

Embodied Visibility, Identity Boundaries, and Relational Negotiation: A Qualitative Study of Digital Illness Narratives Among Chinese Patients With Breast Cancer on Douyin and Xiaohongshu

Bo Deng

Department of Oncology, The Affiliated Hospital of Southwest Medical University

Zhiqiang Wang

Yangtze University Medical School

Xiaoya Li

Yangtze University Medical School

Qingkang Hu

Health Science Center, Wuhan University of Science and Technology

Xiangxue Gao

Department of Surgical Anesthesiology, Xilingol League Central Hospital

Yuchen Yang

Department of Nephrology, Xilingol League Central Hospital

Jing Wang

Department of Surgical Anesthesiology, Xilingol League Central Hospital

Li Yu

879908147@qq.com

Department of Oncology, The Affiliated Hospital of Southwest Medical University

Research Article

Keywords: breast cancer, digital illness narratives, social media, Douyin, Xiaohongshu, qualitative research

Posted Date: October 12th, 2026

DOI: <https://doi.org/10.21203/rs.3.rs-10924997/v1>

License:   This work is licensed under a Creative Commons Attribution 4.0 International License.

[Read Full License](#)

Additional Declarations: No competing interests reported.

Abstract

Background

Breast cancer and its treatment can disrupt identity, family roles, and life trajectories through treatment burdens and bodily changes. Douyin and Xiaohongshu provide spaces for patients to document these changes and negotiate illness identities over time. However, little is known about how breast cancer-specific bodily visibility intersects with identity boundaries, family roles, and digital interaction, or how illness narratives are revised through ongoing posting and response.

Methods

We conducted a constructivist thematic narrative analysis using purposive maximum-variation sampling. Sixteen first-person patient accounts that continuously documented breast cancer diagnosis, treatment, and everyday life on Douyin (n = 9) and Xiaohongshu (n = 7) were included. The dataset comprised 325 illness-related posts (279 videos and 46 image-text posts) and 1,286 closely related comments. Each account's longitudinal posting sequence was treated as the primary narrative case. Analysis included account-level trajectory reconstruction, open coding, within-account longitudinal comparison, cross-account comparison, and theoretical interpretation of embodied visibility, identity positioning, relational experiences, and interaction-driven narrative revision.

Results

Four interrelated narrative positions were identified: disruption of life trajectories, embodied identity negotiation, reconstruction of everyday agency, and relational negotiation and digital connection. Diagnosis and treatment disrupted established life trajectories, while hair loss, breast changes, scarring, and functional limitations made illness tangible and potentially recognizable, shaping body identity, illness identity, and disclosure boundaries. Patients reorganized everyday life through daily activities, family-role adjustments, and digital peer interaction. Videos enabled more immediate presentation of bodily changes and emotions, whereas Xiaohongshu accounts more often combined image-text posts and videos to provide context and retrospective reflection.

Conclusions

Digital illness narratives among patients with breast cancer involved overlapping and shifting positions shaped by illness course, bodily visibility, relationships, and digital interaction. Comments and peer responses contributed to subsequent narrative revision rather than merely responding to existing stories. Nursing practice should address bodily visibility, illness disclosure, family roles, and digital peer

interaction alongside symptoms and psychological distress, while helping patients distinguish personal experience from medical advice.

1 Background

Breast cancer is a major contributor to the global cancer burden among women. GLOBOCAN 2024 data show that female breast cancer accounted for approximately 11.8% of all new cancer cases worldwide in 2024^[1]. The burden of breast cancer is also substantial among Chinese women, particularly younger and middle-aged women, who face life stage-specific challenges related to fertility, family roles, and career development after diagnosis^[2–3]. Its impact extends beyond diagnosis and treatment to rehabilitation, follow-up, recurrence, and long-term survivorship, continually affecting patients' daily lives and social relationships^[4–5]. Hair loss, breast changes, surgical scars, body asymmetry, and functional limitations caused by surgery, chemotherapy, and other treatments affect not only physical appearance and function but also patients' perceptions of bodily integrity and selfhood^[6]. Among younger women, breast cancer and its treatment may further affect fertility decisions, expectations of motherhood, intimate relationships, and future plans. In the Chinese cultural context, post-cancer identity changes are also closely intertwined with family responsibilities, caregiving roles, and social relationships^[2–3]. Breast cancer is therefore not only a biomedical event requiring treatment and follow-up but also a life event that may reshape embodied experience, self-identity, relational roles, and future life trajectories^[3–4].

Disruption of life continuity makes it important to understand how patients interpret and organize their illness experiences. Bury's theory of biographical disruption proposes that serious or chronic illness may disrupt established routines, identity expectations, and assumptions about the future, requiring individuals to reinterpret their experiences and social positions^[7]. In breast cancer, this process is distinctly embodied and relational, as patients renegotiate life after illness across treatment, fertility and motherhood, bodily changes, and family responsibilities^[8]. At the same time, positive identities such as "survivor" or "cancer fighter" do not necessarily align with every patient's self-understanding. Some women modify or reject predefined cancer identities to preserve a sense of self beyond illness and maintain boundaries around private life^[9]. Previous qualitative studies and qualitative meta-syntheses further suggest that acceptance, relational connection, value reappraisal, and self-transformation are often intertwined and change across the illness course and life context^[4, 10]. However, much of this evidence comes from researcher-initiated data such as interviews. When patients choose to discuss illness in naturally occurring settings, how they present their bodies, and how they revise their stories over time remain distinct research questions^[3–4, 6, 8].

Digital media provide a new setting for examining these naturally occurring illness narratives. In China's digital environment, Douyin and Xiaohongshu represent two major spaces for patient-generated content. Douyin is primarily video-based, allowing spoken narration, captions, facial expressions, bodily actions, and medical or family settings to jointly shape illness narratives^[11]. Xiaohongshu combines image-text posts and videos, where titles, text, images, videos, and comment interactions can support more

continuous diary-like documentation^[12–13]. Patient accounts maintained over time may span diagnosis, treatment, rehabilitation, follow-up, and recurrence, giving illness narratives a strong longitudinal structure. After content is posted, peers with similar illnesses and other users may participate through comments, self-disclosure, questions, and advice, while posters may further revise earlier narratives through replies or subsequent posts^[11, 13–14]. Thus, Douyin and Xiaohongshu not only convey health information but also provide distinct media formats through which embodied experiences, identity boundaries, and relational interactions enter digital illness narratives.

Existing digital health research on breast cancer has primarily examined information exchange and social support in online communities^[15–17], treatment experiences and body image in patient-generated videos^[18–19], and social media listening and patient journey research^[12, 20]. Chinese studies have also examined online cancer diaries and individual social media platforms. Research on online cancer diaries has explored cancer framing and psychological characteristics^[21]; studies on Douyin have examined narrative types, identity construction, and user interaction in cancer diaries^[11]; and Xiaohongshu research has begun to analyze illness journeys, emotional meanings, family relationships, and digital illness narratives using patient-generated content and longitudinal first-person posts^[12–13]. Despite this progress, two gaps remain. First, most studies rely on isolated posts, single time points, or cross-user content aggregation, with limited attention to how the same patient repeatedly revises an illness story across diagnosis, treatment, rehabilitation, and follow-up. Second, breast cancer entails salient and gendered forms of embodied visibility. Hair loss, breast changes, scarring, fertility effects, and functional changes may simultaneously shape body identity, illness disclosure, intimate relationships, and family roles. However, how these embodied changes are transformed into identity and relational negotiation through videos, image-text posts, and interactive feedback remains insufficiently understood.

Accordingly, this study used Douyin and Xiaohongshu as digital settings and applied a constructivist thematic narrative analysis to examine how patients with breast cancer organize and revise illness stories across the illness course. Rather than treating isolated posts as the primary unit of analysis, we analyzed each patient's longitudinal posting sequence as a narrative case. We focused on three questions: (1) how diagnosis and treatment disrupt established life trajectories; (2) how breast cancer-related bodily changes enter negotiations of identity and illness disclosure boundaries through embodied visibility; and (3) how family members, peers with breast cancer, and comment interactions contribute to the ongoing construction and revision of illness meanings. Including both platforms increased heterogeneity in media formats and interaction contexts.

