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ORIGINAL RESEARCH

Barriers and Enablers of Electronic Health Literacy in Colorectal Cancer Patients: A Phenomenological Study

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Purpose: The real experience of patients with colorectal cancer in their electronic health (eHealth) practice was investigated to provide recommendations for the formulation of eHealth literacy improvement-oriented interventions in clinical settings.

Patients and Methods: A descriptive phenomenological study using Colaizzi's analysis was conducted. Through purposive maximum variation sampling until data saturation, semi-structured interviews were performed with 14 colorectal cancer patients at a tertiary hospital in Taizhou, China. Data were analyzed following Colaizzi's seven-step method with NVivo 12 qualitative data analysis software (NVivo 12.0). Trustworthiness was ensured via member checking, peer debriefing, and an audit trail.

Results: The following three themes and eight sub-themes were identified: patient personal factors (education level and age, patient illness denial, and willingness to search online for health information), social support factors (double-edged family support and positive effect of support from healthcare professionals), and information carriers and information quality (insufficient knowledge of available helpful information carriers, acceptance and evaluation of information carriers, and questionable information content quality).

Conclusion: Patients with colorectal cancer's eHealth literacy is hindered by low willingness and ability to seek information. Healthcare professionals should motivate patients with colorectal cancer to actively seek information related to their disease; develop a healthcare provider–family–patient coordinated support system; and develop an information platform specifically focusing on patients with colorectal cancer. These integrated interventions at the individual, family, clinical, and systemic levels can collectively improve eHealth literacy and health outcomes.

Keywords: colorectal cancer, electronic health literacy, social support factor, qualitative research, Baidu, Zhihu, TikTok, phenomenological analysis

Introduction

Global Cancer Statistics 2020 indicate that colorectal cancer (CRC) ranks second in incidence and fifth in mortality among all cancers in China.[1] A 2023 report further highlights CRC as the second most common newly diagnosed malignancy, posing a significant burden on patients and their families.[2,3] In China, the incidence of CRC peaks in the 65–69 age group,[4] and a majority of patients (60–70% or more) have an educational level of junior high school or below.[5] Against the backdrop of rapid internet and digital technology advancement, electronic health (eHealth) literacy has emerged as a crucial factor influencing patient health management and medical decision-making. Defined as the ability to seek, comprehend, evaluate, and apply health information from electronic sources to address health issues.[6] eHealth literacy is framed conceptually in this study through the integration of Norman and Skinner's eHEALS model—

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which emphasizes functional, interactive, and critical health literacy skills—and Lloyd's critical digital-health framework, which underscores the sociocritical dimensions of navigating digital health information.[6,7] However, the digital divide continues to hinder equitable access for older adults, those with lower education, and rural residents.[8] Enhancing eHealth literacy enables CRC patients to acquire accurate, updated disease-related knowledge,[9] thereby promoting self-management, supporting shared decision-making, improving treatment adherence, and ultimately enhancing health outcomes and quality of life.[10]

Although some cancer patients access health information through digital channels, many struggle to evaluate, filter, and utilize such information effectively.[11] Existing research on eHealth literacy in CRC patients remains predominantly quantitative, with limited qualitative inquiry into lived experiences, cognitive barriers, and facilitators in eHealth literacy practice. This study therefore adopts a descriptive phenomenological approach, aiming to deeply explore the real-life experiences, barriers, and enablers of eHealth literacy among CRC patients, with a focus on their subjective sense-making during health information engagement. Phenomenology is particularly suited to this aim, as it prioritizes the direct description and essence of lived experience, allowing an in-depth uncovering of patients' perceptions and consciousness in interacting with digital health information. In contrast, grounded theory is oriented toward theory generation from data, and ethnography emphasizes prolonged cultural immersion and observation. Given that the objective here is not to develop a new theory nor to depict cultural systems, but rather to foreground the individual, experiential dimension of eHealth engagement, phenomenology offers a more targeted and appropriate methodological framework. It shown in Figure 1

