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## Influence of Health Literacy on Treatment Adherence in Breast Cancer Care: A Scoping Review

Rina Ha<sup>a</sup>, Anne Nguyen<sup>a</sup>, Caroline F. Illmann<sup>a</sup>, Kathryn V. Isaac<sup>\*a</sup><sup>a</sup>Faculty of Medicine, University of British Columbia, Diamond Health Care Centre, British Columbia, Canada

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## ABSTRACT

**Background:** Health literacy (HL) is an individual's ability to interpret and effectively utilize health information. Low HL has been associated with poorer treatment adherence. The effect of HL on treatment adherence is important to understand when survival is closely tied with treatment, such as in breast cancer (BC). The aim of our review was to examine the influence of HL on treatment adherence in BC patients.

**Methods:** A scoping review was conducted according to the Joanna Briggs Institute methodological framework. A comprehensive search was performed using 5 electronic databases to map the available literature. Studies were included that assessed BC patients' HL with a validated instrument and associated this with treatment adherence.

**Results:** Our review initially yielded 1404 studies. Of these, 9 studies (n=2468) met our inclusion criteria. Five studies (n=1478, 60%) found no association between HL and treatment adherence. Of the 3 studies (n=1175) focused on breast surgery decision-making, 2 studies (n=915, 77.8%) reported a positive association between HL and the decision to partake in reconstruction. In contrast, 3 (n=936) of 5 (n=1147) studies examining adjuvant therapy demonstrated that treatment decisions were not affected by HL.

**Conclusion:** Although it is difficult to determine the relationship between HL and treatment adherence from the contrasting results of the available literature, HL may have a greater impact on surgical decision-making as compared to the receipt of adjuvant therapy. Additional research is required to better characterize the effects of HL on treatment adherence, including surgical decision-making.

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## INTRODUCTION

Health literacy (HL) is a construct that was first introduced in the United States during the 1970s.<sup>1</sup> This term has been described as an individual's ability to interpret and effectively utilize health information.<sup>1</sup> HL is a critical process for patients with any severe and/or chronic illnesses.<sup>1</sup> Further evolution of the concept resulted in a redefinition by the Institute of Medicine

(US) Committee on Health Literacy and is "the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions".<sup>2</sup> While this remains the most common definition of HL, there is still no universal consensus on its definition and conceptual model in research studies.<sup>2-5</sup> However, it is clear that HL plays a key role as a social determinant of health status.<sup>4,6</sup> Low HL has been associated with worsened health outcomes, greater utilization of health services, inequity in health care access, poorer interpretation of medication label warnings, adherence, and higher rates of hospital admissions.<sup>4,7,8</sup>

**\*Address for correspondence:**

Kathryn V. Isaac, MD  
 Faculty of Medicine, University of British Columbia,  
 Diamond Health Care Centre, British Columbia, Canada  
 Tel: +1-604-336-9488  
 Fax: +1-604-336-9488  
 Email: [tkathryn.isaac@ubc.ca](mailto:tkathryn.isaac@ubc.ca)



Inadequate HL has also been linked to a decreased understanding of chronic diseases and the relevant treatments, including cancer.<sup>9–11</sup> For example, cancer patients with poor HL had more difficulty making sense of the rates and proportions of their cancer survival and treatment options.<sup>12</sup> Specifically, breast cancer (BC) patients with low HL had a higher likelihood of inaccurately calculating BC risks and greater difficulties with five-year and life-time risk assessments when numeracy was below average.<sup>13,14</sup> Importantly, these findings suggest that BC patients with inadequate HL may have lower treatment adherence due to a reduced capacity to process relevant information and accurately assess risks.<sup>11,12,15,16</sup> Although there have not been any American national surveys on BC patients' HL, many studies revealed HL to be poor in BC patients and particularly in marginalized populations, such as refugees, immigrants, and those of lower-income status.<sup>13,14,17–21</sup>

BC has been a growing area of study as it is the most common cancer and cause of cancer mortality in women globally.<sup>22</sup> Overall, BC is the second most common cancer worldwide with approximately 2.1 million women diagnosed and 626,000 dying annually.<sup>22</sup> In the United States in 2022, it is estimated that 287,850 will be diagnosed with BC, and 43,250 will succumb to their disease.<sup>23</sup> While BC incidence has increased over the past few decades, there has been a downwards trend in BC mortality worldwide.<sup>22</sup> Advances in BC treatments, including surgery, radiotherapy, and systemic therapy, are associated with higher rates of survival, especially for early-stage BC patients.<sup>24–26</sup> The 5-year survival rate with treatment is 90% compared to 18% in untreated patients with BC.<sup>25,27</sup> As health outcomes and survivorship are closely related to treatment adherence, BC patients with low HL can be disadvantaged in making life-changing treatment decisions.<sup>13,14,17–21,24–26,28</sup>

