

RESEARCH COMMUNICATION

Quality of Life in Breast Cancer Survivors: 2 Years Post Self-management Intervention

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Abstract

Introduction: Today, cancer survivors have an added new role to self manage living with the medical, emotional and role tasks that can affect their quality of life (QOL). The purpose of the study was to evaluate the QOL of women two years after participating in a self-management intervention program. **Method:** The clinical trial was conducted at University Malaya Medical Centre between 2006 and 2008. The experimental group underwent a 4-week self management program, and the control group underwent usual care. Two years after the intervention, questionnaires were randomly posted out to the participants. **Results:** A total of 51 questionnaires returned. There were statistically differences between groups in psychological, self-care, mobility and participation aspects in PIPP ($p < 0.05$). The experimental group reported having higher confidence to live with breast cancer compared to control group ($p < 0.05$). There were significant between-group changes in anxiety scores at T2 (immediately after intervention) to T4 (two years later), and the differences in anxiety scores within groups between time point T2 and T4 were significantly different ($p < 0.05$). **Conclusion:** The SAMA program is potentially capable to serve as a model intervention for successful transition to survivorship following breast cancer treatment. The program needs to be further tested for efficacy in a larger trial involving more diverse populations of women completing breast cancer treatment.

Keywords: Breast cancer survivors - quality of life - self-management

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Introduction

Breast cancer is the most common malignancy among women in Malaysia. One in 20 Malaysian women are at risk in her lifetime (Agarwal et al., 2007). Each year, there is about 3,825 new cases of breast cancer were reported and the incidence rate was estimated to be 46.4, 38.1 and 30.4 per 100,000 population respectively for Chinese, Indian followed by Malay women (NCR, 2006). Although considerable research and attention has been focused on the time of diagnosis, treatment initiation and following the completion of treatment, scarce attention has been paid to the wellness of psychological and physical functioning two years of survivorship amongst Malaysian women.

Significant psychosocial adaptation is required for the diagnosis and treatment of breast cancer because cancer is a deliberating and life-threatening disease. A report from the Institute of Medicine reported about one third to one half of women with breast cancer experience psychosocial distress that involve multiple antecedent and concurrent factors that influence psychosocial functioning and QOL over time (Houldin et al., 2006). In the Antoni and colleagues study, women with early-stage breast cancer who participated in a 10-week stress management program were found with increased benefit-findings from the cancer

experience compared to the control group women (Antoni et al., 2006). The results presented in this paper derive from the final part of the MRC framework for complex intervention (MRC, 2000), to gather the final incremental evidence on the efficacy of a self management program. This study is the final follow up study to explore the QOL of breast cancer survivors two years after participating in a self-management program and compared to the QOL of the non-intervention (usual-care) group.

The 'Stay Abreast, Move Ahead (SAMA) Clinical Trial' (SAMA) is a 'closed-group' intervention offered to women newly diagnosed with breast cancer. The aims of the program are to enable patients with information and skills to stay abreast with the demands of managing the illness, and to facilitate moving ahead by engaging proactive coping and healthful behaviors. The development of this program is based on literature suggesting the main barriers to self-management in Malaysian women with breast cancer were unavailability of information, inability to access services-and-support, as well as other factors like the socioeconomic-cultural issues (entrenched myths, low-socioeconomic status, and inadequate insurance-health legislative coverage) (SY Loh., 2007; SY Loh., 2009). The survivors who participated in the pilot group verified the important need of managing the medical, emotional

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and role management tasks (Loh et al., 2007).

Materials and Methods

Study samples and recruitment

Between 2006 and 2008, a total of 147 Malaysian women participated in the initial clinical trial. These women recruited from the media and medical databases were divided into control (n=78) and experimental (n=69) groups. The control group consisted of women who underwent their usual-care group while the experimental group participated in a 4-week SAMA program (Loh et al., 2009). Data was collected prior to the intervention, immediately after the 4-week intervention.

This study is a follow-up, two years from the time of initiation of the SAMA program. Ethical approval for the study was obtained from the Medical centre research ethics committee. The questionnaires were randomly posted out to the survivors (control, n=25; experimental, n=41). Data were collected by a research assistant, who was trained to administer the research instruments.

