

# The Effect of a Health Literacy Promotion Program on the Level of Health Literacy and Death Anxiety in Women with Breast Cancer

## Abstract

**Background:** With regard to the high rate of death anxiety in women with breast cancer and low levels of health literacy in these patients, this study aimed to investigate the effect of a health literacy promotion program on the level of health literacy and death anxiety in women with breast cancer. **Materials and Methods:** This is a clinical trial that was conducted in two groups of 30 women with breast cancer using a convenient sampling method in 2018. An educational program consisting of four sessions was arranged once every 2 weeks for the intervention group. The data collection tools were Templer Death Anxiety Scale and the Health Literacy For Women with Breast Cancer (HELBA) questionnaire with a demographic information record form. **Results:** Mann-Whitney test showed that there were no significant differences in the level of death anxiety and health literacy before the intervention between the control and intervention groups ( $p \geq 0.05$ ). But there were significant differences in the level of death anxiety between the intervention and control groups immediately after the intervention ( $Z = 3.38, p = 0.001$ ) and one month later ( $Z = 3.10, p = 0.002$ ). Also, there was significant differences in the level of health literacy immediately after the intervention ( $Z = 4.74, p < 0.001$ ) and 1 month later ( $Z = 4.92, p < 0.001$ ). **Conclusions:** The findings of this study showed that the use of a health literacy promotion program for women with breast cancer might increase their health literacy while it might decrease their level of death anxiety.

**Keywords:** Anxiety, breast cancer, death, health literacy, nursing

## Introduction

Research has shown that women with breast cancer have high death anxiety levels.<sup>[1]</sup> In general, anxiety, and death anxiety are at a higher level in people with limited health literacy.<sup>[2]</sup> Those individuals with limited health literacy are not only less likely to understand the information, provided by health professionals, but have more hospitalizations and referrals to the physician, act poorer in their self-care skills, have less preventive care, and consequently, have more medical costs, have less participation in treatment decisions and less tendency to express their health concerns, and have inappropriate communication with the health providers and caregivers.<sup>[3,4]</sup> Research showed that up to 50% of these women, with newly diagnosed breast cancer, were reported to have inadequate and limited health literacy.<sup>[5]</sup>

Use of health literacy promotion strategies and patient education processes is one of the most effective ways to modify the

unpleasant effects of inadequate health literacy in health and treatment system and to improve the learning, understanding and, finally, the optimal use of information and education, provided to the patients.<sup>[6]</sup>

Despite the importance of reducing death anxiety and promoting health literacy in patients with breast cancer, no study has been found in which the strategies to improve health literacy and decrease death anxiety in cancer patients have been applied. However, limited interventional studies have been conducted in relation to other groups of patients. For instance, study of Reisi *et al.* on the use of health literacy promotion strategies to promote self-care in patients with type 2 diabetes resulted in promotion of the quality of educational services.<sup>[7]</sup> Negarandeh *et al.* applied some health literacy promotion strategies, including the feedback-based approach and the use of images in relation to diabetic patients with inadequate health literacy.<sup>[8]</sup> Esquivel used feedback-based approach in patients with heart failure.<sup>[9]</sup> All

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of these studies focused more on people with inadequate health literacy and limited health literacy strategies were used. Therefore, in the present study, the effect of a health literacy promotion program on the level of health literacy and death anxiety in women with breast cancer has been investigated.

## Materials and Methods

The present study was a clinical trial (IRCT20180506039541N1) which was carried out through convenient sampling method from May to August 2018. The study population included women with breast cancer referring to the chemotherapy department of Omid Hospital in Isfahan. Inclusion criteria were diagnosis of breast cancer with the approval of a physician, awareness of diagnosis, a maximum of 6 months period after diagnosis, not being in the advanced stage of disease (non-metastatic), age over 18 years, the willingness to join the study and not having received any education related to the promotion of health literacy. Exclusion criteria were reluctance to continue with the study, patient death, and absence from more than two sessions of the intervention program.

The sample size was determined by referring to similar studies using the power analysis considering  $z_1 = 1.96$ ,  $z_2 = 0.84$ ,  $P = 0.5$ ,  $d = 0.8p$ , and 20% of subject drop in each group. Each patient who had the inclusion criteria was requested to take one odd or even card. Patients who took the even card randomized to the intervention group and the patients who selected the odd card were placed in the control group. According to consort process, 136 patients referring to chemotherapy were assessed for competency, of whom 72 were excluded (56 due to inconsistency with inclusion criteria, 11 were due to unwillingness, and 5 for other reasons such as participation in other programs). Total of 64 subjects entered the study. Then, 2 patients were excluded from each group due to lack of cooperation and the study was conducted with 30 subjects in each group. Finally, 30 patients in each group were followed up and analyzed.

