



## Featured Article

## Delving deeper into disparity: The impact of health literacy on the surgical care of breast cancer patients

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## ARTICLE INFO

## Article history:

Received 3 April 2020  
 Received in revised form  
 8 May 2020  
 Accepted 8 May 2020

## Keywords:

Breast cancer  
 Health literacy  
 Breast surgical oncology  
 Health disparities in breast cancer  
 Health literacy in surgical oncology

## ABSTRACT

**Background:** Breast surgical oncology is a unique field that involves complex cancer management and longstanding patient interactions with the healthcare system, making it potentially challenging for patients with low health literacy. The purpose of this review is to summarize the current knowledge regarding health literacy in breast cancer and identify future directions for research and potential intervention in breast surgical oncology.

**Data sources:** A search of relevant literature querying PubMed and Science Direct was performed and included the following keywords: health literacy, breast cancer, breast surgical oncology, surgery, outcomes, prevention, screening, healthcare utilization, chronic disease.

**Conclusions:** Limited health literacy may detrimentally affect understanding and outcomes in breast surgical oncology. Identifying ways providers can improve patient understanding and utilization of health information is important, and surgeons may have a pivotal role. Further studies addressing health literacy in breast surgical oncology is needed in order to better optimize care of patients.

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## Introduction

Health literacy is an individual's ability to obtain, process, and understand health information in order to make decisions about their care. Data suggest only 12% of the US population has proficient health literacy.<sup>1</sup> Poor health literacy is associated with avoidance of preventative care and worse outcomes in many chronic medical conditions.<sup>2</sup> However, the impact of health literacy on outcomes in surgical oncology is not known.

Breast cancer represents a unique field with well-defined roles for preventative screening, and multimodality treatment after diagnosis. It requires a coordinated integration of patient understanding and participation and multidisciplinary decision-making. Patients with breast cancer have multiple and longstanding interactions with the healthcare system and play an active role in shared decision-making.<sup>3</sup> Improving delivery and adherence to evidence-based care in breast cancer will result in better outcomes

and will be enhanced by increasing our understanding of how health literacy impacts patients with breast cancer.

The purpose of this review is to summarize current available knowledge regarding health literacy in breast cancer and identify gaps in knowledge and future directions for research and potential intervention in breast surgical oncology.

## Introduction to health literacy

The US National Academy of Sciences' Institute of Medicine defined health literacy in 2004 as the degree to which an individual has the capacity to obtain, communicate, process, and understand basic health information and services to make appropriate health decisions.<sup>4</sup> While they are related concepts, a distinction should be made between basic literacy, such as reading ability and numeracy skills, and health literacy. Basic literacy is at the foundation of health literacy and is often a common mediator between health literacy and an individual's ability to interact with the healthcare system and health outcomes. Similarly, other aspects of an individual's culture can influence health literacy, such as native language, race, gender, and socioeconomic status. These related concepts are important to a global health literacy framework but should be considered fundamentally different entities.<sup>4</sup>

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Unfortunately, limited health literacy is prevalent. According to the 2003 National Assessment of Adult Literacy, 21% and 14% of Americans had basic and below basic literacy, respectively. As a result, improving health literacy is a target for the CDC's Healthy People 2020 and 2030 initiatives.<sup>1</sup>

Limited health literacy has been negatively associated with patient outcomes and healthcare utilization in numerous populations and affects multiple aspects of healthcare.<sup>2</sup> It may be independently related to disease knowledge, such that those with lower literacy have less knowledge about their disease.<sup>5</sup> In addition, the health-related information and educational resources available to patients may be written above current recommendations for literacy and reading ability, further inhibiting a patient's opportunity to learn about their disease.<sup>6</sup> Patients with limited health literacy may also be less likely to utilize preventive services, receive standard screenings such as mammograms, receive appropriate vaccinations, and may be less likely to report exercising adequately or eating healthfully compared to patients with proficient literacy.<sup>7–9</sup> Importantly, in a prospective cohort study of Medicare managed-care enrollees, inadequate health literacy was significantly associated with all-cause mortality.<sup>10</sup> Among older adults, limited health literacy may also be associated with worse perceptions of physical and mental health.<sup>11</sup> Limited health literacy can further result in higher healthcare expenditure, which in turn may be related to a higher incidence of hospital admissions, readmissions, and emergency department visits for those with lower literacy.<sup>12–18</sup> Finally, limited health literacy may be a difficult topic for patients to discuss, such that screening for and discussing limited health literacy may be associated with feelings of shame among patients.<sup>19,20</sup> Taken together, there is an important role for identifying limited health literacy and targeting interventions to improve literacy and augment quality care for these patients.

