Social Determinants of Health and Health Literacy in Orthopaedic Surgery

Amanda Lans

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Sociale Gezondheidsdeterminanten in de Orthopedie

(met een samenvatting in het Nederlands)

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Amanda Lans
geboren op 8 november 1992
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Promotor:
Prof. dr. J.J. Verlaan

Copromotoren:
Dr. J.H. Schwab
Dr. L.P. Rossi

Beoordelingscommissie:
Prof. T. Gosens
Prof. dr. L.M.O. de Kort
Prof. dr. L. van Rhijn
Dr. T.J. Snijders
Prof. dr. H.M. Verkooijen (voorzitter)

Dedicated to my greatest inspiration,
my mother, Katja.

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Chapter 1

General Introduction

GENERAL INTRODUCTION

Social Determinants of Health

Social determinants of health (SDOH) have gained increasing recognition as a major health risk and a critical factor influencing treatment outcomes. For example, unfavorable SDOH, particularly housing instability and food insecurity, are associated with worse medication adherence, a notion critical for the treatment of chronic conditions.[1] Furthermore, an individual's SDOH, for instance their socioeconomic status, level of education or employment status, may determine their use of necessary healthcare interventions such as physical therapy.[2]

Access to care is also impacted by SDOH, for example, having public insurance delays diagnosis and increases time to treatment in patients who a suffer an anterior cruciate ligament tear.[3] Similarly SDOH have been demonstrated to influence surgical and patient reported outcomes in patients undergoing rotator cuff repair.[4]

As such, SDOH, which are defined by social structures and socioeconomic patterns, may be the most powerful factors determining general health and treatment outcomes.[5] SDOH are commonly categorized into five domains, namely: economic stability, living environment, educational attainment, access to care and social support (Figure 1).[6] These SDOH should be seen in context with each other as they are undeniably interconnected. To demonstrate: educational attainment generally impacts employment opportunities, which in turn will affect economic stability, access to care, living environment and social support. Although all SDOH domains contribute to treatment outcomes, some may play a larger role than others, depending on the circumstance. For instance, economic stability, or in this case financial insecurity, will have a bigger impact than living environment if patients are unable to pay for treatments, medication, or transportation to a clinic. However, living environment will play a larger role in preventing chronic diseases, including back pain.[7]

The accumulating literature suggesting that the majority, up to 80%, of health outcomes are attributable to favorable SDOH has inspired researchers to investigate these determinants in more detail.[8–10] However, the evaluation of SDOH in orthopaedic populations has been limited. SDOH may be understudied in orthopaedics for several reasons. Firstly, orthopaedic researchers and clinicians may not be aware of how SDOH impact their patients and consequently their treatment outcomes. Additionally, lack of training regarding how to address SDOH in clinical practice, or lack of available resources, limits a clinicals ability to address the different social needs their patients present with. Furthermore, the complex and multifaceted nature of SDOH make it challenging to collect, measure and analyze data on these factors. This may make the topic less popular for investigators. Besides that, the orthopaedic

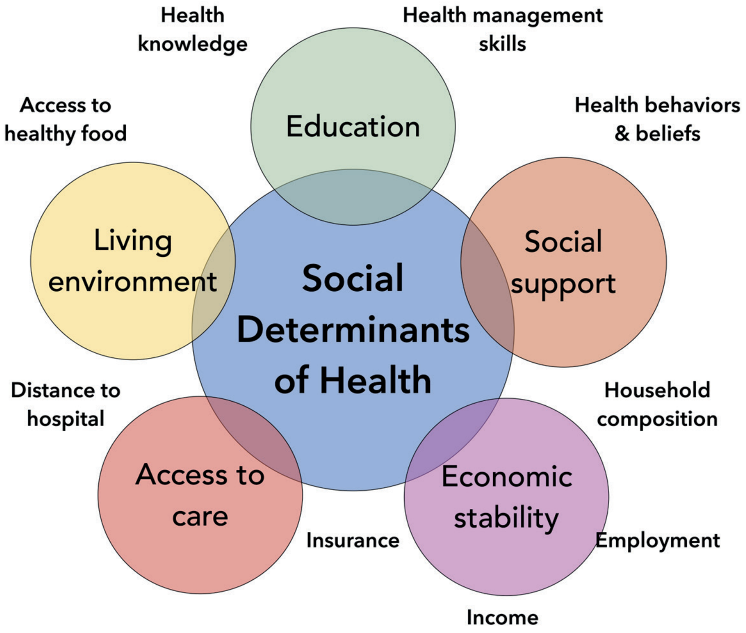

Figure 1 SDOH domains with domain related examples

field has traditionally focused on biomedical interventions, such as surgery and medications, rather than on addressing SDOH. The emphasis on biomedical interventions may have resulted in a lack of consideration and research on the impact of SDOH in orthopaedic patient populations. Finally, orthopaedic research is often funded by private companies or government agencies that may not prioritize research on SDOH. These organizations may primarily focus on research that has direct clinical applications or has a high potential for generating revenue. Addressing these barriers is essential to advancing the understanding of how SDOH impact orthopaedic treatment outcomes and developing more effective approaches to care.

When investigating the impact of SDOH on clinical outcomes, researchers often focus on downstream determinants, such as health behaviors or attitudes. These downstream factors are typically assessed in relation to clinical outcome measures, such as pain levels and disease-specific scores.[11,12] Studies often fail to account for the fundamental relationships with upstream determinants influencing health such as economic resources and social opportunities.[13] For example, lower educational attainment has consistently been associated with increased pain and disability in osteoarthritis patients.[14] One reason for this association could be that individuals with lower educational attainment may healthcare resources less accessibly, including information about self-care strategies and appropriate pain management techniques. As a result, they may not receive optimal treatment for their condition, leading to increased pain and disability. Also, those with less education are more likely to have negative health behaviors which lead to a high body mass index throughout their life course, which in turn contributes to the risk of symptomatic osteoarthritis.[15] Furthermore, there are reports that less educational attainment is predictive of poor outcome in patients presenting with non-spinal musculoskeletal pain in a primary care setting.[16,17] Other studies have also demonstrated benefits of neighborhoods with enhanced walkability, including lower prevalence of knee and low back pain and more engagement in regular fitness programs and social activities.[18,19] A literature review assessing complications after total hip and/or knee replacement in racial and ethnic minority groups found that the minority groups appear to have a higher risk of joint infection and higher mortality rate within 90-days.[13] This may be due to the fact that Black patients have greater difficulty in accessing the proper health care providers and that there is a general underutilization of medical services by Black individuals.[20–22] It has also been demonstrated that the race and ethnicity of patients undergoing total knee and hip arthroplasty is correlated with the degree of patient-reported outcome measure improvement. Additionally, patient-reported outcome scores have been linked to education, gender, comorbidities, and neighborhood poverty.[23] The mentioned studies and related research call for further investigation into the role of SDOH and their impact on shaping musculoskeletal health.

It is challenging to develop internally valid research methods when investigating SDOH, and a scarcity of research that integrates SDOH in orthopaedic outcomes remains.[24] This could be in part because SDOH are multifaceted and complex, encompassing factors such as socioeconomic status, race and ethnicity, gender, and geography. These factors are generally interconnected and can influence each other, making it difficult to isolate individual factors and establish causal relationships. Additionally, measuring SDOH can be challenging, as these factors are often subjective and difficult to quantify. For example, measuring socioeconomic status may involve using income, education, or occupation as proxies, each of which has its limitations. Conducting SDOH research often involves sensitive topics such as poverty, discrimination, and access to healthcare. This can raise ethical concerns, as researchers need to ensure that they do not harm participants by perpetuating existing inequalities. Overall, developing internally valid research methods for SDOH requires careful consideration of these and other factors, as well as an awareness of the potential limitations and biases inherent to the research process. The incorporation of SDOH in evolving technologies or research methods, such as machine learning (ML), should also not be overlooked. Disregarding SDOH when building prediction models can perpetuate underlying inequities, amplifying health disparities.[25,26]

Although many aspects in the context of SDOH may be difficult to change, understanding mediators and moderators and their associations can provide opportunities for effective interventions to improve health outcomes.[27] It will be critical to translate the assessment of SDOH into daily clinical care in order to effectively optimize patient care and recovery while mitigating health disparities.

What has yet to be explored are the tangible markers for unfavorable SDOH which can easily be obtained in routine healthcare processes. One promising mediator for SDOH may be a patient's level of health literacy as limited health literacy has been associated with more health risks and poorer treatment outcomes.[28–32] Yet, screening for unfavorable SDOH will in turn require meaningful interventions and dedicated resources. Developing, implementing and demonstrating that such endeavors are worthwhile will require considerable investments and thoughtful investigations. In order to address SDOH in healthcare institutions, there are several general ideas that could be implemented. One approach is to evaluate and organize available resources by conducting audits across the institution and surrounding community. This would allow for the inventory of readily available resources to be accessed efficiently by both patients and providers. Another approach is to implement screening tools that identify patients who may be experiencing unfavorable SDOH, such as food insecurity, housing instability, or financial strain. The screening results can then be used to provide appropriate resources or referrals, provided that they are in place and readily available. Health care providers can also work with social workers, community health workers, or other non-clinical team members as part of collaborative care teams to offer patients resources and support related to SDOH. These teams can assist patients in finding housing or employment, connecting with community resources, and accessing counseling or behavioral health services. Finally, health care providers can advocate for policy changes that address SDOH, such as increasing funding for affordable housing or expanding access to healthcare services. By implementing these approaches, healthcare institutions can more effectively address SDOH and improve patient outcomes.

Health Literacy

Adequate health literacy (HL) is a prerequisite for appropriate self-care and successful navigation of the healthcare system. HL is commonly defined as an individual's ability to obtain, understand, and comprehend information regarding their health, medical conditions, treatments, and long-term care.[33] However, this definition falls short of encompassing the true complexity of HL by focusing primarily on the individual's baseline comprehensive abilities. While a patient's ability to attain, comprehend, and utilize new information may be improved by basic literacy skills such as proficient reading and writing, there is no guarantee these will be consistent in a health-related context. Health contexts are unique in comparison to other contexts, because of underlying stress or fear.[34] This becomes evident when a patient is placed in an unfamiliar circumstance that requires specific content knowledge for health-related decision-making.[35]

Limited HL has been linked to many disparities and is associated with increased risks of illness and poorer treatment outcomes.[28–32] Patients with limited HL often struggle with important decisions regarding how to seek care and making informed decisions about treatments.[36] As a result, healthcare utilization and related expenditures are often increased due to a higher number of readmissions and longer hospital stays. The impact of limited HL has typically been a concern in the self-management of chronic illness although it is increasingly recognized as a risk for surgical patients.[37,38] It has previously been demonstrated that patients with HL have more emergency room visits but less self-directed care and healthcare engagement.[39–42] Given these associations, one can hypothesize that provider knowledge of a patient's HL level will affect the effectiveness of care delivery. With this information, clinicians can mitigate the impact of limited HL on orthopaedic care. This can be done by using plain language when communicating with patients, providing written materials at an appropriate reading level, and offering additional resources, such as visual aids and interpreters, when necessary. By doing so, patients gain a better understanding of their condition and treatment options, leading more informed decision-making and a better overall patient experience.

HL can have a significant impact on orthopaedic care. Patients with limited HL have difficulty understanding medical terminology and instructions related to their care, which can lead to confusion and misunderstandings. Consequently, they may be less likely to follow recommended treatments, leading to poorer outcomes and higher healthcare costs. In orthopaedic care, this is especially important because patients often require complex surgeries and lengthy rehabilitation programs. In addition, patients with limited HL may be less likely to seek care when needed or communicate effectively with their health care providers. This can lead to delayed diagnosis and treatment, which can further exacerbate their orthopaedic conditions.

As such, HL carries relevance for orthopaedic patient populations and could offer a tangible measure that is also actionable. The potential benefits of addressing limited HL in orthopaedic patients and the subsequent impact on health and treatment outcomes have yet to be revealed. It can be argued that tackling an issue of this magnitude can result in substantial benefits for patient, provider and the healthcare system at large. Benefits may include less progressed disease at presentation, less delay to treatment, better treatment adherence and higher patient satisfaction. Finally, health-related education prior to a patient's pre- and postoperative care has the potential to improve shared decision making and ultimately patient outcomes. Arguably this could also decrease unnecessary or inappropriate healthcare utilization.

The utility of HL in clinical practice remains to be determined. This will require large, high-quality trials across diverse demographics and geographies. An improved body of literature is the necessary foundation for targeted HL interventions that have the highest potential for meaningful improvement of care.

In this thesis, the role of SDOH in orthopaedic care is described with particular attention to the impact of HL (Figure 2).

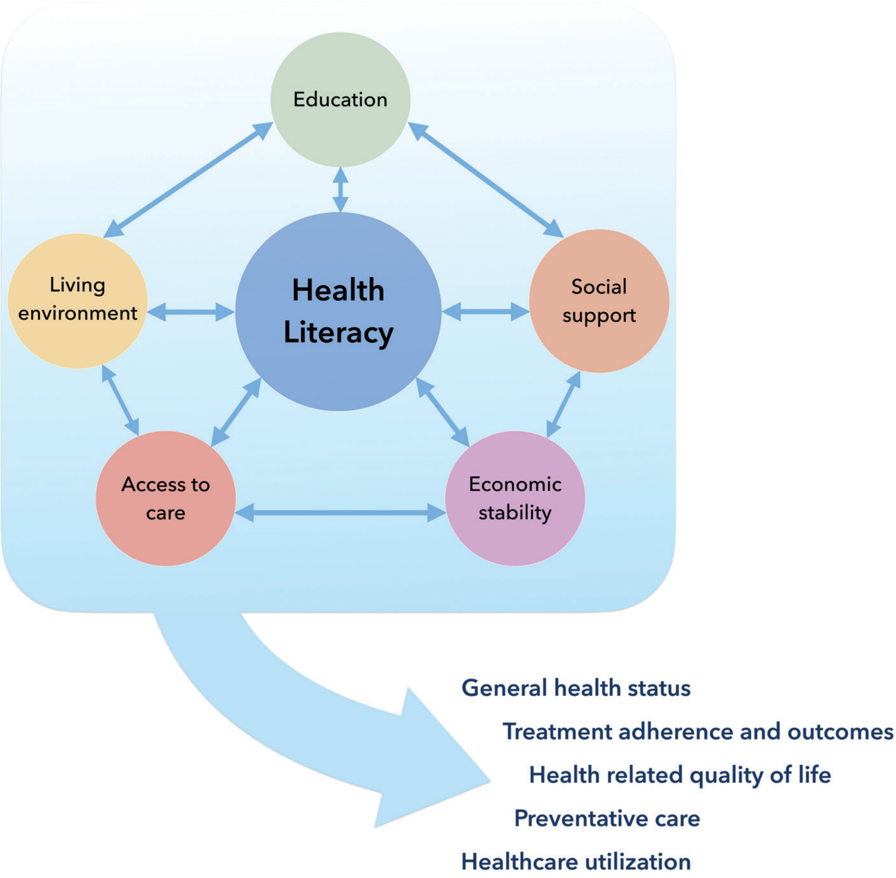

Figure 2 Health Literacy as a potential SDOH mediator and related downstream consequences

THESIS OUTLINE

To effectively address health inequities arising from systematic differences in opportunities that arise due to disparities in social determinants of health (SDOH) among orthopaedic patients, it is crucial to identify the key patient-level SDOH characteristics that impact health outcomes. This requires a comprehensive understanding of the issue, which is the aim of this thesis. Through the exploration of health literacy as a tangible mediator of SDOH, this thesis sets out to establish a strong foundation for SDOH research in the field of orthopaedics. By shedding light on the impact of SDOH and identifying health literacy as a potential avenue for improving care and mitigating disparities, this research aims to pave the way for more equitable and effective orthopaedic healthcare.

