

Determining the Concerns of Breast Cancer Survivors to Inform Practice

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ABSTRACT

Objective: Breast cancer is the most common cancer in women across all ethnicities, accounting for almost one in three incident cancers in female, and the leading cause of mortality in Singapore. Literature reveals that survivors of breast cancer have many concerns, and these concerns can linger on for decades. The primary aim of this secondary analysis was to establish the concerns of breast cancer survivors and use the data to inform practice. **Methods:** The present report was part of a bigger data designed to evaluate the concerns of cancer survivors (top six cancers) across the survivorship trajectory. Data of 438 breast cancer survivors were derived from a cross-sectional survey of the self-reported concerns of 1107 cancer survivors, using the questionnaire adopted from the Mayo Clinic Cancer Centre's Cancer Survivors Survey of Needs. Logistic regression models were fitted to estimate the odds ratios to assess the association of various variables with the presence of ≥ 1 concerned or very concerned issue among patients. Linear regression models

were fitted to identify the variables associated with quality of life (QOL). **Results:** A total of 438 breast cancer survivors responded to this survey. The top five concerns were cancer treatment and recurrence risk (55.5%), followed by fear of recurrence (FOR) (54.6%), long-term effects of treatment (53.4%), osteoporosis/bone health (39.0%), and keeping primary care physicians informed (37.4%). Cancer treatment and recurrence risk, FOR, and long-term treatment effects were among the top concerns across the survivorship trajectory. The mean QOL was 7.5 on a scale of 0–10. **Conclusions:** Irrespective of the cancer trajectory, survivors of breast cancer have serious concerns that warrant attention. Designing patient care delivery that addresses these concerns identified is critical in assisting them in their coping process and enhancing their QOL.

Key words: Breast, cancer survivors, concerns, fear of recurrence, long-term effects, quality of life

Introduction

Breast cancer is the most common cancer in women across all ethnicities, accounting for almost one in three incident cancers in female, and the leading cause of mortality^[1] in Singapore. The age-standardized incidence rate of breast cancer in Singapore has risen threefold from 24.6/100,000 in 1976–1980 to 65.3/100,000 in 2011–2015.^[1]

The rise of incidence of breast cancer is partly caused by an aging population, and rise in affluence affecting dietary changes and a more sedentary lifestyle. Early detection and better treatment modalities have resulted in a significant increase in the survival rates.^[1] The current 5-year survival rate for breast cancer is 79.5% in 2008–2012.^[1]

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Treatment modalities for breast cancer consist of surgery, radiation therapy, chemotherapy, hormonal therapy, and targeted therapy.^[2,3] Although effective in the treatment of breast cancer, many of these therapies cause immediate, residual, latent, or late side effects. Treatment-related side effects are mostly acute, but some can be long term, affecting the physical, functional, emotional, financial, and social aspects of the breast cancer survivors' life.^[4] Cheng *et al.*^[5] reported that 88% of breast cancer survivors reported at least one symptom, with 17% reporting >10 simultaneous symptoms 6 months to 5 years after treatment. In a systematic review by Howard-Anderson *et al.*,^[6] the researchers reported that younger women (aged ≤50 years) were concerned about premature menopause, menopausal symptoms, and infertility, and these concerns had a role in the level of distress after treatment. Weight gain and physical inactivity were also found to be common health outcomes in younger women. Physical effects such as hot flashes, joint pain, night sweats, cold sweats, vaginal dryness, irritability, mood swings, loss of interest in sex and pain with intercourse,^[7-9] lack of energy, fatigue, weakness, numbness/tingling in hands/feet, pain, and cognitive changes^[2,5,8] were major side effects experienced by breast cancer survivors. In addition, poor self-image, worry, anxiety, irritability, difficulty sleeping, depression, fear of recurrence (FOR), fear about cancer spreading, and fear of the children inheriting the disease were some of the psychological problems experienced.^[5,8,10,11] These effects can have a significant impact even years after cancer treatment^[5,12] and can negatively affect their quality of life (QOL).^[9,13,14] Breast cancer survivors are not only at risk of cancer recurrence, but are also at an increased risk of other primary malignancies (e.g., endometrial cancer, lung cancer, and hematological malignancies) due to the treatment they received.^[3,15] Other late effects of cancer treatment include lymphedema, infertility, sexual dysfunction, cardiotoxicity, fatigue, peripheral neuropathy, arthralgia or myalgia, osteopenia, thromboembolic disease, and cognitive impairment.^[3,15] In view of the negative effects of these physical, emotional, social, and financial concerns on the breast cancer survivors' well-being including their health-related QOL, it is important to determine their concerns in order to guide practice. As there is no reported study done to explore the concerns of breast cancer patients in Singapore, and due to its impact on the patients' QOL, an understanding of the concerns of breast cancer survivors is necessary to help develop strategies to address their concerns and needs.

