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# Breast cancer patients' information needs and information-seeking behavior in a developing country



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#### ABSTRACT

Breast cancer is the most common cancer in women both around the world and in Iran. By studying the information needs of patients with breast cancer, the quality of the information provided for them can be improved. This study investigated the information needs of breast cancer patients and their information-seeking behavior.

Methods: This cross-sectional study was conducted from March to June, 2015. The research population was 120 women diagnosed with breast cancer and informed about their disease who referred to oncology outpatient clinics at a specialized cancer hospital and a radiotherapy oncology center in Mashhad (the only specialized cancer centers in eastern and northeastern Iran).

Results: Average participant age was 46.2 years (SD = 9.9). Eighty-five percent of patients desired more information about their disease. Results showed that the attending physician (mean = 3.76), television health channel (mean = 3.30), and other patients (mean = 3.06) were the most popular sources of information for breast cancer patients. Patients stated their strongest reasons for using information sources as achieving a better understanding of the disease (mean = 3.59), less anxiety (mean = 3.92), and curiosity to learn more about the disease (mean = 3.66), sequentially. Results further indicated that disease management (mean = 4.18) and nutritional options during treatment (mean = 4.14) were the most often mentioned areas in which patients required information, while knowing the progress rate of their disease was the least (mean = 3.73).

*Conclusion:* It seems necessary to have a good, organized plan to provide breast cancer patients with information and increase their information literacy, one of their undeniable rights.

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# Introduction

Among all cancers, breast cancer causes a large number of mortalities and is one of the first ten causes of death in women around the world [1]. It is the most common cancer in women both around the world and in Iran [2], accounting for 24.2% of all cancer cases in Iran [3]. Asian countries such as Iran have reported a recent

growth in the rate of breast cancer cases [4]. According to a recent study in Iran, 6160 cases of breast cancer are diagnosed annually, and around 1063 of them result in death [3]. The annual rate of new breast cancer cases in Iran is predicted to reach 15,000 by the year 2030 [4].

In recent decades, more attention has been given to having cancer patients actively participate in their care process. Different patients have different treatment priorities and request different amounts and types of information about their disease [5]. The participation of patients in making decisions about their disease depends on their being provided with enough suitable information [6].

Patients with breast cancer have many information needs [7]. Most patients have no clear concept of cancer at the time of

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diagnosis and require information to better understand and fight their disease [8]. Their needs for information stem from their having incomplete information and a lack of understanding about their current situation [6]. Considering patients' needs for information will assist them in making informed decisions and will increase their satisfaction in choosing treatment options. Creating logical expectations in patients empowers them to cope with cancer [9,10]. Providing enough information to patients may raise their level of participation, improve the quality of care [11], relieve some anxiety about cancer and its treatment process, correct false beliefs, increase patient adherence to treatment recommendations, establish better relationships between physicians and patients, improve one's mental health [12], and increase satisfaction levels among patients [13].

Recent studies have shown that, despite increasing awareness and knowledge among clinicians about the information needs of cancer patients, many patients still feel that they do not get enough information or have received information that is unclear and not understandable [12,14,15].

Studies have also indicated that patients use other information sources, such as the Internet, books, and other patients, to meet their information needs [16,7].

Many cancer patients would like as much information as possible about their disease, treatment options, the rehabilitation process, side effects, and possible outcomes of their disease. However, the type of information they request will change over time [8.13].

By studying the information needs of breast cancer patients, the quality of the information provided for them can be improved. The present study investigated the information needs of breast cancer patients and their information-seeking behavior. The important points of the present study are the simultaneous consideration given to the information sources of breast cancer patients, the evaluation of patient trust in each source, the information needs of patients, and problems in meeting these needs in a developing country.

# Methods

Study design

This cross-sectional study, approved by the Ethics Committee of Mashhad University of Medical Sciences (Code: 931529), was conducted from March to June, 2015. The research population was women diagnosed with breast cancer and informed about their disease who referred to oncology outpatient clinics at a specialized cancer hospital and a radiotherapy oncology center in Mashhad (the only specialized cancer centers in eastern and northeastern Iran).

Oncology physicians in the outpatient clinics identified eligible patients who were then provided with information about the study. Those who agreed by implied consent to participate were given a questionnaire.

# Sample

The questionnaire was offered to 150 women with breast cancer; 120 patients completed the questionnaire, giving an 80% response rate. The inclusion criterion was having breast cancer (regardless of age or level of education). Those patients unable to take part in the study because of tiredness caused by chemotherapy, unwillingness due to mental problems, foreign language-speaking patients, and men with breast cancer were excluded.

#### Questionnaire design

The questionnaire was designed based on factors identified in the published literature and included seven parts: (a) demographic characteristics: gender, age, marital status, education level, occupation, residence; (b) patient attitude toward information; (c) information sources used by patients; (d) reasons for using information sources; (e) patients' information needs; (f) the degree of patient trust in information sources; (g) problems patients faced while obtaining information about their disease. Patient attitude toward information was assessed using yes/no questions, the next five parts rated on a five-point Likert scale (1 = very low to 5 = very high), and one open-ended question: "In general, what is your opinion about the accessibility to the medical information?". The validity of the questionnaire was analyzed using the content analysis method (literature review and expert opinions), and reliability was assessed using the test—retest method (r = 0.78).

# Data analysis

Statistical analysis was performed on this data using the t-test and the chi-squared test. Data was analyzed using SPSS 11.5 software. The "cut off" used for the P value was 0.05.

#### Results

Baseline characteristics

The average participant age was 46.2 years (SD = 9.9). The majority of patients were married (90.8%); 65.5% had less than a high school education, 76.7% lived in urban areas, and 91.7% were housewives.

## Patient information-seeking

Results concerning patient attitude toward information indicated that 45% of patients had previous experience in seeking information about breast cancer; only 10.2% of them sought information before their diagnosis. Eighty-five percent of patients desired more information about their disease. There was a significant relation between information seeking and age. Younger patients ( $\leq$ 46 years) had a higher tendency to seek information (P = 0.036).

Results showed that the attending physician (mean = 3.76), the television health channel (mean = 3.30), and other patients (mean = 3.06) were the most popular sources of information used by breast cancer patients. Pamphlet or brochure (mean = 1.70) and hospital e-mail (mean = 0) were the least used sources (Table 1). Results also identified a significant correlation between use of a book and age; older patients used fewer books as information sources than younger patients (P = 0.008).

Responses regarding the degree of patient trust in information sources revealed that patients trusted their attending physician the most (mean = 4.32), followed by the television health channel (mean = 3.30) and other television channels (mean = 3.60).

Patients stated their strongest reasons for using information sources as achieving a better understanding of the disease (mean = 3.59), less anxiety (mean = 3.92), and curiosity to learn more about the disease (mean = 3.66), sequentially. It should be noted that the weakest reason for using information sources was that it had been suggested by their attending physician (mean = 2.13).

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