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Online health information seeking behavior among breast cancer patients and survivors: a scoping review

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Jialin Chen¹, Yiwen Duan¹, Haozhi Xia², Runxi Xiao¹, Tingting Cai^{1*†} and Changrong Yuan^{1*†}

Abstract

Purpose This scoping review aims to summarize online health information seeking (OHIS) behavior among breast cancer patients and survivors, identify research gaps, and offer insights for future studies.

Methods Following Arksey and O'Malley's framework, we conducted a review across PubMed, Web of Science, CINAHL, MEDLINE, Cochrane, Embase, CNKI, Wanfang Data, and SinoMed, covering literature from 1 January 2014 to 13 August 2023. A total of 1,368 articles were identified, with 33 meeting the inclusion criteria. Two researchers independently screened, extracted, and summarized the data.

Results The studies addressed three main themes:OHIS behavior, factors associated with OHIS, and intervention programs on OHIS. Key information sources included national or nonprofit cancer organizations' websites, search engines, and social media. Commonly sought information involved breast cancer knowledge, treatment options, and prognosis, with information seeking behaviors varying by disease stages. While patients valued the convenience and accessibility of online resources, dissatisfaction was common due to inaccurate or misleading content. Factors such as age, education, income, disease characteristics, and psychological factors significantly influenced OHIS behaviors.

Conclusion This review identifies significant gaps in exploring OHIS behavior among breast cancer patients and survivors, highlighting the inadequacy of current interventions. Future research should focus on diverse age groups, refine the language of web-based health information, enhance user comprehension of professional content, and develop tailored information systems for different stages of the health journey.

Keywords Online health information seeking, Breast cancer, Social media, Health information

[†]Tingting Cai and Changrong Yuan contributed to the work equally and should be regarded as co-corresponding authors.

*Correspondence: Tingting Cai caitingtingguo@163.com Changrong Yuan yuancr@fudan.edu.cn ¹School of Nursing, Fudan University, 305 Fenglin Road, Shanghai 200032, China ²School of Nursing, Nanjing University of Chinese Medicine, Nanjing 210023, Jiangsu, China

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Introduction

The advent of the internet has markedly influenced the dissemination of health information. Compared to traditional health information channels, the internet offers accessible, multi-dimensional, and continuously updated health information [1]. It has been reported that the internet has become the preferred source of information for cancer patients, surpassing healthcare professionals (HCPs) [2–5].

Breast cancer is the second most common cancer globally [6]. Studies indicated that breast cancer survivors possess limited knowledge [7], which is closely related to the timeliness of diagnosis, adherence to therapy, and overall quality of life [8-10]. Online health information seeking (OHIS) behavior is defined as "the processes whereby individuals use network tools to retrieve, browse, assess and select health-related knowledge or information, driven by their health information needs and cognitive motivations" [11]. It is noted that breast cancer patients were more inclined to seek information online compared to those with other cancers [12]. This online engagement not only enhances patients' understanding and awareness of cancer but also promotes informed decision-making [13–15], facilitates self-management [16], strengthens their sense of control over their disease [16, 17], and improves health outcomes [18, 19].

The information topics sought by different cancer patients and survivors online exhibit both commonality and diversity. For instance, esophageal, lung, and breast cancer patients commonly seek information on symptoms, treatments, and prognoses. However, breast cancer patients showed less interest in topics like pain and complementary and alternative medicine, focusing more on specific issues related to hormone therapy and triplenegative cancer [20]. While reviews have summarized OHIS behavior in the broader population [21], those focusing specifically on cancer patients, who have more specialized health information needs, remain limited [22]. Furthermore, Li et al. [23] identified OHIS behavior in cancer patients, particularly breast cancer patients, as a key research hotspot. This highlights the abundance of original research in this area that has yet to be synthesized, providing valuable insights for future studies. Therefore, this review is essential as it integrates diverse original studies, enhances our overall understanding of breast cancer patients' OHIS behavior, and provides a foundation for the development of tailored online information sources and support strategies to meet their specialized health information needs [24–27].

The objective of this review is to comprehensively explore the OHIS behavior among breast cancer patients and survivors, identify limitations in existing research, and provide references for future studies. This review poses three research questions: (1) What is the current state of research on the OHIS behavior of breast cancer patients and survivors? (2) What are the characteristics of the OHIS behavior of breast cancer patients and survivors (where, what, when, and their experiences)? (3) What factors influence their OHIS behavior?

