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REVIEW

Post-Treatment Perspectives on Health Literacy and the Misperception of Breast Cancer Recurrence Risk: A Scoping Review

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Abstract

Introduction: Many breast cancer survivors continue to experience emotional challenges after completing treatment. Fear of cancer recurrence (FCR) and misperception of recurrence risk, including both overestimation and underestimation, can shape survivors' well-being and influence how they participate in follow-up care. Health literacy (HL), defined as the ability to find, understand, and use health information, plays an essential role in how survivors interpret health messages and make decisions about their ongoing care. However, the connection between HL and recurrence risk misperception has not been clearly synthesized. This scoping review maps existing patterns and associations, rather than causal relationships, between HL, FCR, and recurrence risk misperception among post-treatment breast cancer survivors. **Materials and Methods:** Guided by the Joanna Briggs Institute framework and PRISMA-ScR guidelines, searches were conducted in PubMed, Scopus, CINAHL, ScienceDirect, and grey literature from January 2010 to April 2025. Studies were included if they involved adults in the post-treatment phase and examined HL alongside cognitive or emotional outcomes related to recurrence. **Results:** Thirteen studies met the inclusion criteria, most using cross-sectional designs across the United States, Europe, and Asia. Many survivors overestimated their recurrence risk and demonstrated low HL, especially older adults and individuals with lower educational attainment. HL was consistently linked to more accurate risk understanding and, in some studies, mediated the effects of FCR on functional recovery. **Conclusion:** HL is a meaningful and modifiable factor that influences how survivors understand and cope with the possibility of cancer returning. Strengthening survivorship communication and developing culturally responsive patient education strategies may help survivors feel more informed, supported, and confident as they navigate life after treatment.

Keywords: Health Literacy- Breast Cancer Survivors- Recurrence Risk Misperception- Fear of Cancer Recurrence

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Introduction

Breast cancer continues to be the most frequently diagnosed malignancy among women worldwide, representing 11.7 percent of all cancer cases and affecting more than 2.3 million women in 2020 [1]. Improvements in early detection and treatment have increased long-term survival, resulting in a rapidly expanding population of breast cancer survivors. However, the transition from treatment to survivorship is frequently accompanied by emotional challenges, particularly fear of cancer recurrence (FCR). This concern affects 39–70 percent of survivors and can disrupt quality of life, daily functioning, and engagement in follow-up care [2, 3]. A related yet distinct concept is recurrence risk perception, which refers to how survivors interpret their likelihood of experiencing recurrence. This perception often diverges from clinical estimates and may contribute to heightened distress when risk is overestimated or reduced vigilance when risk is underestimated [4].

Health literacy (HL) plays an essential role in shaping survivors' understanding of recurrence-related

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information. HL encompasses the ability to locate, interpret, evaluate, and apply health information in everyday decision-making [5]. Low HL has been associated with challenges in navigating survivorship information, misinterpretation of recurrence risk, and less effective communication with clinicians [6, 7]. Recent conceptual developments in cancer-specific health literacy emphasize the importance of numeracy, critical appraisal of probabilistic information, and emotional self-regulation throughout the survivorship continuum.

The relationship between HL and recurrence risk perception can be understood through behavioral frameworks such as the Health Belief Model and the Self-Regulation Model. The Health Belief Model highlights perceived susceptibility, perceived severity, and cues to action as determinants of how survivors interpret recurrence information. The Self-Regulation Model explains how individuals form cognitive and emotional representations of illness, which are shaped by their ability to understand and use health information.

Survivors' health literacy and risk perception are also influenced by sociocultural and socioeconomic factors such as educational background, cultural norms, stigma, family decision-making patterns, and economic barriers. Research shows that these contextual factors can widen disparities in HL and shape how women interpret their recurrence risk.

Existing studies vary widely in methodologies, populations, and measurement tools, resulting in considerable heterogeneity in how HL, risk perception, and FCR are assessed. This variability limits comparability and conceptual integration across studies.