The present report was part of a bigger data designed to evaluate the concerns of cancer survivors across the survivorship trajectory^[16] at an ambulatory cancer center

in Singapore with the goal of improving care delivery. The primary aim of this secondary analysis was to establish the concerns of breast cancer survivors and use the data to inform practice by focusing on their salient concerns and prioritize and target education and information provision and support programs that can help to equip breast cancer survivors with the needed coping skills and enhance their QOL.

Methods

Design, sample, and setting

Data of the 438 breast cancer survivors were derived from a cross-sectional survey of the self-reported concerns of 1107 cancer survivors (top six cancers). Cancer survivors were defined as individuals from the time of cancer diagnosis through the balance of their lifespan. The survey was conducted over a 3-month period in 2017 at the National Cancer Centre in Singapore using the questionnaire adopted from the Mayo Clinic Cancer Centre's Cancer Survivors Survey of Needs.^[17] A detailed description of the original study design is available in the previous report.^[16] Briefly, a copy of the survey form together with an explanatory note containing detailed explanation of the study purpose and procedure on how to complete the questionnaire was attached to the patient's medical case sheet for each potential eligible patient by the research assistants. On the day of follow-up consultation, upon confirmation on the eligibility of patients, the front counter staff of the respective clinics invited those eligible ones to participate. Participation in the survey was voluntary, and completion of the survey form indicated patient's consent to participate in the study. Exclusion criteria included: (1) survivors who were not inflicted with colorectal, breast, lung, gynecological, prostate, and liver cancers (the six major types of cancer); (2) below age 21; (3) inability to read and write Chinese and/or English; (4) major intellectual or psychiatric impairment; and (5) walk-in patients to the clinics.

Procedures

Ethical approval was obtained from the SingHealth Centralized Institutional Review Board of the Singapore Health Services prior to the study. Waiver of written informed consent was obtained as no personal identifiers of respondents were obtained.

Statistical analysis

Descriptive statistics and graphical plots were used to summarize the quantitative data collected in the survey. The mean and standard deviation or median and range were reported for continuous variables, and frequency counts

and percentages were reported for categorical variables. Logistic regression models were fitted to estimate the odds ratios to assess the association of various variables with the presence of ≥ 1 concerned or very concerned issue among patients. Linear regression models were fitted to identify the variables associated with QOL.

Data were analyzed for the entire cohort of respondents, by cancer survivorship stages. The cancer survivorship stages included in these further analyses were selected and grouped based on the clinical significance and the number of patients of the stage, as follows: patients who were newly diagnosed and on treatment (NT), patients who had completed treatment or were cancer free ≥ 5 years (CT), and patients dealing with recurrence or second cancer (regardless whether the patients were receiving treatment for recurrence or second cancer) (RS).

All reported *P* values were two sided, and *P* < 0.05 was considered statistically significant. All analyses were performed using SAS version 9.4 (SAS Institute Inc.).^[18]

Results

Demographics and clinical characteristics

A total of 438 breast cancer patients were analyzed. The median age of the patients was 56 years (range, 25–81 years) [Table 1]. Majority of the patients were female (99.3%), were Chinese (84.5%), were married (71.0%), had secondary and above qualifications (81.0%), and were staying in Housing Development Board (HDB) flats (79.0%). Nearly 51.4% of the patients were working, 6.2% were looking for work, 22.6% were homemakers, and 18.9% were retirees.

