Relationship between Health Literacy and Special Quality of Life and Body Image in Women Undergone Mastectomy in Reproductive Age

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ABSTRACT

Aims The aim of this study was to investigate the relationship between health literacy and special quality of life and body image in women undergone mastectomy in reproductive age.

Instruments & Methods This cross sectional descriptive-analytical study was conducted on 225 women in reproductive age (15-49) with breast cancer and having a mastectomy referred to Sina Hospital-breast surgery clinic, Breast Research Center, and Mahdieh Hospital from 2014 to 2015. A simple random sampling method as well as 4 questionnaires including the Health Literacy for the Iranian Adults (HELIA), Standard questionnaire of the European Organization for Research and Treatment of Cancer (EORTC version 3.0), special edition of Breast Cancer (QLQ-BR 23), and a Special questionnaire for body images was used. The data were analyzed by SPSS 21 software, using Spearman's correlation coefficient and one way ANOVA test.

Findings There was a statistical significant relationship between job status, education, and health literacy of participants (p=0.001). The significant relationship was observed between health literacy and the overall quality of life (p=0.042). Fatigue and pain had the strongest impact on quality of life of patients. Also, there was a statistical significant relationship between the body image and education level.

Conclusion Women's health literacy is closely related to their education level. There is a significant and positive relationship between the health literacy and overall quality of life. However, no statistical significant correlation is found between health literacy levels and symptom scales of breast cancer.

Keywords Health Literacy; Special Quality of Life; Mastectomy; Body Image; Breast Cancer

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Introduction

Breast cancer is the second main cause of death in women worldwide and it is particularly important because it significantly influences various dimensions of well-being and quality of life including physical, mental, and social well- being [1, 2].

The diagnosis and treatment of breast cancer make the patients suffer from the particular problems such as pain syndrome, lymphedema, limited shoulder motion, decreased muscle strength, and changes in sensations [3].

The majority of the problems of women undergoing mastectomy for the treatment of breast cancer is attributed to the removal of the breast, which damage the identity and femininity of women. This adversely affects woman's psychological well-being and the process of recovery and hinders the reconstruction of a normal life [4, 5].

In some cases, mastectomy may be more psychologically devastating than the cancer diagnosis itself due to a change in body image and the loss of normal breast functions [6]. For these reasons, recent breast cancer diagnosis and treatments besides improving overall and disease-free survival emphasize health-related quality of life after treatment. The quality of life is now considered an important endpoint in cancer clinical trials, particularly in the late stage of breast cancer [7]. Therefore, enhancing patients' ability to control symptoms and to maintain reasonable quality of life is an effective key factor for the successful treatment of breast cancer and cost-effective interventions. However, limited knowledge, guidance, and instructions from health caregivers are important concerns that cause huge costs for repeated visits of patients due to the side effects or stopping the treatment [8].

Health education and factors such as information and improved patients' knowledge about the physical and mental aspects of diseases, motivation, supporting, and advice can improve the physical status, coping abilities, and quality of life and, furthermore, reduce anxiety and mood disorders of patients [9].

An important concept in health education contexts is health literacy started in the United States in the mid-1970s [10]. Health literacy is the mental and social skills, determining the motivation and ability of individuals for reaching, understanding, and using information to make appropriate health decisions in ways that promote and maintain good health [11]. Health literacy addresses the comprehensive group of factors such as environmental, political, and social factors that determine health [12]. Given the increasing options and complexity of cancer care, which require more involvement of patients in decision-making, health literacy is increasingly recognized as a critical factor to achieve appreciate cancer management and treatment [9].

Breast cancer is the most common cancer in women worldwide and its incidence for Iranian women is 22 per 100,000 [13]. According to a recent report, the mean age of women diagnosed with breast cancer in Iran is 10 years less than that in Western countries [14]. With increasing the survival rate of patients with breast cancer in younger age groups, recently, there has been great interest in studying this group [4]. Most of the young women in reproductive age (15-59 years), who suffer from breast cancer, present unique and particular concerns and deal with various intense and conflicting issues related to the fertility, family and social responsibilities, survival for those with young children, beauty and attractiveness, body image and sexuality, career, etc. [15, 16]. In addition to the cancer diagnosis and treatment effects, such side effects may greatly affect quality of life of women in reproductive age [17].