This scoping review was undertaken to be the first to comprehensively describe the status of research regarding the influence of HL on treatment adherence in BC patients. We used a broader definition of treatment adherence in our scoping review to map the full extent of the treatment experience for BC patients. Treatment adherence was defined as the degree to which a person's behaviour and treatment decision-making correspond with the standard recommendations from their medical and surgical care providers. Applying the principles of the Joanna Briggs Institute (JBI) manual of evidence synthesis,<sup>29</sup> for a scoping review, this study aims to identify the types of available evidence on treatment adherence, to examine how research is currently being conducted by describing tools used to evaluate HL, to highlight knowledge gaps in the literature and to identify key factors related to the impact of HL on treatment adherence in BC patients.

## METHODS

This scoping review follows the JBI methodological framework for scoping reviews,<sup>29</sup> and meets the PRISMA checklist criteria for scoping reviews.<sup>30</sup> The study protocol was registered on Open Science Framework (registration DOI: 10.17605/OSF.IO/BAJRW).<sup>31</sup>

### *Search Strategy*

A comprehensive search was performed from database inception until January 31, 2021, with the following databases: MEDLINE (Ovid), EMBASE (Ovid), PsycINFO, CINAHL, and Web of Science. The search strategies were established in collaboration with an experienced librarian and are outlined in Appendix I. Keywords along with the relevant MeSH terms for each database were related to: (1) health literacy, (2) treatment, (3) adherence, (4) breast cancer (or breast AND cancer). Prior to submission, the search was re-run on November 1, 2021, to check for the most recent publications.

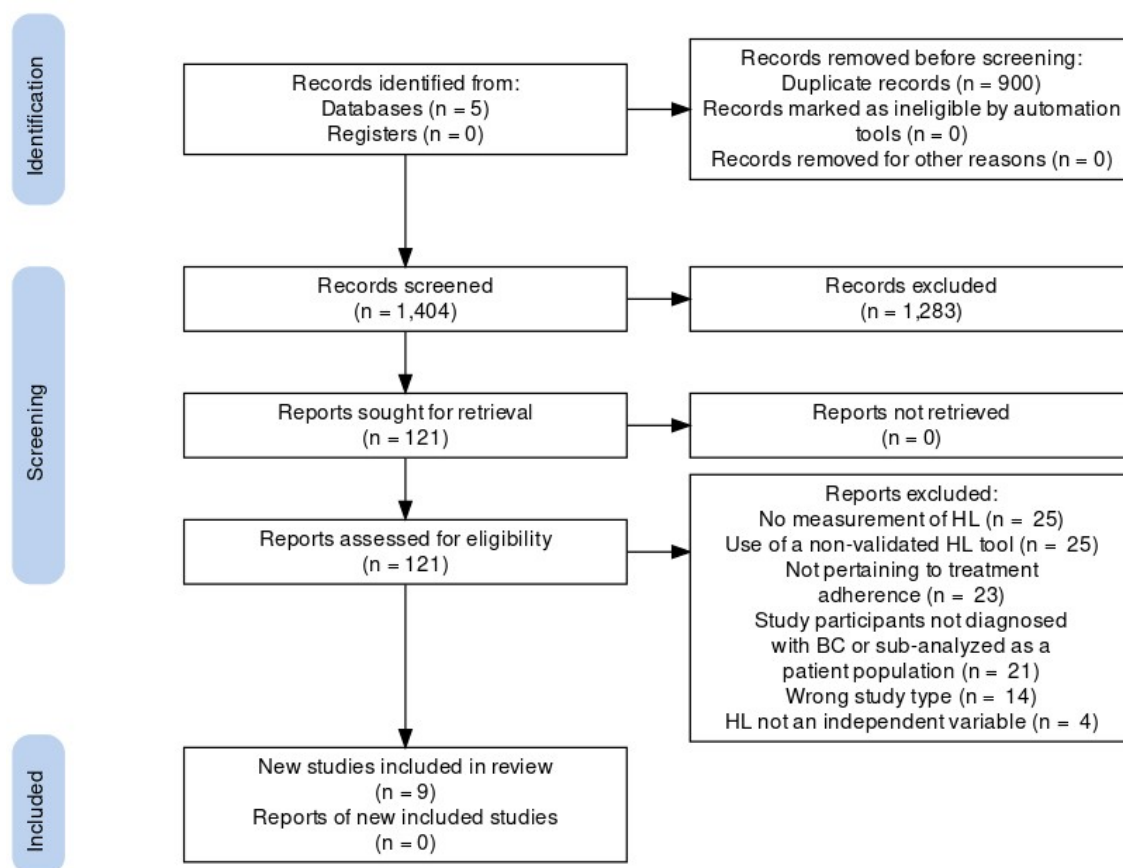
Inclusion criteria were: (1) studies pertaining to BC treatment, where study participants had a BC diagnosis, (2) studies with an assessment of HL using a validated HL tool, and (3) studies with outcomes related to treatment adherence. Outcomes related to treatment adherence were defined as the degree to which a person's behaviour and treatment decision-making correspond with the standard recommendations from their medical and surgical care providers. Exclusion criteria were: (1) literature and systematic reviews, (2) abstracts, (3) commentaries, editorials, or opinion papers, and (4) non-English studies.