Around one-third of the patients were diagnosed with breast cancer within the past 1 year, 34.9% 2–5 years ago, and 27.4% >5 years ago. One-fifth of the patients were newly diagnosed patients (17.8% on treatment), 43.6% completed treatment and on follow-up, 23.5% were cancer free ≥ 5 years, and 9.1% were dealing with recurrence or second cancer. Almost 86.3% of the survivors had surgery, 63.2% had radiation, and 69.2% were treated with chemotherapy.

Of the 438 breast cancer patients, 422 had breast cancer as their only cancer type, 15 had breast cancer and one other cancer types, and 1 had breast cancer and two other cancer types.

Concerns

Overall, the top five concerned/very concerned issues were related to (1) cancer treatment and recurrence risk (55.5%), followed by (2) FOR (54.6%), (3) long-term effects of treatment (53.4%), (4) osteoporosis/bone

Table 1: Demographics and clinical characteristics

Demographics & clinical characteristics	Breast, n (%)
Total	438 (100.0)
Age (years)	
Among patients with nonmissing data	384
Median (range)	56 (25-81)
Sex	
Female	435 (99.3)
Male	1 (0.2)
Missing	2 (0.5)
Race	
Chinese	370 (84.5)
Malay	28 (6.4)
Indian	20 (4.6)
Others	13 (3.0)
Missing	7 (1.6)
Marital status	
Single	81 (18.5)
Married	311 (71.0)
Divorced/separated	29 (6.6)
Widowed	15 (3.4)
Missing	2 (0.5)
Education	
No formal education	12 (2.7)
Primary	67 (15.3)
Secondary	157 (35.8)
Postsecondary	75 (17.1)
Tertiary	123 (28.1)
Missing	4 (0.9)
Employment	
Employed	225 (51.4)
Unemployed	27 (6.2)
Homemaker	99 (22.6)
Student	0 (0.0)
Retired	83 (18.9)
Missing	4 (0.9)
Monthly household income	
Not applicable	152 (34.7)
Below \$6000	173 (39.5)
\$6000-\$9999	59 (13.5)
\$10,000 and above	38 (8.7)
Missing	16 (3.7)
Housing type	
Housing Development Board (HDB)	346 (79.0)
Executive condominium/Housing and Urban Development Company (HUDC)	11 (2.5)
Private apartment/landed property	75 (17.1)
Missing	6 (1.4)
Years since diagnosis	
0-1	127 (29.0)
2-5	153 (34.9)
6 and above	120 (27.4)
Missing	38 (8.7)
Among patients with nonmissing data	400
Median (range)	3 (0-36)
Cancer survivorship stages	
Newly diagnosed, awaiting treatment	10 (2.3)

Contd...

Table 1: Contd...

Demographics & Clinical Characteristics	Breast, n (%)
Newly diagnosed, receiving treatment	78 (17.8)
Completed treatment, undergoing follow-up	191 (43.6)
Cancer free ≥ 5 years	103 (23.5)
Dealing with return of cancer or second cancer, not undergoing treatment yet	4 (0.9)
Dealing with return of cancer or second cancer, receiving treatment	36 (8.2)
Palliative care	0 (0.0)
Others	7 (1.6)
Missing	9 (2.1)
Type of treatment	
Surgery	378 (86.3)
Radiation	277 (63.2)
Chemotherapy	303 (69.2)
Hormonal therapy	107 (24.4)
Others	10 (2.3)

HDB: Housing Development Board, HUDC: Housing and Urban Development Company

health (39.0%), and (5) keeping primary care physician informed (37.4%) [Table 2].

The top three concerned/very concerned issues related to (1) cancer treatment and recurrence risk, (2) FOR, and (3) long-term effects of treatment were consistent across the cancer trajectory.

