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Female Breast Cancer Survivor’s Perspective of Support Systems in Trinidad and Tobago

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INTRODUCTION

Breast cancer is the second leading cause of death among women globally. According to the World Health Organization (2023), breast cancer affects approximately 2.3 million people yearly, and about 685,000 die from breast cancer annually across 158 countries. Recent research indicated that breast cancer death in women accounts for about 4.4 million women, and nearly 1 million children are orphaned due to cancer (Guida et al., 2022). In the Caribbean region, breast cancer among women has the highest mortality rate in Trinidad and Tobago, followed by the Americas, Cuba, and Argentina (Umakanthan et al., 2021). The National Cancer Registry reported that between 2008 and 2018, there were 15,029 breast cancer deaths among women in Trinidad and Tobago (Gopaul, Singh, Williams, Ventour, & Thomas, 2023).

Moreover, the Word Health Organization/Pan American Health Organization, Trinidad and Tobago showed that 36.8% of the breast cancer cases belonged to the African ethnicity, 27.5% Asian Indian, and 32.4% belonged to the mixed ethnicity (Naraynsingh et al., 2010; Parkinson, Cooper, & Alleyne-Mike, 2020). In general, a considerable amount of literature has been published on female breast cancer and highlighted that limited knowledge regarding the signs and symptoms of breast cancer, limited access to mammograms, or high healthcare costs may contribute to the growing prevalence. Other contributing factors are genetics, low socioeconomic status, and lifestyle changes such as dietary behaviors, irregular menstrual patterns, and delayed childbearing (A. Gupta, Shridhar, & Dhillon, 2015; Samaroo, Hosein, Olivier, Ali, & Olivier, 2021).

The diagnosis of breast cancer and its treatments is known to harm physical, social, and psychological health. These impacts sometimes go beyond the initial treatment stage to the recovery period. Some evidence suggests breast cancer negatively affects patients' quality of life due to adverse physical symptoms and psychological distress and often results in economic burdens (Samaroo, Hosein, Olivier, Ali, & Olivier, 2021. Other studies have reported that cancer is associated with pain, suffering, grief, and anger (Losito, 2006). Females diagnosed with breast cancer often experience loneliness, depression, anxiety, and fear of the future, especially those without a significant partner. Previous studies documented that some females are often concerned with their physical appearance and disfigurement of body image (Chang et al., 2014; B. Gupta, Yaduvanshi, Trivedi, & Nischal, 2012).

The reality of cancer diagnosis can be challenging to the patients, caregivers, family members, and friends at all stages and finding a coping mechanism to deal with the issues can be daunting. For example, chemotherapy is one of the treatments used to help most breast cancer patients, which can negatively affect patients by decreasing quality of life due to psychological distress and the uncertainty of treatment outcomes (Seidman et al. 1995). In addition, the estimated cost per treatment varies across the cancer stages. According to a comparison study on cancer treatment and types of services, chemotherapy has the highest percentage of claims, with an average costs per patient allowed by the insurance company in the year after diagnosis were $60,637, $82,121, $129,387, and $134,682 for disease stage 0, I/II, III, and IV, respectively (Blumen, Fitch, & Polkus, 2016). These adverse effects often leave friends and family searching for alternative medicine. A longitudinal study has documented that many patients began to use alternative medicine in the wake of breast cancer diagnosis and find that it could worsen quality of life (Burstein, Gelber, Guadagnoli, & Weeks, 1999).

Despite the many negative challenges around cancer care, support groups are noted to have some positive impact on cancer survivors. Previous intervention studies have reported that support groups provide a safe setting to discuss thoughts about handling various issues related to breast cancer, bringing individuals from different backgrounds together to talk about their experiences and improve the patient's quality of life through compassionate care (Montali, Zulato, Frigerio, Frangi, & Camussi, 2022; Shao et al., 2021).