To date, no scoping review has comprehensively mapped how HL influences recurrence risk perception among post-treatment breast cancer survivors while also examining sociocultural influences, theoretical foundations, and measurement variability. Given the emerging and multidisciplinary nature of this topic, a scoping review is the most suitable approach. Guided by the Joanna Briggs Institute methodology for evidence synthesis [8] and the PRISMA Scoping Review guidelines [9], this review aims to explore the breadth of available evidence, clarify conceptual linkages, and identify gaps that may inform future research, clinical practice, and policy development.

The objective of this scoping review is to map the literature on how health literacy relates to recurrence risk awareness among post-treatment breast cancer survivors, with emphasis on theoretical frameworks, sociocultural influences, measurement variability, and implications for survivorship care.

Methods

Study Design and Framework

This scoping review was conducted to provide a broad and structured overview of how health literacy and recurrence risk awareness are described among breast cancer survivors after completing treatment. The methodological approach was informed by the Arksey and O'Malley framework and enriched with refinements proposed by Levac and colleagues, which emphasize clarity, reflexive refinement, and thoughtful engagement throughout the review process [10]. The reporting adhered to the PRISMA-ScR checklist to ensure a transparent and fully documented workflow.

Although scoping reviews do not require preregistration, this review acknowledges that no protocol was registered and provides this clarification to enhance methodological transparency.

Stakeholder consultation, recommended as an optional step by the original framework, was not undertaken. This decision is noted explicitly to clarify the scope and intention of the review and to remain aligned with JBI expectations for optional steps.

Eligibility Criteria

Eligibility criteria were structured using the Population–Concept–Context (PCC) framework recommended by the Joanna Briggs Institute. The Population consisted of adults with a history of breast cancer who had completed primary treatment. The Concept focused on post-treatment health literacy, recurrence-related understanding, and risk awareness. The Context was open to all survivorship settings, including outpatient follow-up care, survivorship clinics, and community-based contexts.

Eligible sources included empirical studies employing qualitative, quantitative, or mixed methods, as well as relevant reviews and grey literature published from January 2010 to April 2025. Only English-language publications were included. Studies were excluded if they focused solely on diagnosis, active treatment, pediatric populations, or non-human subjects.

All publications listed with 2025 dates were carefully verified, and those included in the review were confirmed as early-online publications (Epub ahead of print), ensuring citation accuracy.

Information Sources and Search Strategy

A comprehensive search was performed in PubMed, Scopus, CINAHL, and ScienceDirect. Additional searches were carried out in Google Scholar and grey literature repositories including OpenGrey and ProQuest Dissertations & Theses Global. To broaden the search further, reference lists of included studies were also screened.

Searches were completed on April 10, 2025. All strategies were developed in close collaboration with an experienced health sciences librarian. Keywords and MeSH terms related to breast cancer, recurrence, health literacy, survivorship, and risk perception were combined using Boolean operators.

To address concerns about restrictiveness, the Boolean search was pilot-tested in advance to assess sensitivity and ensure that the approach captured a broad yet relevant range of studies. Additional synonym mapping and keyword validation were conducted with librarian support to strengthen inclusivity and minimize the risk of missing relevant literature. The complete search strings are provided in the Appendix to support reproducibility and methodological openness.

Selection of Sources of Evidence

All database records were imported into EndNote for deduplication and organization. Screening took place in two stages. First, two reviewers independently screened titles and abstracts using the predefined PCC criteria. Second, full texts were reviewed for final inclusion. Any disagreements were resolved through discussion, with a third reviewer available if needed.

Data Charting Process

A structured data charting form was developed and refined through a small pilot test on several included studies to ensure clarity and usability. The data charting captured key study features such as publication characteristics, methodological design, population details, measurement approaches, and findings related to health literacy and recurrence risk awareness. Charting was completed by two independent reviewers, and any inconsistencies were resolved through discussion to maintain accuracy and coherence.

Synthesis of Results

The synthesis combined descriptive numerical summaries with thematic exploration. Descriptive summaries highlighted trends in study characteristics such as publication year, geographic distribution, and study design. Thematic synthesis identified recurring concepts related to survivors' understanding of recurrence risk and their health literacy pathways.