### *Study Selection*

All citations from the database search were uploaded into Covidence. Duplicates were removed using Covidence electronically. Titles and abstracts were initially screened for eligibility by two independent reviewers (RH and AN). A detailed full-text review was then conducted for all potentially relevant studies. If the inclusion criteria were not met after a full-text review, the study was excluded. Any conflicts throughout the article selection were resolved with the adjudication of a third reviewer (KVI). Results of the study selection process have been reported using a PRISMA Flow Diagram (Figure 1).<sup>32</sup>

### *Data extraction and presentation*

Data extraction of the included studies was completed by two independent reviewers. Author, year of publication, country of origin, objective, study population, study design, HL instrument, participants' HL, and outcome were systematically collected for each of the included articles.



**Figure 1.** Study selection process<sup>32</sup>

## RESULTS

### Search results

Our search strategy initially yielded 2304 articles (Figure 1). Nine hundred duplicates were removed, and the remaining 1404 articles were screened for inclusion by title and abstract. One-thousand eighty-three were excluded at this stage. A full-text assessment was conducted on the remaining 121 studies. A total of 112 studies were excluded during the full-text assessment. Reasons for exclusion were: no measurement of HL (n=25), use of a non-validated HL tool (n=25), not pertaining to treatment adherence (n=23), study participants not diagnosed with BC or sub-analyzed as a patient population (n=21), study type (abstracts, literature, or systematic reviews) (n=14), and HL not being evaluated as an independent variable (n=4). Nine studies were included in our final qualitative synthesis. A summary of the included studies is presented in Table 1.

### Study characteristics

There was much heterogeneity within the study populations, HL tools, and outcomes for the nine included studies. All nine articles were observational in design. The majority were cross-sectional studies (n=7) that were conducted in the United States (n=7). Adherence to treatment was either self-reported (n=5)

and/or collected through chart review of the patients' medical records (n=4).

### Study populations

Of the nine included studies, five articles focused on understanding the effects of HL on treatment adherence in specific ethnic groups,<sup>33–37</sup> namely Iranian,<sup>33</sup> Portuguese,<sup>34</sup> and African American women.<sup>35</sup> Two of these studies focused on minorities and/or marginalized populations. These studies stratified participants by residence in lower-income neighbourhoods and insurance coverage status, with a reported increased likelihood of capturing participants that were Hispanic and/or African American.<sup>36,37</sup> Although the remaining studies had no specified ethnic, insurance, or residential inclusion criteria for study participation,<sup>38–41</sup> these studies had more than 80% of participants identifying as non-Hispanic white American.<sup>38–40</sup>

### Health Literacy in the BC population

A total of 5 different tools were used to measure HL: Set of Brief Screening Questions (SBSQ),<sup>35,36,38,39,41</sup> Rapid Estimate of Adult Literacy in Medicine (REALM),<sup>40</sup> Health Literacy for Iranian Adults (HELIA),<sup>33</sup> Medical Term Recognition Test (METER),<sup>34</sup> and Newest Vital Sign (NVS),<sup>37</sup> (Figure 2).