NT patients had more financial concerns and hair-and-skin care issues than CT and RS patients, who were more concerned on osteoporosis/bone health.

RS patients were more concerned about fatigue, whereas CT patients were more concerned about tingling and numbness in feet and hands.

Predictors for presence of ≥ 1 concerned or very concerned issue

Overall

Patients who had not received chemotherapy had significantly lower probability of having ≥ 1 concerned or very concerned issue.

Physical

Patients who had not received chemotherapy and had completed treatment or cancer free ≥ 5 years (as compared with those dealing with recurrence or second cancers), had significantly lower probability of having ≥ 1 concerned or very concerned issue.

Emotional

Patients who had completed treatment or cancer free ≥ 5 years (as compared with those dealing with recurrence or second cancers) and had not received chemotherapy or surgery, had significantly lower probability of having ≥ 1 concerned or very concerned issue. However, patients who were non-Chinese had higher probability of ≥ 1 concerned or very concerned issue.

Social

Patients who were older and had completed treatment or cancer free ≥ 5 years (as compared with those dealing with recurrence or second cancers) had lower probability of having ≥ 1 concerned or very concerned issue. However, patients who had not received surgery had higher probability of ≥ 1 concerned or very concerned issue.

Spiritual

Patients who were non-Chinese had higher probability of ≥ 1 concerned or very concerned issue.

Others

Patients who were older and had completed treatment or cancer free ≥ 5 years (as compared with those dealing with recurrence or second cancers), had lower probability of having ≥ 1 concerned or very concerned issue [Table 3].

Quality of life

Overall QOL was reported as a mean of 7.5 with a standard deviation of 2.0. The median QOL was 8 (range, 0–10). The boxplot [Figure 1] showed that the QOL of patients who had completed treatment or were cancer free ≥ 5 years tended to have a higher QOL than that of patients who were either newly diagnosed and on treatment or dealing with recurrence or second cancers.

On multivariate analysis, cancer survivorship stages and the presence of ≥ 1 concerned or very concerned physical issue were associated with QOL [Table 4].

Discussion

The primary aim of this secondary analysis was to establish the concerns of breast cancer survivors and use the data to inform practice by focusing on their salient concerns and prioritize and target education and information provision and support programs that can help to equip breast cancer survivors with the needed coping skills and enhance their QOL.

The results support the need for enhancing the information delivery and supportive care services to meet the physical and emotional concerns across the cancer trajectory. FOR is the topmost prominent emotional concern among the breast cancer survivors and also across the cancer trajectory. FOR has been defined as the worry or fear that the cancer will return, progress, or spread.^[19] The FOR is consistent with literature^[8,17,20-25] and may have important implications for survivors' psychological adjustment. Anxiety about recurrence was a common theme expressed by survivors regardless of the type of cancer they had or how many years they had survived cancer.^[26] Nearly 54.1% of the survivors reported needing help in managing their concerns about the cancer coming back.^[27] Studies have