### Health literacy in breast surgical oncology

Health care for patients with breast cancer is complex. Navigation of the healthcare system in the context of breast cancer requires sufficient knowledge and understanding of multidisciplinary treatment options. For patients with a new diagnosis of breast cancer, surgical consultation is frequently the first point of contact with the healthcare system. Surgical patients must often weigh several complex treatments, evaluate and assess detailed information for informed consent and shared decision making, and participate in multidisciplinary care - coordinating appointments and information among oncology, radiation, surgery, and genetics. These patients are also tasked with potentially complex post-operative care, including drain management, wound care, and pain control. Following recovery from surgery, additional important points of shared decision making involve adjuvant therapy (endocrine, systemic chemotherapy, and radiation), and an understanding of how these decisions will affect future cancer risk becomes critical. In addition, a negative correlation may exist between health literacy and unplanned hospitalizations for cancer patients.<sup>21</sup> While the role of health literacy on important topics has been well-studied in chronic medical conditions, the role of health literacy in surgical populations and in breast surgical oncology is less well-defined. However, it has been shown that limited health literacy is similarly prevalent in surgical populations.<sup>22</sup>

#### *Disease-specific knowledge and screening practices*

There has been extensive research exploring the effect of health literacy in chronic medical conditions such as ESRD, diabetes, HIV, and COPD. Poor health literacy is associated with worse patient outcomes in various populations.<sup>23–26</sup> Disease specific knowledge

has been hypothesized to contribute to patient outcomes and screening practices, and the relationship between low health literacy and knowledge of chronic disease is well-documented. For example, one study measured health literacy with the short test of functional health literacy in adults (S-TOFHLA) in 653 Medicare enrollees with at least one chronic medical condition, including asthma, congestive heart failure, hypertension, and diabetes.<sup>3</sup> Participants were then asked specific disease-related questions and found that disease specific knowledge directly correlated with health literacy scores, such that those with inadequate health literacy knew significantly less about their disease than participants with proficient literacy.<sup>3</sup> Another study examining diabetes knowledge demonstrated similar results. Participants with low health literacy measured by the Revised Rapid Estimate of Adult Literacy in Medicines (REALM-R) had significantly worse disease knowledge after adjustment for independent factors associated with glycemic control.<sup>27</sup>

There is a small body of evidence investigating breast cancer specific knowledge. One such cross-sectional study conducted in Iran evaluated health literacy using a country-specific questionnaire and measured breast cancer knowledge with a 28-item questionnaire for 250 healthy women, the majority of which were between 20 and 35 years old. Most women in this study had limited health literacy, and this was significantly associated with worse knowledge about breast cancer.<sup>28</sup> In a separate study looking at 276 uninsured women divided into English- and Spanish-speaking groups and aged 40 years and older, health literacy was inversely associated with the perception of breast cancer and treatment. Those with low health literacy were more likely to report negative perceptions about breast cancer. For example, patients with low health literacy were more likely to endorse statements such as “if you have breast cancer, better not to know” and “the treatment for breast cancer is a long and painful process” and “embarrassing”.<sup>29</sup> Another study of 722 Mexican American women from Texas explored screening practices among women with inadequate or marginal health literacy. Health literacy was measured using the S-TOFLA and approximately half of women had limited health literacy. This was independently associated with lower rates of receiving a screening mammogram within the last two years,<sup>30</sup> which is critical in that screening for breast cancer is associated with decreased mortality.<sup>31</sup> Additionally, data suggests lower rates of screening adherence for mammograms and self-breast exams in other populations, including Turkish women, African American women, and Vietnamese immigrants with low health literacy.<sup>32,33</sup>

#### *Multidisciplinary care and shared decision making*

The role of multidisciplinary care in breast cancer is well-documented, and clinical practice guidelines recommend an integrated approach to develop optimal patient management.<sup>3</sup> In addition, patient-centered care that considers patient preferences may result in better care-congruent patient outcomes.<sup>34</sup> Health literacy strongly influences patient participation in healthcare in other disease populations.<sup>35</sup> In addition, patients with lower health literacy may report less desire for active participation in their care, especially when the perceived stakes of a decision are higher.<sup>36,37</sup> In patients with diabetes, limited health literacy was associated with worse provider communication and decreased desire to participate in medical decision making.<sup>38,39</sup>

