



## Original article

## Experiences and perspectives of ethnocultural breast cancer survivors in the interior region of British Columbia: A descriptive cross-sectional approach

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## ABSTRACT

**Background:** Breast cancer is the most common form of cancer in Canadian ethnocultural survivors. There is little information on the psychosocial impact of experiences and perspectives among ethnocultural survivors.

**Objective:** The purpose of this study was to examine the experiences and perspectives of ethnocultural breast cancer survivors in the interior region of British Columbia.

**Methods:** A descriptive cross-sectional approach was used. A research ethics board approval was obtained. A purposive sample of 115 ethnocultural breast cancer survivors was recruited in the interior region from August 2020 to March 2021. Written and verbal consent was obtained from the participants who completed a survey questionnaire.

**Results:** Patient engagement in care and total satisfaction scores were significantly associated with younger age, higher schooling, living a marital life, being employed, having extended health benefits, having a family history of breast cancer, decreased number of years with the first breast cancer diagnosis, and lesser severity of symptom distress. Participants of a younger age expressed receiving better consultation and advice from health care practitioners for cancer treatment-related distress, building patient-physician communication, relationship and trust.

**Conclusion:** A deeper understanding the cancer-related experiences of ethnocultural breast cancer survivors lies in its importance of integrating return to work, health benefits and extended insurance policies within the framework of cancer supportive care. This research lays a foundation for future work to develop specific supportive care interventions that reduce psychosocial distress, improve work productivity and longevity leading to better quality of life.

## 1. Introduction

Over the last few centuries, the prevalence of cancer has doubled, making it an enormous health burden for Canadian society. Additionally, the empirical evidence regarding the same is undeniable; currently, the burden of cancer care is escalating in all national regions and across wide-ranging socio-economic categories.<sup>1</sup> Consequently, lung, breast, colorectal, and prostate cancers are the most diagnosed cancers in Canada, accounting for approximately half (48%) of all new cancer cases.<sup>2</sup> Data suggest that in 2018, there were 26735 new cancer cases in British Columbia (BC), with a cancer incidence rate of 533.6/100000 representing all ages, genders, and primary cancer sites in BC.<sup>3</sup> Recent

figures, based on the 2020 census, show that more than 115 800 Canadian men were diagnosed with cancer, with 44100 dying from the disease; among women, 110000 were estimated to have received a cancer diagnosis, with 39300 dying from it.<sup>4</sup> A patient can expect deterioration in physical, psychological, emotional, and social well-being throughout a cancer illness, from the initial diagnosis to the treatment and follow-up.<sup>5</sup> The diagnosis, treatment, and side effects of cancer affect quality of life. Hence, cancer care is complex, with significant coordination required to ensure quality and continuity of care throughout the entire disease trajectory.

Ethnocultural group is defined by the shared characteristics such as cultural traditions, ancestry, language, national identity, country of

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origin, and physical traits unique to and recognized by that group.<sup>6</sup> An extensive body of research has documented that some ethnocultural women lack emotional support and support from families.<sup>6</sup> Previous studies on breast cancer reported that participants had a lack of knowledge about breast cancer and its treatment and tried to seek information from peers.<sup>7</sup> A review of qualitative studies found that ethnocultural women had limited access to care, which contributed to their diagnosis of more advanced disease,<sup>8</sup> causing anxiety related to perceived severity and disengagement coping.<sup>9</sup> Studies have suggested a need for continuity of care and support to help survivors cope with changes in cancer treatment and their everyday life.<sup>10,11</sup> Breast cancer is stressful and life-altering, leading to poor psychosocial outcomes<sup>6,8</sup> and difficulty in communicating with health care providers due to cultural factors, lack of familiarity, and language barriers.<sup>10,12</sup> Therefore, ethnocultural breast cancer survivors have more unmet needs regarding information and support after the completion of treatment for breast cancer.<sup>13</sup>

## 2. Background

In recent years, a small number of studies with breast cancer survivors have reported peer support<sup>11,13</sup> and family support can have an effect on depression and anxiety of cancer survivors.<sup>9,14</sup> Past literature has documented that Latina breast cancer survivors' wellbeing is negatively affected by their inability to engage with their care.<sup>8,13</sup> For example, breast cancer survivors complained of not knowing what to expect at the end of their treatment, causing an unfavorable emotional response during the transition to follow-up in the United Kingdom.<sup>11</sup> Psychosocial network support may increase the sense of wellbeing among women with breast cancer and tailor a care plan that is likely to be more effective than generic interventions. Peer-support resources would be helpful for cancer diagnosis within the community.<sup>13</sup> Some women with newly diagnosed cancer expressed a more significant reduction in depressive symptoms when receiving emotional support.<sup>15</sup> In addition, there were no existing support groups for ethnocultural, immigrant, and African women with breast cancer.<sup>16</sup> While there is a limited, albeit growing body of research exploring this phenomenon, there is a need for highlighting the relevance of socio-cultural behaviors in shaping the experiences of ethnocultural breast cancer survivors. These psychosocial concerns associated with breast cancer treatment suggest that experiences of survivors' impact their well-being.

