage at the time of diagnosis, the current study findings of having a higher number of early stage (Stages I and II) cases were in congruence with various local studies. [7,21] In tandem with having majority of survivors with a survival duration of up to 5 years, the number of survivors undergoing active treatment in this study was obviously the majority. This is in contrast with the local studies wherein a majority of the survivors recruited from the community-based support group were survivors of more than 5 years, which corresponded to most of them not undergoing any active treatment.[7]

This study revealed that both the duration of survival and age of respondents were strong factors contributing to the overall unmet needs among breast cancer survivors. Overall, younger survivors (duration of survivorship up to 5 years) and younger respondents (aged below 60 years old) were factors associated with higher unmet needs. A systematic review of factors associated with supportive care needs of women with breast cancer concurred with the current finding that a shorter time since diagnosis and younger age were identified as factors contributing to higher levels of needs.[23] Younger survivors (duration of survival up to 5 years) are within the distinct survival period of "acute survival" as postulated by Mullan. The acute survival stage has been regarded as the period from the time of diagnosis of illness, including the time utilized in the diagnostic and therapeutic efforts which causes fear and anxiety in the patient.[24] Furthermore, newly diagnosed cancer patients had greater physical and emotional needs compared to those already receiving post treatment follow-up care.[25] Meanwhile, the younger respondents being associated with higher needs compared to the older respondents could be a reflection of the differences in the attitudes between younger adults who are more vocal about their unmet needs and the older adults who believe they should have a better coping capacity and therefore do not disclose their actual needs.[26]

In the physical and daily living domain, a regression analysis revealed that the duration of survival, cancer stage, and marital status were significant contributory factors to the unmet needs in this domain with a medium effect. Younger survivors (duration of survival up to 5 years) were associated with higher level of needs within this domain; this was in congruence with a recent systematic review of contributing factors of supportive care needs among breast cancer patients.[23] This predisposition of greater needs in this domain among younger survivors was established by studies among women with breast cancer.[27,28] From a temporal standpoint, younger survivors of up to 5-year survival duration could fall into the "extended survival" period, which is a period when physical limitations are apparent due to the effects of the cancer and its treatment modalities.[24] These survivors are faced with the prospect of permanent complications, such as loss of body image, arm mobility, and lymphedemas, [29] at home, community, or workplace. The cancer stage was a significant factor in this domain, with late stage (Stages III and IV) survivors associated with higher physical and daily living domain needs. The advanced stage of the disease was systematically found to be associated with greater needs in the physical and daily living domain.[23] Advanced stage diseases often entail an aggressive and extensive treatment approach, including destructive surgical procedures and intense systemic therapies or radiation, which then give rise to various permanent complications and unmet needs as reflected by the late stage survivors in this domain. Marital status was found to be strong contributory factor of unmet needs, with married women being associated with lower unmet needs. Indirectly, it concurs with a systematic review of factors contributing to the unmet needs whereby "being single" was found to be associated with greater needs in the physical and daily living domain.[23] Another study of unmet needs among breast cancer patients in Denmark reported higher unmet needs for “not having a partner.”[30] Additionally, studies have found that married patients may experience a lesser impact from stressful life events [31]; therefore, marriage can have a positive effect. This can explain the lower reported needs in the domain on items, such as items pain, lack of energy/tiredness, feeling unwell for a long time, work around the home, and not being able to perform activities that they could previously. It is also likely that that the survivors receive social support from their partners, which lowers their need for help or enable them to identify and access health services.[32]

Within the health system and information domain, regression analysis revealed the treatment status and age of respondents as significant contributory factors with a low effect. In the current analysis, younger age (below 60 years) and being under active treatment was associated with higher needs within the domain. The fact that younger survivors relate to higher needs has been systematically established [23] and is attributed to variations in the attitudes because younger adults would make their unmet needs known compared to older adults who were more discreet, believing that they should have a better coping capacity.[26] Meanwhile, the current finding that survivors under active treatment related to higher needs is consistent with studies which revealed that among general cancer patients or with survivors from a community-based support group, being under active treatment was associated with higher unmet needs [33,7] In contrast, those in remission reported fewer unmet needs in the information domain.[26] This could reflect the higher likelihood of unmet information need among those undergoing active treatment due to an increased association with the healthcare system and utilization of the services.

