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A Five-Stage Patient Journey Mapping of Digital Health Information Behaviors in Breast Cancer and Implications for Nursing Intervention Design

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Abstract

Background

Breast cancer survivors experience substantial physical and psychological burdens across the treatment trajectory and increasingly rely on digital health information to support disease understanding, decision-making, and self-management. However, most existing studies focus on single clinical encounters, with limited insight into how digital health information behaviors evolve across illness stages and interact with patients' emotional trajectories and nursing needs.

Methods

From August to October 2025, the study was conducted in the breast surgery department of a tertiary hospital in Shanghai, China. Fifteen women with breast cancer were recruited using maximum variation convenience sampling, and data were collected via semi-structured interviews, patient journey logs, and electronic medical records. Reflexive thematic analysis supported by NVivo 12 was used to construct a patient journey map.

Results

The journey map comprised five stages -pre-diagnostic symptom perception, diagnosis and decision-making, active treatment, transition and follow-up, and long-term survivorship, each characterized by distinct patterns of digital engagement, emotional processing, self-management, and life impact. Four interconnected thematic modules were identified, forming a dynamic "information-emotion-behavior-outcome" framework.

Conclusion

Digital health information behaviors among women with breast cancer are dynamic and stage-specific. The five-stage journey map provides both theoretical and temporal foundations for stage-tailored digital nursing interventions to manage vigilance cycles and fear of recurrence. Consequently, nursing should be further embedded into patients' digital ecosystems to maximize benefits and minimize risks.

Contributions to the Literature

Text: Contributions to the Literature
1. Maps how breast cancer patients search, judge, and use digital health information across five care stages, a gap in population health evidence.
2. Provides a practical “information-emotion-behavior-outcome” framework that can guide scalable digital health literacy interventions.
3. Offers design targets for nurse-led and system-level actions to improve equitable access to trustworthy information and continuity of care.

Background

Breast cancer is the most common malignancy among women worldwide [1]. From diagnosis to long-term follow-up, patients often undergo multimodal and comprehensive treatment, which imposes not only substantial physiological burdens, such as pain, fatigue, body image changes, and endocrine disturbances, but also broader psychological challenges, including sleep disturbances, impaired social role functioning, and reduced work capacity [2, 3]. The uncertainty, risk of recurrence and metastasis, treatment side effects, and financial pressures throughout this process place patients in a state of sustained high psychological stress and lifestyle reconstruction needs [4]. With the widespread adoption of the internet and mobile health applications, breast cancer patients increasingly rely on digital health information across diagnosis, treatment, and rehabilitation follow-up stages to support disease cognition, decision participation, and self-management. Contemporary digital information environments, search engines, short-video platforms, social media communities, and emerging AI-enabled tools are widely encountered across health systems, and their algorithmically curated content can amplify variability in information quality and emotional responses, making timely professional guidance particularly important.

Current research demonstrates that patients’ abilities and experiences in obtaining and utilizing digital health information differ markedly at various phases of the disease trajectory, with unsuitable sources and information overload potentially intensifying anxiety, hindering treatment adherence, and even influencing clinical outcomes [5, 6]. However, evidence remains limited for nurses systematically assessing information needs and implementing stage-specific interventions across the entire care journey, as most research focuses on single visits or treatment nodes, failing to capture cross-stage information behavior trajectories and key nursing intervention windows. Patient journey mapping (PJM), a relatively recent approach for comprehending patient experiences, has gained traction in healthcare service design and experience enhancement, despite discrepancies in reported methodologies and implications for refining reporting standards. Though its use in oncology nursing, specifically with regard to the digital health information behaviors of breast cancer patients, is still limited, this quickly developing approach has significant potential to inform patient-centered care models [7], assisting clinicians, patients, and healthcare professionals in identifying service gaps and strategic opportunities [8, 9]. Systematically mapping breast cancer patients’ digital health information behaviors and emotional

dynamics from diagnosis through active treatment to rehabilitation follow-up can identify critical nodes such as information confusion, decision dilemmas, trust filtering, and behavioral internalization, thereby supporting the development of stage-based, nurse-led intervention pathways that are adaptable across settings.

Based on the above background, this study targeted breast cancer patients from breast surgery departments in tertiary hospitals in Shanghai, employing qualitative methods that integrated patient journey logs and in-depth interviews to construct a five-stage patient journey map spanning the diagnostic, active treatment, and rehabilitation follow-up periods. The study aimed to elucidate how patients' digital health information behaviors evolve, together with the corresponding emotional changes, and to provide an empirical basis for the development of stage-specific nursing interventions. Specifically, it examined how breast cancer patients seek, evaluate, and use digital health information at different stages of the disease trajectory and how these behaviors relate to their emotional experiences and nursing needs.

Methods

Study design

The study adopted a descriptive qualitative design. Data were analyzed using reflexive thematic analysis (RTA), which is well suited to exploring patterns of meaning across participants' accounts while allowing for iterative interpretation and reflexivity. The study followed the Standards for Reporting Qualitative Research (SRQR) to enhance transparency and rigor. The semi-structured interview guide is included as Supplementary Materials 1.

Participants and recruitment

- The study used convenience and purposive sampling to recruit breast cancer patients from the Breast Surgery Department of a tertiary hospital in Shanghai, China, between August and October 2025. To ensure diverse perspectives, maximum variation sampling was applied, and eligible patients were approached via clinician referrals and ward posters; researchers explained the study, built rapport, and obtained written informed consent. Inclusion criteria were pathologically confirmed breast cancer, age ≥ 18 years, adequate literacy and verbal communication, no clinical evidence of metastasis, and signed informed consent. The final sample size was determined by data saturation, which was assessed continuously during concurrent data collection and analysis. Variation was sought in terms of age, treatment stage, and educational background.

