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Health Information Seeking Behavior of Breast Cancer Patients: A Qualitative Study

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Abstract

Background: Breast cancer is the most common cancer of women worldwide. This study was aimed to review systematically the current literature on the health information seeking behavior of breast cancer patients and to conduct the qualitative analysis of findings.

Methods: We searched PubMed, Web of Science, Science Direct, CINHAL, Embase, Google Scholar, Cochrane database of systematic review, PSYCINO, SID and Magiran databases. A total of 60 articles included in the study. Findings of all studies were extracted, the content analysis was conducted and a series of themes and categories were identified

Results: 13 themes were identified in the published studies. The related findings of all themes are presented and discussed.

Conclusion: We summarized and classified all the findings of studies on the health information seeking behavior of breast cancer patients. Our classification can be used for the comprehensive examination of the breast cancer patients' health information seeking behavior to develop improvement policies.

Background

1- Information, Information Behavior and Information Seeking Behavior

Information is the communicational meaningful symbols that transferred between two points in human relationships or machine networks. Information behavior is defined as any kind of information seeking, passive exposure to information or purposive behaviors of information avoidance. In the other words, it can be said that information behavior refers to the entirety of human behavior in relation to information sources and channels (including both types of active and passive information search and use). [1] Research on the information behavior has a long history. The beginning of this research is reflected in the scientific conference of the Royal Information Society (1948), in which a number of articles on the information behavior were presented. After this conference, thousands of articles were published on user needs, information needs and information seeking behavior. Also, a number of models were developed. A model is, in general, a framework for thinking about a phenomenon that shows the relationships between its components. Models of information behavior mostly are diagrams that attempt to conceptualize an information search activity, the causes and consequences of that activity or the relationship between the steps of information seeking behavior. [2,3] According to Wilson (1997), a general information behavior model should include at least 3 components:

1) Information needs and drives or factors that create the perception of need to information for an individual.

2) Factors that affect the individual's response to the feeling of need.

3) The processes or actions involved in the response. [1]

Figure1. shows the Wilson information behavior model. According to this model, the information seeking behavior is began as a consequence of perceived need of an individual to information which makes demand for formal or informal information resources or services in attempt to satisfy that need. This attempt, ultimately leads to the success or failure to find relevant information. In case of success, the person begins to use the found information which satisfies the perceived information need in partial or fully. If the perceived need does not satisfy fully, the search process will be repeated.

This model also suggests that information behavior may involve others trough the exchange of information. [1,3]

At the same time, more models are proposed as information seeking behavior models. As explained in information behavior, information seeking begins with a perceived need to information and ends with the satisfying point of that need. Therefore, information seeking behavior can be defined as an individual's way or manner to collect and store the information and use it.

Ellis & Haugan (1997), have developed a model of information seeking behavior which describes 6 categories of information seeking activities as starting, chaining, browsing, differentiating, monitoring, and extracting. Also, Wilson's (1981) model of information seeking behavior is one of the most popular models of these kinds. Wilson's model has been constructed on 2 propositions: first, information need is not a primary need, but rather a secondary need which arises as the consequence of a more basic need; and second in the effort to obtain information to satisfy this information need the information seeker is likely to meet different barriers.

Also, Wilson believes that the content of each of the basic needs that create the information need can be the person himself, his/her role in work or life or the environment of that work or life. He then states that information seeking barriers are also created in similar content. Figure2. shows this model along with Ellis' definition of information seeking behavior. [1]

In 1996, Wilson introduced a new model of information seeking behavior by making changes to his original model. In this new model, the main framework of original one was maintained in which the individual in content stated as the focus of the information needs but information barriers introduced as intervening variables and the information seeking behavior was defined. According to this new model, the information needs of an individual lead to the formation of information seeking behavior which is also faced with different barriers. Based on this model information seeking behavior can occur as passive attention, passive search, active search or ongoing search. Once the person has acquired the information, he begins to process and use it. If informational need is not met, information seeking behavior is re-activated. [1-3]

2- Breast Cancer and Information Seeking Behavior:

Breast cancer is the most common cancer among women which causes a large number of mortalities. [4] It is the second leading cause of cancer death in women. [5] Today, breast cancer is one of the major

global health issues in both developed and developing countries. [6,7] In recent years, much attention has been paid to the active participation of women with breast cancer in their care process. [4] Current health policies advocate that active involvement of patients in their health care is one of the most important components of care quality. [8-10] Active participation of women with breast cancer in treatment decision –making is very important due to the high incidence rate of the disease worldwide and the fact that breast cancer patients typically have different treatment options to choose. [8] Participation of breast cancer patients in their treatment process has several positive outcomes, including better quality of care, better quality of life and higher satisfaction from medical care received. [8-10] The effective participation of patients in medical decision-making requires that they have sufficient information about the disease and its different aspects. However, the results of studies show that women with breast cancer have a high level of unmet information needs about their health and also a high degree of dissatisfaction with information provided by the care providers. [10]

One way to involve breast cancer patients in their treatment process is to provide accurate and understandable information to them. To provide this information, first of all, it is necessary to investigate their health information seeking behavior including their informational needs, preferred information sources, information barriers and their attitudes towards health information. [11] According to the definition of information seeking behavior, health information seeking behavior can be described as the identifying of needed health information and trying to satisfy them through the search and use of information. [1-3,11,12]

Health information seeking behavior includes various aspects such as health information needs, health information sources, health information barriers and patient attitudes towards these kinds of information. Diagnosis of cancer often leads to the need for more information among patients and their relatives. Therefore, considerable literature is available on the for health information seeking among cancer patients including seeking information related to prevention, lifestyle and risk factors, treatment, prognosis, patient-doctor communication, new treatments and other information needs. [13,14] Health professionals and researchers have so far published widespread literature on issues such as the characteristics of people involved in the behavior of health information seeking, identifying the motivations of engaging in these behaviors as well as the types of health and medical information that they are looking for. [15]

3- Information Seeking Behavior, Healthcare Utilization and Health outcomes:

Although healthcare utilizations raises due to a variety of factors, there are evidence which shows that health information seeking serves a predictor of health care utilization and health outcomes. Nguyen et al (2017), in a study, have shown that the utilization of physician visits as well as hospitalization in people who use TV and Internet to obtain health information is significantly different from others. They have concluded that wider availability of health information is directly associated with healthcare utilization. [16] Also, Weaver et al (2010) have shown in a study that there is a kind of relationship between the kind

of information sought and the self-assessed health status. [17] The results of 3 unpublished studies from the authors also indicate that seeking online health information is related to the improved patient-physician relationship in hospital settings, the lifestyle of pregnant mothers and the general health of high school girls.

