RESEARCH ARTICLE

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Changes in Health- Related Quality of Life and Psychosocial Well-being of Breast Cancer Survivors: Findings from a Group- Based Intervention Program in Malaysia

Nisha Angela Dominic[1], Valliammai Jayanthi Thirunavuk Arasoo[1], Nevein Philip Botross[1], Amgad Riad[2], Cindy Biding[3], Amutha Ramadas[1]*

Abstract

Background: There is a lack of evidence on the effectiveness of multifaceted group-based interventions to improve psychological well-being and health-related quality of life (HRQOL) of breast cancer (BCa) survivors in Malaysia. This study is aimed at assessing the effectiveness of such intervention program among the BCa survivors. **Materials and Methods:** This was a group-based intervention program with pre- and post-test design, carried out among BCa survivors (n=37) who were members of Breast Cancer Support Group Centre, Johor Bahru. A validated self-administered questionnaire was used to assess the impact of the program on psychosocial well-being and HRQOL of the participants. **Results:** The mean age of BCa survivors was 58.1 years (SD=9.7), with mean age at diagnosis of 49.9 years (SD=9.6). Majority of them were of Chinese ethnicity, married and had secondary level education, but were unemployed. More than 86% of them were diagnosed to have early BCa diagnosis and have since completed the treatment. There were significant decreases in median depression ($p=0.001$), anxiety ($p<0.001$) and stress ($p<0.001$) scores at post-intervention. More than 85% of the participants rated themselves to have a good or very good QOL at post-intervention, as opposed to 75.9% at pre-intervention. Significant improvements in several HR-QOL domain scores were seen, with psychological score improving the most ($p<0.001$), followed by social relationship ($p=0.002$) and physical health ($p=0.004$). **Conclusions:** Group-based multifaceted intervention can be a viable solution to improve psychosocial well-being of BCa survivors.

Keywords: Breast cancer survivors- psychosocial- health-related quality of life- multi-faceted intervention

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Introduction

Breast cancer (BCa) is now the most common cancer in Malaysia, contributing to 32% of cancers among females and almost 18% of all cancers regardless of gender (Azizah et al., 2015). According to the Malaysian National Cancer Registry Report 2007-2011 (Azizah et al., 2015), the age-standardized incidence rate of BCa among all females was 31.1 per 100,000 and the incidence was higher among Chinese females (41.5 per 100,000). Globally, BCa was reported to be the second most common cancer accounting for 25% of all female cancers based on 2012 data (GLOBOCAN, 2013). Among females, the five most common were cancers of the breast (32.1%), colorectal (10.7%), cervix uteri (7.7%), ovary (6.1%) and lung (5.6%).

The American College of Obstetricians and Gynaecologists recommends a baseline vaginal ultrasound, sonohysterography or hysteroscopy to exclude pre-existing endometrial polyps (American College of Obstetricians and Gynaecologists, 2014). The risk of uterine disease should be explained and the necessities of prompt reporting of vaginal spotting or bleeding whilst on Tamoxifen, a Selective Oestrogen Receptor Modulator (SERMs) widely used for pre and post-menopausal BCa patients with ER positive status (Gallo et al., 1997). Cervical cancer screening via Pap Smear is also suggested as it is inexpensive and easy to perform, though the coverage is suboptimal due to lack of awareness of its' benefits by the public (Nor Hayati, 2003).

Quality of life (QOL) is a general multidimensional concept that usually includes subjective evaluations of both positive and negative aspects of life (WHOQOL Group). According to the Centre for Disease Control and Prevention (CDC) the idea of health-related quality of life (HRQOL) has developed to include those aspects of overall QOL that obviously can affect health, either physically or mentally. HRQOL is usually addressed in two levels, individual as

*[1]Jeffrey Cheah School of Medicine and Health Sciences, Monash University Malaysia, Bandar Sunway, [2]Newcastle University Medicine Malaysia, Kota Ilmu, Nusajaya, Malaysia, [3]The Colombo Plan Drug Advisory Programme, Colombo, Sri Lanka. *For Correspondence: amutha.ramadas@monash.edu*

well as community level (Elme et al., 2013). BCa affects various aspects of the patients QOL including the physical health and psychological aspects.

