RESEARCH COMMUNICATION

Qualitative Experiences of Breast Cancer Survivors on a Selfmanagement Intervention: 2-year Post-intervention

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Abstract

Background: Increasing survivorship warrants evidence-based intervention to help women manage living effectively with breast cancer. Breast cancer survivors may have many medical and psychosocial issues in the post-treatment period. Qualitative research was carried out to assess survivors' overall experience and if intervention helps in survivorship care. This paper reports exploration of benefit-findings from participation in an earlier 4-week self management intervention. <u>Methods</u>: We used a grounded theory approach to analyze three focus groups conducted between May and August 2010 in Kuala Lumpur. We used random sampling to recruit the informants (n=21), all of whom had earlier participated in the 4 week self-management program held two years previously. Findings: The women reported positive experience and growth with the self management program. Self-efficacy appears as an important underlying theme for successful experiences. The lack of proactive plans to provide bereavement support to surviving women was a key negative experience. <u>Conclusion</u>: The intervention successfully brought women together to work in close partnership with health professionals on ways to self manage the medical, emotional and role task as they live indefinitely with breast cancer, a new chronic illness. The beneficial effect from the 4 week intervention was expressed by women even at 2 years after the program. Having successfully developed a tightly knitted group, a major oversight was the lack of professional support on bereavement for grieving members when close friends passed away.

Keywords: Breast cancer survivors - chronic disease - focus groups - self management

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Introduction

By 2020, the total number of cases of cancer is projected to increase by 29% and 73% in developed and developing countries respectively (Boutayeb and Boutayeb, 2005). In Malaysia, 3,825 new cases of breast cancer were reported in 2000 and the incidence rate was estimated at 34.8 per 100,000 in the population (National Cancer Registry, 2003). Survivorship has been defined differently by varying organization. The UK Macmillan Cancer Support refers a cancer survivor as one who is living beyond cancer", i.e. completed initial therapy with no apparent evidence of active disease; or living with progressive disease (Support., 2010). The National Coalition for Cancer Survivorship (NCCS) defined survivorship as from the time of diagnosis to the balance of life, including dying from untreatable cancer, and the carers and family members. The contrast between the two concepts is the former is more traditional and exclude those in the terminal phases of illness and those with cancer in the past, whilst the later definition is more encompassing in terms of duration and people involved. However, a common idea on survivorship is the tendency to stress longevity of life after diagnosis, overlooking issues of quality of life (GA, 2010), especially so in developing countries. Quality of life is typically regarded as secondary to survival issues.

Breast cancer survivors have many medical and psychosocial issues and burdens from the time of diagnosis and many needs may lingers in the post-treatment period (Hoffman et al., 2009, Recklitis et al., 2010), which requires many self directed tasks like symptom management and surveillance of recurrence (Yeh et al., 2010). Perspectives from the Institute of Medicine's (IOM) 2006 report (Hewitt and Ganz, 2006) - suggests four key parts of survivorship care: i) prevention of recurrent and new cancers, and other late effects; ii) surveillance for cancer and assessment of medical and psychosocial late effects; iii) intervention for consequences of cancer and its treatment; and iv) coordination between specialists and primary care providers to ensure that all of the survivor's health needs are met. With this perspective, a model of care that enables survivors to self manage risks, late effects and health needs post diagnosis is thus needed.

There is a plethora of research into self-management support which relates to the provision of education and

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Siew Yim Loh et al

skills to enable day-to-day management of the medical, emotional and daily life tasks of living with chronic nononcology conditions (Lorig, 1996; Warsi et al., 2004; Bodenheimer et al., 2002). The central tenet of self management is improving self efficacy and working in partnership for better health. However, very few studies look at self management for cancer. Breast cancer, one of the cancers with good survival rate is gradually taking a form of chronic illness – which warrants a new model of care which can prepare women to live beyond diagnosis period. In this paper, we explore the qualitative experience from breast cancer survivors (i.e. women with first time diagnosis, and have attended a self management program about 2 years ago).

In 2004, we developed a study protocol based on the sequential stages outlined in the MRC Framework (MRC, 2000) for complex interventions, to gather incremental evidence on the efficacy of a self-management programme. The entire study was named as SAMA (staying abreast moving ahead). As an overview the first stage of the project uses focus group methodology to explore the needs of women (n=36), followed by the development of an intervention informed by the findings from the focus group, then a pilot study (n=6) of the 4 week program (below) and a final a clinical trial on the program (n=147, with 69 in experimental group and 78 in the control group) (Loh et al., 2007a; 2007b; 2010). This paper is a report of the final stage of evidence gathering -involving focus groups interviews on women who were on the experimental group and who had undergone the 4-week intervention program two years ago. The aim of the study is to explore both the women perception of and experiences after attending the program and if it has any bearing on their post treatment phase.

