RESEARCH COMMUNICATION

Self Management Pilot Study on Women with Breast Cancer: Lessons Learnt in Malaysia

SY Loh^{1,2}, CH Yip³, T Packer^{2,4}, KF Quek⁵

Abstract

Objective: With increasing survival rates, breast cancer is now considered a chronic condition necessitating innovative care to meet the long-term needs of survivors. This paper presents the findings of a pilot study on self-management for women diagnosed with breast cancer and their implications for Asian health care providers. Methods: A pre-test/ post-test pilot study was conducted to gain preliminary insights into program feasibility and barriers to participation, and to provide justification for a larger trial. Results: The study found the 4 week self management program feasible and acceptable, with a favourable trend in quality of life. The recruitment barriers ranged from competing medical appointments, uncollaborative health providers, linguistic barriers and social-household concerns. Supporting facilitators identified were family, health professionals and fellow participants ("buddies"). Lessons from the study are discussed with regard to Asian health providers. Conclusion: There is preliminary evidence that self management is a workable and potentially useful model even in an Asians entrenched-hierarchical medical model of care. The initial challenge was breaking down barriers in acceptancee of a collaborative stance. A clinical trial is now warranted to gather more evidence.

Keywords: Breast cancer - self-management - pilot study - Asian health providers

Asian Pacific J Cancer Prev, 11, 1293-1299

Introduction

With early detection and improved therapy, there is a sharp declining rate of mortality from breast cancer (Mettlin, 1999; Greenlee et al., 2000), a condition which is increasingly being acknowledged as a form of chronic illness (Fallowfield, 2004). However, interventions for breast cancer are still largely designed for breast cancer as an acute rather than a chronic illness. In sharp contrast to the west, issues of access to medical care persist in many low-middle income countries in Asia Pacific.

The impact of the breast cancer is often extensive ranging from physical, cognitive, and/or psychosocial impairment to role dysfunction. As many as one-third of women continue to experience considerable psychological morbidity in the first two years after initial treatment as cited in few studies (Shapiro et al., 2001; Vahdaninia, Omidvari & Montazeri, 2009). About 20-30% of survivors report a disruption in their quality of life through loss of roles, functional abilities and problems with social relationships (Irvine et al., 1991) and from psychosocial and sexual problems (Schag et al., 1993). Distress increases as cancer progresses and women with later stages of the disease have more unmet needs (Hall et al., 1996) related to the impact on social, marital and family relationships. Chemotherapy that lasts for many months also interferes with childcare, social relations, role functioning such as continuing employment and performing domestic chores (Luoma & Hakamies-Blomqvist, 2004). Indeed, many women wrestle with the physical and psychosocial demands of coping and living with their illness. Despite this extensive understanding, evidence-based rehabilitation interventions have been slow to appear. With the course of the illness now extending to years and even decades, the focus of interventions must extend beyond just immediate diagnosis and medical care to also address issues of long term coping and quality of life. There is an urgency to address breast cancer as a chronic illness, which will require changes in the current health system to meet the needs of the "survivors" of breast cancer.

Research evidence suggests that the effectiveness of care for people with many other chronic conditions is enhanced by health behavioural interventions, particularly self-management interventions (Lorig et al, 2001). Selfmanagement can be seen as a broad set of strategies developed to enable people to cope effectively and reduce the long term impact of the illness. It is characterised by informed, activated patients collaborating with proactive health providers (Bodenheimer et al., 2005). The landmark qualitative work of Corbin and Strauss

¹Department of Rehabilitation Medicine, ³Department of Surgery, Faculty of Medicine, Univerwsity of Malaya, Malaysia, ²Centre for Research into Society and Disability, Curtin Health Innovation Research Institute, Curtin University of Technology, Australia, ⁴School of Occupational Therapy, Dalhousie University, Halifax, Canada, ⁵School of Medicine and Health Sciences, Monash University Sunway Campus, Sunway, Malaysia. *For correspondence: syloh@um.edu.my

(1988) was referenced to address the broad medical, emotional and role management tasks. Programs typically include topics such as problem-solving and health care navigation, and are based on the concept that increasing self-efficacy supports people to live the best possible quality of life (QOL) (Zwar et al., 2005). Literature shows that patients' knowledge, skills and confidence to manage their condition(s) positively affects their well being (Von Korff et al., 1997), with varying clinical outcomes for people with asthma, diabetes, and arthritis (Lorig et al., 1999; Bodenheimer et al., 2005).

