DIGITAL HEALTH
DIGITAL HEALTH
Volume 11: 1–10

DOI: 10.1177/20552076251346240
journals.sagepub.com/home/dhj
Sage

Qualitative study on the characteristics and dilemmas of eHealth literacy among family caregivers of breast cancer patients

Chengcheng Guo[1], Yang Wang[1], Liting Dong[1], Juan Wu[1] and Sijin Guo[1]

Abstract

Objective: To explore the elements and dilemmas of eHealth literacy among family caregivers of breast cancer patients, providing a reference for improving their caregiving abilities.

Methods: From September to October 2023, a phenomenological research method was adopted. Semi-structured interviews were conducted with 10 family caregivers of breast cancer patients in the Department of Breast and Thyroid Surgery of a tertiary grade A hospital in Xi'an. Braun's thematic analysis method was used for data analysis.

Results: Two themes and six sub-themes were extracted. (1) Element characteristics: information acquisition ability, information discrimination ability, and information application ability. (2) Information dilemmas: information overload and chaos, difficulty in judging the authenticity and reliability of information, and obstacles in information application.

Conclusion: There are many problems in the eHealth literacy of family caregivers of breast cancer patients. Medical staff should have provided guidance on information acquisition, conducted training on information discrimination and application, addressed information overload and chaos, strengthened information supervision, improved the proficiency of using e-communication tools, and provided more professional guidance to enhance their eHealth literacy and reduce their information-related distress.

Keywords

Breast cancer, family caregivers, eHealth literacy, qualitative research

Received: 7 October 2024; accepted: 14 May 2025

With the rapid development of digital technology, the field of eHealth has emerged rapidly, and the concept of eHealth literacy has also come into being, playing an increasingly important role in the healthcare field.[1] The definition of eHealth literacy has been evolving. Initially proposed by Norman and Skinner in 2006, it was defined as "the ability to seek, find, understand, and evaluate health information from electronic sources and apply the acquired knowledge to solve or deal with health problems," which emphasized the basic skills of individuals in handling health information in an electronic environment.[2] With the in-depth research, Bautista and Paige further expanded its connotation, believing that eHealth literacy "involves the interaction of individual and social factors in the process of using digital technology to search, obtain, understand, evaluate, communicate, and apply health information, aiming to maintain or improve the quality of life throughout the life cycle."[3,4] This definition not only covers multiple aspects of information processing but also emphasizes the interactive influence of individual and social factors, making the concept of eHealth literacy more comprehensive and in-depth.[5]

Breast cancer is a common malignant tumor. The latest data show that the number of newly diagnosed breast cancer cases among Chinese women exceeds 357,000, which

---

[1]Xijing Hospital Department of Vascular and Endocrine Surgery Xi'an, Shaanxi, China

Corresponding author:
Sijin Guo, Xijing Hospital Department of Vascular and Endocrine Surgery Xi'an, Shaanxi, 710032, China.
Email: guosijinABC@163.com

seriously affects the physical and mental health and quality of life of patients.[6] Its treatment and rehabilitation are long-term and complex processes. Primary caregivers need to shoulder many responsibilities, including assisting patients in treatment decision-making, daily care, psychological support, and managing medical expenses.[7] In this process, eHealth literacy can help caregivers more effectively acquire, understand, and apply eHealth information, thereby providing better nursing services for patients and promoting their rehabilitation.[8] However, existing studies have not fully revealed the experiences, feelings, and specific difficulties of family caregivers of breast cancer patients in the actual use of eHealth information.

In view of the above situation, it is of great significance and necessity to conduct a qualitative study on the eHealth literacy of primary caregivers of breast cancer patients. Qualitative research can deeply explore the inner experiences, viewpoints, and needs of caregivers, revealing their real experiences and difficulties in the acquisition, evaluation, and application of eHealth information. Through this research method, rich and detailed data can be obtained, providing a basis for formulating strategies to improve the eHealth literacy of primary caregivers of breast cancer patients, thus enhancing their caregiving abilities and improving the rehabilitation effects and quality of life of patients.

Subjects and methods

Research subjects

This study is a qualitative research based on phenomenology, aiming to deeply explore the real experiences, feelings, and meaning construction of family caregivers of breast cancer patients during the caregiving process. The phenomenological research method emphasizes the intuitive insight and description of the essence of phenomena, focusing on the subjective experiences of individuals regarding specific phenomena, which is consistent with the purpose of this study to focus on the real experiences of family caregivers of breast cancer patients. Purposive sampling was used.Factors such as the age, occupation, relationship with the patient, current treatment of the patient, and care-giving duration of the interviewees were fully considered, and the maximum difference principle was followed to improve the representativeness of the sample and obtain rich interview information.[9] Family caregivers of breast cancer patients who visited a tertiary grade A hospital in Xi’an from September to October 2023 were selected. Inclusion criteria: (1) Family caregivers of patients with pathologically diagnosed primary breast cancer (regardless of the patient’s surgical method and chemotherapy regimen), and the family caregiver is recognized by the patient as the main family caregiver; (2) Having communication and text-reading abilities; (3) Voluntarily participating in this study; (4) Being able to clearly express their wishes and complete the interview. Exclusion criteria: (1) Those with other major mental or physical diseases who cannot complete the interview. The sample size was determined based on the principle that no new themes emerged in the interview information and data saturation was achieved. A total of 11 family caregivers of breast cancer patients were interviewed in this study. One interviewee withdrew from the interview due to personal reasons (an emergency at home interrupted the interview), and finally 10 interviewees completed the interview. They were numbered N1–N10 in sequence. The information of the interviewees is shown in Table 1. This study has been reviewed and approved by the Medical Ethics Committee of the First Affiliated Hospital of the Air Force Medical University, with the review approval number KY20224020-1.