Data collection tools were Templer Death Anxiety Scale and Health Literacy for Women Breast Cancer (HELBA) Questionnaire, along with a demographic information record form (including age, marital status, number of children, level of education, employment status, family income, lifestyle, place of residence, religion, type of referral and type of treatment, history of immediate relatives' involvement in disease and duration of awareness regarding the disease). Templer Death Anxiety Scale includes 15 Yes or No questions (like fear of death, concerned about doing things before death, fear of being forgotten by care takers, and worrying about post-death events). The total score of the questionnaire ranged from 0 (no death anxiety) up to 15 (very high death anxiety). Its middle point (7-6) was considered as the cutoff point, higher scores (7-15) showed higher death anxiety, and less than that (0-6) showed lower

death anxiety.<sup>[10]</sup> Health literacy questionnaire for Iranian women with breast cancer including 34 items has been designed in five domains of reading, access, perception and understanding, assessment and judgment, and decision making and behavior. Scoring was based on a 5-point Likert's scale in 4 domains of reading, accessing, perception and understanding, and assessing and judging by options of quite simple, simple, not simple, not hard, hard, quite hard), and in the decision and behavior field as options of absolutely agree, agree, indifferent, disagree, and absolutely disagree. Finally, according to the scores, obtained from the entire questionnaire, health literacy was categorized in 4 levels of inadequate (0–50 points), not enough (50.1–66), adequate (66.1–84), and excellent (84.1–100).<sup>[11]</sup> Validity and reliability of the Templer death anxiety scale were investigated in Rajabi's study in 2002, and by internal reliability, yielded Cronbach's alpha coefficient of 0.73.<sup>[12]</sup> The health literacy questionnaire for Iranian women with breast cancer was designed and underwent psychometric process by Moghaddam *et al.* in 2016. The results of exploratory factor analysis showed that the questionnaire (with 5 separate domains and 34 items) had a desirable structure validity and coverage of 64.98 for data dispersion. The Cronbach's alpha coefficient for each of the domains was higher than 0.7.<sup>[11]</sup>

After explaining the goals of the study and emphasizing the confidentiality of information and obtaining informed written consent from patients, all questionnaires were provided to both groups of intervention and control. After the necessary explanations, the questionnaire was completed by the subjects. The subjects, who were not able to complete the questionnaire, had that completed by an educational co-worker and through interviewing to prevent bias. Then, an educational program consisting of 4 sessions was arranged once every 2 weeks for the intervention group. The content of the program was made according to similar studies and consultation with the experts in the field. The sessions were held for 45–60 minutes in the morning and afternoon shifts on the patient's bedside with the presence of the main researcher. The use of feedback-based approach, the use of images during education, and provision of standardized text-based media (leaf sentences) were among the strategies, employed in individual sessions by the main researcher. The content of the sessions was related to causes and symptoms of the disease, diagnostic and treatment methods, principles of proper nutrition and physical activity, breast tissue regeneration methods, and support and information resources.

At the end of the personal sessions, the principal researcher invited the patients to attend the workshop. In addition to question and answer, with the presence of a specialist physician, the successful patients were invited to the workshop as the role models to create experience in the patients and make them believe that they can live well with their cancer by leaning to their abilities. In the workshop, the judgment of the patients was also measured. To do

this, a cancer patient was assumed and his/her problems were described, and the patients were situated so that they could evaluate and judge different aspects of the story and answer the questions. At the end of a month, the main researcher gave the subjects her contact number and called them up once, and in addition to greeting, responded to their questions and problems and reminded them of the important points. The control group received usual care and at the time of referral for chemotherapy, they received a training session by providing a training pamphlet on the importance of improving health literacy. The questionnaires were completed by the patients in both groups at the end of the intervention and 1 month after. The patients in both groups were completed the questionnaires separately so that no contact between them was happened.

The data were analyzed by SPSS version 22 software (IBM SPSS) and the significance level was 0.05. To compare the frequency distribution of the results of the demographic variables between the two groups, Chi-square test and to determine the distribution of the level of health literacy and death anxiety before and after the intervention and the follow-up time in each group, Friedman test and to compare the control and intervention groups, Mann-Whitney test was used.

