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The Relationship Between Health Literacy and Patient Participation in Medical Decision Making Among Breast Cancer Patients

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ABSTRACT

Background: Patient participation in medical decisions is essential and requires sufficient knowledge and awareness. Thus, the aim of this study was to investigate the relationship between health literacy and the participation of breast cancer patients in their medical decisions in Shiraz, Iran.

Methods: This was a descriptive-analytical study conducted on 196 women with breast cancer in 2016-2017. Data were collected using the standardized Health Literacy for Iranian Adults (HELIA) and the Decisional Conflict Scale. The data were analyzed using descriptive statistics and inferential methods (t test, Pearson correlation, ANOVA, and Kruskal-Wallis) on SPSS 21.

Results: The mean age of participants was 46.7 years. Their health literacy was inadequate (18.7) and their decisional conflict was average (51.79). There was also an inverse and significant relationship between health literacy and decisional conflict ($P < 0.001$, $r = -0.81$)

Conclusion: Increasing health literacy could reduce decisional conflict. It requires training individuals be able to access credible and reliable sources of information. This training can be provided through doctors, treatment staff, and public and social media.

Introduction

Clinical governance is one of the tools used to improve the quality of health care in different countries. One of the goals of establishing clinical governance is to promote the participation of patients and communities in therapeutic processes.¹ In fact, patient participation is considered a legal right and an international standard for health care.² During the past 30 years, the concept of patient participation in medical decision making has developed from

informed consent to the exchange of information between physicians and patients, which not only includes the benefits and risks of treatment options, but also includes the preferences and values of patients and physicians.³ Recently, patient participation has become a necessary policy in many countries and health systems all over the world.⁴

Collaborative decision making is considered the key to the quality of patient-centered care, resulting in better health outcomes for patients.⁵ In general, the goal of informed and coordinated participation of patients and physicians in treatment decision making is to involve the patients and physicians in the knowledge, values, preferences, and intentions of each other. As a result, the decisions taken will be more consistent with the patients' values, conditions, and preferences, which in turn may increase the quality of life and access to health objectives.

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Several studies have also shown that shared decision making would lead to a more effective physician-patient relationship and a common understanding of the treatment objectives, as well as reducing the decisional conflicts,³ and bringing about better psychological adjustment, and higher levels of satisfaction.⁶ Cuevas *et al.* mentioned the lower costs of treatment as one of the benefits of patient participation in decision making.⁷ Furthermore, patient participation in decision making was reported to increase their commitment to health behaviors.⁸ Ghiasvandyan *et al.*, too, concluded that the participation of patients in medical decision making would improve their awareness and confidence to start their treatment.⁹

In this regard, behavioral changes through health literacy to have an active role in medical decision making are possible.¹⁰ In fact, health literacy is a prerequisite for making informed health care decisions.¹¹ The World Health Organization considers health literacy a major health determinant.¹² By definition, health literacy is a broad range of cognitive and social skills that empower people to accept, understand, and use information to enhance their health, well-being, and participation in their health-care decision making.^{5,13} Hence, health literacy is one of the influential factors in guiding patients in terms of the information they need for their health care. Besides, since health literacy addresses all aspects of health care such as prevention, screening, diagnosis, and treatment, it is considered the basis for health care delivery systems.¹⁴ According to reports, nearly 80 million Americans do not have adequate health literacy.¹⁵ In Iran, according to the results of the national survey of 20 571 Iranian citizens, about half of the people had limited health literacy.¹⁶

On the other hand, the level of health literacy can affect cancer outcomes.¹⁷ Today, the cause of over 12% of deaths in all countries is cancer.¹⁸ Iran has an annual incidence of 70 000 new cancer cases, which can potentially double in the next two decades due to aging.¹⁹ Of these cancers, breast cancer is the most common one and the second leading cause of death in women.^{20, 21} According to the World Health Organization, this rate is increasing by 1.8% to 2%.¹⁹ In Iran, breast cancer is the most common cancer in women, with an incidence rate increase of about 28.3 new cases per 100 000 women a year.²² Considering the issues raised and insufficient studies in this field in Iran, the present study aimed to investigate the relationship between health literacy and the rate of patient participation in medical decision making among patients with breast cancer in the city of Shiraz, Iran, in 2016-2017.

Methods

Participants

This was a descriptive-analytical study with a cross-sectional design that was conducted on women with

breast cancer in Shiraz, Iran, in 2016-2017. The inclusion criteria were being 18 to 65 years old, being a newly diagnosed case, having the ability to communicate (lack of mental, hearing, visual, or speech disorders), willing to answer the questions, giving informed consent to participate in the study, and having visit with their doctors on how to treat their disease. At first, because of lack of similar articles, a sample of 40 cases was considered as a pilot. Then, based on a type I error of 0.05, a type II error of 0.2, and the correlation between the patients' health literacy and participation in their medical decisions obtained from the pilot study ($r = 0.122$), the sample size was determined to be 160 patients. The calculated sample size was increased to 196 to account for an estimated non-response rate of 20%. Due to the lack of cooperation of the private sector, the patients were selected only from public centers. There were two public centers dealing with breast cancer counseling and treatment in the city of Shiraz. One of the centers was excluded from the study because it provided only outpatient visits, and the patients would be referred to another center if the diagnosis of breast cancer was confirmed. The other center was for hospitalized patients where surgeries were done two days a week. Using the inclusion criteria, three trained interviewers interviewed the patients one day prior to their surgery and completed the questionnaire.