**Table 1.** Study characteristics of HL and treatment adherence in BC patients

Author, Year, Country	Objective	Study Population	Methodology	Participants HL	Outcome
Bonner <i>et al.</i> <sup>36</sup> 2019 United States	Effect of HL on receipt of adjuvant therapy	Self-identified non-Hispanic white, non-Hispanic black, or Hispanic women living in Northern California with stage I-III BC who received breast surgery in 2010-2011 n=386	Cross-sectional study HL measurement: SBSQ Outcome measurement: California Cancer Registry or self-report	Mean: 1.85 (SD = 1.08)	No association between HL and adjuvant therapy receipt
Brewer <i>et al.</i> <sup>40</sup> 2009 United States	Effect of HL on understanding risks when making chemotherapy decisions	English speaking American women previously diagnosed with stage I/II primary breast cancer, who completed surgery and had not received or completed adjuvant chemotherapy n=163	Cross-sectional study HL measurement: REALM Outcome measurement: Self-report	Mean: 63.6 High HL (≥ 63): 125 Low HL (<63): 38	HL was associated with increased sensitivity to recurrence risk percentages when making chemotherapy decisions
Freedman <i>et al.</i> <sup>41</sup> 2016 United States	Effect of HL on receipt of adjuvant therapy	White, black, Hispanic women within the California Cancer Registry living in Northern California in 2010-2011 with stage I-III BC n=414	Cross-sectional study HL measurement: SBSQ Outcome measurement: California Cancer Registry or self-report	Mean: 1.75 (SD = 1.01)	No association between HL and adjuvant therapy receipt
Haghighi <i>et al.</i> <sup>33</sup> 2015 Iran	Effect of HL on surgical treatment decision-making	Aged 15-49 fertile literate Iranian women living in urban centres with breast cancer confirmed by pathology study between August 2014 and August 2015 n=260	Cross-sectional study HL measurement: HELIA Outcome measurement: Self-report	Excellent: 35.1% Enough: 38.8% Barely enough: 18.8% Insufficient: 6.9%	No association between HL and type of surgery received
Keim-Malpass <i>et al.</i> <sup>39</sup> 2019 United States	Effect of HL on adjuvant endocrine therapy adherence	New and returning BC patients in an academic breast surgical oncology setting n=136	Prospective cohort study HL measurement: SBSQ Outcome measurement: Medical oncology patient notes	Adequate (>2): 74.4% Marginal/Inadequate (≤2): 25.6%	No association between HL and adjuvant endocrine therapy adherence
Keim-Malpass <i>et al.</i> <sup>38</sup> 2018 United States	Effect of HL on surgical treatment decision-making	Newly diagnosed and breast cancer survivors in an academic breast surgical oncology setting n=512	Cross-sectional study HL measurement: SBSQ Outcome measurement: Chart review/University of Virginia Clinical Data Repository	Adequate (>2): 74.4% Marginal/Inadequate (≤2): 25.6%	HL associated with breast reconstruction after mastectomy



Author, Year, Country	Objective	Study Population	Methodology	Participants HL	Outcome
Nouws <i>et al.</i> <sup>34</sup> 2019 Portugal	Effect of HL on time from diagnosis to first treatment	Newly diagnosed BC patients who have not received any treatment admitted to the Breast Clinic of the Portuguese Institute of Oncology of Porto, Portugal between January and December 2012 n=282	Prospective cohort study HL measurement: Portuguese version of METER Outcome measurement: Chart review or self-report	Adequate: 54.6% Inadequate: 45.4%	No association between HL and time interval from diagnosis to treatment
Rust <i>et al.</i> <sup>35</sup> 2015 United States	Effect of HL on adjuvant therapy adherence	African-American BC survivors from a minority and underserved based community organization and the American Cancer Society n=48	Cross-sectional study HL measurement: SBSQ Outcome measurement: Adherence to Refills and Medications Scale (ARMS)	Not reported	HL associated with adjuvant therapy adherence
Winton <i>et al.</i> <sup>37</sup> 2016 United States	Effect of HL on surgical treatment decision-making	BC patients receiving treatment or being followed at the Maricopa Medical Centre from January 14, 2010, to May 7, 2012 n=403	Cross-sectional study HL measurement: NVS Outcome measurement: Chart review	Adequate (4-6): 22%	HL associated with breast reconstruction after mastectomy