2 Methods

2.1 Study Design

This study used a constructivist thematic narrative analysis^[22] to examine digital illness narratives among patients with breast cancer on Douyin and Xiaohongshu. Patients' digital content was treated as

a narrative practice shaped by the illness course, sociocultural norms, family relationships, and platform contexts rather than as a neutral account of illness experience^[23]. Each account's longitudinal posting sequence was treated as the primary narrative case, with attention to temporal organization, narrative turning points, self-positioning, bodily presentation, and interaction-driven revision. During data familiarization and initial coding, we drew on Braun and Clarke's principles of open coding, pattern identification, and reflexive interpretation from reflexive thematic analysis^[24–25] to organize the data. Narrative interpretation was then informed by theories of illness narratives, biographical disruption, stigma, and identity^[7, 26–27], which were used primarily to interpret narrative patterns developed during analysis.

2.2 Data Sources and Sampling Strategy

Data were drawn from Douyin and Xiaohongshu accounts in which Chinese patients with breast cancer continuously documented their diagnosis, treatment, and daily lives in the first person. The two platforms were selected to capture digital illness narratives across different media formats: Douyin primarily uses short videos, whereas Xiaohongshu supports both image-text and video content^[11–13]. Sampling across both platforms was intended to increase heterogeneity in modes of expression and interaction contexts. The search covered publicly accessible content from January 2024 through June 2026. On Douyin, iterative searches used keywords and related hashtags including “breast cancer,” “cancer-fighting diary,” “breast cancer diary,” “breast cancer chemotherapy,” “breast cancer surgery,” and “postoperative breast cancer rehabilitation.” On Xiaohongshu, searches used terms including “breast cancer,” “breast cancer diary,” “chemotherapy diary,” “postoperative rehabilitation,” “endocrine therapy,” and “breast cancer follow-up,” supplemented by platform recommendations and account profiles to identify potential accounts.

Purposive sampling with maximum variation was used to capture observable differences in platform, age, and content format, while prioritizing accounts that provided longitudinal illness narratives. Accounts were eligible if: (1) the poster self-identified as an adult patient with breast cancer receiving care in or residing in China and described illness experiences in the first person; (2) the account continuously posted content related to diagnosis, treatment, rehabilitation, or follow-up, allowing reconstruction of a longitudinal narrative; (3) the longitudinal content contained sufficient narrative detail to identify illness experiences, key events, and changes over time; and (4) the account primarily shared personal illness experiences rather than medical education, product sales, or commercial promotion. Follower count was not an inclusion criterion. Sampling and analysis proceeded concurrently, with new accounts continually assessed to determine whether they expanded existing narrative trajectories, narrative positions, or their variations. Sampling stopped when additional accounts no longer substantively expanded the main narrative positions and the sample provided sufficient variation across age, illness stage, platform, and content format.

The final sample included 16 accounts (S01–S16), comprising 9 from Douyin and 7 from Xiaohongshu. Account holders were aged 29–56 years, and account activity spanned 6–30 months. The content

covered periods of awaiting pathology results, neoadjuvant therapy, surgery, radiotherapy, endocrine therapy, functional rehabilitation, return to work, follow-up, and recurrence or metastasis. We analyzed 325 illness-related posts, including 192 from Douyin and 133 from Xiaohongshu; by format, these comprised 279 videos and 46 image-text posts. From the associated comment sections, 1,286 comments highly relevant to the illness narratives were purposively included: 402 author replies, 468 comments from users who self-identified as having experience with breast cancer, and 416 comments from users who did not report such experience.

Product recommendations, folk remedies, and commercial content were also retained when they directly entered illness-related discussions, as these formed part of the digital interaction context. Purely emoji-based comments, repetitive content, marketing unrelated to the illness narrative, and obvious spam were excluded. Comment collection ended on June 30, 2026. For every included post, researchers reviewed all publicly visible comments and author replies available by that date without imposing a maximum number of comments per post. Eligible comments directly concerned illness experiences, treatment, bodily changes, family relationships, emotional expression, experience sharing, or questions about illness or treatment. Consecutive replies within the same thread were retained when they added interactional context or reflected narrative negotiation.

A standardized multimodal extraction framework was applied across content formats. For videos, we recorded account identifier (ID), posting time point, title, spoken narration, captions, on-screen text, setting, tone, and embodied expression. For image-text posts, we recorded the title, main text, text embedded in images, and narrative-relevant visual information. Hashtags, comments, and author replies were recorded for both formats. Each video or image-text post was treated as a micro-narrative unit, whereas the longitudinal posting sequence of each account served as the primary narrative case. This approach preserved differences in platform-specific content formats while maintaining consistency in account-level longitudinal analysis. Basic characteristics of the included accounts are presented in Table 1. Visual, linguistic, and interactive information was not treated as separate data sources for thematic counting; instead, they were interpreted together within each account’s overall narrative sequence to examine how illness experiences were presented, responded to, and revised.

Table 1
Characteristics and content composition of included breast cancer accounts on Douyin and Xiaohongshu

Account ID	Platform	Sex	Age (years)	Followers (n)	Included content (image-text posts/videos/total)
S01	Douyin	Female	29	236	0/22/22
S02	Douyin	Female	36	1486	0/31/31
S03	Xiaohongshu	Female	42	4932	6/15/21
S04	Douyin	Female	47	682	0/14/14
S05	Xiaohongshu	Female	45	2751	7/19/26
S06	Douyin	Female	39	8964	0/28/28
S07	Xiaohongshu	Female	43	1927	6/14/20
S08	Douyin	Female	46	22634	1/23/24
S09	Xiaohongshu	Female	33	513	5/12/17
S10	Douyin	Female	38	3648	1/18/19
S11	Xiaohongshu	Female	51	1104	5/10/15
S12	Douyin	Female	34	6375	1/22/23
S13	Xiaohongshu	Female	49	2419	5/11/16
S14	Douyin	Female	56	327	1/9/10
S15	Xiaohongshu	Female	40	1763	7/11/18
S16	Douyin	Female	50	4286	1/20/21
Total	—	—	—	—	46/279/325

Note: Follower counts reflect the numbers displayed on account profile pages on June 30, 2026, and are used only to describe basic account characteristics, not for cross-platform comparisons of dissemination performance. “Included content” is presented in the order “image-text posts/videos/total” and refers to breast cancer-related content that met the inclusion criteria and was included in the analysis. Information on age, sex, and disease-related characteristics was derived from public self-disclosures by account holders.

Abbreviations: ID, identifier; n, number of followers.

2.3 Data Analysis

Analysis proceeded through three iterative stages^[13, 24–25]. First, account-level narrative trajectories were reconstructed. All included content from each account was reordered chronologically, with the account rather than the individual post treated as the primary unit of analysis. Key events—including abnormal

findings, diagnosis, treatment, surgery, rehabilitation, follow-up, and recurrence—were mapped, together with narrative turning points, temporal organization, self-positioning, bodily presentation, intended audiences, and comment responses. Open coding was conducted while preserving each account's full chronological sequence. Initial codes remained close to patients' own expressions and captured bodily changes, treatment experiences, emotional responses, family roles, social interactions, self-management, and platform interactions.

Second, within-account longitudinal comparison and cross-account thematic comparison were conducted concurrently. Within-account analysis examined shifts in narrative positions across illness stages, such as movement from disorientation at diagnosis and identity negotiation following bodily changes to later efforts to regain control over daily life and clinical communication. Cross-account comparison identified recurrent narrative patterns and variations across patients. Initial codes were grouped into higher-order themes, with theme boundaries repeatedly refined through negative case analysis.

Third, narrative interpretation and theoretical integration were conducted. Building on the descriptive themes, perspectives on illness narratives, biographical disruption, identity, and digital culture were used to examine how patients organized changes in the body, time, family, and social identity. This process generated four interrelated narrative positions: **disruption of life trajectories, embodied identity negotiation, reconstruction of everyday agency, and relational negotiation and digital connection**. These positions represented modes of meaning-making within particular illness stages and relational contexts rather than four fixed patient types. The same account could move across multiple narrative positions over time or express several positions simultaneously.

Platform and content format were also recorded during cross-account comparison to contextualize how similar illness experiences were presented across media forms. Comments were first categorized by interaction source as author replies, comments from users who self-identified as having breast cancer experience, or comments from other users who did not report such experience. They were then coded by interaction content as emotional support, experience sharing, illness- or treatment-related questions, unverified medical advice, or commercial promotion. Interaction source and interaction content were treated as separate analytical dimensions describing who responded and what function the response served; each comment could therefore be characterized simultaneously by source and content. Patients' spoken narratives, post text, and author replies constituted the core narrative data, whereas other comments were primarily used to interpret public responses and interaction contexts. Analytical decisions were continually refined by returning to complete account sequences, comparing analytic memos, and reviewing negative cases.