Part I of this thesis delves into the complex interplay between patient-specific SDOH characteristics, traditional sociodemographic variables, and their impact on physical and mental health outcomes among patients seeking orthopaedic care. The significance of SDOH is further explored with regards to equitable reporting in machine learning risk prediction models for orthopaedic outcomes, highlighting the importance of addressing health disparities in patient care. In addition to traditional determinants of health, this thesis also focuses on the lesser-recognized determinant and mediator of health - health literacy. The role of health literacy in orthopaedic practice in **Part II**. This section investigates the degree of health literacy in two distinct patient populations, namely spine patients and patients with metastatic bone disease. In **Part III**, the impact of limited health literacy on patient-reported outcomes and health-related quality of life is examined. Finally, this thesis concludes with an assessment of the effectiveness of current tools for identifying patients with limited health literacy and the reliability of self-reported health literacy, providing a roadmap for future research in this critical area.

Part I – Social Determinants of Health

Are patients seeking orthopaedic care impacted by specific social vulnerabilities?
To what extent are social determinants of health considered when developing prognostic machine learning models for orthopaedic outcomes?
Why is health literacy relevant for orthopaedic practice?
How many studies use validated measures of health literacy in patients undergoing orthopaedic surgery?

Disparities in healthcare access are a global challenge, with avoidable inequalities existing both within and between countries.[43,44] At the heart of these inequities are socioeconomic patterns that drive differential access to care and contribute to varying health outcomes. In essence, health inequities refer to the unjust differences in health status and access to healthcare that disproportionately affect disadvantaged populations.[5] The need for a comprehensive understanding of these complex issues is critical in developing effective strategies to tackle health inequities and promote health equity globally. Current literature suggests health outcomes are predominantly attributable to SDOH whereas direct medical care may have less of an impact.[45–47]

Indeed, SDOH have been shown to be associated with patient symptoms, accessibility of care, and clinical outcomes.[48] However, patient-specific SDOH characteristics, such as difficulty paying for medication or unreliable transportation, are not routinely considered. Therefore, **chapter 2** evaluates the role of patient-specific SDOH characteristics in addition to traditional sociodemographic variables on presenting physical and mental health among patients seeking orthopaedic care.

In **chapter 3**, equitable reporting of SDOH is explored in novel and increasingly popular decision-making support tools, namely, machine learning (ML) models. Existing orthopaedic ML models cover an array of surgical outcomes such as survival, complications, and re-operation.[49–52] Models use preoperative variables, such as presence of metastatic disease, functional status and blood values, to provide individualized risk predictions. However, these models have an inherent risk of unintended negative consequences if the data is biased. Taking SDOH into consideration in the early stages of model development can limit unintentional perpetuation of health inequalities. Following this exploration of SDOH in ML models, **chapter 4** begins to focus on one patient-specific determinant of health, namely, health literacy. This chapter elaborates on how health literacy affects orthopaedic patients and clinical practice. This is followed by **chapter 5**, in which literature regarding health literacy in orthopaedic surgery patients is systematically reviewed. As previously defined by Okan et al. health literacy "addresses a range of social dimensions of health, including knowledge, navigation and communication, as well as individual and organizational skills for accessing, understanding, evaluating and using information".[53] Although far from a new concept, health literacy is a mediating factor of health disparities and impacts individual and public health.[54] Despite the growing concern for limited health literacy among adults, it has received little consideration in the field of orthopaedics.

Part II – Assessment of Patient Health Literacy

What is the degree of health literacy and cancer health literacy in patients with metastatic bone disease?

What is the prevalence of- and factors associated with limited health literacy in orthopaedic spine patients?

Health literacy is a dynamic, multifaceted skill set that relies on health care providers and patients. It carries serious implications for overall health, safety, expectations, treatment outcomes and healthcare costs. Patients with limited health literacy are less likely to engage in disease management and more likely to misunderstand health information, which can lead to adverse treatment effects and misutilization of medical resources.[55–60] National survey data suggest that only 12% of adults have sufficient health literacy skills to manage their own health and navigate the complexities of the current healthcare system.[61] However, the consideration of health literacy in the orthopaedic surgery arena is limited. This may be due to the surgical nature of the discipline, placing an emphasis on surgical advancements. In order to bridge this gap, in **chapter 6**, health literacy and cancer health literacy are studied in patients with metastatic bone disease. This is followed by **chapter 7**, in which the prevalence of- and factors associated with limited health literacy in orthopaedic spine patients is investigated.

Part III – Health Literacy in Clinical Practice

What role does health literacy play in patients-reported outcome measurement scores?
Does health literacy impact health-related quality of life?
What is the reliability of self-reported health literacy?
Health literacy may also directly impact clinically important metrics, such as patient-reported outcome measures (PROMs). PROMs have become a central tool in assessing symptom severity and treatment success in patients presenting to orthopaedic spine clinics.[62,63] However, the influence of patient health literacy level on PROMs is unknown. As such, **chapter 8** investigates the impact of health literacy on self-reported health measures. Furthermore, **chapter 9** examines the role of health literacy in determining health-related quality of life.

Identifying patients with limited health literacy is important to mitigate health inequality, as clinicians can take specific actions to ensure that patients have sufficient understanding of their condition and treatment. One way for clinicians to help patients with limited health literacy comprehend health information is by appropriately allocating resources where necessary, provided that such resources are available. A self-reported screening questionnaire can be a practical way to identify limited health literacy while considering clinical resource limitations. However, self-reported assessments that identify individuals vulnerable to limited health literacy may either overestimate or underestimate the prevalence within particular patient populations. Therefore, **chapter 10** examines the reliability of self-reported health literacy screening in spine patients.

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Part I

Social Determinants of Health

Chapter 2

Social Determinant of Health Factors Associated with Physical Function and Mental Health among Patients with Orthopaedic Conditions

David N. Bernstein, Amanda Lans, Aditya V. Karhade, Marilyn Heng, Rudolf W. Poolman,
Joseph H. Schwab, Daniel G. Tobert

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ABSTRACT

Background: It is well documented that routinely collected patient sociodemographic characteristics and geography-based social determinants of health (SDOH) measures are associated with health disparities, including symptom severity at presentation. However, the association of patient-level SDOH factors on musculoskeletal health disparities is not as well documented. Such insight might help with the development of more-targeted interventions to help address health disparities in orthopaedic surgery. Therefore, the purpose of this study was to answer the following questions: (1) What percentage of patients presenting for new patient visits in an orthopaedic surgery clinic who were unemployed but seeking work reported transportation issues that could limit their ability to attend a medical appointment or acquire medications, reported trouble paying for medications, and/or had no current housing? (2) Accounting for traditional sociodemographic factors and patient-level SDOH measures, what factors are associated with poorer patient-reported outcome physical health scores at presentation? (3) Accounting for traditional sociodemographic factor patient-level SDOH measures, what factors are associated with poorer patient-reported outcome mental health scores at presentation?

Methods: New patient encounters at one Level 1 trauma center clinic visit from March 2018 to December 2020 were identified. Included patients had to meet two criteria: they had completed the Patient-Reported Outcome Measure Information System (PROMIS) Global-10 at their new orthopaedic surgery clinic encounter as part of routine clinical care, and they had visited their primary care physician where they completed a series of specific SDOH questions. The SDOH questions focused on transportation, housing, employment, and ability to pay for medications. Two multivariable linear regression models were created to determine which traditional metrics and patient-specific SDOH factors were associated with worse physical and mental health symptoms at initial presentation. The concept of minimum clinically important difference (MCID) was used to assess clinical importance.

Results: Among the 9057 included patients, 8% (685/9057) were unemployed but seeking work, 4% (399/9057) reported transportation issues that could limit their ability to attend a medical appointment or acquire medications, 4% (328/9057) reported trouble paying for medications, and 2% (181/9057) had no current housing. Lack of reliable transportation to attend doctor visits or pick up medications (β = -4.52 [95% CI -5.45, -3.59]; p < 0.001), trouble paying for medications (β = -4.55 [95% CI -5.55, -3.54]; p < 0.001), Medicaid insurance (β = -5.81 [95% CI -6.41, -5.20]; p < 0.001), and workers compensation insurance (β = -5.99 [95% CI -7.65, -4.34]; p < 0.001) were associated with clinically worse function at presentation. Trouble paying for medications (β = -6.01 [95% CI -7.10, -4.92]; p < 0.001), Medicaid insurance

($\beta = -5.35$ [95% CI -6.00, -4.69]; $p < 0.001$), and workers compensation ($\beta = -6.07$ [95% CI -7.86, -4.28]; $p < 0.001$) were associated with clinically worse mental health at presentation.

Conclusion: Although transportation issues and financial hardship were found to be associated with worse presenting physical function and mental health, Medicaid and workers compensation insurance remained associated with worse presenting physical function and mental health after controlling for these more detailed, patient-level SDOH factors. Because of that, interventions to decrease health disparities should focus on not only sociodemographic variables but also tangible patient-specific SDOH characteristics. For example, this may include giving patients taxi vouchers or ride-sharing credits to attend clinic visits for patients demonstrating such a need, initiating financial assistance programs for necessary medications, and/or identifying and connecting certain patient groups with social support services early on in the care cycle.

INTRODUCTION

Disparities in healthcare access and outcomes exist in the United States.[1] Socioeconomic patterns are a predominant factor driving this disparity.[2] This broad entity can be organized into social determinants of health (SDOH), which includes economic stability, living environment, educational attainment, as well as access to healthcare and social support. Current research suggests that direct medical care may have less of an impact on healthcare outcomes than SDOH, which may play a more outsized role than previously thought.[3–5] Indeed, SDOH have been shown to be associated with patient symptoms, access to care, and clinical outcomes.[6]

Recent scholarly endeavors have sought to better appreciate the relationship between SDOH factors and musculoskeletal care. For example, prior research on surgical outcomes demonstrates that a number of routinely collected patient sociodemographic characteristics are associated with important differences in resource use and clinical outcomes. Black race (as designated in the Nationwide Inpatient Sample) was found to be associated with greater risk of complications and discharge to a facility (rather than home) after undergoing total joint arthroplasty.[7] Of note, it is important to consider race in context and remember that race is often times a proxy variable for the true underlying factor associated with poorer outcomes or access.[8,9] Additionally, Medicaid insurance was found to be associated with decreased access to orthopaedic care compared with commercial insurance.[10] Separate efforts have used geographically organized measures (such as the Area Deprivation Index) to identify disparities in patients presenting with symptoms and undergoing hand surgery, spine surgery, and surgery in a range of orthopaedic subspecialties.[11–14] These measures provide additional insight into healthcare disparities, and the inclusion of the national Area Deprivation Index is recommended in orthopaedic studies that consider socioeconomics.[15] However, the use of geographic grouping precludes patient-specific correlations. As the healthcare community continues to address musculoskeletal health disparities, it is important to assess the association between patient-specific SDOH characteristics, such as food insecurity, housing instability, challenges with affording medication, lack of reliable transportation, educational attainment, and employment status, and a patient's ability to cope with and manage symptoms, disease, and injury. When doing so, it is also vital that health care professionals remain cognizant of and resistant to the cognitive biases that may be introduced with the assessment of patient-specific SDOH characteristics.[16] Nonetheless, such insight can allow for the development of more targeted initiatives and interventions that may lead to better clinical care and outcomes for patients.

We therefore asked: (1) What percentage of patients presenting for new patient visits in an orthopaedic surgery clinic who were unemployed but seeking work reported transportation issues that could limit their ability to attend a medical appointment or acquire medications, reported trouble paying for medications, and/or had no current housing? (2) Accounting for traditional sociodemographic factors and patient-level SDOH measures, what factors are associated with poorer patient-reported outcome physical health scores at presentation? (3) Accounting for traditional sociodemographic factors and patient-level SDOH measures, what factors are associated with poorer patient-reported outcome mental health scores at presentation?

METHODS

Study Design and Setting

This is a cross-sectional study performed at one Level 1 academic trauma medical center. The institution is located in a large city in the northeastern United States, and patients from all orthopaedic subspecialties were eligible for inclusion.

Participants

We identified all new patients presenting for an orthopaedic surgery clinic visit and who had visited their primary care physician at Massachusetts General Hospital between March 1, 2018, and December 31, 2020, using our institution's patient database. As part of routine orthopaedic clinical care, patients were asked to complete the Patient-Reported Outcomes Measure Information System (PROMIS) Global-10, a 10-question patient-reported outcome measure (PROM) that assesses a patient's overall physical and mental health.[17] In addition, during the study period, patients visiting their primary care physician—if the provider was affiliated with our institution—were asked to complete a series of SDOH questions (Supplementary Digital Content 1; http://links.lww.com/CORR/A963). Thus, patients included in our study met the following two criteria: new patient visit to an orthopaedic surgery clinic at our institution with completion of the PROMIS Global-10 and a primary care visit at our institution with completion of the SDOH questionnaire. Although our institution measured aspects of SDOH for patients before this period, the yearly screening requirement for Medicaid Accountable Care Organizations provided an opportunity for our institution to develop a more comprehensive approach to collect and measure specific SDOH outcomes for all patients seeking primary care services beginning in March 2018.[18,19] In the current study, the primary SDOH questions of interest focused on housing insecurity, unemployment, challenges with affording medication, and transportation issues that could limit the patient's ability to attend a medical appointment or acquire medications. Patients who completed the PROMIS Global-10 questionnaire and at least one SDOH question of interest were included. The Area Deprivation Index was not included as a variable, given the overlap between the patient-specific factors used and the factors incorporated into the area-based calculation of the

Area Deprivation Index. In addition, the following characteristics were recorded: age (in years), gender (women or men), self-reported race (White, Black, Asian, or other), language (English or non-English/unknown), marital status (married, single, divorced, widowed, or other), payor (commercial, Medicaid, Medicare, workers compensation, and other), questionnaire completion location (office or electronic medical record portal), and orthopaedic subspecialty (hand, foot and ankle, trauma, arthroplasty, oncology, spine, or other).

Because we did not have a way to determine how many patients had both primary care provider office visits and new orthopaedic surgery clinic visits over the study period, we were unable to determine how many patients could have been included. Overall, 9057 patients met our inclusion criteria. To get a better sense of how this study cohort compared with the overall patient population seen at the participating center during the time in question, we reviewed all new patient clinic encounters (n = 135,223). The demographic information between the full patient sample and our study subgroup appeared similar.

Patient Characteristics

Among the patients, the mean age was 61 ± 15 years, most were women (61%; 5551/9057), and most were White (83%; 7561/9057) (Table 1). More than two-thirds of patients completed their PROMs in the outpatient clinic at the time of the encounter (67%; 6035/9057), and the remainder completed their assigned PROMs via the electronic medical record portal before the appointment (33%; 3022/9057). Our patient sample is similar to the overall orthopaedic patient population treated at this center over the same timeframe (Supplementary Digital Content 2; http://links.lww.com/CORR/A964).