Breast cancer survivors' role as caregivers, alongside the stress of potentially burdening their families, adds to the challenges they face such as lack of insurance, unfamiliarity with the healthcare system, and lack of available social support.<sup>16</sup> The available comparative studies showed that breast cancer experiences differed among ethnocultural breast cancer survivors where most women were given written information solely in English and did not consider their cultural influences on post-treatment recommendations.<sup>11</sup> Navigating the health care system is a challenge faced by many participants that has consequences such as symptom distress, financial burden, and potential health consequences.<sup>16</sup> Cancer treatment distress may reflect illness-related perceptions about cancer, decreased physical health due to fatigue, irritability, memory loss, and recurring pain, with emotional health being directly associated with the physical quality of life.<sup>16</sup> This suggests that a return to everyday life is difficult, and having side-effects has a significant distressing and emotional impact on breast cancer experience.<sup>10</sup> This experience therefore elicits a need for more professional translational services to be available in cancer-related treatment.<sup>11</sup> A recent study revealed that patients' caregiver and peer mentor support is beneficial for women's medical adherence, and counselling services addressing concerns about stigma and communication among family members may benefit patients' adjustments.<sup>16</sup> There is, however, limited focus on understanding psychosocial wellbeing, supportive care, and the increasing complexity of experiences among immigrants, refugees, minority and racialized populations.

## 3. Literature

Many cancer survivors viewed surviving cancer as an improvement in wellness, giving them a sense of thriving, build resilience, and the confidence and satisfaction of having "beat cancer" without "falling and giving up".<sup>17</sup> Sharing survivorship experiences among women was important and interfaced with shared ethnicity and language for African American and Latina breast cancer survivors.<sup>18</sup> Experiences of racialized women are different from Euro-American women's experiences, further supporting existing research that has examined ethnic group differences among cancer survivors.<sup>19</sup> Current evidence on South Asian women reported higher anxiety, depression, internal and fatalistic beliefs about cancer, and a poorer body image than white women.<sup>19</sup> Latina and Chinese breast cancer survivors reported loss of self-esteem resulting from bodily changes caused by breast cancer treatment and the importance of treatment satisfaction in predicting quality of life outcomes.<sup>20</sup> Low-to-middle-income Chinese immigrant survivors could not afford cancer care services at convenient locations and were preoccupied with concerns about costs and harming their productivity at work.<sup>21</sup> Quantitative studies reported that university graduates and occupation groups showed a significantly higher level of empowerment, with the survivors of breast cancer showing significant differences in their quality of life, based on self-help group participation.<sup>22</sup> A positive attitude helped participants during their survivorship journey; a positive outlook was described as "living stress-free" and gaining information from the American Cancer Society website to help them during their ongoing survivorship.<sup>17</sup>

These previous findings were also coupled with the empirical evidence of inadequate support and lack of follow-up services regarding transparency, support, and patient-provider communication from the survivors' perspective. Another study indicated that self-efficacy in patient-physician communication was significantly correlated with satisfaction with being cured, suggesting a relationship between self-efficacy in patient-physician communication and psychological outcomes post-surgical treatment.<sup>20</sup> Fatigue, cognition, upper body limitation, and pain were reported as most likely to diminish the functional ability of performing activities among African American breast cancer survivors.<sup>12</sup> Comparing ethnocultural breast cancer survivors' experiences can help identify whether changes to practice and policy are needed to ensure that they receive appropriate care. The recent health policy has highlighted a gap in understanding patient stories, culturally appropriate care and ethnocultural experiences.<sup>19,21</sup>

## 4. Methods

### 4.1. Human ethical considerations

Ethical approval was obtained through the Research Ethics Board of Thompson Rivers University, BC Cancer and Interior Health Research Information Systems.

### 4.2. Research aim

This study aimed to examine the experiences and perspectives of ethnocultural breast cancer survivors in the interior region of British Columbia.

### 4.3. Design and approach

This study used a cross-sectional descriptive design as part of the larger community-based participatory research (CBPR) approach to provide a study conceptualization, dissemination of findings, being grounded in socio-cultural orientations and provide a deep understanding of the experiences.<sup>23</sup> Cross-sectional approach emphasizes experience and its relationship to power analysis and examines ethnocultural challenges from the point of view of breast cancer survivors who

experience them.

#### 4.4. Sample and setting

A sampling framework of all eligible ethnocultural women diagnosed with, treated for, and surviving breast cancer was obtained through purposive sampling. Caucasian women included British, French, Dutch, German, Polish, Italian, Portuguese, Spanish etc. Racialized women included Arabs, African, Chinese, Japanese, Korean, Filipino, Vietnamese, East Asian, Southeast Asian etc. A purposive sample was used to select participants from Thompson-Nicola, Cariboo, Kootenay, Okanagan and Columbia-Shuswap in the interior region. The sample size was decided based on G\*Power 3.1 statistical software's one-way ANOVA, an effect size of 0.35,  $\alpha$  error prob = .05, a power (1- $\beta$  err prob) of 0.80, thus, a minimum sample size of 105 was required. A total of 115 samples were taken, considering 10% attrition in the study. Eligible criteria included English-speaking/literate adults, aged eighteen and above, diagnosed with primary breast cancer and having completed more than one year post-diagnosis; treated with surgery, radiation, chemotherapy, hormonal therapy, and immunotherapy; and capable of providing informed consent. Women who were not English speaking/literate, were not willing to consent, had advanced breast cancer, were diagnosed with a different primary cancer, and palliative care were excluded.

