Psychological Distress of Women Newly Diagnosed with Breast Cancer: Relationship with a Self Management Intervention Program

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Abstract: Psychological distress is especially common with any cancer diagnosis. This study examined the psychological distress in a cohort of women newly diagnosed with breast cancer. A longitudinal study of a cohort of women (n=147) diagnosed with breast cancer (within the past 1 year), were conducted at University Malaya Medical Centre, Kuala Lumpur. Data were collected at baseline and at post 4-week intervention. Analysis of variance was conducted to examine for any significant differences in the change-scores between the experimental group (n=69) and the control group (n=78). Using the change scores, analysis of variances shows significant differences between groups for stress, $F(1,140) =13.68, p<0.0001$, anxiety, $F(1,140) = 8.44, p<0.004$, and depression, $F(1,140) =11.57, p<0.0001$. Levels of stress, anxiety and depression generally decreased significantly in the experimental groups ($p<0.05$), but either maintained or increased in the control group. This study indicates that the level of psychological distress of women with breast cancer can be ameliorated with a 4 week self management intervention. Lower stress was also found in women who reported engagement in higher physical activity than women with low physical activity. Future studies may examine role of physical activity in ameliorating distress.

Key words: patient self management, women, breast cancer, psychological distress

Introduction

Emotional distress, a common sequela of a cancer diagnosis, is a core indicator of a patient’s wellbeing and has been promoted as the sixth vital sign in cancer care (Bultz & Carlson, 2005). Emotional distress varies in level of intensity, depending on severity of disease and phase of treatment (Simonton & Sherman, 1998). Earlier research have documented that up to 50% of women with breast cancer experience psychiatric morbidity (Hall, Fallowfield & A’Hern, 1996), coupled with anxiety and depression commonly faced right from the moment they are diagnosed with breast cancer (Dow, 2000). It has also been reported that the onset of reactive anxiety and depression also often coincides with the fatigue experienced with daily radiation treatments (Rowland & Holland, 1990). Thus, management of emotion is crucial as one quarter to one third of women undergoing chemotherapy experienced distress (Campora, Naso & Vitullo, 1992; Newell, Sanson-Fisher, Girgis & Ackland, 1999). Breast cancer, among all cancers, is the leading cause of cancer mortality in women worldwide. Out of the 35 million people who died from chronic disease in 2005, half were under 70 years and half were women (WHO, 2005). Breast cancer is primarily a woman’s disease, although among males there is a minimal risk of developing breast cancer as well, with a ratio of 1:100 as reported by the American Cancer Society (American Cancer Society, 2005). This paper examines the Depression, Anxiety and Stress of women newly diagnosed with breast cancer who participated in a 4 week self management clinical controlled trial in University Malaya Medical Centre, a large teaching hospital situated in the central part of Kuala Lumpur, Malaysia.
Methods

Design & subjects

A longitudinal study with repeated measures was conducted on an experimental group and followed by a control group (Fig. 1). There were 147 women newly diagnosed (within one year) with breast cancer from December 2006 to February 2008 who were recruited. The experimental group undertook the 4-week self management sessions and the control group were those from the usual-care group. Both groups completed the questionnaire as the baseline, and at 4 weeks as well as 8 weeks from baseline. The participants were selected based on the following eligibility criteria: (i) more than 18 years of age, (ii) confirmed by physician, a diagnosis of Stage 1-III (within one year since diagnosis), (iii) completed surgery, may or may not be undergoing chemotherapy and/or radiotherapy, (iv) may or may not be undergoing Tamoxifen (or other endocrine therapy), (v) can read and understand English, and (vi) give informed-consent. The exclusion criteria are (i) marked cognitive impairment or learning disabilities (through observation/ interview), and (ii) has other form of medical problem interfering with participation and attendance (from self report).

Tools

The Depression, Anxiety and stress (DASS) tool was used to measure psychological distress in Malaysian women diagnosed with breast cancer. The DASS tool has been established as having excellent psychometric properties (Crawford & Henry 2003). It measures 3 distinct items - the depression, anxiety and stress. DASS-21 is a self report questionnaire (Lovibond & Lovibond, 1995) which allows simultaneous assessment of three emotional states - depression, anxiety (hyper arousal) and stress. A Likert-type scale is used to rate items according to symptoms experienced in the past week, ranging from 0 (not at all) to 3 (most of the time). Alpha value for the 7-item scales ranged from 0.73 (anxiety), 0.81 (depression) and 0.81 (stress) and has adequate convergent and discriminate validity (Crawford & Henry, 2003; Lovibond & Lovibond, 1995). It is a valid, reliable routine clinical outcome measure of these constructs in clinical and non-clinical groups (Antony, Bieling, Cox, Enns & Swinson, 1998; Brown, Chorpita, Korotitsch & Barlow, 1997) and for inpatient setting (Ng et al., 2006).