In addition, research suggested that support groups assist with the maximization of treatment from healthcare providers by helping patients, relatives, and caregivers to complete the proper care (Covington, Hidde, Pergolotti, & Leach, 2019). Support groups can help people regain control over their lives, reduce the sense of isolation, and provide a safe and confidential environment to communicate effectively about similar situations and emotions (Montali et al., 2022). Other studies documented that support groups provide coping strategies to maintain their cancer treatments and commence the recovery process (Antoni & Dhabhar, 2019; Niedzwiedz, Knifton, Robb, Katikireddi, & Smith, 2019). Therefore, this study aims to examine female breast cancer survivors' perspective of support systems and care in Trinidad and Tobago.

The study embarks on a crucial exploration into the lived experiences of female breast cancer survivors amidst the complex landscape of survivorship. Understanding the challenges faced by these women is pivotal to shedding light on their viewpoints regarding support structures and the healthcare system. The study uniquely conducted in Trinidad and Tobago and adds some cultural context to the inquiry as well as identify potential gaps and a platform to enhance the well-being and quality of life for these resilient survivors.

METHODS

Study Setting and Design

This cross-sectional study seeks to understand female breast cancer survivors' perspectives on support systems and their impact on quality of life. The participants were recruited from the Trinidad and Tobago Cancer Society, SMARA Cancer Support Group, and the Embracing All Real Survivors (EARS) clinics in Trinidad and Tobago. These facilities provide support services such as counseling, nutrition education, and support groups for males and females diagnosed with cancer. However, this study focuses on females who were diagnosed with breast cancer. Eligibility criteria for this study include being a female adult aged 18 years or older, a resident of Trinidad and Tobago diagnosed with breast cancer and attending any support group session. Individuals who were very ill, not diagnosed with cancer, could not speak English, and experiencing mental challenges were excluded from the study.

The researchers for this study contacted the medical directors and head nurses at both facilities and provided brief information about the study's potential and patient eligibility. If the survivors agreed to participate, the researcher would then be contacted to schedule an appointment to explain the study's purpose and procedures in detail. During the scheduled session, participants who agreed to participate, the research team explained the study's purpose, obtained consent forms, and assured confidentiality. Eligible participants received a questionnaire to be completed in a semi-private location, which took approximately 10-15 minutes. All surveys were returned in a sealed envelope.

Instrument Development

The self-administered questionnaire was adapted from previously validated questionnaires. For this study, the researcher re-validated some of the questions by administering them to 10 survivors who have used support groups and feedback was obtained from experts. The aim of the pilot was to ensure the instrument was capturing information pertinent to the survivor. In addition, to ensure reliability experts reviewed the questionnaire to confirm appropriateness of the question for the study. The final instrument was comprised of a 14-item questionnaire organized into three sections. Section 1 contained six (6) sociodemographic characteristics questions, section II contained eight (8) closed and nine (9) open-ended questions that aim to evaluate the service and benefits of support groups offered to breast cancer survivors. The final section has seven (7) questions that explore the quality of life for breast cancer survivors.

Data Analysis

All responses recorded were coded and entered with IBM Statistical Package for Social Sciences (SPSS) Software Version 17. The demographic characteristics of the respondents were presented in descriptive analysis. Fisher's exact test was carried out to determine associations between the reasons for joining a support group and changes experienced in the individuals' lives after joining a support group.

RESULTS

A total of 74 survivors completed the questionnaires (Table 1). Most participants were between 46-65 years old (n = 52; 70.2%). Regarding race, the sample consisted of Indian 32 (43.2%), African 16 (21.6), mixed race 22 (29.7), and 4 (5.4%) indicated their ethnicity as other. Almost 35% of the respondents had Kindergarten or primary education, 39.2% had secondary levels, and 12.2% had Trade and/or Technical Vocational Skills Training. Only 5.4% of them have a Tertiary School education, and 8.1% did not specify their education level. Thirty-two of the subjects were married, 23 were widowed, 16 were divorced, two were separated, and one was single. Their income ranges from low (less than $5000.00) to high ($10 001 or more).