In cancer care, research indicates improved QOL enhances the survivorship experience, and can lower the levels of morbidity and mortality (Fawzy, 1990). The Malaysian health care system appears to follow a medicalmodel care approach for women with breast cancer which remains "cure" oriented with limited attention to the psychological and social consequences (CGP, 2002). To date, there are no reported self-management programs for women with breast cancer in Malaysia. The existing literature leads to two overall conclusions. First, although breast cancer is now considered a chronic condition, development of evidence-based interventions lags behind the complex needs of women. Second, in other chronic long-term conditions, self-management programs have proliferated in western countries with promising patient outcomes. However, to date, there has been little attempt to tailor such programs for women with breast cancer. Given that self-management programs are designed to be complementary to medical care (Bodenheimer et al., 2002), and given the lack of evidence of any self-management interventions in Malaysia, a 4-week self-management program, designed to augment usual care was developed. This paper reports on the feasibility of implementation in a clinical setting and provides preliminary evidence of outcomes. With limited application of this intervention strategy with women with breast cancer internationally, this early insight will inform practitioners within and outside Malaysia.

For ease of reporting, a description of the program is presented first followed by the details of the study and a preliminary evaluation of effectiveness. The specific research questions were:

- 1. Is a four week self-management program feasible and acceptable to women with breast cancer?
 - 2. What are the perceived barriers to participation?
- 3. Was participation in the program associated with improvements in Quality of Life, participation, self-efficacy and proactive coping and a reduction in distress four weeks after completion of the program?

The self management program for Malaysian women newly-diagnosed with breast cancer was conceptualised based on themes derived from several focus groups held with survivors at different stages of breast cancer illness (Loh et al., 2007). The focus group themes supported the landmark qualitative findings from the work of Corbin and Strauss (1988) that people need to manage the related medical, emotion and role tasks on a day-today-basis. The focus group findings also led to the adoption of "SAMA" as the acronym for the program, which stands for "Staying Abreast, Moving Ahead". The name convey

the two pronged aims- i) to provide information to women to facilitate them to stay abreast with breast cancer management and ii) to provide the skills and support to enable them to move on and move ahead. The word 'sama' in the Malay, the national language of Malaysia means 'same' and it conveys the message that women with breast cancer, regardless of their stages of cancer, have similar self management tasks to consider and which can be managed effectively in partnership with health providers.

Literature on chronic disease interventions indicates that to positively affect patient well-being, systematic efforts to increase patients' knowledge, skills, and confidence to manage their condition (Korff et al., 1997) are required. Thus ways to increase self-efficacy, or people's belief in their ability to produce desired results by their own actions (Bandura, 1998), were systematically embedded in each session. Self-management skills like problem solving, decision making, taking action, resource utilisation, cognitive restructuring and use of helpful coping skills were built into the discussion topics. The resultant 4 week program was then pilot tested on a group of six women.

Materials and Methods

Design

This is a pre post study to test the newly developed program. Permission to conduct this study was received from the Human Research Ethics Committee at Curtin University and the Medical Ethics Sub-Committee, University Malaya Medical Centre, Kuala Lumpur and, from the Malaysian Ministry of Health's Research Committee. All participants received an information sheet giving full details of the study, and informed, written consent was obtained. Anonymity and confidentiality was emphasized early in the program. Data on the barriers to participation and the feasibility of the program were gathered using qualitative interviews (during screening interviews) and group discussions/feedback sessions at completion of the program. Outcome data were collected using a pre-test post-test design. Baseline testing was completed prior to participation with post-test data collected 4 weeks after completion.

Subjects

Participants were recruited from the breast cancer clinics at the University Malaya Medical Centre. The inclusion criteria were - more than 18 years of age, a physician confirmed diagnosis of Stage 1-III breast cancer (with no evidence of recurrence), all surgical interventions complete, and the ability to read and understand English. The exclusion criteria were marked cognitive impairment or learning disabilities (through observation/ interview) or any additional medical diagnosis that would interfere with participation and attendance (from self report). The surgical database of patients diagnosed with breast cancer within the previous year was screened. Those who met the inclusion criteria were informed of the study and the first few participants who gave consent were included in the study.

Procedures and Tools

Research questions one and two were addressed via screening interview and group feedback, whilst three used quantitative measures to examine effectiveness (Table 1). Demographic data (marital status, working status, selfreported activity-level, body mass index (BMI) and profile of breast cancer) were collected at baseline. The variables for investigation in the preliminary effectiveness study reflect those of interest in self-management programs generally and were chosen in preparation for future studies with larger sample sizes and more robust designs.