Methods

In this study, we strictly followed Arksey and O'Malley's framework for conducting a scoping review, which involves five key steps [28]: (1) identifying the research question, (2) identifying relevant studies, (3) selecting studies, (4) charting the data, and (5) collating, summarizing, and reporting the results. First, we formulated the research question, focusing on the OHIS behavior of breast cancer patients and survivors. Next, we conducted a comprehensive search across multiple databases to identify relevant literature within the specified timeframe and thematic scope. We then screened and selected studies that met our inclusion criteria. Subsequently, we charted the data to extract key findings. Finally, we synthesized the current state of research, identified gaps, and provided directions for future research. We also adhered to the PRISMA-ScR (Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews) guidelines [29].

Literature search

A comprehensive literature search was conducted in both English and Chinese databases, including PubMed, Web of Science, CINAHL, MEDLINE, Cochrane, Embase, CNKI, Wanfang Data, and SinoMed. The search was conducted between August 2023 and January 2024. The search strategy comprised a mix of Medical Subject Headings (MeSH) terms and free-text terms. The detailed search strategies are depicted in Supplementary. Titles and abstracts retrieved from these databases were independently reviewed by two researchers to ascertain their relevance based on predefined inclusion and exclusion criteria. Articles with disagreements were decided by a third researcher for inclusion.

Inclusion and exclusion criteria

The scoping review included studies that were: (1) published between 1 January 2014 and 13 August 2023; (2) written in English or Chinese; (3) focused on breast cancer patients or survivors; and (4) provided information about OHIS behavior. Reviews, letters, replies, or meeting abstracts were excluded.

Study identification

From the initial search, 1368 articles were identified. After screening, 33 articles were selected for inclusion, as illustrated in Fig. 1. Notably, while some included studies



Fig. 1 Selection process for study inclusion

also encompassed other cancer types [12, 30, 31], those focusing on breast cancer predominated and thus their findings were incorporated into this review.

Data extraction

Data extraction was performed independently by two researchers using a standardized data extraction chart in Microsoft Excel. The extracted information encompassed authorship, publication year, journal, study location, aims, design, participants, and outcomes, including information sources, information topics, frequency and timing of information seeking, and seeking experiences. Any discrepancies or disagreements between the researchers were discussed and resolved through consensus or by consulting a third researcher when necessary. The final extracted data were cross-checked for accuracy and completeness before analysis.

Results

Basic characteristics of the included articles

The majority of the included articles were published in 2023 (n=7) and 2018 (n=6). The studies reviewed were conducted in 12 different countries, with the most frequent contributions coming from the United States (10 studies), followed by China (4 studies) and Spain (4 studies). The studies primarily revolved around three central themes: (1) OHIS behavior, including dimensions such as information sources, information topics, frequency and timing of information seeking, and information seeking experiences, (2) factors related to OHIS behavior, and (3) intervention programs targeting OHIS. The subjects

of these studies predominantly included breast cancer patients and survivors. Figure 2 illustrates a conceptual framework of OHIS behavior and factors associated with OHIS.

Out of the 33 included studies, 24 were observational studies using questionnaires or interviews (Table 1). Among these, 19 studies provided detailed descriptions of specific dimensions of OHIS behavior, whereas 3 studies offered limited data on these dimensions [5, 12, 32], and 2 studies focused on factors influencing OHIS behavior [33, 34]. The included studies employed diverse methodologies to explore OHIS behavior. While quantitative studies identified preferences, trends, and factors influencing OHIS, qualitative research offered insights into patients' information seeking experiences and emotional responses, providing complementary perspectives on OHIS behavior. Additionally, 2 studies required participants to perform specific seeking tasks:one captured the activity through video and audio recordings of computer interactions [35], while another required participants to narrate their actions and provide real-time responses for qualitative descriptive analysis [24]. Four studies analyzed content from online communities or search engines [20, 22, 36, 37], and three investigated OHIS behavior through the implementation of intervention programs [19, 38, 39], which will be discussed subsequently.