Ethical Approval

This retrospective observational study was approved by our institutional review board.

Statistical Analyses

After descriptive statistics were calculated, two multivariable linear regression models were created. One model included the PROMIS Global Physical Health as the dependent variable and the other had the PROMIS Global Mental Health as the dependent variable. To ensure the models did not include excessive multicollinearity, we used the variance inflation factor. Multicollinearity was considered present if the variance inflation factor was greater than five.[20] Across both multivariable regression models, the variance inflation factor was less than two, suggesting no need to address multicollinearity.

Regression coefficients were considered in the context both of clinical importance and statistical significance. Effect size was evaluated using the minimum clinically important difference (MCID); that is, the minimum change in a given PROM score that represents true

Table 1 Patient characteristics (n = 9057)	
Age in years (SD)	61 (15)
Gender	
Female	61 (5551)
Male	39 (3506)
Self-reported race	
White	83 (7561)
Black	3 (298)
Asian	6 (570)
Other	7 (628)
English language speakers	96 (8736)
Marital status	
Married	53 (4804)
Single	30 (2732)
Divorced	8 (751)
Widowed	6 (503)
Other	3 (267)
Payor	
Commercial	46 (4167)
Medicaid	15 (1363)
Medicare	37 (3318)
Workers compensation	1 (134)
Other	1 (75)
Questionnaire completion location	
Office	67 (6035)
EMR* portal	33 (3022)
Orthopaedic subspecialty	
Hand	33 (3006)
Foot & ankle	12 (1083)
Trauma	18 (1598)
Arthroplasty	17 (1540)
Oncology	7 (628)
Spine	12 1047
Other	2 (155)

Data presented as % (n) or mean and standard deviation (SD); *Electronic medical record.

clinical improvement (or worsening) appreciated by a patient.[21] For the PROMIS Global Physical Health, we used an MCID of 4.2, which represents an evidence-based anchor-based estimate.[22] For PROMIS Global Mental Health, we used an MCID value of 5.1, which was calculated using the distribution-based approach. We did not find an anchor-based MCID estimate for the PROMIS Global Mental Health. The concept of MCID was used to assess clinical importance in the following way: regression coefficients represented the projected change in PROMIS physical or mental health symptom scores (that is, the dependent variable in our regression analyses), accounting for the other included variables. Thus, a regression coefficient for a given variable at or above a known MCID value suggests a clinical difference between those patients with and without the presence of that given characteristic. For all analyses, p values < 0.05 were considered significant, whereas regression coefficients at or above 4.2 (or at and below -4.2) for PROMIS Global Physical Health and at or above 5.1 (or at and below -5.1) for PROMIS Global Mental Health were considered clinically important.

RESULTS

Percentage of Patients with Challenging Social Determinants of Health

In this cohort, 8% (685/9057) were unemployed but seeking work, 4% (399/9057) reported transportation issues that could limit their ability to attend a medical appointment or acquire medications, 4% (328/9057) reported trouble paying for medications, and 2% (181/9057) had no current housing (Table 2).

Table 2 Patient sample characteristics (n = 9057)

Social determinant of health	Value
Patients who lack transportation	4 (399)
Patients with no current housing	2 (181)
Patients with trouble paying for medications	4 (328)
Patients who are unemployed but looking for work	9 (685)

Data presented as % (n)

Factors Associated with Poorer Scores for Physical Health

Lack of reliable transportation to attend doctor visits or collect medications (β = -4.52 [95% CI -5.45, -3.59]; p < 0.001) and trouble paying for medications (β = -4.55 [95% CI -5.55, -3.54]; p < 0.001) were associated with worse physical health at presentation (Table 3). Additionally, Medicaid (β = -5.81 [95% CI -6.41, -5.20]; p < 0.001) and workers compensation insurance (β = -5.99 [95% CI -7.65, -4.34]; p < 0.001) were also associated with worse physical health at presentation. The β coefficients for these four variables met or exceeded the MCID estimate for the PROMIS Global Physical Health, suggesting the effect sizes are clinically important. As a reminder, these findings indicate that patients with a lack of reliable transportation to attend doctor visits or collect medications have PROMIS Global Physical Health scores that represent clinically worse physical function than those who do not have this challenge, even when accounting for other factors.

Table 3 Multivariable linear regression analysis for PROMIS Global Physical Health

Characteristics	β coefficient (95% CI)	p value
Age	-0.03 (-0.046 to -0.013)	**< 0.001**
Gender		
Female	Reference	
Male	1.46 (1.08 to 1.84)	**< 0.001**
Race		
White	Reference	
Black	-1.12 (-2.14 to -0.10)	0.032
Asian	-1.72 (-2.48 to -0.95)	**< 0.001**
Other	-2.51 (-3.26 to -1.76)	**< 0.001**
Marital status		
Married	Reference	
Single	-1.24 (-1.69 to -0.79)	**< 0.001**
Divorced	-2.85 (-3.54 to -2.16)	**< 0.001**
Widowed	-2.55 (-3.39 to -1.71)	**< 0.001**
Other	-0.76 (-1.84 to 0.32)	0.169
Payor		
Commercial	Reference	
Medicaid	-5.81 (-6.41 to -5.20)	**< 0.001**
Medicare	-2.38 (-2.85 to -1.90)	**< 0.001**
Workers compensation	-5.99 (-7.65 to -4.34)	**< 0.001**
Other	-1.57 (-3.70 to 0.57)	0.150
Questionnaire completion location		
Office	Reference	
EMR* portal	0.32 (-0.07 to 0.70)	0.109
Lack of transportation	-4.52 (-5.45 to -3.59)	**< 0.001**
No current housing	-3.17 (-4.50 to -1.83)	**< 0.001**
Trouble paying for medications	-4.55 (-5.55 to -3.54)	**< 0.001**
Unemployed but looking for work	-1.59 (-2.32 to -0.86)	< 0.001

Boldface type indicates statistical significance ($p < 0.05$); CI = confidence interval; β = β coefficient; For categorical variables, the β coefficient reflects the change in PROMIS score that would occur assuming all else remains constant; for example, patients who have troubling paying for medications have a decrease in their PROMIS Global Physical Health score of 4.55. For continuous variables, the β coefficient reflects the change in PROMIS score that would occur assuming all else remains constant for each one-unit change; for example, for each year older, patients have a decrease in their PROMIS Global Physical Health score of 0.03. The r^2 of this regression model is 0.15; this means that the independent variables in this model account for 15% of the observed variance in dependent variable, or PROMIS Global Physical Health; *Electronic medical record.

Factors Associated with Poorer Scores for Mental Health

Trouble paying for medications was associated with worse mental health at presentation (β = -6.01 [95% CI -7.10, -4.92]; p < 0.001). Medicaid (β = -5.35 [95% CI -6.00, -4.69]; p < 0.001), workers compensation (β = -6.07 [95% CI -7.86, -4.28]; p < 0.001), and other insurance type (β = -6.25 [95% CI -8.56, -3.94]; $p < 0.001$) were associated with worse presenting mental health (Table 4). The β coefficients for these four variables met or exceeded the MCID for the PROMIS Global Mental Health, suggesting the effect sizes are clinically important.

Table 4 Multivariable linear regression analysis - PROMIS Global Mental Health

Characteristics	**β coefficient (95% CI)**	**p value**
Age	0.02 (0.004, 0.040)	0.016
Sex		
Female	Reference	
Male	0.90 (0.49, 1.31)	**< 0.001**
Race		
White	Reference	
Black	-2.30 (-3.41, -1.20)	**< 0.001**
Asian	-0.81 (-1.64, 0.01)	0.054
Other	-2.35 (-3.16, -1.54)	**< 0.001**
Marital status		
Married	Reference	
Single	-2.77 (-3.26, -2.28)	**< 0.001**
Divorced	-4.06 (-4.81, -3.31)	**< 0.001**
Widowed	-3.08 (-3.99, -2.17)	**< 0.001**
Other	-1.34 (-2.51, -0.17)	0.025
Payor		
Commercial	Reference	
Medicaid	-5.35 (-6.00, -4.69)	**< 0.001**
Medicare	-2.96 (-3.47, -2.45)	**< 0.001**
Workers compensation	-6.07 (-7.86, -4.28)	**< 0.001**
Other	-6.25 (-8.56, -3.94)	**< 0.001**
Questionnaire completion location		
Office	Reference	
EMR* portal	1.05 (0.64, 1.47)	**< 0.001**
Lack of transportation	-4.19 (-5.19, -3.18)	**< 0.001**
No current housing	-4.04 (-5.48, -2.59)	**< 0.001**
Trouble paying for medications	-6.01 (-7.10, -4.92)	**< 0.001**
Unemployed but looking for work	-2.01 (-2.80, -1.22)	**< 0.001**

Boldface type indicates statistical significance ($p < 0.05$); CI = confidence interval; β = β coefficient; For categorical variables, the β coefficient reflects the change in PROMIS score that would occur assuming all else remains constant; for example, patients who have trouble paying for medications have a decrease in their PROMIS Global Mental Health score of 6.01. For continuous variables, the β coefficient reflects the change in PROMIS score that would occur assuming all else remains constant for each one-unit change; for example, for each year older, patients have an increase in their PROMIS Global Mental Health score of 0.02. The r^2 of this regression model is 0.16; this means that the independent variables in this model account for 16% of the observed variance in dependent variable, or PROMIS Global Mental Health; *Electronic medical record.

DISCUSSION

A growing body of studies in orthopaedic surgery are focusing on understanding health disparities better, but much of this work focuses on broad, nonspecific SDOH variables or traditional sociodemographic factors (such as race) that do not address the core reasons for these disparities. It is important to understand what aspects drive healthcare inequity at a more detailed level to help guide public policy and individual interventions. Additionally, an understanding of these aspects provides an essential context for clinical outcomes research that seeks to improve the value of healthcare. In the present study, we found a minority of patients reported having transportation issues that affected medical care, unstable housing, financial hardship with medications, and unemployment. Nevertheless, extrapolated to the general population, a sizeable number of patients are impacted by unfavorable SDOH factors. We did not see a relationship of housing instability and unemployment with clinically worse physical health or mental health. However, the results from this study indicate that a lack of transportation and trouble paying for medications were associated with worse physical health at presentation. Trouble paying for medications was also associated with worse presenting mental health. Even after accounting for specific SDOH confounders, Medicaid and workers compensation insurance remained associated with worse presenting physical and mental health, suggesting other elements engrained in these insurance variables are important to determine and consider. Implementing initiatives to address these findings may include providing taxi or ride-sharing credits to patients who otherwise do not have reliable transportation and lifting any barriers to timely care access for patients with Medicaid insurance.

Limitations

We acknowledge there are several limitations to this study. First, this study only included patients who visited a primary care provider affiliated with our health system and completed SDOH questionnaires, had a new orthopaedic surgery clinic visit, and completed PROMIS Global Health forms during the study period. This may introduce a component of selection bias. However, we are unaware of specific patient subgroups that would be excluded at higher rates solely based on this set of inclusion criteria. Further, our patient sample was found to be similar to the entire orthopaedic patient population that sought musculoskeletal care at our clinics over the study timeframe. Thus, we believe our sample likely represents patients who seek orthopaedic surgery at our institution and likely—at a minimum—those healthcare institutions with similar patient demographics. In addition, although our institution is an urban academic medical center, it draws from a broad rural, suburban, and urban geographic area and includes a mix of insurance types. Nonetheless, it is important to consider how different healthcare settings and geographic areas may lead to different findings given the variability of social services, for example. Second, only a small minority of patients

(< 10%) had the SDOH factors of interest; however, given the large sample size of more than 9000 patients in the present study, we were still able to appropriately detect meaningful differences when present. Third, the request for sensitive social information may have led to social desirability bias, which is the tendency to underreport socially unfavorable characteristics and overreport desirable traits.[23] Therefore, patients may not disclose the sensitive information sought—such as transportation issues—in our questionnaires.[24] However, because patients were assured that this information would be confidential at the patient level as part of routine healthcare privacy regulations, we do not believe this issue would drastically alter our overall findings. Fourth, the SDOH questionnaire was developed at our institution and has not been externally validated. Additionally, the survey has a Flesch-Kincaid Reading Level of 12.9. However, the survey was developed through multiple iterations to assure question clarity, and some of the phrases that are needed in the survey (for example, "medical appointments") to appropriately capture the information substantially raise the reading level by themselves.

There are also a few limitations associated with the use of the MCID in this study. First, there are multiple methods to calculate MCID thresholds without a definitive approach.[21,22,25] Although distribution-based methods are simple to calculate, they do not consider how patients perceive their change in symptom severity; thus, when possible, we used an anchor-based estimate, but we were only able to find such an estimate for the PROMIS Global Physical Health not the PROMIS Global Mental Health.[22] However, both estimate techniques are well-documented approaches to estimating the MCID, so we believe our clinical findings are still valid. Second, the MCID is usually used to assess change in scores over time. However, in the current study, we used these estimates to assess whether the presence of a given SDOH factor was associated with a change in PROMIS scores for patients that would be clinically relevant. Although this may not be the typical use of the MCID, we believe it provides greater context to the level of association certain SDOH characteristics have with patient health and wellbeing. Lastly, MCID estimates are likely context-specific and may differ based on the treatment being assessed. Generally speaking, however, estimates tend to be similar across conditions, and we believe using the best available estimate is appropriate when evaluating a heterogeneous patient sample.

Percentage of Patients with Challenging Social Determinants of Health

One of the major issues with area-based measures of social deprivation or lower socioeconomic status is that they group all people from a similar geographic region as the same when differences exist. These differences can drive targeted solutions. The 4% of patients in our sample who reported transportation issues related to receiving healthcare is similar to that previously reported and not only in orthopaedic surgery.[26] Thus, transportation is a known issue across healthcare, and broad interventions across health systems or from a public policy standpoint may be beneficial, including need-based taxi or ride-share credits. Further, in our patient sample, only 4% of patients reported being unable to afford prescribed medications, which is well below the 7% across the United States reported in June 2021.[27] We think this difference may be a function of the many over-the-counter medications used in orthopaedic surgery, such as non-steroidal anti-inflammatory drugs, which are available as generics at a low cost when a prescription is provided. Financial support from a hospital, clinic, or insurer may help patients in need receive the medications they need; this may not only lead to improved clinical outcomes for such patients but also improved financial outcomes for hospitals who may avoid unnecessary emergency room visits or readmissions. Also, we found 2% of our patient sample had no current housing, whereas the estimated proportion of people in the United States who are unhoused is approximately 0.2%.[28] One possible reason for this discrepancy is that our patients are faced with housing instability more often than prolonged homelessness. Another possible reason is because the cost of living in and around Boston tends to be quite high, which may mean that a greater proportion of the patients in our cohort experienced homelessness; however, in 2019, Massachusetts experienced a 0.3% (18,471/6,892,503) rate of homelessness.[29,30] This calls for further investigation, as it is not clear what is causing the discrepancy between the national and state level homelessness rates and our patient sample. Lastly, 8% of patients in our sample were unemployed but actively looking for work, which is well above the current 3.6% unemployment rate in the United States.[31] Patients with housing and/or employment concerns would benefit from being connected with social work and other services early on; therefore, identifying these individuals at the onset of care is critical. Overall, these findings emphasize the importance of understanding in detail the community being served at a local level as policy is being developed because the percentages of people with certain issues varies from those of the entire population. Ultimately, focused interventions at the local level should build on the broader policy being implemented on a larger scale. Although the proposed interventions do not necessarily lead to patients seeking care earlier, studies are needed to assess whether such initiatives may be able to improve clinical outcomes for those with certain SDOH characteristics.