#### 4.5. Measurements and outcomes

A survey questionnaire was developed based on a literature review, discussions with breast cancer survivors, and validation by oncology nurses and key informants. The survey questionnaire (See Table 1) consisted of 15 items on patient engagement in care addressing the following: consultation, side effects of treatment, supportive cancer services, navigating cancer care services, complementary and alternative care, knowledge and awareness about breast cancer, psychosocial health and wellness and survivorship. Self-reported demographic and clinical information included age, ethnicity, school, marital status, income, employment, extended health care benefits, family history of breast cancer, regular family practitioner, first breast cancer diagnosis, second breast cancer diagnosis, and health problems after breast cancer treatment. The survey instrument was validated with a nurse educator, a physician, a nurse practitioner and a clinician. Reliability of the survey was assessed with an internal consistency of total satisfaction score and dimensions, as measured by Coefficient of Cronbach's alpha, was 0.74.

#### 4.6. Data collection procedures

One hundred fifteen breast cancer survivors were screened and were deemed to be eligible. Oral and written informed consent was obtained from the survey. The adult survivors were free to withdraw their

**Table 1**  
Survey questionnaire items on dimensions of experiences and perspectives.

1. Consultation and advice availed from health care practitioners for cancer treatment-related distress
2. Informed and aware of side effects of treatment and patient role expectations
3. Informed about cancer supportive services and follow up from health care practitioners
4. Building patient-physician communication, relationship and trust
5. Language translation through family interpreters
6. Access and use of cancer supportive services, health and wellness resources
7. Ease to navigate cancer care services and community health and wellness resources
8. Availability and use of complementary and alternative care approaches
9. Use of patient voice for advocacy in cancer care
10. Knowledge and awareness about breast cancer diagnosis, treatment, survivorship and palliatives care
11. Use of psychosocial health and wellness services
12. Use of peer support groups and peer mentors
13. Psychosocial support to cope with diagnosis, treatment, survivorship
14. Access to survivorship to cope and self-manage after completion of treatment

participation from the study at any time during the study and would continue to receive their health care services. Participants were recruited through announcement posters and brochures in hospitals, clinics, support groups and social media. Interested participants contacted the researchers and were briefed about the study information, purpose, procedures, human ethics, and informed consent. We recruited participants for eight consecutive months in the interior region from August 2020 to March 2021. Participants who volunteered for the study completed the surveys in paper format, through survey monkey, and/or electronic mail. The participants took 40–45 min to complete the study and received a voucher. Each participants' survey was assigned a unique code.

#### 4.7. Data analysis

Data were entered and analyzed using the SPSS-25 statistical software (IBM Corporation, Armonk, NY, USA). Descriptive statistics and Pearson Chi-square tests were used to examine the relationships between socio-demographic variables and the total satisfaction score.

Categorical variables such as socio-demographic variables and numerical variables such as experiences and perspectives were covariables. Statistical analysis was performed at a 0.05 level of significance.

### 5. Results

Of the 115 breast cancer survivors, six survivors did not return the surveys, five survivors chose not to participate, and four survivors submitted partly-completed surveys after three reminders. One hundred survivors completed the survey, giving a response rate of 87%.

#### 5.1. Demographic characteristics of women survivors with breast cancer

Forty-six percent of the participants were older than 60 years, 43% had trade and vocational education, 73% were married, and 44% were retired (Table 2). Women belonged to British, French, Dutch, German, Polish, Italian, Portuguese, Spanish (74%); Middle East, African, Pakistan, Syrian (6%), Chinese, Japanese, Filipino, Vietnamese (9%) and East Asian, Bangladesh, Sri Lankan, Afghanistan (11%)

**Table 2**  
Demographic characteristics of Women Survivors with Breast Cancer N = 100.

Determinant categories	Valid Percent	Cumulative Percent
<b>Age (years)</b>		
Below 40	23.0	23.0
40–60	31.0	54.0
Above 60	46.0	100.0
<b>School education</b>		
High school	18.0	18.0
Trade and vocational	43.0	61.0
Undergraduate and above	39.0	100.0
<b>Marital status</b>		
Married, Common law partner	73.0	73.0
Widow, Single	10.0	83.0
Divorced, Separated	17.0	100.0
<b>Income</b>		
Less than \$35,000 CAD	17.0	17.0
\$35,000–69,999 CAD	25.0	42.0
\$70,000 CAD and more	58.0	100.0
<b>Employment</b>		
Full time employment	34.0	34.0
Part time employment	22.0	56.0
Retirement	44.0	100.0
<b>Ethnicity and culture</b>		
British, French, Dutch, German, Polish, Italian, Portuguese, Spanish	74.0	74.0
Middle East, African, Pakistan, Syrian	6.0	6.0
Chinese, Japanese, Filipino, Vietnamese	9.0	9.0
East Asian, Bangladesh, Sri Lankan, Afghanistan	11.0	11.0

ethnocultural groups.

5.2. Clinical characteristics of women survivors with breast cancer

Twenty percent of the participants had a family history of breast cancer, 86% had a family general practitioner, 32% were diagnosed with breast cancer for less than three years, and 40% had major symptom distress from cancer related treatment (Table 3).

5.3. Association between total satisfaction scores and demographic characteristics

Age: There was a highly significant association between age and total satisfaction scores and consultation and advice available from health care practitioners for cancer treatment-related distress (78%;  $p < .003$ ); use of psychosocial health and wellness services (62%;  $p < .049$ ); building patient-physician communication, relationship, and trust (58%;  $p < .003$ ); language translation through a family interpreter (49%;  $p < .001$ ); and psychosocial support to cope with diagnosis, treatment, or survivorship (47%;  $p < .012$ ) (Table 4).