Research methods

Developing the interview outline. This study used the phenomenological method in qualitative research to conduct semi-structured in-depth interviews with family caregivers of breast cancer patients. The research team developed a preliminary interview outline based on literature review.[7,10–14] It was reviewed and revised by two nursing experts (one with a senior professional title and one with an associate senior professional title). Then, three family caregivers were selected for a pre-interview. After modification and improvement, a formal interview outline was formed. The content includes: (1) What electronic channels do you usually use to obtain breast cancer-related information during the process of taking care of the patient? (2) What experiences and feelings did you have during the information-acquisition process? Did you encounter any confusing or difficult-to-handle situations? (3) How do you apply the acquired electronic information to the care of the patient? (4) What are the help and challenges of electronic channels for you when obtaining the patient’s treatment information? (5) What support or help do you think you need most to improve your information literacy?

Data collection method. Guo Chengcheng, Wang Yang and Wujuan, as the female responsible nurses for the patients, had become familiar with and established trust relationships with the patients and their families during daily nursing. The researchers explained their identities and the content of the research project to the family members of the patients who met the inclusion criteria, and asked if they were interested in participating in this study. If they agreed, the family caregivers were invited to the pre-determined interview location for the interview.

From September to October 2023, the researchers selected research subjects in the Department of Breast and Thyroid Surgery of a tertiary-grade-A hospital in Xi’an,

Table 1. Relevant information of interviewees.

No.	Sex	Age	Education background	Career	Relationship	Care duration (mouths)	Pathological Grade Molecular	Subtype	Tumor Stage	Interview duration (minutes)
N1	Male	30	Bachelor	Self-employed	Mother	6	Invasive carcinoma	Luminal-B	II	25
N2	Male	35	Diploma	Cadre	Spouse	3	Invasive carcinoma	Luminal-A	I	20
N3	Female	33	Bachelor	Clerk	Mother	5	Invasive carcinoma	HER2-positive	II	23
N4	Male	32	Bachelor	Cadre	Spouse	4	Invasive carcinoma	HER2-positive	I	17
N5	Female	46	Secondary school	Social-Worker	Mother	60	Invasive carcinoma	Triple-negative breast cancer	III	49
N6	Female	43	Diploma	Teacher	Spouse	3	Invasive carcinoma	HER2-positive	I	22
N7	Female	43	Diploma	Clerk	Mother	38	Invasive carcinoma	Luminal-A	I	35
N8	Male	44	High school	Farmer	Spouse	3	Invasive carcinoma	Luminal-B	II	18
N9	Female	42	Bachelor	Cadre	Sister	2	Invasive carcinoma	Luminal-B	II	18
N10	Female	53	Secondary school	Jobless	Daughter	40	Invasive carcinoma	Triple-negative breast cancer	III	16

Shaanxi Province, according to the inclusion and exclusion criteria. This study used semi-structured interviews. The interviews were conducted by researchers who had systematically studied qualitative research. Based on the interview outline as a guide, the researchers conducted face-to-face interviews with the interviewees and adjusted the order of the questions in the interview outline according to the interviewees' answers. If the interviewees' answers contained content that interested the researchers and was relevant to this study, the researchers would conduct follow-up questions to obtain as much rich interview data as possible.

Before each interview, the researchers prepared the interview outline, informed consent form, self-designed general demographic data record form, voice recorder, mobile phone, pen, notebook, and tissues. The researchers introduced their identities to the interviewees, explained the purpose and significance of this study. When obtaining the oral consent of the interviewees, the interviews were arranged during the interviewees' free time to avoid affecting their patient-care time. Before the interview, the interviewees were asked to fill out the informed consent form and the demographic data record form, and the purpose of audio-recording was explained to obtain the interviewees' consent. The interview location was selected in a quiet and bright follow-up office with no third-person present to facilitate the interviewees to express their true feelings.