### Ethical considerations

This project has been approved by Isfahan University of Medical Sciences in March of 2018 (IR.MUI.REC.1396.3.705). The purpose of the project was explained to the participants, and it was emphasized that at each stage, they could leave the study. A written informed consent was obtained from the patients.

### Results

The age range of the patients varied from 27 to 60 years. The mean (SD) ages of the patients in the intervention and control groups were 44.97 (7.76) and 45.83 (8.44) years, respectively, which were not statistically significant ( $p = 0.680$ ). The mean (SD) duration of diagnosis in the intervention and control groups were 3.77 (1.25) and 4.13 (1.36) months, respectively, which were not statistically significant ( $p = 0.280$ ). Chi-square test showed the difference in demographic variables between the two groups was not significant in any of the cases [Table 1].

Mann-Whitney test showed that there was no significant differences in the level of death anxiety before the intervention between the control and intervention groups ( $p \geq 0.05$ ). But there was significant differences in the level of death anxiety between the intervention and control groups immediately after the intervention ( $Z = 3.38$ ,  $p = 0.001$ ) and 1 month later ( $Z = 3.10$ ,  $p = 0.002$ ) [Table 2].

Also, there was significant differences in the level of health literacy immediately after the intervention ( $Z = 4.74$ ,  $p < 0.001$ ) and 1 month later ( $Z = 4.92$ ,  $p < 0.001$ ) [Table 3].

### Discussion

This study was designed to investigate the effect of a health literacy promotion program on the level of health literacy and death anxiety in women with breast cancer. Results were generally promising indicating that the health literacy promotion program can generally improve the health literacy level and decrease the death anxiety issues. This might be related to strategies were used in the study. One of the health literacy promotion strategies was feedback-based approach. As the patients with lower levels of health literacy, on average, understand less than 50% of what they are trained, the feedback-based approach, which is an interactive training method, can guarantee patients' understanding of the patient-trained content.<sup>[13]</sup> Similar to other research studies,<sup>[9]</sup> in this research, messages were transmitted simply and comprehensively, talked with the patient in a language familiar and free from any term. Moreover, active sentences were used instead of passive sentences, for example, instead of saying to the patient that these pills could damage your stomach, it was said that your nausea may be due to this medication.

Other approaches that were used were the use of related images in education. Several studies have found positive effects on the use of images in educating patients with limited health literacy.<sup>[14]</sup> However, a study on Human Immunodeficiency Virus (HIV) patients showed that the use of images did not make a difference in outcome; therefore, people with low health literacy may require a more complex approach to their health promotion.<sup>[15]</sup>

Among other things, effective on improving the health literacy of patients, is the use of standardized written media. In the healthcare system, written media are provided to the patients with inadequate health literacy. They are unable to understand and may misunderstand them. In this regard, the National Association of American Quality has emphasized on the improvement of the readability of written media. In fact, the leaflet is a standard media text that is recommended to be applied to promote health literacy in which a combination of picture messages and text both are seen and the use of professional terminology and unnecessary additional explanations are avoided.<sup>[7]</sup>

Impossibility of holding training sessions at a similar time for the patients and lack of cooperation to attend classes were among the limitations of the research, so the researcher held the sessions in the morning and afternoon working shifts and on the patient's bedside.

### Conclusion

The findings of the study indicated that application of health literacy promotion strategies led to an improvement in the level of health literacy and the reduction of death anxiety in women with breast cancer. These strategies can be an affordable and understandable way for patients to learn and understand relevant issues.