The HRQOL in BCa patients can be influenced by various factors. For instance, obesity and a sedentary lifestyle are correlated to poor physical performance, increased risk of cardiovascular diseases (CVD) and impaired HRQOL, which leads to a vicious circle, that impairs patients' physical health and HRQOL (Spector et al., 2012). Attending community-based wellness workshops can have an enhancing effect in HRQOL in cancer patients (Mohammadi et al., 2013).

Co-morbidity of BCa has a negative impact on HRQOL with CVD and depression being the strongest associates (Schoormans et al., 2015). In addition to its impact on HRQOL, CVD is the leading cause of late morbidity and death among cancer survivors, and the risk has been found to be greater than the risk of tumour recurrence (Weaver et al., 2013). Adverse effects of chemotherapy, radiation in addition to other risk factors such as overweight, hypertension, diabetes, dyslipidaemia and smoking enhance the CVD risk.

Various studies have demonstrated that anxiety and depression are important and prevalent problems (Schoormans et al., 2015; Fallowfield et al., 2001) that affect QOL in patients with cancer. Tailored interventions for survivors, targeting comorbidities and psychosocial factors are suggested to improve QOL of BCa survivors (Highland et al., 2015). Adding to that, psychological interventions have been shown to be effective in reducing emotional distress and improving QOL in cancer survivors (Osborn et al., 2006). Psychological interventions were regarded as an inexpensive way to reduce psychological distress (Gordon et al., 2011) and possibly to improve immune system functioning and prolong survival in cancer patients (Anderson et al., 2008).

A cross-sectional study among BCa survivors in Iran showed low uptake of physical activity despite it being shown to be beneficial in terms of emotional and cognitive functions (Mohammadi et al., 2013). While studies have reported BCa survivors to make some level of positive changes to their diet after treatment (Pierce et al., 1997; Newman et al., 2005), there is a possibility for them to revert to unhealthy dietary habits after some years. This emphasize the need for a continuous reinforcement of dietary and lifestyle changes among BCa survivors after a certain period of time.

Data on HRQOL among BCa survivors and risk factors associated with it was collected in the Phase 1 (Ramadas et al., 2015). In brief, 15% of the participants had poor self-rating of QOL, and 25% of them were dissatisfied with their health. Occupational well-being, income, living arrangement and various health behaviours were identified to be predictive factors of the survivors' HRQOL. Majority of the survivors were married, had secondary level education, earned an income between RM1,801 and RM4,500, and were living with family. More than 80% of them were diagnosed at early stage of BCa and 58% were diagnosed less than 5 years ago, indicating they may lack information about BCa and its management. In addition to the quantitative assessment, a pilot half-day workshop was conducted to explore the needs of the BCa survivors. The workshop received encouraging feedback from the attendees, and 100% of them agreed/strongly agreed that the workshop met its objective and was applicable to them. The content of the workshop as then expanded and covered in Phase 2 of the project in which we implemented an intervention program.

Apart from a group psycho-education done in 2013 (Ram et al., 2013), no recent study has explored effectiveness of a multifaceted group intervention to improve psychological well-being and HRQOL of BCa patients and survivors in Malaysia. Therefore, this study is aimed at assessing the effectiveness of an intervention program that includes the medical, gynaecological, nutritional and psychological well-being of BCa survivors.

Materials and Methods

Study design

This was a group-based intervention program carried out among BCa survivors with pre- and post-test design. This study was conducted as a follow-up to the needs assessment that was carried out in the same population (Ramadas et al., 2015). The recruitment, intervention and assessments were conducted at Breast Cancer Support Group Johor Bahru (BCSGJB), Malaysia. The ethical approval to conduct the study was obtained from Monash University Human Ethics Committee (CF14/814-2014000330).