4- Justification of This Study:

Breast cancer is the most common cancer in women that is expected to cause significant human and financial losses in the coming years. [11] Women with breast cancer often describe the decision making process about their treatment as worrying and confusing. Patients who do not have complete information about treatment options may choose options that are not optimal. For this reason, the institute of medicine has called for more research on the awareness of breast cancer patients about treatment options. [18] On the other hand, promoting self-care and health literacy, one of the most important functions of health systems, is directly influenced by the health information seeking behavior. [11] Therefore, studies on the breast cancer patients' health information seeking behavior are beneficial. Investigation of health information seeking behavior should be done specifically for each disease. There is some evidence which shows that health information seeking behavior can be varied based on the health condition and the type of disease. [13] Also, although there are many studies available on the health information seeking behavior of breast cancer patients but each of these studies has addressed one or some aspects of health information seeking behavior among these patients. These aspects include some ones such as patients' health information needs, their preferred information sources, information barriers and the benefits of seeking health information. According to this description, this study, aimed to review the literature on the health information seeking behavior of breast cancer patients and categorizing their results using a qualitative research method is unique and useful.

Methods

This study was aimed to review the current literature on the health information seeking behavior of breast cancer patients and summarizing and categorizing the findings. Although many articles have been published on this topic, but each of them has reported a unique aspect of breast cancer patients' health information seeking behavior. Some authors have reported the patients' reasons, predictors or determinants of information seeking behavior while some others have focused on the other aspects of subject such as the process of information seeking including information seeking styles, the informational needs and requirements of patients, the most common informational resources used by patients, outcomes/benefits of seeking information, improvement strategies and so on. Based on our knowledge, there is no study available which has reviewed the current literature on the subject and summarized and categorized all the findings. It seems that reviewing the existing literature and summarizing and categorizing of their findings can provide a comprehensive document of the current trends of studies on this subject. This study was aimed to provide such a document. Therefore, first we did a systematic review of the current literature on the subject using the relevant protocol to systematic

reviews and then we applied the qualitative content analysis to categorize the findings from our systematic review due to their diversity. Although, the combination of these research methods is not observed in studies on the subject of our work, but some authors have recruited these 2 methods ie systematic review and qualitative content analysis sequentially in their studies. [19-23] According to this explanation, our work was conducted in 2 separate phases:

1. Systematic review of current literature on the breast cancer patients' information seeking behavior: In this phase, the eligible studies on the subject were identified and their findings were extracted. The details of this phase of study are as followings:

Search strategy for the identification of studies: Figure 3. graphically summarizes the methodology and search strategy of our review. We searched the most reputable online databases including Pubmed, Web of Science, Science Direct, CINHAL, Embase, Google Scholar, Cochrane database of systematic review, and PSYCINO, SID and Magiran (Persian databases). Searching theses databases provides the possibility to retrieve the most of available literature. Also, the references of retrieved studies were searched manually. Our search was done using the free text search terms information, health information, information seeking behavior, breast cancer, online information seeking behavior and their combinations. The searched keywords were identified through a mini review which was conducted prior to main review. The search was carried out without any time limitation. Studies in Persian and English languages were included. Using the keywords we found a total of 1173 articles.

Study selection: All these articles were entered into the Endnote software and the duplicate titles were removed using Endnote's Remove Duplicates Function. Then, the abstracts of the articles were reviewed and the irrelevant studies were removed. If determination of the relevance of a study for inclusion in the study was not possible by reviewing titles and abstracts, the full text was studied. After removal of repeated and irrelevant studies, the remaining studies were entered into the quality assessment process.

Quality assessment of the studies: Quality assessment of the retrieved articles was carried out using the STROBE checklist by two researchers, independently. The STROBE statement has been developed by a collaborative effort of epidemiologists, methodologists, statisticians, researchers and journal editors to improve the reporting of observational studies including cohort, case-control and cross-sectional ones.

Inclusion and exclusion criteria: The inclusion criterion was to examine at least one aspect of health information seeking behavior in patients with breast cancer. Also, if a study was conducted on patients with various types of cancer including breast cancer and its findings had been reported separately for each cancer, it was entered in the quality assessment process.

Data Extraction: The required data from the selected studies including the name of authors, year of publication, title of the journal, location, type of study, sample size, characteristics of the participants and the findings related to the information seeking behavior of participants were extracted by 2 researchers using an authors developed form.

2. The qualitative content analysis of extracted data from systematic review: After extracting all the findings of included studies in our review, as in some previously published systematic reviews, we conducted an adjunctive qualitative content analysis to categorize the extracted findings. Content analysis has been defined in many different ways but the essence of them is that content analysis is a scientific method which is used to draw conclusions about the content in different kinds such as interviews, observations or articles. In our content analysis, the researchers and 2 gynecology oncologists performed a qualitative analysis to generate main themes and themes from extracted data until saturation. The saturation was defined as the point in which the extracted data yielded no new main themes or themes. The qualitative analysis was carried out in an expert panel consisted from researchers and 2 gynecology oncologists. Based on this qualitative analysis, all the extracted findings from our systematic review were categorized under the 3 main themes including determinants/predictors of health information seeking behavior, the process/procedure of health information seeking behavior and the consequences of health information seeking behavior. Also, we identified a total of 13 related themes and their relevant sub-themes in our qualitative analysis. Finally, the adequacy validation of the analysis was carried out through consultation with two independent oncologists. In this regard, we obtained the viewpoints of these independent consultants about our qualitative analysis. These consults did not change our main results.

Results

The characteristics of the studies reviewed have been presented in Table 1:

Table 1

Summary of the included articles in review

ID	Authors	Year of publication	Journal	Location	Type of study	Sample size
1	Nies et al. (24)	2017	Patient Preference and Adherence	Malaysia	Cross-sectional	204
2	Boman, et al. (25)	2017	Patient education and counseling	Sweden	Qualitative	16
3	Wang et al. (26)	2017	Int J Radiation Oncol Biol Phys	USA	Survey	-
4	Holmesa et al. (27)	2017	Complementary Therapies in Medicine	UK	Qualitative	11
5	Fletcher-Browna et al. (28)	2017	Journal of business research	New Delhi, India	Qualitative	20
6	Harder et al. (29)	2017	J Cancer Surviv	UK	Qualitative	9
7	Kimiafar et al. (4)	2016	The Breast	Mashahd, Iran	Cross sectional	120
8	Rogitha et al. (30)	2016	International Journal of Medical Informatics	Texas, USA	Cross-sectional	100
9	Robinson et al. (31)	2016	Journal of Surgical Oncology	USA	Qualitative	132
10	Shen et al. (32)	2016	Psych oncology	New York, USA	Qualitative	21
11	Burke et al. (33)	2016	PLoS ONE	USA	Qualitative	38
12	Shim et al. (10)	2016	BMC Women's Health	Seul, Korean	Qualitative	7
13	Recio-Saucedo et al. (34)	2016	The Breast	UK	Systematic review	-

The themes and sub-themes identified have also been presented in Table 2.