Table 1: Socio-Demographic Characteristics of Participants (n=74)

Variable	n	%
Age		
18-45	2	2.7
46-65	52	70.2
66-75	20	27.0
Ethnicity		
Indian	32	43.2
African	16	21.6
Mixed	22	29.7
Other	4	5.4
Marital Status		
Single	1	1.4
Married	32	43.2
Divorced	16	21.6
Widowed	23	31.1
Separated	2	2.7
Education		
Kindergarten to Primary School	26	35.1
Secondary School up to O’ Levels (Form 5 CSEC)	21	28.4

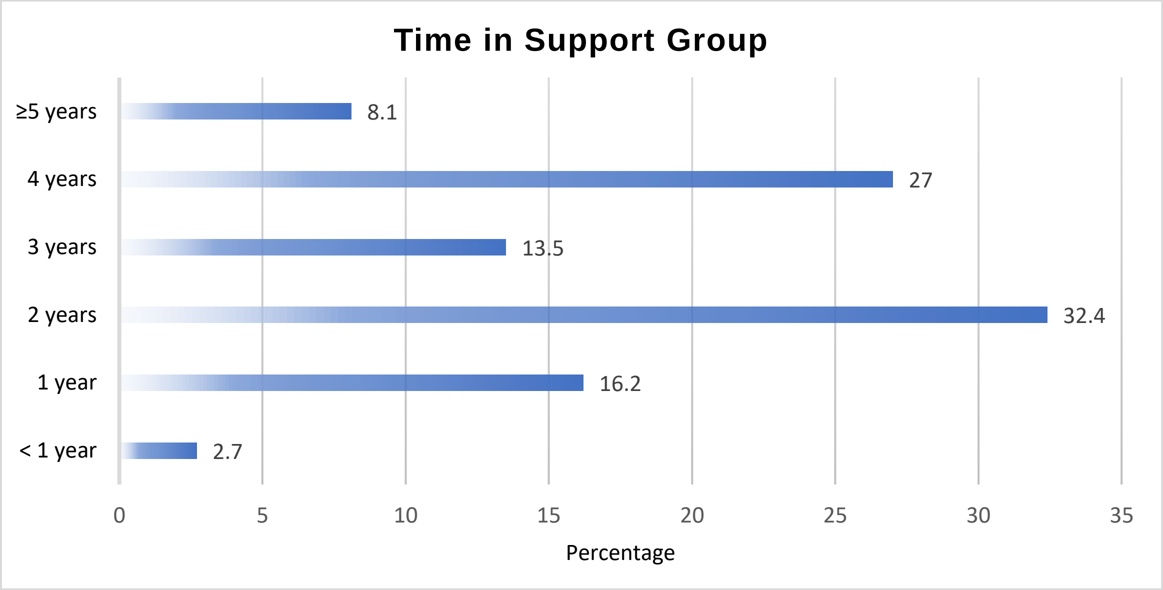
Secondary School up to A’ Levels (Form 6 CAPE)	8	10.8
Tertiary School	4	5.4
Trade/Technical skills/ Skills Training	9	12.2
None	6	8.1
Income		
High income ($10,001 or more)	7	9.5
Middle income ($ 5,001 ≤ $10,000)	38	51.4
Low income (≤ $5,000)	29	39.2
Religion		
Christian (Catholic, Pentecostal, Presbyterian, Anglican, Seventh-day Adventist, Jehovah Witnesses)	43	58.1
Hindu	19	25.7
Muslim	5	6.8
Baptist/ Shouter Baptist/ Orisha	7	9.5

Support Systems

A Cancer Support System refers to a network of resources, services, and people that offer emotional, practical, and informational assistance to individuals affected by cancer (Carlson & Bultz, 2004). Studies show that a cancer diagnosis can be overwhelming, not only for the patient but also for their family and friends (Erfani, Blount, & Abedin, 2016; Given, Given, & Kozachik, 2001). Other intervention research indicated that a well-structured support system could play a crucial role in helping them cope with cancer challenges.

All (n=74) participants indicated they were part of a support group at the facility or other places. Approximately eight percent (8%) of the participants stated that they had been in the group for over five years (Figure 1), 20 (27%) for four years, 10 (13.5%) for three years, 24 (32.4%) have been present for two years, 12 (16.2%) were members for one year, and two (2.7%) under one year. Most participants indicated they joined the support group to obtain advice and information about cancer and health education regarding diet for cancer, exercise group services, and funding for their treatments.