Study participants

The survivors from BCSGJB were invited to participate in the study after obtaining written consent. No selection restriction was imposed with regards to ethnicity, histology of BCa, disease stage, and demographic characteristics. All the participants were assured of confidentiality. Forty-two women were recruited and participated in the intervention. However, 5 women dropped out at post-intervention, leaving 37 study participants (n=37) with valid data to be included in the study.

Intervention

A full-day intervention program was carried out for all participants (Table 1). The intervention program was conducted in small groups (10-12 survivors) by a team of health professionals which comprises of gynaecologists, physicians, nutritionist and counsellor.

Measures

Once written consent has been given, the participants were asked to complete a self-administered structured questionnaire. Socio-demographic data collected included age, marital status, education level, house-hold income, employment status, type of accommodation and number of children, and medical characteristics consisting of age of onset, disease stage and completion of treatment were also obtained. We assessed the HR-QOL using the validated WHOQOL-BREF (The WHOQOL Group) with items on overall QOL and satisfaction with health,

experience during past 4 weeks, ability to look after oneself and manage challenges, along with negative feelings the women may have experienced. Depression Anxiety Stress Scales (DASS-21) (Lovibond and Lovibond, 1995) was used to assess the psychosocial well-being of the survivors. DASS-21 is a self-report instrument designed to measure the three related negative emotional states of depression, anxiety and stress.

The questionnaire took approximately 20 minutes to be completed. The same questionnaire was administered at 4-weeks post-intervention.

Statistical analysis

Descriptive statistics was used to describe the data. Normality of the continuous data was determined using Kolmogorov–Smirnov test. The difference in median DASS-21 scores were determined using Wilcoxon Signed Rank test, while changes in mean HR-QOL scores were determined with paired t-test. The statistical analysis was performed with IBM® SPSS® Statistics 23.0, and statistical significance was set at $p<0.05$.

Results

Of 37 BCa survivors who completed the study, majority were aged more than 60 years (54.1%) with an average age of 58.1 years (Table 2). More than 70% of them were Chinese, married and had secondary level education. Almost 50% were unemployed and this was reflected in the lower personal and household income. More than 80% of the participants stayed with their family. The average age of BCa onset was 49.9 years. More than