Data collection

According to the research objectives, the study team developed an initial semi-structured interview guide based on literature review, expert consultation, and team discussions. Concurrently, a five-stage patient journey log was designed to systematically record participants' key experiences across different phases. The log consisted of four sections: core questions, digital health information behaviors, emotional experiences, and free notes. The first three sections corresponded to interview themes to facilitate tracking patients' information practices and psychological changes, while the free notes section allowed participants to document important but unaddressed content, thereby comprehensively capturing their authentic experiences throughout the care process.

Before the formal interviews, two breast cancer patients who met the criteria were chosen for pilot testing to see how well the guide worked and how easy it was to use the log. Based on their feedback, the structure and instructions were improved. Formal interviews were conducted face-to-face from August to October 2025, lasting 20–40 minutes each. Locations were selected based on participants' preferences (single-bed rooms or quiet conference rooms), and interviews were conducted by researchers proficient in qualitative approaches. All sessions were audio-recorded, accompanied by simultaneous documentation of nonverbal indicators like facial expressions, tone, and body language to enhance data richness.

Following log distribution, participants were encouraged to first backfill important events and online information-seeking behaviors from the diagnostic and previous treatment periods while researchers personally discussed the five-phase definitions, section meanings, and completion techniques. To accurately reestablish experiencing continuity, real-time recording of new events and instantaneous emotions was encouraged during active therapy and follow-up stages. For patients who had trouble writing, their main caregivers helped them keep track of important times and events by using their cell phones. During hospitalization, researchers conducted daily rounds to monitor log completion, uniformly reviewing and retrieving new entries the following morning; ambiguous or unclear entries were clarified on-site with patients or caregivers. Post-collection, log contents were cross-verified against electronic medical records, with confirmation from primary nurses on critical clinical events and timelines to ensure data accuracy and trustworthiness.

All of the interviews were done in Mandarin Chinese. A bilingual member of the research team translated the selected quotes in this manuscript into English. To preserve meaning rather than literal wording, translations were reviewed and discussed within the research team, and discrepancies were resolved through consensus. All quotations were de-identified prior to analysis and reporting, with references to specific hospitals, clinicians, locations, or other potentially identifying details removed.

Data collection and analysis proceeded concurrently. Saturation was assessed based on the point at which no new codes or themes emerged from successive interviews. During the final two interviews, no substantively new themes were identified, and existing themes were further elaborated rather than expanded. Decisions regarding data saturation and cessation of recruitment were made during regular team meetings involving three researchers.

Data analysis

Data collection and analysis were conducted concurrently. Within 24 hours of each interview, two researchers transcribed the audio recordings verbatim, with a third researcher verifying the transcripts to ensure completeness and accuracy. Subsequently, two researchers used NVivo 12 software to perform reflexive thematic analysis, following principles of induction and iteration. After thorough data familiarization, researchers identified and coded the smallest meaningful units relevant to the primary research questions.

Building on initial coding, similar codes were clustered and condensed into candidate themes, which were iteratively refined and reorganized through multiple team discussions. The team ultimately generated preliminary themes reflecting patients' digital health information behavior evolution across the diagnosis-treatment-rehabilitation continuum: (1) information chaos and uncertainty amplification under diagnostic shock, (2) individualized matching dilemmas in surgical decision-making, (3) excessive referencing and side effect anxiety during treatment experiences, (4) information trust filtering in long-term treatment, (5) digital health behavior internalization and anxiety resurgence in rehabilitation, and (6) cross-stage information behavior transformation characteristics and nursing intervention windows. The systematic development of themes focused on three areas: the inherent meaning of each theme as a separate unit, the connections between themes, and how the themes as a whole affected the overall story of how patients used information. The team held weekly meetings to talk about and introduce changes to the code and framework. This facilitated reflexive dialogue, critical comparison of interpretations, and shared understanding of the evolving analytic framework.

Additionally, two researchers independently analyzed the patient journey logs, focusing on associations between key clinical events and corresponding emotional and information behavior responses. The analysis also identified important experiences omitted from interviews but essential for the journey map, such as patients' emotional responses during treatment and their interactions with healthcare providers. Visualization of the patient journey map was collaboratively completed by the graduate researcher and corresponding author to depict trajectories of digital health information behaviors and emotional dynamics throughout the breast cancer diagnosis-treatment-rehabilitation process.

Rigor and reflexivity

The research team comprised one oncology psychology expert and three nursing graduate students with experience in qualitative research and oncology nursing. Throughout the study, the team maintained ongoing reflexive awareness, critically examining how their professional backgrounds and clinical experiences might influence data collection, participant interactions, and result interpretation. While acknowledging that subjectivity can provide analytical insights, interpretations were grounded in data rather than preconceived assumptions through rigorous team discussions and peer review.

The team created a preliminary framework for the patient journey map during the preparatory stage by combining participatory observation and literature research. To increase trust, data triangulation was used throughout the analysis, cross-referencing electronic medical records, journey logs, and interviews. To confirm the accuracy and clinical relevance of the trip map, six patient representatives, two specialized nurses, and one oncology expert jointly reviewed the final outputs.

Results

The personal and professional characteristics of the participants are presented in Table 1. The five-stage journey map serves as the temporal structure of the results, while the four thematic modules represent cross-cutting analytic lenses applied across all stages.