During the interview, the researchers used methods such as careful listening, repeating questions, and timely follow-up to encourage the interviewees to actively express their subjective feelings, and avoided any inductive, suggestive, or evaluative language. In addition to recording with a voice recorder, the researchers also used a pre-prepared notebook to record the interviewees' expressions, emotional reactions, and body movements to assist in data analysis later. The interview time was controlled within 15–20 minutes. The text was transcribed within 24 hours after the interview. During the interview process and data analysis, when new interview content no longer generated new themes, concepts, or viewpoints, it was considered that the sample data had reached saturation.[15]

Data analysis method. The researchers transcribed the recorded content into text within 24 hours after each interview and marked non-verbal information such as body movements and expression changes. No repeat interviews were conducted. A graduate nurse (Dong Liting) checked whether the recording was consistent with the written record. If there were differences, the recording was replayed and modified. After the collation was completed, a copy of the interview record was sent to each interviewee for verification. Two researchers (Guo Chengcheng and Wang Yang) used Braun's thematic analysis method for independent analysis.[16] The steps were as follows: (1) Carefully read all materials to get familiar with the interview data; (2) Form initial codes; (3) Potentially classify the initial codes to generate a set of themes and sub-themes; (4) Further check and verify each theme, following the principles of internal consistency and external heterogeneity of themes. If not satisfied, split or revise them immediately; (5) Conduct further detailed analysis to clarify the definition and naming of each theme; (6) Write the research report. If there were any disputes, researchers (Dong Liting and Wu Juan) needed to conduct further group discussions and consult an expert (Guo Sijin) until the final results were determined. Finally, two themes and six sub-themes were extracted from the interview text in this study. The report was presented according to the comprehensive criteria of qualitative research.[12]

Quality control method. The five researchers in the research group all had a bachelor's degree or above, two of them were full-time postgraduate students, and three researchers had more than 10 years of clinical experience in breast surgery. All of them had received training in qualitative research, completed qualitative interviews, and were proficient in interview skills. During the formal interview process, the selected family caregivers were representative in terms of age, education, economic status, care-giving time, and relationship with the patient. Before data collection, a friendly relationship was established with the interviewees, and the interview time was appropriately extended according to the interview situation. During the interview process, the researchers guided the interviewees to maintain a neutral attitude while answering questions and did not judge the interviewees' answers. After the interview, the recording was listened to repeatedly within 24 hours, transcribed into text data, and returned to the interviewees for verification to improve the reliability of the data. During the data analysis process, the researchers tried their best to discard their preconceptions and truly reflect the interviewees' feelings.[15]

Results

Theme 1: Elements of information literacy

Information acquisition ability. Family caregivers can actively search for breast cancer related information through the Internet (such as Baidu, Douyin, etc.), including disease knowledge, treatment methods, drug side-effects, diet and nutrition, medical insurance policies, etc. N1 said, "I searched on the browser for precautions after breast cancer surgery and chemotherapy, as well as information about diet, such as what can and cannot be eaten." N2 said, "I look up treatment cases of breast cancer online to see how others are treated and gain some experience." At the same time, family caregivers also pay attention to new drug information and clinical trials of breast cancer to obtain the latest treatment information. N4 said, "I learn about the latest research progress of breast cancer through the Internet, including clinical trials of new drugs, hoping to find better treatment opportunities for my wife." N7 said, "I saw on Douyin that breast cancer patients can apply for two-cancer subsidies, so I went to the local medical insurance office in my county to inquire."

Information discrimination ability. Due to the lack of medical knowledge, the information discrimination abilities of family caregivers vary. Some family caregivers have a certain ability to judge the authenticity and reliability of online information. They can distinguish the credibility of information from different sources, screen out valuable information for patient care, and avoid being interfered by false or misleading information. N4 said, "I will check the source of the information. If it comes from an authoritative medical institution, I will trust it more." N6 said, "I will compare information from several websites to see which ones are consistent, so as to judge the reliability of the information." N1 said, "I filter the online information based on the doctor's advice and professional medical knowledge, and only select the information that is helpful for my mother's treatment."

However, not all family caregivers can well distinguish the credibility of information from different sources. Facing the vast amount of online information, family caregivers sometimes feel confused. N10 said, "I read an article online before that said not to eat soy products, fish, and shrimp, as they might cause recurrence. Later, Doctor Zhang (the attending doctor) told me what not to eat and do, telling me not to be misled by some videos." Some family caregivers lack the ability to distinguish between authoritative medical institutions and personal experience sharing and may confuse the two. N9 said, "After the surgery, a patient who also had lymph node dissection said in a video that it's not good to do rehabilitation exercises too early, as it's not good for wound healing. So I told her (the patient) to keep her arm clamped, and she could only move it when changing dressings or putting on and taking off clothes." In addition, some family caregivers may easily believe the content of an information just because it seems attractive or has been forwarded many times, ignoring the verification of the information source. N8 said, "I never doubted whether the videos with a large number of likes are reliable. Is there any difference?"

Information application ability. Family caregivers can apply the acquired electronic information to actual care. For example, they can arrange a reasonable diet for patients according to diet and nutrition information and cooperate with the medical staff's treatment plan according to treatment information. N1 said, "I bought some nutritious foods for my mother according to what was said online, such as cordyceps and donkey-hide gelatin, and also paid attention to a light diet." N2 said, "I adjusted my wife's diet according to the online suggestions, increased the intake of protein, and also provided some psychological counseling." N7 said, "I inquired about the process and proportion of medical insurance reimbursement to maximize the reimbursement of my mother's treatment costs."

