

RESEARCH COMMUNICATION

Targeting Health Disparity in Breast Cancer: Insights into Women's Knowledge of their Cancer Profile in Malaysia

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Abstract

Objective: Poor health literacy is positively associated with poorer quality of health decision-making and health outcomes in women facing a cancer diagnosis. In developing countries, poor access to complete and accurate information continues to pose a challenge for women. This paper describes the knowledge of Malaysian women with regard to breast cancer and how participation in a self-management program can improve the situation. **Methods:** Secondary analysis of data collected during a clinical trial on women newly diagnosed with breast cancer (n=147) was performed to examine baseline knowledge of breast cancer profile. Knowledge levels of women in the experimental (n=69) group attending a self-management program were compared to a control group (n=78) to determine change in the level of knowledge over time. **Results:** At baseline, a high percentage of women were unaware of their breast cancer profile. Not a single woman had knowledge of all six basic characteristics; 83% did not know their HER2 status, type of breast cancer (68%), grade of cancer cell (64%), hormonal receptor status (55%), size of breast cancer (18%) and/or their stage of breast cancer (13%). At post intervention, there was significantly better knowledge within the experimental group. **Conclusion:** Malaysian women in this cohort study demonstrated very low levels of knowledge of their cancer profile. Clinical implications for countering treatment-decision difficulties include the need for a shift in the way information and services are delivered to allow women to take a more active role in their own care. Multi-modal efforts including basic information dissemination to increase women's knowledge can contribute to narrowing of the gap in health disparity.

Key Words: Breast cancer - knowledge level - treatment decision making - health disparity

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Introduction

Women's health can be negatively affected by lack of education, inadequate information and a lack of awareness of the factors contributing to the disease (Luddy, 2007). Low health literacy contributes to poor treatment compliance, uncontrolled chronic disease, and high health-care utilization (Nielsen-Bohlman et al., 2004). Treatment decision difficulties, defined as difficulty in making decision about treatment, have been shown to predict persistence of psychological morbidity following breast cancer surgery (Lam et al., 2005; 2007).

In many health care settings, the emerging trend is for involvement of patients in the management of their illness and thus it is important for them to have access to essential information to assist with decision-making (Rees & Bath, 2000; Lam et al., 2007). Health literacy research has focused on patients' ability to obtain and understand information and services relevant to appropriate health decision-making (Healthy People 2010, 2006). It appears that adequate, relevant information helps to facilitate decision-making, coping and psychosocial adjustment (Yadav, 2001; Iconomou et al., 2002; Lam et al., 2007;

Luddy, 2007) and was a key reason for the variation in survival rate (Wishart et al., 2009). Thus, women newly diagnosed with breast cancer need to know the characteristics of their breast cancer to assist decisions regarding treatment options. While it may not be possible for women to know everything, little is published and there is no consensus on what constitutes essential, basic information on cancer characteristics, particularly for women in Asia. There is even less understanding of the information needs of family members of cancer patients (Rees and Bath, 2000; Adams et al., 2009), an area of potential importance and practice implications for the tightly knit Asian families. Evidence now indicates that women with breast cancer are dissatisfied with information received from their health professionals (Raupach and Hiller, 2002; Loh et al., 2007).

A systematic review by Degner (1997) gave rise to nine categories of information needs of people with cancer covering causes, cure, treatment and side-effects, effect on family and friends, risk to family, as well as its impact on daily activities, social and sexual concerns. Graydon et al (1997) proposed five information needs : 1) nature of disease, its process and prognosis, 2) cancer treatments,

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3) investigative tests, 4) preventive, restorative, and maintenance physical care and 5) patient's or family's psychosocial concerns. These broad areas are aligned with the content and theoretical underpinnings of self-management programs. Although common in some countries (Gore-Felton and Spiegel, 1999; Lam et al., 2007) most developing countries in the Asia Pacific region do not include patient self-management (incorporating patient education) in their clinical practice guidelines.

This research aimed to understand the level of knowledge on six basic characteristic in cancer profiles of Malaysian women (n=145). Thus, the main research question was - How much do women newly diagnosed know about their breast cancer profile? To further examine the impact on knowledge of a self-management intervention, knowledge levels of women allocated to a self management intervention group (n=69) were compared to the knowledge levels in the control group undergoing usual care (n=78).