Table 1
Characteristics of participants (N = 15)

Variables	Groups	N(%)
Age, years	30–45	8 (53.3%)
	46–60	5 (33.3%)
	61–75	2 (13.4%)
Educational Level	Primary or below	3 (20%)
	Junior or senior high school	3 (20%)
	College or above	9 (60%)
Material Status	Single/Widowed	3 (20%)
	Married	12 (80%)
Place Residence	Rural	5 (33.3%)
	Urban	10 (66.7%)
Disease Stage	Early	2 (13.4%)
	Middle	9 (60%)
	Late	4 (26.6%)
Treatment Phase	Diagnosis phase	3 (20%)
	During treatment	8 (53.3%)
	Recovery phase	4 (26.7%)

Characteristics of Participants

The study included 15 women with breast cancer, aged 30 to 75 years, primarily consisting of middle-aged and young people, reflecting the trend of declining age at breast cancer diagnosis. The majority of educational attainment was at the college level or higher (60.0%), encompassing various educational gradients to enable the comparison of digital health information practices across diverse backgrounds. Demographically, 80.0% were married, indicating a stable family support system for the majority, although vulnerable subgroups were also present; urban residents comprised 66.7%, facilitating an analysis of urban-rural disparities in healthcare resources and access to digital health services. Clinically, middle-stage disease represented 60.0% (early: 13.4%; late: 26.6%), indicating variability in tumor staging; the journey phases encompassed diagnosis (20.0%), active treatment (53.3%), and rehabilitation follow-up (26.7%), enabling a thorough depiction of stage-specific digital health information behavior characteristics and transitions to assist in journey map development.

Five-Stage Journey of Digital Health Information Behaviors in Breast Cancer Patients

This study constructed a patient journey map of digital health information behaviors based on breast cancer patients' experiences from initial symptom onset to rehabilitation follow-up, incorporating associated cognitive-emotional changes. The map's horizontal axis delineates five stages aligned with pre-diagnostic symptom perception, diagnosis and decision-making, active treatment, transition and follow-up, and long-term survivorship to illustrate patients' continuous evolution from symptom awareness to chronic disease management. The vertical axis characterizes experiential and behavioral differences across seven dimensions: care and information contact pathways, digital health information behaviors, symptoms and physical sensations, subjective cognition and meaning construction, coping actions, emotional experiences, pain points and nursing needs, all while incorporating influences from key stakeholders at each stage (Fig. 1). This map integrates timelines, critical clinical events, information behaviors, and emotional trajectories to provide a visual basis for identifying intervention windows and optimizing comprehensive digital health support.

Furthermore, the study synthesized mechanisms of digital health information behaviors into four interrelated thematic modules (Fig. 2): A. Digital information environment and exposure (platform ecology, algorithmic recommendations, information quality, and intelligent tools); B. Cognitive-emotional processing (uncertainty, risk perception, trust judgment, and decision conflict); C. Behavior and self-management actions (information retrieval/utilization, self-management, adherence, and behavioral change); D. Outcomes and life impacts (physiological/psychological outcomes, social roles, and economic effects). Although presented separately, these modules interconnect through information input and feedback loops in real-world contexts, repeatedly interweaving across the five stages to form a dynamic "information environment-cognitive & emotional processing-behavioral action-outcome impact" framework.

Theme 1: Digital Information Environment and Exposure Across Five Stages

Pre-diagnostic symptom perception: To learn more about breast abnormalities and assess the risks involved, patients mostly used search engines: “When I first felt a small hard lump, I searched online and saw many cases indicating it was benign, so I thought I’d wait a bit longer” (P3). “The more I looked at home, the more scared I got; I felt all those online symptoms matched mine, so I went to the hospital to be safe” (P7) describes how anxiety and uncertainty increased as symptoms persisted or platform recommendations frequently reinforced malignancy cues.

Diagnosis and decision-making: Patients’ exposure to information increased after emotional shock, such as when they actively sought information on the cancer and its treatments: “After confirmation, I searched about staging, treatment options, survival rates, and the impact of radiotherapy and chemotherapy on life” (P7).

Active treatment: Information needs centered on side effects and lifestyle taboos: “The doctor briefly mentioned nausea and fatigue, so I searched online ‘how to prevent chemotherapy side effects’; seeing people share drinking more water and resting in advance, I noted them down and followed” (P2). “Every day I checked what not to eat during chemotherapy and what to watch out for” (P4).

Transition and follow-up linkage: Patients’ sensitivity to small discomforts increased when fewer clinic interactions occurred, and their perceptions of risk were heightened by search results suggesting recurrence or metastasis: “After discharge, if there is any discomfort anywhere, my first reaction is to search online” (P8). Indicator interpretation and online report checking became routine: “Every blood test result, I’d scrutinize the indicators; if one was slightly high, I’d immediately search what it meant” (P11).

Rehabilitation and long-term monitoring: Platform content increasingly supported lifestyle maintenance: “Now my body is normal; I follow some Xiaohongshu bloggers daily for exercise, and feeling persistence reduces recurrence risk” (P4). However, recurrence cases still push a disrupted sense of security: “Sometimes scrolling to others’ recurrence stories makes me fear it could happen to me too; I tend to overthink” (P12).