However, some family caregivers cannot well apply the acquired electronic information to actual care. Some family caregivers know a lot about diet and nutrition information but don't know how to arrange the patient's diet in practice. N8 said, "I know that patients need nutritious food, and the online information seems reasonable, but when it comes to cooking, I don't know what to do…" Some family caregivers understand medical insurance policies and chronic-disease subsidy information but encounter many difficulties in the actual application process and cannot effectively reduce the economic burden. N3 said, "I know about the chronic-disease subsidy, but after reading the instructions in the video, I still find the process too complicated. I've tried several times but haven't succeeded."

Theme 2: Dilemmas of information literacy

Information overload and chaos. There is a large amount of complex information about breast cancer on the Internet. Family caregivers are easily overwhelmed by information overload and find it difficult to screen out accurate and useful information. N3 said, "There is too much information on the Internet, with various opinions. I don't know who to believe and feel very confused." N4 said, "Although I try to identify the authenticity of information consciously, the current Internet platforms are like information cocoons. They keep pushing similar videos through algorithms, which are like information bombs. Sometimes, after watching for a long time, I feel inexplicable anxiety." Information from different sources may conflict, making family caregivers confused when judging and choosing information. N5 said, "Some say this drug is good, and some say that drug is good. I don't know which one to choose." N6 said, "The statements about the same issue on different websites are different. I'm really confused and don't know who to believe."

Difficulty in judging the authenticity and reliability of information. Due to the lack of professional knowledge, family caregivers have difficulty distinguishing the authenticity and reliability of online information and may be misled by false information. N3 said, "I don't know much about medical knowledge. I can't tell whether some online information is true or false and may be misled sometimes." Some inaccurate or outdated information may affect the decisions of family caregivers and the treatment of patients. N5 said, "I found that some online information is outdated. If I take care of the patient according to this information, it may delay the illness condition." N6 said, "Some information is inaccurate. If I follow this information, it may have an adverse impact on her (the patient's) treatment, which makes me very worried."

Obstacles in information application. Family caregivers face many obstacles in information application, which seriously restricts their careful care for patients. In the use of e-communication tools, they encounter many problems when communicating with medical staff through electronic channels. N8 said, "I wanted to make an appointment for a review through the hospital's online platform, but I couldn't figure out the operation process after searching for a long time. Finally, I had to call for consultation, which wasted a lot of time." N9 said, "After the surgery, the nurses used an AI phone for follow-up. I said one thing, and it replied with another. I had a lot of questions, but it either didn't answer or gave random answers. I didn't know how to respond or who to turn to, so the call ended hastily. Then they sent some guidance videos and text instructions on the patient's rehabilitation training in the (nurse–patient communication) group, but I couldn't open the files." N5 said, "I wanted to describe the patient's latest symptoms to the doctor on the online consultation platform, but my typing speed was too slow, and there were always typos. I was worried that the doctor would misunderstand me, resulting in poor communication." N1 said, "I don't know how to use the hospital's electronic medical record system at all. I can't check the patient's previous medical records and medication information, so I can't fully understand the changes in the illness condition."

On the other hand, due to the lack of professional knowledge, they have difficulty distinguishing the authenticity and reliability of online information and are easily misled by false information. N3 said, "I don't know much about medical knowledge. I can't tell whether some online information is true or false and may be misled sometimes." Some inaccurate or outdated information can also influence the decisions of family caregivers, thus affecting the patient's treatment. N5 said, "I found that some online information is outdated. If I take care of the patient according to this information, it may delay the illness condition." N6 said, "Some information is inaccurate. If I follow this information, it may have an adverse impact on her (the patient's) treatment, which makes me very worried." Facing the professional terms and complex charts in the copied materials, they don't know how to extract useful information without anyone to interpret. N2 said, "The professional terms and complex charts in these copied materials make me confused. I don't know how to extract useful information for my family. Without professional interpretation, I feel like I'm groping in the dark." In special situations, they feel extremely helpless. N10 said, "Some time after the last surgery, she felt that her arm was getting thicker and had a stabbing pain. Although the doctor had told me that this was a possible complication after the surgery, at that time, I really hoped that a medical staff could immediately tell me what to do to relieve her pain instead of leaving me in uncertainty and distress (frowning)."