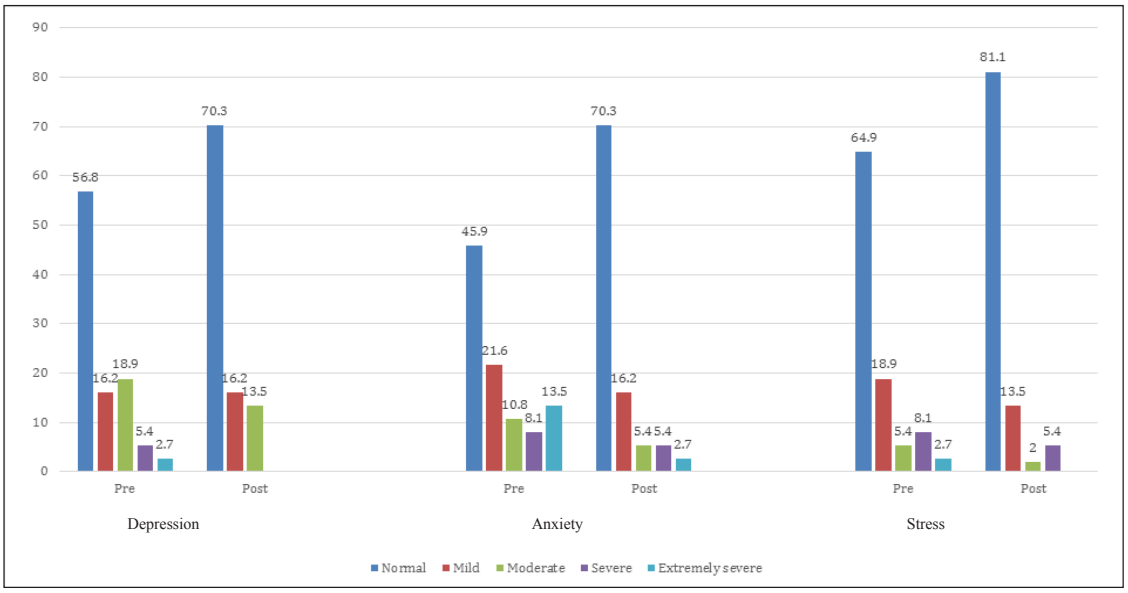

Figure 1. Changes in Prevalence of Depression, Anxiety and Stres

Table 1. Intervention Sessions

Session	Intervention content
Women's health education and screening	• Education on gynae-related issues arise from BCa treatment • Screening for cervical cancer (Pap smear) • Ultrasound of pelvis (for common gynaecological pathologies eg fibroids, ovarian tumours and measurement of endometrial thickness).
Cardiovascular risk assessment	•Assessment of survivors' risk of developing cardiovascular disease using Framingham General Cardiovascular Risk Score (D'Agostino et al., 2008). • ECG was performed. • High risk individuals (score >20%) were referred to government clinic to start preventive medical treatment, in addition to cardiovascular health related materials that were given out to all survivors.
Psychosocial well-being	• Psycho-education o Knowledge sharing on managing stress and coping with fear and anxiety. Activities included sharing of experiences on coping and managing stress with positive comments and recommendations from therapist. • Supportive Expressive Therapy o Exploration of experiences of pain, fear, anxiety, depression and sexual or intimate relationship. Survivors were helped and supported to face their experiences by therapist. • Relaxation techniques o This was a simple deep breathing and progressive muscle exercises.
Diet and lifestyle	• Macro-nutrient vs micronutrients • Food preparation (cooking techniques and eating out) • Supplements and complementary / traditional medicine • Exercise (do's and don'ts)

Table 2. Demographic and Clinical Characteristics of Study Participants

		N=37
Age (years)	Mean (SD)	58.1 (9.7)
	<50	9 (24.3)
	50 – 59	8 (21.6)
	>60	20 (54.1)
Ethnicity	Malay	5 (13.5)
	Chinese	27 (73.0)
	Indian	4 (10.8)
	Others	1 (2.7)
Marital status	Single	4 (10.8)
	Married	26 (70.3)
	Divorced or widowed	7 (18.9)
Highest education level	No education	1 (2.7)
	Primary	6 (16.2)
	Secondary	27 (73.0)
	Tertiary	3 (8.1)
Occupation	Unemployed	18 (48.6)
	Employed	7 (18.9)
	Retired	12 (32.4)
Personal income (MYR)	No income	18 (48.6)
	<1,000	6 (16.2)
	1,001 – 3,000	7 (18.9)
	3,001 – 5,000	3 (8.1)
	>5,000	3 (8.1)
Household income (MYR)	<1,000	12 (32.4)
	1,001 – 3,000	11 (29.7)
	3,001 – 5,000	10 (27.0)
	>5,000	4 (10.8)
Living arrangement	Alone	6 (16.2)
	With family	31 (83.8)
Age of BCa onset	Mean (SD)	49.9 (9.6)
BCa stage	Early	32 (86.5)
	Late	5 (13.5)
Completion of BCa treatment	Yes	32 (86.5)
	No	5 (13.5)