Participants and Methods

Participants

A sample was selected from the patients with colorectal cancer treated at a Grade A tertiary (3A) general hospital in Taizhou, Jiangsu Province, China, between June 2024 and August 2024 using a purposive, maximum-variation sampling method. The inclusion criteria were 1) clinical diagnosis of colorectal cancer; 2) age ≥ 18 years; 3) presence of no language disorder, capable of normal communication, and demonstration of verbal expression skills; and 4) provision of informed consent to voluntarily participate in this study. The exclusion criteria were 1) extensive metastasis or end-stage cancer; 2) serious complications or serious physical disease of the heart, lung, or kidney; 3) serious cognitive disorder or mental disorder making the patient incapable of cooperation for an interview. The sample size was determined based on the principle of information saturation. The final sample included 14 patients numbered P1–P14, whose basic information is presented in Table 1. The study was conducted in accordance with the ethical principles outlined in the Declaration of Helsinki.This research was approved by The Clinical Research Ethics Committee of Taizhou People's Hospital (No.KY2024-075-01).Written informed consent was obtained from all participants, including consent for the publication of anonymized responses and direct quotes.

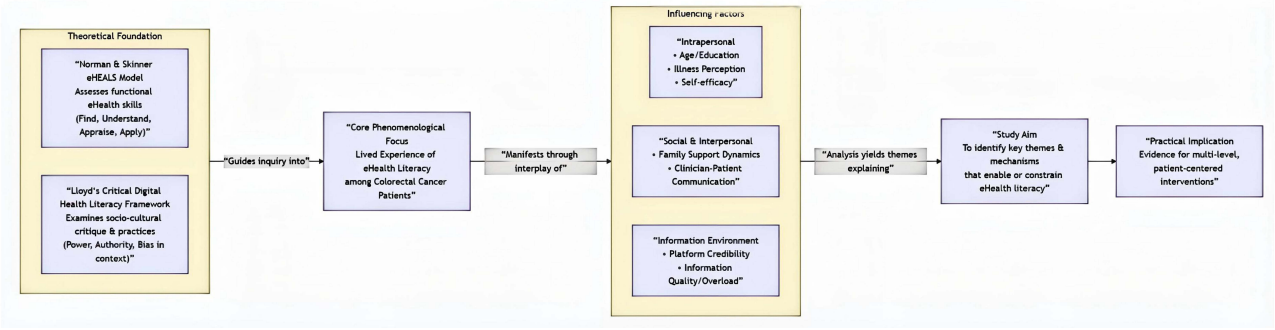


Figure 1 A multi-level conceptual framework of eHealth literacy determinants in colorectal cancer patients.

Table 1 General Information of Respondents (n = 14)

Identification Code	Sex	Age	Level of Education	Occupation Before Diagnosis	Disease Description	Stoma Surgery (Yes/No)
N1	Female	62	Elementary school	Worker	Colon cancer	No
N2	Male	41	Master's degree	Teacher	Colon cancer	No
N3	Female	73	Elementary school	Farmer	Rectal cancer	No
N4	Male	57	Middle school	Automobile mechanic	Colon cancer	Yes
N5	Female	76	Secondary technical school	Retired teacher	Rectal cancer	No
N6	Male	55	Middle school	Worker	Colon cancer	No
N7	Male	49	Middle school	Carpenter	Rectal cancer	Yes
N8	Male	61	High school	Retired armed police	Colon cancer	No
N9	Male	56	Associate degree	Freelancer	Colon cancer	No
N10	Female	68	Elementary school	Farmer	Colon cancer	No
N11	Female	72	Elementary school	Farmer	Rectal cancer	No
N12	Male	48	Undergraduate	Company employee	Rectal cancer	Yes
N13	Male	67	Associate degree	Retired worker	Colon cancer	No
N14	Female	61	Secondary technical school	Retired worker	Rectal cancer	Yes

Research Methods

Study Design and Theoretical Orientation

This study adopted a descriptive phenomenological approach rooted in the philosophical tradition of Husserl, which emphasizes the exploration of individuals' lived experiences and the essence of phenomena as they are perceived by the participants[12.] To maintain objectivity, the researchers practiced "bracketing" (epoché), setting aside preconceived notions about the topic throughout the research process.