Discussion

Discussion of information literacy element characteristics

Information acquisition ability. Information acquisition ability refers to the ability of an individual to actively collect information in a specific field through multiple channels. This study found that family caregivers of breast cancer patients have an internal motivation to actively acquire information out of deep concern for the patients and a strong desire to improve the quality of care.[7,17] The widespread of the Internet and the high convenience of information dissemination offer caregivers accessible channels to obtain a large amount of relevant information.[10] They mainly utilize the Internet, such as Baidu, Douyin, and other platforms, to gather information on disease knowledge, treatment methods, drug side-effects, diet and nutrition, medical insurance policies, etc., and also keep an eye on new drug information and clinical trial dynamics.[18]

This ability is of great significance to family caregivers. By actively acquiring information, they can comprehensively understand breast cancer-related knowledge and offer more scientific and professional care for patients.[17] The information obtained by these caregivers is mainly applied in treatment decision-making, daily care, and medical insurance policies. It helps patients understand more comprehensive treatment plans, make more reasonable dietary arrangements, and reduce the economic burden, addressing the unmet information needs of patients and caregivers.[19] Family caregivers of breast cancer patients show a proactive attitude in information acquisition, leveraging the Internet's convenience to collect various types of information and provide strong knowledge support for patient care.

Although there are difficulties similar to those in previous studies during the information acquisition process,[11] information acquisition ability is the foundation of the e-information literacy of family caregivers of breast cancer patients. A good information acquisition ability can further enhance its advantages and improve the quality of patient care.

Information discrimination ability. Information discrimination ability is the capacity of an individual to analyze and judge the acquired information to determine its authenticity, reliability, and value. In the caregiving context, family caregivers need a certain level of health literacy. They must screen useful patient related information from a large amount of network data, accurately assess its reliability, avoid being misled by false or inaccurate information, and provide accurate and scientific nursing and treatment advice.[8] In this study, breast cancer patients' family caregivers judged information credibility by checking sources and comparing info from multiple websites.[20] This ensured the authenticity and effectiveness of the information, providing a reliable basis for patient care decisions.

However, some caregivers have been misled by incorrect dietary information on the Internet and easily believed video information with a large number of likes but an unknown source, indicating insufficient information discrimination ability. This may be closely related to factors such as cultural level, age, and health literacy. Overall, information discrimination ability is crucial for family caregivers of breast cancer patients to screen effective information and is one of the key abilities to ensure they obtain useful information. Given the increasing complexity of network information, it is urgent to improve the information discrimination ability of caregivers through the joint efforts of multiple parties to ensure the quality of patient care.[14]

Information application ability. Information application ability refers to the ability to transform the acquired and discriminated information into practical actions and use it to solve practical problems. For family caregivers of breast cancer patients, this ability is reflected in applying breast cancer-related information to daily care, treatment cooperation, and economic burden management. Information application ability directly impacts the actual effect of breast cancer patient care. In this study, family caregivers adjusted the existing care plans for patients based on online suggestions and inquired about medical insurance reimbursement processes and proportions, which are manifestations of successful information application.[21]

Nevertheless, some caregivers face obstacles in translating information into practical operations during the information application process. Despite these problems, information application ability is a key component of the e-information literacy of family caregivers of breast cancer patients. A good information application ability can significantly improve the quality of patient care, offer practical help to patients, and enhance the patient's quality of life and treatment effect.

Discussion of information literacy dilemmas

Information overload and chaos. In the current information-saturated era, the Internet provides family caregivers with a vast amount of information.[22] However, it also gives rise to the problem of information overload and chaos. When seeking breast cancer-related information, family caregivers are often inundated with a large number of complex and contradictory pieces of information on the Internet. This not only greatly increases the difficulty of screening effective information for caregivers, consuming a significant amount of their time and energy, but also disrupts their decision-making process, making it hard for them to make accurate and timely decisions.[12,21] Prolonged exposure to such an information environment can easily cause caregivers to experience negative emotions like anxiety and fatigue, which can affect their physical and mental health and indirectly reduce the quality of care for patients.[10]

The main reasons include the rapid spread of Internet information and the low publishing threshold, lacking an effective screening and sorting mechanism. Different information publishers release content with significant differences or even conflicts for various purposes, exacerbating the chaos of information.[23] The severe information overload can remarkably increase caregivers' information anxiety. Additionally, the information cocoon phenomenon resulting from the algorithm recommendation mechanism of social media makes the information received by caregivers highly homogeneous, making it difficult for them to access diverse and comprehensive content.[25] This further worsens the information overload dilemma and may even lead to information search stagnation or information avoidance.[10,24]

This shows that information overload and chaos among family caregivers of breast cancer patients have become a common issue. Medical staff should have established a professional breast cancer information integration platform,[10] where professionals can screen, classify, and organize the information. Relevant platforms should have optimized their algorithms, reduce the push of low-quality information, and provide caregivers with more accurate and orderly information display. Moreover, information screening auxiliary tools could have been developed with the help of artificial intelligence technology to assist caregivers in filtering out low-quality information and improving information acquisition efficiency.[26]

Difficulty in judging the authenticity and reliability of information. Family caregivers of breast cancer patients face a tough challenge in determining the authenticity and reliability of information during the information acquisition and processing process. Most caregivers lack professional medical knowledge,[14] making it difficult for them to distinguish the authenticity of complex breast cancer information on the Internet. Once misled by false or outdated information, caregivers may make wrong decisions, such as improper dietary arrangements and inappropriate nursing measures.[27] These wrong decisions can directly affect the treatment effect and rehabilitation process of patients and even pose a serious threat to the patient's health.