Health literacy has a profound impact on the effectiveness and quality of life in patient with cancer from prevention and screening to explanations of diagnoses and treatment outcomes [18].

On the other hand, health literacy is a very important issue in patients with cancer because of the high prevalence of chronic diseases and the subsequent requirements for diagnosis and treatment plans. Despite the importance of health literacy, especially for women in reproductive age, there are very few studies on the health literacy level and its effects on quality of life of patients with breast cancer in reproductive age in the world, and we found no study in this area from Iran.

Therefore, the aim of this study was to measure the health literacy level in patients with breast cancer, who underwent mastectomy in reproductive age, and to evaluate the relationship between health literacy levels, special quality of life, and body image in this group.

Instruments and Methods

This cross sectional descriptive-analytical study was conducted in Tehran from September 2014 to September 2015. The study sample consisted of women, who underwent mastectomy breast cancer and, for follow-up, were referred to the health centers, including Center for Breast Cancer affiliated to Jahad Daneshgahi, Sina Hospital affiliated to the Shahid Beheshty University of Medical Sciences (SBUMS), and Mahdiyeh Hospital affiliated to Tehran University of Medical Sciences (TUMS).

Eligible patients included women in productive age (15-49 years), being married, having adequate reading and writing skills, living in urban areas, not abusing alcohol, drugs, stimulants psychiatric drugs, and without chronic systemic diseases such as cardiovascular disease and diabetes. They had previously undergone breast surgery as a treatment for breast cancer (unilateral or bilateral

mastectomy) at least 6 months before this study and they had not done chemotherapy or radiotherapy in the past 2 weeks.

Due to the lack of similar studies in this field, a randomized controlled pilot study with a sample of 70 patients was carried out. The sample size of the study was estimated 209 patients at a confidence level of 95 % and the error probability of 5 %. A total of 225 eligible patients were investigated.

The Ethics Committee of University of Tarbiat Modares (TMU) approved the study and all participants were informed about the purpose and details of the study. Prior to completing the questionnaires, participants were informed of the objectives, the importance of objectives, and the importance of the study and, then, they signed a consent form. A simple random sampling method was used in the study. Next, demographic and clinical productivity data, which mainly included age, educational level, occupation, and marital status of the participants, were completed by the authors during the first meeting and, if necessary, some data were extracted from existing case records in the center. Then, they were handed by other self-report questionnaires and they completed the questionnaires by themselves and gave them to the authors.

The following questionnaires were used in the study:

Health Literacy for Iranian adults (HELIA): Health literacy of participants was measured by Health Literacy for Iranian adults (HELIA) questionnaire that has been prepared and approved according to Iranian socio-cultural characteristics for measuring health literacy of the general population of Iran aged 18 to 65 years [19]. Each item was scored on a 5-point Likert scales, ranging from 1 to 5. The scores were calculated according to the HELIA scoring manual. The scores for the items in a scale were summed and divided by the number of items in the scale to give a scale raw score (Theoretically, ranging 1–5), which were transformed from 0 to 100 scales according to the guidelines of HELIA. Final scores were classified and interpreted as follow:

0 to 50: inadequate literacy, 50.1 to 66: marginal health literacy, 66.1 to 84: adequate health literacy, and 84.1 to 100: high health literacy.

EORTC QLQ-C30 Version.3 (QLQ-C30): In order to collect more relevant patient-reported outcomes about the quality of life in the mentioned group, the questionnaire of EORTC QLQ-C30 Version.3 (QLQ-C30) with its breast cancer-specific module (QLQ-BR23) was also used. From EORTC QLQ-C30 questionnaire, 3 symptom scales, including pain, fatigue, and nausea and vomiting, and 5 single item scales, including dyspnoea, insomnia, appetite loss, constipation, and diarrhea and global health status/quality of life scale were chosen and evaluated [20, 21].