The 4 week Staying Abreast, Moving Ahead (SAMA) programme is a 'closed-group' intervention offered to women newly diagnosed with breast cancer. The development of this programme was guided by Bandura's social cognitive theory, and informed by four focus groups conducted earlier (Loh et al., 2007). The four week programme was designed to provide self management education, learn generic skills that can be applied to new problems as they arise, to practice new health behaviors and support via a patient-provider partnership.

Participants attended a once a week session over four week and were provided a workbook with group and individual exercises, according to the themes of each week. The activities for each week were theme-focused, respectively, on medical tasks management, emotional management, health and role management. Participants have to work out an action planning for each week. The aim of the programme was to enable women to stay informed by supporting them with the needed education. A further aim was to facilitate them in moving forward by engaging proactive coping and healthy behaviors. The program covers healthful behavioral intervention via core self management skills -i.e. problem solving, decision making, resource utilization, the formation of a patientprovider partnership, action planning, and self-tailoring. The detailed findings from the trial will be presented elsewhere.

Materials and Methods

Recruitment

This study was approved by the Medical Centre Ethics Committee (UMMC Ref 818.9). The study involved three focus group discussions (n=21). The groups comprised women with breast cancer identified from the database of those who had attended the self-management programme (on the experimental group). Participants were recruited by telephone, informed of the follow up study and invited to participate. Following their agreement 00.0 to participate, invitations were given. Prior to the focus group, explanations on the purpose of the study and the opportunity to withdraw at any time were offered to the 75.0 women. Women who attended the experimental group of the self management program 2-year ago were randomly selected to participate in the focus groups. Permission to audio-tape the sessions were obtained from participants.50.0 Confidentiality was assured and participants were reminded to respect the confidentiality of others due to the nature of the group format. One lead researcher together 25.0 with an independent note-taker, were present to moderate all three groups to ensure consistency.

Focus Group Guide

The group discussion focused on questions about the women's experiences after the four week self-management programme. The group explored insights into how members felt they had progressed or adjusted after SAMA. The women were also asked to discuss any messages they had for fellow survivors and health care professionals in relation to improving the quality of life of survivors. The focus group guide key questions were:

How would you describe your experience on the SAMA Program- Were there key positive experiences-Were there key negative experience

How have you progressed after the SAMA program?

Adjustment, coping ability, development

What should be considered in program to help women with breast cancer?-Unmet needs in treatment phase- New need in survivorship period

Share your last word about surviving and living with cancer

Data Analysis

The analysis of the interview transcripts was undertaken by two researchers and data management was aided with NVivo 8 software. The content were transcribed and anonymised and independently read - subjected to thematic analysis by two independent researchers to ensure internal reliability of the results (Pope et al., 2002). During this process, texts with a certain concept were axial-coded. These axial codes were expanded during the analysis process, and then grouped into larger categories and ultimately into themes by each researcher. Comments made by the participants were assigned to the appropriate categories and are used in this paper to illustrate and illuminate the findings. Finally the findings were compared and reanalyzed and decided by consensus if there were conflicting views. There were three groups of interviews which we felt was sufficient to get a

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Key Theme	Benefit-findings	Setbacks (Negative findings)	New or Special Needs	Self efficacy development
Sub theme 1	Increase sense of empowerment	Not prepared for death of buddies	Bereavement support	Information needs and role of moderator
Sub theme 2	Better emotional management, coping skills	Feeling abandoned	Follow-up care, and Survivorship series of Talks	Vicarious modeling
Sub theme 3	Dispel unhelpful myths	Unpleasant experience with their medical practitioners	Tailored program for those with recurrence	Actual performance and accomplishments
Sub theme 4	Improve healthy and balanced lifestyle		SAMA and Reach- out group for newly diagnosed	
Sub theme 5	Comradeship			

 Table 1. Categories and Sub-categories from the Focus Group Findings

feel/ feedback from the women on what happens after the two year break from the program and if they have progress because of their participation. There were no new themes after the third group.

Results and Discussion

Three main themes were identified: benefit-findings (positive experiences), setbacks (negative experiences) and self-efficacy and self development. These sub-themes under each category are presented in Table 1.