Some caregivers are easily influenced by subjective factors, overly relying on others' experiences or being affected by their own cultural concepts, resulting in unscientific and inaccurate information discrimination.[20,28] Although some caregivers have a certain ability to judge information and can screen out valuable information for patient care by checking the source and comparing the content of different websites, judging the quality of information remains a dilemma for family caregivers of breast cancer patients.

Upon in-depth exploration, the lack of medical knowledge among caregivers is one of the main factors.[14] They lack the professional ability to judge the authenticity and reliability of information. Meanwhile, the lack of network information supervision allows false information to spread easily.[29] Breast cancer-related information on the Internet also has such problems. Especially for issues without clear evidence, the relevant information may be contradictory, confusing caregivers.[23] Many online information lack clear author identities or professional reviews, and some breast cancer websites have poor information quality and lack professional attribution, making it hard for caregivers to judge the credibility of information.[10,30] Additionally, the readability of online patient-education materials for breast cancer is problematic, with an average readability at the junior high school or high school level, which increases the difficulty for caregivers to understand and screen information.[30,31] Despite these limitations, caregivers still tend to trust disease-related information released by government official agencies or public welfare organizations.

To address this problem, the joint efforts of multiple parties are required. Medical staff should have strengthened the popularization of medical knowledge among caregivers,[32] regularly conduct medical knowledge lectures, and improve their ability to distinguish common medical information. The government and relevant agencies should have strengthened network information supervision, establish strict information review mechanisms, and severely punish the release of false information. At the same time, caregivers should have been encouraged to refer to information from professional medical institutions, authoritative medical journals, and other reliable channels to improve the reliability of information acquisition and provide scientific care support for patients.

Obstacles in information application. Family caregivers of breast cancer patients encounter difficulties in the actual operation and transformation of electronic information during the information application process, which seriously affects the quality and effect of patient care. Some caregivers can obtain information but struggle to translate it into practical actions. Others are restricted by factors such as economy and time and cannot fully utilize the acquired information. These situations lead to the ineffective application of information in actual care, making it difficult for patients to receive the best care and treatment, delaying the rehabilitation process, and undermining the caregivers' enthusiasm and self-efficacy while increasing the caregiving burden.

Upon further analysis, unskilled use of e-communication tools is a major obstacle. Some family caregivers use mobile phone functions less and have a relatively low educational level,[33,34] reflecting the generally low familiarity of the caregiver group with new technologies.[21] When using hospital e-communication tools, caregivers often face problems such as difficulty in making an appointment for a review and inability to open files in the nurse–patient communication group. This hinders the timely transmission and application of information, preventing them from obtaining accurate treatment information and guidance in a timely manner. This may be related to the complex design of e-communication tools, which increases the operation difficulty for caregivers.[35]

The lack of professional guidance is another cause of information application obstacles. Due to limited medical resources, there is a lack of an effective communication mechanism between caregivers and medical staff, and the support system for caregivers in the medical system is not perfect.[36] Caregivers receive insufficient professional guidance. When faced with complex medical information and practical problems, they often feel at a loss and are prone to make mistakes during the information application process, increasing their psychological pressure and reducing their caregiving quality and confidence.[21] In addition, some caregivers cannot afford the costs required for information application, such as purchasing special nursing supplies due to economic difficulties. And some are too busy with work to have enough time and energy to fully implement nursing measures.

To improve this situation, the joint efforts of multiple parties are necessary. Medical staff should have conducted training on the use of e-communication tools and adopt e-tools with features like the combination of pictures and texts, simple operation, operation guidance, and a smooth search experience.[20,35,37] For specific patient situations, personalized information interpretation and operation demonstrations should be provided to guide caregivers to reasonably apply information to actual care. Meanwhile, a communication and sharing network for caregivers should have been established to promote experience exchange and mutual assistance.[38] For caregivers with economic difficulties, necessary economic assistance information and application guidance should have been provided. For those with limited time and energy, reasonable nursing suggestions and time management guidance should have been given to help them balance work and patient care responsibilities. Only by solving these problems can the information application ability of caregivers be improved, the value of information be fully utilized, and better care services be provided for patients.

Limitations

This study has several limitations in exploring the eHealth literacy of family caregivers of breast cancer patients. Firstly, the sample is only from a tertiary-grade-A hospital in Xi'an, presenting significant regional limitations. There are differences in culture, economy, and medical resources among different regions. Thus, this sample is difficult to represent the situations of caregivers in other regions, which affects the generalizability of the research results. Secondly, the research was conducted from September to October 2023. The caregiving process of breast cancer is long-term, and the information needs and dilemmas faced by caregivers vary at different stages. This study cannot fully cover these changes. Finally, the questionnaire used in this study has not been validated. Although a pre-interview was conducted before the study and the questionnaire was modified and improved based on the pre-interview results, the validity and reliability of the questionnaire cannot be fully guaranteed as those of a strictly validated questionnaire.