Factors Associated with Poorer Scores for Physical and Mental Health

The factors associated with worse presenting patient physical and mental health were not entirely unexpected. The association of transportation difficulties with worse presenting symptoms likely represent the combined impact of poor physical function (inability to drive) and psychosocial (less robust social or family support) factors, whereas the inability to pay for medications may highlight that some patients are simply trying to make ends meet and not seeking care unless symptoms become severe. Although we accounted for these patient-specific factors, insurance type continued to be a clinically relevant variable. The finding that patients covered by Medicaid have worse presenting symptoms was unsurprising, given prior research.[32,33] This finding suggests that unrecognized driving factors among patients covered by Medicaid are not captured by patients' sociodemographic data or our included SDOH questionnaire. One potential explanation for this finding is the known association between Medicaid insurance and decreased access to musculoskeletal care.[10,34] Patients with Medicaid might not be able to afford the time off from work or other responsibilities to seek musculoskeletal care until symptoms are quite severe and debilitating. A prior investigation has also demonstrated that patients with public insurance and those with a lower education level visited the emergency department for musculoskeletal complaints that generally only need outpatient care.[35] Additionally, patients with adequate health literacy seek outpatient care more than those with limited health literacy, and Medicaid insurance may be a proxy for limited health literacy.[36] Thus, patients with Medicaid insurance might delay orthopaedic care until symptoms and disease processes are more advanced. Similarly, patients with workers compensation insurance also had clinically worse symptoms at presentation to an orthopaedic surgery clinic. Prior research has demonstrated worse symptoms and clinical outcomes in patients with workers compensation insurance who have lumbar disc herniation or who are undergoing upper extremity surgery.[37,38] Workplace injuries might be more severe, leading to worse physical function at presentation. Additionally, the known psychosocial relationship between workers compensation and outcomes may account for this finding in this study. Because insurance type remains associated with worse symptoms, and even though we accounted for detailed, patient-specific data, more work is needed to highlight the modifiable factors that can be addressed with interventions to improve health equity. Patients on Medicaid may benefit from proactive care teams who reach out before clinic visits to assess what support services may be needed to try to ensure any barriers to timely, high-quality care are alleviated as best as possible.

Conclusion

By using novel patient-specific data, we demonstrated that transportation issues and financial hardship were associated with worse patient-reported physical and mental health. Additionally, certain traditional demographic variables (such as insurance type) remained relevant, whereas others (age, gender, race, and marital status) were not found to be associated with clinically important effect sizes. The patient-level SDOH findings provide data to support the development and implementation of targeted policy and interventions to help address disparities. For example, taxi vouchers or ride-sharing credits to attend clinic visits might be beneficial for patients demonstrating such a need. Telemedicine may also contribute to ensuring improved access to orthopaedic care, especially among those with financial hardship and an inability to travel to clinic visits easily.[39] Additionally, support services that provide medication related financial assistance may allow patients to obtain necessary medications and not only benefit patient-reported physical and mental health but also decrease avoidable complications and readmissions. Lastly, patients on Medicaid, who have housing instability, or who report employment concerns may benefit from proactive outreach from clinic or institutional support staff, such as social work, to help connect them to local, state, and/or federal programs that may alleviate barriers to care. As programs and initiatives are implemented, frequent evaluations of their successes (or failures) will be needed to ensure progress is being made in reducing healthcare disparities in orthopaedic surgery; this can begin by evaluating whether providing taxi vouchers or ride-share credits decrease the “no show” frequency in clinics or assessing whether connecting patients to local, state, and/or federal programs makes a positive change on patient health, as measured by PROMs. Studies can also examine how these detailed, patient-level SDOH factors are associated with clinical outcomes after treatment.

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Chapter 3

Social Determinants of Health in Prognostic Machine Learning Models for Orthopaedic Outcomes: A Systematic Review

Amanda Lans, Laura N. Kanbier, David N. Bernstein, Olivier Q. Groot, Paul T. Ogink.
Daniel G. Tobert, Jorrit-Jan Verlaan, Joseph H. Schwab

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ABSTRACT

Background: Social determinants of health (SDOH) play an important role in postoperative outcomes after orthopaedic surgery and are being considered more frequently when providing clinical care. However, it is unclear if and how machine learning (ML) models consider SDOH variables during development. Therefore, the purpose of this systematic review was to investigate whether prognostic ML models in orthopaedic surgery account SDOH and to what extent SDOH features are included in final models.

Methods: A systematic search was conducted in PubMed, Embase and Cochrane for studies published up to November 17th, 2020. The search yielded 7,138 studies, of which 59 met the inclusion criteria. Two reviewers independently extracted SDOH features using the PROGRESS+ framework (Place of Residence, Race/Ethnicity, Occupation, Gender/sex, Religion, Education, Social capital, Socioeconomic status, "Plus+" age, disability, and sexual orientation).

Results: Across all studies, 96% (57/59) considered at least one PROGRESS+ factor during development. The most common factors were age (95%; 56/59) and gender/sex (96%; 57/59). Despite being measured regularly, differential effect analyses were seldom reported (10%; 6/59). The majority of models included age (92%; 54/59) and gender/sex (69%; 41/59) as final input variable. However, factors such as insurance status (7%; 4/59), marital status (7%; 4/59) and income (3%; 2/59), were seldom included.

Conclusion: The current level of reporting and consideration of SDOH during the development of prognostic ML models for orthopaedic outcomes is limited. Health care providers should be critical of the models they consider using and knowledgeable regarding the quality of model development, such as adherence to recognized methodological standards. Future efforts should aim to avoid bias and disparities when developing ML driven applications for orthopaedics.

INTRODUCTION

In the field of orthopaedic surgery, machine learning (ML) models are becoming increasingly popular and support decision-making, covering an array of surgical outcomes such as survival, complications, and reoperations.[1–4] Specific examples include prediction models for length of stay following femoral fractures, 90-day or one year survival in patients with metastatic disease of the extremities, and discharge disposition after spine surgery.[5–7] Such models use preoperative variables, such as presence of metastatic disease, functional status and blood values to provide individualized risk predictions.

However, these models could be at risk of unintended negative consequences, such as the perpetuation of health inequities, if not considered during model development. In suboptimal situations, similarities can be drawn with inequalities caused when clinical trial participants do not represent the patients ultimately receiving the treatment with respect to sex and race.[8,9] Algorithmic inequity has previously been demonstrated by Obermeyer et al. who found evidence of racial bias in a widely used algorithm to guide health decision which reduced the number of Black patients identified for extra care by over half.[10] Health inequities are systematic differences in the opportunities people have to achieve optimal health and arise from disparities in social determinants of health (SDOH).[11] SDOH include economic stability, living environment, educational attainment, access to care and social support.[12]

The current literature reveals that SDOH play an important role in outcomes after musculoskeletal surgery.[13–16] For example, Ziedas et al. argue in a systematic review of 76 studies that for anterior cruciate ligament reconstruction, certain SDOH, including race, ethnicity, type of health insurance and socioeconomic status contribute to unequal access to care. Another literature review assessing complications after total hip and knee replacement for racial and ethnic minority groups found that racial and ethnic minority groups appear to have a higher risk for complications within 90-days, namely, joint infection after total knee replacement and perhaps a higher risk of mortality after total hip replacement.[17,18] A prospective study assessing the role of race and ethnicity in 1220 patients undergoing total knee and hip arthroplasty demonstrated that black race was negatively correlated with knee Patient Reported Outcome Measures (PROMs) improvement and Hispanic ethnicity was negatively correlated with hip PROMs improvement compared to white race. Additionally, significant associations were found based on education, gender/sex, comorbidities, and neighborhood poverty.[19] In knee arthroplasty, marital status and living environment contributed to health care costs and length of stay.[20]

Recognizing the importance of SDOH in medical care is an initial step towards improving overall population health and reducing health disparities. Therefore, the purpose of this review is to 1) investigate whether prognostic ML model studies account for indicators of social disadvantage, and 2) evaluate to what extent individual SDOH variables are included in final ML models that are available for use. Findings from this review serve to inform design of future ML models and identify areas for methodological innovation to mitigate bias and improve health equity when developing ML based prediction models for patients undergoing orthopaedic surgery.

METHODS

Search Strategy

Prior to initiation, this study was registered in the PROSPERO international prospective register of systematic reviews (CRD42020206522). A systematic search, in collaboration with a medical professional librarian, was conducted in PubMed, Embase and Cochrane for studies published up to November 17th, 2020. Terms and keywords of different medical subject headings (MeSH) were combined with 'AND'. The following two domains with related words were included in the search: ML and orthopaedic specialties (Appendix 1). The PRISMA guidelines were used as reporting guidelines (Figure 1).[21]

Eligibility Criteria

Studies were included if they evaluated ML models for any prediction in an orthopaedic surgery outcome, such as survival, PROMs, or complications.[1,2] Exclusion criteria were: (1) non-ML techniques (such as standard logistic or linear regression), (2) conference abstracts, (3) non-English studies, (4) unavailability of full-text through library, and (5) non-relevant study types such as animal studies, letters to the editors, and case-reports. Orthopaedic specialties were defined as any operation for patients with musculoskeletal disorders.

Data Extraction

Two investigators (OQG, PTO) independently performed identification and screening of titles and abstracts, and eligibility assessment. Any disagreements were adjudicated by the principal investigator (JHS) of the study.

The following variables were extracted from each of the included studies: name of first author, year of publication, journal of publication, title, sample size, data sources, predicted outcome, Prediction model study Risk Of Bias Tool (PROBAST) domains, SDOH/PROGRESS+ items, differential analysis (subgroup analysis, covariate adjustment and baseline comparison), and predictors included in final model.[22]

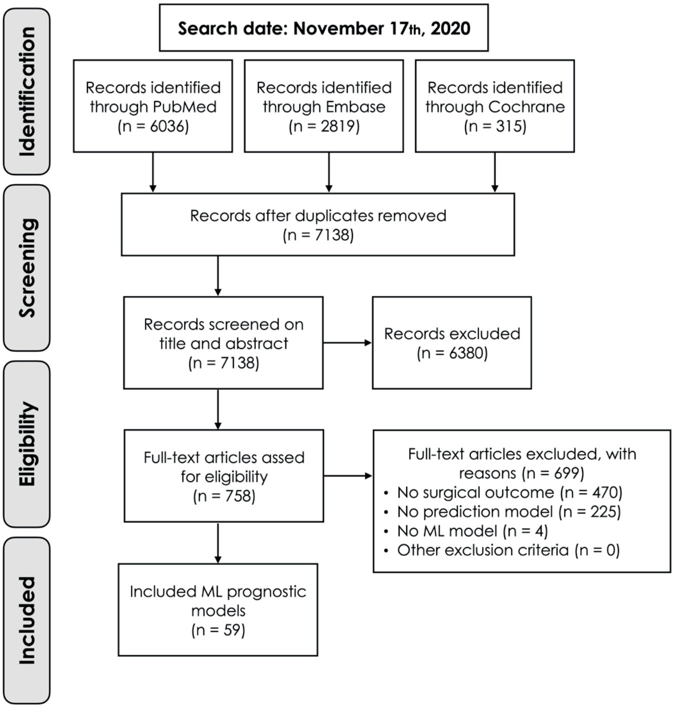

Figure 1 Flow of included studies

To assess the quality of the included studies, the PROBAST tool was used. PROBAST assesses the risk of bias of a study that validates a prognostic prediction model.[23] The following domains were assessed: (1) participants, (2) predictors, (3) outcome and (4) analysis.

The SDOH were extracted using the PROGRESS+ framework (Appendix 2).[22,24] This framework is a tool first published in 2014 to guide equity analyses and to ensure explicit consideration of equity in the design of new intervention studies and in systematic reviews. In 2016 the additional "Plus+" items were introduced. The PROGRESS+ framework consists of the following characteristics: place of residence, race/ethnicity/culture/language, occupation, gender/sex, religion, education, socioeconomic status, social capital, plus personal characteristics associated with discrimination (e.g. age, disability), features of relationships (e.g. smoking parents/excluded from school), and time-dependent relationships (e.g. leaving the hospital). Individual SDOH features were included in the final model. Individual SDOH features considered were age, sex, health status, marital status, insurance status, race/ethnicity, income, built environment and employment status. The assessment was conducted independently by two reviewers (AL, NK) and disagreements were resolved by a third investigator (OQG).

Software

Extracted data from each study was visualized by bar graphs (Microsoft Excel Version 19.11). Mendeley Desktop Version 1.19.4 (Mendeley Ltd) was used as a reference management software.

RESULTS

The search resulted in 7138 studies. Seven hundred and fifty-eight potential studies were selected by title and abstract screening, of which 59 remained after full-text screening (Table 1; Appendix 3). The most common orthopaedic subspecialty for which models were developed was spine (48%; 27/59), followed by arthroplasty (19%; 17/59). The least common subspecialties were oncology (8%; 5/59) and sports (3%; 2/59).

Table 1 Characteristics of included studies

Sample size, median (IQR)	4782 (616-23264)
Data Sources	
Prospective database	3 (5)
National/Registry database*	47 (28)
Year of publication	
< 2017	22 (13)
> 2018	78 (46)
Subspecialty	
Spine	27 (48)
Arthroplasty	17 (29)
Trauma	8 (14)
Oncology	5 (8)
Sports	2 (3)
Predicted outcome	
Complications	24 (14)
Patient-reported outcome measures	20 (12)
Mortality	19 (11)
Health management	19 (11)
Other	19 (11)

Data presented as n (%) unless stated otherwise; IQR = interquartile range; *This includes databases such as Surveillance, Epidemiology, and End Results (SEER) or the American College of Surgeons National Surgical Quality Improvement Program (ACS NSQIP).

Reporting of Social Determinants of Health and PROGRESS+

Of all 59 studies, 97% (57/59) considered at least one PROGRESS+ factor in their development analyses. The most common being gender/sex (97%; 57/59), age (95%; 56/59), race

(35%; 21/59), and socioeconomic status (17%; 10/59) (Figure 2). Despite being reported regularly, differential effect analyses like subgroup analysis, covariate adjustment and baseline comparisons were merely stated in a handful of studies (16%; 10/59). Only 12% (7/59) studies reported subgroup or interaction analyses exploring different effects across at least one PROGESS+ factor.