Schooling: There was a highly significant association between schooling and total satisfaction scores and knowledge and awareness about breast cancer diagnosis, treatment, survivorship, and palliative care (64%;  $p < .008$ ); building patient-physician communication, relationship, and trust (58%;  $p < .030$ ); information and awareness of the side effects of treatment and patient role expectations (54%;  $p < .004$ ); language translation through family interpreters (49%;  $p < .017$ ); psychosocial support to cope with the diagnosis, treatment, or survivorship (47%;  $p < .019$ ); and ease of navigating cancer care services and community health and wellness resources (41%;  $p < .05$ ) (Table 4).

Employment: There was a significant association between employment and total satisfaction scores and consultation and advice available from health care practitioners for cancer treatment-related distress (78%;  $p < .018$ ); knowledge and awareness about breast cancer diagnosis, treatment, survivorship, and palliative care (64%;  $p < .050$ ); use of psychosocial health and wellness services (62%;  $p < .050$ ); building patient-physician communication, relationship, and trust (58%;  $p < .002$ ); language translation through family interpreters (49%;  $p < .050$ ); ease in navigating cancer care services and community health and wellness resources (41%;  $p < .047$ ); and access and use of supportive cancer services and health and wellness resources (38%;  $p < .024$ ) (Table 4).

**Table 3**  
Clinical characteristics of Women Survivors with Breast Cancer N = 100.

Determinant categories	Valid Percent	Cumulative Percent
<b>Extended Health care benefits and insurance</b>		
Yes	65.0	65.0
No	35.0	100.0
<b>Family history of breast cancer</b>		
Yes	27.0	27.0
No	73.0	100.0
<b>Having a regular medical practitioner</b>		
General family practitioner	86.0	86.0
Nurse practitioner	3.0	89.0
Oncologist, Specialist	11.0	100.0
<b>First diagnosis of breast cancer</b>		
Less than 3 years	32.0	32.0
3–5 years	28.0	60.0
6–10 years	13.0	73.0
More than 10 years	27.0	100.0
<b>Cancer related treatment distress</b>		
No distress 0 score	18.0	18.0
Minor symptom distress 1–3 score	7.0	25.0
Moderate symptom distress 4–6 score	35.0	60.0
Major symptom distress >7 score	40.0	100.0

5.4. Association between total satisfaction score and clinical characteristics

Extended health care benefits: There was a significant association between extended health care benefits and total satisfaction scores and knowledge and awareness about breast cancer diagnosis, treatment, survivorship, and palliative care (64%;  $p < .005$ ); use of psychosocial health and wellness services (62%;  $p < .022$ ); patient-physician communication, relationship, and trust (58%;  $p < .050$ ); ease in navigating cancer care services and community health and wellness resources (41%;  $p < .016$ ); and access and use of supportive cancer services and health and wellness resources (38%;  $p < .002$ ) (Table 5).

First diagnosis of breast cancer: There was a significant association between first diagnosis of breast cancer and total satisfaction scores and consultation and advice available from health care practitioners for cancer treatment-related distress (78%;  $p < .042$ ); use of psychosocial health and wellness services (62%;  $p < .004$ ); building patient-physician communication, relationship, and trust (58%;  $p < .047$ ); availability and use of complementary and alternative care approaches (53%;  $p < .050$ ); information about cancer support services and follow-up from health care practitioners (48%;  $p < .050$ ); and psychosocial support to cope with diagnosis, treatment, and survivorship (47%;  $p < .050$ ) (Table 5).

Symptom distress: There was a significant association between symptom distress and total satisfaction scores and consultation and advice available from health care practitioners for cancer treatment-related distress (78%;  $p < .050$ ); knowledge and awareness about breast cancer diagnosis, treatment, survivorship, and palliative care (64%;  $p < .050$ ); use of psychosocial health and wellness services (62%;  $p < .050$ ); psychosocial support to cope with diagnosis, treatment, and survivorship (47%;  $p < .050$ ); and access and use of supportive cancer services and health and wellness resources (38%;  $p < .001$ ) (Table 5).

6. Discussion

This study showed that younger age, higher education, living with a spouse, and full-time employment significantly correlated with total satisfaction scores among the ethnocultural breast cancer survivors. Other studies showed that Latina women had limited access to care<sup>8</sup> and felt less satisfied with their care.<sup>14</sup> Financial and economic disadvantages influenced satisfaction with care and patient-provider communication.<sup>14</sup> While Chinese women are expected to be patient's caregivers, which becomes an essential part of their identity and a priority in their lives.<sup>16</sup> Our study showed that extended health benefits, family history of breast cancer, first breast cancer diagnosis, and symptom distress were significantly associated with total satisfaction scores among the ethnocultural breast cancer survivors. Other studies showed that culture was associated with physical well-being and experiences of difficulties with patient-physician communication,<sup>8</sup> with less access to written information in their native language regarding treatment side-effects.<sup>24</sup>