The interviews were conducted by a master's-level stoma therapist with 15 years of clinical experience. To address potential biases arising from the researcher's clinical background, several reflexivity strategies were employed, including maintaining a reflexive journal and engaging in peer debriefing with two qualitative research experts.[13]

Sampling and Saturation

A purposive sampling strategy with maximum variation was used to recruit 14 participants, varying in sex, age, education level, and stoma status. Sample size was determined based on qualitative sampling principles and data saturation, as defined by Guest et al,[14] where no new codes emerged after the 12th interview, confirming that thematic saturation had been achieved.

Development of the Interview Guide

An initial version of the interview guide was developed based on a literature review[15,16] and discussion with two experts in colorectal cancer, two head nurses specializing in gastrointestinal surgery, and a specialist nurse in stoma care. The initial version was used to conduct mock interviews with two patients with colorectal cancer and, based on the results of the interviews, the guide was improved and revised. The final guide included the following questions: 1) Have you searched online for health information related to your disease after you were diagnosed? Where do you usually do your search? 2) Do you usually have difficulty conducting your search? What are your difficulties? How do you deal with those difficulties? 3) Can you understand the information? What do you do if you cannot understand it? 4) How do you think about the content of the health information? Have you ever found contradictory information? Does it help you to resolve your problems? 5) Do you adjust your lifestyle or medical decisions based on the obtained information?

Data Collection Methods

Data were collected using semi-structured, face-to-face interviews conducted in Chinese. All interviews were audio-recorded, transcribed verbatim, and later translated into English for analysis. Translation accuracy was verified through back-translation and bilingual checking by two independent researchers. Interviews lasted between 30 and 45 minutes

and were conducted in a quiet, comfortable setting such as a meeting room. The researcher also took field notes to capture non-verbal cues and contextual observations. All data were stored securely with identifiers removed to ensure confidentiality.

Before each interview, the investigator familiarized themselves with the interview guide to ensure understanding of its objectives. At the beginning of the interview, the investigator introduced the purposes and requirements, built a relationship of trust with the participant, and obtained signed informed consent. They avoided leading questions and used various interview skills, such as rhetorical questioning, follow-up questioning, echo questioning, repetition, rephrasing, and summation. All verbal and nonverbal data were carefully and truthfully recorded to fully reflect participants' opinions, with ambiguous messages clarified promptly.

Data Analysis Method

Data analysis followed Colaizzi's seven-step phenomenological method,[17] which included: (1) reading and rereading transcripts, (2) extracting significant statements, (3) formulating meanings, (4) clustering themes, (5) developing an exhaustive description, (6) producing the fundamental structure, and (7) seeking verification from participants. Steps 2–4 were particularly important for ensuring confirmability, as they involved independent coding and theme development by two researchers. An audit trail was maintained through memos, decision logs, and codebook evolution. Data were organized and coded using NVivo 12 Plus (Release 2024). Initial codes (eg, "search barriers," "information appraisal," "behavioral adaptation") were derived inductively and grouped into broader themes. Each coded transcript was reviewed jointly by two researchers to ensure coding consistency.

Trustworthiness and Quality Control

The research team comprised two stoma therapists with a master's degree and two master's students trained in qualitative methods. All researchers completed systematic training in qualitative research methods, covering basic theories, interview techniques, data coding, and analytical procedures. During the interviews, the interviewer remained neutral, avoided leading questions, and used a variety of interview techniques. Each interview was conducted by two researchers: one conducted the interview, while the other provided on-site assistance, particularly considering the advanced age of participants and potential safety risks.