Materials and Methods

Design

Secondary analysis of data collected during a clinical controlled trial (CCT) was undertaken to investigate the baseline knowledge of women newly diagnosed with breast cancer participating in the trial and to compare follow-up knowledge levels of the intervention and control groups. The aim of the CCT was to test the impact of a 4 week patient self-management intervention program to enable women to self-manage the medical, emotional and role-related tasks, i.e. tasks that need to be dealt with on a day to day basis by patients with chronic illness (Corbin, 1998). In addition to receiving usual care, the 69 women in the experimental group meet once a week over four weeks to discuss medical, emotional, and role tasks and how to live a healthy life after a diagnosis of breast cancer. The self-management intervention was informed by four qualitative focus groups conducted to explore the self management needs of Malaysian women with breast cancer (Loh et al., 2007). Chronic disease self-management principles and psychosocial theory underpinned the intervention; themes from the four focus groups also informed the content.

The control group consisted of 78 women who received only standard medical care or surgery, adjuvant therapies and, as appropriate, targeted therapies. The time series clinical trial with the experimental arm preceding the control arm was nonrandomized to counteract the possibility of contamination by diffusion (Trochim, 2002) because the cancer clinic is confined to a specific location, and the intervention was not a single session but lasted for four weeks. Ethical approval for the trial was obtained from the University Malaya Medical Centre Research Ethics Committee, the Malaysian Ministry of Health Ethical Board and the Curtin University Human Research Ethics Committee.

Participants

All participants (n=147) had been diagnosed with stage 1-IIIa breast cancer within the twelve months prior to

commencement of the trial. The women were screened for eligibility based on the following inclusion criteria: i) more than 18 years of age; ii) diagnosed with Stage 1-IIIa cancer within the last 12 months (first diagnosis, and confirmed by a physician); iii) undergoing adjuvant/hormonal therapy; iv) able to read and understand English; and v) gave informed-consent. Exclusion criteria were: i) marked cognitive impairment or learning disabilities (through observation/ interview); or ii) based on self-report, any other form of medical problem(s) that would interfere with participation and/or attendance. Prior to commencement all provided signed, informed consent to participate.

Measurement Tool

A patient information questionnaire (PIQ) was specifically designed for use in the self-management intervention and trial. The PIQ collected demographic data and self-reported data on women's knowledge of their health profile, cancer profile and treatment profile. The PIQ was reviewed by researchers and a breast surgeon for face and content validity. It was then pilot tested with six women with breast cancer. Minor alterations improved comprehension and presentation of the PIQ. During the CCT, the PIQ was completed at three different times: baseline, follow-up at four weeks and at eight weeks later.

Data analysis

For each of the six characteristics in the breast profile, level of knowledge was categorized as either known or not known. Those who knew any of the characteristics were asked to provide information (e.g. for stage, to indicate whether 1,2 or 3). The demographic and clinical characteristics of the sample and the level of knowledge (at baseline and at post intervention) were described using descriptive statistics, including number of women in each of the two categories, and where appropriate, the two groups were compared using either Pearson Chi-Square (χ^2) for categorical variables or independent-samples and t-tests for continuous variables. The analysis compared the baseline data to the data obtained at follow-ups (i.e. at the 4th and 8th weeks)

Results

Demographic data

Most participants were between 40-59 years of age (almost 80%), married (76%), of Chinese ethnicity (65%), and had at least secondary level formal education (49%) or tertiary education (51%). About 53% of the women had some form of insurance whilst 47% had no insurance. About 75 % had been newly diagnosed within the previous six months while the other 25% had been diagnosed for at least six months to one year.

Level of knowledge at baseline

Out of 147 women, not a single woman was found to know all six basic characteristics of their breast profile at baseline. Most women were unaware of one or more of the six characteristics of their breast cancer profile. The most common areas of knowledge were the stage, type,

Table 1. Participants' Self-reported Knowledge of Breast Cancer Profile (at baseline and at 4-8 weeks later)