Table 2: Concerns across cancer trajectory

Concerns	Overall (n=438), n (%)	NT (n=78), n (%)	CT (n=294), n (%)	RS (n=40), n (%)
Physical effects				
Pain	128 (29.2)	27 (34.6)	74 (25.2)	18 (45.0)
Fatigue	162 (37.0)	33 (42.3)	94 (32.0)	23 (57.5)
Sleep disturbances	139 (31.7)	23 (29.5)	86 (29.3)	18 (45.0)
Memory and concentration	118 (26.9)	19 (24.4)	77 (26.2)	15 (37.5)
Nausea/vomiting	60 (13.7)	16 (20.5)	29 (9.9)	8 (20.0)
Poor appetite	54 (12.3)	13 (16.7)	31 (10.5)	7 (17.5)
Trouble swallowing	45 (10.3)	9 (11.5)	27 (9.2)	6 (15.0)
Dental and mouth problems	75 (17.1)	14 (17.9)	46 (15.6)	10 (25.0)
Weight changes	110 (25.1)	22 (28.2)	70 (23.8)	14 (35.0)
Balance/walking/mobility	105 (24.0)	18 (23.1)	69 (23.5)	12 (30.0)
Loss of strength	134 (30.6)	29 (37.2)	80 (27.2)	17 (42.5)
Tingling and numbness in feet and hands	157 (35.8)	30 (38.5)	103 (35.0)	16 (40.0)
Swelling of legs and arms	102 (23.3)	21 (26.9)	60 (20.4)	13 (32.5)
Osteoporosis/bone health	171 (39.0)	24 (30.8)	115 (39.1)	23 (57.5)
Hair-and-skin care issues	136 (31.1)	36 (46.2)	76 (25.9)	16 (40.0)
Body changes	110 (25.1)	27 (34.6)	66 (22.4)	13 (32.5)
Bowel-and-bladder changes	87 (19.9)	18 (23.1)	53 (18.0)	10 (25.0)
Sexual issues	51 (11.6)	9 (11.5)	32 (10.9)	7 (17.5)
Fertility issues	42 (9.6)	12 (15.4)	26 (8.8)	2 (5.0)
Hot flashes/menopause	85 (19.4)	23 (29.5)	54 (18.4)	6 (15.0)
Others	10 (2.3)	4 (5.1)	6 (2.0)	0 (0.0)
Emotional aspects				
Defining a new sense of normal	96 (21.9)	28 (35.9)	52 (17.7)	10 (25.0)
Managing difficult emotions	120 (27.4)	24 (30.8)	72 (24.5)	15 (37.5)
Coping with grief and loss	84 (19.2)	21 (26.9)	45 (15.3)	9 (22.5)
Living with uncertainty	135 (30.8)	29 (37.2)	77 (26.2)	21 (52.5)
Fear of recurrence	239 (54.6)	46 (59.0)	149 (50.7)	34 (85.0)
Managing stress	125 (28.5)	22 (28.2)	74 (25.2)	19 (47.5)
Isolation/feeling alone	70 (16.0)	15 (19.2)	41 (13.9)	7 (17.5)
Intimacy issues	49 (11.2)	8 (10.3)	31 (10.5)	6 (15.0)
Looking for a brighter side	126 (28.8)	29 (37.2)	70 (23.8)	17 (42.5)
Having a sense of well-being	136 (31.1)	32 (41.0)	76 (25.9)	19 (47.5)
Changing relationships with spouse, family, and others	68 (15.5)	14 (17.9)	39 (13.3)	9 (22.5)
Finding support resources	89 (20.3)	20 (25.6)	52 (17.7)	9 (22.5)
Connecting to counseling services	46 (10.5)	10 (12.8)	24 (8.2)	5 (12.5)
Genetic counseling (worry about children getting cancer)	122 (27.9)	22 (28.2)	79 (26.9)	16 (40.0)
Others	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)
Social issues				
Managing household activities	95 (21.7)	20 (25.6)	53 (18.0)	13 (32.5)
Caring for family members	113 (25.8)	24 (30.8)	64 (21.8)	14 (35.0)
Talking about cancer with family and friends	92 (21.0)	21 (26.9)	53 (18.0)	12 (30.0)
Returning to work	89 (20.3)	24 (30.8)	48 (16.3)	10 (25.0)
Health insurance	132 (30.1)	31 (39.7)	75 (25.5)	14 (35.0)
Financial concerns	163 (37.2)	40 (51.3)	87 (29.6)	21 (52.5)
Debt from medical bills	120 (27.4)	27 (34.6)	69 (23.5)	12 (30.0)
Others	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)
Spiritual issues				
Religious or spiritual support	87 (19.9)	21 (26.9)	48 (16.3)	9 (22.5)
Religious or spiritual distress	51 (11.6)	6 (7.7)	30 (10.2)	8 (20.0)
Loss of faith	36 (8.2)	3 (3.8)	18 (6.1)	8 (20.0)
End-of-life concerns	69 (15.8)	11 (14.1)	36 (12.2)	14 (35.0)
Others	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)
Other issues				
Staying connected with the medical system	146 (33.3)	33 (42.3)	86 (29.3)	16 (40.0)

Contd...