Incidence of OHIS

In Australia, the prevalence of the internet as a source of information among breast cancer patients has seen a remarkable increase, rising from 2 to 8% in 2002 to 70%



Fig. 2 Conceptual framework of OHIS behavior among breast cancer patients and survivors, categorizing sources, key topics, seeking frequency, seeking experiences, and factors influencing OHIS behavior

Table 1	Characteristics of	ΓO	bservationa	l stuc	lies	based	on	questionaires	or interviews	(n=24	.)
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Study	Country	Methodological	Theoretical	Subjects
Maloney et al., 2015 [40]	USA	QUANT	Not given	Breast cancer patients/survivors who read online
				breast cancer information
Ahern et al., 2015 [5]	Australia	QUANT	Not given	Breast cancer patients
Schmidt et al., 2016 [41]	USA	QUANT	Not given	Breast cancer patients
Holmes et al., 2017 [42]	UK	MIXED	Not given	Breast cancer survivors
Pugh Yi et al., 2018 [43]	USA	QUANT	Not given	Young women with breast cancer history or previvors (genetic risk)
Yin, 2018 [44]	China	QUANT	Knowledge and belief theory	Breast cancer patients
Casellas-Grau et al., 2018 [33]	Spain	QUANT	Not given	Breast cancer patients/survivors who sought online breast cancer information
Corter et al., 2019 [45]	Canada	QUAL	Not given	Young women with breast cancer
Perrault et al., 2020 [46]	USA	QUAL	Not given	Breast cancer survivors
Li et al., 2020 [25]	China	QUANT	Not given	Breast cancer patients
Ochoa-Arnedo et al., 2020 [47]	Spain	MIXED	Not given	Breast cancer patients/survivors who sought online breast cancer information
Yuen et al., 2020 [32]	Singapore	QUAL	Not given	BRCA1/2 pathogenic variant carriers
Mallmann et al., 2021 [48]	Germany	QUANT	Not given	Breast cancer patients
Zou, 2023 [49]	China	QUAL	Develop a theory	Breast cancer patients
Mendes-Santos et al., 2023 [50]	Portugal	QUANT	Not given	Breast cancer survivors
Grynne et al., 2023 [51]	Sweden	QUAL	Integrated health literacy model	Breast cancer patients
Yip et al., 2023 [<mark>52</mark>]	Portugal	QUANT	Not given	Breast cancer patients
Madge et al., 2023 [53]	Romania	QUAL	Not given	Breast cancer patients
Valero-aguilera et al., 2014 [34]	Spain	QUANT	Technology accep- tance model	Patients with breast and urological cancers
Heiman et al., 2018 [54]	Germany	QUANT	Not given	Patients with cancers and their caregivers
Davis et al., 2021 [12]	USA	QUANT	Not given	Survivors of breast, prostate, colon cancers, and others
Fahmer et al., 2022 [55]	Germany	QUAL	Not given	Patients with breast or gynecological cancers
Melhem et al., 2023 [31]	Jordan	QUANT	Not given	Survivors of breast and colorectal cancers
Thiessen et al., 2023 [30]	Canada	QUAL	Develop a theory	Adults with a history of cancer and informal caregiving

in 2013 [5]. Similarly, in Germany, the utilization rate of the internet by breast cancer patients for health information has significantly increased, from 36% in 2012 to 62.5% in 2020 [48]. A recent study indicated that 65% of breast cancer survivors sought health-related information online [50]. In summary, those studies reported the incidence of OHIS behavior, showing a significant increase in the prevalence of OHIS among breast cancer patients across different countries.

OHIS behavior

OHIS behavior was explored across several dimensions, including information sources, information topics, frequency and timing of information seeking, and information seeking experiences. Participants primarily accessed information through search engines (e.g., Google, Baidu) [25, 30, 45, 49, 52, 53], websites of national or nonprofit cancer organizations (e.g., American Cancer Society) [24, 40, 41, 43, 46, 48] and social media platforms (e.g., Facebook, WeChat) [25, 43, 45, 49, 52, 53], utilizing an average of 3.76 different categories of sources [40]. They focused on topics such as basic breast cancer knowledge

(e.g., signs, diagnosis) [20, 24, 40, 46, 48–50], treatment plans (e.g., chemotherapy, mastectomy) [20, 24, 37, 40, 46, 48], and prognosis (e.g., recurrence, metastasis) [20, 24, 40, 49, 50], reading an average of 4.61 types of information topics [40].