Similar themes emerge in the multidisciplinary care of and shared decision-making in breast cancer. Breast cancer patients with limited health literacy, for example, may be less likely to participate in multidisciplinary care. In a prospective, multicenter cohort study, women with breast cancer were followed for up to 40

weeks following surgery. 6.8% of these patients participated in a multidisciplinary conference, and results suggest that those women with lower health literacy were less likely to contribute.<sup>40</sup> Another study reports that patients with limited health literacy have higher rates of missed appointments in a breast clinic, but insurance status, income, and education were not significantly associated with missed appointments.<sup>41</sup> Breast cancer patients with low health literacy also endorse less perceived shared decision making.<sup>42</sup> Further studies are needed to better understand the relationship between low health literacy and participation in multidisciplinary care given its importance in the treatment of breast cancer patients.

### *Risk perception*

Low health literacy may affect a patient's perception of their disease. In patients with poorly controlled diabetes and elevated hemoglobin A1c, a majority of patients with low health literacy believed they were managing their blood glucose well, and as a result, were less likely to make changes to improve control.<sup>43</sup> With regards to breast cancer, a cross-sectional study specifically examined risk perception of breast cancer in a family clinic. While most women overestimate their personal lifetime risk of breast cancer, there was a significant moderate correlation among women with low health literacy and increased risk perception inaccuracy.<sup>44</sup>

Low health literacy may also be associated with fear of cancer progression in breast cancer patients. In a prospective cohort study, women aged 65 years and older with newly diagnosed breast cancer completed a validated measure of health literacy and a questionnaire assessing various domains in cancer progression including loss of autonomy and emotional distress. Results suggest that women with low health literacy have greater fear of cancer progression both immediately after surgery and 40 weeks later than their high literacy counterparts.<sup>45</sup> Another interesting study presented hypothetical recurrence risk estimates from a genomic test to women in several different verbal and numerical formats. Results suggest that women with low health literacy were more likely to overestimate their recurrence risk than women with higher health literacy,<sup>46</sup> which has important implications for communication of risk to these patients. In sum, these studies highlight the importance of modifying clinician communication strategies for patients with lower health literacy in order to effectively convey recurrence risk.

The inaccuracy of risk perception may not translate into surgical treatment decisions, however. In a study of 512 patients with breast cancer, health literacy was not significantly associated with breast surgery type (breast conserving therapy vs mastectomy). Multivariate analysis did suggest that women with low health literacy were less likely to undergo reconstruction.<sup>47</sup> An important limitation of this study, however, is that information regarding candidacy for either procedure was not accounted for in the data.

### *Medication adherence*

Low health literacy is associated with worse medication adherence in both acute and chronic illness.<sup>48</sup> One study examined medication adherence in an elderly population with chronic disease including cardiovascular disease, diabetes, and gastrointestinal disease such as hepatitis, and found that only 30% of patients had good medication adherence. Health literacy was the strongest predictor of adherence in this population.<sup>49</sup> Another study reports similar results in an older adult population with asthma. Adherence to controller medication was significantly associated with health literacy, measured by the S-TOFLA, such that low health literacy was associated with worse adherence.<sup>50</sup> In addition, in a sample of 197 patients with open angle glaucoma, health literacy predicted

medication adherence and the number of medication refills obtained. In this study, as seen in others, patients with low health literacy were less likely to adhere to their medication regimen over six months.<sup>51</sup>

Adjuvant (or neoadjuvant) therapy in the form of endocrine therapy for hormone-positive cancers, chemotherapy for advanced stage cancers and axillary node positive disease, and immune modulators for herceptin-receptor positive disease is a mainstay of treatment in breast cancer.<sup>52</sup> Medication adherence to endocrine therapy, which is standard of care of hormone receptor positive cancers, can be challenging for patients, in part due to a significant side effect profile, which includes hot flashes, vaginal dryness, dizziness, and increased risk of endometrial cancer, and many women may not even initiate therapy.<sup>53</sup> As evidenced in other populations, medication adherence is a complex issue with multiple factors at play, including a patient's beliefs about the risks and benefits of medication,<sup>54</sup> and health literacy certainly has a role. In a prospective study of 340 women with hormone positive breast cancer who were recommended adjuvant endocrine therapy, approximately 87% of patients started treatment. At two years, 79.4% of patients were adherent to therapy. Health literacy was measured by the Set of Brief Screening Questions (SBSQ), which is a 3-item patient reported health literacy assessment. Health literacy was not significantly associated with either initiation of therapy or adherence at follow-up.<sup>55</sup> Given this unexpected finding when compared to other populations, further study is needed to understand the effect of low health literacy on adjuvant therapy adherence in patients with breast cancer.