Table 2: Contd...

Concerns	Overall (n=438), n (%)	NT (n=78), n (%)	CT (n=294), n (%)	RS (n=40), n (%)
Who to call for medical problems	132 (30.1)	20 (25.6)	87 (29.6)	14 (35.0)
Keeping primary care physician informed of cancer treatment and recurrence risk	164 (37.4)	32 (41.0)	100 (34.0)	18 (45.0)
Use of complementary or alternative therapies	117 (26.7)	21 (26.9)	67 (22.8)	16 (40.0)
Cancer treatment and recurrence risk	243 (55.5)	46 (59.0)	151 (51.4)	31 (77.5)
Concerns about the long-term effects of treatment	234 (53.4)	50 (64.1)	135 (45.9)	32 (80.0)
Others	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)

NT: Newly diagnosed and on treatment, CT: Completed treatment or were cancer free ≥ 5 years, RS: Recurrence or second cancer

No. 1 Concern No. 2 Concern No. 3 Concern

No. 4 Concern No. 5 Concern

Table 3: Multivariate logistic regression to identify variables associated with the presence of at least 1 concerned or very concerned issue

Issues	Breast variables	Categories	OR (95% CI)	P	
Overall	Chemotherapy	No versus yes	0.41 (0.21-0.77)	0.006	
Physical	Cancer survivorship stages	Completed treatment/cancer free versus dealing with return of cancer or second cancer	0.33 (0.15-0.73)	0.007	
		Newly diagnosed, receiving treatment versus dealing with return of cancer or second cancer	1.13 (0.32-4.05)		
		Others versus dealing with return of cancer or second cancer	0.64 (0.15-2.79)		
Emotional	Race	No versus yes	0.50 (0.30-0.81)	0.005	
		Malay versus Chinese	3.41 (0.96-12.17)	0.047	
		Indian versus Chinese	3.68 (0.80-16.87)		
		Others versus Chinese	4.40 (0.54-35.77)		
	Cancer survivorship stages	Completed treatment/cancer free versus dealing with return of cancer or second cancer	0.33 (0.16-0.69)	0.001	
		Newly diagnosed, receiving treatment versus dealing with return of cancer or second cancer	1.96 (0.50-7.70)		
		Others versus dealing with return of cancer or second cancer	0.23 (0.07-0.78)		
Social	Surgery	No versus yes	0.43 (0.22-0.85)	0.015	
		Chemotherapy	No versus yes	0.55 (0.34-0.88)	0.014
			Age	Per year increase	0.98 (0.96-0.99)
	Cancer survivorship stages	Completed treatment/cancer free versus dealing with return of cancer or second cancer		0.53 (0.30-0.94)	0.004
		Newly diagnosed, receiving treatment versus dealing with return of cancer or second cancer	1.25 (0.52-3.04)		
		Others versus dealing with return of cancer or second cancer	3.89 (0.80-18.90)		
Spiritual	Surgery (see note 1)	No versus yes	2.93 (1.35-6.35)	0.007	
		Race	Malay versus Chinese	5.40 (2.38-12.25)	0.001
			Indian versus Chinese	1.85 (0.71-4.86)	
			Others versus Chinese	1.36 (0.35-5.39)	
Others	Age	Per year increase	0.98 (0.96-1.00)	0.045	
		Cancer survivorship stages	Completed treatment/cancer free versus dealing with return of cancer or second cancer	0.49 (0.26-0.93)	0.005
			Newly diagnosed, receiving treatment versus dealing with return of cancer or second cancer	1.94 (0.58-6.48)	
		Others versus dealing with return of cancer or second cancer	3.55 (0.43-29.42)		