2.4 Reflexivity and Research Rigor

A reflexive approach was used to support qualitative research rigor, emphasizing analytical transparency, interpretive reflexivity, and traceability between data and themes^[24-25]. The research team comprised

four researchers with experience in oncology nursing and qualitative research. Two researchers primarily conducted data familiarization, account-level trajectory reconstruction, and initial coding, while all four participated in cross-account comparison, theme development, negative case review, and theoretical interpretation. The study followed the **Standards for Reporting Qualitative Research**^[28]. Records were maintained for sample selection, data extraction, account-level narrative trajectories, analytic memos, and theme development.

Throughout the analysis, the team repeatedly examined theme boundaries, negative cases, and theoretical interpretations, while reflecting on how prior theoretical knowledge, cultural understandings of breast cancer, and platform experience might shape interpretation. Interpretations were checked against the full context through repeated reading, multimodal cross-referencing, within-account longitudinal comparison, and cross-account comparison.

When data did not align with the dominant interpretation, researchers returned to the complete account context and revised the theme accordingly. Basic account information, content identifiers, posting sequences, and linguistic style were also checked for internal consistency to strengthen the traceability of analytical decisions. The results provide sufficient account context, multimodal information, and representative material to allow readers to assess the relationship between the data and interpretations.

2.5 Ethical Considerations

This study analyzed only publicly accessible content from Douyin and Xiaohongshu and involved no direct interaction with account holders or commenters. Under institutional guidance for research using publicly available internet data, the study did not involve activities requiring formal ethics committee review and therefore did not require ethics approval. Because the study involved noninteractive observation and analysis of existing public content without collecting additional personal information, informed consent from account holders or commenters was not required. Data access, collection, and use complied with the platform terms of service and public-access rules applicable during the study period.

To minimize privacy and traceability risks associated with online health data, all accounts were anonymized as S01–S16, and usernames, profile images, precise locations, hospital names, and other identifying information were removed. Representative quotations were translated into English while preserving their original meaning, but accompanying details that could directly identify or enable triangulation of specific accounts were omitted. Commenter information was used only to interpret interaction contexts and not to identify or track individuals. Reporting followed the principle of minimum necessary disclosure, and no combination of information that could enable re-identification of account holders was provided.

3 Results

3.1 Overview

The final sample comprised 16 accounts of women with breast cancer, including 9 from Douyin and 7 from Xiaohongshu. The mean age was 42.4 years (range, 29–56 years). A total of 325 illness-related posts were analyzed, including 192 from Douyin and 133 from Xiaohongshu; by format, 279 were videos and 46 were image-text posts. Accounts had been active for 6–30 months and covered periods of awaiting pathology results, diagnosis, systemic treatment, postoperative rehabilitation, long-term endocrine therapy, return to work, follow-up, and recurrence or metastasis. Account characteristics and included content are presented in Table 1.

In terms of content presentation, Douyin accounts mainly developed longitudinal records through serial videos, spoken narration, captions, treatment milestones, and bodily or clinical settings. Xiaohongshu accounts more often alternated between image-text posts and videos, using titles, main text, and comment replies to provide additional illness context and experiential detail. Despite these differences, both platforms supported continuous documentation, public responses, and interaction with peers with breast cancer. These platform differences were treated as media contexts for digital illness narratives.

Within-account longitudinal analysis and cross-account narrative comparison identified four interrelated narrative positions: **disruption of life trajectories, embodied identity negotiation, reconstruction of everyday agency, and relational negotiation and digital connection**. These positions were not fixed to particular patients. The same account could shift across positions as treatment stages, bodily changes, and relational contexts changed, or could express several positions simultaneously. Narrative positions, subthemes, and representative excerpts are presented in Table 2.

Account-level longitudinal comparison further showed that these narrative positions did not emerge in a uniform sequence but shifted and recurred throughout the illness course. For example, S01 initially expressed dissonance between a healthy identity and a cancer diagnosis while awaiting pathological confirmation, and later connected illness uncertainty with fertility decisions. Through digital interaction with peers of similar age, she gradually developed a sense of shared illness identity and later began organizing questions before follow-up visits and requesting further explanations from clinicians. S02’s narrative shifted from concerns about motherhood and the bodily impact of hair loss after diagnosis to reorganizing family life around treatment schedules, responding to external expectations to “stay strong,” and eventually reframing vulnerability and agency as compatible. These longitudinal trajectories further demonstrated how narrative positions shifted dynamically with the illness course, bodily changes, and relational interactions.

Table 2. Digital illness narrative positions, subthemes, and representative excerpts in breast cancer accounts

Narrative position	Subtheme	Thematic meaning	Representative excerpt
Disruption of life trajectories	Diagnostic dissonance	The diagnosis disrupts continuity between the pre-existing healthy identity and expectations for the future. Younger patients, in particular, juxtapose the illness with unfinished life plans such as marriage, childbearing, and career development.	"I always thought cancer was far away from me. After I got the result, I realized that suddenly I no longer knew what to do with all the things I had planned for the future." [S09-V03]
Disruption of life trajectories	Disruption of everyday life	Treatment cycles become embedded in daily schedules, requiring repeated adjustments to work, caregiving, transportation, and family responsibilities around treatment-related appointments.	"I used to be the one accompanying family members to the hospital; now it's me. For a few days before and after every treatment, everything at home has to be rearranged." [S11-V06]
Embodied identity negotiation	Bodily estrangement	Hair loss, breast changes, scarring, and functional limitations make illness a tangible and visible bodily experience, requiring patients to become reacquainted with their altered bodies.	"The first time I changed clothes by myself and saw that side, I just stood there for a long time. I knew the surgery was necessary, but my body really wasn't the same as before." [S10-V09]
Embodied identity negotiation	Identity boundary negotiation	By controlling to whom, when, and how they disclose their illness, patients maintain boundaries between their cancer identity and other social identities.	"My coworkers asked why I was always wearing a hat. I didn't explain it to everyone. It wasn't that I wanted to hide it; I just wanted to be able to go to work normally sometimes." [S12-V12]
Reconstruction of everyday agency	Emotional reframing	Patients gradually allow fear and fatigue to coexist with everyday life and continue navigating treatment and daily responsibilities by reframing what it means to be "strong" and what it means for the disease to be stable.	"It would be a lie to say I'm not afraid, but being afraid doesn't stop me from going for my follow-up tomorrow. Now I don't expect myself to stay positive every day." [S13-V11]
Reconstruction of everyday agency	Re-routinization of everyday life	Rehabilitation, medication use, return to work, and follow-up visits gradually become part of a regular rhythm of life; repetitive actions help patients maintain everyday order.	"I took half a day off for my follow-up. After the tests, I went back to the office that afternoon. A follow-up used to leave me unable to do anything for days; now it is gradually becoming just one

Narrative position	Subtheme	Thematic meaning	Representative excerpt
			more thing I need to fit into my life.” [S15-P06]
Relational negotiation and digital connection	Reorganization of family roles	Illness changes the division of caregiving responsibilities within the family. While accepting help, patients continue to negotiate the family responsibilities and decision-making authority they wish to retain.	“My daughter keeps telling me to leave everything to her, but I still want to decide for myself what I can do. It’s good to have someone care for me, but I don’t want everything decided for me.” [S14-V08]
Relational negotiation and digital connection	Digital peer support and connection	Patients recognize peers through shared illness experiences and develop reciprocal digital support relationships through help-seeking, exchange of experiences, and ongoing responses to one another.	“Right after surgery, I searched every day for examples of how other people exercised their arms. Now when someone asks me in the comments, I explain the exercises I tried and the pitfalls I encountered. If it helps her avoid some of the same difficulties, that’s enough.” [S16-V12]

Note: In each excerpt code, the number following V or P denotes the sequence number of that content type within the corresponding account.

Abbreviations: S, account code; V, video; P, image-text post.