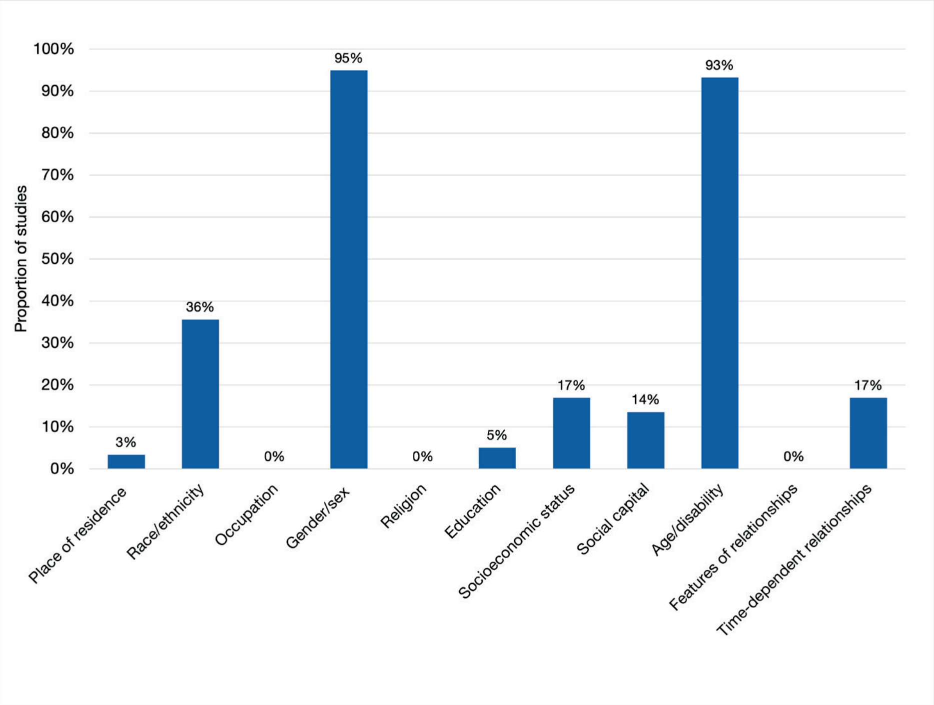

Figure 2 PROGRESS+ factors considered as features during the development of machine learning models

The median number of predictors which were included in the final ML model was 10 (interquartile range [IQR] 7-14). When considering age, gender/sex, health status, race or ethnicity, marital status, built environment, educational attainment, insurance status and income as SDOH features, the median number of SDOH features included in final models was 2 (IQR 2-3). During feature selection, 49% (29/59) of the studies considered additional SDOH, 12% (7/59) did not consider any SDOH variables besides age and gender/sex. When excluding age and gender/sex as SDOH variables, the median number of SDOH features included in final risk prediction models was 1 (IQR 0-1) (Table 2; Figure 3). When looking at the mean number of SDOH features included per subspecialty, we found that sports most often incorporated SDOH features (n = 3.5). However, there were only two sports studies among the included studies. The lowest mean number of SDOH features reported was in oncology (n = 1.2). However, there were only five oncology studies. The majority of studies were in the subspecialties spine (n = 27) and arthroplasty (n = 17), which both had a mean incorporation of SDOH features of 2.7 (Appendix 4).

Table 2 Variables included in final models

Predictors included in final model*, median (IQR)	10 (7-14)
SDOH° variables included†, median (IQR)	2 (2-3)
SDOH° variables excluding Age & Gender/Sex, median (IQR)	1 (0-1)
Individual features	
Age	92 (54)
Sex	69 (41)
Health status	47 (28)
Race/ethnicity	25 (15)
Built environment	7 (4)
Educational attainment	7 (4)
Marital status	5 (3)
Employment status	3 (2)
Insurance status	2 (1)
Income	0 (0)

Data presented as n (%) unless stated otherwise; IQR = interquartile range; *The number of predictors that were included in the final, best performing machine learning algorithm. For 9 studies this data was not available; °Social determinant(s) of health; †SDOH variables: age, sex, health status, race/ethnicity, educational attainment, marital status, employment status, income, insurance status, living environment.

Risk of Bias Assessment

Across all included studies the overall risk of bias was high or unclear in 56% (33/59) and low in 44% (26/59) (Figure 4). Bias in the analysis domain, for reasons such inadequate handling of missing data or small data sets, was the most common reason for studies being rated with high overall risk of bias (41%; 24/59).

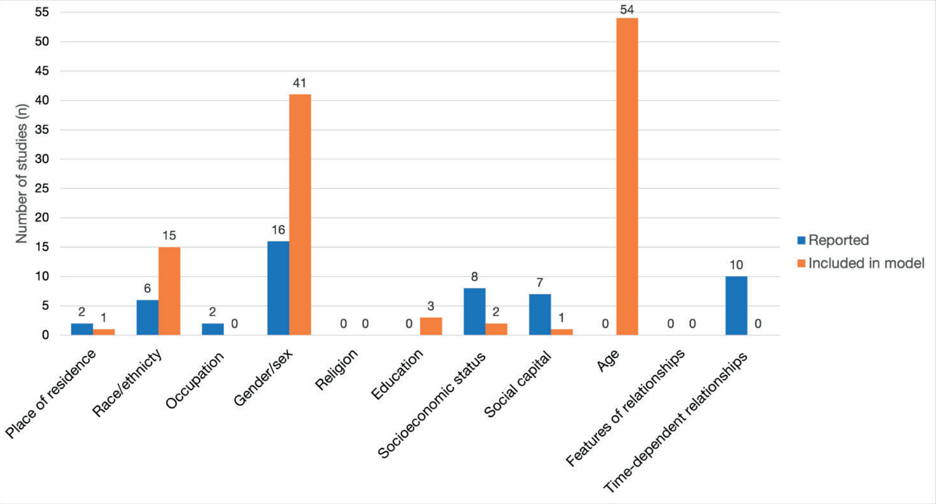

Figure 3 Frequency of induvial social determinants of health (SDOH) reported (blue) and the rate of individual SDOH included as features in final machine learning models (orange)

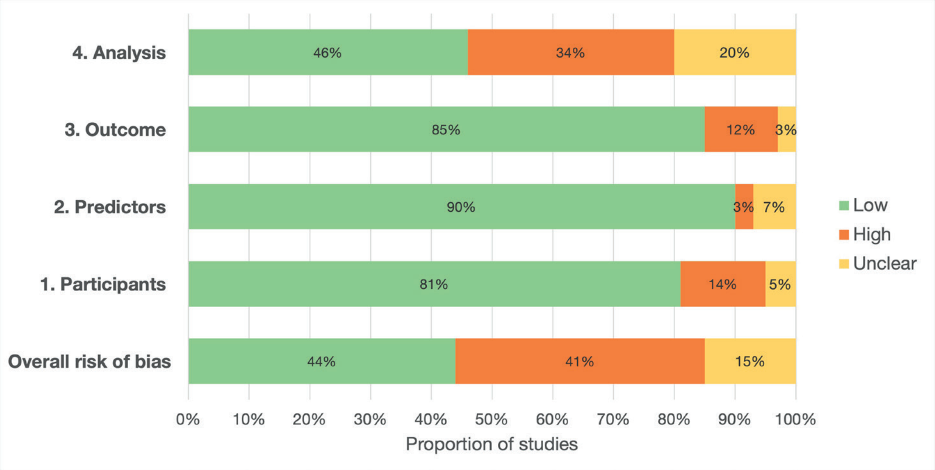

Figure 4 Prediction model study Risk Of Bias Tool (PROBAST) assessment for all included studies

DISCUSSION

In this systematic review, we found that the majority of included studies reported at least one SDOH, namely gender/sex and age. It can be argued that these basic variables should always be reported in scientific studies. This study also found that the consideration of SDOH variables during feature selection and the inclusion of SDOH features in the final model was limited. If excluding the basic demographic variables of age and gender/sex, SDOH were rarely considered. These findings suggest that notable biases may exist in ML models currently developed in orthopaedic literature. Thus, if there is a desire to use ML models in practice, caution should be used so that disparities are not worsened.

In orthopaedic surgery various components of SDOH, including race/ethnicity, educational attainment, socioeconomic status and social context have been reported to impact health outcomes such as length of stay, PROMs, and revision surgery.[20,25–29] Therefore, lack in reporting of basic demographic characteristics or failing to justify why certain factors are excluded during model development may limit the quality and impact models. Although SDOH indicators may not always be appropriate for a ML, the addition of SDOH indicators in risk adjustment models has previously been demonstrated to reduce disparities in several vulnerable populations.[30] Additionally, unfamiliarity with potentially biased data may cause unintended propagation of existing systemic inequalities. Although the concept of inequity in health care is not novel or unique to the prognostic modelling for orthopaedic surgery, it should still be deemed important to aim at mitigating biases, regardless of which approach is used. As we increase to rely on ML driven algorithmic decisions aids in clinical practice, it will be vital that these models are held to a high, equitable standard.

Recommendations

Findings from this review provide researchers who are developing ML models for orthopaedic purposes insights regarding the inclusion of SDOH and how it may impact the quality of their models. Guidelines for transparent reporting have previously been developed, however adherence has also found to be poor.[31,32] Building on this prior work, we recommend that researchers additionally take into account and report SDOH features that have been shown to impact surgical outcomes in orthopaedics and should be incorporated into reporting guidelines.[18,19] We recognize that this may be challenging, but frameworks such as the PROGRESS+ can be used as a tool to guide equity analyses for researchers to ensure explicit consideration of equity in the design of new ML models.[24] However, the limitations of the PROGRESS+ must also be taken into account, such as the rudimentary definitions of SDOH. For example, the guideline uses either race/ethnicity/culture or language as a measurement of race/ethnicity. How this data is recorded is also important as there is a difference in self-reported or objective measures. Additionally, studies often use gender and sex interchangeably even though these two terms have different definitions. The WHO defines ''sex'' as the ''biological and physiological characteristics that define men and women.'' The WHO further defines ''gender'' as the ''socially constructed roles, behaviors, activities and attributes that a given society considers appropriate for men and women''.[33,34] Standardization of definitions and how they were reported may improve quality data used to train models and help identify disparities or bias, which in turn can be addressed. However, to our knowledge, no other recognized SDOH frameworks exist other than PROGRESS+.[35] With that, the context in which the model is intended to be used must be taken into account as this plays a role when determining which inequalities may be driving inequities.[36] In some instances certain PROGRESS+ factors may be especially important, such as social capital with regards to discharge disposition. An additional consideration when using framework such as the PROGRESS+ is that some factors may change over time, for example marital status and income, whereas others such as race/ethnicity do not. The impact these changes may have on the model should be evaluated and considered during development and updating of models. Finally, some SDOH may not be appropriate features for the intended use of the ML model, not be independent predictors or simply are not readily available. However, transparent reporting of such data limitations and justifying why reporting of basic features may not be necessary should be provided. Without this it will be challenging for readers to fairly evaluate the quality and usability of ML models.

This study is not without limitations. First, despite utilizing multiple online medical databases and comprehensive search strategies, studies may have been missed. However, we do not believe that the possibility of this impacts the findings of this study as we included over 50 studies. Second, the PROGRESS+ framework was used as reporting benchmark. However, acceptable scores and the relative importance of domain is yet to be defined and subject to the context of each model and its intended use. Additionally, we reported if studies included a subgroup analysis but did not note if this would be appropriate for the study in terms of power or if prompted by a hypothesis. Therefore, the finding that hardly any studies did such an analysis should be seen in light of this limitation. Despite these limitations, this review offers profound insights into the reporting and use of social determinants of health in ML driven prognostic tools for orthopaedic surgery.

Conclusion

The current reporting and consideration of various social determinants of health for the development of prognostic ML models for orthopaedics is limited. ML-based prediction models may support clinical decision making, but health care providers should be aware of the models they consider using based on what data was used to develop them. Knowledge regarding the quality of model development, such as adherence to recognized methodological standards, should always be considered. ML models are useful in orthopaedic surgery, however, if these models are integrated into clinical care, they should consider reporting SDOH factors. Future efforts should aim to avoid bias and the perpetuation of disparities when developing ML-driven applications for orthopaedics.

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APPENDICES

Appendix 1 Literature search strategies per search engine

Appendix 2 PROGRESS+ framework definitions

Appendix 3 List of included studies

Appendix 4 Mean number of social determinants of health features per subspecialty

Chapter 4

Health Literacy in Orthopaedics

Amanda Lans, Joseph H. Schwab

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ABSTRACT

Health literacy is a dynamic, multifaceted skill set that relies on patients, health care providers, and the healthcare system. Additionally, health literacy assessment provides an avenue for evaluating patient understanding and offers insights into their health management capabilities. Inadequate health literacy results in poor patient outcomes and compromised care by considerably hindering successful communication and comprehension of relevant health information between the patient and the provider. In this narrative review we explore why limited health literacy poses serious implications for orthopaedic patient health and safety, expectations, treatment outcomes, and healthcare costs. Furthermore, we elaborate on the complexity of health literacy, provide an overview of key concepts and offer recommendations for clinical practice and research investigations.

INTRODUCTION

Health literacy has been defined as an individual's ability to obtain, understand, and comprehend information regarding their health, medical conditions, treatments, and long-term care.[1] However, this definition may fall short of encompassing the true complexity of health literacy by focusing primarily on the individual's baseline comprehensive abilities. While a patient's ability to attain, comprehend, and utilize new information may be improved by literacy skills such as proficient reading and writing, there is no guarantee these skills will be applied in a consistent form. This is particularly apparent when patients find themselves in an unfamiliar or stressful circumstance that requires specific content knowledge for health decision-making.[2] This is also true when delivering orthopaedic care. However, to date, health literacy has received little consideration in orthopaedic literature.[3]

Limited health literacy is associated with worse overall physical and mental health, inadequate self-management of chronic disease, higher mortality, higher rates of hospitalization, greater healthcare expenditure and worse patient-reported outcome measure scores.[4–9] The 2003 U.S. Department of Education National Assessment of Adult Literacy (NAAL) survey found that 36% of the adult U.S. population (approximately 87 million adults) had basic or below basic health literacy levels.[10] Unlike the intermediate literacy and proficiency literacy levels defined by the survey, basic literacy and below basic literacy levels are considered insufficient for function within the healthcare setting. Inability to navigate the healthcare system can lead to missed opportunities to prevent illness or delays in rendering necessary care. Low levels of health literacy have also been associated with lower socioeconomic status.[11,12] Modeling assumptions using data from the 2003 Medical Expenditure Panel Survey (MEPS) have estimated the annual cost of low health literacy to range from $106 billion to $238 billion.[10] Besides achieving and maintaining healthy behaviors in the form of lifestyle and preventative care, factors driving the cost of low literacy include inefficient mixed use of healthcare services and increased utilization of inpatient and emergency room services.[13]

Despite this enormous economic burden, increased visibility of issues regarding social inequity, and growing patient and physician advocacy regarding low levels of health literacy nationwide, little has been done to transform health literacy into a currency for improving health outcomes. This is also true in the field of orthopaedic surgery, offering a worthwhile opportunity to explore what may significantly benefit orthopaedic patients. This narrative review illustrates the complexities of health literacy and explores how it impacts different facets of orthopaedic care, focusing on potential advances in clinical practice and future research.

Health Literacy in Orthopaedic Practice

Orthopaedic pathologies can be complex and challenging for patients to understand, and overestimating patient literacy can contribute to misunderstandings, poor perception and actualization of care.[14] Cosic et al. reported that patient comprehension of common orthopaedic terminology, for example "broken bone" as opposed to "fracture", was poor in both the inpatient and emergency department settings.[15] Kadakia et al. observed similar shortcomings in orthopaedic trauma patients, with deficiencies in their comprehension of the nature of their injuries, the surgery that was performed, and their postoperative instructions. On average, only half of the patients' health literacy survey responses were correct, reflecting poor overall patient comprehension.[16] A study utilizing the Literacy in Musculoskeletal Problems (LiMP) questionnaire, a musculoskeletal specific health literacy survey, found that 69% of patients who presented to the emergency department with a single musculoskeletal complaint, had limited musculoskeletal health literacy.[17,18] Additionally, in a cross-sectional survey study among patients seen at a multispecialty orthopaedic clinic, Mertz et al., 37% of participants had limited health literacy according to the LiMP.[19] These findings were corroborated by measurements with The Newest Vital Sign Health Literacy Assessment Tool (NVS), a validated measure of general limited health literacy, which found that 48% of the study's population had limited health literacy. These findings suggest that understanding musculoskeletal health information is even more challenging for patients than understanding general health information.