Greater unmet needs within the psychological domain was contributed by the age of respondents and duration of survival, wherein the regression analysis revealed that younger respondents and younger survivors related to higher unmet needs with a small to medium effect within this domain. This finding was in congruence with a systematic review that stated both younger age and shorter time since diagnosis contribute to greater need within the psychological domain.[23] Further, a local study among breast cancer survivors from a community-based support group also yielded a similar association of younger age and survival with higher psychological needs.[7] Such observations of younger respondents and younger survivors having greater unmet needs within the psychological domain is neither surprising nor alarming, as they find themselves to be within the “acute survival” stage with psychological stress as a constant element.[24] Furthermore, it has been established that cancer diagnosis disrupts the psychological functioning of a person and is a dynamic process involving a constant balance of the stress and burden of cancer experience with the resources available to cope.[2]

The current study revealed that the duration of survival was a significant contributory factor of unmet needs within the patient care and support domain with a small effect. The model showed that younger survivors had greater needs within the domain. This finding is consistent with findings from other studies.[27, 34] Younger survivors who in their course of cancer care would more frequently encounter with the healthcare providers, utilize more healthcare services during the early stages of their care, and be in the “acute survival” stage, predisposing them to greater anxiety in coping with the new reality.[12] These episodes of contact could indicate higher needs based on the items included in the domain, such as more choices about which cancer specialists you visit, reassurance by medical staff that the way you feel is normal, and acknowledgment by the hospital staff by showing sensitivity to your feelings and emotional needs. Thus, higher emotional needs among younger cancer survivors compared to those already receiving post-treatment follow-up care have been demonstrated.[25] Additionally, emotional distress among younger survivors in response to cancer diagnosis has been established as an expected reaction and will be experienced by all cancer patients to a certain degree.[12]

Within the practical, social, and spiritual support domain, the employment status, duration of survival, and age of respondents were significant contributing factors of unmet needs. Regression analysis showed that employment, younger age, and younger survivors were associated with greater needs in the domain with a medium effect size. Employment being associated with greater needs in this domain appears logical. The practical, social, and spiritual support domain included the category relevant to the practical needs as proposed in the Supportive Care Framework for Cancer Care [12] and included items, such as getting employed or retaining current employment and getting the support of your employer or supervisor, which could be rated as a high need among survivors who are employed. Additionally, younger survivors and being aged below 60 years in this study were factors that contributed to greater needs within the domain. Univariate analysis revealed that both factors contributed to significantly higher domain mean scores. This reflects an increased need in items relevant to the spiritual and social category of Supportive Care Framework for Cancer Care, [12] which was included within this domain. The spiritual category items, such as feelings of hurt and helplessness, suggest issues relevant to the existential despair in which newly diagnosed patients question the meaning of life and its value, whereas the items of building spiritual strength or receiving spiritual support, reflect the need to cope through spirituality. Spiritual well-being brings a meaning to life and improves the psychological challenges and physical problems.[35] It also reduces chronic pain, improves coping skills, and entails a higher quality of life.[36] Clearly, spirituality is not merely a subjective feeling or meanings construed by the survivor but rather has tangible benefits in other areas of life and survival. Meanwhile, the social category of the framework within the domain included getting the support of your family or relatives, staying strong for your children or loved ones, and getting help from support groups or friends and colleagues. Higher needs in this area as indicated by younger respondents (below 60 years of age) was most likely associated with the fact that they were still within the reproductive age and have younger families to take care of. A diagnosis of breast cancer among younger respondents could mean changes in roles and social relationships or difficulty dealing with the responses of family members or children.[12] Furthermore, the long-term physical and emotional health of the survivors could be impaired due to altered social roles and limited social activities owing to the cancer and its treatment could impair.[35]