The SF 36 v2 (UK) Health Survey (Ware, Kosinski, & Gandek) is a 36-item self-report measure of healthrelated QOL in 8 domains. The reliability for the PCS has been reported as 0.92 and for MCS as 0.88 (Ware, 2002). Construct validity of the SF36 tested in ten Western European countries (Ware et al., 1999) found no major differences in scores.

The Inventory of Participation and Autonomy (IPA) measure participation and autonomy in people with chronic disorders (Cardol, 2001). Test-retest reliability at the subscale level of the original Dutch version is good with all intraclass correlation coefficients (ICC) greater than 0.90. Internal reliability of the IPA was confirmed by high Cronbach alpha's on all subscales (all > 0.8) (Sibley et al., 2006).

The Depression, Anxiety, Stress Scale (DASS-21) (Lovibond & Lovibond, 1995) is a brief version of the original 42-item tool. Alpha value for the 7-item scales range from 0.73 (anxiety) to 0.81 (stress and depression) and has adequate convergent and discriminate validity (Lovibond & Lovibond, 1995; Crawford & Henry 2003).

The Cancer Behaviour Coping Index (CBI-B) is a brief, 14 item form of the 33-item CBI tool (Merluzzi, Nairn, Hegde, Sanchez & Dunn, 2001). The alpha for the whole CBI has been reported as 0.94, and the testretest (1 week) reliability coefficient as 0.74 (Merluzzi et al., 2001).

The Strategies used By People to Promote Health (SUPPH) measures "self-care self-efficacy" in patients with cancer (Lev & Owen, 1996). The 29-item tool has a total score for total self-care self-efficacy.

The Stanford Emotional Self-efficacy Scale (SESES) is a 15 item measure of perceived emotional self-efficacy (Giese-Davis et al., 2004). Test-retest reliability has been

shown to be about 0.69-0.95. In a previous study on breast cancer (n=117), patients with low emotional selfefficacy demonstrated the greatest risk for traumatic stress symptoms (Koopman et al., 2002).

The Proactive-coping scale (PCI-14) is a 14-item multidimensional and forward-looking coping tool, to enable promotion of action-plans for personal growth (Greenglass, 2001; Greenglass, 2005). The internal consistency reliability using Cronbach's Alpha (α) was 0.85 with good factor validity and homogeneity (Greenglass et al., 1999).

Intervention

SAMA is a four week program where participants met once a week for four weeks, at the University of Malaya Medical Centre in Kuala Lumpur. The group work, led by health professionals and with about eight to twelve participants who meet once a week over four weeks, follows a structured, repeatable protocol accompanied by a manual for therapists and a workbook-cum resource book for participants. At the end of each week, participants are 100.0 provided with 'homework' (e.g., completing their breast cancer profile, distress monitoring, challenging their own myths, completion of a symptom management chart, etc). Throughout the program, a built in "buddy system" encourages and provides mutual support for women to support each other and take active action on improving their health. 50.0

Data Analyses

Demographic and disease-related data were analysed descriptively using means and standard deviations. In order to obtain an overall judgement of this program, data analysis for research questions 1 and 2 were conducted by evaluating participant feedback in terms of acceptability and feasibility as well as perception of benefits and perceived barriers limiting participation of future participants. Data analysis for research question three was via the Statistical Package for Social Sciences (SPSS) Version 16. Normality test indicated data were skewed and with small sample size, the nonparametric Wilcoxon signed rank test was used to examine changes over time.

Table 1. Research Questions, Variables, Data Collection Strategy and Analysis

Research Questions	Outcome(s)	Data Collection Methods	Data Analysis
Is the 4-week SAMA program feasible and acceptable to women with breast cancer?	Feasibility (logistics)	Group interview – Post-program feedback.	To identify and to record concensus. Frequency count
What are the perceived barriers to participation?	Perceived barriers	Screening interview Post-program feedback	Barriers identified and tabulated
Is participation in program associated with better Quality of Life, self-efficacy, proactive coping and lowered distress?	Quality of life (SF36), Depression, Anxiety and Stress Scale (DASS-21), Participation (IPA), Proactive coping (PCI), Self-efficacy tools (SUPPH, CBI, SESES)	Pre-test / Post-test self-administered paper and pencil tests.	Non-parametric analysis using Wilcoxon's one-sample signed rank test

Primary outcome measures were Quality of life (SF36), Distress, Anxiety and Stress Scale (DASS-21), Inventory of Participation and Autonomy (IPA). The secondary tools were Cancer Self efficacy and Proactive Coping Index (PCI)