Consistent with JBI guidance for scoping reviews, formal critical appraisal was not performed, as the objective was to map existing knowledge rather than evaluate study quality. This methodological choice is acknowledged and further discussed as a limitation in the Discussion section.

Ethical Considerations

This review involved no original data collection or interaction with human participants. All data were derived from publicly available sources; therefore, ethical approval was not required.

Results

Searching Results

A total of 511 records were identified through comprehensive searches of four databases (PubMed, Scopus, CINAHL, and ScienceDirect, n = 472) and supplementary sources (Google Scholar, OpenGrey, ProQuest; n = 39). After removing 75 duplicate records, 436 titles and abstracts were screened. Of these, 248 were excluded for not meeting inclusion criteria. The remaining 188 full-text articles were sought for retrieval, of which 10 could not be accessed. A total of 178 full-text articles were assessed for eligibility. Following full-text screening, 165 reports were excluded for reasons including irrelevance to the post-treatment phase (n = 85), lack of evaluation of health literacy or recurrence risk perception (n = 47), and not meeting language or publication date criteria (n = 33). Thirteen studies were included in the final review.

Characteristics of Included Studies

The thirteen included studies represented diverse geographical regions, methodological approaches, and participant populations. Most studies used cross-sectional survey designs, although one applied a mixed-methods approach and another used mediation analysis. Sample sizes ranged from fewer than 100 participants to more than 13,000.

Populations spanned breast cancer survivors in the post-treatment phase, long-term survivors, women with a family history of breast cancer, and general female samples. Studies were conducted in the United States, Norway, Ireland, Hungary, Iran, China, Hong Kong, and Europe, illustrating a wide range of cultural, socioeconomic, and health system contexts relevant to understanding health literacy and risk perception.

Health literacy was assessed in eight studies using various instruments such as the Brief Health Literacy Screen (BHLS), the Health Literacy Questionnaire (HLQ), and the Health Literacy for Iranian Adults (HELIA). Prevalence of low HL varied substantially from 22 percent in Norway to 90 percent in Iran highlighting clear geographic and sociocultural differences. Common predictors of low HL included older age, lower education, and poorer self-rated health. Several studies also examined recurrence risk perception using structured scales or self-assessed estimates, with a consistent tendency toward overestimation of recurrence risk among survivors and general populations (Table 1).

Key Findings

Health Literacy Patterns and Geographic Variation

Across the included studies, health literacy varied markedly across countries and demographic groups. Higher-income settings demonstrated lower prevalence of inadequate HL, while middle-income contexts showed substantially higher limitations, reflecting both structural and cultural factors. Beyond geographic differences, consistent individual-level predictors such as aging, lower educational attainment, and poorer health were observed across multiple studies.

Measurement heterogeneity emerged as a notable issue.

The HLQ captured multiple domains of functional, communicative, and critical literacy; the BHLS measured brief self-reported comprehension; and HELIA assessed numeracy and appraisal. These differences limited comparability across studies and contributed to divergent HL prevalence estimates.

Risk Perception and Fear of Recurrence

A prominent pattern across studies was the widespread overestimation of recurrence risk. Between 41 and 61 percent of survivors believed their recurrence risk to be higher than clinically estimated, and accuracy was even lower in several general population samples. Determinants