ID	Authors	Year of publication	Journal	Location	Type of study	Sample size
14	Foley et al. (35)	2016	The breast	Ireland	Prospective randomized control trial	18
15	Akhtari-Zavare et al. (7)	2015	Asian Pacific Journal of Cancer Prevention	Malaysia	Cross-sectional	425
16	Jacobs et al. (36)	2015	CSCW	USA	Cross-sectional, questionnaire, interview	21
17	Rutten et al. (37)	2015	J Canc Educ	USA	Survey	-
18	Henriksen et al. (38)	2015	BMC Res Notes	Denmark	Qualitative	6
19	Potteret et al. (39)	2015	The breast	UK	Qualitative	31
20	Yu et al. (40)	2015	Asian Pac J Cancer Prev	Malaysia	Meta-synthesis	NA
21	Goss et al. (41)	2015	European journal of oncology nursing	Italy	Qualitative & observational	70
22	Bei et al. (42)	2015	Asia-Pacific Journal of Oncology Nursing	Hong Kong	A cross-sectional exploratory study	275
23	Lifford et al. (43)	2015	BMC Medical Informatics and Decision Making	UK	Semi-structured interviews	35
24	Han et al. (44)	2014	Health Commun.	USA	Clinical trial	325
25	Kowalski et al. (45)	2014	J Med Internet Res	Germany	Postal survey	27491
26	Patrão et al. (46)	2014	Conference	Portugal	Qualitative	8
27	Kim et al. (5)	2013	J Comput Mediat Commun	USA	Cross-sectional	231

The themes and sub-themes identified have also been presented in Table 2.

ID	Authors	Year of publication	Journal	Location	Type of study	Sample size
28	Kim et al. (47)	2013	J Comput Mediat Commun.	Mchigan, USA	Survey	221
29	Kim et al. (48)	2013	Journal of Computer-Mediated Communication	Michigan, USA	Population-based study	231
30	Sacksa et al. (49)	2013	Gac Sanit	Spain	Qualitative	41
31	Shaffer et al. (50)	2013	J Med Internet Res	USA	Cross-sectional	56
32	Littlechild & Barr (51)	2013	Patient Educ Couns.	UK	Cross-sectional	200
32	Nakashima et al. (52)	2012	Fukuoka Acta Med	Japan	Retrospective cross-sectional	104
33	Han et al. (53)	2012	J Health Commun.	Mchigan, USA	Survey	221
34	Kratzke et al. (54)	2012	J Community Health	New Mexico	Cross-sectional	157
35	Tan et al. (55)	2012	Cancer Epidemiol Biomarkers Prev	USA	longitudinal cohort study	352
36	D'Agostino et al. (56)	2012	Patient education and counseling	USA	Cross-sectional	70
37	Almyroudi, et al. (57)	2011	Psycho-Oncology	Greece	Cross-sectional	329
38	Sharpley et al. (58)	2011	Educ Thr Patient	Australia	Cross-sectional	253
39	Radina et al. (59)	2011	Cancer Nursing	USA	a secondary analysis of data from 2 separate qualitative studies	35
40	Skeels et al. (60)	2011	CHI Conf. Proc.	USA	Participatory Design	4

The themes and sub-themes identified have also been presented in Table 2.

ID	Authors	Year of publication	Journal	Location	Type of study	Sample size
41	Namkoong et al. [61]	2010	Patient education and counseling	USA	Cross-sectional	231
42	Nagler et al. [9]	2010	Patient Education and Counseling	Pennsylvania, USA	Population-based survey	678
43	Eheman et al. [62]	2009	J Health Commun.	USA	Longitudinal study, interview, survey	374
44	Longo et al. [6]	2009	Journal of Communication in Healthcare	USA	Cross-sectional supplemented with interview	158
45	Halkett et al. [63]	2009	Radiotherapy and Oncology	Australia and New Zealand	A descriptive questionnaire design	30
46	Chesser et al. [64]	2009	Kansas journal of medicine	USA	Qualitative	51
47	Shaw et al. [65]	2008	J Health Commun.	Wsconsin, USA	Cross-sectional	144
48	O'Leary et al. [66]	2007	Patient education and counseling	Canada	Systematic review	NA
49	O¨ zcelik et al. [67]	2007	Annals of Oncology	Germany	Cross-sectional	632
50	Yi et al. [68]	2007	Asian Nursing Research	Korea	Cross-sectional	164
51	Fagerlin et al. [69]	2006	Patient education and counseling	USA	Cross-sectional	1225
52	Talosing-Garcia & Davis [70]	2005	Journal of Health Communication	USA	Cross-sectional	287
53	Maly et al. [8]	2004	Breast Cancer Research and Treatment	Los Angeles, USA	Cross-sectional, interview	222
54	Fogel et al. [71]	2004	Cyber Psychology & Behavior	USA	Cross-sectional	178

The themes and sub-themes identified have also been presented in Table 2.

ID	Authors	Year of publication	Journal	Location	Type of study	Sample size
55	Fogel et al. (72)	2003	Psycho-Oncology	USA	Cross-sectional	180
56	Fogel, et al. (73)	2002	J Med Internet Res	USA	Cross-sectional	251
57	Girgis et al. (74)	2000	Australian and Newzeland Journal of Public Health	New South Wales, Australia	Cross-sectional	129
58	Lee & Wkins (75)	2000	Journal of Health Communication	USA	Randomized trial	122
59	Pereira, et al. (76)	2000	Clinical Breast Cancer	Canada	Survey	107
The themes and sub-themes identified have also been presented in Table 2.						