**Table 1: Frequency distribution of demographic variables in control and intervention groups**

Group Variable		Intervention No (%)	Control No (%)	Chi-square		
				$\chi^2$	df	p
Marital status	Single	0 (0%)	3 (10.00%)	-	1	0.120
	Married	30 (100.00%)	27 (90.00%)			
Employment status	Employed	2 (6.70%)	3 (10.00%)	4.67	2	0.100
	Home maker	28 (93.30%)	24 (80.00%)			
	Retired	0 (0.00%)	3 (10.00%)			
The history of cancer in First class relatives	Yes	11 (36.70%)	12 (40.00%)	0.07	1	0.79
	No	19 (63.30%)	18 (60.00%)			
Lifestyle	Alone	1 (3.30%)	3 (10.00%)	2.58	3	0.460
	With spouse	7 (23.30%)	4 (13.30%)			
	With spouse and children	20 (66.70%)	19 (63.30%)			
	With children	2 (6.70%)	4 (13.40%)			
Type of admission	Outpatient Visit	30 (100.00%)	29 (96.70%)	-	1	0.50
	Hospitalization	0 (0.00%)	1 (3.30%)			
Residence	Urban	24 (80.00%)	22 (73.30%)	0.37	1	0.540
	Rural	6 (20.00%)	8 (26.70%)			
Type of treatment	Chemotherapy	1 (3.30%)	1 (3.30%)	4.32	3	0.23
	Surgery	1 (3.30%)	0 (0.00%)			
	Surgery and chemotherapy	26 (86.70%)	29 (96.70%)			
	Surgery, Radiotherapy and Chemotherapy	2 (6.70%)	0 (0.00%)			
				<b>Mann Whitney Test</b>		
				<b>Z</b>		<b>p</b>
Education level	Illiterate	5 (16.70%)	7 (23.30%)	0.85		0.400
	Under diploma	12 (40.00%)	14 (46.80%)			
	Diploma	7 (23.30%)	4 (13.30%)			
	Associate degree	4 (13.30%)	1 (3.30%)			
Number of children	MS and higher	2 (6.70%)	4 (13.30%)	0.35		0.73
	No child	3 (10.00%)	7 (23.30%)			
	One child	5 (16.70%)	2 (6.70%)			
	Two children	7 (23.30%)	6 (20.00%)			
Family income	More than two children	15 (50.00%)	15 (50.00%)	1.09		0.270
	<\$ 100	8 (26.70%)	11 (36.70%)			
	Between \$ 100-300	15 (50.00%)	15 (50.00%)			
	Between \$ 300-600	7 (23.30%)	4 (13.30%)			

**Table 2: Comparison of frequency distribution of death anxiety level between two groups before and after intervention and follow up time**

Group	Time Variable	Before intervention No (%)	After intervention No (%)	Follow up time No (%)	Friedman test		
					$\chi^2$	df	p
Intervention	Low death anxiety	8 (26.70%)	24 (80.00%)	23 (76.70%)	26.78	2	<0.001
	High death anxiety	22 (73.30%)	6 (20.00%)	7 (23.30%)			
Control	Low death anxiety	10 (33.30%)	11 (36.70%)	11 (36.70%)	1	2	0.61
	High death anxiety	20 (66.70%)	19 (63.30%)	19 (63.30%)			
Mann Whitney test		Z=0.56, p=0.58	Z=3.38, p=0.001	Z=3.10, p=0.002			

By these strategies, nurses can overcome patients' inadequate educational literacy challenges in education and improve the learning, understanding and, ultimately, the effective use of the training, provided to the patients. This can reduce their death anxiety too. However, it is recommended that these strategies be applied to other patient groups in future research. It is also recommended that telephone follow up, which was carried out once

after 1 month due to time limitation in the current study, be done over a longer time. It is advisable to hold individual training sessions in an environment separate from the patients bedside so that the patients could reply to questions more comfortably.

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**Table 3: Comparison of frequency distribution of health literacy level between two groups before and after intervention and follow up time**

Group	Time Variable	Before intervention	After intervention	Follow up time	Friedman test		
		No (%)	No (%)	No (%)	$\chi^2$	df	p
Intervention group	Inadequate health literacy	7 (23.40%)	0 (0.00%)	0 (0.00%)	41.37	2	<0.001
	Somehow adequate health literacy	12 (40.00%)	3 (10.00%)	2 (6.70%)			
	Adequate health literacy	10 (3.33%)	23 (76.70%)	24 (80.00%)			
	Excellent health literacy	1 (3.30%)	4 (13.30%)	4 (13.30%)			
Control	Inadequate health literacy	9 (30.00%)	10 (33.30%)	8 (26.70%)	2.0	2	0.37
	Somehow adequate health literacy	11 (36.70%)	10 (33.30%)	12 (40.00%)			
	Adequate health literacy	10 (33.30%)	10 (33.30%)	10 (33.30%)			
	Excellent health literacy	0 (0.00%)	0 (0.00%)	0 (0.00%)			
Mann Whitney		Z=0.56, p=0.58	Z=4.74, p<0.001	Z=4.92, p<0.001			

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### Conflicts of interest

Nothing to declare.

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