Parameter	Category	At baseline (T1)					At 4-8 weeks later				
		Exp (n=69)		Control (n=78)		χ^2 p	Exp (n=69)		Control (n=78)		χ^2 p
		n	%	n	%		n	%	n	%	
Stage	1 -3	62	89.9	66	84.6	-	69	100	74	94.9	-
	Not Known	7	10.1	12	15.4	0.108	0	0	4	5.1	0.075
Type	In situ/Lobul/Ductal	23	33.3	24	30.8	-	55	79.7	26	33.3	-
	Not Known	46	66.7	54	69.2	0.651	14	20.3	52	66.7	0.001*
Size	0.1cm to >5 cm	62	89.9	58	74.4	-	67	97.1	69	88.5	-
	Not known	7	10.1	20	25.6	0.017*	2	2.9	9	11.5	0.083
Grade	Grade 1-3	26	37.7	27	34.6	-	51	73.9	36	46.2	-
	Not known	43	62.3	51	65.4	0.943	18	26.1	42	53.8	0.002*
Receptor	ER / PR +/-	30	43.5	36	46.2	-	57	82.6	42	53.8	-
	Not known	39	56.5	42	53.8	0.720	12	17.4	36	46.2	0.000*
Her2 status	Her2 +/-	11	15.9	14	18.0	-	41	59.1	20	26.6	-
	Not known	58	84.1	64	82.1	0.925	28	40.6	58	74.4	0.000*

Exp, Experimental; +, positive, - negative; ER, Estrogen, PR, Progesteron, HER2, Herceptin

Table 2. Number and Percentages of Women Unaware of their Profile at T1 and at T2

Profile	Experimental Arm (N=69)					Control Arm (N=78)				
	T1		T2		% change	T1		T2		% change
	n	%	n	%		n	%	n	%	
Stage	7	10.1	0	0	100.0%	12	15.4	4	5.1	66.7%
Type	46	66.7	14	20.3	69.6%	54	69.2	52	66.7	3.7%
Size	7	10.1	2	2.9	71.4%	20	25.6	9	11.5	55.0%
Grade	43	62.3	18	26.1	58.1%	51	65.4	42	53.8	17.6%
Receptor	39	56.5	12	17.4	69.2%	42	53.8	36	46.2	14.3%
HER2	58	84.1	28	40.6	51.7%	64	82.1	58	74.4	9.4%

size and grade of breast cancer (Table 1). A higher number of women were unaware and were never informed of their hormonal receptors and/or HER2 status. Comparisons between groups at baseline indicate that, with the exception of tumor size, there was no difference in knowledge between the two groups. In terms of tumor size, there was a significant difference (p=0.017) with 10.1% women in the experimental group unaware compared to only 2.9% of women in the control groups.

Level of knowledge at follow up

With at least four weeks follow up (data from the 4th and 8th week follow-ups), there was a significant reduction in number of women who were unaware of their cancer profile (compared to baseline). On all 6 characteristics (stage, type, size, grade, receptor and HER2 status), women in the control group had lower levels of knowledge than women in the intervention group. The differences between groups reached significance for all characteristics except for the stage and size of cancer (Table 1). The percentages of women in the experimental whose knowledge level remained in the "not known" category were much lower than in the control group: 20.3% versus 66.7% (p=0.001) for type of cancer, 26.1% versus 53.8% (p=0.002) for grade of cancer cells, 17.4% versus 46.2% (p<0.001) for hormone receptor status, and 40.6% versus 74.4% (p<0.001) for HER2 status.

For each of the six characteristics in the profile the percentage of women whose knowledge level moved from "not known" to "known" was also examined (Table 2). In the experimental group the improvement by characteristic ranged from 52% -100% compared to 3.7% to 66.7% in the usual-care control group (p<0.05). This

showed that the intervention program had an effect on women's awareness of their breast profile. The result showed a positive shift and an increased level of knowledge from the baseline self-reported level.

Discussion

The majority of the women in this study had at least a secondary level education and over half had been diagnosed from six to twelve months prior to data collection. However, over 50% did not know their breast cancer profile, and not even one of them was aware of the full 6 basic characteristics of their cancer profile at baseline. This data supports results of a previous focus group with Malaysian women with breast cancer in which unavailability of information emerged as a key theme (Loh et al., 2007). The consensus voice was that there was a serious lack of information on breast cancer, and that information was not easily available from the medical centre and/or hospitals in Malaysia.

Information was not offered by health professionals in the field (Loh et al., 2007). Inability to access accurate information at the right level of clarity needed by women generated feelings of helplessness and a sense of loss and distress (Raupach & Hiller, 2002; Ankem, 2006). These findings are echoed by others, who have demonstrated that unavailability of information influences various patients' treatment preference, decision making and participation in care effectively (Abotchie & Shokar, 2009).