Table 2

Themes and sub-themes identified in the qualitative analysis

No.	Themes	Sub-themes
1	Patients' desire to seek information and it's determinants	Patients' desire to seek information
2	Cancer knowledge of patients	Cancer knowledge of patients
3	Information seeking experience	- Experience of information seeking - Average time spent on seeking information and its associated factors - Information seeking at different stages of disease - Thematic categories of sought information
4	Determinants of information seeking	Determinants of information seeking
5	Patients' reasons for information seeking	Patients' reasons for information seeking
6	Patients' Informational needs	- Common informational needs of breast cancer patients - Factors Influencing patients' informational needs
7	Information sources	- The most common sources of information using by patients - Patients' trust in information sources - Methods of providing information to patients by care givers - Number of sources searched - Determinants of preferred information sources
8	Information seeking style	Information seeking style
9	Information seeking barriers	Information seeking barriers
10	Patient Satisfaction with sought information	Patient Satisfaction with sought information
11	Outcomes/ Consequences of information seeking	Outcomes/ Consequences of information seeking
12	Interest in sharing cancer information	- The willingness of patients and care providers to share information - Common information types which interested to be shared - Factors affecting patients' desire to share information - Differences between patients' and providers' preferences for sharing information
13	Emerging Information sources used by patients	- Internet and Mobile phones

1) Patients' desire to seek information and its determinants:

14 articles had studied the patients' desire to seek information. All of these studies have shown that the majority of breast cancer patients tend to have information about their disease. [4,9,24,37,57,59,65,66] Breast cancer patients compared to those with other types of cancer are more likely to seek information actively. [37,59,62] It has also been reported that a significant percentage of breast cancer patients don't want to receive detailed information and are merely inclined to have the information they need. Also, a smaller percentage of them are willing to receive bad news and information. [32] Personal history, perceived need to information, ethnicity, education and marital status are among the determinants but age, religion, employment and income have not shown to have relationship with patients' preference for seeking information. [24,37,39,65,72]

2) Cancer knowledge of patients: Although a study from Malaysia has reported the studied patients' knowledge as poor [40], the majority of studies have reported that a significant percentage of breast cancer patients have an acceptable degree of knowledge about the disease. Also, a considerable percentage of patients think that they have knowledge about their disease. Studies show that higher education and income are associated with better knowledge. [30,52,54] Some factors such as ethnicity, race, education and the patients' sources of information affect their cancer knowledge. [69] Surprisingly, although greater perceived knowledge is favorable, but it have some negative consequences. A study has shown that patients' perceived knowledge about prevention is one of the reasons for not using messages related to breast cancer prevention. [30,52,54] So it seems that perceived cancer knowledge can affect patients' information behavior. In the other words, it can act as a predictor of patient's information seeking behavior.

3) Information seeking experience:

- Experience of information seeking: In the reviewed studies, between 45% and 93% of the participants had reported previous information seeking experience. [4,52,57,72] A large percentage of patients also, had occasionally looked for information. [9]

- Average time spent on seeking information and its associated factors: One study has reported this matter. The study reported that participants spent an average of 32 minutes on the online information seeking in a period of 4 months. [34] Factors such as unmet and perceived informational needs, functional well-being, health self-efficacy, emotional well-being, negative emotions, participation in health care, information competence, barriers to seeking information and perceived social support have significant association with the mean time spent on searching information by the participants. [34,40]

- Information seeking at different stages of disease: Current literature shows that very few patients seek breast cancer information before disease diagnosis. This percentage had been reported in one study as 10.2% [1]. Another study has shown that in the pre-treatment period, only 16% of its participants actively looked for information and the rest of them were moderately active (71.4%) or passive (12.6%). [62] In

another study, the majority of patients (73%) reported that they had not searched for more information about their disease after the diagnosis [54].

Another study has reported that search for topics related to the breast cancer at stage III of the disease was more than that other stages which followed by stages II, I, 0 and IV, respectively. [9] Another study found that higher stages of the disease are associated with a reduction in the use of Internet to search information. [45]

- Thematic categories of sought information: Various studies have investigated the types of information searched by breast cancer patients. A summary of the findings of studies shows that the patients seek the following information:

- **General information on cancer and its treatment:** Breast cancer patients look for information about cancer and its treatment more than other information such as care providers or psychosocial consequences. This information includes laboratory tests and radiographies; treatment options, their advantages and disadvantages; medications; the best treatment; description of treatment and therapeutic procedures; treatment complications and treatment schedules; rehabilitation; complementary comments on proposed treatments by physicians; the process of recovery and its time frame; the probability of disease relapse and its spread to other parts of the body and the chance of survival. [9,24,30,32,4,45,47,67,70]
- **Psychosocial management:** A significant percentage of breast cancer patients are searching information about managing the effects of cancer on family and social life including the management of side effects; psychological support for overcoming disease; required personal and family care and the probability of losing job. [9,46,47,65]
- **Care providers:** Information about care providers such as the best physicians or hospitals is an important information category which is sought by patients. [9,30,67]

4) Determinants of information seeking: Some factors affect patients' desire to seek information positively and some another negatively. Five studies have grouped all the affecting factors of information seeking behavior for online and non-online information as followings:

A) Contextual factors including healthcare structure, delivery of care, information environment factors and cross-cultural communication. [6]

B) Individual factors including demographic factors such as age [4,6], socioeconomic factors, health history, genetics, family medical history, culture, language, attitudes, intentions and behaviors, current health status and health literacy [6], education [6,45], race [8], having private insurance coverage and living with a partner. [45] Also, women with higher self-efficacy have more active role in seeking information. [42] Moreover, higher disease stages [45] could reduce the patients' desire to seek online information. This one can be due to the reduced ability of patients to seek information as a result of their disease progression.

5) Patients' reasons for information seeking:

A study has reported that having a better understanding of disease, reducing the anxiety and curiosity for learning are the most important causes of information seeking, while the physician advice is the less important one. [4] Another study reported that most patients seek information to protect and support themselves. They seek information to be able to control their status, to be supportive of themselves and to understand the physicians' conversations better. [35]

6) Patients' Informational needs:

- Common informational needs of breast cancer patients: The most important information that breast cancer patients need includes:

- Disease causes and risk including its heredity [44,46].
- General information about disease and its prognosis: includes information on screening and degree of invasiveness, progression of disease and the chance of recurrence [4,8,33,46,66,70].

- Information about treatment options: Includes information on the best treatment approach, benefits and side effects of treatments and their chances of success [1,11,12,27,37,50,54,58].
- Information about disease consequences: Includes information about the potential effects of cancer on life expectancy [58,11].
- Information about the management of side effects and self-care strategies: Includes some information about the management of cancer-related psychological issues such as anxiety and stress, self-care strategies, disease management and its negative effects at home, the diet, physical activity and tobacco use during the treatment periods, recovery methods and what the patients can do to help themselves [1,12,18,31,58].

- Information about the care providers and support groups: Includes useful information for finding the best care provider as well as the available support groups in the area [1,12,58].
- Financial information: Includes the amount of direct out of pocket payments in the course of treatment [11].