SBSQ, a three question based instrument validated against the short version of the Test of Functional Health Literacy in Adults (STOFHLA) and REALM, was the most common instrument utilized.<sup>42,43</sup> The SBSQ is a self-reported instrument, which asks patients to rank their comprehension of medical documentation.<sup>43</sup> A mean cut-off score of 2 was determined if the participant had either adequate or marginal/inadequate HL, and this was congruent across studies when reported.<sup>42,43</sup> Of the five studies that used SBSQ, an inadequate HL was reported in 26% of participants in the studies by Keim-Malpass and colleagues.<sup>38,39</sup> Bonner *et al.* and Freedman *et al.* reported an inadequate HL in the majority of their participants.<sup>36,41</sup>

The REALM instrument is one of the first objective assessments developed where patients are evaluated on their ability to correctly recognize, read, and pronounce a list of 66 medical terms by an assessor.<sup>44</sup> One point is given if the word is pronounced correctly for a total possible score of 66.<sup>44</sup> A score of 63 or above is considered high HL.<sup>44</sup> The study conducted by Brewer and colleagues was the only study that utilized REALM and a minority of participants were reported as having low HL.<sup>40</sup>

Overall, four studies reported high HL in a total of 1447 participants,<sup>33,38-40</sup> and three studies with low HL in a majority of the 1203 participants.<sup>36,37,41</sup> (Table 1). Nouws and colleagues had an almost equal number of participants with low and high HL.<sup>34</sup> Rust *et al.* did not report the HL of their participants.<sup>35</sup>

#### *Impact of HL on treatment*

We identified four main themes from the evaluation of the impact HL had on treatment: time from diagnosis to treatment, type of breast surgery received, receipt of adjuvant therapy, and adjuvant therapy adherence (Figure 3). These themes reflected the key aspects of BC treatment reported in the literature and the decisions needed to be made in the management algorithm.

#### *Time from diagnosis to treatment*

One study discussed the impact of HL on the time between diagnosis and treatment. Nouws and colleagues conducted a prospective cohort study of 282 patients in Portugal over the course of 1 year.<sup>34</sup> HL was measured using the Portuguese version of METER (a medical term comprehension tool), and 55% of the participants had an adequate HL.<sup>34</sup> No



association was found between HL and the time interval to treatment (OR 0.82, 95% CI 0.39-1.72).<sup>34</sup>

*Type of Breast Surgery Received*

Three cross-sectional studies explored the relationship between HL and the type of breast surgery BC patients received.<sup>33,37,38</sup>

Keim-Malpass *et al.* studied the relationship between HL and surgical decisions. Surgical options included breast-conserving therapy, mastectomy with or without breast reconstruction, and mastectomy and contralateral prophylactic mastectomy (CPM) with or without breast reconstruction.<sup>38</sup> Breast reconstruction after mastectomy was the only decision that was associated with HL. Patients with low HL were less likely to undergo breast reconstruction (OR 0.81, 95% CI 0.69-0.94, P=0.007).<sup>38</sup> Similarly, Winton and colleagues investigated the effects of HL on the decision for lumpectomy compared to mastectomy alone or mastectomy with breast reconstruction.<sup>37</sup> An association was found between HL and breast reconstruction after mastectomy. Patients with adequate HL were more likely to undergo breast reconstruction than those with inadequate HL (OR, 3.13, 95% CI 0.95–10.30, P=0.06).<sup>37</sup>

These two studies had similar cross-sectional study design, sample size (i.e., 512 vs. 403), and average age (i.e., 59 vs. 53), but differed in how HL was measured.<sup>37,38</sup> Keim-Malpass and colleagues utilized the SBSQ tool and found an adequate HL in 74% of the participants.<sup>38</sup> In contrast, Winton *et al.* identified 22% of participants with an adequate HL using NVS, which is a test of comprehension and numeracy.<sup>37</sup>

The third study conducted in Iran by Haghghi and colleagues found no association between HL and receipt of total or partial breast surgery in BC patients (P=0.538).<sup>33</sup> The average age was 43 and the sample size was 260.<sup>33</sup> Thirty-nine percent of the participants

were found to have “enough HL”, while 35% had “excellent HL” measured using the HELIA tool (a self-reported instrument).<sup>33</sup>