3.2 Disruption of Life Trajectories: Reorganization of Everyday Life Around Illness Time

This narrative position emerged primarily when diagnosis and treatment entered patients’ everyday lives. Patients organized their stories around a temporal break between “before illness” and “after diagnosis.” Pathology results, treatment dates, and hospital settings not only marked the onset of illness but also reshaped understandings of work, marriage and fertility, family responsibilities, and future plans. As treatment progressed, this disruption could be gradually incorporated into new routines or re-emerge during follow-up or disease progression.

3.2.1 Diagnostic Dissonance

Before diagnosis, several patients interpreted breast lumps, pain, or imaging abnormalities as benign breast changes, menstrual-cycle effects, or inflammation. Pathology results disrupted these benign explanations. Video titles often contrasted age with diagnosis, while close-up narration in hospital

corridors, parking lots, or bedrooms emphasized the immediacy of the event. Rather than recounting medical details, patients repeatedly described being unable to process what they heard, reflecting dissonance between a healthy identity and a cancer identity.

“I was 29. The pathology result came back: breast cancer. I stared at those words for a long time and still felt they were not about me. The doctor said a lot afterward, but I did not take in a single sentence.” [S01-V02]

In these narratives, the pathology report often became a tangible confirmation of illness. Reports with personal information concealed, titles such as “the pathology result is back,” and pauses in narration conveyed the abruptness of diagnosis and the need to shift quickly from “it may just be benign” to treatment and uncertainty about the future.

Among younger patients, this dissonance was also intertwined with unrealized plans for marriage, fertility, and career development. Breast cancer was often juxtaposed with milestones such as “not yet married,” “not yet had children,” or “just starting my career,” extending treatment-related uncertainty into an anticipated future.

“The doctor first asked whether I still wanted children in the future. I suddenly did not know how to answer. I used to think that whether to have children was my choice. Now it suddenly feels as if that choice may no longer be mine.” [S01-V05]

Some mothers spoke less directly about death and instead expressed fear through concerns about their children’s future.

“My first thought was not what would happen to me, but what would happen to my daughter. She had just started first grade. I even began wondering who would do her hair and who would attend parent-teacher meetings.” [S02-V03]

These narratives translated medical risk into concrete family concerns. Patients worried not only about survival but also about whether they could continue participating in their children’s lives, maintaining intimate relationships, and fulfilling family responsibilities.

3.2.2 Disruption of Everyday Life

After diagnosis, treatment time rapidly displaced ordinary life schedules. Patients organized posts around markers such as “first chemotherapy,” “day 3 after chemotherapy,” and “countdown to surgery.” Calendars once filled with meetings, parent-teacher conferences, and travel plans became structured around blood tests, infusions, follow-up visits, and recovery.

“My calendar used to contain meetings and my child’s parent-teacher conferences. Now it shows which chemotherapy cycle I am on, when to have blood tests, and when to get the granulocyte colony-stimulating factor injection. Everything has to make way for treatment.” [S02-V08]

Treatment also reorganized bodily energy. Fatigue, nausea, taste changes, and sleep disruption made ordinary activities such as cooking, commuting, and childcare unpredictable. Some videos showed only unfinished meals, cups of water, or patients lying quietly, while on-screen text such as “even water tastes bitter” conveyed bodily loss of control more directly than extended explanation.

Some patients described treatment burden through transportation, accommodation, work interruption, and health insurance reimbursement. Rather than using the abstract term “financial toxicity,” they counted trips to the hospital or days that family members had to close their businesses.

“After reimbursement, the medication cost is manageable. What really wears us down is making the trip every 21 days. If my husband comes with me for one day, our shop closes for one day. It is not about how much one visit costs; it is that everyday life keeps getting interrupted.” [S04-V05]

Illness also altered family roles. Patients who had previously managed housework, childcare, or care for parents became care recipients, often generating guilt and a sense of burden.

Disruption therefore involved more than altered routines. Work, caregiving, and family arrangements were reorganized around treatment cycles. Serial videos on Douyin and image-text and video posts on Xiaohongshu made these changes visible through everyday details such as transportation, meals, calendars, and household tasks, revealing temporal and role burdens that were less visible in medical records.

3.3 Embodied Identity Negotiation: From Embodied Visibility to Identity Boundaries

Embodied identity negotiation involved more than changes in body image. It concerned how illness became perceptible, visible, and potentially recognizable to others through the body. Hair loss, breast changes, scarring, and functional limitations transformed cancer from a diagnosis in a pathology report into an embodied and socially visible experience. Patients therefore had to reinterpret their changed bodies while deciding when, to whom, and how illness should be disclosed, continually negotiating boundaries among feminine, patient, professional, and intimate identities.

3.3.1 Bodily Estrangement

Hair loss marked an important transition from medical knowledge to embodied illness experience across several accounts. Some patients remained composed when receiving pathology results but became visibly distressed when washing, combing, or shaving their hair. Fallen hair, shaving scenes, and before-and-after comparisons with wigs made an otherwise concealable illness identity more visible.

“I did not cry when the pathology result came back. What really broke me was washing my hair. It came out in handfuls. That was when I finally admitted that I really had cancer.” [S02-V06]

Some patients used humor, rapid editing, or upbeat music when documenting head shaving, yet pauses after laughter still conveyed a loss of control over rapid bodily change. Their concerns extended beyond hair itself to how children, colleagues, and strangers might reinterpret them based on appearance.

Breast surgery further challenged bodily integrity and feminine identity. Although patients understood the necessity of treatment, they still had to confront irreversible bodily change and often resisted simplified statements such as “life matters more than a breast.”

“People say, ‘Your life matters. It is only a breast.’ I know my life matters. But the first time I saw the wound during dressing change, I could not accept that it was my body. It was not about vanity. I simply did not recognize myself anymore.” [S03-V09]

Embodied changes also included less visible but persistent functional impairment. Postoperative arm numbness, tightness, and restricted movement turned routine activities such as combing hair, hanging laundry, and lifting a pan into tasks that had to be relearned.

Over time, some patients no longer treated “returning to my pre-illness body” as the only goal and gradually developed a more acceptable relationship with the changed body.

“I used to avoid looking at myself in the shower. Now I see this scar as part of my body. I do not have to like it, but I do not have to hide from it every day either.” [S03-V15]

This shift did not eliminate bodily loss but reflected a new way of viewing, using, and accepting the treated body.

3.3.2 Identity Boundary Negotiation

Bodily changes and the cancer label led some patients to disclose illness selectively. They might inform only supervisors or close relatives and friends, while using wigs, hats, or clothing to reduce embodied visibility. Such choices reflected active management of illness visibility and disclosure boundaries.

“Only my supervisor knows at work. I wear a wig every day. It is not because I am ashamed of being ill. I just do not want everyone to ask about my condition as soon as they see me, as if there is nothing else about me except this disease.” [S06-V03]

Boundary negotiation was more complex in intimate relationships. Patients faced insecurity related to breast changes while also assessing whether partners genuinely understood these concerns rather than dismissing them with statements such as “I do not care.”

Younger patients repeatedly discussed whether choices about fertility and future relationships still belonged to them. Such videos often attracted comments from patients at similar life stages, whereas simplified responses such as “focus on staying alive first” could reduce long-term life concerns to treatment compliance.

Supportive language could also impose new emotional norms. Comments such as “you must stay strong for your children” or “a positive attitude prevents recurrence” placed pressure on patients to remain positive, making fear, anger, and fatigue harder to express openly.

“‘You have to stay strong for your child’ is what I hear most often. Sometimes I want to say that I really do not want to be strong today, but I worry people will think I have given up.” [S02-V11]

Identity boundary negotiation therefore involved both responses to actual or anticipated judgments and efforts to preserve a self beyond illness. Douyin and Xiaohongshu provided spaces for active disclosure and explanation, but embodied visibility, comment feedback, and continuous posting also prompted patients to repeatedly assess what appearance, emotions, and recovery status they should present.

3.4 Reconstruction of Everyday Agency: Regaining Control of Daily Life Amid Vulnerability

Reconstruction of everyday agency did not frame “defeating cancer” as the endpoint. Instead, repeated activities such as medication use, rehabilitation, return to work, and follow-up gradually repositioned illness within ordinary life. Patients acknowledged persistent pain, fatigue, and uncertainty about recurrence while regaining control by asking questions, completing rehabilitation exercises, and resuming selected work and family activities.