QLQ-BR23: Moreover, to evaluate quality of life in the patients, 2 multi-item symptoms scales of breast cancer and the QLQ-BR23 questionnaire were used. Both questionnaires have had the appropriate validity and reliability and they were designed by Likert and any question had 4 options (no, low, high, very high) scored from 1 to 4 and its overall score is in the range of 0 to 100. Considering the symptom dimensions, the higher scores demonstrate higher levels of the symptoms [20, 21].

Body Image Scale (BIS): Body image of women was assessed by Body Image Scale (BIS). The scale (BIS) evaluates the impact of surgery and adjunct therapy on physical and sexual attractiveness, femininity, body satisfaction, scab, and physical integrity. Ten questions were developed in collaboration with the European Organization for the Study of Cancer Research (EORTC) and the Quality of Life Study Group. The questionnaire (BIS) was validated by Raeisi *et al.* and the reliability of this questionnaire was confirmed by Cronbach's alpha of 0.9 as an excellent value. On this scale, patients are asked to have 4 options (0), slightly (1), high (2), and very high (3) of the last week, according to a Likert scale, in their feelings about their appearance and changes from the disease. The final score is 7, with a range of 0 to 21, in which a score of 0 indicates a lack of concern or dissatisfaction and higher scores indicate more dissatisfaction with the mental image [22].

The data were analyzed by SPSS 21 software. Health literacy and quality of life of the participants were evaluated, using descriptive statistic. The association between overall quality of life and health literacy level was evaluated, using inferential statistic by Spearman's correlation coefficient and the association between symptoms severity of the specific quality of life and health literacy levels was evaluated, using one way ANOVA test.

Findings

The mean age of patients was 43.8±5.3 years and the greatest percentage placed in the age group of over 46 years was 45.3%, while the group of less than 30 years had the lowest rate (2.7%). Most of the participants (77.8%) were housewives and elementary/secondary school, high school, and collegiate education constituted 33.2%, 33.4 %, and 33.4%, respectively.

The mean score of health literacy levels among the mastectomized women in reproductive age was 75.59±16.37. Only small percent of patients (6.6%) had inadequate health literacy, and 22.2% had marginal, 36.0% had adequate, and 35.1% had high health literacy skills. Overall, the majority of patients (71.1%) had high literacy skills (Table 1).

Mean scores of the overall quality of life in the women was 66.63±19.72 (Table 2).

There was a significant relationship between health literacy and overall quality of life (β=0.157; p=0.042). There was a significant relationship between the education level and fatigue (β=0.233; p=0.014) and quality of life (β=0.192; p=0.033).

Table 1) Demographic characteristics of the participants (N=225)

Variables	Frequency	Percentage of frequency	Percentage of accumulative frequency
Age			
Under 30 years	6	2.7	2.7
35-31 years	10	4.4	7.1
36-40 years	41	18.2	25.3
41-45 years	66	29.3	54.7
46-49 years	102	45.3	100
Education level			
Elementary and second school	76	33.2	33.8
High school and diploma	76	33.4	67.8
Collegiate education	73	33.4	100
Job status			
Housewives	175	77.8	77.8
Employed	50	22.2	100

Also, the overall quality of life (β=0.142; p=0.034), sleep problems (β=-0.228; p=-0.001), arm symptoms (β=-0.146; p=0.031), and breast symptoms (β=-0.141; p=-0.036) were related to the time elapsed since mastectomy. Overall quality of life was significantly correlated with health literacy (r= 0.140; p=0.036).

There were no statistical significant differences in patients' symptom scores in mastectomized women in reproductive age with different levels of health literacy (Table 3).

The majority of mastectomised women (81.8%) were disturbed in terms of body image and 18.2% of them were not disturbed in terms of body image.

There was a significant relationship between body image and levels of health literacy (p=0.035; Table 4).