*Receipt of Adjuvant Therapy*

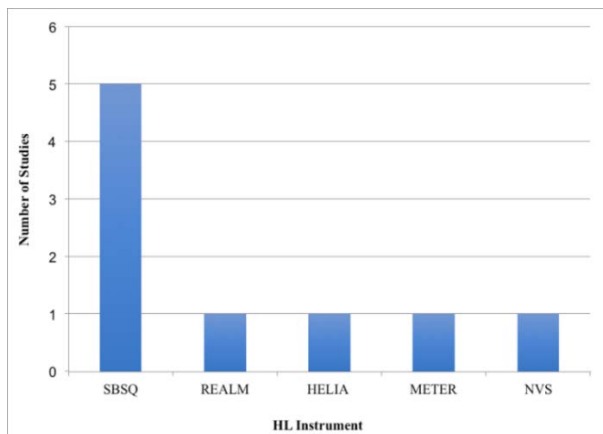
Three cross-sectional articles reported on the relationship between HL and receipt of adjuvant therapy in BC patients.<sup>36,40,41</sup>

Bonner *et al.* found no significant relationship between HL and receipt of adjuvant chemotherapy (OR 1.34, 95% CI=0.719–2.49, P=0.515), radiation (OR 0.94, CI=0.54–1.63, P=0.689), or hormone therapy (OR 0.96, CI=0.66–1.40, P=0.329).<sup>36</sup> Likewise, Freedman *et al.* discovered no association between HL and receipt of adjuvant chemotherapy (OR 1.20, 95% CI=0.66-2.19, P=0.3), radiation (OR 0.88, CI=0.53-1.45, P=0.963), or hormone therapy (OR 0.97, CI=0.67-1.39, P=0.473).<sup>41</sup> In contrast, Brewer and colleagues reported HL was associated with the ability to understand risks when making adjuvant therapy decisions.<sup>40</sup> Specifically, their findings suggested patients with higher HL were better able to utilize recurrence risk percentages to decide on the receipt of chemotherapy (interaction, F1,154=5.86, P=0.02).<sup>40</sup> To define HL, Bonner *et al.* and Freedman *et al.* used the SBSQ tool whereas Brewer *et al.* used REALM.<sup>36,40,41</sup>

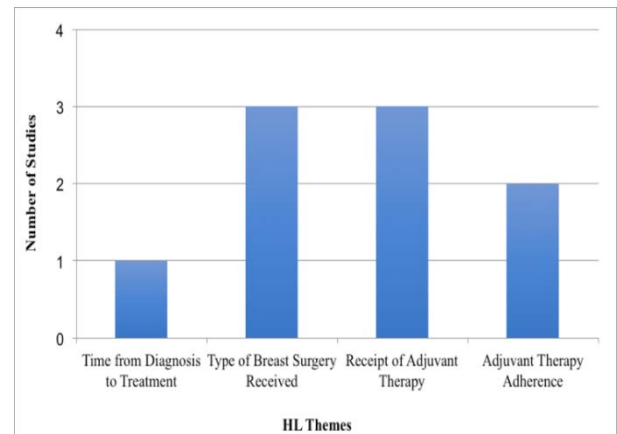
*Adjuvant Therapy Adherence*

Two studies found differing results upon investigating the effects of HL on adjuvant therapy adherence.<sup>35,39</sup>

Rust and colleagues’ cross-sectional study discovered a significant relationship between HL and adjuvant therapy adherence in 48 African American BC survivors (B=0.582, 95% CI=28.42-41.73, r=0.29, t(46)=2.07, P=0.044, two-tailed).<sup>35</sup> Every point increase in HL was associated with



**Figure 2.** HL instruments utilized by our nine included studies. Out of the five different instruments, SBSQ was the most common tool used by five studies



**Figure 3.** Main HL themes identified from our nine included studies



a concomitant 0.552 increase in adjuvant therapy adherence. Participants had an average age of 54. HL was measured with the SBSQ tool, but the score was not reported.<sup>35</sup>

Keim-Malpass and colleagues prospectively followed BC patients for two years after initiating endocrine therapy.<sup>39</sup> HL was measured with the SBSQ tool, and 74% of the patients had an adequate HL.<sup>39</sup> No association was discovered between HL and adjuvant therapy adherence ( $P=0.645$ ).<sup>39</sup> However, there were limitations noted in the study. They began with a cohort of 512 participants, of which 296 patients actually initiated adjuvant endocrine therapy and only 136 had their adherence measured due to loss to follow-up.<sup>39</sup>

## DISCUSSION

In this scoping review, we sought to understand the effects of HL on treatment adherence in BC patients. Our review identified 9 studies and 4 main themes when treatment adherence was defined as the degree to which a person's behaviour and treatment decision-making correspond with the standard recommendations from their medical and surgical care providers. While no significant relationship was found in 5 studies ( $n=1478$ ),<sup>33,34,36,39,41</sup> 2 out of 3 ( $n=915$  out of 1175) studies found an association between HL and treatment adherence with regard to surgical decision-making.<sup>35,37,38,40</sup>