- Factors influencing patients' informational needs: Although all cancer patients need some information about the disease, their informational needs are not same. It has been showed that some factors affect the informational needs of breast cancer patients. A study has reported that the spreading of cancer to other parts of body and the gross household income are among such factors. In another study, patients were asked about the informational needs at different stages of disease. Participants have stated that in the preoperative stage, much more information is not needed; but as they going forward in treatment spectrum, more detailed information is needed [7]. Age, education, preferred level of control over decision-making and the patient's real role in decision making, having family history of illness, the time elapsed

since the diagnosis of disease, religious beliefs, living with others or alone, income and education are other factors influencing the amount and types of information that is needed by patients [11,19,27,50].

7) Information sources:

- The most common sources of information using by patients:

The common information sources of breast cancer patients can be divided into 4 categories:

1. Interpersonal sources: Interpersonal sources are the most used sources of information by breast cancer patients. The most commonly used interpersonal sources are physicians, nurses and other health professionals [1,3,4,6,22,38,54]. Also, other breast cancer patients, face-to-face or online support groups, family members, spouses or partners, friends and colleagues are other interpersonal sources of information for such patients [3,4,6,10,13,22,24,28,39,42,43,44,47,48,53,54].
2. Paper sources: Including magazines, brochures and pamphlets, newspapers, books, specialized journals and health exhibitions [1,3,4,5,22,38,39,54].
3. Digital sources: Including television and radio [1,3,38,42,44,50,53,54].
4. Websites: Cancer-related websites are the expanding sources used by breast cancer patients [10,12,24,38,44,47,50,51,53,54].

According to the findings of studies, it seems that health care providers are still the most common information sources for breast cancer patients, although the findings of studies are scattered among other information sources.

- Determinants of preferred information sources: Some factors affect patients' preferred information sources including cultural factors, race or ethnicity, language, age, education, participation rate in decision making and the type of treatment [3,44,50].

- Patients' trust in information sources: A study has examined the patients' trust in various information sources. According to this study, patients have the most trust in the attending physicians and health and other television networks [1]. A study has reported that patients are cautious about unusual information provided by production companies [12]. Another study has reported that 53% of participated patients are suspicious about the reliability of online information [60].

- Methods of providing information to patients by care givers: Care givers' communication behavior with patients in terms of information providing includes the following 2 types:

1) Interactive information: Refers to the top disease-related issues that are considered as the most important ones by patients which should be provided by care givers.
2) Tangible information: Refers to specific informational sources such as books, pamphlets, medical records and the information of support groups for patients provided by care givers [5].

Also, cancer-related information can be provided for patients in 2 ways of explicit and implicit information introduction. In implicit introduction, physicians refer to the questions which patients previously brought up while in explicit manner physicians explicitly ask patients if they have any question about cancer-related information [17].

- Number of sources searched: In a study, the number of sources searched by patients has been examined. According to this study, each breast cancer patient, on average, seeks information from 2.5 ± 3.8 sources. This study also has shown that as the disease progresses, the number of informational sources which are searched by patients is reduced [6].

8) Information seeking style: Breast cancer patients, generally, use 2 different styles of information seeking: Narrative and Instructive information seeking [2,32,33]. In this case, two studies have found that patients' perception of social support can affect their information seeking style. Women with lower perceived social support use narrative form more than those with higher perceived social support [2,32].

Also based on the role of the patients, information seeking styles are divided into 3 categories:
1) Passive information seeking: Patients do not seek information, but they get the information that happened to pass their way.

2) Moderately passive information seeking: Patients seek information curiously or only to fill the gap of their knowledge.
3) Active information seeking: Patients seek information as a complementary viewpoint of their health care providers' recommendations [3,32,43,46].

In this case, the results of studies show that although breast cancer patients seek information more actively before the treatment, but in the post-treatment phase they become passive recipient of information [43,46].

Also, breast cancer patients can be categorized in the following groups according to the amount of information they use in making their health decisions:

1) Information using phases for active information seekers:
- Patients are not aware of available information.
- Patients are aware of available information, but do not attempt to access it.
- Patients are aware of the available information and attempt to access it.
- Patients have access to available information, but are not able to use it.
- Patients have access to available information and are able to use it.
- Patients have access to available information, but do not use it to make their healthcare decisions.
- Patients have access to available information and use it to make their healthcare decisions.

2) Information using phases for passive information recipient:
- Patients do not receive information from informational sources.

- Patients receive information from informational sources, but do not use it.
- Patients receive information from informational sources and use it.

- Patients receive information from informational sources, but do not use it to make their health-related decisions.

- Patients receive information from informational sources and use it to make their health-related decisions [3].

9) Information seeking barriers: The most important problems for patients in seeking information are low familiarity with medical terminology; limited knowledge of informational sources and inaccessibility of sources; concerns about the quality of information and negative experiences in seeking information such as spending too much time to find the information they need, tending to have more information, problems related to the understanding of searched information and frustrating and disappointing feeling towards seeking information [1,15,36]. A study has reported that higher level of education reduces the information seeking problems because patients with higher education are more familiar with medical terminology and have less linguistic problems [36].

10) Patient Satisfaction with sought information: Generally, 3 factors affect the patients' satisfaction from information seeking including the sources of information, the amount of information received and the manner of giving information. One study reported that 40% of its participants were not satisfied with the manner of giving information by their nurses. The participants of this study stated that information giving by physicians and nurses, especially in regard to the mental and emotional supports, should be improved [1,60]. However, some studies have reported a moderately good satisfaction of their participants from received information [14,24,51].

11) Outcomes/ Consequences of information seeking: According to the existing literature, information seeking experience is related to improved patient knowledge, more active participation in care decisions, improved self-care, empowerment, higher satisfaction, more activated daily life, better emotional well-being, better patient-physician relationship and even the better health outcomes [3,15,20,36,39,45].

12) Interest in sharing cancer information:

- The willingness of patients and care providers to share information: Sharing disease information with care providers has positive effects on the treatment and its outcomes trough creating a better understanding of the disease. A study has shown that care providers believe that it is necessary for them to have information about their patients' physical and mental health factors [21]. This study reported that most patients also tend to share their health information with the care providers [21]. In addition to share information with the care providers, patients often share their health information with their family and friends, other patients, cancer survivors and other people who can help them [44]. Patients try to discuss

their information with others for some reasons such as to become more aware, ask for more information, actively engage in improving their health and satisfying their psychological and emotional needs [40].