Theme 2: Cognitive-Emotional Processing Across Five Stages

Pre-diagnostic symptom perception: Symptom abnormality triggered repetitive rumination. Patients frequently utilized the internet for self-diagnosis, attributing symptoms to inflammation or benign conditions for temporary alleviation; however, encountering search terms such as “malignant” or “tumor” swiftly intensified fear: “During the day I believed I was overthinking, but at night, while lying down, I would ruminate incessantly” (P3). Thus, pre-diagnosis exhibited denial-probing-worry oscillations, gradually transitioning to sustained vigilance and anxiety.

Diagnosis and initial decision-making: Emotions rapidly shifted from shock to intense uncertainty: “After learning it was malignant, my mind kept circling ‘What to do next?’” (P7). Patients thoroughly examined staging, treatment alternatives, and prognosis to reestablish predictability; however, informational inconsistencies and numerous comparisons exacerbated uncertainty, leaving discomfort unresolved.

Active treatment: The cognitive focus was limited to the burdens of side effects and efficacy assessments. Physical discomfort and changes in appearance led to a constant evaluation of the costs of treatment compared to its necessity: “Before each chemotherapy, I would wonder if skipping it might be better, but I feared regretting my decision if I gave up” (P2). Patients were highly sensitive to lab indicators and bodily changes, interpreting minor abnormalities as progression signals, resulting in emotional oscillations between anticipation, anxiety, and exhaustion.

Transition and follow-up linkage: As the treatment intensity decreases, the patient's surface emotions tend to stabilize; however, the fear of recurrence exhibits periodic fluctuations during review points. Tension peaked while awaiting results, briefly relaxed with normal outcomes, and then entered the next worry cycle: “Since getting this disease, every day feels like walking on eggshells” (P11). This cycle of anxiety relief followed by re-anxiety kept patients in a state of chronic vigilance.

Rehabilitation and long-term monitoring: Although constant monitoring of body signals continued, most patients eventually decided to see breast cancer as a chronic illness and integrated self-management into their daily lives: “When checkup results are all normal, I feel slightly reassured, but any odd touch immediately triggers recurrence fears” (P8). Patients reinforced control through diet, exercise, and routine checkups, but case-specific information triggers could rekindle deep concerns, creating a cognitive-emotional landscape where vulnerability and resilience coexist.

Theme 3: Behavior and Self-Management Actions Across Five Stages

Pre-diagnostic symptom perception: Several individuals attempted self-treatment methods, such as relaxation, hot compresses, or vitamins, postponing medical consultation. The actions emphasized were seeking information and adopting a vigilant approach: “Online recommendations suggested increased rest and reduced late-night activity would alleviate it, so I attempted that initially rather than proceeding to the hospital” (P3). At this juncture, information was primarily utilized for self-reassurance and postponing judgments.

Diagnosis and initial decision-making: Behavioral focus shifted to healthcare pathways and treatment selection. Patients purposefully compared hospitals, physicians, and schemes to form decisions: “I first checked breast specialty hospital and doctor reviews online, then saw what surgeries others had on Xiaohongshu before deciding where to treat” (P10). Adherence manifested mainly in timely preoperative tests and admission preparation, though online doubts occasionally caused brief hesitation.

Active treatment: With information retrieval closely linked to dietary restrictions, skin care, and side effect alleviation, self-management significantly increased. Before putting the advice into practice, online experiences were repeatedly cross-checked against medical advice: “I summarized precautions from fellow patients’ Douyin and Xiaohongshu posts, then asked the doctor during rounds which ones were correct” (P2).

Transition and follow-up linkage: Behavioral emphasis turned to self-monitoring and prompt medical seeking. Patients used hospital apps for appointments and result checking, conducting self-palpation and symptom logging between checkups, and seeking care immediately upon doubts: “I felt asymmetry at home, so I first looked for possible causes on DeepSeek and then made an appointment through a mini-program to confirm with the doctor early” (P6). Adherence was evident in timely checkups and rapid responses to warning signals.

Rehabilitation and long-term monitoring: Self-management was incorporated into daily routines. “Within physical limits, I follow bloggers doing Baduanjin at home daily” (P9) is an example of how patients integrated health behaviors into daily routines by consistently recording their exercise, nutrition, and weight control. Long-term maintenance was encouraged by the continuous support and behavioral reinforcement that came from community involvement and experience sharing, which helped patients stay motivated and accountable in their health journeys.

Theme 4: Outcomes and Life Impacts Across the Five Stages

Pre-diagnostic symptom perception: Outcomes primarily involved mild to moderate discomfort and sleep disturbances, with functional limitations not yet pronounced. However, the unresolved question of malignancy potential triggered persistent hypervigilance. Although many patients maintained their routine lifestyles, some began covertly reallocating expenditures and savings to prepare for potential medical costs.

Diagnosis and initial decision-making: Psychological sequelae escalated rapidly, dominated by shock and profound uncertainty, compounded by intensified anxiety, depressive symptoms, and apprehensions about future role functioning. Patients proactively organized work leave, domestic duties, and caregiving logistics while allocating funds for treatment, thereby exacerbating perceptions of financial strain within the family.

Active treatment: The physiological consequences manifested most intensely, including pain, fatigue, hair loss, endocrine disturbances, and noticeable changes that significantly diminished physical endurance and daily activities while undermining self-concept and gender identity; reductions in quality of life were especially pronounced. Cognitively, emotional states fluctuated between fear of negative outcomes, expectation of therapeutic benefits, and persistent fatigue, occasionally leading to inconsistent dedication to treatment. Simultaneous strains on social roles and finances resulted in employment disruptions, alterations in family caregiving dynamics, and persistent expenses that

strained personal relationships and household finances, occasionally requiring the exhaustion of long-term reserves.