Health Literacy and Patient Comprehension

The relationship between health literacy and treatment outcomes, including adverse events, has previously been demonstrated in patient populations outside of orthopaedics. Mitchell et al. evaluated the relationship between health literacy level and the 30-day readmission rate of adult patients with medical conditions such as pneumonia and acute renal failure. After adjusting for potential confounding factors, including income, race, marital status, depression, length of stay and Charlson Comorbidity Index, it was found that patients with limited health literacy were 50% more likely to return to the hospital or emergency department within 30-days.[5] This increased rate of readmission was thought to be the consequence of patients not understanding their discharge instructions and difficulty managing self-care after leaving the hospital. Therefore, an argument can be made for interventions aimed at identifying and assisting patients with limited health literacy.

Discharge instructions can be confusing for patients with low levels of health literacy. A cross-sectional investigation of 248 trauma patients found that less than 50% of the included patients knew what bone they had fractured, less than 20% knew their expected healing time, and only 26% were able to name their prescribed medications at their first postoperative visit.[16] Patients without a high school degree were almost three times less likely to know the name of the medications they were taking compared to those who had at least a high school degree.

Low health literacy also leads to preventable waste of medical resources. A study of patients with lumbar degenerative disease found that those with limited health literacy were more likely to underutilize non-steroidal anti-inflammatory drugs (NSAIDs), likely leading to indications for more expensive and aggressive management before exhaustion of less costly, less invasive, conservative measures.[23] Although previous studies have noted the increased use of prescription medications by patients with low levels of health literacy, the underutilization observed in this study may be due to the fact that NSAIDs are generally over-the-counter and self-directed. Hence, without proper guidance and comprehension, patients with low levels of health literacy may have hesitated at self-directive use or failed to understand what they could take, thereby leading to poor conservative treatment outcomes.

It can be speculated that results of these studies indicate that orthopaedic surgery patients often do not understand the ‘one-size-fits-all’ directions they are given. Misunderstandings in a clinical setting may lead to over- or under-dosing of medications, resulting in mismanagement of pain and potential systemic consequences such as deep venous thrombosis. Additionally, patients with limited health literacy may be less likely to comply with postoperative weight-bearing guidelines that puts the patient’s healing and implanted hardware integrity at risk. Other examples include poor risk aversion strategies, such as not-submerging a postoperative wound, which can lead to preventable wound breakdown, infection, readmission, or re-operation, which may ultimately contribute to debilitation and increased financial burden on both the patient and the healthcare system. Unnecessary errors related to patient comprehension should not be attributed to the patient. They are errors caused by the system failing to recognize patients with poor health literacy, inadequate understanding of their postoperative care, and consequently should be considered the shortcomings of the care team. With this approach, we can motivate ourselves and our care teams to reduce avoidable errors, in a similar manner as standardized preoperative “time-out” or a postoperative sponge count.

Patient Perspectives

Low health literacy impacts patient expectations regarding their treatment outcomes and may influence their overall experience of the care received. For example, it has been reported that total knee arthroplasty (TKA) and total hip arthroplasty (THA) patients with low level health literacy have worse expectations for walking after surgery compared to patients with higher health literacy.[24] Yet, if these low postoperative expectations regarding walking impacted outcomes was not evaluated.

However, a relationship between health literacy and self-reported health outcomes among new patients seen at an outpatient orthopaedic spine center has previously been demonstrated.[4] When controlling for multiple confounding variables, the author's analysis revealed that patients with limited health literacy reported significantly worse baseline Patient Reported Outcome Measure Scores across seven different domains (Physical Function; Depression; Global Health – Physical; Global Health – Mental; Pain Interference; Pain Intensity; Anxiety).

Limited health literacy has also been associated with lower treatment satisfaction. Roh et al. in their study of health literacy and acute mallet finger treatment outcomes reported that low treatment satisfaction was associated with low health literacy and poor adherence.[25] This can be attributed to patients with limited health literacy who struggle to comprehend their postoperative care instructions, limitations, and expectations. Not understanding the limitations to expect during recovery, nor the rules of long-term immobilization (such as not soaking the splint), as well as unanticipated pain, are likely to lead to adverse events, readmissions, and prolonged recovery times, which in turn contribute to worse treatment satisfaction. Improving health literacy in such a group requires appropriate communication from health care providers, improved patient education tools and resources, simplified instructions, and a more diligent follow-up. By incorporating these steps into standard care, patient comprehension will improve, which can in turn optimize treatment adherence, outcomes, and satisfaction.

Healthcare Utilization

Health literacy plays a key role in access to care and resource utilization. It has been reported that patients with low levels of health literacy often fail to understand both the global (i.e. primary care physicians) and situational (i.e. chest pain) importance of seeking medical attention, neglect to take medication as prescribed and overutilize certain resources such as the emergency department over standard preventative measures.[26] Glassman et al. reported that patients with limited health literacy, who were evaluated for lumbar degenerative disease, had far more visits to a chiropractor than those with adequate health literacy.[23] This highlights the importance of situational thinking. Although a chiropractor may indeed be an appropriate measure for patients with muscle imbalances or mild non-radicular degenerative disc disease, no chiropractic adjustment can treat radicular disease due to, for example, severe foraminal stenosis caused by spinal instability. However, it is reasonable to believe that patients not well versed in the utility of spine surgeons vs. chiropractors would not understand when the latter measure is no longer a viable solution to their pathology.

Accommodating for patient health literacy level can also reduce medical costs, and there is no evidence that health literacy interventions, such as preoperative education for patients receiving TKA or THA, increases their overall cost of care. However, it should be noted that educational interventions should not be done so early as to expect patients to remember their trainings many months later. For example, a prior study found no difference in total cost of care between those patients who received a preoperative education course before a TKA/THA and those who did not. However, on average the course was taken 31 and 28 weeks prior to a TKA or THA surgery respectively. Given this time frame and that the duration of the course was 30 minutes, one can anticipate that this may not have a meaningful impact on the total cost of care. A subsequent study found that an enhanced recovery program with focused patient direction and early physical therapy decreased the duration of hospitalization and reduced overall cost of care.[27]

Sociodemographic Disparities

Sociodemographic and socioeconomic factors contribute to the risk of limited health literacy.[28] A growing body of literature regarding orthopaedic patients populations indicates that poor health literacy is more prevalent in older patients, minorities, unemployed/low-income individuals, those with public insurance or those with less educational attainment.[17,29–33] For instance, a study among 405 new patients seen at an outpatient spine clinic found that limited health literacy was independently associated with characteristics of socioeconomical disadvantage.[32] These included a higher Area Deprivation Index, having housing concerns, unemployment, lower educational attainment and below ninth grade reading level. In line with these findings, Menendez et al. found that advanced age, not having insurance or being publicly insured and lower income were associated with limited health literacy in patients being seen by a hand surgeon.[34]

The healthcare setting where care is sought, such as an outpatient clinic or emergency room, is also related to socioeconomic and sociodemographic status. Records from the Medical Expenditure Panel Survey from 2007 to 2015 found that those who generally relied on the emergency department for musculoskeletal care were minorities, less-educated, low-income, and had public insurance.[35] Median healthcare expenditures from such encounters were much higher compared to office care, and emergency department care generally does not provide access to the necessary musculoskeletal procedures such as injections, physical therapy, and arthroplasty. Rosenbaum et al. found that privately insured patients indicated for a TKA were almost three times more likely to arrive at a treatment decision during their first visit compared to publicly insured and uninsured patients.[22] Patients who were White and those who had at least a college degree were more likely to have adequate musculoskeletal health literacy compared to minorities and those with less educational attainment. The LiMP study also demonstrated that patients with adequate musculoskeletal health literacy were more likely to seek outpatient care than those with limited health literacy. Such socioeconomic and sociodemographic disparities in orthopaedic care, if not addressed adequately, will prevent those with limited health literacy from accessing appropriate care and limit the opportunity to make well informed decisions regarding their health. However, health literacy is merely one of many factors that contribute to disparities in orthopaedic care and there is a more complex social interplay to be aware of.

Addressing Limited Health Literacy in Orthopaedic Care

Addressing inadequate health literacy can be a daunting task for healthcare providers. Successful health literacy interventions require a multifaceted approach, with collaboration from all levels of society. At the core of such interventions is the need to simplify healthcare services and improve health education.[12] Healthcare professionals should assume a poor level of comprehension during their interactions with orthopaedic patients, and ensure that patient communication is clear, concise, and informative to facilitate better patient comprehension, informed consent, and an improved doctor-patient relationship. Accurately identifying patients with limited health literacy can permit targeted guidance when selecting and providing materials for patient education, health education and counselling in orthopaedic rehabilitation. Preoperative education and postoperative instructions tailored to the patient's level of health literacy can have an enormous impact on postoperative treatment outcomes.[36]

Along with the LiMP and NVS, commonly used tools for measuring general health literacy are the BRIEF literacy screening tool, the Rapid Estimate of Adult Literacy in Medicine (REALM), and the Test of Functional Health Literacy in Adults (TOFHLA).[12,21,22] Construct measures vary from test to test. For example, the REALM is the only test that evaluates communication (pronunciation and verbalization), while the TOFHLA and NVS evaluate comprehension (prose and reading, problem-solving), numeracy, and quantitative skills. The TOFHLA and NVS have also been validated in Spanish. Rosenbaum et al. noted that the measurements of each assessment must be interpreted with caution, as they each evaluate different components of health literacy.[22] Therefore, it is vital that the clinician or researcher thoroughly understands the aspects of health literacy that each tool measures prior to selecting and administering a health literacy assessment. A challenge in providing an "all encompassing" metric is the likelihood of creating an extensive survey that causes participant fatigue, which affects the utility and reliability of the measures. Analysis of the principal predictive components of each validated survey to create a "compact" short-form metric has the potential to optimize health literacy measurements.

Communication is essential to patient comprehension and adequate health literacy. Menendez et al. evaluated if the health literacy of orthopaedic hand patients is related to the number of questions that they asked during their first visits, noting that those with lower health literacy asked fewer questions than better educated patients, and patients with a race other than White, asked fewer questions than White patients.[29] However, the study further reported that regardless of health literacy level, 79% of patients asked a question when prompted by the physician but only 29% of physicians asked patients if they had questions. Physicians and health coaches can help reduce confusion by simply prompting patients to ask a question or allowing patients to list questions before seeing their physician. The Ask Me 3 approach may be an effective tool for promoting communication, which encourages patients to ask their doctor three questions at each visit 1. “What is my main problem?” 2. “What do I need to do about the problem?” 3. “Why is it important for me to do this?”. Pre-discharge discussions are often underperformed and a critical way to improve patient health literacy and confidence. A comparative study evaluated the impact of a simple predischarge discussion between a provider and orthopaedic trauma patients on their health literacy. The pre-discharge discussion provided by orthopaedic staff included written and verbal information, as well as patient radiographs. Patients who received the structured pre-discharge discussion were four times more likely to have higher health literacy scores, with regards to their trauma, on subsequent evaluations than those discharged without a focused discussion.[30]

Furlough et al. proposed several strategies that healthcare providers can use to combat limited health literacy, which in an elective or referral-based service such as orthopaedics can be overwhelming and confusing to patients with limited health literacy.[37] By using the teach-back method, where the patient teaches the treatment plan to the provider, emergency medicine and primary care physicians can assess if the patient understands the scope of their condition and what is required to ensure a smooth recovery process. In addition, by providing underprivileged areas that are at a much higher risk of forgoing orthopaedic care with a multi-disciplinary care team, marginalized patients can receive sorely needed individualized care. Collaboration between social workers, advanced practice providers, and behavioral health specialists is much more effective in combating the effects of limited health literacy.

An exciting and noteworthy method for addressing health literacy is through novel digital technologies aimed at overcoming the challenges associated with limited health literacy. Huang et al. introduced an interactive infotainment system to patients who had just received a TKA. The purpose of the infotainment system was to improve patient education regarding their postoperative care through programs and video demonstrations that described preoperative preparation and postoperative precautions, physical therapy, and wound care. The infotainment system significantly reduced the patient’s hospital length of stay if their surgery was performed by a low-volume surgeon. Low-volume surgeon was defined as a surgeon performing less that 50 TKAs per year.[38] A reason that the infotainment system did not significantly improve surgical outcomes for high volume surgeons may be attributed to their experience and uniform practice for patients undergoing TKA, with the exception of fewer of medical orders. Given that the study was limited to 86 patients, three high-volume and nine low-volume surgeons, more studies are needed to determine to what extent infotainment systems affect the volume of medical orders and surgical outcomes. Nevertheless, by prioritizing improvement of a patient’s understanding of their diagnosis and the treatments associated with it, patients’ capacity to understand outcomes will increase. This may result in fewer readmissions, more effective resource utilization, and reduced costs.

Conclusion

If we place the responsibility on patients to play the critical role in their own health decisions, it is vital we also ensure and verify adequate health literacy and provide appropriate assistance where necessary. Health literacy is a dynamic, multifaceted skill set that carries serious implications for overall health and safety, expectations, treatment outcomes and healthcare costs in patients who require orthopaedic care. Orthopaedic surgeons should be aware of the large proportion of patients who have inadequate health literacy and great difficulty understanding health-related information, particularly with respect to their diagnosis, treatment, and prognosis. It is crucial to identify patients at risk of poor health literacy and to use appropriate assessment tools to measure the patients’ true understanding of their diagnosis, and to supplement their education when necessary.

The potential impact that improving health literacy has on orthopaedic patients and their outcomes has yet to be determined, and requires thoughtful, high-quality trials across diverse demographics and geographies. An improved body of literature can help physicians target specific aspects of health-related education throughout the course of preoperative and postoperative care of a patient, maximizing patient/physician collaboration while providing high-quality and resource-respecting care.

Health Literacy in Orthopaedic Practice: A Review

Health literacy can have a significant impact on the overall health and safety, treatment outcomes, expectations, and healthcare costs for orthopaedic patients

A comprehensive understanding of health literacy in orthopaedic practice can translate into better health outcomes

Outcomes associated with poor health literacy

50% increase in the likelihood of readmission

Confusion regarding discharge instructions, expected healing time, and prescribed medications

Poor compliance on postoperative guidelines contributing to further debilitation of condition

Poor conservative treatment outcomes and the consequent need for aggressive and expensive management

Low treatment satisfaction and low postoperative expectations in patients

Role of socioeconomic factors in determining health literacy

Income, age, employment, education status, and lack of insurance are known to influence health literacy levels

They also influence the choice of healthcare setting and guide informed decision-making among orthopaedic patients

Improving health literacy in orthopaedic patients

Assessment of health literacy using optimized health literacy measurements

Clear, concise, and informative communication to facilitate better patient comprehension

Tailored preoperative education and postoperative instructions

Structured pre-discharge discussions with patients

Teach-back method, video-based physical therapy guidance, wound care, and general precautions

Collaboration between social workers and behavioral specialists to spread literacy

Limited health literacy can have debilitating consequences for patients requiring orthopaedic care. A multi-faceted and literature-guided approach to health-related education can overcome these challenges

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Chapter 5

Systematic Review of Health Literacy and Orthopaedic Surgery Outcomes

Amanda Lans, John R. Bales, Mitchell S. Fourman, Pranati P. Borkhetaria,
Jorrit-Jan Verlaan, Joseph H. Schwab

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ABSTRACT

Background: Limited health literacy has been associated with adverse health outcomes. Undergoing orthopaedic surgery often requires patients to make complex decisions and adhere to complicated instructions, suggesting that health literacy skills might have a profound impact on orthopaedic surgery outcomes. Therefore, the purpose of this study was to review the literature for studies investigating the level of health literacy in patients undergoing orthopaedic surgery and to assess how those studies report factors affecting health equity.