Some ethnocultural breast cancer survivors expressed that they were partly aware of cancer-related treatment distress and expected physicians to be more open about symptom distress related to treatment. These women felt that they were not adequately prepared for emotional distress due to fear, weight gain, and radiation marks. Some ethnocultural breast cancer survivors were more likely to consult for symptom distress, take advice from their physicians and oncologists, and perceive their physician as necessary in their treatment care. These results reflect previous research, which showed that participants were eager for information but were uncertain about which questions to ask their doctor, mainly due to a lack of understanding about concepts of prognosis, diagnosis, and cancer stage/grade.<sup>24</sup> The gaps were noted along with the continuity of care and cancer patient navigation from early diagnosis to treatment, survivorship, and palliative care. Consultation and advice from physicians were helpful and a primary source of information for treatment decision-making; participants reported a lack of decision-making support tools, tracking outcomes, and collaboration

**Table 4**  
Association between Total Satisfaction Score and Demographic characteristics N = 100.

Social determinants	Healthcare dimensions of wellbeing and satisfaction	Feeling Uninformed 0	Satisfaction 1	Pearson Chi-Square, Value	Chi-Square Tests, df	Asymptotic Significance (2-sided) p-value
Age	Consultation and advice availed from health care practitioners for cancer treatment-related distress	22	78	11.668 <sup>a</sup>	2	0.003
	Informed and aware of side effects of treatment and patient role expectations	46	54	.570 <sup>a</sup>	2	.752
	Informed about cancer supportive services and follow up from health care practitioners	52	48	.264 <sup>a</sup>	2	.876
	Building patient-physician communication, relationship and trust	42	58	11.899 <sup>a</sup>	2	.003
	Language translation through family interpreters	51	49	13.076 <sup>a</sup>	2	.001
	Access and use of cancer supportive services, health and wellness resources	62	38	3.657 <sup>a</sup>	2	.161
	Ease to navigate cancer care services and community health and wellness resources	59	41	2.887 <sup>a</sup>	2	.236
	Availability and use of complementary and alternative care approaches	47	53	.762 <sup>a</sup>	2	.683
	Use of patient voice for advocacy in cancer care	75	25	3.506 <sup>a</sup>	2	.173
	Knowledge and awareness about breast cancer diagnosis, treatment, survivorship and palliatives care	36	64	1.275 <sup>a</sup>	2	.529
	Use of psychosocial health and wellness services	38	62	6.038 <sup>a</sup>	2	.049
	Use of peer support groups and peer mentors	38	62	2.085 <sup>a</sup>	2	.353
	Psychosocial support to cope with diagnosis, treatment, survivorship	53	47	8.791 <sup>a</sup>	2	.012
	Access to survivorship to cope and self-manage after completion of treatment	51	49	1.863 <sup>a</sup>	2	.394
	Schooling	Consultation and advice availed from health care practitioners for cancer treatment-related distress	22	78	1.546 <sup>a</sup>	2
Informed and aware of side effects of treatment and patient role expectations		46	54	10.964 <sup>a</sup>	2	.004
Informed about cancer supportive services and follow up from health care practitioners		52	48	3.130 <sup>a</sup>	2	.209
Building patient-physician communication, relationship and trust		42	58	6.981 <sup>a</sup>	2	.030
Language translation through family interpreters		51	49	8.180 <sup>a</sup>	2	.017
Access and use of cancer supportive services, health and wellness resources		62	38	3.767 <sup>a</sup>	2	.152
Ease to navigate cancer care services and community health and wellness resources		59	41	5.540 <sup>a</sup>	2	.050
Availability and use of complementary and alternative care approaches		47	53	3.381 <sup>a</sup>	2	.184
Use of patient voice for advocacy in cancer care		75	25	.152 <sup>a</sup>	2	.927
Knowledge and awareness about breast cancer diagnosis, treatment, survivorship and palliatives care		36	64	9.754 <sup>a</sup>	2	.008
Use of psychosocial health and wellness services		38	62	2.892 <sup>a</sup>	2	.235
Use of peer support groups and peer mentors		38	62	.639 <sup>a</sup>	2	.727
Psychosocial support to cope with diagnosis, treatment, survivorship		53	47	7.882 <sup>a</sup>	2	.019
Access to survivorship to cope and self-manage after completion of treatment		51	49	2.215 <sup>a</sup>	2	.330
Marital Status		Consultation and advice availed from health care practitioners for cancer treatment-related distress	22	78	2.871 <sup>a</sup>	2
	Informed and aware of side effects of treatment and patient role expectations	46	54	.162 <sup>a</sup>	2	.922
	Informed about cancer supportive services and follow up from health care practitioners	52	48	.423 <sup>a</sup>	2	.809
	Building patient-physician communication, relationship and trust	42	58	1.451 <sup>a</sup>	2	.484
	Language translation through family interpreters	51	49	6.451 <sup>a</sup>	2	.040
	Access and use of cancer supportive services, health and wellness resources	62	38	.896 <sup>a</sup>	2	.639
	Ease to navigate cancer care services and community health and wellness resources	59	41	.804 <sup>a</sup>	2	.669
	Availability and use of complementary and alternative care approaches	47	53	1.317 <sup>a</sup>	2	.518
	Use of patient voice for advocacy in cancer care	75	25	3.687 <sup>a</sup>	2	.158
	Knowledge and awareness about breast cancer diagnosis, treatment, survivorship and palliatives care	36	64	6.304 <sup>a</sup>	2	.043
	Use of psychosocial health and wellness services	38	62	6.231 <sup>a</sup>	2	.044
	Use of peer support groups and peer mentors	38	62	3.837 <sup>a</sup>	2	.147
	Psychosocial support to cope with diagnosis, treatment, survivorship	53	47	1.128 <sup>a</sup>	2	.569
	Access to survivorship to cope and self-manage after completion of treatment	51	49	5.398 <sup>a</sup>	2	.050