Table 2: Participants' time participating in a support group.



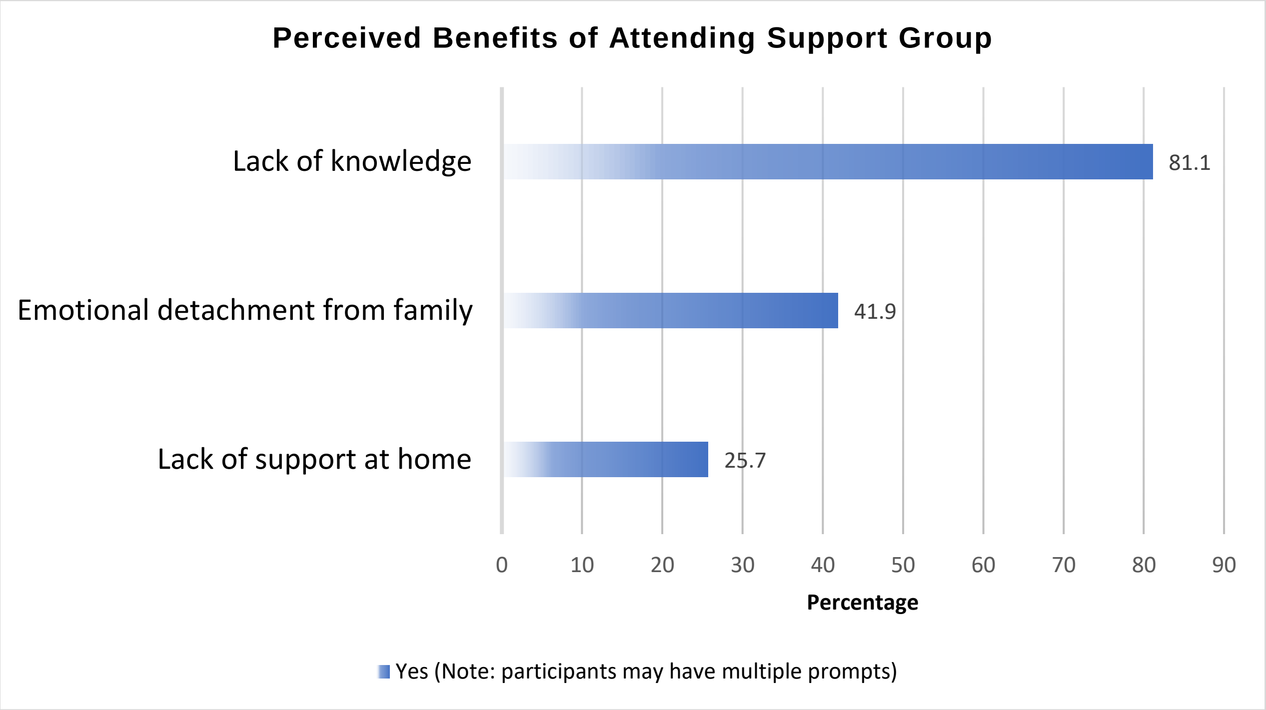
Factors Promoting Frequent Visits to the Support Group

Table 3 highlights some primary reasons cancer survivors attended and maintained the support group services. Prior to joining the group, the participants felt an emotional detachment from family members (n = 31, 41.9%); they had no knowledge of how to care for themselves and sometimes a lack of support at home (n = 19, 25.7%).

After joining the support group, all the participants believed that their overall health and lifestyle, spirituality, and emotional and psychological well-being improved. Sixty-seven (90.5%) of them believed the support group helped improve the financial aspect of their lives. The individuals who saw an improvement in the financial aspect of their lives received sponsorship with testing and treatments. Therefore, some of them sixty-seven (90.5%) perceived to have reduced anxiety and stress.