### *Perioperative care*

Perioperative care is an important component of the treatment of women with breast cancer. Much of the postoperative care in breast surgery is done in the outpatient setting. Patients with limited health literacy may have more information needs than those with proficient health literacy.<sup>56</sup> Data from other populations, such as patients undergoing ambulatory surgery at the Veterans Administration, has shown that patients with limited health literacy were less likely to adhere to preoperative instructions.<sup>57</sup> Lower health literacy has also been associated with worse comprehension of postoperative discharge instructions in general surgical patients.<sup>58</sup>

Several surgical subspecialties have explored the potential effect of health literacy on surgical outcomes. Limited health literacy was associated with lower expectations for walking after joint arthroplasty in an orthopedic surgical population, a decreased likelihood of transplant listing and increased waitlist mortality in a kidney transplant population, and lower rates of follow-up following discharge from the hospital after trauma.<sup>59–61</sup> In another study, limited health literacy was associated with increased odds of developing a minor postoperative complication, such as ileus, urinary tract infection, or wound infection, in patients who underwent radical cystectomy.<sup>62</sup> Similarly, lower health literacy may be associated with worse postoperative recovery and quality of life measured by various health surveys following elective surgery and with longer hospitalization length of stay in patients undergoing major abdominal surgery.<sup>63,64</sup> One study examined functional exercise adherence in postoperative breast cancer patients and demonstrated that patients with low health literacy were less likely to comply with rehabilitation.<sup>65</sup>

These studies highlight the importance of targeted care coordination postoperatively, such as the addition of a nurse navigator for those with limited health literacy.<sup>66</sup> A positive relationship may exist between cancer care coordination and quality of life in patients with low health literacy. As part of the Greater Plains

Collaborative study, women with Stage 0–3 breast cancer completed a quality of life questionnaire following completion of their cancer treatment. Results demonstrated that for those with low health literacy, care coordination by a dedicated health professional was associated with greater reported quality of life.<sup>67</sup> Multimedia education tools, in addition, may be effective to this end.<sup>68,69</sup>

A better understanding of the specific role health literacy plays in perioperative care of breast cancer patients may lead to improved outcomes, morbidity, and healthcare utilization in breast surgical oncology.

### Future directions

Surgery represents an important arena for health literacy research as patients are often required to understand and apply medical information in order to participate in shared decision-making. In addition, there is a wide range of pre- and post-operative instructions, new prescriptions, and clinic appointments to navigate. Surgical oncology and breast surgical oncology, in particular, highlight the need for coordination of care between patients and providers. Extrapolating from other disease populations, limited health literacy may detrimentally affect both understanding and outcomes in breast surgical oncology, as well as impact a patient's perceived health-related quality of life.<sup>70</sup> However, there is a lack of research exploring these concepts in surgical populations. In order to address this research question, we must be able to accurately and efficiently measure health literacy. In this way, we will be better able to correlate health literacy with important patient outcomes, treatment adherence, and quality of life. In fact, incorporating health literacy screening in outpatient clinics and electronic health records has been shown to be feasible and well-accepted.<sup>71,72</sup> Furthermore, in accordance with the Healthy People 2030 initiative, identifying ways in which healthcare providers can work together with patients and communities to improve understanding and utilization of health information is important. Developing interventions will be critical to achieving this goal, and as surgical consultation is often a patient's first interaction with the healthcare system, interventions aimed at improving health literacy at this juncture may have lasting and meaningful benefits in other aspects of breast cancer care. Continued education for providers of the effects of limited health literacy on patient care is crucial, and studies addressing the interaction of limited health literacy and outcomes in breast surgical oncology is needed in order to better optimize care of these patients.

### Funding

This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors.

### Author contributions

Jaclyn Portelli Tremont contributed to the literature search, writing, and critical revision of the manuscript. Stephanie Downs-Canner and Ugwuji Maduekwe contributed to the writing and critical revision of the manuscript.

### Declaration of competing interest

The authors report no proprietary or commercial interest in any product mentioned or concept discussed in this article. The authors have no direct or indirect conflicts of interest to report.

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