The intervention program

The intervention group went through usual care and the 4 week self management program is a group format for 8 to 15 women who meet weekly (about 2 ½ hours) for four consecutive weeks. The sessions with its respective self-management themes for each sequential week, on medical management tasks, emotional management tasks, healthmanagement and role management tasks (see Fig. 2). The facilitation style was based on Tuckman’s theory (Tuckman, 1965). Use of didactic and experiential exercises, were drawn from the social cognitive theory and cognitive behavioral principles. The first session was scheduled one hour earlier while the final session was scheduled one hour later than the middle two sessions, to cater for the pen-paper testing. Group work, mini lectures and homework were incorporated in each of the four sessions. The last session also finished off with a tea and

Fig. 1. Line graph of repeated measures between the experimental and control group.

\[ \text{anx = Anxiety, dep = depression} \]

\[ \text{T1 = Time 1 (baseline), T2 = Posttest at 4 weeks, T3 = Posttest at 8 weeks} \]

- - - = Experimental | — = Control
exchange of gifts to show mutual support to their new partner (or known as the SAMA buddy). The 2-tier buddy system was added to the program as an inbuilt support-mechanism for the participants to encourage each other as well as to discuss their homework. The usual-care group went through the typical treatment which comprises of surgery and combination of chemotherapy, radiotherapy and targeted therapy. Details of the trial have been published elsewhere (SY Loh, 2009).

Data analysis

The data was entered into the SPSS (Version 15). All missing data from dropouts at post test and follow up were input using the last observation of carried forward

<table>
<thead>
<tr>
<th>Session</th>
<th>Group work strategy (Example of exercises from SAMA*)</th>
<th>Facilitator’s style (Tuckman’s theory on group and facilitation style)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Session 1</td>
<td>Focus on Relationship building: Facilitator highlight common problems and goals. ‘Buddy system’* to promote closeness - first tier buddies are assigned to encourage each other; Second tier buddies are self-selected to support each other with transportation, problem-solving etc.</td>
<td>Moving from a ‘Directing’ style, moving through a ‘Coaching’ style, then into ‘Participating’- to finishing- Delegating and ending with an almost- Detached style</td>
</tr>
<tr>
<td>Managing my</td>
<td>Explanatory stage: Paying attention to feelings and acknowledging them. Also, increasing the group work, from simple tasks like ‘understanding the adjustment process’, ‘finding what relaxes me’, to ‘challenging myths and self-defeating thoughts in groupwork’. Homework is used to shape the team transitions from “as is (the present)” to “to be (the future)”.</td>
<td></td>
</tr>
<tr>
<td>Breast cancer</td>
<td>Decision-making stage: Requires more team-work with task-oriented actions e.g. finding yourself an exercise group or visiting a wig shop. (This encourages participants to look for common themes and common work). Action planning focus on health plan. (The team reaches consensus on the “to be” process).</td>
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<td></td>
<td>Working Stage: Encourage the participants to take an active role. Group representative and members coordinate meeting dates, ensure attendance, plan food, outing, and visits to breast welfare association, breast resource centers. (The team has settled its relationship dynamics, and the overall group as well as personal expectations).</td>
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<td></td>
<td>Termination Stage: The group may be exposed to another group to expand its networking. The optional 3rd line buddies can be initiated by any group member. (They share their improvements and personal growth).</td>
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</tr>
</tbody>
</table>

Fig. 2. Overview of the sessions, exercises and facilitation style. SAMA* = Staying Abreast, Moving Ahead, a 4-week program. ‘Buddy system’* - a SAMA strategy to improve groupwork and cohesiveness of members
Demographic data were obtained from the Patient Information Questionnaire (PIQ) and tabulated in Table 1 below. A total of 147 women participated in the study. The majority of the participants were Chinese (65%), with a mean age of 50 years (± 9 SD) and within a range of 25–75 years. Most were married (76%), living with spouse and children (68%), had fewer than 2 children (42%), and had at least a secondary education (44%). Most had no extra role looking after aged parents (73%). Only about 6.8 percent were living alone, the rest were living with someone, indicating the traditional Asian trend of living within an extended family system which is still highly prevalent, although the family today have fewer children.