Data analysis was performed by C. Q.and L. Y.C., who integrated audio recordings and on-site notes for transcription. NVivo 12 software was used for independent data analysis and coding. In case of any divergences, further analysis and discussion were conducted among team members until a consensus was reached to enhance the credibility of the findings. The identified themes were reviewed and validated by W.M. and X.Y.H. Transcripts were returned to participants for validation. As the principal investigator of the entire project, X.Y.H. oversees its overall execution. All research team members are acquainted with one another and maintain regular communication and feedback exchanges through telephone calls and in-person meetings.

This study was reported in accordance with the Consolidated Criteria for Reporting Qualitative Research (COREQ) 32-item checklist,[18] Refer to Supplementary File 1 for details.

Results

A total of 14 patients with colorectal cancer (numbered P1–P14) were included in this study. Their ages ranged from 41 to 76 years, with 8 males and 6 females. Educational levels varied from primary school to a master's degree, and 7 participants had undergone stoma surgery. Detailed demographic characteristics are presented in Table 1.

Three core themes were identified from the analysis. Themes and Subtopics are shown in Figure 2.

Theme 1: Patient Personal Factors

Age and Education Level

A previous study[6] showed that the age and education level of patients affect their eHealth literacy: The younger and the higher the education level of the patient, the higher the level of eHealth literacy. The patient's cultural level affects their

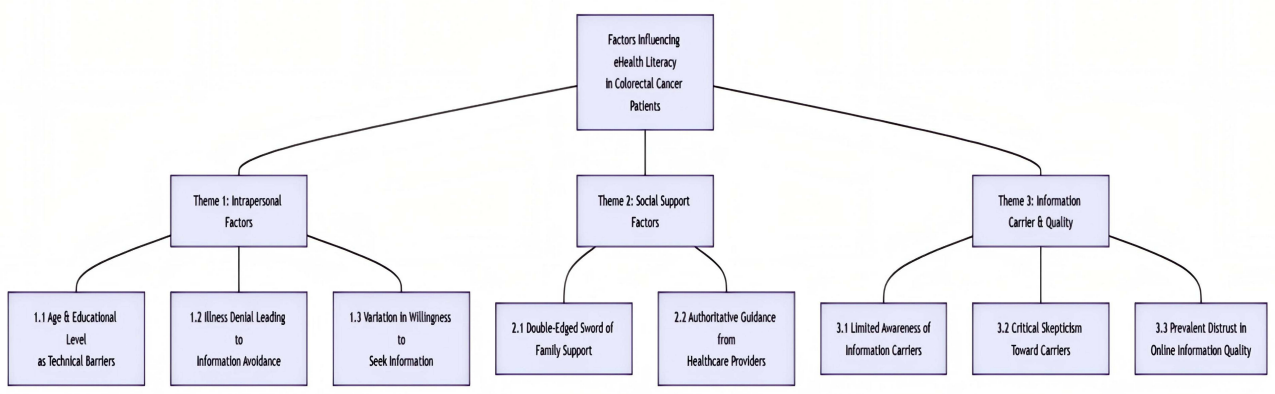


Figure 2 Thematic structure of factors influencing eHealth literacy among colorectal cancer patients.

spelling and understanding of text that they obtain online. Some participants had a low education level and were advanced in age, which affected their search skills:

P1: I am using a smartphone, but I ended my schooling at the fifth grade of elementary school, [I am] not very literate. I do not know how to search online for such information.

P8: I am old. I am illiterate in pinyin, so I use the handwriting input method. Also, I have poor eyesight. Such searching is not easy for me.

Text comprehension is a prerequisite for understanding electronic information. Some participants had a low education level and experienced difficulty understanding complex, specialized disease-related information:

P10: I have a limited education. I know those characters, but sometimes I do not know their meanings.

Patient Illness Denial

Some participants had difficulty acknowledging their disease and adopted an attitude of denial toward information related to their disease. Most of these participants had a higher education level.

P2: I am feeling a bit aversive. I do not want to see information related to my disease, a feeling of denial. I do not want to know at all. I have shunned all disease-related keywords.