Tools

Socio-demographic and medical characteristics survey: information gathered on age, ethnicity, marital status, household size, caring roles, highest education, occupational and financial condition. Medical history such as first diagnosis date, stage and type of breast cancer, size of tumor, type of surgery, type of chemotherapy as well as type of hormonal treatment.

Quality of Life survey (SF-36): This self-report measure contains 36 questions to measure the quality of life. The SF-36 includes eight health domains: physical functioning (PF), role-physical (RP), bodily pain (BP), general health (GH), vitality (VT), social functioning (SF), role limitations due to emotional problems (RE) and mental health (MH) (Ware et al., 1999). Each subscale is standardized on a scale from 0 to 100, so that higher scores indicating better functioning. To reduce the number of outcome measures, the physical component summary (PCS) score and the mental component summary (MCS) score have been extracted from the eight original scales. They are standardised through norm-based scoring to a normal distribution with a mean of 50 and a standard deviation of 10.

Rotterdam symptom checklist: This 39-item checklist (De Haes et al., 1990) constitutes of physical symptom distress (e.g. headaches or fatigue), psychological distress scale (e.g. worrying, depressed), activity level scale (relates to functional status). A study conducted on patients with advanced breast cancer concluded that Rotterdam symptoms checklist has a good predictive value and could be used in patients with advanced cancer to help screen out those with an affective disorder (Hopwood et al., 1991).

Perceived Impact of Problem Profile (PIPP): A 23-item self-report instrument assesses both the impact and the distress of health problems from the patient's perspective. The key domains include mobility, self-care, relationships, participation and psychological well-being. The instrument is designed to be generic to allow for comparisons across conditions. Pallant and

colleagues suggested that the PIPP provides a brief, but comprehensive means to assess the key International Classification of Functioning, Disability and Health (ICF) of components, focusing on the individuals' perspective of the impact and distress caused by their health condition (Pallant et al., 2006).

Depression, anxiety and stress scale (DASS-21): This is a 21-item self report questionnaire designed to measure the severity of a range of symptoms common to depression, anxiety and stress. In order to complete the scale, the individual is required to indicate the presence of a symptom over the previous week. Each item is scored from 0 as 'did not apply to me at all over the last week' to 3 as 'applied to me very much or most of the time over the week'. The DASS allows not only a way to measure the severity of a patient's symptoms but a means by which a patient's response to treatment can also be measured. The DASS-21 tool has been established as having excellent psychometric properties (Crawford and Henry 2003).

Data analysis

Questionnaire scores were used as rounded means with a tolerance of missing items in Rotterdam, PIPP, SF-36 and DASS-21. The raw scores from Rotterdam symptoms checklist were transformed into standardized scores ranging from 0 to 100-point scale, which 0 implies a level of no impairment, 100 implies the highest level of impairment (de Haes et al., 1996). The results in SF-36 were transformed into norm-based scores, by comparing the scores using the original 0 to 100 algorithms (Ware et al., 2004). Descriptive statistics were applied for sample description. For differences between groups, the Mann-Whitney U test, a non-parametric statistical hypothesis test for assessing whether two independent samples of observations have equally large values was used for two groups. Calculations were performed with SPSS (version 17.0) and Microsoft Excel 2007. The p value significance was taken as < 0.05.

Results

A total of 66 questionnaires randomly posted out to the participants who enrolled in the SAMA trial two years ago. About 19 (76%) respondents came from the control group, and 32 (78%) from the experimental group returned the questionnaire. Reasons for no response from the questionnaire included those who either did not received the questionnaire or were lost in delivery; deceased, too busy and forgot to return. The participants' and control socio-demographic and medical backgrounds were similar. An independent Chi-square test ($p < 0.05$) showed that the diagnostic stage was significantly different between the experimental and control groups. This variable was entered into the model to be adjusted for and accounted for in the analyses.