There is a growing body of evidence demonstrating HL as an important social determinant of health.<sup>4,6-8</sup> Patients with low HL have greater difficulties managing and making appropriate care decisions because of their limited capacity to comprehend relevant health information.<sup>6-8</sup> This gives rise to higher rates of hospitalization and mortality in these patients.<sup>4,7,8</sup> Therefore, it is imperative to identify individuals with low HL as patient understanding can be improved with appropriate resources and support.<sup>2,45</sup> Effective strategies include adjusting the level of communication for each patient,<sup>2,45</sup> and providing short, clear educational materials written without medical jargon at a sixth-grade level or lower.<sup>2</sup> Simpler resources have been demonstrated to improve receptiveness to clinicians' recommendations and adherence rates.<sup>2</sup>

Patients' compliance to treatment is particularly important in BC patients due to higher risks of complications with noncompliance.<sup>24-26,46</sup> Although it has been previously identified that HL has an influence on adherence in non-cancer patients, our review demonstrated that there are mixed findings reported on the relationship between HL and treatment adherence in BC patients. This was due to the lack of consensus, the small number of studies investigating this topic using validated instruments, and the heterogeneity in

the instruments assess HL. Our findings are consistent with those found in previously published reviews on HL and treatment adherence in other cancer types.<sup>47-49</sup>

However, our results do provide greater insight into how HL influences different types of BC treatment. When results from multiple studies were subdivided into surgical,<sup>37,38</sup> versus adjuvant medical therapy,<sup>36,39,41</sup> we identified opposing results for and against an association between HL and treatment adherence respectively. This influence of HL on surgical decision-making is an important consideration in BC patients requiring surgery as post-mastectomy breast reconstruction is associated with improved health-related quality of life.<sup>50</sup> In general, breast surgeons spend less time with patients compared to medical oncologists.<sup>51</sup> Furthermore, patients may be pressured to make surgical decisions earlier as there is an overall decrease in survival with prolonged time to surgery.<sup>52</sup> This faster-paced surgical environment may further marginalize patients with low HL by reducing the accessibility of shared decision-making. In particular, Lee and colleagues demonstrated that after having discussions with their clinicians, patients answered only 37.9% of questions about breast reconstruction correctly.<sup>53</sup> Further study is warranted to investigate HL and other social determinants of health and assess which influence shared decision-making in post-mastectomy breast reconstruction.<sup>54,55</sup>

Of the nine included studies, SBSQ was the most commonly used instrument ( $n=1496$ ). Prevalence of SBSQ was likely because of its simplicity as a self-reported tool, and the benefit of reduced feelings of shame and embarrassment seen in low HL patients compared to when objective instruments were used.<sup>42,43,56</sup> Although SBSQ is a convenient tool, it was validated in a predominantly white male sample population and to our knowledge, has only been further validated in Hispanic, Spanish-speaking populations by Sarkar *et al.*<sup>42,57</sup> This could have potentially affected the HL measurement and results of the studies by Bonner *et al.*, Freedman *et al.*, and Rust *et al.*<sup>35,36,41</sup> These three studies investigated the effects of HL on adjuvant therapy adherence in primarily African-American and Hispanic participants, a population that has not yet been validated to use SBSQ.

The challenge of choosing an appropriate HL tool validated for the population of study relates to the wide selection of tools available, and the lack of a comprehensive gold-standard instrument reliable across diverse populations.<sup>58-60</sup> A systematic review conducted by Haun *et al.* in 2014 revealed 51 different HL instruments available for clinicians and/or researchers.<sup>59</sup> The large number of instruments reflect the evolving HL definition and concept since its first conceptualization in the 1970s.<sup>2-5,58,59,61</sup> In particular, some tools measure only certain elements of HL that



were important at the time of development.<sup>58-61</sup> REALM is an example of a one-dimensional instrument developed in 1993.<sup>2,44</sup> REALM is a word recognition test that fails to capture other important aspects of HL, such as the patients' understanding and ability to make informed decisions.<sup>2,44,58</sup> Ultimately, comparing HL between studies can become difficult when the instrument is not suitable for the population and when different domains of HL are evaluated.<sup>58,59,62</sup> Our review highlights both the occurrence and implications of this challenge, where five different instruments were used measuring different HL domains and applied in study populations without prior validation. These challenges and the need for a reliable gold standard multi-dimensional tool remain to be well-acknowledged in the literature.<sup>58-61</sup> Until such an instrument is developed, mindful selection of a tool that is the right fit for the population and HL domain of interest is recommended.<sup>59</sup>