P5: I do not want to see information related to my disease when playing on my phone. If I happen to see such a piece of information, I do not read it.

P12: I am averse to things like patient groups. I do not want people to know I have a stoma.

Willingness to Search Online for Health Information

Some participants lacked the initiative to find information related to their disease, had a low willingness to search for it, and relied on their doctors to provide them with information.

P1: All the information I have about my illness was told [to me] by my doctors. I follow what my doctors tell me. If they tell me to go East, I go East. If they tell me to go West, I go West.

P4: For everything, I follow my doctors' instructions. I follow what my doctors tell me.

P11: I am not a doctor. I am left to follow what my doctors tell me. You just do what your doctors instruct you to do. It's brain-racking for me to search and discuss.

Some participants had a positive attitude.

Theme 2: Social Support Factors

Double-Edged Family Support

Digital backfeeding from family members can enhance patients' ability to search for electronic health information.

P4: My daughter taught me how to search online for information and, for fear that I had not learned it, even wrote down the steps.

P6: In the initial days after my diagnosis, my daughter sent me everything she had found and warned me about lifestyle do's and don'ts. Now, I try it on my own while she continues to teach me. Even I have learned it!

However, some participants exhibit excessive dependence on their families, which impedes them from raising their eHealth literacy.

P1: My daughter-in-law takes care of everything for me. I simply do not concern myself with these things. Just that they tell me what to do, and I rely on them. If they say I cannot eat something, then I do not eat it.

P13: My wife scrolls though her phone searching for information about my disease every day. I think, as my wife has understood so much, I would just leave her to find out all. I am now a bit dependent on my wife.

N3: My two daughters help me find out all. I have no idea.

Positive Effects of Support from Healthcare Professionals

Patients value and accept the ways to access online health information provided by healthcare professionals, and they take the initiative to search for, learn, and apply the relevant knowledge.

P13: There's so much information on the internet. I would consult my doctor, who told me there's a website specially for our type of stoma. I am grateful.

P14: During my hospitalization, the doctors and nurses invited us to join a group and follow their WeChat official account, which publishes disease care knowledge. I read it, which is good.

Theme 3: Factors Related to Information Carriers and Information Quality

Insufficient Knowledge About Helpful Information Carriers

Despite the availability of rich online information resources, diversified information carriers, and a multitude of ways to access information, some participants did not know how to access information on any or more than one of the information carriers.

P10: I also want to find information related to my illness, but I do not know where to find it.

N6: I often read on Baidu. I only know there is a Baidu. I have no knowledge of other options.

Perception and Evaluation of Information Carriers

Some participants were skeptical about the credibility of electronic information.

P8: The content on TikTok is rubbish. I simply scroll through it. I do not quite trust things on mobile apps. Everyone has different situations. In the case of a misfortune, one still needs to go to the hospital.

Some participants felt annoyed by pop-up advertisements on platforms.

P9: The content on Baidu is inaccurate, many ads, always popping up.

Quality Challenges of Network Information (Complexity; Contradiction; Falsity; Overload)

Some patients were wary of the information content quality in terms of complexity, contradiction, falsification, and overload. Only after patients had gained sufficient understanding of the information could they apply it. If the information was overly complex, contradictory, or difficult to understand, its use by the patients was negatively affected.

P13: Information on the internet nowadays is too complex. Sometimes, views are even inconsistent. For example, for my stoma, some people say I can eat corn, but other people say I cannot eat it. I do not know whom to follow.

P14: Some content on the internet is quite specialized. I read it, but I did not quite understand it. I still prefer information given in simple words that is not complex and understandable.