Demographics of Informants

The three focus groups were held in May to August 2010 at the University Malaya Medical Centre in Malaysia. The self management trial conducted in 2006-2009 (n=147) comprises of the experimental group (n=69) and the control group (usual care, n=78). Of the 69 women who attended the SAMA intervention program, about 10 percent (n=9) have since passed away - eight passed away due to the progression of the breast cancer and one passed away due to trauma sustained from a snatch thief incident. In addition, eight women had a recurrence of their breast cancer. Letters were randomly sent out to 50% of these women, and those who agreed on the telephone were invited to attend a focus group interviews. A total of 21 women participated across the three focus groups (n=6, n=6, n=9 respectively). Demographic information included: an age range of 30 to 64 (mean = 50.67), and education levels from grade 6 to tertiary education. Their occupations include: housewives (n = 5), nurse (n = 2), manager/administrator (n = 4), clerk (n=2), freelance writer (n = 1), beautician (n=1), retired newscaster (n = 1)1), retired accountant (n = 1), shop owner (n = 1), public officer (n = 1), and non-government worker (n=2). In terms of marital status, they were mostly married (n=16), with one divorcee and the remainder are single women. Of the 21 survivors, 81.0% were Chinese (n=17), followed by 9.5% Malay (n=2) and 9.5% Indian (n=2). The mean body mass index for all women was 22.1, ranging from 17 to 31.

Theme 1: Benefit Findings

The first theme relates to the positive experiences derived from the SAMA programme. Survivors reported

being very satisfied with the four week self-management programme and most of their views indicate a level of positive self development both during and after the intervention. The emergent categories were feeling empowered, better emotional management, myths dispelled, an increase in coping skills, comradeship benefits, improved health and a more balanced lifestyle. One of the aims of the programme itself had been to address the lack of information as revealed in the earlier study which found that unavailability of information was a key issue (Loh et al., 2007). The participants acknowledged that the information provided in the SAMA manual and during the sessions was sufficient and had empowered them. One woman added,

"The programme provided me the needed information, but what was important was, the information was delivered in incremental dosage so that I don't feel overloaded. In fact, it also made me more resourceful, seeking services and help proactively. I feel I can talk better and more confidently now with my doctor" (n2f2).

"...this is very good programme especially for people who are still in the process of treatment. If they come to SAMA, I think they can dispel a lot of negative thinking and unhelpful beliefs (myths) that some other people have been planting into their head. You know a lot of people will come and tell you; and cautioned you that you cannot eat this, cannot do this, cannot do that etc.... For me, I can do everything... and am still working actively" (n4fg1).

"The SAMA programme is really good but I joined it late in my treatment, it was almost a year after diagnosis. So I feel for me personally the benefit was more in comradeship because I was reading a lot about cancer at that time, I knew quite a lot already, but I loved the companionship. And I think the SAMA programme is very good for people who have maybe just before surgery or they are admitted into this programme it would be very beneficial" (f1n3).

Another key aim of SAMA was to enable women to move on by providing them with self- management skills and support. Women revealed that they kept close contacts with their buddies (women were assigned to each other during the programme based on similar medical characteristics and/or similar housing to facilitate rapport and support) even after the programme ended.

Siew Yim Loh et al

They organized their own get together in the community and kept follow up with each other. Almost all of the women openly shared that the SAMA programme contains proactive processes which enhanced their selfmanagement skills, rendering them more able to cope with the condition and the day-to-day tasks of living. One woman even expressed,

"Without SAMA, I most probably would go into depression. I was crying all the time because of the diagnosis and everything including my marriage was falling apart. Joining SAMA at the right time saves my life and I could be independent for my children. I have even gone into advocacy work. My colleagues at work even commented that I am a more confident person today". (n1f6)

Theme 2: Setbacks (Negative Experiences)

With the second theme of setbacks, a key category was about unpreparedness for the death of members of the group. At least three groups faced the death of one of its group members during the two year period. The women expressed that SAMA was proactive in preparing them to live and self manage but with regards to the passing of their buddies, they were unprepared. They expressed that SAMA have knitted them closely together like sisters and although they were positively living their lives, but felt that they were ill equipped for the loss of member (buddies) from their close group. Many women revealed that they were badly affected, especially when one of the women who were very active in their group succumbed to the breast cancer. One woman shared,

"I think all of us were affected too (death of another member). It's only natural. But for me I feel that at the end of the day you don't have to have cancer to die. You can just walk out and a car can knock you down....And I have a friend...42 years old –died of heart attack. Yes I do worry when I hear about your friend (i.e. another member's sharing) who had relapse after 7(surviving) years. It's definitely frightening and sad but I think we have to be positive. Face it. Go for treatment again if there's a chance. If really no chance you have to accept it. It's part and parcel of life. (n1fg3)

"When I heard she passed away, I was so shocked because she was so active, I really liked her and I find it hard to accept her death, I was crying away. Although a few of us decided to meet up to console-support one another, we were quite lost and were looking for some guidance or professional help" (n1fg2).