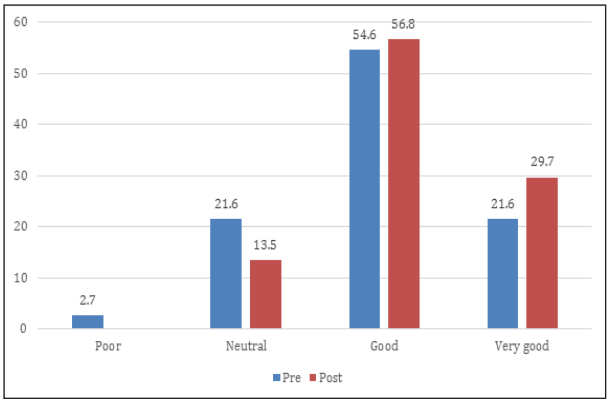

Figure 2. Changes in Self-rated QOL

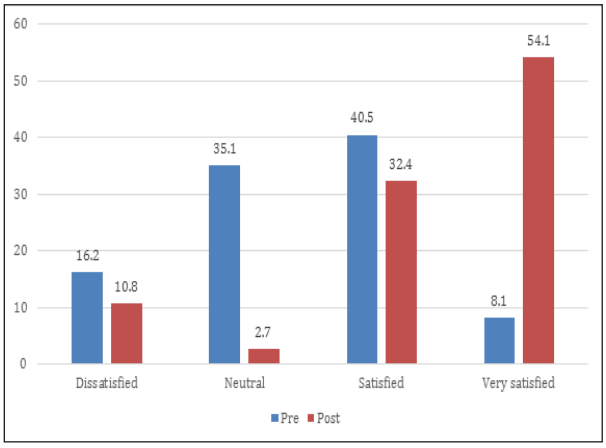

Figure 3. Changes in Satisfaction with Health

86% of them were diagnosed to have early BCa diagnosis and have since completed the treatment.

There were significant decreases in median depression, anxiety and stress scores between pre- and post-intervention (Table 3). The changes in prevalence of depression, anxiety and stress are presented in Figure 1. None of the survivors had severe or extremely severe depression or stress at post-intervention, while the prevalence of moderate depression reduced from 18.9% to 13.5%. The proportion of BCa survivors with moderate to

Table 3. Comparison in DASS-21 Scale Scores between Pre- and Post-intervention

DASS-21 domain	Median (IQR)		P
	Pre	Post	
Depression	4.00 (7.00)	1.00 (6.00)	0.001*
Anxiety	4.00 (5.00)	2.00 (4.00)	<0.001**
Stress	6.00 (4.00)	2.00 (5.00)	<0.001**

Higher score indicates higher tendency towards the assessed domain; Data were not normally distributed and compared with Wilcoxon Signed Rank test; *significant at p<0.05; **significant at p<0.001

Table 4. Comparison of QOL Domain Scores between Pre- and Post-intervention

QOL domain	Mean score (SD)			P
	Pre	Post	Difference	
Psychological	15.32 (2.36)	16.02 (2.09)	0.69 (1.01)	<0.001**
Social relationship	15.06 (2.11)	15.55 (2.15)	0.49 (0.88)	0.002*
Environment	15.02 (2.45)	14.74 (2.35)	-0.29 (1.44)	0.233
Physical health	15.24 (2.64)	15.66 (2.42)	0.42 (0.84)	0.004*

Data were normally distributed and compared with paired t-test; *significant at p<0.05; **significant at p<0.001

extremely severe anxiety also reduced at post-intervention, with the largest decrease in prevalence seen among those with extreme anxiety (13.5% to 2.7%). Similar trend was also seen in the stress domain, with a total decrease of 14.2% of any form of stress at post-intervention.

More than 85% of the participants rated themselves to have a good or very good QOL at post-intervention, as opposed to 75.9% at pre-intervention (Figure 2). There was decrease in neutral rating of QOL, and none of the survivors rated themselves to have poor QOL at post-intervention. Satisfaction with health (Figure 3) has also improved at post-intervention (86.5% vs 48.6%). Significant improvements in several HR-QOL domain scores were seen (Table 4). The mean psychological score improved the most (Δ=0.69 (1.01), $p<0.001$), followed by social relationship (Δ=0.49 (0.88), p=0.002) and physical health (Δ=0.42(0.84), p=0.004).