More than half the women had some form of insurance policy (53%) and had a household income of 1000-5000 ringgit per month (55%). The independent Chi-square tests (Tables 1, 2) showed only two personal demographic variables were significant at baseline. These were ethnicity ($p=0.04$) and insurance status ($p= 0.005$).

Prior to the analysis the baseline differences between the two groups were assessed using t-test. There were no statistically significant differences in the mean scores of the two groups for stress ($p=0.08$), anxiety ($p=0.299$) and depression ($p=0.44$) suggesting that the two groups are from the same population. Thus any changes in the find-
ings can be interpreted with confidence as changes were likely due to the intervention. Descriptive statistic (Table 2) shows that with the experimental group, a favorable decrease on all three scales ranging from −19.8 percent (stress) to 33.3 percent (depression) at T1 to T2 and a further decrease of 13.7 percent anxiety to 17.1 percent stress at T2 to T3. In the control group, all three scales had unfavorable increase with higher measures on stress, anxiety and depression with a percentage ranging from 8.9 percent to 14.9 percent on T1 to T2 period and 4.5 percent to 4.4 percent stress improves slightly with a decrease mean score of 2.5 percent for T2 to T3. Overall, the trend of change from baseline T1 to Post test T2 was favorable for the experimental group, but unfavorable in the control group.

Changes over time between the two groups for depression, anxiety and stress

Using the change scores (T2-T1), analysis of variances shows significant differences between groups for stress, $F(1,140) = 13.68, p<0.0001$, anxiety, $F(1,140) = 8.44, p<0.004$, and depression, $F(1,140) = 11.57, p<0.0001$. Figure 1 showed the changes over time in the experimental and control groups. There were no significant difference between the age group (young and old), mental status and ethnic groups. With level of physical activity, significant differences were found between the low (sedentary to light physical activity) and high (moderate to active) group for stress ($p=0.031$) but not for depression and anxiety. The within subject repeated measure (on just the experimental group, $n=69$) showed that the changes were statistically significant ($p<0.001$) for all three variables on stress, anxiety and depression.

Discussion

At baseline the level of distress of women with breast cancer who were allocated to a 4 weeks self management program were higher although the differences were not statistically significant at the level of $p<0.05$. This also shows that the two groups did not differ at baseline and thus are comparable. It is postulated that a reason for the higher scores in the experimental group could be due to the added psychological arousal from the knowledge that they needed to come into the medical centre for an additional five sessions on top of all the other multiple appointments that they need to adhere to like chemotherapy or radiotherapy.

The pattern of reduced distress appears significant over the repeated measures for the experimental group ($p<0.05$). However, a pattern of unfavourable increase in distress (stress, anxiety and depression) was observed in the control group. Cancer diagnosis can lead to enduring feelings of vulnerability (Bower et al., 2005) resulting in cognition errors and faulty beliefs which can lead to distress and interfere with physiologically ready states for self-management. Thus, the 4 weeks self management intervention was purposefully designed to provide components of cognitive behavioural exercises such as identifying negative self deprecating thoughts and challenging them with positive statement and practice of relaxation skills. Cognitive behavioural therapy (CBT) utilize a multimodal approach and is particularly effective in decreasing symptom severity for patients with cancer (Antoni et al., 2001; Dodd & Miaskowski, 2000; Sherwood et al., 2007). The favourable findings in this study is supported by a study which shows that CBT was effective for depression (ES = 1.2; 95% CI = 0.22–2.19), anxiety (ES = 1.99; 95% CI = 0.69–3.31), and QOL (Osborn, Demonca & Feuerstein, 2006).

This provision of knowledge, skills and support in a group of about 6-10 people, increase the women self efficacy to self manage the medical, emotion and role tasks. Thus, although there were extra demands for them to attend the sessions, the women reported feeling supported by the health team. The unavailability of information (Loh et al., 2007) – a barrier to self management, may have been addressed in the program. In a group for-