Discussion

Implementing Multi-Dimensional Intervention Strategies and Increasing Patient Willingness to Seek Information

Research shows that education level is a fundamental determinant of eHealth literacy,[19] a relationship clearly evident in our participants' struggles with textual comprehension and digital navigation. Patients with a low education level generally have low Chinese character and pinyin literacy and face barriers to understanding electronic texts, resulting in their inability to effectively use online health information. This finding is consistent with the functional health literacy model and the eHealth literacy model proposed by Norman and Skinner,[6] which proposes that fundamental reading and writing literacy is a prerequisite for eHealth literacy. In this study, participants with a higher education level exhibited illness denial and information avoidance. This can be framed within coping and adaptation theory (Case et al, 2005)[20,] where denial serves as a psychological mechanism to manage overwhelming health threats, rather than simple resistance. When highly educated individuals perceive the threat of their disease as excessively high, they may resort to information avoidance to reduce anxiety and build psychological defenses.[20] This aligns with Fujisawa et al,[21] who found that colorectal cancer-specific self-stigma, such as having a stoma, promotes information rejection, thereby inhibiting information-seeking behavior.

Additionally, participants differed remarkably in their level of information-seeking initiative. Dependent-type participants placed excessive trust in healthcare professionals, while active-type participants actively sought information on social media and online platforms. These findings are consistent with the health information-seeking behavior model proposed by Lambert and Loiselle,[22] which posits that individuals' information-seeking strategies are affected by their health beliefs and disease perception. Patients' dependence on doctors is a remnant of the traditional paternalistic doctor–patient relationship, reflecting insufficient patient self-efficacy. Bandura's social cognitive theory posits that low self-efficacy inhibits information-searching motivation[23] and requires the accumulation of successful experiences to rebuild confidence. Therefore, to increase the willingness of patients with low education, excessive dependence, and emotional avoidance to actively seek disease-related information, healthcare professionals need to design health education materials in plain language augmented with graphs, and strengthen psychological interventions to enhance patient self-efficacy. Moreover, digital anxiety and age-related disparities—part of the "digital divide" notably present among older cancer populations[24]—must be addressed through tailored, accessible digital literacy support.

Building a Health Provider–Family–Patient Coordinated Support System to Improve Patient Information Search Skills

Social support has both positive and negative effects on patient eHealth literacy. In this study, some participants developed an excessive dependence on their families, which impeded the development of their own information search skills. Although digital literacy education provided by family members can improve patient skills, over-reliance inhibits autonomy. This finding accords with Peng et al,[25] who concluded that family support needs to be balanced with empowerment and independence cultivation. It is useful to distinguish between empowerment-oriented support, which fosters autonomy and self-efficacy,[23] and dependence-oriented support, which may undermine initiative. This perspective suggests that family support should focus on cultivating patient autonomy in information seeking, encouraging patients to

actively learn about their disease. This agrees with Ancker et al's[26] description of the role of the "healthcare professional as a gatekeeper."

The high acceptance of official information channels (eg, WeChat groups and official accounts) provided by healthcare professionals indicates that these professionals play an important role in guiding patient eHealth information-seeking behavior. Information provided by or under the direction of the healthcare system is perceived as more trustworthy. Therefore, it is particularly important to develop a healthcare provider–family–patient coordinated support system.[27] Healthcare professionals should regularly recommend authoritative information channels and select high-quality disease-related information. When providing digital literacy education, family members should seek balance but prioritize empowerment, thereby encouraging patients to improve their capacity for autonomous information management and avoid excessive dependence.