3.4.1 Emotional Reframing

Emotional reframing involved no longer interpreting crying, fear, or temporary withdrawal as failure. Patients increasingly understood “strength” as allowing difficult emotions while continuing with treatment and daily life, rather than maintaining constant positivity.

“I used to think crying meant I was not strong enough. Later I realized that I could cry and still go to chemotherapy the next day. That also counts as being strong.” [S02-V14]

As illness knowledge increased, patients moved from passive acceptance toward active participation. Early videos often included statements such as “the doctor explained a lot, but I did not understand.” Later posts described preparing questions before appointments, documenting adverse effects, and checking treatment milestones.

“The first time the doctor explained the treatment plan, I understood nothing. Now, before every follow-up visit, I write my questions on my phone and ask them one by one. If I do not understand something, I am comfortable asking the doctor to explain it again.” [S01-V12]

This participation reflected greater integration of symptoms, lived experience, and personal values into clinical communication. Statements such as “this is only my experience” and “everyone’s treatment plan

is different” also indicated active boundary-setting around experiential knowledge.

Among patients with metastatic disease, emotional reframing more clearly rejected heroic cancer narratives. Rather than expecting tumor shrinkage at every assessment, they treated disease stability, completing treatment, or having an ordinary day as meaningful outcomes.

“I do not want to be a cancer fighter every day. If I can eat, pick up my child, and sleep well today, that is enough for me. If the scan shows no change, stability is good news.” [S08-V08]

These narratives no longer organized illness around “winning” or “losing.” Stability, treatment completion, and ordinary daily life became acceptable goals, allowing vulnerability and agency to coexist.

3.4.2 Re-routinization of Everyday Life

Re-routinization was repeatedly documented through serial posts. Postoperative exercises, long-term medication, return to work, and follow-up became recurring daily tasks. Time markers such as “postoperative day X” or “day X of medication” helped patients track small changes and gradually incorporate treatment into new routines.

“Postoperative day 82. Ten minutes of wall-climbing exercises again today. I raised my arm a little higher than yesterday. Only a little, but it is still progress.” [S05-V18]

Long-term endocrine therapy was similarly normalized through pillboxes, medication reminders, and nighttime images of insomnia. Although hot flashes, joint pain, and fatigue continued after visible recovery, taking medication gradually became as routine as brushing their teeth.

“Today is day 238 of endocrine therapy. My joints still hurt, but taking the medication has become like brushing my teeth—just something I do every day. It is not to prove how disciplined I am. I just do not want to regret not taking it later.” [S06-V17]

Returning to work helped patients regain identities beyond the patient role, while also revealing reduced physical endurance and challenges related to illness disclosure.

Follow-up visits could temporarily disrupt this new routine. Accounts that usually featured cooking, work, or travel often shifted toward insomnia, repeated online searching, and heightened bodily vigilance as follow-up approached.

“Most of the time I hardly think about cancer anymore, but before a follow-up visit I cannot help it. If my shoulder hurts, the first word that comes to mind is still ‘metastasis.’” [S07-V13]

Re-routinization did not mean that illness disappeared from everyday life. Follow-up, physical symptoms, and long-term treatment could still disrupt established routines, but patients increasingly developed sustainable ways to balance treatment, ordinary activities, and uncertainty.

3.5 Relational Negotiation and Digital Connection: Shared Participation in Illness Narratives

Within this narrative position, the illness story extended beyond the patient. Partners, parents, children, peers with breast cancer, and commenters entered the narrative, transforming breast cancer from an individual biomedical event into a shared experience shaped by family role negotiation and digital interaction. Patients received care and emotional support while also responding to overprotection, enforced positivity, and unverified advice. Some gradually shifted from seeking help to sharing experiential knowledge.

3.5.1 Reorganization of Family Roles

After diagnosis, established caregiving responsibilities within families often changed. Patients who had previously managed housework, childcare, and family arrangements began relying on partners, parents, or siblings for accompaniment and care. Although supportive, this shift could also unsettle their previous family roles.

“I used to organize everything whenever someone in the family was ill. Now my husband remembers my chemotherapy dates, and my mother keeps track of how much I eat every day. Everyone is taking care of me, and I do not know what I can still do.” [S04-V10]

Young mothers did not necessarily withdraw completely from motherhood. When physical capacity declined, some selectively maintained everyday tasks to preserve connection with their children and continuity in their maternal identity.

“After chemotherapy I did not have the energy to play with her, but I still checked her homework every day. It was not about forcing myself to be strong. I just wanted to keep some sense of being her mother.” [S02-V09]

Family caregiving could also create tension. Relatives sometimes restricted housework, outings, or employment out of concern, whereas patients interpreted repeated reminders that they were “patients” as a further loss of autonomy.

“They do not let me do anything because they say I am a patient. But being reminded every day that I am a patient also makes me feel as if I cannot do anything anymore.” [S05-V11]

Over time, caregiving also led some patients to reinterpret family relationships in which emotions had previously been expressed less openly.

Reorganization of family roles therefore involved care, role preservation, and negotiation of autonomy. Patients were not passive recipients of support but continually negotiated responsibility and decision-making across tensions between dependence and independence, and between protection and control.

3.5.2 Digital Peer Support and Connection

Douyin and Xiaohongshu enabled patients to identify others with similar experiences based on age, treatment stage, and bodily changes. Comments such as “me too” and “another sister at the same stage checking in” provided low-threshold peer recognition and a sense of being understood that was often unavailable offline.

“When I saw so many women in their twenties in the comments, it was the first time I felt I was not the only one. I do not know anyone with breast cancer in real life, but here there were suddenly many people who understood.” [S01-V06]

Digital peer support included not only emotional reassurance but also highly contextualized experiential exchange, such as preparation for chemotherapy, wig selection, front-opening clothing after surgery, arm exercises, and communication about returning to work. Patients often qualified such advice with statements such as “this is only my experience” or “follow your own doctor’s advice.”

“Someone asked what to wear after surgery, so I showed the front-opening clothes I used. I am not recommending a product; I genuinely found them convenient at the time. Everyone should prepare according to their own situation.” [S05-V16]

In some accounts, patients shifted from seeking help in comment sections to providing experiential support, including videos created in response to comments from newly diagnosed patients.

“When I was first diagnosed, I asked other people questions every day. Now when someone asks me how to prepare for the first chemotherapy session, I want to pass on the help that others gave me.” [S06-V24]

Comment sections also contained interactions beyond support. Some posts promoted treatment refusal, folk remedies, or supplements, while others attributed recurrence simplistically to attitude or diet. The cessation of posting, disease progression, or death of peers could also create emotional distress. Some authors therefore added statements such as “I do not recommend medications,” “this may not apply to everyone,” or “please consult your own doctor” to distinguish personal experience from medical advice.

For some accounts, digital interaction did more than follow the publication of an illness story; it contributed to its subsequent revision. Patients sometimes reinterpreted their own experiences after reading peers’ self-disclosures and redefined the meaning and limits of those experiences through replies, clarification, or later posts in response to questions, enforced positivity, folk remedies, or commercial content. Digital peer support therefore served both as a source of emotional and experiential support and as a context for ongoing negotiation of identity boundaries, the applicability of experiential knowledge, and illness narratives. At the same time, it introduced risks related to health misinformation, social comparison, and emotional burden.

4 Discussion

4.1 From Embodied Visibility to Interactive Revision: The Dynamic Structure of Digital Illness Narratives in Breast Cancer

This study identified four narrative positions that patients could repeatedly move across during the illness course: **disruption of life trajectories, embodied identity negotiation, reconstruction of everyday agency, and relational negotiation and digital connection**. These positions shifted with illness events, bodily changes, and relational contexts. Hair loss, breast changes, scarring, and functional limitations could make illness socially visible and bring identity and disclosure boundaries into negotiation. Everyday activities, participation in clinical care, and adjustments in family roles could help patients reorganize daily life. Meanwhile, comments, peer responses, and subsequent posts were continually incorporated into and reshaped earlier narratives, making digital illness narratives an iterative process of response and revision rather than one-way self-expression.

Previous Chinese research on digital illness narratives has shown that disruption, stigma, resilience, and solidarity can serve as important meaning-making resources for young people with chronic illness^[13]. Extending this framework, our findings show that in breast cancer narratives, visible bodily changes are closely linked to illness disclosure, feminine identity, and relational negotiation. Breast changes, hair loss, scarring, fertility effects, and changes in intimate relationships shape body identity, motherhood, and relational roles^[3, 6], while also becoming visible, interpretable, and repeatedly reinterpreted through videos, images, text, and comments on digital platforms^[11-13]. Digital interaction therefore becomes part of the ongoing revision of illness meaning.