Table 2) The mean scores of the symptom-specific quality of life among the mastectomized women in reproductive age (N=225) measured by QLQ-C30 and QLQ-BR23

Symptom	Mean
Fatigue	55.70±17.52
Pain	38.22±24.87
Sleep problems	31.16±26.22
Arm symptoms	22.37±22.32
Breast symptoms	16.18±13.19
Asthma	20.24±12.44
Irregularity	23.82±12.30
Anorexia	21.25±9.39
Nausea and vomiting	13.45±6.00
Diarrhea	14.80±4.89
Overall quality of life	66.63±19.72

Table 3) The mean scores of symptom scale scores for the specific quality of life in the mastectomized women in reproductive age with different level of health literacy (N = 225)

Symptom Scale	Inadequate Mean±SD	Not more adequate Mean±SD	Adequate Mean±SD	High Mean±SD	ANOVA test p-value
Fatigue	38.9±24.1	37.7±25.6	41.1±24.3	35.5±25.2	0.563
Pain	60.7±14.5	52.2±16.7	56.5±16.8	56.1±19.2	0.332
Sleep problems	15.3±8.9	19.8±11.3	22.9±14.7	18.5±11.5	0.633
Arm symptoms	31.7±26.7	27.9±18.7	29.2±27.2	34.7±29.9	0.249
Breast symptoms	21.1±13.3	17.4±6.0	24.9±13.4	19.5±8.1	0.182
Asthma	12.3±8.9	17.9±9.3	25.4±13.4	27.2±15.4	0.816
Irregularity	11.7±4.4	17.8±4.7	14.6±5.7	13.6±4.3	0.972
Anorexia	27.4±26.5	22.8±21.6	21.5±12.5	22.7±22.4	0.228
Nausea and vomiting	20.8±7.8	12.8±5.3	14.8±6.7	10.6±5.4	0.852
Diarrhea	18.7±15.0	17.9±12.8	14.0±13.3	16.9±12.9	0.563
Overall Quality of life	63.9±18.8	67.0±17.7	63.7±21.4	19.0±70.0	0.332

Table 4) Relationship of body image with levels of health literacy (At two levels enough and inadequate) among women (N=225)

Body image	Inadequate Literacy (Percent)	Enough Literacy (Percent)	p-value (Chi-square test)
Disrupted	47 (%73.4)	138 (%85.7)	0.035
Without disturbance	17 (%26.6)	23 (%14.3)	

Discussion

To our knowledge, this is the first study reporting health literacy levels among patients with breast cancer undergone mastectomy in productive age and their association with symptom scales of the specific quality of life.

In all, 225 women participated in this study with a mean age of 43.8±5.3 years. Mean health literacy

score in the studied patients was 75.6±16.4 and 71.1% were identified as having adequate and high health literacy skills.

Although health literacy skills can decline under stressful circumstances and severe symptoms/illness, the mean scores of the studied participants were rather good in comparison with previous studies conducted in different cities of Iran on general populations. For instance, Tehrani Banihashemi *et al.* estimated the prevalence of inadequate health literacy to be 56.6% and only 28.1% of general people had high health literacy. They reported a mean raw score of health literacy as 41.1 for women and 45.3 for men and they attributed low health literacy to the lower economic status [23].

In addition, in a recent study conducted in Isfahan to measure health literacy, using Consumer Assessment of Healthcare Providers and Systems (CHAP) questionnaire, the mean score of health literacy of adults was reported as 2.4 out of 4 [24]. The mean score of 21.23 was reported for health literacy among patients with diabetes mellitus in Saqez, Iran [25].

A descriptive study conducted in the United States to measure the health literacy of American adults estimated the prevalence of inadequate health literacy to be 53%, while only 12% of adults had high health literacy levels and women had higher average health literacy than men [26]. The higher health literacy for the studied patients could be attributed to the large amounts of health-related information that they have been often provided during the tests, procedures, consultations, hospital stay, and following-up the cancer [9]. Higher level of health literacy would enable patients to understand and manage the probable effects of cancer treatment, which in turn positively affect their health-related quality of life [27].