Transition and follow-up linkage: Acute symptoms diminished with gradual functional recovery; nevertheless, lingering discomfort, limitations in the upper extremities, menopausal-like symptoms, and sleep difficulties persisted. The emotional focus changed to anxiety about recurrence and heightened sensitivity to test results, resulting in cyclical emotional fluctuations near monitoring appointments. Social role reequilibration occurred, while vocational insecurity persisted; economically, complete restoration to baseline levels remained difficult.

Rehabilitation and long-term monitoring: While most patients recovered essential social skills alongside overall physiological improvement, residual effects such as chronic fatigue, joint pain, weight variability, and endocrine dysfunction continued to undermine health-related quality of life. A psychologically adaptive model of “coexistence with illness” emerged, marked by acute distress reactivation due to recurrence concerns at critical moments. Financial burdens diminished in relation to treatment peaks; nonetheless, ongoing monitoring, medication, and screenings incurred persistent fixed costs, promoting caution in consuming habits and career paths as essential long-term decision-making factors.

Intervention windows across the patient journey

Based on recurring high-risk patterns identified across interview data and journey logs, clear nurse-led intervention windows were delineated across the five stages.

Diagnostic stage

- High-risk information behavior: Unfiltered exposure to fragmented, alarming online information immediately after diagnosis.
- Emotional/decision risk: Acute uncertainty, fear amplification, and difficulty forming an initial understanding of the disease.
- Nurse-executable action: Nurses proactively assess patients’ primary online information sources and provide brief guidance toward reliable, clinically aligned platforms.

Surgical decision-making stage

- High-risk information behavior: Excessive comparison of individualized online narratives and peer experiences regarding surgical options.
- Emotional/decision risk: Decisional conflict, regret anticipation, and delayed or unstable treatment decisions.
- Nurse-executable action: Nurses help patients contextualize online peer stories by clarifying individual applicability and aligning information with clinical recommendations.

Active treatment stage

- High-risk information behavior: Repeated searching for side effects and treatment-related complications during chemotherapy or radiotherapy.
- Emotional/decision risk: Anticipatory anxiety, symptom hypervigilance, and misinterpretation of normal treatment reactions.
- Nurse-executable action: Nurses deliver anticipatory education and timely reassurance to normalize common side effects and correct misinformation.

Long-term treatment and follow-up stage

- High-risk information behavior: Selective trust filtering between professional advice and peer-generated digital content.
- Emotional/decision risk: Inconsistent adherence and fluctuating confidence in long-term treatment plans.
- Nurse-executable action: Nurses reinforce evidence-based guidance while acknowledging patients' experiential knowledge from peer communities.

Rehabilitation stage

- High-risk information behavior: Internalized, repetitive monitoring of symptoms and online searching related to recurrence or long-term prognosis.
- Emotional/decision risk: Recurrence-related anxiety and excessive self-surveillance.
- Nurse-executable action: Nurses guide appropriate symptom appraisal and support patients in balancing self-management with psychological well-being.

Discussion

The study delineates digital health information behaviors across five continuous stages in breast cancer patients, with the resulting patient journey map offering-for the first time, a comprehensive visualization of how digital engagement, emotional trajectories, and self-management behaviors evolve throughout the disease continuum. Inductive thematic analysis revealed four interconnected modules that collectively illustrate recursive feedback loops, showing how the acquisition and interpretation of information gradually influence patients' perceptions of control, emotional regulation, and behavioral adaptation over time. The results immediately pertain to the fundamental research inquiries concerning the methods by which breast cancer patients seek, assess, and utilize digital health information at various illness stages, as well as the interplay between these processes and their emotional experiences and nursing requirements. This research enhances the existing evidence base by adopting a longitudinal journey approach instead of a single-encounter focus, which often isolates specific clinical periods or information activities. The findings indicate that the utilization of digital information by breast cancer patients is a dynamic adaptive process situated within fluctuating emotional and contextual environments. This study enhances existing models of online health information behavior by providing a

time-sensitive framework that directs stage-specific nursing interventions and the design of digital assistance.

Prior research demonstrates that patients' informational requirements and online health information-seeking activities fluctuate along the cancer continuum, with the majority of available studies concentrating on specific clinical stages like diagnosis, active treatment, or survivorship. Chen et al.'s scoping analysis of online health information seekers among breast cancer patients and survivors primarily examined patterns during treatment phases [10]. The subsequent study on young Chinese women, instead, concentrated on diagnostic and early survival behaviors without examining the temporal changes in these behaviors. This study enhances existing literature by outlining a continuous five-stage process from pre-diagnostic symptom evaluation to long-term monitoring, illustrating how digital engagement, emotional reactions, and self-management priorities evolve and accumulate over time rather than manifesting as discrete events. This journey-oriented perspective emphasizes temporal connections between initial information activities and subsequent patterns of vigilance, dread of recurrence, and care-seeking, thus enhancing previous phase-specific descriptions. The findings further verify and enhance evidence that digital health information functions as a double-edged sword for breast cancer patients. Prior study has indicated that online tools can promote disease comprehension, facilitate joint decision-making, and bolster self-management, while simultaneously contributing to information overload, confusion, and heightened anxiety. Duan et al.'s scoping study of patient journey mapping in breast cancer acknowledged digital tools' usefulness in service optimization but identified shortcomings in managing information-induced discomfort throughout whole trajectories [11]. One study indicated that peer-generated survivorship content on social platforms promotes symptom coping but raises recurrence anxieties through anecdotal relapse narratives [12]The present study adds nuance by illustrating how this duality varies by stage: in pre-diagnostic and diagnostic phases, algorithm-driven exposure can both prompt earlier medical consultation and intensify catastrophic interpretations; during treatment and follow-up, peer-generated content facilitates symptom management yet heightens recurrence apprehension and decisional conflict regarding ongoing therapies. The findings refine existing models of online health information behavior by elucidating the sequential progression from information retrieval to cognitive-emotional processing and subsequent behavioral change. Prior frameworks have generally perceived these components as static or linear [13]; however, this study demonstrates that individuals perpetually cycle between evaluation, emotional regulation, and behavioral adjustment as they progress through the stages of illness. The proposed paradigm of "information environment-cognitive-emotional processing-behavior and self-management-outcomes and life impacts" offers a process-oriented and temporally attuned perspective on the application of digital health information by breast cancer patients. This theoretical advancement establishes a basis for creating stage-specific, emotionally responsive nursing interventions that better correspond with patients' changing digital contexts.