Methods: A systematic search of PubMed, Embase, and Cochrane Library for all health literacy studies published in the orthopaedic surgery literature up to February 8th, 2022. Search terms included synonyms for health literacy and for all orthopaedic surgery subspecialties. Two reviewers independently extracted study data in addition to indicators of equity reporting using the PROGRESS+ checklist (Place of Residence, Race/Ethnicity, Occupation, Gender/sex, Religion, Education, Social capital, Socioeconomic status, plus age, disability, and sexual orientation).

Results: The search resulted in 616 studies; 9 studies remained after exclusion criteria were applied. Most studies were of arthroplasty (4/9; 44%) or trauma (3/9; 33%) patients. Validated health literacy assessments were used in 4 of the included studies, and only 3 studies reported the rate of limited health literacy in the patients studied, which ranged between 34% and 38.5%. At least one PROGRESS+ item was reported in 88% (8/9) of the studies.

Conclusion: We found a paucity of appropriately designed studies that used validated measures of health literacy in the field of orthopaedic surgery. The potential impact of health literacy on orthopaedic patients and their outcomes has yet to be elucidated. Thoughtful, high-quality trials across diverse demographics and geographies are warranted.

INTRODUCTION

Health literacy is an individual's ability to obtain, understand, and comprehend information regarding their health, medical conditions, treatments, and long-term care.[1] However, this definition falls short of encompassing the true complexity of health literacy by focusing primarily on the individual's baseline comprehensive abilities. While a patient's ability to attain, comprehend, and utilize new information may be acquired by literacy skills such as proficient reading, writing, and listening, there is no guarantee that these skills will be applied in a consistent form.

Inadequate health literacy is associated with worse overall physical and mental health, inadequate self-management of chronic disease, higher mortality, higher rates of hospitalization, and greater healthcare expenditure.[2–6] The 2003 U.S. Department of Education National Assessment of Adult Literacy (NAAL) survey found that 36% of the adult U.S. population (approximately 87 million adults) had basic or below basic health literacy levels. Modelling assumptions using data from the 2003 Medical Expenditure Panel Survey (MEPS) estimated that the annual cost of low health literacy ranges from \$106 billion to \$238 billion.[7] Besides achieving and maintaining healthy behaviors in the form of lifestyle and preventative care, factors that drive the cost of low literacy include increased utilization of inpatient and emergency room services and an inefficient mix of healthcare services.[8]

Despite the established role of health literacy and outcomes in non-surgical patients, the role of health literacy in patients undergoing orthopaedic surgery is not well defined. However, limited health literacy may have a profound impact on surgical outcomes in orthopaedic patients. Therefore, the main objectives of the current systematic review were to 1) investigate the level of health literacy in patients undergoing orthopaedic surgery, and 2) assess studies regarding equitable reporting.

METHODS

Search Strategy

A systematic search of PubMed, Embase and Cochrane in collaboration with a medical professional librarian was performed for studies related to orthopaedic health literacy published up to February 8th, 2022. Terms and keywords of different medical subject headings (MeSH) were combined with 'AND'. The following two domains with related words were included in the search: HL and orthopaedic specialties (Appendix 1). The Preferred Reporting Items for Systematic Reviews and Meta-Analyses guidelines were used as reporting guidelines (Figure 1).[9]

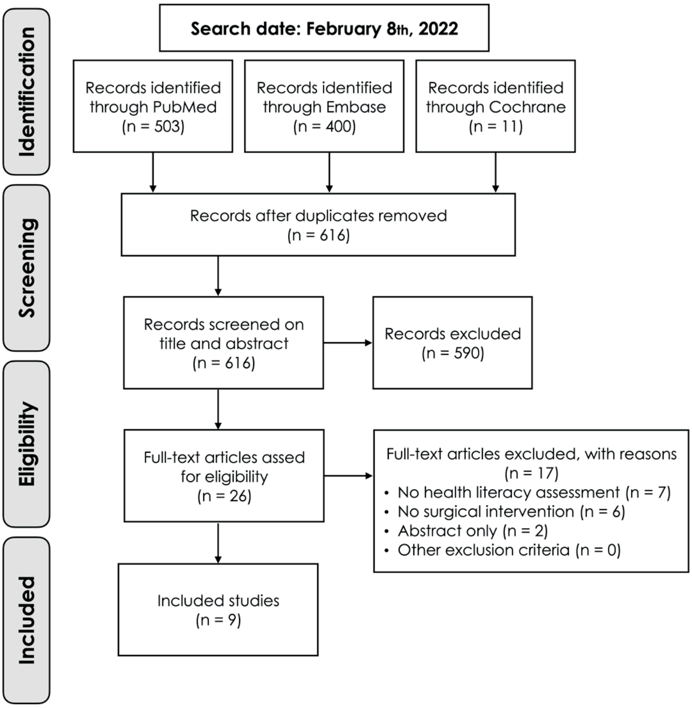

Figure 1 Flow chart of include studies

Eligibility Criteria

Studies were included if they evaluated health literacy and orthopaedic surgery.[10,11] Exclusion criteria were: (1) no health literacy assessment, (2) conference abstracts, (3) unavailability of full-text through library, and (4) non-relevant study types such as animal studies, letters to the editors, and case-reports. Orthopaedic specialties were defined as any group of clinicians that treat musculoskeletal disorders.

Data Extraction

Two investigators (AL, PB) independently identified and screened the titles and abstracts of papers to identify eligible works. Any disagreements were adjudicated by the principal investigator (JHS).

The following variables were extracted from each of the included studies: name of the first author, year of study, title, orthopaedic specialty, surgical intervention, sample size, health literacy instrument, outcome, and results.

Equity of reporting was assessed using the PROGRESS+ framework (Appendix 2).[12,13] PROGRESS+ was published in 2014 to guide equity analyses and to ensure explicit consideration of equity in the design of new intervention studies and systematic reviews. Additional "Plus+" items were introduced in 2016. The PROGRESS+ framework consists of the following characteristics: place of residence, race/ethnicity/culture/language, occupation, gender/sex, religion, education, socioeconomic status, social capital, personal characteristics associated with discrimination (e.g., age, disability), features of relationships (e.g., smoking parents/ excluded from school), and time-dependent relationships (e.g., leaving the hospital). Equity of reporting assessments were performed independently by two reviewers (AL, JR) and disagreements were resolved by a third investigator (MSF).

Quality Assessment

To assess the quality of the included studies, the National Institutes of Health quality assessment tool for observational cohort and cross-sectional studies was used.[14] The assessment tool consists of 14 items and rates studies as good, fair or poor (Appendix 3).

Software

Extracted data from each study was visualized by bar graphs (Microsoft Excel Version 19.11). Mendeley Desktop Version 1.19.4 (Mendeley Ltd) was used as reference management software.

RESULTS

Twenty-six studies were selected by title and abstract after screening an initial pool of 616 studies. Nine studies remained after full-text screening. The majority of these studied arthroplasty (4/9; 44%) or trauma (3/9; 33%) patients (Table 1).

Table 1 Summary of included studies

Authors	Year	Orthopaedic Specialty	Sample size	Surgical intervention	Health literacy instrument	Validated instrument
Cosic et al.[7]	2017	Trauma	190	Surgical facture management	Self-made questionnaire	No
Kadakia et al.[11]	2013	Trauma	146	Surgical facture management	Self-made questionnaire	No
Kee et al.[12]	2019	Arthroplasty	325	Total joint arthroplasty	Self-reported question about medical forms	No
Kesänen et al.[13]	2019	Spine	100	Lumbar spine decompression	KNOWBACK*	No
MacMahon et al.[14]	2021	Foot and Ankle	202	Foot or ankle surgery[¥]	LIMP°	Yes
Narayanan et al.[19]	2021	Arthroplasty	453	Total knee arthroplasty	LIMP°	Yes
Rohringer et al.[28]	2021	Arthroplasty	77	Total knee arthroplasty	European Health Literacy Questionnaire	Yes
Sabbagh et al.[31]	2021	Shoulder	90	Shoulder arthroplasty	LIMP°	Yes
Tsahakis et al.[34]	2014	Trauma	299	Surgical facture management	Self-made questionnaire	No

*27-item KNOWBACK Test was designed for this study, assessing patients' empowering knowledge level related to the surgical care of lumbar spinal stenosis

°LiMP= Literacy in Musculoskeletal Problems

[†] Intervention was providing additional predischarge instructions

[‡] WOMAC = Western Ontario and McMaster Universities Osteoarthritis Index (WOMAC),

Validated health literacy assessments were used in only five of the included studies, and only three reported the rate of limited health literacy in their study population, which ranged from 34%-38.5%. Two studies examined health literacy interventions, in both cases looking at predischarge instructions. The most frequently reported items included in the PROGRESS+ framework were sex/gender and age (Figure 2). Place of residence and relationship features, such as marital status, were not reported in any of the included studies. The most complete reporting of PROGRESS+ items was 55% (6/11), and the lowest was 0% (0/11) (Figure 3).

Rate of limited health literacy	Study design	Outcome	Results	Quality[^]
Not determined	Observational; intervention[†]	Comprehension	Predischarge discussion improved patient health literacy	Fair
Not determined	Observational	Comprehension	orthopaedic trauma patients demonstrated limited comprehension	Poor
Not determined	Observational	After hour calls following total joint arthroplasty	Suboptimal health literacy was associated with increased calls within the first week after surgery	Fair
Not determined	Randomized controlled trial	Understanding of surgical intervention	Understanding improved significantly with no statistically significant differences between the groups	Good
34.0%	Cohort	Patient-surgeon expectations	There were no associations found between musculoskeletal health literacy and differences in expectations	Good
34.7%	Cross-sectional	WOMAC[‡] and satisfaction following surgery	Low musculoskeletal health literacy was associated with worse outcome scores and less satisfaction	Good
Not determined	Observational	Patient-reported outcome measures	No association between health literacy and clinical outcomes was found	Fair
38.8%	Cross-sectional	Factors associated with limited health literacy	Significant positive relationship between patient income and adequate LIMP° scores	Fair
Not determined	Cross-sectional; intervention[†]	Comprehension	Performance on comprehension questionnaires significantly improved	Good

[¥] Surgeries included: urgeries included Lapidus bunionectomy, total ankle replacement, midfoot/hindfoot/ankle fusion, tendon repair/reconstruction, other, first metatarsophalangeal joint fusion, flatfoot reconstruction, cheilectomy ± Moberg osteotomy, bunionectomy (first osteotomy), first metatarsophalangeal joint synthetic cartilage implant, hammertoe correction, ankle stabilization neuroma resection, sesamoidectomy, ankle open reduction and internal fixation, soft tissue mass excision, lesser metatarsal osteotomy, osteochondral lesion debridement/microfracture, revision total ankle replacement

[^] Quality Assessment used: National Institutes of Health quality assessment tool for observational cohort and cross-sectional

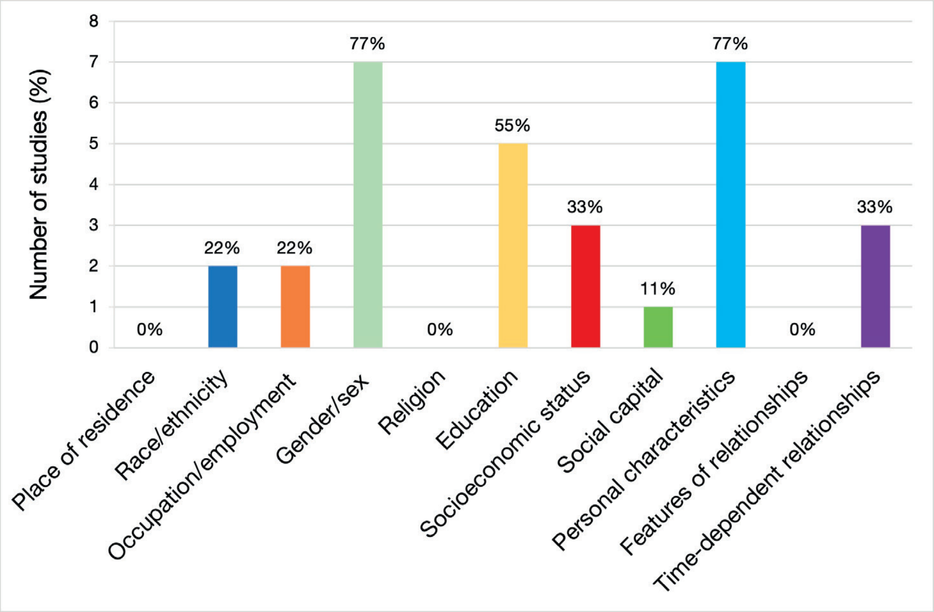

Figure 2 Reporting of PROGRESS+ items

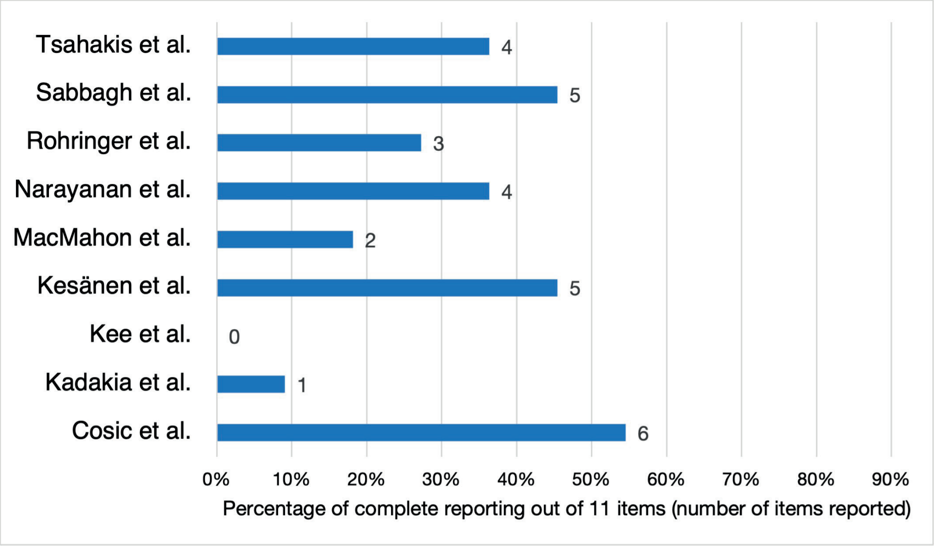

Figure 3 Completeness of reporting PROGRESS+

Quality Assessment

A minority of studies (4/9) were considered good quality while the remaining five articles were rated fair or poor.