0

Table 2. Background of Participants in the Pilot Study (n=6)

	n1	n2	n3	n4	n5	n6
Demographic Character	ristic					
Age	60	50	42	57	48	51
Education Level	College	College	Secondary	Secondary	University	Secondary
Children	2	2	0	2	2	4
BMI (mean=25.2)	29 kg/m^2	22 kg/m^2	31 kg/m^2	27 kg/m^2	20 kg/m^2	22 kg/m^2
Activity level	Light	Active	Light	Light	Active	Active
Cancer Characteristic						
Duration diagnosis	3-6mths	>1 year	<3 mths	<3 mths	I year	3-6mths
Type of Surgery	Lump.	Mastec.	Mastec.	Lump.	Lump.	Lump.
Stage of cancer	2A	2A	2	0	1	1
Type of cancer	Ductal	Mucinous	Ductal	Sqamous	Ductal	Ductal
Size of cancer	2-5cm	2-5cm	>5cm	2-5cm	2-5cm	1-2cm
Grade of cancer	Unsure	Unsure	Unsure	Grade-1	Grade-2	Grade-2
Hormone-status	Unsure	Positive	Positive	Negative	Negative	Negative
Her2-status	Unsure	Negative	Unsure	Negative	Negative	Unsure

Lump, lumpectomy; Mastec, mastectomy; BMI, body mass index; Ductal, infiltrating ductal carcinoma of the breast; Squamous, squamous cell carcinoma

Table 3. Median and Change Scores on Primary and Secondary Endpoints

	Median S	Median Scores			Mean Change So	cores		
(n=6)	Pre Test	Min-max	Post Tes	Min-max	Change Score*	SD	p-vale	Effect size Cohen's d
Sf36 Quality of Life								
PF	51.80	(36.0-54.9)	52.80	(40.2-57.0)	2.45	1.58	0.04	0.35
RP	55.60	(37.3-56.9)	47.10	(42.2-56.9)	-1.22	10.7	0.83	-0.15
BP	58.70	(37.2-62.1)	56.60	(46.1-62.1)	1.62	8.31	0.59	0.18
GH	49.40	(42.5-52.9)	52.90	(42.5-61.5)	3.42	7.94	0.28	0.65
VT	52.10	(39.6-58.3)	50.50	(42.7-70.8)	1.56	9.62	0.83	0.18
SF	51.40	(40.5-56.9)	54.10	(35.0-56.9)	1.82	8.21	1.00	0.23
RE	48.10	(28.7-55.9)	48.10	(40.3-55.9)	3.24	13.80	0.68	0.32
MH	45.80	(33.1-55.6)	44.40	(38.7-52.8)	0.94	8.70	0.68	0.12
Total PCS	52.50	(46.9-60.0)	53.90	(45.3-60.1)	1.18	2.48	NS	0.22
Total MCS	46.90	(33.7-55.0)	47.80	(38.0-54.6)	2.09	4.66	NS	0.28
Depression, Anxiety,	Stress Scale	(DASS)						
Stress	5.00	(0.0-18.0)	6.00	(0.0-16.0)	0.67	2.42	0.48	0.10
Anxiety	6.00	(2.0-24.0)	9.00	(2.0-12.0)	-0.67	6.02	0.79	-0.10
Depression	4.00	(0.0-26.0)	7.00	(0.0-20.0)	0.33	3.44	0.71	0.03
Impact on Participation	n and Autor	nomy (IPA)						
FamilyRole	0.30	(0.0-1.4)	0.10	(0.0-1.4)	-0.14	0.20	0.08	-0.30
SocialRelationship	0.30	(0.0-0.9)	0.40	(0.0-1.0)	0.10	0.17	0.27	0.25
Strategies Used by Pe	ople to Pror	note Health (SUPPH)	,				
Positive Attitude	58.00	(40.0-76.0)	69.00	(49.0-80.0)	8.33	14.45	0.21	0.60
Stress Reduction	33.00	(24.0-48.0)	37.50	(28.0-50.0)	3.67	12.66	0.35	0.40
Make Decision	10.50	(7.0-15.0)	11.00	(9.0-15.0)	0.83	2.86	0.58	0.30
Total	112.0	(71.0-128.0)	118.0	(86.0-145.0)	12.83	25.50	0.25	0.60
Cancer Behaviour Inv	entory (CB)	()						
CBI total	105.0	(73.0-118.0)	107.0	(81.0-126.0)	4.67	10.86	0.35	0.30
Stanford Emotional Se	elf-efficacy	Scale (SESES	S)					
Express Emotion	82.00	(52.0-86.0)	82.00	(60.0-96.0)	5.67	6.12	0.07	0.40
Enjoy Presence	72.00	(48.0-96.0)	77.00	(54.0-98.0)	3.33	8.55	0.34	0.20
Confront death	70.00	(20.0-94.0)	73.00	(56.0-100.0)	13.00	17.65	0.09	0.50
SESES Total	74.50	(48.0-91.0)	77.00	(57.0-98.0)	7.50	8.78	0.12	0.40
Proactive Coping Inde	ex (PCI)							
Proactive Coping	42.50	(26.0-50.0)	42.50	(29.0-51.0)	1.00	3.35	3.35	0.13