- Common information types which interested to be shared: Breast cancer patients are mostly interested in sharing information about their height, weight, pain, nausea, constipation /diarrhea, fatigue, insomnia, heat flashes, hair loss picture, medication adherence, details of surgery, disease stage, survival history, wound image, breast image, diet, stress, anxiety, fear, loneliness, support seeking and having a good or bad day with their care providers.

Providers also wish to receive information on different topics including biometric factors, physical factors, constipation/diarrhea, hot flashes and medication adherence, patients' dietary regimen and insomnia as well as psychological factors and support seeking.

Although this list can include many factors, it seems that a combination of information about a variety of factors can help the care providers to understand their patients better [21].

- Factors affecting patients' desire to share information: A study reported that the following factors affect patients' desire to share their disease information:
a) Patients' perceptions: Patients' perception of the desire of information recipients to receive information and their ability to help them

b) Cancer identity: Some patients consider cancer as a small part of life and, therefore, they can more easily share their cancer information with others.
c) Imposing problems on others: Patients' unwillingness to impose their own problems on others and lack of desire for glory and grievance [21].

- Differences between patients' and providers' preferences for sharing information: A study has shown that there are significant differences between the preferences of patients and care providers in sharing information. For example, patients and providers' preferences of sharing some kinds of information, including hair loss images, breast images, psychological factors as well as patients' dissatisfaction from care providers are considerably different [21]. Investigation of the causes of these differences and providing best solutions to reduce them can improve information sharing between patients and care providers which, in turn, will help the treatment process.

13) Emerging Information sources: Internet and mobile phones are newly expanded sources of information for patients. Today, internet is one of the most important sources of health information which strengths the patients' empowerment process and helps them to manage their disease [34]. Despite the expanding of Internet, healthcare providers continue to be the most important source of information for breast cancer patients and the use of emerging technologies is still limited [3,24,51,53,54,57]. A study has reported that participants' awareness of the books is higher than that of websites. This study has found that interpersonal communication is used more than internet as an informational source [3]. Another study reported that only 31% of its participants actively search for internet information and 14% of them

passively received internet information [6]. In another study from south Manchester on the using of internet for information about breast cancer about half of the participants have reported to use internet in seeking cancer information from which 73% have found it beneficial. This study also has confirmed those younger patients and those with a higher household income being most likely to search internet for their disease information. 3 other studies have reported that only 22, 28 and 17 percent of participants search disease information on the internet. It is notable that internet information searchers do not use retrieved information to make their health decisions at all times [17,22,54]. For example, in a study that aimed to assess the level of awareness and use of 5 major American cancer websites, it had been reported that, despite good awareness, less than half of the patients had searched disease information on these websites. Also, of these, about half of them had used the retrieved information in their care decisions [3]. However, a study has shown that the use of internet for seeking the disease-related information is expanding [30].

Patients can be divided into 2 groups based on their use of internet to seek disease information:

- Non-users: Those who do not use internet as a cancer information source.
- Users: Those who use internet as a cancer information source. This group is subdivided into followings:
  - Lurkers: Those who read texts about their disease but rarely send a message.
  - Posters: Those who both read internet texts and send messages.

Some factors such as age, race, living alone or with partner, cancer stage, information capability, patients' confidence to the physician-patient relationship, perceived social support, perceived need for information, level of depression, knowledge and functional well-being are associated with patient placement in each of non-users or users groups [29,37].

Also, some factors have been reported to affect the breast cancer patients' internet search. Age, language, education, disease stage, income and time elapsed since the diagnoses are among these factors. Studies show that seeking information via internet is more prevalent between patients with higher education, patients who have private insurance coverage and those live with a partner. Higher stage of the disease is also associated with a decline in the use of internet [3,30,54,56,57].

In general, the reasons for using Internet as an informational source by breast cancer patients include finding out more information such as more information about alternative treatments and more searching for information provided by physicians [60]. The most barriers to internet search also include the lack of access, complexity of internet use (poor IT skills) [54] and the concerns about the validity of internet findings [17]. At the same time, a study has reported that oncologists can encourage patients to use internet and help them to improve their internet skills [17].

About the type of information which the breast cancer patients search on the internet, studies show that the majority of patients search general information about disease and information related to the

prevention, risk factors, disease prognosis, diagnosis and treatment options [54]. It seems that breast cancer patients search for medical information on the internet more than information related to the management of the disease [56].

Mobile phone today is considered as a tool for information seeking, especially through receiving messages about the disease but studies show that the use of mobile phones to receive information in women with breast cancer is still low [4,6,38]. A study has shown that only 10.6% of participants actively search information via cell phones [6]. The most important barriers to using mobile phones include patient's perceived knowledge of disease, limited access to mobile phones and lack of interest [38]. Also, studies have shown that use of the mobile phones for disease information seeking is related to factors such as age, income, race, nationality and education. Women with lower age, higher income and higher education are more likely to use mobile phones to seek disease information [4,38].

Discussion

We conducted a comprehensive review of the existing literature on the breast cancer patients' information seeking behavior. Our purpose was to summarize and classify all the available findings on the subject. A total of 60 studies were reviewed. These studies have a large disparity in terms of those aspects of information seeking behavior which they have examined. They have studied various aspects of information seeking behavior.

After extracting the findings of included studies we analyzed them qualitatively in a specialized panel and divided the examined aspects into 13 subjective themes (domains). These 13 domains can be categorized into 3 general categories. Some studies have examined the determinants of information seeking behavior in breast cancer patients. Some others, which are the major part of the studies, have studied issues related to information seeking process such as information seeking styles, the preferred information sources and the type of information sought. The last category, also have examined the outcomes/benefits of information seeking. These studies have reported some outcomes such as improvement of patients' participation in treatment decision-making and better management of the disease as the consequences of information seeking.

Our findings showed that most breast cancer patients have desire to seek or receive information about their disease. However, a smaller portion of them engage in information seeking behavior (especially actively) [1,6,9,22,41,43,49,50].

The nature of information seeking behavior varies in different stages of disease [1,46,54]. Breast cancer patients seek 3 categories of information including general information about different aspects of the disease and treatment options; management of psychosocial side effects and superior providers of cancer care [6,9,15,26,30,31,32,41,49,54].

Some factors, including individual and context factors affect the information seeking behavior of breast cancer patients (1,9,10,31,1321). In spite of the development of informational and communicational technologies, interpersonal relationships are still the most important source of information for the patients. In this regard, it seems that the use of emerging technologies such as internet and mobile phones in seeking disease-related information is still limited but is growing [1,4,6,24,38,51,52,53,54].