Within our sample, Douyin accounts more often conveyed embodied experiences through serial videos, voice, captions, and bodily movements, whereas Xiaohongshu accounts more often combined image-text posts and videos to provide illness context, retrospectively document treatment, and support longer reflective narratives^[11-13]. These differences help contextualize how digital illness narratives are shaped by media form.

4.2 Biographical Disruption, Embodied Visibility, and Identity Boundaries

Disruption of life trajectories was primarily expressed through the reorganization of everyday time by medical time. Previous qualitative evidence on breast cancer shows that diagnosis often disrupts identity, life plans, and assumptions about the future, while uncertainty and questions about “returning to normal life” may persist after primary treatment^[4, 29]. In our study, patients frequently organized posts around pathology results, chemotherapy cycles, surgery dates, and follow-up visits, dividing everyday

time previously structured by work, childcare, and family activities into treatment-related intervals. Among younger patients, this disruption was also intertwined with unrealized plans for marriage, fertility, and career development, prompting a reassessment of the anticipated future.

Importantly, temporal markers did not simply signify being controlled by treatment. Serial records such as “chemotherapy cycle X,” “postoperative day X,” and “day X of medication” also divided an unpredictable illness course into more manageable milestones. Completion of treatment did not remove illness time from everyday life; fear of recurrence and scan-related anxiety could re-emerge around follow-up visits^[30-31], whereas returning to work allowed some patients to regain social identities beyond being a patient^[32]. Temporal adjustment after breast cancer therefore involved developing a new rhythm across treatment demands, ordinary life, and illness uncertainty.

Bodily changes made this disruption more tangible. A qualitative meta-synthesis of body image after breast cancer found that patients commonly experience disruption in body image, altered social presentation, and gradual acceptance of the changed body^[6]. In videos, hair loss, head shaving, wigs, and rehabilitation exercises could be shown dynamically; in image-text posts on Xiaohongshu, scars, pathology reports, and rehabilitation processes could also be documented through images and text^[11-12]. Illness thus shifted from medical information in a pathology report to an embodied experience that was perceptible to patients and potentially recognizable to others, with media formats shaping distinct forms of embodied visibility.

Such visibility did not necessarily imply shame. Wearing wigs, limiting workplace disclosure, or restricting access to illness information more often reflected management of illness-related identity boundaries than simple social withdrawal. Previous research has shown that not all women identify with social labels such as “cancer survivor”; some actively modify or reject these identities to preserve continuity of self beyond illness^[9]. Identity reconstruction among Chinese patients with breast cancer similarly involves repositioning illness identity, self-worth, and relational roles^[3]. Selective disclosure in our study showed that patients actively determined when, to whom, and how illness should be visible, preventing cancer from becoming the sole framework through which others understood them.

Digital interaction added emotional pressure to this boundary negotiation. Chinese research on short-video cancer narratives has identified positive “cancer-fighting” discourse and positivity as prominent frames^[11]. In our study, comments such as “you must stay strong for your children” or “a positive attitude will prevent recurrence” were intended as support but could turn positivity into an emotional expectation that patients felt obliged to meet. Nursing practice should therefore avoid treating optimism alone as evidence of successful adaptation; vulnerability, ambivalence, and uncertainty are also legitimate expressions during adjustment. Embodied visibility in digital breast cancer narratives is thus not merely a body image issue but an important link among biomedical illness, social identity, and digital self-presentation.

4.3 Everyday Agency and Re-routinization

Reconstruction of everyday agency showed that long-term adaptation did not require constant optimism or a goal of “defeating cancer.” Some patients with breast cancer distance themselves from singular “survivor” or heroic identities^[9], and qualitative survivorship evidence indicates that persistent symptoms, rebuilding normal life, personal growth, and uncertainty may coexist^[29]. In our study, patients continued treatment and daily activities despite fear, fatigue, or crying, suggesting that vulnerability and agency can coexist within the same adaptive process.

Rehabilitation exercises, long-term medication, return to work, and family activities translated agency into everyday practice. Narrative research on “normality” among cancer survivors describes **“doing normality”** as maintaining identity continuity through repeated everyday activities^[33]. In our study, rehabilitation exercises, medication records, and follow-up check-ins were not merely adherence behaviors; they also helped patients establish new daily rhythms. Although returning to work brought fatigue and disclosure pressures, it also restored social identities beyond being a patient^[32]. Re-routinization therefore did not mean returning to the pre-illness state but incorporating treatment demands into a sustainable everyday order.

Everyday agency was also evident in clinical communication. In some longitudinal account trajectories, patients moved from “not understanding what the doctor said” to preparing questions before follow-up visits, recording adverse effects, and actively requesting clarification. A qualitative systematic review of shared decision-making in breast cancer surgery found that patient participation is shaped by information exchange, values clarification, decision support, and health system factors^[34]. Our findings suggest that bringing embodied experiences and life preferences into clinical communication is part of regaining control. Nurses can support this process by creating space for patients to report symptoms, ask questions, and participate in decisions.

4.4 Connection and Negotiation Within Family and Digital Relationships

Relational connection was particularly evident within families. Breast cancer can alter parenting roles, illness communication, and the distribution of family responsibilities^[35]. In our study, patients who had previously managed housework and caregiving became recipients of care from partners or parents. Some continued limited maternal activities, such as checking their children’s homework during chemotherapy, suggesting that they did not necessarily wish to withdraw from established roles but sought to preserve participation as mothers, partners, or family members within their physical capacity.

Family support also had boundaries. When relatives restricted work, housework, or outings in the name of protection, patients could experience care and reduced autonomy simultaneously. Relational autonomy theory emphasizes that autonomy does not require independence from relationships but

involves the capacity to express values and participate in decisions within them^[36]. This perspective aligns with patients' negotiation across tensions between dependence and independence, and between protection and control. When encouraging family involvement, nurses should also ask which roles and decisions patients wish to retain to reduce the helplessness associated with overprotection.

Digital relationships were built through rapid recognition of similar experiences. A meta-ethnography of peer support in breast cancer found that shared experience can foster mutual understanding, emotional connection, and experiential support aligned with patients' needs^[37]. In our study, expressions such as "sisters" and "me too" enabled patients to identify peers by age, treatment stage, and bodily changes. Some also moved from seeking help soon after diagnosis to sharing experiences with newly diagnosed patients. This reciprocity indicates that digital peer support involves not only information seeking but also shared identity and reciprocal knowledge exchange.

Comment sections contributed to the continued development of illness narratives. Research on online breast cancer support groups has shown that mirroring, observation, imitation, belonging, and alienation can shape how patients understand illness^[38], and patients often seek comparable experiences by asking whether "anyone else is like me"^[39]. In our study, peers' self-disclosures, questions from other commenters, author replies, and subsequent posts continually supplemented earlier narratives, while patients redefined the meaning and applicability of their experiences through interaction. Comment sections therefore became important sites where digital illness narratives continued to develop through posting, response, and revision.

However, digital connection was not inherently beneficial. A realist review of online cancer support groups found that their effects depend on platform environments, group norms, trust, safety, and alignment with patients' needs, and that some interactions may increase psychological distress^[40]. The unverified medical advice, folk remedies, and commercial promotion observed in our study show that boundaries between experiential knowledge and medical advice are not inherently clear. Reviews have similarly identified misleading treatment information and commercialized content as important risks in digital cancer communication^[41]. Patients' use of disclaimers such as "consult your doctor" reflected active efforts to limit the applicability of personal experience.

Peer relationships could also involve loss. Research on support groups for metastatic breast cancer has shown that deterioration or death among group members can cause substantial emotional distress and even lead some patients to avoid support groups^[42]. In our study, prolonged silence in peer accounts, reports of disease progression, or the death of peers similarly triggered worry and grief. Digital breast cancer communities on Douyin and Xiaohongshu may therefore be better understood as low-threshold, highly visible support spaces that provide emotional connection and experiential knowledge while also exposing users to mixed-quality information, social comparison, enforced positivity, and peer loss.