Another woman suggested that the centre should provide bereavement training to prepare them to better deal with the passing of their buddies, which was supported by the rest in the group. Several women also added that the two years after the programme was a long lapse of time, making them expressed that they felt neglected or unattended for far too long, and thus were really looking forward to coming when they were invited to attend the focus group meeting. They expressed that there should be some kind of follow-up programme after SAMA.

"Definitely I feel that the idea of an aftercare **1562** Asian Pacific Journal of Cancer Prevention, Vol 12, 2011

programme is very crucial...the two year lapse was too long. I feel that it is a very, very good idea because there are also many aspects of after care to think of......I think there's a lot of work...but even so (now) in terms of (after treatment period)... that's why it would be nice if you can offer us after care so that we could take it up from here." (n8fg3)

Almost half of the women felt that they had had unpleasant experiences with their medical practitioners after the diagnosis of breast cancer. Across all groups, the main complaints were related to the lack of time and the hurried manners of the doctors and some poor relational –communication skills. Women across the focus groups shared their identification of their physician's lack of communication skills, often evading their questions and showing inattention to their psychological needs - as very frustrating.

"I hardly see the oncologist, they must be really very busy... it's always the medical officer on duty" (n3, fg1) "(Sigh)... you don't have much time to talk to the doctor... always so busy and I was always seen by the medical officer only – where is the oncologist?" (n5fg2).

"Health staff ... needs to be more humane! You don't have to hold us and cry with us, but just be a bit more humane. (Sigh) 'Why you ask me that question? -- You know the way some (health staff) answered you? .. It's like "Ok and that's it!....as if telling us - please don't come near me and pushing us away. We're desperate at that point in time. So I tell you- this SAMA programme really stood out and hold us up because that was where I found myself again. If I were to go through those docs' retorts - I may die faster. Health professionals should put themselves in our shoes in order to understand us better, we are not demanding, we are quite fearful and all out to seek help and support" (n1fg3).

There is ample research evidence indicating that medical practitioners' behavior may influence the patientprovider communication which is crucial for ultimate therapeutic effect (Martinez et al., 2009, Step et al., 2009, Venetis et al., 2009, Vogel et al., 2009). Literature also suggests that patients' anxiety and dissatisfaction is commonly related to uncertainty and lack of information, explanation, and feedback from the doctor (Arora, 2003).

Theme 3: New Needs/ Special unmet needs

There were four categories under this theme on new needs. These were bereavement-support, follow up care and talks, programmes for women with recurrences, and outreach groups for the newly diagnosed.

i)Bereavement-specific information: Grieving the death of a person often involves intensely painful feelings which may come and go with varying intensity over months or years. The buddy-system-like mechanism established within the SAMA programme had facilitated a close kinship relationship, and thus the lost of a buddy was like the loss of a loved one. It also triggered introspection about their existence and survival status. The women

Barriers to Exercise: Perspectives from Multiethnic Cancer Survivors

suggested a structured session to help them dealt with death. A bereavement group would seem to be needed for the survivors to prepare them with ways of dealing with grief as well as monitoring their psychological adjustment to loss and death. The health care team can help normalise the grief process and helping the survivor view death as a natural part of life which can lead to an enhancement personal development (Kutner and Kilbourn, 2009).

"Especially in our group, if we hear of someone who had a recurrence or someone who has passed away, fear sets in. I could go on and say I am fine, but if I look inwards I'm going to see I am afraid, I am scared. .. need some support" (n6fg3)

"We actually wanted to call you up (the group facilitator) and maybe meet and just talk about it as we were quite affected." (n2fg2).