All participants ranged in age from 28 to 71 years old ($M = 54$ years, $SD = 8$). The mean age of participants in the control and experimental groups, were 55 ($SD \pm 10$) and 53 ($SD \pm 7$) respectively. The mean body mass index (BMI) was 23.4, with an overall increase of 0.61 between after SAMA program (T2) and two years after SAMA (T4). The

Table 1. Quality of Life (Rotterdam Symptoms Checklist)

Variable	Control (n=19)	Exp (n=32)	p-value [#]
Physical distress*	18.0±10.7	16.2±14.4	0.297
Psychological distress*	25.7±21.0	18.4±18.0	0.254
Activity impairment [^]	95.0±9.04	98.3±3.36	0.180
Overall QoL*	20.4±13.02	17.3±15.5	0.306

[#](2-tailed); * Higher score= Higher level of impairment; [^] The higher the score, the better the function

increase in BMI was noted to be slightly higher in control group (0.99 ± 2.82) compared to the experimental group (0.38 ± 1.80), despite the fact that the difference between two groups was not statistically significant.

Depression, Anxiety and Stress

The normality test from Shapiro-Wilk was significant (p<0.05), suggesting a not normally distributed population. The descriptive box-plots for changed scores between T2 and T4 were wider in control groups for stress (-22 to 12), anxiety (-18 to 6) and depression (-20 to 18); compared to the experimental group with smaller variances for stress from (-12 to 8), anxiety (-8 to 6) and depression (-8 to 10). There were significant differences in the between-group mean anxiety scores (using change scores of T2 and T4) (p<0.05). There were no significant between-group differences for stress and depression scores between T2 and T4. Within the experimental group per se, there was significant increase in anxiety level from T2 to T4(p<0.05). The raw scores in the control group showed higher score across stress, anxiety and depression scales at all time points (Figure 1).

Rotterdam symptoms analysis

However, there was no statistically significant difference found between control and experimental groups regarding the four aspects of physical distress, psychological distress, activity impairment and overall QOL (p>0.05) (Table 1).

Perceived Impact of Problem Profile (PIPP)

There were significant difference between-groups in psychological, self-care, mobility and participation scales (p<0.05), with the experimental group having lower score in all domains of the PIPP. The experimental group expressed significantly higher confidence level in managing activities of daily living despite having a breast cancer illness, when compared to the control group (p<0.05).

Quality of life after cancer

Using Mann Whitney analysis, the differences in physical component summary (PCS) score between control and experimental groups at T4 were significant [U (51) = 189, Z = -2.241, p <0.05]. Both groups showed a trend of improvement over time in the PCS scores, with median scores significantly higher (better) for experimental group than in control group. Quality of life scores improves gradually with increasing time from the date of diagnosis. The between-groups median scores were significantly different at T4 for general health and social

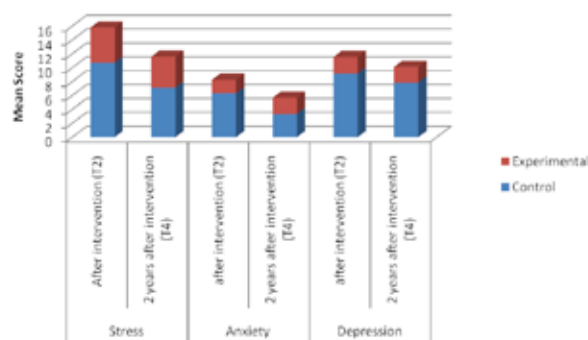


Figure 1. Median Scores of Stress, Anxiety and Depression at Post-intervention (T2) and Two Years Post-intervention (T4)

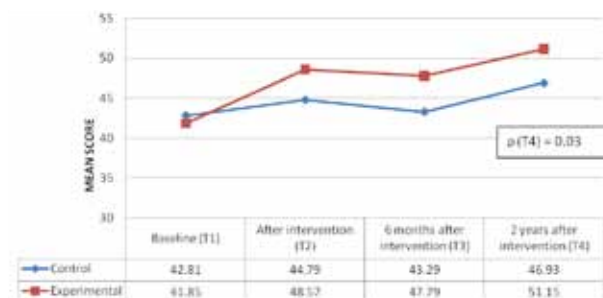


Figure 2. Trend of Physical Component Summary Scores (Quality of Life)