Category with 95% CI for OR excluding value 1 (an OR=1 means that the category did not have a significant different probability to experience the event of interest as compared with those in the reference category, an OR <1 means that patients in the category had a lower probability to experience the event of interest as compared with those in the reference category, and an OR >1 means that patients in the category had a higher probability to experience the event of interest as compared with those in the reference category). 1: Most of the social issues rated as concerned or very concerned by patients who had no surgery were #4.5 health insurance, #4.6 financial concerns, and #4.7 debts from medical bills. OR: Odds ratio, CI: Confidence interval

consistently shown the negative impacts associated with FOR, including elevated emotional distress,^[28] impaired functional status,^[29] and poorer QOL.^[9,29-31] A study reported that moderate to high level of FOR is experienced by 56% of breast cancer survivors and was negatively correlated with all domains of QOL.^[13] Our study reveals that breast cancer survivors were also concerned about the long-term effects of treatment, which is supported by literature.^[32]

Among the physical concerns, osteoporosis/bone health was the top concern and affects CT and RS patients more.

This is a valid concern that warrants attention as evidence indicates that survivors of breast cancer had a 68% higher risk of osteopenia and osteoporosis compared to cancer-free women.^[33] Breast cancer survivors are at very high risk of bone loss and osteoporosis due to adjuvant therapies with aromatase inhibitors^[3,33,34] and supportive steroid therapies.^[2,33] Osteoporosis causes deterioration of the bony microstructure, resulting in fragility fractures and an increase in overall mortality.^[3] Other concerns that were identified related to hair-and-skin care issues by NT patients. RS

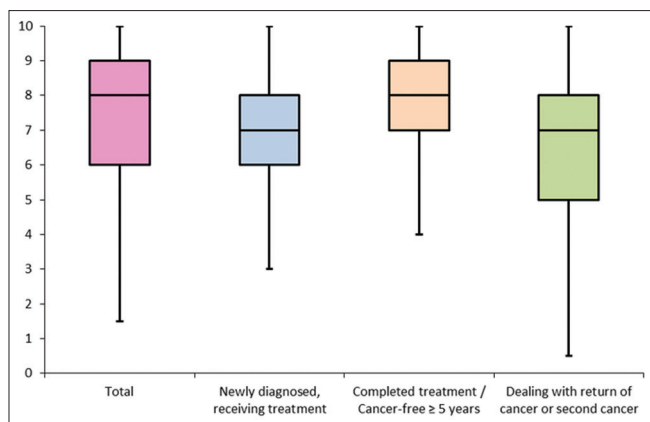


Figure 1: Quality of life by survivorship stages

Table 4: Linear regression to identify variables associated with quality of life

Variable	Breast			
	Univariate			Multivariate [^]
	n	Mean QOL (SD)	P	
Cancer survivorship stages	71	7.08 (1.87)	<0.001	<0.001
	258	7.79 (1.86)		
	35	6.80 (2.35)		
Physical issues	16	6.19 (2.10)		<0.001
	297	7.25 (2.04)	<0.001	
Emotional issues	85	8.35 (1.39)		0.044
	276	7.35 (1.99)		
Social issues	100	7.81 (1.89)		0.027
	203	7.27 (2.09)		
Spiritual issues	173	7.72 (1.80)		0.789
	96	7.42 (2.21)		
Other issues	271	7.48 (1.90)		0.017
	260	7.30 (1.98)		
	108	7.84 (1.91)		

[^]Only significant variables in the final multivariate model indicated in the table. QOL: Quality of life, SD: Standard deviation

patients were more concerned about fatigue, whereas CT patients were more concerned about tingling and numbness in feet and hands. As such, breast cancer survivors must be cognizant of the side effects of cancer therapies including the long-term effects of their treatment and be given information, resources, and support to enable them to cope with these effects including how to recognize the signs of recurrence.