| Table 2. Descriptive (mean ±SD) at repeated measures with percentages of change scores |
|-------------------------------------------|---------------------------------|-----------------|---------------|-----------------|-----------------|-----------------|
| DASS subscales                      | Repeated Measures | Change Score | % change scores | Change Score | % change scores |
|                                | Baseline (T1) | Post-test (T2) | Follow Up (T3) | (T2-T1) | (T3-T1) | (T2) | (T3) |
|                                | Mean   | SD     | Mean   | SD     | Mean   | SD     | Mean   | SD     | Mean   | SD     | Mean   | SD     |
| Stress                          | Exp    | 12.67 | 8.22  | 9.86  | 7.21  | 8.29  | 6.98  | -2.81 | 6.9   | -22.2* | 8.15  | -34.6* |
|                               | Ctrl   | 10.31 | 8.05  | 11.92 | 9.82  | 11.33 | 9.89  | 1.62  | 6.6   | 15.7   | 1.02  | 8.27  |
| Anxiety                         | Exp    | 9.13  | 7.57  | 7.16  | 6.45  | 6.64  | 6.90  | -1.97 | 5.37  | -21.6* | 5.46  | -27.3* |
|                               | Ctrl   | 7.92  | 6.47  | 9.05  | 7.95  | 8.97  | 7.84  | 1.13  | 5.45  | 14.3   | 1.05  | 5.75  |
| Depression                      | Exp    | 9.28  | 8.7   | 6.09  | 6.59  | 5.54  | 6.33  | -3.19 | 7.21  | -34.4* | 7.04  | -40.3* |
|                               | Ctrl   | 8.21  | 8.04  | 9.26  | 9.53  | 9.41  | 9.92  | 1.05  | 6.46  | 18.3   | 1.21  | 8.16  |
| DASS= Depression, Anxiety and Stress scale. Exp= experimental arm [n=69], ctrl=control arm [n=77]. * significant at $p<0.05$
mat, stressors may be mediated by the embedded buddy mechanism where each person was assigned a buddy, and can select a second buddy based on needs. Thus the program provided a built-in support system from their peers’ (buddies) and from the health team. This perhaps led to a favourable outcome for the experimental group. The positive results have been supported by several studies that promote that groups produce greater benefits than individual therapy, e.g. in weight loss programs (Renjilian et al., 2001), gastrointestinal symptom reduction (Vollmer & Blanchard, 1998) and in the level of QOL of breast cancer patients (Sakiko et al., 2000). Evidence suggest that structured support group intervention can significantly improve depression ($p=0.0001$), anxiety ($p=0.0001$) and QOL ($p=0.0009$) (Lindemalm, Strang & Lekander, 2005).

Also, the health of disadvantaged women is compromised due to a lack of education, lack of information and lack of awareness of factors that contribute to the disease (Luddy, 2007). Thus facilitating them with information, skill and inbuilt support system may have improved their confidence in self management and consequently reduces their stress level. Indeed, self-management education ‘complements traditional patient education in supporting patients to live the best possible quality of life with their chronic condition’ (Bodenheimer, Davis & Holman, 2007).

On the aspect of depression, the profile in the control group shows a sharper rise even at the third repeated measure. One study has shown that in a large cohort of breast cancer patients ($n=2943$), the post-hoc multivariate analysis revealed that chemotherapy (HR: 1.2; 95% CI: 1.0 –1.5), and hormonal receptor positive status (HR: 1.2; 95% CI: 1.0–1.5) were significantly and independently associated with an increased risk for developing depression (Lee, Ray, Thomas & Finley, 2007). A cut off score of 5 for anxiety and 12 for depression is recommended. This study found significant improvement in the experimental group in terms of cut off score. Nevertheless, any clinical significance (as a means of assessing outcome as appropriate), should be interpreted with caution. This is because improvement can also be expected upon completion of treatment. Another significant finding is that women who reported higher physical activity level showed significant difference in terms of stress. Larger study is needed to confirm the role of physical activity in buffering stress during treatment. These findings suggest that women with breast cancer need support in managing the multiple tasks even after breast surgery, as chemotherapy and radiation can be equally distressing and it alters participation in life because of its duration of treatment. One limitations of the study is that data were obtained by self report. Future studies can include larger cohorts and examine the role of physical activities on the psychological distress of these women.

**Conclusion**

Having a diagnosis of breast cancer is distressing to most women but women who were offered the self management support as they go through the multiple appointments for treatment, showed statistically significant reduction in their psychological distress. Women with breast cancer who went through a 4 week patient self management programme led by health professionals showed significant reduction in stress, anxiety and depression over time. In contrast, women who were in the usual care group showed unfavourable increases in distress over time. Having a higher physical activity level is also significantly associated to a lowered stress, and as such exercise as a lifestyle strategy should be offered to women newly diagnosed with breast cancer. The psychosocial rehabilitation of women with breast cancer needs to be emphasised as increasingly more women are living with this condition. The 4 week self management intervention is a timely blueprint to improve education, information and awareness amongst women with breast cancer. The program can be embedded as an essential part of clinical practice guidelines to be delivered by occupational therapists, as an early intervention therapy for women with breast cancer.

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**References**