(continued on next page)

Table 4 (continued)

Social determinants	Healthcare dimensions of wellbeing and satisfaction	Feeling Uninformed 0	Satisfaction 1	Pearson Chi-Square, Value	Chi-Square Tests, df	Asymptotic Significance (2-sided) p-value
Employment	Consultation and advice availed from health care practitioners for cancer treatment-related distress	22	78	8.030 <sup>a</sup>	2	.018
	Informed and aware of side effects of treatment and patient role expectations	46	54	2.300 <sup>a</sup>	2	.317
	Informed about cancer supportive services and follow up from health care practitioners	52	48	.504 <sup>a</sup>	2	.777
	Building patient-physician communication, relationship and trust	42	58	12.470 <sup>a</sup>	2	.002
	Language translation through family interpreters	51	49	5.342 <sup>a</sup>	2	.050
	Access and use of cancer supportive services, health and wellness resources	62	38	7.456 <sup>a</sup>	2	.024
	Ease to navigate cancer care services and community health and wellness resources	59	41	6.102 <sup>a</sup>	2	.047
	Availability and use of complementary and alternative care approaches	47	53	2.955 <sup>a</sup>	2	.228
	Use of patient voice for advocacy in cancer care	75	25	.898 <sup>a</sup>	2	.638
	Knowledge and awareness about breast cancer diagnosis, treatment, survivorship and palliatives care	36	64	4.746 <sup>a</sup>	2	.050
	Use of psychosocial health and wellness services	38	62	4.868 <sup>a</sup>	2	.050
	Use of peer support groups and peer mentors	38	62	.192 <sup>a</sup>	2	.908
	Psychosocial support to cope with diagnosis, treatment, survivorship	53	47	3.771 <sup>a</sup>	2	.152
	Access to survivorship to cope and self-manage after completion of treatment	51	49	3.432 <sup>a</sup>	2	.180

among health care providers. Only 50% of the ethnocultural breast cancer survivors who reported cancer treatment distress consulted their physicians. This shows that continuity of care or follow-up care requires attention for developing a cost-practical care framework to promote health and wellness for meeting survivors' needs.

The data obtained in this study provided insight into the experiences of ethnocultural breast cancer survivors who expressed being informed and aware of the side effects of cancer-related treatment, with patient role expectations being significantly associated with the schooling level. These findings can be explained by the diverse cultural and language differences that exist among ethnocultural breast cancer survivors. Women reported difficulties managing the side effects of treatment and found it to be a distressing element of women's cancer experience,<sup>10</sup> which was also seen in South Asian women.<sup>13</sup> This perspective can aid in understanding how ethnocultural breast cancer survivors view the intent to be informed and being aware of the side effects of cancer-related treatment, with differing capacity to obtain information. Survivors who reported receiving information tended to ask questions, have conversations, and express concerns compared to those who could not assert their decision-making preferences with their family physicians, specialists, or oncologists. This shows that survivors should receive information about continuity of care and transition to self-care after treatment is completed to help them understand the importance of cancer treatment distress and seeking health care.

Ethnocultural women stated that physicians provided valuable information about breast cancer treatment options and follow-up care to their cancer-related treatment distress until they were satisfied. But some ethnocultural breast cancer survivors who were partly engaged in shared decision-making, more passive and more accepting of how physicians responded to their concerns and had less than moderate satisfaction. Additionally, research found that women did not know what to expect at the end of treatment or the structure and content of follow-up care, thereby feeling unprepared for life after treatment.<sup>11</sup> Participants expressed inadequate follow-up appointments with physicians, questioning how well they knew their medical history. Appointments with an unknown need further deterred women from asking questions,<sup>11</sup> which led to distress, financial burden, and potential health consequences.<sup>16</sup>

Patient-physician communication and relationship was an essential expectation at the time of breast cancer treatment among ethnocultural

breast cancer survivors. Medical care and information sharing was necessary; physicians were expected to be knowledgeable about breast cancer and its prognosis and trustworthy in providing diligent care. Consistent with the literature, appointments were hurried and not long enough to discuss post-treatment concerns, leaving the women uncomfortable or unable to ask questions, thereby inducing practical and emotional concerns.<sup>11</sup> Latinas were most likely to report that no counsellors could speak their language or understand their cultural values.<sup>25</sup> Other studies have shown that interaction may be presented as a choice, but some Chinese cancer survivors were unable to make an informed decision.<sup>24</sup> Black women expressed a lack of contact with breast cancer nurses, less opportunity to talk, and a lack of post-treatment visits.<sup>11</sup> Ethnocultural women in rural areas reported ease in engaging with physicians compared to urban women, and hence, better emotional and physical well-being.<sup>8</sup> This can result in ethnocultural breast cancer survivors reporting a lack of knowledge about cancer support services and a lack of follow-up from health care practitioners regarding recognizing and managing cancer treatment distress, impacting the quality of life. The findings highlight the concerns and needs expressed by survivors for best practice recommendations and health promotion strategies to improve their quality of life.