The frequency and timing of information seeking among breast cancer patients and survivors vary by disease stage. According to specific studies, 68% of patients sought information online before their first medical consultation, but this dropped to 49% before treatment initiation [25, 44]. Two studies reported that patients increased their information seeking time from 1.51 h/ week pre-diagnosis to 2.80 h/week shortly after diagnosis, with a nearly fourfold spike in seeking behavior during this period [22, 47]. Other studies found that posttreatment, the frequency of seeking gradually declined to less than once a month, with an average of 2.61 h/week reported [31, 47]. Additionally, one study highlighted a shift in information sources:while oncologists were the main source during active treatment, the internet gained prominence in the post-treatment phase [54].

Patients' experiences with online health information varied widely based on the perceived quality and relevance of the content. On one hand, online resources offered convenience, helping to close gaps in cancer knowledge and provide emotional support [42, 47, 51]. On the other hand, many patients expressed concerns about information quality, particularly regarding accuracy and comprehensibility [5, 32, 42, 48, 54]. Furthermore, an overwhelming volume of information [30, 45], negative content [30, 45, 51], and complex medical terminology contributed to anxiety and confusion among users [30, 31, 55].

Factors associated with OHIS

Younger breast cancer patients and survivors, and those with higher education, income, and eHealth literacy were more likely to seek health information online [25, 31, 34, 41–43, 54]. Younger patients and survivors often focused on genetic counseling, fertility, and the experiences of other cancer patients [40, 43]. Those without recurrence looked up side effects and alternative therapies, whereas advanced-stage patients focused on prognosis and clinical trials [40]. Psychological factors also played a rolepatients with posttraumatic stress sought both medical and psychosocial information, while those experiencing posttraumatic growth prioritized lifestyle and support resources [33]. These findings provide a deeper understanding of the factors that not only shape patients' intent to seek online health information but also influence the topics of information they prioritize.

Intervention programs on OHIS

Among the 33 studies reviewed, three focused on delivering web-based interventions to breast cancer patients to further investigate OHIS behavior, as detailed in Table 2. These studies involved e-health educational programs or websites specifically designed for women recently diagnosed with breast cancer. Longitudinal data from the study by Lee and Hawkins [19] indicated that providing internet access effectively increased health knowledge and reduced patient worry. The study by Bruce et al. [38] demonstrated that providing high-quality web-based information before surgical consultations improved patients' readiness for decision-making and consultation efficiency. In contrast, the study by Ciria-Suarez et al. [39] found that multimedia content was particularly effective in meeting both emotional and informational needs, suggesting that future digital health platforms may benefit from incorporating diverse content formats to better support patient needs. Overall, these studies demonstrate the effectiveness of tailored digital interventions in enhancing breast cancer patients' OHIS behavior, reducing worry, and increasing engagement with health resources.

Content analysis about OHIS

Four articles conducted online analyses using various platforms:the Microsoft Bing Web search engine [22], the "Yahoo! Answer Japan" question-and-answer portal [36], the "Ganjoho service" website maintained by the National Cancer Center Japan [20], and Chinese online health communities with interactive Q&A functions in a breast cancer forum [37]. These studies employed diverse methodologies, including coding schemas, text-mining, and advanced statistical techniques. For instance, the study on "Yahoo! Answer Japan" utilized a coding schema to categorize 2392 breast cancer-related questions into themes [36]. Okuhara et al. [20] used an embedded questionnaire, which asked respondents to describe "information visitors needed but could not obtain," and applied text-mining techniques to identify gaps in cancer-specific information. Furthermore, the study on Chinese online health communities systematically examined user-generated content in forums using the weighted knowledge network technique to explore key topics and user behaviors [37]. Additionally, Paul et al. [22] employed Multiple Additive Regression Trees to classify health information seekers and analyze patterns in diagnosis timing.

Discussion

This scoping review reveals notable variations in the rates at which breast cancer patients and survivors engage in OHIS across different countries, with rates ranging from 29 to 82% between 2012 and 2020. Current research on OHIS behavior in this population predominantly focuses on behavior characteristics, influencing factors, and associated intervention programs.