^{*}change score, (Post-test Mean) minus (Pretest Mean); PCS, physical composite score, MCS, mental composite Score; SF36, short form QOL

Results

A total of 60 women were given the information, out of which only 20 were eligible. The reason for the ineligibles were, having a diagnosis outside the stage 1-3, had recurrences, unable to converse in English and/or unable to attend all four session. Of those eligible, 12 refused,

and eight expressed interest and signed the consent form but the final turn up was only 6 women (see Table 2).

Participants were four Chinese (66%) and two Indian women (34%). Four were diagnosed within the last month whilst two others had been diagnosed about one year prior to participation. Their ages ranged from 42 to 60 years with a mean of 51.33 years. The majority (83%) were

married with two to four children. Three had completed education up to secondary level and another three had college level education. In terms of health status, fifty per cent had an activity level of "light" while the other fifty per cent rated their activity level as "active". Half had stage I cancer and the other half had stage II cancer. The size of tumors ranged from 1cm to more than 5 cm. All six had surgery (4 lumpectomy and 2 mastectomies). One woman received radiotherapy alone, two underwent adjuvant chemotherapy, two other underwent adjuvant radiotherapy and one received both chemotherapy and radiotherapy as adjuvant interventions. Fifty per cent of them were unsure of their grade of breast cancer; the other fifty per cent had grades of one to two. Half were unsure of their receptor status; the other half were Estrogen-receptor positive.

The nonparametric Wilcoxon one-sample signed rank tests were used for outcome evaluation (question 3). No significant differences (at p=0.05) were found on any outcome variables between pre test and post test (Table 3). Changes in scores for DASS and IPA showed minimal changes and mixed direction, although most other scores show a favourable unidirection. All three self-efficacy and the proactive coping scores showed a trend toward improvement at post-test. The result is in line with the positive feedback from the participants, and warrants a larger clinical trial. Facilitators for the program were identified as support from health providers, family and fellow 'buddies'. Numerous barriers were encountered during the recruitment process.

Discussion

There were several pertinent lessons and observations that were learnt during the trial. The evidence gathered from the earlier focus groups (Loh et al., 2007) informed the design of the 4-week SAMA that was pilot tested and presented in this paper. Since the sample size is small, this paper will present the quantitative findings briefly but will discuss the experience gain during the trial.

Firstly, facilitators for the participation of the program included the support from family, health professionals and fellow participants ("buddies"). Barriers to participation in the program were multi-factorial, ranging from medical appointments/ individual needs, linguistic barriers, work-child-household concerns, inadequate resources (transportation, accommodation during the 4-week program), side-effects, linguistic barriers and work concerns, children-household concerns and emotional distress of the cancer diagnosis. The most common barriers to accessing self-management support resources have been identified as lack of awareness, transportation problems, physical symptoms, and financial /lack of insurance coverage (Jerant et al., 2005). Thus, efforts to recruit participants for such intervention require support for the all involved –both health providers and family members. Ortherwise potential survivors in need of treatment may be missed out because they were either unreachable or they were avoiding contacts due to their depression. The result of this pilot showed improvement in raw mean-scores for quality of life, and cancer self efficacy as well as decrease scores in limitation in participation and psychological

distress, although the differences between pre and post test were not significant at p<0.05 level.

Psychological distress following cancer is another key issue amongst survivals (Baucom et al., 2006; Bultz & Holland, 2006; Kim et al., 2010), and hindering patients' participation in the program. Evidence showed that women with early breast cancer has twice higher prevalence of depression, anxiety, or both in the year after diagnosis than that of the general female population (Burgess et al., 2005). Predictors of depression and anxiety have been identified to be associated with lack of an intimate confiding relationship, younger age, previous psychological treatment, and severely stressful non-cancer life experiences (Burgess et al., 2005). Low support, insomnia (Burgess et al., 2005) and pain (Vahdaninia et al., 2009) were uniquely related to anxiety. Older age, decrease role function (Burgess et al., 2005), pain and fatigue (Vahdaninia et al., 2009) correlates uniquely to depression. Both the Burgess's 5-year cohort study (n=222) and Kim's study (n=828) provided the evidence that patient-factor, (not disease-related clinical factors) were related to either anxiety or depression. Depression, pain, and financial problems were noted as key barriers to active self-management (Jerant et al., 2005). Thus, patient self management targeting at the patient-factor by providing confidence, relaxation, financial support and plans to change behaviours is a justifiable therapeutic approach to improve care for patient.