Breast cancer patients, often seek cancer-related information to improve their knowledge, to reduce cancer-related psychological disorders as well as curiosity to learn [1,50]. Other findings showed that, despite the desire of breast cancer patients to seek information, they experience barriers in accessing information. Concerns about the quality of received information from various sources is one of the main barriers; which discourages patients to seek information [1.36,15].

Published studies show that patients' satisfaction with the sought information can be improved. This satisfaction is influenced by some factors such as information sources, the amount of received information and the way in that information is provided to patients [1,60]. Information seeking of breast cancer patients has various positive consequences such as improving patients' relationships with providers and empowering them to cope with disease [3,7,1520,36,39,45]. Our findings also revealed that there is a great deal of disparity between the willingness of patients and care providers to share disease information. This disparity is seen for example in the type of shared information [21].

In this study we tried to summarize and categorize the findings on the breast cancer patients' health information seeking behavior. As stated previously, available studies on this subject are diverse and each study has been devoted to one or a few specific aspects of the issue. So, summarizing of the findings is hard and, of course, helpful. However, the main purpose of all studies is to contribute in the improvement of breast cancer patients' information seeking which can be resulted to the improvements of their health status. It seems that developing and implementing of effective policies to improve health information seeking behavior of breast cancer patients can be helpful. In these policies, the predictors of health information seeking behavior must be taken into consideration. Also, the barriers of information seeking which are described in this article should be removed. Increasing the patients' access to emerging informational potentials such as internet, improving their abilities and skills to use communicational technologies, encouraging the support groups and building responsive structures for the production and dissemination of accurate information are among the useful recommendations.

Conclusion

Our study aimed to review and summarize the published studies on the information seeking behavior of breast cancer patients. We reviewed the available literature on the various aspects of the subject and categorized their findings in a qualitative method. According to our knowledge, this is the first study of this kind. Although there are many studies available on the health information seeking behavior of breast cancer patients but each of these studies has addressed one or some aspects of health information seeking behavior among these patients. In this study, we tried to provide a picture of all the components

of breast cancer patients' information seeking behavior, including associated variables (determinants) of information seeking, its process and consequences.

Abbreviations

Not Applicable

Declarations

Ethics approval and consent to participate: All participants provided informed consent to be included in the study and were assured that their personal information would be kept confidential. All the study procedures were conducted in accordance with the ethical standards of the Declaration of Helsinki.

Consent to publish: Not Applicable

Availability of data and materials: All data have been presented within the manuscript.