Our findings indicate that patients prefer information sources managed by non-profit organizations or national cancer organizations, such as the American Cancer Society and the National Cancer Institute, reflecting their high trust and satisfaction ratings among patients. However, the readability of these websites was relatively low [56, 57], requiring more in-depth and evidence-based content [58]. Efforts could be made to further optimize these official health information websites by presenting medical terminology in simplified language and expanding the breadth and depth of information, thereby enhancing their accessibility and appeal. Additionally, since search engines are commonly used as a source of information, emphasizing health information quality in rankings could help patients encounter accurate information and mitigate the health risks associated with misinformation.

This study also highlights that younger breast cancer patients tend to obtain information through social media platforms. Although using social media requires significant time investment, its interactive resources provide young patients with valuable peer connections,

Table 2	Study Purpose, Subjects, I	Intervention Ir	nplementation, and Significant Results for the 3 Articles with intervention progra	ams
Study	Purpose	Subjects	Intervention Implementation	Significant Results
Lee and	To understand how and	224 women	- Strategy: Patients were randomly assigned to three groups: (a) internet access, (b)	Worry increased patients' motivation to seek additional
Hawkins,	why worry motivates	recently	Comprehensive Health Enhancement Support System (CHESS) access, and (c) control	information, leading to more amount of time spent
2016 [1 <mark>9</mark>]	health-related informa-	diagnosed	group with books or audio tapes.	searching for such information during the first 2 months.
	tion seeking, and whether	with	- Access and Support: Patients in groups (a) and (b) received computers and internet	This behavior resulted in a significant increase in patients'
	worry decreases after	breast cancer	access at home for 5 months.	perceived breast cancer knowledge and a reduction in
	obtaining health-related		- Study Design: Baseline survey conducted before intervention, followed by a post-	worry, demonstrating that internet-based support can
	information.		intervention survey and two months of web usage tracking.	effectively enhance knowledge and reduce worry.
Bruce et	To test an approach for	244 breast	- Strategy: Patients were offered web-based information through phone contact, either	High-quality web-based information prior to surgical
al., 2018	delivering high-quality	cancer	at diagnosis or when their surgical appointment was scheduled.	consultation improved patients' engagement, with 85%
[38]	web-based informa-	patients	- Access and Support: High-quality information links (from nonprofit organizations	reporting that the information helped them prepare for
	tion to breast cancer	considering	websites/ commercial cooperative agreement) were emailed to patients before their	their surgery. Surgeons also noted increased consulta-
	patients before surgical	surgery	first surgical consultation.	tion efficiency, as patients were more informed and pre-
	consultations.		- Study Design: Baseline questionnaire completed before consultation. Surgeons com-	pared, showing that pre-consultation online resources
			pleted a survey post-enrollment to assess the impact on patient interactions.	can enhance decision-making.
Ciria-	To describe and assess	234 women	- Strategy: Patients accessed the ICOnnecta't app, a digital ecosystem designed to sup-	Patients engaged most with medical and emotional sup-
Suarez et	ICOnnecta't usage in	recently	port cancer patients through various content formats.	port content, especially in video format, suggesting that
al., 2022	newly diagnosed breast	diagnosed	- Access and Support: Patients received multimedia resources (videos, texts, infograph-	multimedia resources are effective in addressing both
[39]	cancer patients within	with breast	ics) covering medical, emotional, and lifestyle topics.	informational and emotional needs. The study highlights
	the first two years of	cancer	- Study Design: Usage data tracked across content types (e.g., video, text) for two	the importance of diverse content formats in digital
	implementation.		years post-diagnosis. Analysis focused on patterns of spontaneous vs. guided use and	health interventions to improve patient satisfaction and
			engagement with different content areas.	OHIS engagement.

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particularly in addressing emotional support and information needs. This finding aligns with Gupta et al.'s review [59], which suggests that social media platforms like Facebook and Twitter are popular channels for patients to obtain disease information and share treatment experiences. While current interventions on social media primarily focus on cancer prevention education and social support [18], its potential for cancer management remains underexplored. To better serve young patients, future interventions could leverage multimedia content (e.g., videos, interactive Q&A) and personalized recommendations on social media platforms, meeting both emotional and informational needs. Social media-based interventions could complement traditional healthcare by providing continuous support for patients' informational and emotional needs.