ii)Follow-up care and special needs: Some group members reported being 'left unattended (n5fg2)' due to the fact that there was no programme or any activity available upon the termination of the four week SAMA programme. They proposed a follow-up programme as a source of social, moral and emotional support during their survivorship period. They suggested a series of monthly talks on current topics. They proposed updates or specific talks or seminars by the experts on breast cancer which may address newer long term side-effects from their previous treatment. Current strategies to reduce this disparity in care does focus on logistical and information needs, whilst contextual factors, such as concerns about long term treatment side effects, may also represent significant barriers to quality living during survivorship period. Survivorship clinics perhaps can be initiated for those faced with new symptoms or new quality-of-life issues to assist with action planning or provide counseling sessions to self manage living indefinitely with cancer.

iii) New needs: A number of women experiencing recurrence of their cancer also expressed a need for a special group to help those affected by a cancer recurrence. Women felt that such programs need not be long programmes, but that it can be more of a revisiting of activities from the SAMA programme, as these women needed additional support to manage their emotional upheavals again.

iv) Out-Reach for newly diagnosed: The women felt the program beneficial to them and thus would be beneficial to other newly diagnosed who would be searching for support upon diagnosis –just as they have experienced. Thus, with an established center or location gazette for cancer survivorship agenda within the medical setup, newly diagnosed can easily self referred for such similar self management program.

Finally, one woman (a writer) was very vocal about the term 'survivor' and 'survivorship' as it had a negative connotation to her. Her interjection received some agreement from the group, but as suggested by another member – "*I have not really dissect the word', just happy that I am surviving cancer'*. Although this was not heard throughout the group, but it is a proactive issue that can be explored in more depth in future groups. If indeed cancer is becoming a chronic disease just like stroke and arthritis, perhaps the word survivor should be dropped if it is not helpful in facilitating people to move on in life..

"Survivorship suggests there's a possibility of it (cancer recurrence) around the corner. There's always that thought which is not so pleasant, although I'm very upbeat about things. For me, cancer was... a moment in my life where there WAS (word was stressed) a bump, I'm happily on my way now. Still sometimes when things don't feel right –e.g, when I get a bit of pain or lump here and there, it does throws me back into that gloom...that word scares and restrict me and thus, I don't like the word 'survivorship ... "(n6fg3).

Theme 4: Self Efficacy Development

This fourth theme emerged, and was related to expressions of personal development and confidence with life experiences, which we felt was specific and could be explained as the self efficacy processes. This theme was finally renamed, 'self-efficacy building'. These efficacy expectations or processes relates to Bandura's self efficacy (Bandura, 1977) which was defined as - the personal judgments in one's ability to succeed in a particular situation, and which is determined by how people think, behave and feel. Efficacy expectations are formed through information derived from actual performance, accomplishments, vicarious experience, verbal persuasion and physiological states. The women expressed that the information provided in the programme as well as the support amongst group members has helped build-up a sense of empowerment and confidence to self manage the illness and promote health. The categories grouped under the theme self efficacy building were: i) Information needs and the role of moderator, ii) vicarious modelling and iii) actual performance and accomplishments.

The first category of findings comprised of comments from women related to how the information and manual provided the needed support during their sickness. Women with breast cancer described the programme as a positive experience and one through which their primary need for information was met in incremental ways, thus building confidence to make decision and move on.

"My surgeon just said "Ok you got stage 1, and it's near to the nipple –and that's it!.(with higher tone, both hands lifted up and a agitated/ disbelief look). I didn't know that there are other things in that as well which in a way I was only informed when joining SAMA. Then, I was able to refer back to the surgeon during my checkup... like, Ok you removed my lymph nodes? May I know how many you removed? How many was cancerous?" Do I have this oestrogen hormone positive, what about my herceptin status things like that you know, which I am now more confident and able to ask..." (n4fg1).

"It really helps me understand what is wrong with me actually, and the information over the four weeks was so helpful and no, there was no information overloaded- it was given in tolerable dose over the weeks with lot of support to help me through the crisis period" (n1fg2).

"I didn't wanted chemo...for all the bad things I heard and some of the people I know didn't have chemo. And I

Siew Yim Loh et al

had made decision base mainly that I didn't want to lose my hair....then I slowly understood from SAMA that some women like myself will need chemo...because my stage and grade was high and this sort of decision based on being informed is important for my survival . hey, I want to live to see my kids have kids...." (n1, fg3)

Also, the non-stigmatised milieu of the SAMA programme allowed group members to ease themselves into full participation and be open in sharing or learning from each other. For example, during a SAMA session, each survivor was asked to describe what she would like to tell other women who were newly diagnosed with breast cancer. The implication was that survivors were able to exert control and choice over aspects of their reactions to their diagnosis and treatment. For most women, their main source of support throughout their experience was SAMA - buddies and the health facilitators who provided formal support, and whose efforts were valued. Some women had negative feeling about the diagnosis and their altered body image but these negative emotions were calmed after they realized other participants in the groups had similar issues:

"When she said "I've got a pain here and there" and then I said, "Yeah! Me too!" Then you don't feel like you're so abnormal, or something is wrong with you, or that you will get a recurrence ...some days i feel like I am becoming psychotic. But, being in the SAMA group gives reassurance..like a sense of 'security'- to feel at ease to move on ... and/or makes me able to see what I can do about some symptoms or to live with it, without worrying excessively like before" (n1fg3).