In the pre-diagnostic symptom appraisal and diagnosis/initial decision-making phases, patients predominantly operate within domestic and social environments, rendering direct clinical nursing services challenging to deliver; consequently, these stages lend themselves more readily to analysis

through individual-level information processing and decision-making behaviors to discern associated risks and needs. During the symptom appraisal and pre-consultation period, patients frequently resort to self-attributional benign interpretations of symptoms, thereby engendering diagnostic delays. Data from the Canadian RUBY cohort (women ≤ 40 years, n = 1,148) indicate that approximately one-third of young patients delay initial medical evaluation for over 4 weeks post-symptom onset, with attributed factors encompassing “lack of concern/belief in spontaneous resolution,” “awaiting the next menstrual cycle,” “informal benign reassurances from healthcare professionals or medical acquaintances,” and “access barriers compounded by lifestyle conflicts.” [14] This underscores that the pivotal tension in this early phase resides in patients’ translation of disparate online cues into actionable thresholds amid profound uncertainty. A pragmatically viable support trajectory thus entails provision, by hospitals or authoritative entities, of comprehensible public-domain materials elucidating consultation prompts, diagnostic workflows, and risk communications to attenuate the likelihood of self-monitoring–self-reassurance–delayed seeking cascades.

The diagnosis and initial decision-making phase is characterized by heightened emotional turmoil and uncertainty, as patients exhibit urgent requests for information regarding disease nature, treatment options, and prognosis, while simultaneously struggling with confusion and helplessness due to insufficient, excessive, or conflicting information [15]. Simultaneously, considerable data confirms the internet’s significance as a source for breast cancer information, however the content quality is variable, sometimes includes complex terminology, and lacks sufficient critical evaluation skills, leading to misunderstandings or increased worry [16, 17]. In this context, choice aids clearly enhance knowledge acquisition and reduce decisional conflict and regret without increasing anxiety, thereby providing empirical support for structured, tiered decision facilitation during diagnostic peaks.

At the clinical nursing level, research shows that healthcare providers have advantages in sustained engagement and real-time correction across the three post-system-entry phases. This means that digital health information behavior assessment should be a key part of routine nursing evaluations, with stage-specific supports put in place as needed. Specifically, nurses can embed structured inquiries into admission assessments, ward rounds, and follow-up consultations, probing information sources, trust allocations, and usage intents, to gauge mastery of authoritative content while concurrently flagging high-risk patterns such as information overload, compulsive re-searching, algorithm-driven diversions, or substitution of peer anecdotes for medical directives, thereby reframing information-related distress into proactive screening and tiered interventions. A Mexican ePRO non-randomized pilot demonstrated that continuous electronic symptom and support-needs monitoring with feedback correlates with diminished supportive care demands and quality-of-life gains, charting a feasible pathway for early distress detection and linkage during high-burden phases like chemo-radiotherapy [18]. Active treatment-phase nursing thus shifts from generic education to integrated symptom-information-behavior triad interventions: patients heavily rely on unvetted online content for side-effect palliation, potentially leading to ineffective or hazardous actions. Nurses offer symptom-specific self-management procedures to juxtapose patient-reported peer narratives with platform-derived content. Meta-analyses validate that nurse-led mobile health treatments reduce symptom intensity during chemotherapy and

enhance quality of life, highlighting the effectiveness of the nurse-plus-mobile-health model in addressing gaps in outpatient management [19]. During the transition to the survivorship bridging phase, the focus of information shifts to interpreting results and analyzing risk signals, with a tendency to quickly attribute catastrophic outcomes online to slight irregularities noticed at home. Nurses are required to proactively provide explanations of results and individualized discussions about recurrence risk: standardized, comprehensible explanations clarify metric variations, accompanied by psychological support for high-anxiety groups to disrupt negative emotional loops. The Mexican nurse-led ePRO clinical algorithm RCT substantiates these methods in regulating post-treatment vigilance cycles, reducing unnecessary visits by 41% and enhancing interpretive confidence by 67% [18]. In rehabilitation and long-term surveillance, nursing escalates from mere information dissemination to composite emotional regulation and self-management reinforcement; the Danish MyHealth phase III RCT evinced that nurse-led individualized follow-up yields superior breast cancer-specific quality of life in early post-primary-treatment patients, markedly attenuating recurrence fears, anxiety, and depression-while substituting physician contacts with nurse touchpoints [20]. Domestically, prospective RCTs signal that user-profiled “internet-plus-nursing” modalities alleviate postoperative progression/recurrence apprehensions and elevate overall quality of life, affirming digital touchpoints’ viability for nursing continuity [21]. Operationally, standardize telehealth junctures, e.g., short-term post-discharge mood screens, psychological bolstering at pivotal check-ins, and phased lifestyle coaching, with intensified frequencies and referral cascades for high-risk cohorts, effecting a paradigm shift from crisis-reactive to information-triggered prevention.