Table 1. References

First Author and Year	Country of Region	Study Design	Participant Characteristic	Sample Size	Key Findings Related to Health Literacy	Key Findings Related to Risk Perception
Rosenberg et al. (2025) [11]	USA	Cross-sectional survey (patient-reported outcomes)	Women with hormone receptor-positive breast cancer, post-treatment	Not specified	Not focus; literacy inferred from knowledge/perception	Approximately 45% of patients underestimated their recurrence risk; 15% reported low knowledge about recurrence
Vandraas et al. (2022) [12]	Norway	Cross-sectional, nationwide survey	Long-term breast cancer survivors	1355	22% of participants had low HL; low HL significantly associated with older age (OR=1.45, 95% CI 1.21–1.72). Low education and poor self-report health	Not applicable (no direct risk perception/FCR outcome)
Kelly et al. (2011) [13]	USA (Appalachian region)	Cross-sectional	Cancer survivors (mixed types), including breast cancer	263	Not reported	Strong positive correlation between risk perception and recurrence worry ($r = 0.62$. $p<0,001$)
Burris et al. (2012) [14]	USA	Cross-sectional	Breast cancer survivors, post-treatment	181	Not reported	73% believed behavioral changes (e.g. exercise, diet) reduced recurrence risk ; those who held these beliefs were more likely to engage in preventive actions ($p<0,05$)
Zhu et al. (2025) [15]	China	Cross-sectional, mediation analysis	Breast cancer survivors, return to work study	314	HL significantly mediated the relationship between FCR and return-to-work (indirect effect $\beta = -0.024$. $p<0,05$)	FCR negatively associated with return-to-work ($\beta = -0.31$, $p < 0.001$); HL buffered this effect
Lee et al. (2018) [4]	USA	Mixed-methods (survey and qualitative interviews)	Women with early-stage breast cancer, post-treatment	400	Not reported	41% of patients overestimated their recurrence risk; younger women (<50) and lack of provider discussion were significant predictors of misperception (OR=1.82 95% CI 1.15–2.87).
Lambertini et al. (2025) [16]	Europe (multi-country)	Cross-sectional survey (ASKHER2)	Women with HER2-positive early breast cancer (mixed stages of care)	2631	Not reported	61% overestimated risk of recurrence; higher misperception associated with lower shared decision-making
Ziner et al. (2012) [17]	USA	Cross-sectional	Breast cancer survivors	223	Not Aplicable	Younger age at diagnosis associated with higher FCR and lower self-efficacy ($p < 0.05$)
Poon et al. (2023) [18]	Hong Kong	Cross-sectional	General female population (not survivors)	1093	Low HL associated with higher perceived barriers ($p < 0.001$)	Low HL participants were more likely to overestimate their breast cancer risk (OR = 1.83)
Coughlin et al. (2022) [7]	USA	Secondary data analysis (BRFSS survey)	Cancer survivors (all types)	13126	Approximately 25% had low HL; associated with lower preventive service use	Not measured
Rutherford et al. (2018) [19]	Ireland	Cross-sectional	Women with family history of breast cancer attending a risk clinic	86	37% had inadequate HL; HL strongly correlated with accurate risk perception ($r = 0.55$, $p < 0.001$)	Participants with low HL overestimated their risk of breast cancer
Rakhshkhorshid et al. (2018) [20]	Iran	Cross-sectional	General female population	260	90% of women had low HL	Low HL associated with lower knowledge and lower screening behaviour
KovÃ¡cs et al. (2025) [21]	Hungary	Cross-sectional	Women from general population	624	Low HL significantly predicted inaccurate risk perception ($p < 0.001$)	Only 18% of participants correctly estimated their breast cancer risk

of misperception included younger age, limited patient–provider communication, and low health literacy. Inaccurate risk perception was consistently associated with heightened fear of recurrence, reduced self-efficacy, and challenges in navigating survivorship care.

Interrelationship Between Health Literacy and Risk Perception

Across studies, a consistent relationship emerged in which lower HL predicted greater inaccuracies in recurrence risk estimation. Health literacy influenced both cognitive understanding and emotional responses. For example, HL mediated the relationship between fear of recurrence and return-to-work outcomes, and women with lower HL were significantly more likely to overestimate their cancer risk. These findings suggest that HL functions as a central mechanism through which survivors interpret and make meaning of recurrence information.

Cross-Study Patterns and Integrated Themes

Synthesizing results across the evidence base revealed several recurring themes:

(1) limited HL was consistently linked to inaccurate risk perception;

(2) misperceived risk often amplified psychological burden and influenced survivorship behaviors;

(3) provider communication emerged as a key determinant of survivors' understanding;

(4) sociocultural and health system contexts shaped both HL and risk-related beliefs.

Together, these themes emphasize the importance of considering individual and contextual factors when addressing recurrence-related concerns in survivorship care.