Secondly, in Malaysia's health system delivery, many traditional Asian practitioners still hold paternalistic and time-conscious attitudes which do not facilitate collaboration. However, patient self management is not a concept unacceptable to Asian patients as there is research study (n=954) showing that it work even in mainland China (McGowan et al., 2003). Many patients were uninformed of their illness profile (Loh et al., 2009), and will remains unaware without a patient self management support. Half the participants reported needing more help to complete their assigned homework, especially the Profile of my Breast Cancer, a homework which required c ommunication with their health providers. These subjects were English educated ladies, and despite the program's inbuilt efforts to increase patients' confidence to approach their health care physicians via support and homework; their feedback does indicate a greater need for a change in the attitude of traditionally trained health providers who are not so willing/ready to partner with patients on care delivery. As an example, one woman expressed - "I know I don't need (and don't want) to go for a bone scan, but I am afraid to cancel the appointment and/or discuss [this] with my doctor". He/she might reply, 'Am I the doctor or are you the doctor?'. I don't want to offend her, and I am also worried that the staff may not accommodate [me] if I do need one in future". Frequent barrier to active self management have been identified as poor physician communication, low family support, having weight problems, difficulty exercising and fatigue (Jerant et al., 2005). More research evidence is needed to evaluate not just the efficacy of the self-management program in improving quality of life, but the barrier faced by patients and the readiness of Asian health providers to collaborate

with their patients by relinquishing some amount of autonomy to their patients. Thus, patient self management work should not just target at the patient, but education is needed to prepare the family and their healthcare team to work in partnership. Changes to the provider system, particularly within Asia's stiffled medical model system of delivery must be looked into. Asian traditionalists may feel that their ability to exercise their clinical judgement and professional autonomy is threatened by such change. However, these are process changes (not practice changes) that can start with increasing patient-provider clinical encounters (Jordan et al., 2008) and mapping patients' view (Ben-Trovim et al., 2008), thus making health services more relevant and effective. Barriers and incentives for new interventions clearly do not just occur at patients' level. Grol and Wensing (2004) highlighted factors at the organizational level such as improving the social context (network-collaboration-leadership); improving manpower and facilities (e.g. capacities and resources), economic and political context (e.g. policies and financing), as well as, selling the program (i.e.branding).

Thirdly, patient self management is a patient centred care (Barlow et al., 2002). The philosophy guided the planning of the 4 week SAMA self-management program with the short term aim of adhering to medical treatment and long term aim to prepare women to self manage living effectively with breast cancer. Intervention must improve the patients' confidence and proactive skills, so that they eventually focus (not on the cancer) but on building their health and wellbeing. The women reported a cognitive shift from being 'fixated' in the search for the elusive cancer cure, towards health-building and prevention of recurrence. There was also a misperception amongst the women who were called up, suggesting a prevailing view they were being invited to help rather than to receive intervention/support). This suggests a clinical environment with a lack of awareness of clinical trials and lack of information-dissemination or access to clinical trials. Perhaps more awareness of trials and trial registry (which is also not an urgent requirement yet in the Asian research community) would speed up awareness and acceptance. Having a website on cancer trials in Malaysia may help educate both the patients and health providers. Innovative program and services needed more awareness and support just for it to be tested, before it can be integrated into the health system (Rogers et al., 2008).

In conclusion, this study provides preliminary evidence that self-management programs are relevant to the needs of women with breast cancer in Malaysia, and have been tested subsequently in a controlled trial to gather the final incremental evidence based on the UK, MRC framework (MRC, 2000). The intervention at this stage seems feasible and acceptable to patients, despite features of medical model care that does not promote collaborative partnership with patients. Care for women with breast cancer should encompass the medical and non-medical issues because breast cancer impacted the quality of life of both the person's and carers/family. Greater action is needed so that health care providers, particularly within Asia's entrenched medical model of care adapt and innovate towards provision of comprehensive quality care

for the cancer survivors. The need for dedicated psychosocial service provision for survivors around Asia is warranted as women are becoming more educated and affluent. There is also a dire need to proactively plan for the numbers, placement and core skill set of the Asian health care workforce in order to meet the health needs of a rising population of cancer survivors with increasingly high expectations of health care. More staffing in (both quality and quantity sense) can ensure need-based intervention are developed carefully and implemented effectively, to ascertain successful delivery besides ensuring evidence based care.