Discussion

BCa survivors now have many more years of cancer-free life. However, it is also known that the various treatment options for the treatment of BCa can also cause other debilitating diseases. Rozenberg et al., (2007) upon a review of post- BCa treatment diseases, stressed that prevention other diseases is essential to improving QOL after BCa. This is achievable through behaviour change programs and health screenings. Leveille et al., (1999) had earlier found that health promotion activities benefits individuals especially those related to maintaining function, independence as well as improving quality of life due to longevity. Thus, workshops that not only dispense educational nuggets but also incorporates health screening like the one we conducted will go a long way in improving health related quality of life of BCa survivors.

From our research, we found no similar multi-faceted intervention program that had been conducted to assess improvement in HRQOL in BCa survivors, especially in this region. We recruited 37 Bca survivors, and the mean age was 58.1, with the average age of diagnosis being 49.9. This is in keeping with the study by Yip et al., (2006) who found that 50% of Asian women were less than 50 years when diagnosed with BCa. Most of them (86%) were at an early stage, and had completed treatment, which is higher than data from the Malaysian National Cancer Registry Report 2007-201 that was 56.9% (Azizah et al., 2015).

We found the prevalence of moderate to severe depression amongst our participants at baseline to be at 27%. This concurs with the findings of previously published studies to report the prevalence to be around 22-23% (Ram et al., 2013; Hassan et al., 2015). We also found a high prevalence of our participants to suffer from moderate to severe anxiety (32.4%), which confirms findings by Hassan et al., (2015). More than 16% of participants had moderate to severe stress, and a recent study has shown BCa patients tend to have an increased incidence of stress-related disorders, among other psychological issues especially within 6 months of diagnosis (Yang et al., 2017).

Survivorship care programs have been suggested to include psychological aspects, while addressing the physical needs of BCa patients (Edib et al., 2016; Nápoles et al., 2017). Pahlevan Sharif (2017) has suggested psychological interventions to "shift cancer patients' locus of control from external to internal in order to improve their quality of life and reduce their depression and anxiety". Our intervention program has taken these into consideration and resulted in an improved psychosocial well-being of the BCa survivors. A comparable finding was reported by Ram et al., (2013).

Similar to psychosocial well-being, we also found an improvement of HRQOL, with more than 10% increase in participants who rated themselves to have a good or very good QOL at post-intervention compared to pre-intervention assessment. Our study also found significant improvement in psychological, social relationship and physical health domains of HR-QOL and overall satisfaction with health at post-intervention. We hypothesize these to be the positive outcomes from our multi-faceted intervention strategies.

Diet and lifestyle behaviour changes were crucial components of our intervention program. Healthy eating practices and physical activity have been shown to improve the HRQOL of BCa survivors (Mohammadi et al., 2013). The latest study among Malaysian women BCa survivors suggests the survivors were more keen on a healthier diet, though they only made small changes in their diet at two years post-diagnosis (Shaharudin et al., 2013). Besides the modification in food intake, studies have reported high level of supplement intake and practice of complementary and alternative medicine (CAM) among BCa survivors. More than 80% of BCa survivors within 4 years of diagnosis reported use of dietary supplement, and those who consumed supplements were found to consume more dietary fibre and less dietary fat (Rock et al., 1997). Studies in Malaysia (Shaharudin et al., 20111, Saibul et al, 2012) found 51% to 64% of the BCa survivors interviewed used CAM as a complement to their usual care at the hospital. Dietary intake in terms of diet quality has been suggested to be related with manifestation of depressive symptoms in BCa survivors (Tangney et al., 2002).