Null and Omitted Findings

Several studies presented outcomes related to understanding, communication, or behavior but did not formally report HL measures, despite discussing HL-relevant constructs. Similarly, some studies examined recurrence perception but did not quantify risk accuracy. These gaps suggest inconsistencies in operational definitions and reporting practices, potentially limiting evidence completeness.

Discussion

This scoping review aimed to map and synthesize existing evidence on post-treatment perspectives regarding health literacy (HL) and risk awareness of breast cancer recurrence, focusing on survivors and women at risk across diverse global contexts. Using the Joanna Briggs Institute (JBI) framework and PRISMA-ScR guidelines, thirteen studies published between 2011 and 2025 were analyzed. The review reveals converging evidence that both HL and risk perception are critical and often interlinked factors in shaping psychological, behavioral, and functional outcomes after breast cancer treatment. These findings resonate with prior systematic reviews in psychosocial oncology, which similarly highlight HL and risk misperception as influential determinants of survivorship outcomes.

Health Literacy as a Foundational Determinant

A central thematic finding across the included studies is the pivotal role of HL as a modifiable determinant in survivorship care. Low HL was frequently associated with older age, lower educational attainment, and reduced engagement in preventive health behaviors [7, 12]. More than one study demonstrated a direct link between HL and key survivorship outcomes, such as the ability to return to work [15], accurate risk comprehension [19], and psychological self-efficacy [17]. Despite heterogeneity in measurement tools, the collective evidence underscores HL not merely as a knowledge deficit but as a determinant of agency, informed decision-making, and health system navigation. This aligns with broader HL research, which shows that numeracy, appraisal skills, and communication capacity influence how patients process complex cancer-related information.

The Miscalibration of Risk Awareness and Fear of Recurrence

Another consistent finding was the widespread overestimation of recurrence risk, reported in 41–61% of survivors [4, 16]. Misperception was especially pronounced among younger women, those with limited provider communication, and individuals with lower HL [11, 18]. These patterns align with earlier psychosocial oncology literature, which suggests that inadequate communication about prognosis can exacerbate fear of cancer recurrence (FCR), regardless of clinical risk status [13]. Notably, accurate perception is not merely a matter of information transfer; it is deeply shaped by personal experiences, emotional states, and sociocultural frames of understanding. This review strengthens that evidence by highlighting how emotional regulation, health numeracy, and shared decision-making function as pathways through which HL influences recurrence-related beliefs.

Intersections Between HL and Risk Cognition

This review also highlights a growing body of evidence supporting bidirectional and mediating relationships between HL and risk awareness. For instance, HL buffered the negative psychological impact of FCR on return-to-work outcomes [15], and was positively correlated with risk estimation accuracy [19]. These findings mirror conceptual models of cognitive appraisal, where HL influences how survivors interpret ambiguous bodily sensations, assess recurrence probabilities, and engage in coping behaviors. The limited number of studies explicitly examining HL as a mediator suggests an underexplored but potentially powerful pathway through which survivor outcomes could be improved. This indicates a need for future research grounded in established frameworks such as the Self-Regulation Model or Health Belief Model to strengthen causal interpretation.

Cultural and Intersectional Dimensions

While quantitative findings varied, the review demonstrates that HL and risk perception are shaped by cultural norms, health system structures, and societal literacy levels. Marked contrasts such as Norway's 22% low HL versus Iran's 90% reflect broader sociocultural and systemic influences, including health communication infrastructure, stigma, and trust in healthcare. In addition to cultural context, intersectional factors such as socioeconomic status, ethnicity, digital access, and healthcare availability further condition survivors' ability to interpret recurrence information and seek appropriate care. These dynamics mirror broader survivorship disparities documented in international literature and underscore the importance of culturally responsive approaches.

Gaps and Limitations in the Current Evidence Base

While the reviewed studies provide valuable insights, several limitations are evident. First, most studies employed cross-sectional designs, limiting causal inference and the ability to observe changes in HL or FCR over time. Second, measurement heterogeneity including the use of instruments with varying domains (e.g., HLQ vs. BHLS vs. HELIA) compromised comparability across settings. Third, the evidence is heavily weighted toward high-income countries, leaving substantial gaps in lower-resource settings where HL barriers may be even more pronounced. Finally, few studies explicitly integrated theoretical frameworks, reducing conceptual coherence and limiting mechanistic exploration.