Participants believed that their family and friends would not be able to offer much help.<sup>10</sup> There was a lack of available social support in a foreign country, with other family members still living in their home countries.<sup>16,26</sup> Furthermore, the findings of this study showed that less psychosocial support to cope with the cancer continuum was significantly associated with age, school, family history of breast cancer, and symptom distress. Family and friends played a significant role in providing participants with emotional support, reassurance, information, and practical assistance.<sup>10</sup> The family and community also provided transportation and acted as interpreters when there were language barriers.<sup>13</sup> Family support was associated with better understanding and coping by reducing symptom distress and cancer treatment related distress. This study had some limitations. First, there is a need to include larger heterogeneous samples from different sites in the interior region, which will allow for appropriate statistical comparison between ethnocultural breast cancer survivors. The inclusion of non-English speaking ethnocultural groups to look at experiences and language translations, assessment of the objective measures' and psychometric properties. Second, the surveys were conducted in English and the

**Table 5**  
Association between Total Satisfaction Score and Clinical characteristics N = 100.

Social determinants	Dimensions of experiences and perspectives of well-being and satisfaction	Feeling Uninformed 0	Satisfied with Care 1	Pearson Chi-Square, Value	Chi-Square Tests, df	Asymptotic Significance (2-sided) p-value
Extended health care benefits	Consultation and advice availed from health care practitioners for cancer treatment-related distress	22	78	.023 <sup>a</sup>	1	.879
	Informed and aware of side effects of treatment and patient role expectations	46	54	.214 <sup>a</sup>	1	.644
	Informed about cancer supportive services and follow up from health care practitioners	52	48	.571 <sup>a</sup>	1	.450
	Building patient-physician communication, relationship and trust	42	58	3.336 <sup>a</sup>	1	.050
	Language translation through family interpreters	51	49	.127 <sup>a</sup>	1	.721
	Access and use of cancer supportive services, health and wellness resources	62	38	9.942 <sup>a</sup>	1	.002
	Ease to navigate cancer care services and community health and wellness resources	59	41	5.801 <sup>a</sup>	1	.016
	Availability and use of complementary and alternative care approaches	47	53	.371 <sup>a</sup>	1	.542
	Use of patient voice for advocacy in cancer care	75	25	.718 <sup>a</sup>	1	.397
	Knowledge and awareness about breast cancer diagnosis, treatment, survivorship and palliatives care	36	64	7.814 <sup>a</sup>	1	.005
	Use of psychosocial health and wellness services	38	62	5.241 <sup>a</sup>	1	.022
	Use of peer support groups and peer mentors	38	62	.987 <sup>a</sup>	1	.320
	Psychosocial support to cope with diagnosis, treatment, survivorship	53	47	.053 <sup>a</sup>	1	.817
	Access to survivorship to cope and self-manage after completion of treatment	51	49	1.429 <sup>a</sup>	1	.232
	Family history of breast cancer	Consultation and advice availed from health care practitioners for cancer treatment-related distress	22	78	2.768 <sup>a</sup>	1
Informed and aware of side effects of treatment and patient role expectations		46	54	.510 <sup>a</sup>	1	.475
Informed about cancer supportive services and follow up from health care practitioners		52	48	.220 <sup>a</sup>	1	.639
Building patient-physician communication, relationship and trust		42	58	3.923 <sup>a</sup>	1	.048
Language translation through family interpreters		51	49	.636 <sup>a</sup>	1	.425
Access and use of cancer supportive services, health and wellness resources		62	38	4.838 <sup>a</sup>	1	.028
Ease to navigate cancer care services and community health and wellness resources		59	41	.001 <sup>a</sup>	1	.974
Availability and use of complementary and alternative care approaches		47	53	1.474 <sup>a</sup>	1	.225
Use of patient voice for advocacy in cancer care		75	25	.829 <sup>a</sup>	1	.363
Knowledge and awareness about breast cancer diagnosis, treatment, survivorship and palliatives care		36	64	.651 <sup>a</sup>	1	.420
Use of psychosocial health and wellness services		38	62	3.012 <sup>a</sup>	1	.050
Use of peer support groups and peer mentors		38	62	1.617 <sup>a</sup>	1	.204
Psychosocial support to cope with diagnosis, treatment, survivorship		53	47	2.773 <sup>a</sup>	1	.050
Access to survivorship to cope and self-manage after completion of treatment		51	49	.120 <sup>a</sup>	1	.729
First breast cancer diagnosis		Consultation and advice availed from health care practitioners for cancer treatment-related distress	22	78	8.189 <sup>a</sup>	3
	Informed and aware of side effects of treatment and patient role expectations	46	54	3.065 <sup>a</sup>	3	.382
	Informed about cancer supportive services and follow up from health care practitioners	52	48	7.221 <sup>a</sup>	3	.050
	Building patient-physician communication, relationship and trust	42	58	7.946 <sup>a</sup>	3	.047
	Language translation through family interpreters	51	49	3.750 <sup>a</sup>	3	.290
	Access and use of cancer supportive services, health and wellness resources	62	38	6.218 <sup>a</sup>	3	.101
	Ease to navigate cancer care services and community health and wellness resources	59	41	1.328 <sup>a</sup>	3	.723
	Availability and use of complementary and alternative care approaches	47	53	7.539 <sup>a</sup>	3	.050
	Use of patient voice for advocacy in cancer care	75	25	6.200 <sup>a</sup>	3	.102
	Knowledge and awareness about breast cancer diagnosis, treatment, survivorship and palliatives care	36	64	1.587 <sup>a</sup>	3	.662
	Use of psychosocial health and wellness services	38	62	13.427 <sup>a</sup>	3	.004
	Use of peer support groups and peer mentors	38	62	3.718 <sup>a</sup>	3	.294
		53	47	7.769 <sup>a</sup>	3	.050