Strengths and limitations

The principal strength of this study resides in the amalgamation of several data sources, encompassing patient journey diaries, semi-structured interviews, and electronic medical records, along with reflexive theme analysis and visual journey mapping. This methodological triangulation enhances the contextual depth, reliability, and applicability of the findings, enabling the reconstructed patient journey to include both complex experiential details and chronological continuity. Visual mapping enhances the identification of intervention opportunities pertinent to nursing practice and digital health design. However, several limitations should be acknowledged. The study was conducted in a single tertiary hospital in Shanghai, with participants predominantly drawn from an urban, middle-aged, and relatively well-educated population. As a result, the perspectives of rural residents, older adults, and individuals with lower health or digital literacy may be underrepresented, which constrains the generalizability of the findings to more diverse populations. Furthermore, while the journey diary aimed to document ongoing experiences, several segments of the data depended on retroactive recall, potentially introducing recall bias or affective reconstruction. Subsequent investigations utilizing longitudinal or multicenter methodologies may facilitate the validation and expansion of these findings across diverse sociocultural and technological frameworks.

Conclusions

The study delineated five sequential stages of digital health information behavior among women with breast cancer, spanning from pre-diagnostic symptom perception to long-term survivorship, and demonstrated that information practices, emotional trajectories, self-management actions, and life impacts are tightly interwoven and dynamically evolving. Digital health information behavior emerges not as discrete or static events, but as iterative cycles in which repeated exposure to online content continually reshapes uncertainty, risk appraisal, and coping strategies across different disease stages.

By integrating patient journey diaries, in-depth interviews, and electronic medical records, the study identified four interrelated modules, digital information environment and exposure, cognitive–emotional processing, behavior and self-management, and outcomes and life impacts, thereby constructing a dynamic "information environment–cognition/emotion–behavior–outcomes" framework. This framework clarifies how digital information can facilitate symptom understanding, decision participation, and self-management, while simultaneously, in the absence of appropriate guidance, exacerbating information overload, fear of recurrence, and decisional conflict. The findings point out the need for nursing practice to move beyond single-encounter education toward longitudinal, journey-based support that is explicitly embedded within patients' digital realities. At the individual level, this entails integrating digital health information behavior assessment into routine nursing evaluations, providing structured decision support at diagnosis, verifying and contextualizing patient-generated content during active treatment, and using nurse-led telehealth and ePRO tools to manage vigilance cycles in transition and survivorship phases. At the service level, the five-stage journey map offers a practical blueprint for designing stratified, stage-specific digital support packages and nurse-led hybrid online-offline care models that align with patients' evolving needs. Collectively, this study contributes a time-sensitive, process-oriented perspective on the use of digital health information in breast cancer care and furnishes an evidence-informed foundation for developing more precise nursing interventions.

Declarations

Ethical approval and consent to participate

The study was approved by the Medical Ethics Committee of Shanghai Seventh People's Hospital (Approval No. 2024-0156). All participants were fully informed about the study purpose and procedures, the confidentiality measures for protecting their personal information, the voluntary nature of participation, and their right to withdraw at any time without any consequences. Formal interviews were conducted only after written informed consent was obtained from each participant. This study was conducted in accordance with the Declaration of Helsinki.

Consent for publication

Not applicable.

Availability of data and materials

Data is provided within the manuscript or supplementary information files.

Competing interests

The authors declare no competing interests.

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Authors' contributions

Liyao Su and Jihong Yuan contributed to the conceptualization and study design, survey design, provision of research materials, as well as editing, reviewing, drafting, and critically revising the manuscript for important intellectual content, and proofreading. Yancheng Wang and Peilun Ding were responsible for data analysis and interpretation, and contributed to the preparation of research materials. Zizhang Ren contributed to data collection and organization, writing of the initial and final drafts of the manuscript, and provided logistical support. Yongmei Jin conceived the study, participated in survey design, supervised data acquisition, critically revised the manuscript, and served as the corresponding author.

All authors reviewed the manuscript. The authors read and approved the final manuscript.