The results also helped to identify gaps in information delivery and supportive care during care transitions. Overall, 37.4% of the respondents (top 5) were concerned about “keeping primary care physicians informed of cancer treatment and recurrence risk.” The Institute of Medicine (IOM) in “From Cancer Patient to Cancer Survivor: Lost in Transition^[35] outlined the following as the essential components of survivorship care: (1) prevention and detection of new cancers and recurrent cancer; (2) surveillance for cancer spread, recurrence, or

second cancers; (3) intervention for consequences of cancer and its treatment; and (4) coordination of care between specialists and primary care providers. Survivorship care plans have been recommended by the IOM^[35] as a tool to assist cancer survivors transit from cancer treatment to follow-up care through educating survivors and providers. It contains both a treatment summary (including information on type and timing of diagnostic tests, cancer type, stage, grade, treatment, and contact details of the hospital and specialists) and a follow-up care plan (including information on the possible short-term and long-term effects, effects on social and sexual life, signs of recurrence and secondary tumors, rehabilitation, psychosocial support, and supportive care services).^[35] Another identified gap was the health care professionals’ (HCPs) lack of attention to the patient’s social needs, which included financial concerns. In all, 37.2% of the respondents reported having financial concerns, with the NT patients (51.3%) and RS patients (52.5%) reporting more financial concerns. Financial concerns are well reported in the literature^[20,32,36,37] due to the escalating cost of cancer treatment. Attention to the financial burden is critical because increased financial burden as a result of cancer care costs is the strongest independent predictor of poor QOL and adverse psychological issues such as depression, anxiety, and distress^[37-39] among cancer survivors.

The findings identified breast cancer patients at risk for cancer-related concerns throughout the cancer trajectory, and survivorship trajectory and physical concerns have an impact on their QOL. There were several implications based on the findings. With growing evidence that well-informed patients are more satisfied with their care and do better clinically,^[40] efforts are needed to improve the content and delivery of cancer-related information to breast cancer survivors.^[41] This may indicate that more attention needs to be paid to assess, explain, and develop education materials relating to identified concerns, such as potential late effects and long-term effects of cancer treatment, risks of cancer recurrence, fatigue, and financial support and resources. The results also indicated the need for patient-centered communication, with discussion about patients’ concerns. For example, encouraging patients to verbalize their financial concerns would help determine whether a referral to social work would be beneficial in determining national and local assistance programs for which the patient may qualify. In addition, HCPs should also ideally work with the breast cancer survivors to develop an individualized cancer survivorship care plan. This could potentially address their concern about the integration of survivorship care between oncology and primary care settings. Finally, a periodic audit of the concerns of breast cancer survivors and how well their needs were met is a

patient-centered approach in understanding and addressing their concerns. The importance of maintaining the health of cancer survivors and managing long-term and late effects of cancer treatment has been identified as key components of delivering high-quality cancer across the care continuum.^[42]

Limitations

There were limitations in this survey. As this was a cross-sectional assessment of perceived concerns of breast cancer survivors at a specific point in time, longitudinal studies during the survivorship trajectory would provide more complete insights to the concerns at different times in the continuum of care. The study sample included only patients from a single cancer center, and data on nonrespondents were not systematically collected and as such, the participants may not be representative of the general population of patients with breast cancers. Despite these limitations, we analyzed data based on landmarks in medical treatment such as during treatment, on treatment completion, and recurrence instead of the commonly used variable of months or years since cancer diagnosis. In addition, our large sample size should have mitigated these limitations. The study also provided insights into the scope of the concerns of breast cancer survivors helped establish which concerns should be the focus of possible prevention and remediation efforts through effective information and supportive care delivery.

Conclusion

Evaluating the self-identified concerns of breast cancer survivors is instrumental in developing appropriate and effective survivorship programs to meet the unique and evolving needs of breast cancer survivors. The results of this survey demonstrate the concerns of breast cancer survivors across the cancer trajectory and their information and supportive care needs. With the competing demands for the finite resources to provide quality cancer care, effective survivorships programs that can meet the breast cancer survivors at different stage of their disease trajectory are critical in helping them cope through the provision of information and supportive services. This may enhance the health-related QOL and anxiety and depression levels, thereby increasing their satisfaction and health outcomes.

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Conflicts of interest

There are no conflicts of interest.

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