Instruments

Health literacy was measured using the Health Literacy for Iranian Adults (HELIA) questionnaire. The questionnaire consists of two sections including demographic characteristics and 33 questions in five domains of reading (4 questions), access (6 questions), comprehension (7 questions), assessment (7 questions), and decision making (12 questions). The validity and reliability of the questionnaire were determined by Montazeri *et al* (Cronbach's alpha coefficient range: 0.72 to 0.89).²³ Izadirad and Zareban, too, evaluated its validity and reliability (Cronbach's alpha coefficient: 0.92).²⁴ The items were rated on a 5-point scale (1 = totally disagree, and 5 = totally agree). The scores were then transferred to 0-100 scale so that scores 0-50 indicated inadequate health literacy, 50.1-66 indicated almost inadequate health literacy, 66.1-84 represented sufficient health literacy, and 84.1-100 represented excellent health literacy.

Patient participation in medical decision making was evaluated using the Decisional Conflict Scale, which has been identified in various studies as a standard for assessment of the uncertainty and factors influencing the decision-making process in health care.^{25, 26} The questionnaire measures an individual's uncertainty about a course of action and the factors contributing to uncertainty through 16 questions on a scale from 0 (totally agree) to 4



(totally disagree). The uncertainty factors comprise five groups: a feeling of awareness, individual values, support, uncertainty, and effective decision making. Total score ranges from 0 (the highest certainty about the best decision taken) to 100 (the highest uncertainty about the best decision taken). The questionnaire was translated and validated by Mousavizadeh *et al.*, with the Cronbach's alpha being 0.94.⁹

Data Analysis

Descriptive statistics (percentage, frequency distribution, mean, and standard deviation) were used to provide a summary of participant characteristics, and nonparametric (Kruskal-Wallis) and parametric (t test, ANOVA, and Pearson correlation) tests were used to analyze the differences between groups. The nonparametric test was used if the data on a particular variable had not a normal distribution. Analyses were performed using SPSS 21.

Results

Demographic Information

A total of 196 breast cancer patients with the mean age of 46.7 ± 9.92 years were enrolled in the study. In terms of education, 37.5% had elementary, 30.5% had a middle school degree, 18.5% had a high school certificate, and 13.5% had a university education. The majority of patients (81%) were housewives, with retired and employed patients making up the remaining 6.5% and 12.5% of the study sample, respectively. Regarding the access of the study population to the sources of health and illness information, 36% got information from doctors and health-care staff, 21.4% used radio and television, 17% used the Internet, 12.46% got information from their friends and acquaintances, 6.07% used booklets, pamphlets, and brochures, 3.8% used newspapers and magazines, and 0.32% used the interactive voice dialer (IVR)(a technology that allows a computer to interact with humans through the use of voice and DTMF (Dual-tone multi-frequency signaling) tones input via a keypad), and 2.88% did not know how to get the information they needed.

Health Literacy

The mean health literacy score of the patients under study was 18.70 ± 7.34 . The mean scores on health literacy subscales were 33.45 ± 14.5 (decision making), 19.59 ± 9.8 (comprehension), 16.76 ± 7.1 (access), 11.72 ± 5.5 (reading), and 11.54 ± 4.7 (evaluation). The results of the Kruskal-Wallis test did not show a significant relationship between health literacy and education levels ($P = 0.06$). Furthermore, the ANOVA test did not show any significant relationships between health literacy and employment status ($P = 0.8$), the t test showed that general health literacy had no significant relationship with information-gathering methods ($P = 0.98$). No significant relationship was observed between health literacy and age ($P = 0.09$).

Decisional Conflict

The overall mean decisional conflict score was 51.79 ± 29.1 , with the scores on subscales being 53.72 ± 32.1 (uncertainty), 53.3 ± 34.9 (support), 52.77 ± 35.8 (effective decision making), 50.67 ± 30.7 (value), and 49.64 ± 29.0 (awareness). There was no significant relationship between decisional conflict and age, job, education, and information-gathering methods ($P = 0.3, P = 0.81, P = 0.95, P = 0.3$).

Health Literacy and Decisional Conflict

There was a significant inverse relationship between health literacy and decisional conflict in general ($r = -0.81, P < 0.001$). Pairwise analyses of the correlations between the dimensions of health literacy and decisional conflict are shown in Table 1. A similar inverse relationship was observed for each pairwise comparison at a 99% confidence level.