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Figures

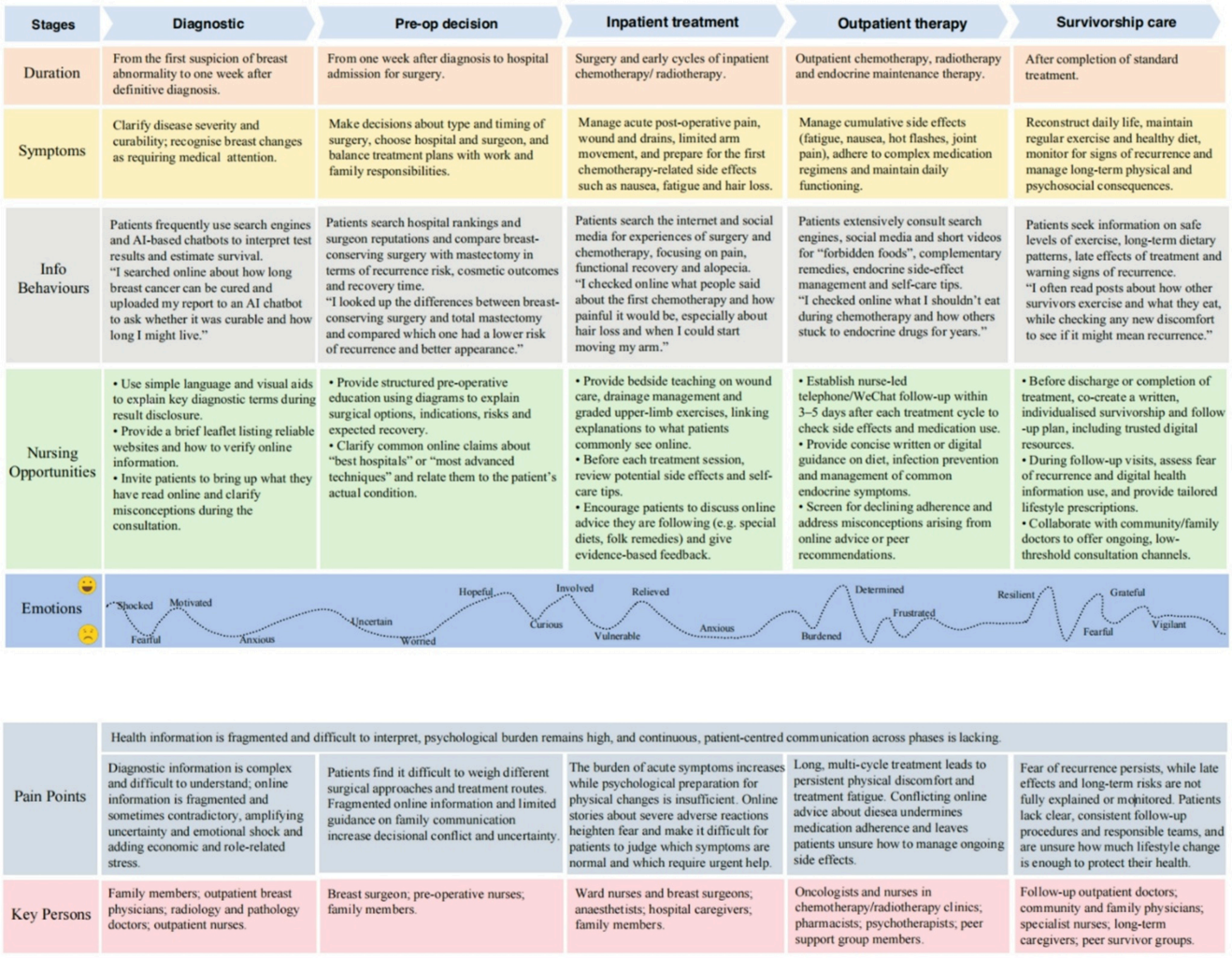


Figure 1

Five-stage patient journey map of digital health information behaviors and nursing opportunities in breast cancer care.

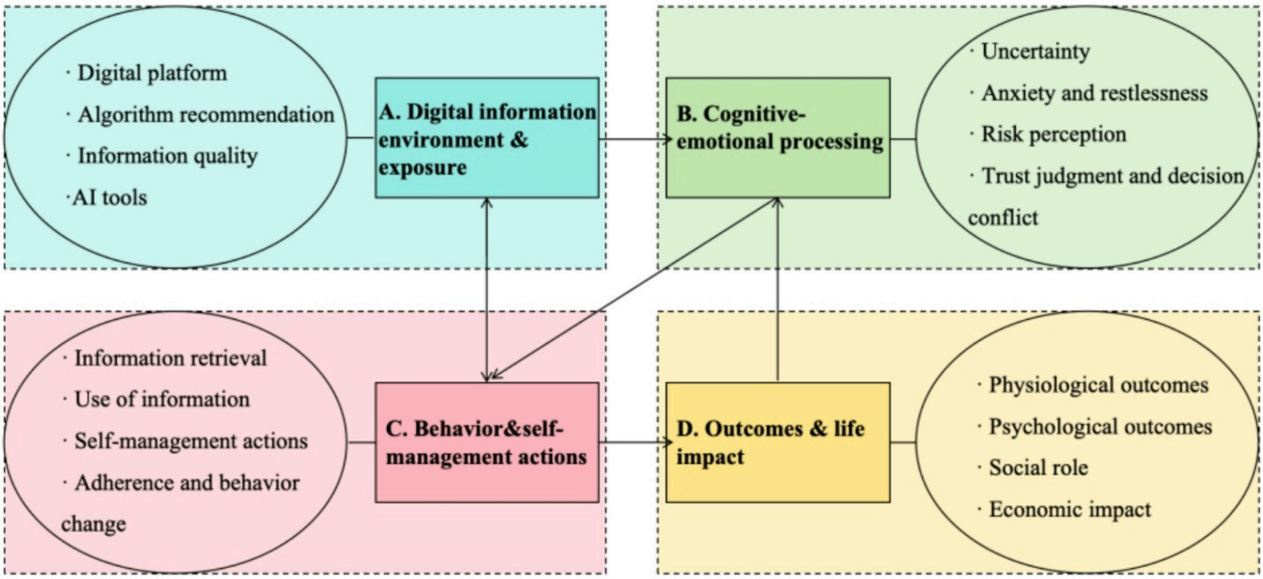


Figure 2

Dynamic framework of breast cancer patients' digital health information use across four interrelated modules

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