4.5 Implications for Nursing Practice

Our findings suggest that supportive breast cancer care in digital contexts should extend beyond asking patients about symptoms to examining how illness affects bodily presentation, identity, and relational life. Nursing assessment could explore which bodily changes patients find most difficult to adapt to, whether hair loss or breast changes have altered disclosure decisions, which family and occupational roles patients wish to retain, and whether they use social media to document illness experiences or seek illness-related information and support. Evidence from breast cancer survivorship shows that rebuilding normal life, identity change, uncertainty, and needs for social support may persist throughout long-term survivorship^[29]. Such open-ended narrative questions may identify embodied visibility, identity boundaries, role changes, and relational pressures that standardized scales may not fully capture.

Nursing priorities may also be adjusted across the illness trajectory. Early after diagnosis and during treatment, support may focus on information processing, perceived threat to life, fertility, and motherhood. When bodily changes become prominent, greater attention may be given to hair loss, breast changes, scarring, and functional recovery. During rehabilitation or long-term treatment, priorities may shift toward return to work, re-routinization of everyday life, and long-term medication management. Fear of recurrence and scan-related anxiety also warrant attention around follow-up because physical symptoms or surveillance milestones may reactivate perceptions of threat even after patients resume ordinary life^[30-32].

For patients who actively use digital peer resources, nurses should also assess the effects of emotional norms such as “you must stay strong,” as well as the effects of peer deterioration or death, social comparison, and information overload. The value of peer support derives from experiential similarity and reciprocity, but its effects depend on whether interactions match patients’ needs^[37, 40]. Nurses can help patients verify treatment-related information, recognize commercial promotion and potentially misleading health information, and distinguish personal experience from medical advice^[41]. When appropriate, they can also discuss digital disclosure boundaries, including what bodily or treatment-related information patients wish to share and with whom, as well as when reducing exposure to illness-related digital content may be beneficial.

4.6 Strengths and Limitations

A key strength of this study was the use of longitudinal accounts rather than isolated posts as the primary narrative cases, allowing changes in the same patient’s narratives to be traced across illness stages. By including Douyin videos and Xiaohongshu image-text and video content, the analysis integrated spoken narration, captions, main text, text embedded in images, bodily presentation, settings, and comment interactions. This approach captured not only what patients said but also how illness experiences were presented through different media and socially responded to. Author replies and interactions with other users further revealed the relational nature of digital illness narratives.

Several limitations should be considered. Patients who continuously post illness-related content may be more willing to engage in digital expression and self-disclosure and therefore may not represent patients who do not use Douyin or Xiaohongshu or who choose not to discuss illness publicly. All included account holders were women, predominantly younger and middle-aged, so the findings mainly reflect a digitally active group. Publicly available content is itself a selective form of self-presentation and cannot be equated with patients' complete internal psychological states. Although longitudinal account sequences captured changes in public narratives over time, the "narrative shifts" described here refer to changes in publicly expressed positions rather than objective stages of psychological adaptation. Commenters' identities and illness experiences could not be fully verified from public information; therefore, comments were primarily used to interpret interaction contexts. In addition, account holders' age, breast cancer diagnosis, treatment experiences, and disease stage were based on public self-reports and could not be independently verified using medical records or other clinical data; these characteristics were therefore used only for narrative context and sample description.

Including both Douyin and Xiaohongshu increased coverage of video, image-text, and mixed-format content, but the platforms differ in content production, recommendation, and interaction mechanisms. Because sampling was neither matched nor equally allocated by platform, our findings cannot be used to compare the frequency of particular narrative types across platforms or infer causal effects of platform mechanisms on patient expression. We also had no access to platform recommendation algorithms, exposure mechanisms, or nonpublic content. Finally, this study was conducted within a single linguistic and cultural context. Future studies could test these interpretations across other platforms and cultures and by combining online narratives with patient interviews.

5 Conclusions

Digital illness narratives among patients with breast cancer involved narrative positions that shifted dynamically with the illness course, embodied visibility, and relational contexts. Diagnosis and treatment disrupted established life trajectories, while hair loss, breast changes, scarring, and functional limitations transformed illness into an embodied experience that was perceptible to patients and potentially recognizable to others, bringing identity and disclosure boundaries into negotiation. At the same time, patients reorganized everyday life through daily activities, participation in clinical care, and adjustments in family roles, while interactions with peers and commenters contributed to the interpretation and revision of illness stories. Digital breast cancer narratives therefore reflect an intertwined process of meaning-making involving the body, identity, relationships, and digital interaction. In addition to treatment and symptom management, nursing practice should support patients in addressing challenges related to embodied visibility, illness disclosure, family roles, and digital peer interaction, while helping them use online experiential resources safely and critically.

List of abbreviations

ID, identifier; S, account code; V, video; P, image-text post.

Declarations

Ethics approval and consent to participate

This study analyzed only publicly accessible content from Douyin and Xiaohongshu and involved no direct interaction with account holders or commenters. Under institutional guidance for research using publicly available internet data, formal ethics committee review was not required. Informed consent from account holders or commenters was not required because the study involved noninteractive observation and analysis of existing public content without collecting additional personal information.

Consent for publication

Only de-identified, translated excerpts from publicly accessible posts are presented. Usernames, profile images, precise locations, hospital names, and other identifying information were omitted. Informed consent from account holders or commenters was not required for this noninteractive analysis of existing public content.

Availability of data and materials

The source data consisted of publicly accessible posts and comments on Douyin and Xiaohongshu during the study period. Because the compiled analytic dataset contains patient-generated social media content and redistribution could increase traceability and re-identification risks, it is not included with the article.

Competing interests

The authors declare that they have no competing interests.

Funding

This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.

Authors' contributions

B.D.: Conceptualization, Methodology, Investigation, Data curation, Formal analysis, Writing – original draft, Writing – review & editing. Z.W.: Conceptualization, Methodology, Investigation, Formal analysis, Visualization, Writing – original draft, Writing – review & editing. X.L.: Conceptualization, Methodology, Investigation, Data curation, Formal analysis, Writing – original draft, Writing – review & editing. Q.H.:

Investigation, Data curation, Validation, Writing – review & editing. X.G.: Investigation, Data curation, Validation, Writing – review & editing. Y.Y.: Investigation, Data curation, Validation, Writing – review & editing. J.W.: Conceptualization, Methodology, Supervision, Validation, Writing – review & editing. L.Y.: Conceptualization, Methodology, Supervision, Project administration, Validation, Writing – review & editing.

B.D., Z.W., and X.L. contributed equally to this work and share first authorship. J.W. and L.Y. are co-corresponding authors. All authors read and approved the final manuscript.

Acknowledgements

Not applicable.

References

1. Sung H, Filho AM, Laversanne M, Ferlay J, Siegel RL, Soerjomataram I, et al. Global cancer statistics 2024: GLOBOCAN estimates of incidence and mortality worldwide for 34 cancers in 186 countries. *CA Cancer J Clin*. 2026;76(4):e70090. 10.3322/caac.70090.
2. Hu L, Xu B, Chau PH, Lok KYW, Kwok JYY, Choi EPH, et al. Reproductive concerns among young adult women with breast cancer: a systematic review and meta-analysis. *Psychooncology*. 2024;33(8):e9304. 10.1002/pon.9304.
3. Li C, Li J, Rosenzweig MQ, Liu JE. Identity transformation after breast cancer: a qualitative study informed by attention reorientation. *Eur J Oncol Nurs*. 2026;81:103121. 10.1016/j.ejon.2026.103121.
4. Smit A, Coetzee BJ, Roomaney R, Bradshaw M, Swartz L. Women's stories of living with breast cancer: a systematic review and meta-synthesis of qualitative evidence. *Soc Sci Med*. 2019;222:231–45. 10.1016/j.socscimed.2019.01.020.
5. Ciria-Suarez L, Jimenez-Fonseca P, Palacin-Lois M, Antoñanzas-Basa M, Fernández-Montes A, Manzano-Fernández A, et al. Breast cancer patient experiences through a journey map: a qualitative study. *PLoS ONE*. 2021;16(9):e0257680. 10.1371/journal.pone.0257680.
6. Rodrigues ECG, Neris RR, Nascimento LC, de Oliveira-Cardoso EA, dos Santos MA. Body image experience of women with breast cancer: a meta-synthesis. *Scand J Caring Sci*. 2023;37(1):20–36. 10.1111/scs.13102.
7. Bury M. Chronic illness as biographical disruption. *Sociol Health Illn*. 1982;4(2):167–82. 10.1111/1467-9566.ep11339939.
8. Kirkman M, Winship I, Stern C, Neil S, Mann GB, Fisher JRW. Women's reflections on fertility and motherhood after breast cancer and its treatment. *Eur J Cancer Care (Engl)*. 2014;23(4):502–13. 10.1111/ecc.12163.