Furthermore, our findings indicate that patients and survivors commonly seek information on basic knowledge of breast cancer, treatment plans, and prognosis, consistent with previous studies [60]. However, cancer websites in certain regions lack specific information on surgical treatments, chemotherapy, radiotherapy, and other pharmaceutical options, especially on African government and non-profit organization websites [61]. We also found that younger patients are more likely to seek information on fertility and heredity. Given the aggressive nature of breast cancer in this demographic [62], clinical trial participation may also be considered a survival strategy. Therefore, developing health information content should be more comprehensive, covering a broad spectrum of topics, and tailored according to patients' age, disease stage, and specific health needs to enhance relevance and usability.

Patients' experiences with OHIS were multi-dimensional, primarily influenced by the perceived quality and accuracy of the information found online. To mitigate this concern, patients verified information by consulting multiple sources, relying on prior experiences, engaging with healthcare providers, or limiting their inquiries to websites they consider credible. Moreover, studies found that due to complex medical terminology, poor search experiences, and a lack of effective search skills, patients use professional websites less frequently, despite their generally high-quality information [31, 55]. These challenges suggest that future interventions should focus on enhancing patient-centered information seeking experiences by simplifying medical language, integrating verification tools to cross-check information, and optimizing website design for ease of use.

It is noteworthy that OHIS behavior also impact interactions between patients. Studies indicate that 36-68% of patients have discussed, or plan to discuss, cancer-related information found online with their healthcare team [40, 43, 48]. HCPs' attitudes toward OHIS directly influence patient behavior, with some providers encouraging patients to use reliable resources and offering guidance, supporting patients' autonomy in decision-making [38]. However, some providers remain cautious about patients' use of online information due to concerns over accuracy and personalization [45, 47]. Enhancing these interactions may involve HCPs inquiring about the sources of information patients' access, with a focus on verifying accuracy and relevance. Facilitating discussions about online information during consultations could provide timely guidance and clarification, potentially improving patient understanding, adherence, and strengthening the patient-provider relationship.

This review synthesizes findings from different methodological approaches to provide a comprehensive understanding of OHIS behavior among breast cancer patients and survivors. It highlights the diverse informational needs and patient-centered preferences in OHIS, emphasizing the importance of accessible and relevant resources to support tailored interventions. To enhance patient engagement with credible health information, improving the breadth and usability of these resources by addressing specific gaps remains essential. Future research should focus on developing adaptable OHIS platforms that accommodate diverse patient backgrounds, ultimately fostering informed decision-making and empowering self-management.

Limitations of review

This review has several limitations. First, our search was limited to publications in English and Chinese, which may reduce the representativeness of our findings, as studies in other languages could provide additional perspectives. Second, our selection of databases was relatively limited, which may have constrained the breadth of research included in this review. Expanding the range of databases in future reviews could help capture a more comprehensive exploring of OHIS behavior across diverse populations.

Conclusion

This study identified central themes in current research on OHIS behavior among breast cancer patients and survivors, focusing on OHIS behavior, influencing factors, and related intervention programs. Although the dimensions of OHIS behavior discussed in each article were relatively limited, we explored the four primary dimensions:information sources, information topics, frequency and timing of information seeking, and information seeking experience. Generally, breast cancer patients and survivors mostly sought breast cancer knowledge and treatments, primarily using websites of search engines and non-profit cancer organizations. The frequency and timing of information seeking varies across different stages of the disease. Moreover, breast cancer patients tend to be less satisfied with the information available on the internet. Given that breast cancer patients and survivors are increasingly turning to online sources for health-related information, further research into the factors influencing OHIS behavior and the development of interventions remains necessary.

Supplementary Information

The online version contains supplementary material available at https://doi.or g/10.1186/s12905-024-03509-x.

Supplementary Material 1

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Author contributions

TC and JC had the idea for the article. Authors (JC, HX, TC, CY) contributed to the study conception and design. Abstract screening, data extraction, and data analysis were performed by JC, YD, and RX. Original draft was written by JC. Review and editing were performed by YD, HX, RX, TC, and CY. All authors read and approved the final manuscript.

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Data availability

The datasets generated and analyzed during the current study are available from the corresponding author (TC) upon reasonable request.

Declarations

Ethical approval

Not applicable.

Consent for publication

All co-authors approve the manuscript.

Competing interests

The authors declare no competing interests.

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