In addition to dietary changes, our intervention program also included another vital aspect of QOL – physical activity. A meta-analysis of randomised-controlled trial showed positive effects of physical activity on physiology, body composition, physical functions, psychological outcomes, and QOL of Bca survivors (Fong et al., 2012). A study among more than 1,500 BCa survivors showed physical activity indirectly affects QOL through changes in self-efficacy and health status indicators (Phillips and MCAuley, 2014). Misra et al., (2012) also indicated that "exercise may have beneficial effects on HRQOL and certain HRQOL domains including cancer-specific concerns (BCa), body image or self-esteem, emotional well-being, sexuality, sleep disturbance, social functioning, anxiety, fatigue, and pain at varying follow-up periods".

In addition to a multi-faceted intervention, we have also conducted health screening for the study participants. Corkum et al., (2013) suggested cancer survivors received more frequent screening for a second primary BCa and other cancers compared to non-cancer controls. As many

cancer survivors are at increased risk of developing a second primary cancer, they suggested future research to determine if increased uptake of cancer screening leads to improved outcomes during cancer survivorship. However, not much has been reported about improvements in HRQOL after participating in health screening. Another more recent meta-analysis (Uhlig et al., 2017) compared utilisation of breast, cervical and colorectal screening amongst cancer survivors compared to cancer-free controls. It was concluded that compared to cancer-free control, cancer survivors were more likely to utilise cancer screening services. However, further studies need to be done to assess if this translates into prolonged survival rates. This meta-analysis showed that cancer survivors are more responsive to cancer screening as they may be aware that they are at increased risk to develop a second primary cancer. Cancer survivors will naturally appreciate a comprehensive screening and wellness program similar to our intervention program. Women who believed that screening could provide early diagnosis of cervical cancer also valued the reassurance and peace of mind a negative screen result could provide (Bush, 2000).

Hafslund et al., (2012) studied pre-screening HRQOL in women who were invited to participate in mammographic screening for BCa and compared that with HRQOL of the age matched comparison group. The study group scored significantly higher HRQOL and it was suggested that they had confidence in mammography screening and viewed screening as a health assurance. Our study showed significantly higher score of several HRQOL domains and this may also suggest that the BCa survivors may have felt reassured by being screened by professionals.

In addition to PAP smear and ultrasound of pelvis, screening and prevention of cardiovascular diseases (CVD) among BCa survivors become increasingly significant issue as it has become the leading cause of mortality among BCa survivors after the age of 65 (Patnaik et al., 2011). High CVD risk has also been associated with impaired HRQOL (Koh et al., 2015). There are many factors may contribute to the increased risk of cardiovascular morbidity and mortality in BCa survivors. The factors include age, psychological distress and effect of cardiotoxic cancer treatment.

Strength and limitation

As there were no recent studies on multifaceted group intervention to improve psychological well-being and HRQOL of BCa patients and survivors, this study paved the way for more engagement in this new and emerging area of research. Furthermore, the research method and design applied made it relatively easy to analyse data which is reliable. However, sampling of survivors from a single location could have resulted in possible selection bias. Although most intervention studies used a small sample sizes as ours, a larger sample size could have eased the generalizability of the findings. The lack of recent similar studies could not result in a more robust discussion to compare or concur with other studies.

In conclusion, our results emphasize that the HRQOL especially in the domain of psychosocial aspect was greatly improved with our day long screening and group-based intervention programme of the BCa survivors who participated. We have produced a viable solution for countries with medical needs competing for limited medical resources especially when it comes to funding and personnel. Group-based multifaceted intervention uses less resources and covers more ground than would be possible if these survivors were to be seen individually.

Besides giving dietary and lifestyle advise in a non-threatening environment, screening for important aspects of possible complications of BCa therapy was conducted. Being educated on possible complications and also undergoing screening tests in a friendly environment plus take home information on diet and lifestyle most probably contributed to the improvement in test scores seen. Group-based screening also allows for them to interact with each other exchanging ideas and information, and to a certain extend, providing support and strength to one another.

Similar studies amongst Asian BCa survivors are limited. There is a need for further research in this area, with the increasing rates of BCa amongst Malaysian women.

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