The survivors explained that their spirituality has improved tremendously. Sixty-four (86.5%) of the survivors believed their relationship with God improved, five (6.8%) stated they prayed more frequently, and ten (13.6%) indicated they were introduced to yoga and meditation for the first time in their lives. The survivors perceived that meditating (n = 59, 79.8%), yoga (n = 50, 67.6%), counseling by a psychologist (n = 42, 56.8%), and talking to other breast cancer survivors (n = 41, 55.6%) were useful coping strategies. Fifty-one (69.2%) of them learned the benefits of a balanced diet, and forty-five (62.5%) became aware of which foods to avoid. Most participants felt they incorporated more fruits and vegetables into their daily meals.

Table 3: Breast Cancer Survivors Perceived Benefits of Attending Support Group



Perceived benefits of Support Group

The majority, n = 70 (94.6%) of survivors believed the support group was beneficial in educating them about the essential skills needed to prevent relapsing or change from the prescribed treatment. Ninety percent (n = 67) of them felt they were in full control of their own situations and lives. Approximately ninety-seven percent (n = 72) of them experienced feeling extreme happiness, ninety-eight (n = 73) felt useful in life, and eight six percent (n = 64) indicated seeing excellent improvement in their overall quality of life after joining the support group.

In addition, the participants believed that the support group was very helpful in providing information on foods to consume and avoid, healthy eating tips, the benefits of exercise, stages of cancer treatments, ways to cope with depression, and what treatment options were available.

Table 3. Assessment of situations after joining a support group

	Scale				
	None (%)	Minor (%)	Neutral (%)	Somewhat (%)	Extreme (%)
Feel in control of situations	-	1 (1.4)	-	6 (8.1)	67 (90.5)
Feel a sense of happiness	-	-	-	2 (2.7)	72 (97.3)
Feel useful	-	-	-	1 (1.4)	73 (98.6)
Overall quality of life	-	-	-	10 (13.5)	64 (86.5)
Experience stress and anxiety	71 (95.9)	3 (4.1)	-	-	-
Importance of participation in religious activities	-	-	-	-	74 (100)
Importance of spiritual activities	-	-	-	-	74 (100)
Educated on foods to consume and avoid	-	-	-	-	74 (100)
Educated on the importance of healthy eating	-	-	-	-	74 (100)
Educated on the benefits of exercise	-	-	-	-	74 (100)
Educated on avoiding relapse	-	-	4 (5.4)	-	70 (94.6)
Educated on stages of treatment	-	-	-	-	74 (100)
Coping with Depression	-	-	-	-	74 (100)
Educated on treatments available	-	-	-	-	74 (100)

DISCUSSIONS

This study examined female breast cancer survivors' perceptions of their support systems and overall life quality. Our findings reveal that support groups positively impact the quality of life for breast cancer survivors in Trinidad and Tobago. The three primary factors influencing initial participation in the support groups were feeling emotionally detached from family, having no family support, cancer education opportunities, and spiritual well-being.

A cancer diagnosis is a significant life event that can trigger many emotions, including fear, sadness, anger, and uncertainty (Zamanian et al., 2021). Our study shows that cancer survivors in the support group were less likely to experience stress and anxiety. This was due to the services offered, such as financial support and the opportunity to express their feelings openly with other peers experiencing similar symptoms. The findings are similar to previous studies showing that cancer support groups provide different ways to control emotions, enhance problem-solving skills and coping strategies, and help comply with the disease and treatment process (Zamanian et al., 2021). Thus, support groups can be a helpful resource for breast cancer survivors to overcome loneliness.

More than seventy percent of the survivors noted that their spiritual health increased (improved) after attending the services provided by the centers. Spirituality is considered a fundamental dimension of an individual's health and well-being (Caldeira, Timmins, de Carvalho, & Vieira, 2017). The current literature has indicated that intervention strategies incorporating spirituality into healthcare uniquely address the broader perspective of cancer care and promote long life (Weathers, McCarthy, & Coffey, 2016).

The services provided at the support center identified as the most influential in controlling negative life challenges were financial support offered, nutrition, and exercise education. Based on this study's sampled population, thirty-eight of them only make between $ 5,000 and $10,000 annually. This is less than the average cost of cancer treatment. After completing the prescribed sets of treatment and care, if there is no family support or financial stability, this can be detrimental for the survivors.