The second category highlighted the importance of vicarious experience to encourage a positive learning environment in groups. The SAMA programme provided a vicarious modelling environment for the group of survivors with a diagnosis of breast cancer. Women with breast cancer perceived that taking an active self-help approach contributes to their calmness (i.e. physiological) and the empowerment feelings which then facilitates confidence-building (psychological) in self-managing breast cancer (behavioural) as well as fostering lifestyle changes. The programme was facilitated by a health professional with counseling background. The motivational interaction strategies were used to motivate women to contemplate changing towards more healthy lifestyles (Bandura, 1997). One survivor shared,

"... I see how other women change and I followed (i.e. modeled) and work towards living well such as eating well and exercise more, and using the SAMA workbook provided by Dr LSY ...and guided me step by step" (n3fg1). "Luckily for me, the group I came to know - most of us did somehow have quite positive attitude. It also lends support to myself – I consoled myself that if people can be like that (positive), why can't you? I also think if everybody comes in with that kind of positive attitude, if among the group members, there are some who are not so, probably it (group) will help to bring them up also. I think the package **1564** Asian Pacific Journal of Cancer Prevention, Vol 12, 2011

(program) is very good because other than talking about what to treatment and what eat and all that. I feel the emotional support is there. It was there, it did give me a boost ...and I can carry on with life! Other people can, so can I! I mean all of us share our experience, what we do and all that.. and we see and hear and learn" (n4fg2).

The third category refers to the significance of the actual performance in promoting change in behaviour. The SAMA manual encompassed a range of management options to develop self-management skills such as the guide on behaviour change related to lifestyle, being proactive, and effective use of community resources. Participants reported they had adopted what they learnt from each other such as building a physical activity routine. They gained a sense of accomplishment from repeated practicing of skills which subsequently persevered with became part of their lifestyles. Some women shared that they have moved on from self preoccupation to being able to share their knowledge and experience learned from the SAMA programme with others and as a result gain more mastery and confidence.

"After participating in this SAMA programme, I even taught my friend how to do breast self examination" (n2fg3). I'm a non exercise person actually...but I find that I am now more aware and conscious about exercise and diet and managing even my emotions. (n2fg1).

The development of self efficacy through the various mechanisms was found to be a major driver in the ways women attempt to adjust to living after their breast cancer treatment. Literature suggested that interventions to promote self-efficacy may increase quality of life and decrease symptom distress for women diagnosed with breast cancer (Lev and Owen, 2000). It was encouraging that the programme had obviously been designed with a strong theory base. In addition using the themes identified in the focus groups, we could reflect and justify how and why the programme has worked for these participants.

Overall, the participants reported a strong positive experience and response towards the SAMA programme. The findings here provided the qualitative evidence to support the findings from the SAMA programme which offered the self management program in incremental ways, thus building their self confidence. It is a potential model of intervention for positive transition to survivorship. It fills a significant gap in supportive cancer care services to facilitate the cancer recovery and increase to the quality of life for survivors of breast cancer. Insights from these expert patients (survivors of breast cancer) provided convincing evidence that a comprehensive survivorship care and in line with the perspectives from the Institute of Medicine (Hewitt and Ganz, 2006) on key aspects of survivorship care is long awaited. These expert patients voiced a need for empowering them with support to prevent recurrences, monitoring late effects, self managing consequences of cancer and its treatment, and coordination between specialists and primary care providers to ensure that all of the survivor's health needs are met (Hewitt and Ganz, 2006). Lastly, in the light of breast cancer becoming

Barriers to Exercise: Perspectives from Multiethnic Cancer Survivors

a chronic illness, and the call for better survivorship care, we conclude with the assertions from Rowland and colleagues, 2006 from the NIH's Office of Cancer Survivorship.

"But no individual with a cancer history should be treated as though his or her illness never happened; ...will need to be educated about what implications their illness has for their future health care and decision making".

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