Improving Information Carriers and Patient Information Use Skills

Regarding information carriers and information quality, patients face challenges such as limited choices in information carriers, information overload, difficult-to-understand specialized information, and information of questionable credibility. In the interviews, participants demonstrated limited knowledge of diversified information platforms. They often relied on a single platform, such as Baidu, and were unaware of authoritative medical resources like specialized medical websites and academic databases. This indicates a great need for improvement in health information navigation and seeking skills, a challenge noted in studies of patients with limited eHealth literacy.[28] The necessity for healthcare professionals to guide patients toward diversified and credible information channels is evident.[29] Additional challenges included information overload and contradictory information affecting patient dietary behavior, supporting the "health information paradox" described by Jung et al,[30] which posits that excessive information compromises patient decision making. Furthermore, patient doubt about the credibility of platforms—such as excessive advertisements on TikTok and Baidu—reflects the mixed quality of health information online. This "mixed" nature stems from the contradiction between the profit-making nature of commercial platforms and the public welfare nature of health information, making it difficult to fill the "information credibility gap".[31] The trust patients place in online health information directly affects their behavioral intentions.[32] Thus, for non-professionals, content producers should avoid difficult jargon and adhere to plain language principles in health communication, as recommended by health literacy universal precautions toolkits.[33] Healthcare professionals should recommend diversified, easy-to-operate internet platforms. Additionally, where technically feasible, an authoritative, integrated information platform specifically for colorectal cancer should be built, equipped with information screening and interpretation services, as a major measure for improving patient information-use skills.

To address these challenges, several practical strategies are recommended. First, developing plain-language health materials, pictorial interfaces, video tutorials, and clinician-moderated social media groups can enhance comprehension and engagement, especially for patients with limited literacy.[34] Second, incorporating peer-to-peer communities and social-media interventions can foster supportive information exchange and mitigate feelings of isolation, as demonstrated in cancer support communities.[35] The use of visual and interactive formats—such as infographics, short videos, and animated explanations—can make complex medical information more accessible and memorable by leveraging well-established principles of multimedia learning.[36] The strategic use of pictures has been consistently shown to improve attention, comprehension, recall, and adherence in health communication.[37]

A coherent conceptual integration shows that eHealth literacy is shaped by personal (eg, education, self-efficacy), interpersonal (eg, family and clinician support), and system-level (eg, information platform quality and accessibility) factors.[38] These dimensions interact, influencing how patients access, interpret, and use digital health information. Future interventions should therefore adopt a multi-level approach, combining individual skill-building with systemic supports to sustainably enhance eHealth literacy.

Although this study made several noteworthy findings, several limitations must be acknowledged. All participants were recruited from a single 3A hospital in Taizhou, resulting in a small sample and limited transferability of findings. The interview setting may also have introduced social-desirability bias, and nuances may have been affected by translation from Mandarin to English. Additionally, this study relied solely on patient reports without triangulation

with family or provider perspectives. Future research could expand the sample size and diversity, incorporate multiple stakeholder views, and adopt a sequential mixed-methods design to track longitudinal changes in eHealth literacy following interventions.

Conclusion

This interview study of 14 colorectal cancer patients analyzed factors affecting their eHealth literacy from different perspectives, identifying three themes and eight sub - themes. Factors like lack of willingness to seek health information and poor information skills affect patients' eHealth literacy to varying degrees, highlighting the need for integrated, multi - level intervention strategies. At the individual level, enhancing patients' self - efficacy and motivation to seek health information through digital health literacy training or peer - education programs is essential. Involving families in a coordinated support system, such as through family health education sessions or joint eHealth platform activities, can strengthen information acquisition and emotional support. Health professionals should guide patients to reliable information sources and provide simplified educational materials during consultations or follow - ups. At the system and policy level, there is a need to develop certified oncology eHealth platforms with professional information interpretation services, integrating features like appointment scheduling, online consultations, and personalized information delivery. These steps can improve eHealth literacy and patient outcomes. The schematic figure summarizing findings are shown in Figure 2.

Data Privacy and Security

To ensure confidentiality, all interview transcripts were anonymized by removing all personally identifiable information and assigning unique participant codes (eg, P1, P2). Digital audio files and corresponding identifiers were stored separately from the anonymized transcripts on a password-protected, encrypted drive accessible only to the core research team.

Data Sharing Statement

The datasets analyzed during the current study are not publicly available due to ethical and privacy reasons.

Ethical Statement

This study was approved by The Clinical Research Ethics Committee of Taizhou People's Hospital (No.KY2024-075-01). Written informed consent was obtained. The study complied with the Declaration of Helsinki.

Disclosure

The authors report no conflicts of interest in this work.

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