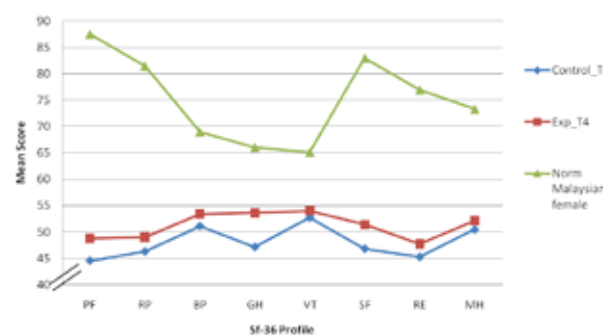


Figure 3. Median Scores of QOL Domains (Azman et al., 2003)

functioning (Figure 3).

Discussion

The majority of the participants were Chinese. The ethnic demographic pattern was in congruence with data reflected, where Chinese women had the highest incidence rates of breast cancer among all races in Malaysia (NCR, 2006). More than 75 percents of participants assumed the role responsibility for either care of their own children or their aged parents, indicating the collectivist family of an extended family system which is highly prevalent in Malaysia. One of the primary aims of cancer survivorship care is to improve QOL because breast cancer has been acknowledged as a form of chronic illness (Fallowfield, 2004). Breast cancer survivors today have an additional role to self manage their health beside taking responsibility in their household and child-elder care. The aim of this study was to assess the QOL in patients following a self-management program to examine if QOL improvement was maintained over time.

In general, breast cancer survivors showed poorer scores for all functioning scales in the physical, role, emotional, and social functioning scales of SF-36) in comparison with the non-cancer population. However, the progression pattern of SF-36 PCS scores indicated that both groups (experimental and usual care group) exhibited improvements over time, with the experimental group demonstrating statistically significant improvement at T4. This suggested the physical wellbeing promotion in the SAMA program has long-term additive value for improving overall physical health of women with breast cancer. This finding is consistent with findings from a 6-weekly cognitive-behavioral psychosocial meetings, which showed less depression, less mood disturbance, better overall quality of life starting at immediately post-intervention and at 2-years post-intervention compared to the control group (Simpson et al., 2001).

Emotional distress is common for women with breast cancer. An estimated 20 percent of women with breast cancer have anxiety symptoms from unresolved distressing cancer-related experiences (Koopman et al., 2002). A meta-analysis study suggests that the cognitive-behavioral self-management intervention is effective for managing depression and anxiety up to eight months in cancer survivors and has long-term positive effects on QOL (Osborn et al., 2006). Both groups demonstrated improvements in depression and stress levels. However, the experimental group exhibited statistically non-significant increase in anxiety level. This may be due to participants from the experimental group feeling "abandoned" after the completion of SAMA program as no follow-up or after-care was provided which induced anxiety. The "buddy system" in SAMA program postulated advantages but also disadvantages for participants. Some of the participants from the experimental group lamented they were influenced intensely when some group members passed away and there were no grief support system offered.

The 4-week SAMA program provided knowledge and skills for women to self-manage an active and emotionally satisfying life in the face of living with breast cancer (Loh et al., 2009). The experimental group perceived to experience less negative impact from their health condition on the psychological, self-care, mobility and participation level. On the other hand, the control group experienced higher level of physical and psychological distress as well as activity impairment compared to the experimental group although the difference was not statistically significant. Women from the experimental group also reported having significantly higher confidence to manage living with breast cancer. The result indicated that the self-management approach showed substantial beneficial effects on QOL in breast cancer patients in the long term.

In spite of the positive findings, a few limitations should be cautioned when interpreting the results. Firstly, this study utilized self-report measures and the sample size was not large. Nevertheless, the study showed that women with breast cancer who participated in a 4-week patient self-management moderated by health professionals showed significant lower perception of the impact of breast cancer on their different aspects of life. Although

the change scores in QOL were not significant between groups, the experimental group reported better general health, social functioning and overall physical well-being at T4. Having a diagnosis of breast cancer can be distressing to most women, even in the long term after diagnosis but women who were offered the self-management support program showed reduced psychological distress and better quality of life maintained even at two years post-diagnosis. The findings provide evidence on the potential benefits of educational and supportive intervention for ameliorating psychological distress and improving QOL for breast cancer survivors.

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