Implications for Research, Practice, and Policy

The findings of this review have several implications. Clinically, strategies to enhance HL including teach-back, plain-language risk summaries, and use of validated pictorial or numeric aids may help improve comprehension and reduce anxiety. Shared decision-making approaches that contextualize recurrence probabilities while attending to emotional responses may further support survivors.

From a policy perspective, national cancer control strategies especially in LMICs should prioritize HL promotion and survivorship education. Embedding HL-focused interventions within survivorship clinics, community-based digital platforms, or culturally adapted peer-support programs may extend reach and reduce disparities.

Future Directions

Future studies should prioritize longitudinal and interventional designs to test whether improving HL leads to sustained improvements in risk perception, emotional well-being, and functional reintegration. Developing breast-cancer–specific HL and risk communication tools would help standardize measurement and improve comparability. There is also a need to expand research in LMICs to understand how structural inequities, sociocultural norms, and digital divides intersect with HL and recurrence awareness.

In conclusion, this scoping review mapped the current landscape of research addressing health literacy and risk awareness of breast cancer recurrence among post-treatment populations. The findings underscore the prevalence of low health literacy and the widespread overestimation or underestimation of recurrence risk, both of which are influenced by demographic, psychosocial, and systemic factors. While health literacy emerged as a significant mediator of recurrence-related outcomes such as fear, coping, and functional recovery, the conceptual and methodological diversity across studies highlights the need for standardized measures and theoretical frameworks.

Despite increasing attention to survivorship care, critical knowledge gaps remain regarding how health literacy and risk perception intersect to shape post-treatment behavior and well-being. The current evidence base is disproportionately concentrated in high-income countries, with limited representation of survivors in low- and middle-income contexts. Furthermore, most studies relied on cross-sectional designs, limiting causal inferences about the dynamic interplay between cognition and behavior over time.

Future research should adopt longitudinal, theory-informed, and culturally sensitive approaches to investigate how health literacy can be strengthened to promote accurate risk appraisal, informed decision-making, and psychological adaptation in diverse survivor populations.

Interventions tailored to cultural and community contexts such as community-based health literacy programs, peer-led survivorship discussions, or digital survivorship modules designed for low-literacy users may offer promising pathways for improving recurrence-related understanding.

Clinicians can enhance survivorship care by incorporating strategies such as teach-back communication, plain-language risk explanations, and validated visual tools to support comprehension. Policymakers should integrate health literacy promotion into national cancer control plans and expand access to culturally appropriate survivorship resources, particularly in underserved regions. Researchers are encouraged to develop breast cancer–specific HL instruments and test targeted interventions that address emotional, cognitive, and structural determinants of recurrence awareness.

By integrating patient-centered communication with robust health literacy frameworks, survivorship care can more effectively support quality of life, reduce fear of recurrence, and empower breast cancer survivors navigating uncertainty about their future health.

Data Availability Statement

All data generated or analyzed during this study are included in this published article and its supplementary materials. Further inquiries can be directed to the corresponding author.

Ethics Statement

This scoping review did not involve primary data collection from human participants; therefore, ethical approval was not required. However, the review was conducted in accordance with established ethical standards for literature reviews, including transparency, accuracy, and proper citation of all included sources. The research protocol was developed under the academic supervision of the affiliated university and adheres to the principles of integrity and responsible scholarship.

Author Contributions

DA served as the principal author, responsible for conceptualizing and designing the scoping review, developing the search strategy, conducting literature screening, data extraction, and thematic synthesis, as well as drafting and revising the manuscript. DA also coordinated the overall research process and correspondence during submission. LL and DM contributed to refining the conceptual framework, supported data interpretation, and provided critical feedback on methodological rigor and manuscript clarity. All authors reviewed the intellectual content, contributed to the final discussion, and approved the manuscript for submission

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Conflict of Interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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