Some common lifestyle modifications documented in the literature to help improve cancer survivors' health and well-being were eating a healthy diet and increased physical activity (Chlebowski, 2013; Losito, 2006; Paladino et al., 2019). Epidemiological studies have shown that some foods are considered to be risk factors for promoting cancer cells, and increasing fruits and vegetables are essential to reduce chronic inflammation and oxidative stress markers (De Cicco et al., 2019).

The strengths and limitations of this study are worth noting. This cross-sectional study focuses on breast cancer survivors in Trinidad and Tobago support system. Also, these findings can inform future studies in other countries about effective strategies to promote and improve breast cancer survival rates. The limitations are that the data was self-reported, and the information may contain some biases.

There are a few implications that can be concluded from our study. First, the findings have important implications for developing interventions focusing on cultural relevance and addressing challenges that can significantly improve survivorship experiences. For example, survivor-centered care and policy decision-makers can improve access to specialized services and increase awareness that can positively impact the individual and family. Also, it is critical to engage survivors and their entire communities in awareness campaigns and support initiatives to create a supportive network, reducing trauma and providing essential resources.

In summary**,** the results from this study show that there is a need to provide female breast cancer survivors with support group services to increase their quality of life through education on spirituality, religion, food choices, and healthy eating. Future studies may need to focus on continuous education on essential coping skills after a breast cancer diagnosis. Recognizing survivors' needs and experiences, healthcare providers can foster a more compassionate and supportive environment. The provision of support groups reduces stress and anxiety by creating a safe environment to maintain a healthier quality of life and coping behavior and improve survival rate. When monitoring breast cancer patients, the treatment regime should contain education on healthy eating and lifestyle practices, ways to prevent relapse, and applicable skills to reduce psychological and emotional changes.

REFERENCES

Antoni, M. H., & Dhabhar, F. S. (2019). The impact of psychosocial stress and stress management on immune responses in patients with cancer. *Cancer, 125*(9), 1417-1431.

Blumen, H., Fitch, K., & Polkus, V. (2016). Comparison of treatment costs for breast cancer, by tumor stage and type of service. *American health & drug benefits, 9*(1), 23.

Burstein, H. J., Gelber, S., Guadagnoli, E., & Weeks, J. C. (1999). Use of alternative medicine by women with early-stage breast cancer. *New England Journal of Medicine, 340*(22), 1733-1739.

Caldeira, S., Timmins, F., de Carvalho, E. C., & Vieira, M. (2017). Spiritual well-being and spiritual distress in cancer patients undergoing chemotherapy: utilizing the SWBQ as component of holistic nursing diagnosis. *Journal of religion and health, 56*, 1489-1502.

Carlson, L. E., & Bultz, B. D. (2004). Efficacy and medical cost offset of psychosocial interventions in cancer care: making the case for economic analyses. *Psycho-Oncology: Journal of the Psychological, Social and Behavioral Dimensions of Cancer, 13*(12), 837-849.

Chang, O., Choi, E.-K., Kim, I.-R., Nam, S.-J., Lee, J. E., Lee, S. K., . . . Cho, J. (2014). Association between socioeconomic status and altered appearance distress, body image, and quality of life among breast cancer patients. *Asian Pacific Journal of Cancer Prevention, 15*(20), 8607-8612.

Chlebowski, R. T. (2013). Nutrition and physical activity influence on breast cancer incidence and outcome. *The Breast, 22*, S30-S37.

Covington, K. R., Hidde, M. C., Pergolotti, M., & Leach, H. J. (2019). Community-based exercise programs for cancer survivors: a scoping review of practice-based evidence. *Supportive care in cancer, 27*, 4435-4450.

De Cicco, P., Catani, M. V., Gasperi, V., Sibilano, M., Quaglietta, M., & Savini, I. (2019). Nutrition and breast cancer: a literature review on prevention, treatment and recurrence. *Nutrients, 11*(7), 1514.

Erfani, S. S., Blount, Y., & Abedin, B. (2016). The influence of health-specific social network site use on the psychological well-being of cancer-affected people. *Journal of the American Medical Informatics Association, 23*(3), 467-476.