Competing interests: Not Applicable

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Figures

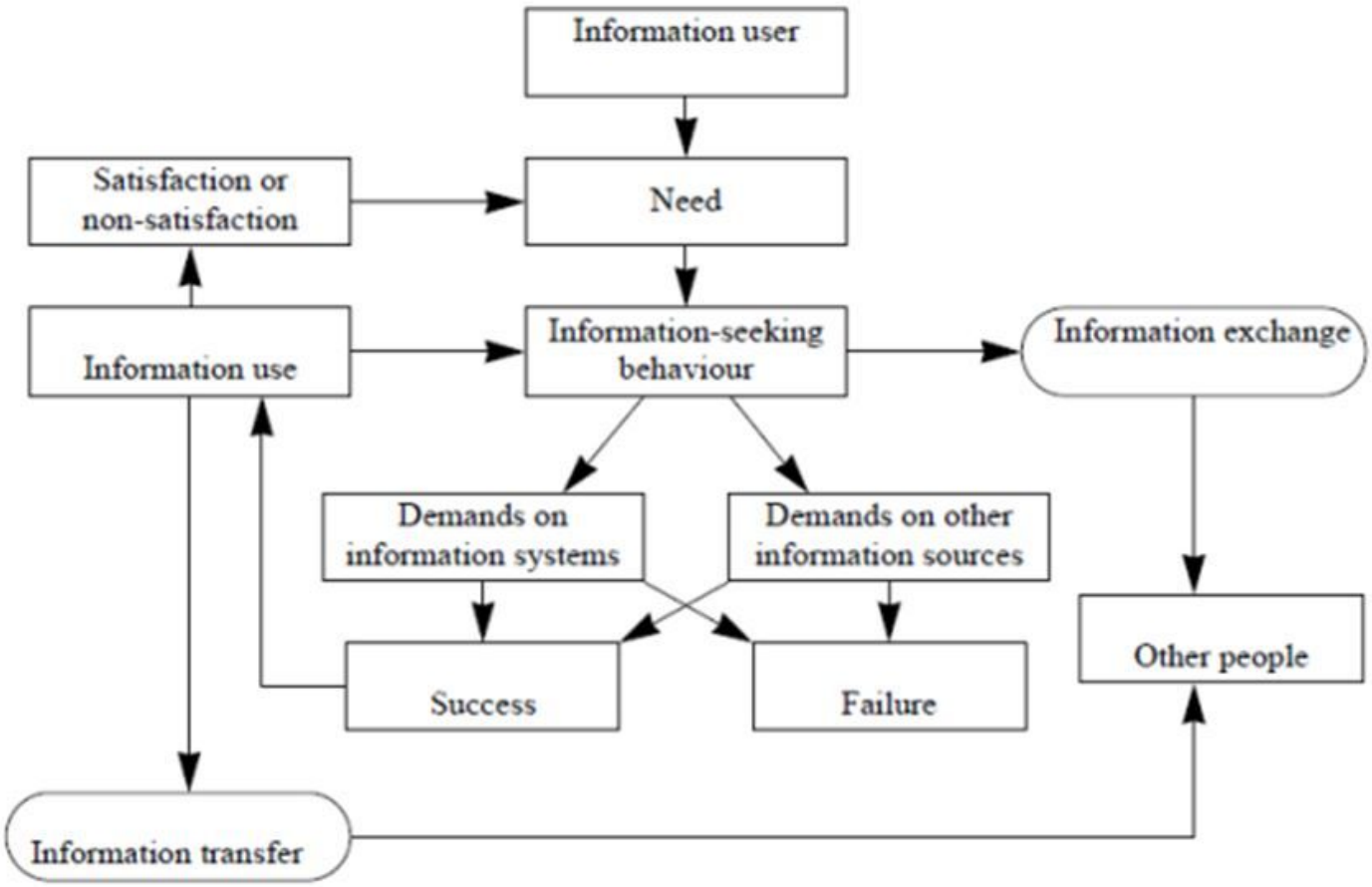


Figure 1

Wilson's model of information behavior

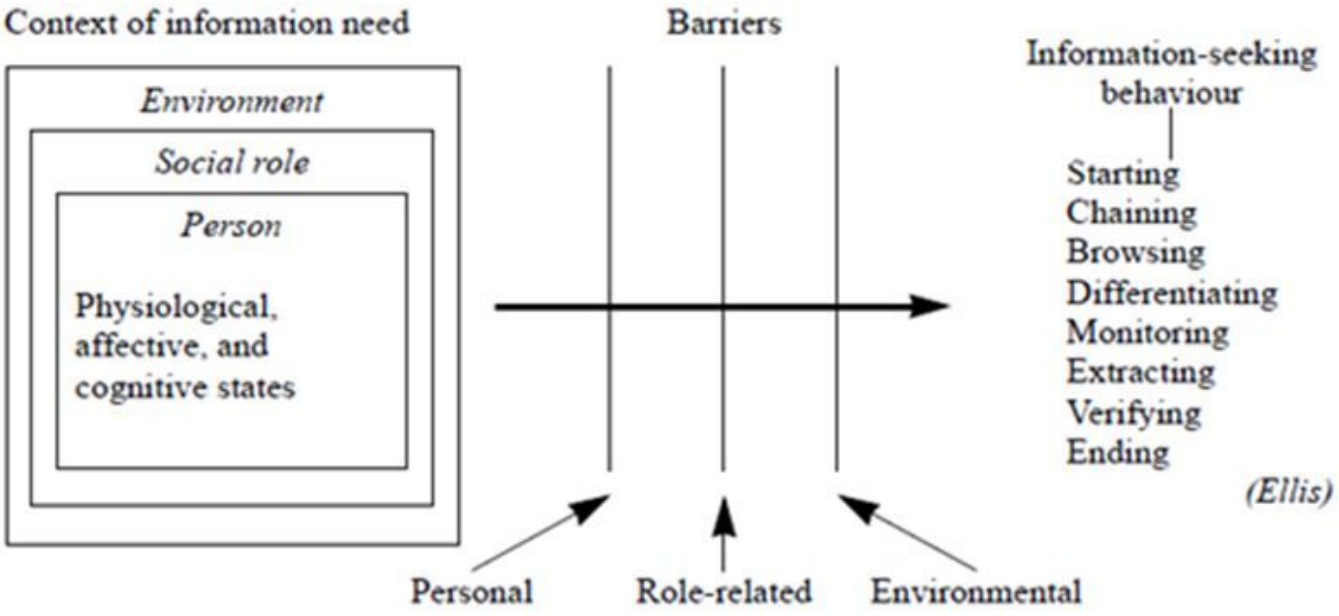


Figure 2

Wilson's model of information seeking behavior

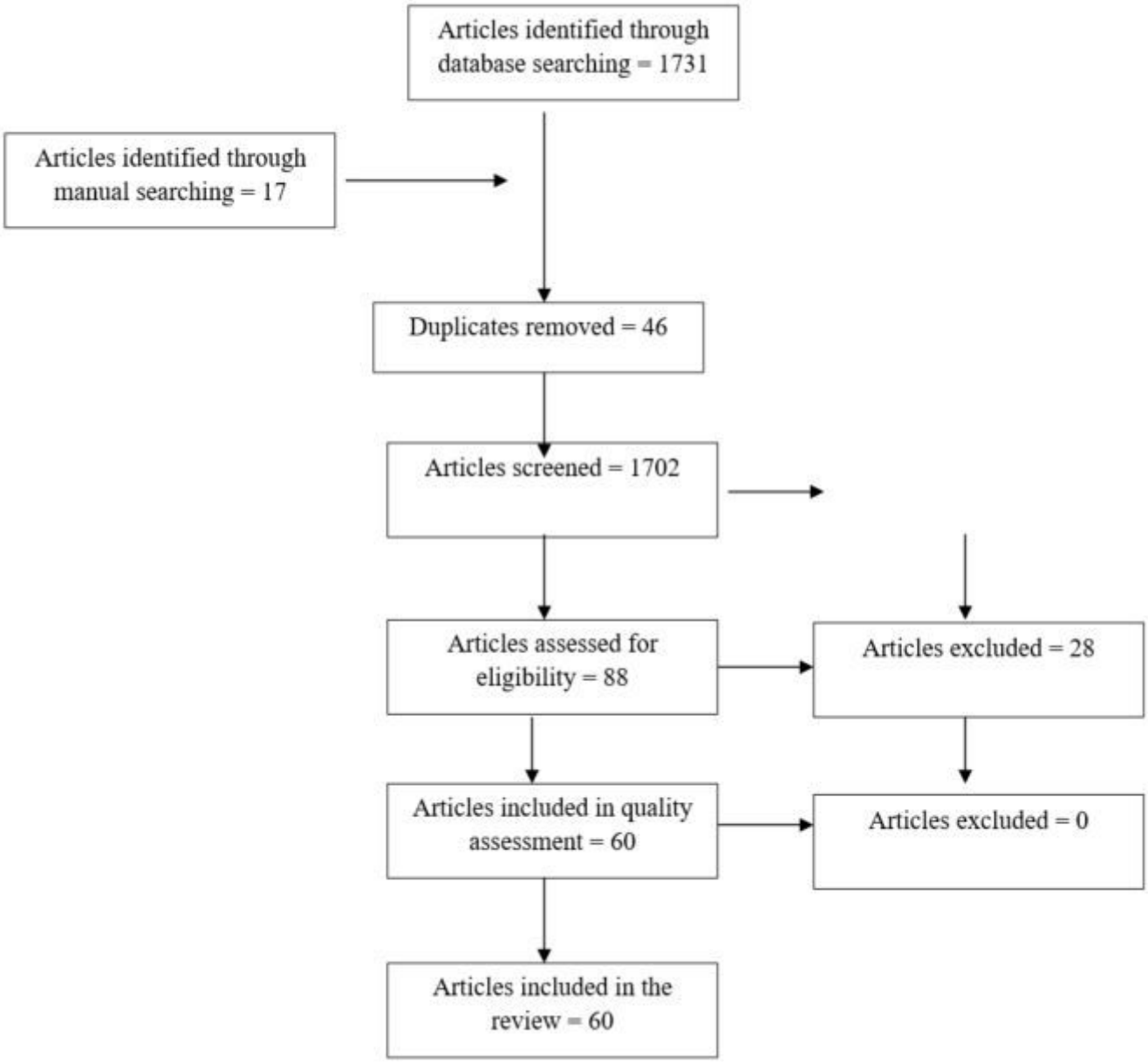


Figure 3

PRISMA flowchart of the present study