Discussion

The main objective of the present study was to investigate the relationship between health literacy and the rate of participation in one's medical decisions making among breast cancer patients in Shiraz, Iran. The results of this study showed an inadequate level of health literacy in the women with breast cancer (18.70), which was consistent with the results of a study by Sahrayi *et al.* on adults in Karaj (24.2%)²⁷ and that of Izadirad and Zareban carried

Table 1. Correlations Between Health Literacy Dimensions and Decisional Conflict Dimensions

Health literacy \ Decisional conflict	Reading	Access	Comprehension	Assessment	Decision making and behavior
Awareness	R = -0.661a	R = -0.534a	R = -0.66a	R = -0.549a	R = -0.594a
Personal values	R = -0.655a	R = -0.536a	R = -0.726a	R = -0.513a	R = -0.668a
Support	R = -.0678a	R = -0.516a	R = -0.787a	R = -0.504a	R = -0.724a
Uncertainty	R = -0.665a	R = -0.516a	R = -0.771a	R = -0.554a	R = -0.723a
Effective decision making	R = -0.696a	R = -0.537a	R = -0.825a	R = -0.553a	R = -0.793a

a $P < 0.001$

out in Baluchestan (34%).²⁴ However, it was inconsistent with the results of a research by Haghighi *et al.* on women with breast cancer in Tehran (38.8%).²⁸ The reason for this inconsistency can be the difference in the populations studied. The participants in our study were newly diagnosed patients, while in the study of Haghighi *et al.*,²⁸ the participants were patients living with breast cancer and were more likely to have obtained knowledge during the treatment period.

In the present study, nearly one-third of the participants received their health and disease information from doctors and health-care staff (36%), and through radio and television (21%). In the studies by Sahrayi *et al.* and Izadirad and Zareban, radio and television (42.5% and 19%) and health-care staff (37% and 49.8%) were the most important sources of getting health information, which is consistent with the results of the present study.^{24,27} In a systematic review, Hur *et al.* concluded that learning and health literacy could be improved by using multimedia tools and teaching in a simple language.²⁹ Another study suggested that a simple and understandable language used by the providers could be useful for patients' effective communications and better understanding.³⁰ The aforementioned issues indicate the importance of knowledge and awareness of the providers about health information and how to transfer them to patients, and also the importance of the mass media. In this regard, policy makers can plan to increase health literacy through the use of popular technologies.

The decisional conflict was reported at a moderate level (51.79) in this study, indicating the patients' uncertainty about their medical decision making. In a study by Essink *et al.* in 2016 to assess decision making knowledge and awareness of the patients with colon cancer, a low decisional conflict was reported (21.12).³¹ Besides, in the study by Jukkala *et al.* in 2013 on women with breast cancer, decisional conflict was 48.5% and at a moderate level,³² which is consistent with the present study. The conflict and hesitation could be due to the patients' uncertainty about their best medical decisions.³² Uncertainty might also be due to the patients' inadequate awareness and knowledge of the disease and therapies, and it is recommended that service providers spend more time counseling their patients in order to reduce this uncertainty.

Finally, there was an inverse and significant relationship between decisional conflict and health literacy ($r = -0.81$, $P < 0.001$), which is consistent with the study done by Tagai on patients with colon cancer ($P < 0.001$),²⁶ the one by Doyle *et al.* on patients with AIDS ($P = 0.05$),³³ that of Essink *et al.* in colon cancer screening ($P = 0.05$), and also the study by Jukkala *et al.* on women with breast cancer ($P < 0.001$).³²

High levels of uncertainty and concern for decision making can be caused by inadequate health

literacy.³⁴ Low health literacy can be due to the patients' inadequate knowledge of their disease. This inadequate knowledge might lead to uncertainty in the patients and they might feel that the treatment was imposed on them and was not based on their preferences. In fact, they may think they made a useless choice that would ultimately lead to regret over the decision.³⁵

Given that low health literacy causes conflict and uncertainty in patient decision making, it can be concluded that factors such as low ability to read, understand, and evaluate health information, the lack of access to reliable information, the lack of adequate knowledge of the benefits, risks, and side effects of the treatment, a perceived lack of support or the feeling of being under pressure, and the lack of attention paid to the patients' personal preferences and values are matters of concern and regret of the patients about their choice. Therefore, health literacy increases the ability of the patient, and subsequently the patient participation in decision making.³⁶ Hence, in order to increase the patients' health literacy and reduce their doubts in decision making, and considering patient-centeredness of the health care, it is suggested that required information along with methods of access to reliable information be provided to patients by the medical staff, and that patients be counseled about the disease and the treatment methods in a simple and understandable language, especially when there are more than one choice. This can lead to a better patient-doctor communication and mutual trust between them, increased patient commitment to health-care and treatment outcomes, increased quality of life, increased satisfaction, reduced decisional conflict, and reduced costs of the health care system.

The present study showed that increased health literacy could lead to reduced decisional conflict. Given the low level of health literacy observed in this study and the role of health-care providers and media in providing health information, it is suggested that these sectors should receive incentives to provide more comprehensive information to patients. Also, the use of mass media programs a simple and understandable way can help.

One limitation of this research was the lack of access to patients in private clinics, which reduced the study generalizability to some extent. It is suggested to consider the socioeconomic conditions that can affect patient decision-making, and take into account the use of educational packages and assess the patients' health literacy before and after using the packages.

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Conflict of Interests

The authors declare no competing interest.

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