The sexuality domain in this study had the highest number of significant contributory factors, such as marital status, race, age at diagnosis, and education level (Table 5). The regression model revealed that marriage was the greatest factor contributing to higher needs in this domain, followed by Malays and Sarawak indigenous groups, diagnosis at less than 50 years, and secondary and tertiary education with a large effect size. The findings concurred with a systematic review by Fiszer and colleagues [23] in which "living with partner" and "higher education" were associated with greater needs in the sexuality domain. Furthermore, married patients in Korea as well as survivors from a community-based support group were significantly more likely to indicate greater needs in this domain. [37,7] Such observations are logical, given that married survivors have a spouse or partner in whom they can confront their sexuality needs and self-image more frequently. Higher education attainment was associated with greater needs among breast cancer survivors.[37,38] This is likely because these survivors are more aware and receptive of their underlying condition, which would have created a need in them to identify ways to overcome their current situation; any setbacks or barriers faced would be reflected as unmet needs. Moreover, younger age at the time of diagnosis was associated with greater needs in the sexuality domain because they would still be sexually active at the time of diagnosis and may have to deal with the changing physiology due to the physical impact of treatment and menopause-inducing cancer therapies. Furthermore, a greater sense of loss could be perceived by those diagnosed at younger age compared to those diagnosed later. Regarding race as a contributory factor of unmet needs within the sexuality domain, Chinese were found to associate with lesser needs compared to Malays and Sarawak indigenous groups. Such observations were consistent with survivors from a local community-based breast cancer support group [7] in which Malays and Sarawak indigenous group reported significantly higher mean scores in the sexuality domain compared to Chinese respondents. Such variation could highlight the differences in the cultural background especially among the Asian Confucian-Chinese community, wherein personal problems or seeking help reflects poorly on the family and may bring shame to the family name; therefore, it is thought to be better for them to keep personal issues especially related to sexuality needs to themselves.[39] However, not reporting needs does not mean the needs do not exist, [23] rather it could also be a form of passive coping mechanism at play, such as being occupied, having a different perspective, and not contemplating extensively.[40]

This study recognizes the potential presence of a survey bias as not all breast cancer patients present themselves to the healthcare facilities. Those who never presented themselves to the healthcare facilities due to various sociocultural barriers or preferred traditional treatment elsewhere [41] or with a preference for private healthcare facilities could therefore not be included in the study.

In contrast, critics might argue that the qualitative exploration component should only involve breast cancer survivors, as it was their needs and experiences that needed to be elicited. However, this study maintains that by engaging healthcare providers and informal caregivers, the triangulation of sources could in fact provide a more holistic and complete view of the issue at hand and could be a strength of the study.

Conclusion

As a conclusion, the findings revealed that the factors contributing to higher unmet needs overall were younger age and shorter duration of survival. These contributory factors prevail across other domains as well. Other significant factors associated with higher unmet needs include late stage (Stages III and IV) cancer, undergoing active treatment, being employed, being Malays and Sarawak indigenous groups, higher education attainment, and age at diagnosis of <50 years. Marriage was associated with higher needs in the sexuality domain but lower needs in the physical and daily living domain.

The current study provided valuable insights into and served as baseline data of the characteristics and unmet supportive care needs of breast cancer survivors attending breast cancer clinic follow-ups at Sarawak General Hospital, Kuching, Sarawak. There is a need for a systematic delivery of supportive care that is patient-centered, targeted, culturally sensitive, responsive to changing needs, and linguistically appropriate especially for survivors who are younger and have a shorter duration of survival. Furthermore, by identifying the unmet needs and associated contributing factors, healthcare planners would be able to allocate resources in an effective and efficient manner. Ultimately, the aim of addressing the unmet supportive care needs of breast cancer survivors is to continuously improve the quality of life and well-being of these unique, expanding group of survivors who have a pivotal role in determining the health and well-being of the modern world.

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