Overall, our scoping review highlights the complexity of BC management decisions and the impact HL can have on the different types of treatment. The effects of HL on treatment adherence are conflicting based on the present literature, which may stem from the inherent challenges of the absence of a universal definition and instrument to evaluate HL. Further research is required to understand how HL affects each surgical and medical treatment decision given that HL may have varying implications on adherence according to the type of treatment under consideration. At present, there are only a small number of studies examining the relationship between HL and surgical decision-making. Breast surgery decisions can be difficult to make in a fast-paced surgical environment and this may disproportionately disadvantage those with low HL. Thus, it is imperative to understand how we can optimize shared decision-making in these settings.

Study limitations include the small sample size and heterogeneity. This review provides a map of the currently available literature on HL in the BC population and highlights the need for further investigation

## CONCLUSION

Our review identified nine relevant studies investigating the relationship between HL and treatment adherence in BC patients. Defining treatment adherence as the degree to which a person's behaviour and treatment decision-making correspond with the standard recommendations from their medical and surgical care providers, the current literature examines four main themes. The small number of conflicting heterogeneous findings rendered it difficult to determine if BC patients with low HL were less likely to be compliant with their treatment. However, this study highlights the impact

of HL on different types of BC treatment. With HL possibly playing a greater role in surgical decision-making, further investigation is needed to examine the effects of HL on surgery treatment adherence.

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## ETHICAL CONSIDERATIONS

Research Ethics Board approval was not required for this scoping review of the literature.

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## CONFLICT OF INTEREST

The authors have no conflicts of interest to declare.

## APPENDIX I: SEARCH STRATEGY

MEDLINE (Ovid):

(Health Literacy/ or Health literacy.mp. or Numeracy.mp. or "rapid estimate of adult literac\*".mp. or realm.tw. or medical achievement reading test.mp. or realm-r.tw. or realm-sf.tw. or HHLT.tw. or newest vital signs.mp. or real-g.tw. or NVS.tw. or SAHL.tw. or tofhla.tw. or MART.tw. or SAHLS.tw. or wide range achievement test.mp. or WRAT.tw. or set of brief screening questions.mp. or SBSQ.tw. or nutritional literacy.mp. or literacy assessment\*.mp. or (reading adj1 abilit\*).mp. or reading skill\*.mp. or reading comprehension.mp.) AND ((Therapeutics/ or treatment\*.mp. or treatment outcome/ or therap\*.mp. or Surgical Procedures, Operative/ or Surger\*.mp. or radiotherap\*.mp. or chemotherap\*.mp. or Intervention\*.mp. or irradiation.mp. or management.mp. or care.mp. or reconstruction.mp. or Mastectomy/ or Mastectomy.mp. or Breast implants/ or Breast Implant\*.mp. or retreatment/ or Health Services/ or Antineoplastic Protocols/ or Chemoradiotherapy/ or Antineoplastic Agents/ or Chemotherapy, Adjuvant/ or Antineoplastic Combined Chemotherapy Protocols/ or consolidation chemotherapy/ or hormone replacement therapy/ or chemotherapy/ or Maintenance chemotherapy/ or molecular targeted therapy/ or medication errors/ or self administration/ or self medication/ or radiotherapy/ or Health Services Accessibility/ or Health Services Administration/ or Pharmaceutical Preparations/) OR





(Guideline Adherence/ or Adherence.mp. or Compliance.mp. or Decision-making.mp. or Decision making/ or decision making, shared/ or patient compliance.mp. or patient adherence.mp. or "Continuity of Patient Care"/ or "Treatment Adherence and Compliance"/ or Physician-Patient Relations/)) AND ((Breast Neoplasms/ or Breast

Neoplas\*.mp. or Breast Cancer\*.mp. or Breast Carcinoma In Situ/) OR ((Breast/ or Breast\*.mp. or Breast Cyst/ or Breast Diseases/ or Breast Disease\*.mp.) AND (Cancer\*.mp. or Neoplas\*.mp. or Neoplasms/ or Carcinoma\*.mp. or Malignan\*.mp. or Tumor\*.mp. or metastas\*.mp. or oncolog\*.mp. or adenocarcinoma\*.mp. or adenom\*.mp.))

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