Given, B. A., Given, C. W., & Kozachik, S. (2001). Family support in advanced cancer. *CA: a cancer journal for clinicians, 51*(4), 213-231.

Gopaul, C. D., Singh, A., Williams, A., Ventour, D., & Thomas, D. (2023). Cancer morbidity and mortality trends in Trinidad and Tobago (2008–2018). *Journal of Health, Population and Nutrition, 42*(1), 58.

Guida, F., Kidman, R., Ferlay, J., Schüz, J., Soerjomataram, I., Kithaka, B., . . . Parham, G. (2022). Global and regional estimates of orphans attributed to maternal cancer mortality in 2020. *Nature medicine, 28*(12), 2563-2572.

Gupta, A., Shridhar, K., & Dhillon, P. (2015). A review of breast cancer awareness among women in India: Cancer literate or awareness deficit? *European Journal of Cancer, 51*(14), 2058-2066.

Gupta, B., Yaduvanshi, R., Trivedi, J., & Nischal, A. (2012). A comparative study of body image and coping style in breast cancer patients. *Delhi Psychiatry Journal, 15*(1), 177-182.

Losito, J. M. (2006). The effects of group exercise on fatigue and quality of life during cancer treatment. *Number 4/July 2006, 33*(4), 821-825.

Montali, L., Zulato, E., Frigerio, A., Frangi, E., & Camussi, E. (2022). Mirroring, monitoring, modelling, belonging, and distancing: Psychosocial processes in an online support group of breast cancer patients. *Journal of Community Psychology, 50*(2), 992-1007.

Naraynsingh, V., Hariharan, S., Dan, D., Bhola, S., Bhola, S., & Nagee, K. (2010). Trends in breast cancer mortality in Trinidad and Tobago—a 35-year study. *Cancer epidemiology, 34*(1), 20-23.

Niedzwiedz, C. L., Knifton, L., Robb, K. A., Katikireddi, S. V., & Smith, D. J. (2019). Depression and anxiety among people living with and beyond cancer: a growing clinical and research priority. *BMC cancer, 19*(1), 1-8.

Paladino, A. J., Anderson, J. N., Graff, J. C., Krukowski, R. A., Blue, R., Jones, T. N., . . . Graetz, I. (2019). A qualitative exploration of race-based differences in social support needs of diverse women with breast cancer on adjuvant therapy. *Psycho‐Oncology, 28*(3), 570-576.

Parkinson, G., Cooper, A., & Alleyne-Mike, K. (2020). Investigation of triple negative breast cancer rates in women diagnosed with breast cancer in Trinidad and Tobago. In: American Society of Clinical Oncology.

Samaroo, K., Hosein, A., Olivier, L. K., Ali, J., & Olivier, L. (2021). Breast cancer in the Caribbean. *Cureus, 13*(8).

Shao, D., Zhang, H., Cui, N., Sun, J., Li, J., & Cao, F. (2021). The efficacy and mechanisms of a guided self-help intervention based on mindfulness in patients with breast cancer: A randomized controlled trial. *Cancer, 127*(9), 1377-1386.

Umakanthan, S., Bukelo, M., Chattu, V. K., Maharaj, R., Khan, N. N., Keane, K., . . . Kong, R. (2021). Breast cancer in Trinidad and Tobago: Etiopathogenesis, histopathology and receptor study. *Journal of Family Medicine and Primary Care, 10*(12), 4438.

Weathers, E., McCarthy, G., & Coffey, A. (2016). *Concept analysis of spirituality: An evolutionary approach.* Paper presented at the Nursing forum.

World Health Organization. (2023). *Global breast cancer initiative implementation framework: assessing, strengthening and scaling-up of services for the early detection and management of breast cancer*: World Health Organization.

Zamanian, H., Amini-Tehrani, M., Jalali, Z., Daryaafzoon, M., Ala, S., Tabrizian, S., & Foroozanfar, S. (2021). Perceived social support, coping strategies, anxiety and depression among women with breast cancer: Evaluation of a mediation model. *European Journal of Oncology Nursing, 50*, 101892.