The present survey data reflected a significant and positive relationship between the overall quality of life and health literacy score. Similarly, a recent study has mentioned that higher health literacy was significantly associated with a higher quality of life. Furthermore, scores of quality of life (mental and physical) have been shown to be associated with the results of treatment and survival rates in patients with breast cancer [28]. This positive relationship between health literacy and overall quality of life supports that the intervention of healthcare providers and implementation of patient navigation and universal health literacy best practices could contribute to improved cancer treatment and patient outcomes.

The results of this study showed that the intense symptoms reported by studying participants were fatigue, pain, sleep problems, arm symptoms, and breast symptoms, respectively. In comparison with the values previously reported [29], in the present study, most of the symptoms showed lower score

and higher standard deviation. This could be explained from the inclusion criteria applied for the present study, while eligible patients had passed at least 6 months since the last mastectomy treatment, which could reduce or even eliminate some side effects of treatment. Kulesza *et al.* reported that the global health status by the EORTC QLQ-C30 questionnaire was significantly higher in women examined 1 year after mastectomy than in those examined 1 month after the mastectomy [30]. Using EORTC QLQ-C30 questionnaire, poorer global quality of life was reported in Kuwaiti women with breast cancer and most distressing symptom on the symptom scales of QLQ-C30 was dyspnea, followed by appetite and diarrhea and more financial difficulty [31].

The results of the current study indicated no significant association between health literacy levels and severity of breast cancer symptoms. This means that the relationship between health literacy level and health-related quality of life is complex and various factors other than health literacy can influence the health-related quality of life.

The determination of body image of mastectomized women in reproductive age showed that the majority of mastectomized women (81.8%) have a distorted body image. Raheleh Sadeghi *et.al* in their study in mental and self-esteem body image of women with breast cancer indicated that there was no difference between perceived body image of mastectomised women and other who motioned their breast, which was different from the results of this study [32]. This is probably due to the use of a specific cancer questionnaire (BIS) in the present study.

In another study, the relationship between body image and psychological distress in women with breast cancer has been investigated by Moradi Manesh *et al.* [33]. The body image was measured by the BIS scale. Young women with breast cancer were reported to have more mental problems in comparison with older women. This result is similar to the population of women aged 15 to 49 years in this study.

In a study conducted by Fobair *et al.*, the body image and sexual problems of young women with breast cancer in 549 women aged 22 to 55 years had been assessed by the BIS questionnaire; 99% of women experienced disturbed body image that is similar to the present study [34].

The study of the relationship between the level of health literacy and body image showed that the disrupted body image is higher in women with well-educated levels and health literacy level. The relationship between health literacy levels and body image showed a significant correlation between these two variables (p=0.035).

In McLean *et al.*'s study entitled "The relationship between literacy and childbearing", in adult women, 467 female students completed media literacy,

physical dissatisfaction, internalization, and simulation. There was a strong and reciprocal relationship between literacy and body image [35].

We hoped that the findings of this study might contribute to the existing literature and could help health policy makers to design a proper intervention to decrease breast cancer burdens. The results of this study may contribute to planning better educational and clinical interventions improving the quality of life of patients with cancer. Understanding the level of health literacy and clarifying the relationship between health literacy and quality of life in mastectomized women can contribute to constructing a suitable support system to enhance cancer treatment outcomes and quality of life in patients with breast cancer.

The study limits the lack of study of two femininity interwoven concepts including body images and breast cancer in Iranian literature. It is inevitable to confirm that the body image will be conceptualize in social constructivism paradigm.

It is suggested that in subsequent studies, breast cancer health educational intervention addresses health literacy particular in family support concept. Actually, this complex meaning needs to be explored in a qualitative research method study to shed lite black side of body images from women perspective and the relevant issues.

Conclusion

Women's health literacy is closely related to their education level. There is a significant and positive relationship between the health literacy and the overall quality of life. However, no statistical significant correlation is found between health literacy levels and symptom scales of breast cancer. Mastectomized women has relatively high levels of health literacy compared to the general population of women, presumably due to the necessity of following-up and treatment of cancer.

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