Acknowledgement

This part of the study was funded by the University Malaya Vot F, the Australia International Research Scholarship, and the Malaysian National Cancer Council (MAKNA)

References

- Avis NE, Crawford S, Manuel J (2005). Quality of life among younger women with breast cancer. *J Clin Oncol*, **23**, 3322-30.
- Bandura A (1997). Theoritical perspectives. In self-efficacy: the exercise of control (pp. 1-10). New York: W.H. Freeman.
- Bandura A (1998). Health promotion from the Perspective of Social Cognitive Theory. *Psychol Hlth*, 13, 623-49.
- Barlow J, Wright C, Sheasby J, et al (2002). Self-management approaches for people with chronic conditions: a review. *Patient Educ Counseling*, **48**, 177-87.
- Baucom D, Porter L, Kirby J, et al (2006). Psychosocial issues confronting young women with breast cancer. *Breast Disease*, **23**, 103-13.
- Ben-Trovim D, Dougherty M, O'Connell T, et al (2008). Patient journeys: the process of clinical redesign. *Med J Aust*, 188, S14-7.
- Bodenheimer T, Lorig K, Holman H, et al (2002). Patient self-management of chronic disease in primary care. *JAMA*, **288**, 2469-75.
- Bodenheimer T, Lorig K, Holman H, et al (2005). Patient selfmanagement of chronic disease in primary care. Unpublished manuscript.
- Bultz B and Holland J (2006). Emotional distress in patients with cancer: the sixth vital sign. *Commun Oncol*, **3**, 311-4.
- Burgess C, Cornelius V, Love S, et al (2005). Depression and anxiety in women with early breast cancer: five year observational cohort study. *BMJ*, **330**, 702.
- Cardol M (2001). Beyond disability Assessing participation and autonomy in medical rehabilitation. WFOT Bulletin, 2004, 21-3.
- Crawford J, Henry J (2003). The depression anxiety stress scales (DASS): Normative data and latent structure in a large non-clinical sample. *Br J Clin Psychology*, **42**, 111-31.
- Fallowfield L (2004). Evolution of breast cancer treatments: current options and quality-of-life considerations. *Eur J Oncol Nurs*, **8S**, S75-82.
- Fawzy F (1990). In Merluzzi and Sanchez (1997) perception of coping behaviours Psycho-Oncology, **6**, 197-203.
- Fu D, Fu H, McGowan P, et al (2003). Implementation and quantitative evaluation of chronic disease self management programme in Shanghai, China: randomized controlled trial. *Bull World Hlth Organ*, **81**, 174-82.