Research evidence confirms a positive relationship between lack of information and increased uncertainty, anxiety, distress, and dissatisfaction (Van der Molem,

1999). In fact, studies specifically suggest that the level of distress in patients with serious illness is reduced when they perceive that they have received adequate information (Robert et al, 1994; Raupach & Hiller, 2002). Efforts to ensure women receive adequate information, especially fundamental information, appears to have a profound impact on quality of life (Fallowfield et al., 1990). It was encouraging that the experimental group showed an increased level of knowledge of their breast cancer profile over time, when compare to the women in the control group. The results showed moderate-to-large reduction in the number of women in the experimental group selecting the 'I don't know' option compared to the control group. Although the reason for the increase cannot be confirmed, it is likely to have been the result of one structured homework exercise women were asked to complete. Women were given information about the causes of and treatments for breast cancer and invited to collate their breast cancer profile over the four weeks of the program. Other activities during the four weeks included discussion of issues related to the medical, emotional, health and role tasks that they encountered. Women shared their own situation and experience, often speaking of their disease during the discussions.

The results showed that there were improvements over time in the intervention as well as in the control groups who underwent usual care. Nevertheless, a substantial percentage of women in the control group were still unaware of their breast profile even after a period of eight weeks. Between the control and intervention groups, the number of women unaware of their profile were - stage of cancer (0 versus 5%), type of cancer (20 versus 67%), size of tumor (3 versus 12%) grade of cancer (26 versus 54%), hormonal receptor status of cancer (17 versus 46%) and HER2 status of cancer (41 versus 74%) respectively. As an example, 10 percent of women in the intervention group (n=69) were unaware of their stage of cancer at baseline, but at follow-up all developed awareness of their stage of breast cancer. In contrast, there were 15 % of women in the control group (n=78) who did not know their stage of cancer at baseline. Although there was also a reduction at follow up (which suggests information obtained over time) about five percent women still did not know such basic information (Table 1). Although there was a reduction in the number of women who were unaware of their breast profile, it was minimal. In fact, with knowledge of tumour size at baseline measurement, there were significantly more women in the experimental group than the control (10.1% versus only 2.9%), but improvement in level of knowledge was greater in experimental at 4-8 months later.

A large quantitative survey (n=2,331) has also refuted the prevailing myth that people with cancer prefer not to know the specific nature of their cancer, and it provided conclusive evidence that they wanted specific information about their illness (Jenkins et al., 2001). Despite this, other studies have shown that the majority of the decisions continue to be made by health professionals on patients' behalf with little input from patients themselves (Degner et al., 1997) and aggravated by the finding that members in the multidisciplinary team are unaware of each others'

informational roles (Jenkins et al., 2001). Perhaps if people were provided with the necessary information, they would be more able to adopt decision-making responsibilities in collaboration with their health professionals. This process may also decrease cost-utilisation of hospital services and enhance the quality of patients' participation and collaboration. This finding has practice implication as such fundamental information can facilitate women's ability to participate and be actively involved in their care plan and take informed actions. The International Alliance of Patient Organizations (IAPO, 2006) championing patient-centered care, contends that "Health systems in all world regions are under pressure and cannot cope if they continue to focus on disease rather than the patients, they require the involvement of individual patients who adhere to their treatments, make behavioral changes and self manage" (p1). In line with this contention, education is needed, and at the very least, the most fundamental information of the disease must be provided and be easily accessible to women and their families.

In order to make informed decisions about treatment options and living with a cancer diagnosis, studies are needed to further understand what information do health professionals provides or should be providing to the women with breast cancer to improve participation in decision-making, self management skill, and ultimately quality of life. This paper presents preliminary evidence that women with breast cancer were unaware of very basic information. The study has clinical implications suggesting the need for health system to address this deficiency by ensuring all patients are provided with the fundamental information readily at diagnosis. There is an urgent need to impart education and self management skills as part of patient self-management interventions for women, since education plays a vital role in reducing the mortality and morbidity of women with breast cancer. Its role in reducing health disparity should be emphasized and disseminated in clinical care practice and education of health care professionals. Both the women and the health professionals need to learn how to improve collaborative care and contribute to improvement in health outcomes for people with breast cancer. Clinical practice guidelines should specify patient self management support as a component of care for women with breast cancer.

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