(continued on next page)

Table 5 (continued)

Social determinants	Dimensions of experiences and perspectives of well-being and satisfaction	Feeling Uninformed 0	Satisfied with Care 1	Pearson Chi-Square, Value	Chi-Square Tests, df	Asymptotic Significance (2-sided) p-value
Symptom distress	Psychosocial support to cope with diagnosis, treatment, survivorship					
	Access to survivorship to cope and self-manage after completion of treatment	51	49	5.652 <sup>a</sup>	3	.130
	Consultation and advice availed from health care practitioners for cancer treatment-related distress	22	78	6.480 <sup>a</sup>	3	.050
	Informed and aware of side effects of treatment and patient role expectations	46	54	3.605 <sup>a</sup>	3	.307
	Informed about cancer supportive services and follow up from health care practitioners	52	48	5.977 <sup>a</sup>	3	.113
	Building patient-physician communication, relationship and trust	42	58	5.993 <sup>a</sup>	3	.112
	Language translation through family interpreters	51	49	3.962 <sup>a</sup>	3	.266
	Access and use of cancer supportive services, health and wellness resources	62	38	15.548 <sup>a</sup>	3	.001
	Ease to navigate cancer care services and community health and wellness resources	59	41	1.625 <sup>a</sup>	3	.654
	Availability and use of complementary and alternative care approaches	47	53	2.564 <sup>a</sup>	3	.464
	Use of patient voice for advocacy in cancer care	75	25	3.179 <sup>a</sup>	3	.365
	Knowledge and awareness about breast cancer diagnosis, treatment, survivorship and palliative care	36	64	6.538 <sup>a</sup>	3	.050
	Use of psychosocial health and wellness services	38	62	6.680 <sup>a</sup>	3	.050
	Use of peer support groups and peer mentors	38	62	.819 <sup>a</sup>	3	.845
	Psychosocial support to cope with diagnosis, treatment, survivorship	53	47	6.538 <sup>a</sup>	3	.050
Access to survivorship to cope and self-manage after completion of treatment	51	49	4.908 <sup>a</sup>	3	.179	

samples were not representative of Indigenous, Inuit and Metis people. Third, cause and effect relationships, recall bias and mental fatigue were not explored in this study.

The study innovation highlight how participants of a younger age expressed receiving better consultation and advice from health care practitioners for cancer treatment-related distress; building patient-physician communication, relationship, and trust; using a family interpreter for language translation; using psychosocial health and wellness services; and receiving psychosocial support to cope with diagnosis, treatment, and survivorship. The findings suggest that undergraduate education enabled better awareness of the side effects of treatment and patient role expectations; more knowledge and awareness about breast cancer diagnosis, treatment, survivorship, and palliative care; and psychosocial support to cope with cancer care compared to older age groups. The data suggested that participants living with a spouse had better access to language translation through family interpreters; had knowledge and awareness about breast cancer diagnosis, treatment, survivorship, recurrence and palliation; used psychosocial health and wellness services; and had access to survivorship to cope after completion of treatment.

The novelty of the study will help to interpret social justice and equity policies for ethnocultural women seeking cancer supportive care that require navigation to cope with breast cancer treatment-related distress. The inability to attain appropriate social support through health services can cause psychosocial distress, increased sick days and negatively impact their quality of life. The findings regarding better access to psychosocial wellness among the ethnocultural breast cancer survivors may be influenced by younger age, higher education, living with a spouse, full-time employment, extended health benefits, family history of breast cancer, the first diagnosis of breast cancer, and symptom distress. This psychosocial perspective can affect the feeling of being informed and satisfaction with care that enhances patient-physician communication and decision-making choices. This study is a groundwork to understand how complexity of experiences in ethnocultural breast cancer survivors influence their navigation with cancer care services.

A deeper understanding the cancer-related experiences of ethnocultural breast cancer survivors lies in its importance of assimilating return to work, health benefits and extended insurance policies within the cancer care framework. The findings can be translated into practice through digital applications and care co-ordination to enhance patient-oriented outcomes, thus enabling an opportunity to produce data-driven measures. This research lays a foundation for future work to develop cancer supportive care interventions that reduce psychosocial distress, improve work productivity and increase longevity leading to better quality of life. This study raises awareness for academia, clinical and research coalition between health care providers, researchers, decision-makers, health planners and policymakers to streamline cancer navigation in the health care system.

#### Author contributions

Melba Sheila D'Souza (MSD), Ehsan Latif (EL), Ann McCarthy (AM) and Subrahmanya Nairy Karkada (SNK) made substantial contribution to conception and design, acquisition of data, analysis, and interpretation of data findings; been involved in drafting the manuscript, revising it critically for important intellectual content; giving final approval of the version to be published and agreed to be accountable for all aspects of the work related to accuracy and integrity of the work.

#### 7. Declaration of conflict of interest statement

The authors have no conflicts of interest to disclose. The views expressed in this study do not necessarily represent the views of the institutes and organizations.

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## Code of ethics

The study has been approved through University of British Columbia Research Information Systems and Research and Ethics Board of Thompson Rivers University, Interior Health and BC Cancer UBC H19-02099-A002/0305/2020.

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## Submission checklist

We have adhered to the journal standards, scope, and author guidelines. We have uploaded Cover letter, Abstract and key words, Text and References, Tables, and Title Page (Separate).

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