In view of the above limitations, future studies can expand the sample scope to include caregivers from different regions, combine multiple research methods to reduce the influence of subjective factors, extend the research time to track the situations of caregivers at different stages, and strictly validate the questionnaire used in the research. These measures can improve the scientificity and reliability of the research and provide a more solid basis for enhancing the information literacy of caregivers.

Conclusion

Through interviews with family caregivers of breast cancer patients, this study deeply explored the elements and dilemmas of their e-information literacy. It revealed the current situation and problems of the e-information literacy of family caregivers of breast cancer patients, providing a direction for further improving their e-information literacy.

Acknowledgements

We are also grateful to the first affiliated hospital of air force medical for providing access to the necessary research facilities and data. Special thanks go to our colleagues for their assistance in data collection and analysis. Finally, we thank our patients and caregivers for their continuous support and encouragement.

ORCID iD

Chengcheng Guo https://orcid.org/0009-0002-9258-1780

Ethics approval and informed consent statements

This research was conducted in strict accordance with ethical guidelines.For all interview subjects, informed consent was obtained.Their privacy and confidentiality were safeguarded throughout the research process. The study was approved by the appropriate institutional review board to ensure the protection of the rights and welfare of the participants. The data presented in this paper are genuine and have not been fabricated or manipulated in any way.

Consent to participate

The study was approved by the Medical Ethics Committee of the First Affiliated Hospital of the Air Force Medical University with the approval number KY20224020-1 in January 2022. All participants provided written informed consent prior to participating.

Written informed consent was obtained from a legally authorized representative for anonymised patient information to be published in this article.

Author contributions

Guo Chengcheng: study design, data collection, data analysis, and manuscript writing. Wang Yang, Wu Juan: data collection. Dong Liting, Wu Juan: data analysis and manuscript revision. Guo Sijin: manuscript review and revision.

Funding

The authors received no financial support for the research, authorship, and/or publication of this article.

Declaration of conflicting interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Data availability statement

The data used in this study is derived from the interview texts of patient caregivers. We have taken strict measures in the process of data collection and processing to ensure the reliability of the data. For these texts, as they may contain sensitive information or personal privacy content, we have implemented strict confidentiality measures. Therefore, if it is extremely necessary and available for public release, we can only share it after obtaining the explicit consent of all participants.

Publication consent form—SAGE publishing

We have seen and approved all of the work to be published that includes the Personal Information.

Writing assistance and third-party submissions

It has not been obtained.

References

1. Tian H and Chen J. A bibliometric analysis on global eHealth. *Digit Health* 2022; 8: 20552076221091352.
2. Norman CD and Skinner HA. Ehealth literacy: essential skills for consumer health in a networked world. *J Med Internet Res* 2006; 8: e9.
3. Bautista JR. From solving a health problem to achieving quality of life: redefining eHealth literacy. *Journal of Literacy and Technology* 2015; 16: 33–54.
4. Paige SR, Stellefson M, Krieger JL, et al. Proposing a transactional model of eHealth literacy: concept analysis. *J Med Internet Res* 2018; 20: e10175.
5. Efthymiou A, Middleton N, Charalambous A, et al. Adapting the eHealth literacy scale for carers of people with chronic diseases (eHeals-carer) in a sample of Greek and Cypriot carers of people with dementia: reliability and validation study. *J Med Internet Res* 2019; 21: e12504.
6. Zheng RS, Chen R, Han BF, et al. Cancer incidence and mortality in China, 2022. *Zhonghua Zhong Liu Za Zhi* 2024; 46: 221–231.
7. Kusi G, Boamah Mensah AB, Boamah Mensah K, et al. The experiences of family caregivers living with breast cancer

patients in low-and middle-income countries: a systematic review. *Syst Rev* 2020; 9: 165.