- Giese-Davis J, Koopman C, Butler LD, et al (2004). The stanford emotional self-efficacy scale--cancer: reliability, validity, and generalizability. . In L. T. Nyklícek, & A. Vingerhoets (Eds.) (Ed.), emotional expression and health: advances in theory, assessment and clinical applications: . Hove, UK & New York 204-222 Brunner-Routledge.
- Globocan (2002). Cancer incidence, mortality and prevalence worldwide. version 1.0, from http://www-dep.iarc.fr/.
- Greenglass E (2001). Proactive coping, work stress and burnout. Stress News, 13.
- Greenglass E (2005). Domain specific proactive coping scale. In Oasis (Ed.) (pp. personal communication). Perth.
- Greenglass E, Schwarzer R, Jakubiec D, et al (1999). The proactive coping inventory (PCI): a multidimensional research instrument. Cracow, Poland.
- Greenlee R, Murray T, Bolden S, et al (2000). Cancer statistics-2000. CA Cancer J Clin, 48, 6-29.
- Hall A, Fallowfield L, A'Hern R (1996). When breast cancer recurs: a 3-year propective study of psychological morbidity. *Breast J*, **2**, 197-203.
- Irvine D, Brown B, Crooks D, et al (1991). Psychosocial adjustment in woman with breast cancer. Cancer, 67, 1097-117.
- Jemal A, Thomas A, Murray T, et al (2002). Cancer statistics 2002. CA Cancer J Clin, 52, 23-47.
- Jerant A, Von Friederichs-Fitzwater M, Moore M (2005). Patients' perceived barriers to active self-management of chronic conditions. Patient Educ Couns, 57, 300-7.
- Jordan J, Briggs A, Brand CA, et al (2008). Enhancing patient engagement in chronic disease self-management support initiatives in Australia: the need for an integrated approach. Med J Aust, 189, S9-13.
- Kim SH, Kang S, Kim YM, et al (2010). Prevalence and predictors of anxiety and depression among cervical cancer survivors in Korea. Int J Gynecol Cancer, 20, 1017-24.
- Koopman C, Butler L, Classen C, et al (2002). Traumatic stress symptoms among women with recently diagnosed primary breast cancer. J Trauma Stress, 15, 277-87.
- Lev E (2001). Counseling women with breast cancer using principles developed by Albert Bandura. Perspect Psychiatr Care, 36, 131-8.
- Lev E and Owen S (1996). A measure of self-care self-efficacy. Res Nurs Hlth, 19, 421-9.
- Lorig K, Sobel D, Ritter P, et al (2001). Effect of a selfmanagement program on patients with chronic disease. Eff Clin Pract, 4, 256-62.
- Lorig KR, David S, Anita LS, et al (1999). Evidence suggesting that a chronic disease self-management program can improve health status while reducing hospitalization: a randomized trial. Med Care, 37, 5-14.
- Lovibond S and Lovibond P (1995). Manual for the depression anxiety stress scales (2nd. Ed.). Sydney: psychology foundation.
- Luoma M and Hakamies-Blomqvist L (2004). The meaning of quality of life in patients being treated for advanced breast cancer: a qualitative study. Psychooncology, 13, 729-39.
- Merluzzi T, Nairn R, Hegde K, et al (2001). Self-efficacy for coping with cancer: revision of the cancer behavior inventory (version 2.0). Psychooncology, 10, 206-17.
- Merluzzi TV, Nairn RC, Hegde K, et al (2001). Self-efficacy for coping with cancer: revision of the cancer behavior inventory (version 2.0). Psychooncology, 10, 206-17.
- Mettlin C (1999). Global breast cancer mortality statistics. CA Cancer J Clin, 49, 138-44.
- MRC (2000). A framework for development and evaluation of RCTs for complex interventions to improve health In U. MRC health services and public health research board (Ed.)

- (pp. 1-19). London: Medical Research Council, UK. Rogers A, Kennedy A, Bower P, et al (2008). Optimising care for people with chronic disease: The United Kingdom expert
- patients programme: results and implications from a national evaluation. MJA, 189, S21-4.
- Schag C, Ganz P, Polinsky M, et al (1993). Characteristics of woman at risk for psychosocial distress in the year after breast cancer. J Clin Oncol, 11, 783-93.
- Shapiro S, Lopez A, Schwartz G, et al (2001). Quality of life and breast cancer: relationship to psychosocial variables. JClin Psychol, 57, 501-19.
- Sibley A, Kersten P, Ward CD, et al (2006). Measuring autonomy in disabled people: validation of a new scale in a UK population. Clinical rehabilitation. Measuring autonomy in disabled people: validation of a new scale in a UK population. Clin Rehabil, 20, 793-803.
- Loh SY, Packer T, Yip CH, et al (2009). Targeting health disparity in breast cancer: insights into women's knowledge of their cancer profile in Malaysia. Asian Pac J Cancer Prev, 10,
- Loh SY, Packer T, Yip CH, et al (2007). Perceived barriers to self management in Malaysian women. Asia Pac J Public Hlth, 19, 52-7.
- Vahdaninia M, Omidvari S, Montazeri A (2009). What predict anxiety and depression in breast cancer patients? A followup study. Soc Psychiatry Psychiatr Epidemiol, 45, 355-61.
- Von Korff M, Gruman J, Schaefer J, et al (1997). Collaborative management of chronic illness. Ann Intern Med, 127, 1097-102.
- Ware J (2002). SF-36® Health survey update, 2007, from http:// www.sf-36.org/tools/SF36.shtml
- Ware J, Keller S, Hatoum H, et al (1999). The SF-36 arthritisspecific health index (ASHI): I. development and crossvalidation of scoring algorithms. *Med Care*, **37**, MS40-50.
- Ware J, Kosinski M, Gandek B (2004). SF-36 health survey manual & interpretation guide. Lincoln, RI,: Quality metric Incorporated; 2004. .
- Zwar N, Harris M, Griffiths R, et al (2005). Systematic review of chronic disease management in primary care. Retrieved may 23, 2008, from http://www.anu.edu.au/aphcri/Domain/ ChronicDiseaseMgmt/approved_1_Zwar.pdf