9. Kaiser K. The meaning of the survivor identity for women with breast cancer. *Soc Sci Med*. 2008;67(1):79–87. 10.1016/j.socscimed.2008.03.036.
10. Saab M, Pi Z. Meanings made in women with breast cancer: a meta-synthesis. *Psychol Health*. 2026;41(8):1219–44. 10.1080/08870446.2025.2509073.
11. Julihati K, Liu Z. Cancer diaries: a study of communication characteristics in cancer patients' illness narratives on Chinese TikTok. *Front Commun*. 2025;10:1634011. 10.3389/fcomm.2025.1634011.
12. Duan Y, Huang Y, Wang L, Da C, Sun Q, Cai T, et al. Thematic patterns of social media content by patient-led breast cancer key opinion leaders: a topic modeling study. *Asia Pac J Oncol Nurs*. 2026;13:100940. 10.1016/j.apjon.2026.100940.
13. Liu Z, Fu D, Liu Y, Meng Y. Digital illness narratives of young Chinese adults with diabetes on RedNote: qualitative narrative analysis. *J Med Internet Res*. 2026;28:e96543. 10.2196/96543.
14. Ziebland S, Wyke S. Health and illness in a connected world: how might sharing experiences on the Internet affect people's health? *Milbank Q*. 2012;90(2):219–49. 10.1111/j.1468-0009.2012.00662.x.
15. Falisi AL, Wiseman KP, Gaysynsky A, Scheideler JK, Ramin DA, Chou WYS. Social media for breast cancer survivors: a literature review. *J Cancer Surviv*. 2017;11(6):808–21. 10.1007/s11764-017-0620-5.
16. Espinoza Suarez NR, Morrow AS, LaVecchia CM, Dugas M, Carnovale V, Maraboto A, et al. Connected and supported: a scoping review of how online communities provide social support for breast cancer survivors. *J Cancer Surviv*. 2026;20(2):415–26. 10.1007/s11764-024-01660-w.
17. Mikal JP, Grande SW, Beckstrand MJ. Codifying online social support for breast cancer patients: retrospective qualitative assessment. *J Med Internet Res*. 2019;21(10):e12880. 10.2196/12880.
18. Morena N, Htite ED, Ahisar Y, Hayman V, Rentschler CA, Meguerditchian AN. Breast cancer vlogs on YouTube: descriptive and content analyses. *JMIR Infodemiology*. 2025;5:e66812. 10.2196/66812.
19. Basch CH, Hillyer GC, Yalamanchili B, Morris A. How TikTok is being used to help individuals cope with breast cancer: cross-sectional content analysis. *JMIR Cancer*. 2022;8(4):e42245. 10.2196/42245.
20. Suter MB, D'Antona R, Mazza M, Francavilla E, Messi A, Maurya A, et al. Exploring the experiences and perspectives of patients with early breast cancer, caregivers, and health care professionals: Italian social media listening study. *JMIR Cancer*. 2026;12:e73371. 10.2196/73371.
21. Yu L, Li Y, Wu C. Cancer framing and psychological characteristics in online cancer diaries: a mixed-methods study in China. *Soc Sci Med*. 2025;377:118120. 10.1016/j.socscimed.2025.118120.
22. Riessman CK. *Narrative methods for the human sciences*. Los Angeles: SAGE; 2008.
23. Esin C, Fathi M, Squire C. Narrative analysis: the constructionist approach. In: Flick U, editor. *The SAGE handbook of qualitative data analysis*. London: SAGE; 2014. pp. 203–16. 10.4135/9781446282243.n14.
24. Braun V, Clarke V. Reflecting on reflexive thematic analysis. *Qual Res Sport Exerc Health*. 2019;11(4):589–97. 10.1080/2159676X.2019.1628806.

25. Braun V, Clarke V. Toward good practice in thematic analysis: avoiding common problems and be(com)ing a knowing researcher. *Int J Transgend Health*. 2023;24(1):1–6. 10.1080/26895269.2022.2129597.
26. Frank AW. *The wounded storyteller: body, illness, and ethics*. Chicago: University of Chicago Press; 1995.
27. Goffman E. *Stigma: notes on the management of spoiled identity*. Englewood Cliffs, NJ: Prentice-Hall; 1963.
28. O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. Standards for reporting qualitative research: a synthesis of recommendations. *Acad Med*. 2014;89(9):1245–51. 10.1097/ACM.0000000000000388.
29. King R, Stafford L, Butow P, Giunta S, Laidsaar-Powell R. Psychosocial experiences of breast cancer survivors: a meta-review. *J Cancer Surviv*. 2024;18(1):84–123. 10.1007/s11764-023-01336-x.
30. Mardani A, Maleki M, Hanifi N, Turunen H, Vaismoradi M. Coping strategies for fear of cancer recurrence among breast cancer survivors: a systematic review and thematic synthesis of qualitative studies. *Support Care Cancer*. 2025;33(6):459. 10.1007/s00520-025-09503-9.
31. Bui KT, Liang R, Kiely BE, Brown C, Dhillon HM, Blinman P. Scanxiety: a scoping review about scan-associated anxiety. *BMJ Open*. 2021;11(5):e043215. 10.1136/bmjopen-2020-043215.
32. Zhang L, He W, Zhu X, Deng J, Liang M, Zhang H. Psychological changes among breast cancer patients completed treatment and factors influencing their return to work during rehabilitation: a qualitative study. *Work*. 2026;83(2):500–8. 10.1177/10519815251375813.
33. Plage S. Deploying normality: cancer survivor identity and authenticity in ritual-like practice. *Med Anthropol*. 2021;40(5):473–89. 10.1080/01459740.2021.1909582.
34. Zheng H, Yang L, Hu J, Yang Y. Behaviour, barriers and facilitators of shared decision making in breast cancer surgical treatment: a qualitative systematic review using a 'Best Fit' framework approach. *Health Expect*. 2024;27(2):e14019. 10.1111/hex.14019.
35. Tavares R, Brandão T, Matos PM. Mothers with breast cancer: a mixed-method systematic review on the impact on the parent-child relationship. *Psychooncology*. 2018;27(2):367–75. 10.1002/pon.4451.
36. Shih P, Rapport F, Hogden A, Bierbaum M, Hsu J, Boyages J, et al. Relational autonomy in breast diseases care: a qualitative study of contextual and social conditions of patients' capacity for decision-making. *BMC Health Serv Res*. 2018;18(1):818. 10.1186/s12913-018-3622-8.
37. Clougher D, Ciria-Suarez L, Medina JC, Anastasiadou D, Racioppi A, Ochoa-Arnedo C. What works in peer support for breast cancer survivors: a qualitative systematic review and meta-ethnography. *Appl Psychol Health Well Being*. 2024;16(2):793–815. 10.1111/aphw.12473.
38. Montali L, Zulato E, Frigerio A, Frangi E, Camussi E. Mirroring, monitoring, modelling, belonging, and distancing: psychosocial processes in an online support group of breast cancer patients. *J Community Psychol*. 2022;50(2):992–1007. 10.1002/jcop.22696.

39. Sillence E. Giving and receiving peer advice in an online breast cancer support group. *Cyberpsychol Behav Soc Netw*. 2013;16(6):480–5. 10.1089/cyber.2013.1512.
40. Bender JL, Scruton S, Wong G, Squires LR, Babinski S, Englesakis M, et al. How cancer online support groups work, for whom, and in what circumstances: realist review. *J Med Internet Res*. 2026;28:e77445. 10.2196/77445.
41. Loeb S, Langford AT, Bragg MA, Sherman R, Chan JM. Cancer misinformation on social media. *CA Cancer J Clin*. 2024;74(5):453–64. 10.3322/caac.21857.
42. Mackie GM, Boyle F, Lewis S, Smith AL. Finding my tribe: a qualitative interview study of how people living with metastatic breast cancer perceive support groups. *J Cancer Surviv*. 2026;20(1):107–22. 10.1007/s11764-024-01639-7.