8. Efthymiou A, Middleton N, Charalambous A, et al. Health literacy and eHealth literacy and their association with other caring concepts among carers of people with dementia: a descriptive correlational study. *Health Soc Care Commun* 2022; 30: 1109–1119.
9. Chen XM. Qualitative research methods and social science research: qualitative research. *Met Soc Sci Res* 2000: 332–336.
10. Melhem SJ, Nabhani-Gebara S and Kayyali R. Evaluating online health information utilisation and its psychosocial implications among breast cancer survivors: qualitative explorations. *Health Promot Perspect* 2024; 14: 61–69.
11. Yussof I, Mohamed Shah N, Ab Muin NF, et al. Challenges in obtaining and seeking information among breast cancer survivors in an Asian country: a qualitative study. *J Cancer Educ* 2024; 39: 383–390.
12. Moore C, Gallagher P and Dunne S. Health literacy, eHealth literacy and their association with burden, distress, and self-efficacy among cancer caregivers. *Front Psychol* 2024; 15: 1283227.
13. Zou Y, Tong DT, Yang WJ, et al. A scoping review of studies on the health information needs of breast cancer patients. *Chin J Nurs Educ* 2024; 21: 627–633.
14. Yoo SH, Sung JH, Lee K, et al. The needs for digital health and eHeath literacy of cancer patients, caregivers, and healthcare providers: a multicenter, descriptive correlational study. *Eur J Oncol Nurs* 2024; 70: 102581.
15. Francis JJ, Johnston M, Robertson C, et al. What is an adequate sample size? Operationalising data saturation for theory-based interview studies. *Psychol Health* 2010; 25: 1229–1245.
16. Braun V and Clarke V. What can “thematic analysis” offer health and wellbeing researchers? *Int J Qual Stud Health Well-Being* 2014; 9: 26152.
17. Yeung NCY, Zhang Y, Ji L, et al. Guilt among husband caregivers of Chinese women with breast cancer: the roles of male gender-role norm, caregiving burden and coping processes. *Eur J Cancer Care (Engl)* 2018; 27: e12872.
18. Melhem SJ, Nabhani-Gebara S and Kayyali R. Informational needs and predictors of Jordanian breast and colorectal cancer survivors: a national cross-sectional study. *Support Care Cancer* 2022; 30: 6827–6837.
19. Benedict C, Nieh JL, Hahn AL, et al. Looking at future cancer survivors, give them a roadmap": addressing fertility and family-building topics in post-treatment cancer survivorship care. *Support Care Cancer* 2021; 29: 2203–2213.
20. Chen J, Duan Y, Xia H, et al. Online health information seeking behavior among breast cancer patients and survivors: a scoping review. *BMC Womens Health* 2025; 25: 1.
21. Verma R, Saldanha C, Ellis U, et al. Ehealth literacy among older adults living with cancer and their caregivers: a scoping review. *J Geriatr Oncol* 2022; 13: 555–562.
22. Kim S. Caregivers’ information overload and their personal health literacy. *West J Nurs Res* 2021; 43: 431–441.
23. Suarez-Lledo V and Alvarez-Galvez J. Prevalence of health misinformation on social Media: systematic review. *J Med Internet Res* 2021; 23: e17187.
24. Soroya SH, Farooq A, Mahmood K, et al. From information seeking to information avoidance: understanding the health information behavior during a global health crisis. *Inf Process Manag* 2021; 58: 102440.
25. Yuan X and Wang C. Research on the formation mechanism of information cocoon and individual differences among researchers based on information ecology theory. *Front Psychol* 2022; 13: 1055798.
26. Abreu AA, Murimwa GZ, Farah E, et al. Enhancing readability of online patient-facing content: the role of AI Chatbots in improving cancer information accessibility. *J Natl Compr Canc Netw* 2024; 22(2D)
27. Latte-Naor S. Managing patient expectations: integrative, not alternative. *Cancer J* 2019; 25: 307–310.
28. Fransen MP, Damman OC, Bas S, et al. Decision-making in breast cancer screening: a qualitative exploration of the match between women’s beliefs and screening information in The Netherlands. *Patient Educ Couns* 2024; 122: 108155.
29. Ma H. The way forward for online public opinion governance in the age of big data. *Academic J Manag Soc Sci* 2024; 7: 26–30.
30. Gu JZ, Baird GL, Escamilla Guevara A, et al. A systematic review and meta-analysis of English language online patient education materials in breast cancer: is readability the only story? *Breast* 2024; 75: 103722.
31. Bald A, Richardson H, Al Samaraee A, et al. Quality and readability of online information and materials on post-surgery breast seroma. *Br J Hosp Med (Lond)* 2024; 85: 1–9.
32. Xiong M, Young AT, Fernandez A, et al. Understanding breast cancer surgery through tiktok: an analysis of video content and viewer engagement. *Ann Surg Oncol* 2024; 31: 4182–4184.
33. Rangraz Jeddi F, Nabovati E, Mobayen M, et al. Health care needs, eHealth literacy, use of mobile phone functionalities, and intention to use it for self-management purposes by informal caregivers of children with burns: a survey study. *BMC Med Inform Decis Mak* 2023; 23: 236.
34. Wang K, Gao X, Sun F, et al. Ehealth literacy and caregiver burden among Chinese caregivers of older adults with cognitive impairment: does education matter? *J Appl Gerontol* 2021; 40: 1837–1845.
35. Wanchai A and Panploy S. The effects of a web application for reducing the risk of breast cancer-related lymphedema on health literacy and self-efficacy in managing symptoms among patients with breast cancer. *Int J Nurs Pract* 2024; 30: e13311.
36. Moore C, Hassett D and Dunne S. Health literacy in cancer caregivers: a systematic review. *J Cancer Surviv* 2021; 15: 825–836.
37. Xu RH, Zhu L, Sun R, et al. Impact of caregiver’s eHealth literacy, financial well-being, and mental health on quality of life of pediatric patients with osteogenesis imperfecta. *Health Qual Life Outcomes* 2023; 21: 67.
38. Batchelor R, Gulshan S, Shritharan H, et al. Perceived acceptability and experiences of a digital psychoeducation and peer support intervention (COPe-support): interview study with carers supporting individuals with psychosis. *J Med Internet Res* 2022; 24: e27781.