DISCUSSION

Poor health literacy can limit adequate comprehension and participation in medical care, leading to inadequate treatment of manageable medical issues, wider social disparities, and preventable cost inefficiency.[24–26] One challenge of managing health literacy is its variability between medical domains and the inconsistent quality of the overall body of literature. In a systematic review of works that assessed the health literacy of orthopaedic surgery patients, few studies evaluated health literacy, and none used validated health literacy assessments. Analysis using the PROGRESS+ framework found that the majority of studies had limited equity reporting, and a quality assessment found that a minority of the included studies were of adequate quality. This systematic review demonstrated the need for high quality, replicable investigations of health literacy in patients undergoing orthopaedic surgery procedures.

Studies included in this review were mostly observational. One study examined a low-literacy patient communication intervention using a randomized controlled design. However, the findings of this study were limited in quality because health literacy was assessed using an unvalidated measure. The findings of the studies included in the present work suggest that poor health literacy may be associated with inadequate comprehension of the surgical procedure and discharge instructions, leading to increased healthcare utilization. However, the absence of large studies with structured interventions assessing and addressing limited health literacy makes it difficult to support these preliminary findings. Studies included in this review also seldom accounted for confounding factors despite the large body of literature that reported a higher prevalence of poor health literacy in older patients, minorities, unemployed/low income individuals, those on government insurance, and those who did not complete high school.[15,16,27–30]

Health equity and health literacy appear to have many common pathways, given that socially disadvantaged groups such as low-income patients, ethnic minorities, and low education levels are associated with poor health literacy. However, Paasche-Orlow et al. lament that despite their potential synergy, health disparity and health literacy research remain largely separate.[31] The authors promote the potential value of educational, information technology, self-care support, and professional training interventions as ways to marry these fields. The near ubiquitous availability of internet and electronic resources in recent years has markedly improved our ability to render potential literacy and disparity interventions to at-risk patients. Ozkan et al. reported that even among those with poor health literacy, the most frequently used medium in Turkey for health-related information was the internet (48.6%), followed distantly by television (33%).[32] Beyond accessibility is the need to combine the concepts of health disparities and poor literacy and ways to identify them during training. We have not fully married social equity and literacy to medical training. Altschuler et al. surveyed residents across seven programs at a single institution from 2013-2014, reporting that only 65% of respondents received any health literacy training, with minimal exposure during residency. Many were also unable to locate printed materials for low-literacy patients and had minimal understanding of interventions available for low-literacy patients.[33] Ubbes and Njoku proposed a curriculum and framework for teaching and evaluating health literacy education in medical schools, including written/oral communication strategies and skill-based instruction.[34] It is anticipated that health literacy will continue to be integrated into undergraduate and graduate medical education as social disparities continue to be incompatible with high quality, value-based health care.

The rather narrow domains of health literacy covered by the orthopaedic literature are reflective of general medical literature as a whole. Weiss in his narrative summary of current health literacy interventions noted that works appear to rehash the same concepts: assessing patient and provider health literacy skills and assessing the reading comprehension of patient education/discharge materials.[35] Pleasant et al. identified these same limitations and emphasized the need for "positive interventions", in which potential solutions for poor health literacy are tested rather than further works that identify the same deficits.[36] Examples of such positive interventions are discussed by McCormack et al., who classified them by level of impact, from individual to macro/national.[37] Their proposed social ecological health literacy model also identified implementation strategies for use in research protocols, which included the accumulation of multiple levels of intervention, amplification of existing interventions with a separate additional intervention, facilitation of existing intervention with overarching strategies for magnifying their effects, and measuring interventions by phase of impact (cascade). However, a challenge to devising and testing positive interventions is our ability to evaluate their efficacy in a standardized and comparable manner. Roy et al. in their systematic review of the health literacy of surgical patients found that 19 different health literacy tools were used between 51 included studies, and findings were highly heterogeneous.[38] An ideal health literacy intervention would be well targeted to a specific population (regardless of breadth), repeated across multiple works, able to be evaluated using validated metrics, and able to be modulated or compounded by additional interventions. To date, this implementation strategy has not been utilized in orthopaedic surgery.

This systematic review should only be interpreted in the context of its limitations. First, despite utilizing multiple online medical databases and comprehensive search strategies, eligible studies may have been missed. However, we do not believe that a missed work would have substantially altered the conclusions of the present work. Second, we were unable to perform a quantitative analysis due to the heterogenous nature of the included studies and the lack of validated health literacy assessments. Finally, with only nine studies from various orthopaedic subspecialties meeting our inclusion criteria, firm conclusions cannot be fairly drawn. Despite these limitations, this review offers insights into the health literacy of patients undergoing orthopaedic surgery.

Conclusion

This systematic review investigated the level of health literacy of patients undergoing orthopaedic surgery and assessed the equitable reporting of included studies. Only nine studies were identified, highlighting the paucity of available literature. Empirical evidence demonstrating the impact of limited health literacy can offer avenues for identifying at-risk patients, provide additional support, and improve the overall quality of care. The potential impact of health literacy on orthopaedic patients and their outcomes has yet to be determined, and requires thoughtful, high-quality trials across diverse demographics and geographies. An improved body of literature can help physicians target specific aspects of health-related education over the course of a patient’s pre- and postoperative care, maximizing patient/physician collaboration while providing high quality and resource-respecting care.

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APPENDICES

Appendix 1 Search strategies health literacy in orthopaedics

Appendix 2 PROGRESS+ framework definitions

Appendix 3 The National Institutes of Health (NIH) quality assessment tool for observational cohort and cross-sectional studies

Part II

Assessment of Patient Health Literacy

Chapter 6

General Health Literacy and Cancer Health Literacy in Patients with Metastatic Bone Disease

Amanda Lans, Julian H. Lang, Hester Zijlstra, Dylan Koole, Pranati Borkhetaria,
Jorrit-Jan Verlaan, Santiago A. Lozano-Calderon, Joseph H. Schwab

Submitted

ABSTRACT

Background: Despite being widely studied in various patient populations, health literacy (HL) has received little consideration in patients with metastatic bone disease. Therefore, the purpose of this study was 1) to evaluate the degree of general health literacy (GHL) and cancer health literacy (CHL) and 2) to identify patient characteristics associated with limited GHL and CHL in patients with metastatic bone disease.

Methods: Between December 2021 and December 2022, 106 English-speaking adult patients diagnosed with metastatic bone disease agreed to participate in this study. Participants verbally completed a sociodemographic questionnaire, and general health literacy assessment, a cancer-specific health literacy assessment and a reading assessment. Additional sociodemographic variables were collected from patient records, and online mapping tools were used to collect the Social Vulnerability Index, and the Area Deprivation Index (ADI) for each patient. Multivariable regression analysis was performed to identify independent factors associated with limited GHL and CHL.

Results: Overall, 50% (53/106) were found to have limited GHL, 50% (53/106) were found to have limited CHL, and 32% (34/106) had both limited GHL and CHL. Adjusted regression analysis demonstrated that limited GHL was independently associated with a higher ADI state decile (B = 0.86, [CI 0.27, 1.45], p = 0.004) and a higher ADI national percentile (B = -0.11, [CI -0.18, 0.03], p = 0.007. Similarly, adjusted analysis found that limited CHL was independently associated with higher ADI state decile (B = -0.61, [CI -1.09, 0.17], p = 0.015) and a higher ADI national percentile (B = 0.075, [CI 0.00, 0.15], p = 0.041).

Conclusion: Our findings demonstrate that one in two patients with metastatic bone disease have limited GHL or CHL. Orthopaedic oncologists should be aware that a large proportion of their patients may not have the necessary skills to understand and manage their disease. Additionally, ADI was independently associated with both limited GHL and CHL, offering a potential avenue for identifying patients at risk for limited HL.

INTRODUCTION

Health literacy (HL) refers to an individual's ability to obtain, understand and process basic health information and services necessary to make appropriate health decisions.[1] As the healthcare system in the United States shifts towards more patient-centered care and self-management of health conditions, possessing adequate HL is becoming critical for patients to have meaningful discussions about their condition with their care providers. Complex health issues can be challenging to understand, leaving even highly educated patients vulnerable when navigating their care.[2] The importance of having adequate HL is amplified as technology advances in cancer diagnosis and treatment, especially in the context of metastatic disease. Patients with metastatic cancer are expected to make informed decisions about their treatment, so even a minor lack of comprehension can result in serious health consequences and worse prognoses.[3,4]

A 2003 national survey estimated that 87 million adults in the United States have insufficient HL skills to adequately partake in healthcare.[5,6] Additionally, nearly 40% of the US population will be diagnosed with a form of cancer in their lifetime of whom over 5% will develop metastatic bone disease.[7,8] These findings demand that orthopaedic oncologists understand the role HL plays when delivering care to their patients. Limited HL has previously been associated with worse health outcomes in oncology patients, greater difficulties understanding and processing cancer related information, poorer quality of life, and poorer experience of care.[9,10] Several literature reviews have echoed the sentiment that limited HL is associated with unfavorable health outcomes and requires further studies in cancer patients.[9–11]

HL has yet to receive consideration in patients with metastatic bone disease. Therefore, to gain insights into regarding HL in this patient population, the purpose of this study was 1) to evaluate the degree of general health literacy (GHL) and cancer health literacy (CHL) and 2) to identify patient characteristics associated with limited GHL and CHL in patients with metastatic bone disease.

METHODS

Study Design and Setting

Under the approval of our institutional review board, we conducted a single-center, cross-sectional study which took place between December 2021 and December 2022 at a tertiary urban academic outpatient orthopaedic oncology clinic in the United States. Patients diagnosed with metastatic bone disease were approached for participation if they were 18 years or older, were fluent in English, and were able to provide informed consent. Patients were ineligible if they did not consider themselves fluent in English, required a translator, or were visually impaired. Informed consent was obtained from each study participant prior to any study procedures.

Outcome Measures and Explanatory Variables

Patients were approached by one of three trained research study staff. Participants who had consented were asked to verbally complete a sociodemographic questionnaire and three HL assessments, namely: the Newest Vital Sign Health Literacy Assessment Tool (NVS), the Short Form Rapid Assessment of Adult Literacy in Medicine (REALM-SF), and the Cancer Health Literacy Test-6 (CHLT-6).

The NVS is a widely used GHL assessment originally validated against the Test of Functional Health Literacy in Adults (TOFHLA) in a population of primary care patients.[12,13] The assessment incorporates several essential elements of HL including reading, oral comprehension, interpreting numbers, and applying basic arithmetic. The NVS is administered verbally and uses an ice cream nutrition label formatted as those found on packaged food in the United States. The assessment consists of six questions related to the nutrition label, and each correct answer earns one point (Appendix 1). Patients were categorized as demonstrated in the NVS validation study and as employed in previous orthopaedic populations.[13-15] This categorization considers patients scoring 4-6 points to have adequate GHL and patients scoring 0-3 points to have limited or inadequate GHL. This binary mode of classification achieved a sensitivity of 100% and a specificity of 64% for identifying patients with limited HL.[13]

The CHLT-6 is a six-question HL assessment designed to quickly identify individuals with inadequate CHL. This tool was derived from the original 30-question Cancer Health Literacy test (CHLT-30) from which the six most informative questions for identifying individuals with limited CHL were included in the CHLT-6.[16] Patients were categorized in the same binary manner as in the validation study where any score of fewer than six questions answered correctly categorizes patients as having inadequate CHL. If all questions are answered correctly, they are categorized as having adequate HL.[17]

The REALM-SF was administered as a literacy assessment.[18] The REALM-SF is a validated tool which consists of seven words that patients are asked to read out loud. Each correct word results in one point. REALM-SF scores were categorized into below ninth-grade reading level (< 7 correct words) and at least ninth-grade reading level (7 correct words). In the United States, a ninth-grade reading level is expected from individuals ages 14-15 years.

Variables collected during the verbal sociodemographic survey included native English speaking, race, ethnicity, educational attainment, employment status, and marital status. Variables collected through manual chart review were age, sex, body mass index (BMI), insurance status, smoking status (former/current/never), alcohol use (former/current/never), the Charlson Comorbidity Index, primary tumor type and time from primary tumor to metastatic bone disease. Additionally, Social Vulnerability Index (SVI) and Area Deprivation Index (ADI) were extracted using online mapping tools and individual patient addresses.[19–22] The SVI is an index created by the Centers for Disease Control and Prevention which utilizes 16 census variables to help identify communities that may need support before, during, or after disasters (Appendix 2). The ADI uses Census Block Groups to rank neighborhoods by socioeconomic disadvantage on both a national percentile and a state decile (Appendix 3). A higher SVI or ADI is indicative of more socioeconomic disadvantage.

Statistical Analysis

Descriptive statistics were used to summarize the data. Continuous variables were tested for normality using histograms, and Shapiro-Wilk tests. As none of these variables followed a normal distribution, all continuous variables were reported using medians and interquartile ranges. Discrete variables were reported as frequencies and percentages. Bivariate analysis was conducted to assess differences across all baseline demographics and disease characteristics between adequate and limited health literacy cohorts. Two sample, two-tailed Mann-Whitney U tests were conducted for continuous variables. Discrete variables were assessed using chi-squared tests.

Two regression models were constructed with level of GHL or level of CHL as the outcome of interest. Age, sex, BMI, race, ethnicity, fluent English speaking, highest educational degree, grade-level reading, marital status, employment status, type of insurance, SVI, ADI (state decile and national percentile), Charlson Comorbidity Index, type of primary cancer, time from primary cancer to metastatic disease, and GHL or CHL level were included as covariates in both regression models. Adjusted regression coefficients (B) and 95% confidence intervals (CI) were calculated for each health literacy domain. A p value of < 0.05 was designated a priori as indicative of statistical significance.

RESULTS

Over the course of this study, 117 patients were approached, of which 106 agreed to participate, resulting in a response rate of 91%. Three patients did not participate due to a lack of time and eight patients were not interested in participating (Figure 1). The median age of included patients was 68 years (IQR 60-75), of which a slight majority was female

(55%; 58/106) (Table 1). Half of the patients were found to have limited GHL (50%; 53/106) or limited CHL (50%; 53/106). Of the 79 patients who had limited GHL or CHL, 16% (13/79) had only limited GHL, 16% (13/79) had only limited CHL, and 51% (40/79) had both limited GHL and CHL. Among all patients, 32% (34/106) were found to have both limited GHL and CHL. Most patients had at least a ninth-grade reading level (81%; 80/106).

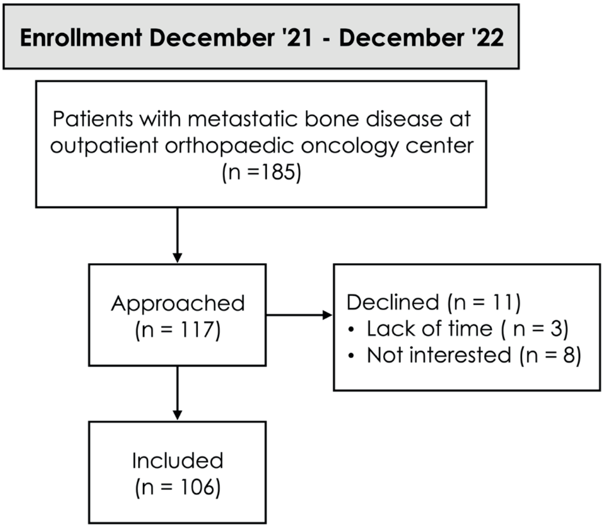

Figure 1 Flow of patient enrollment

Unadjusted analysis of patient characteristics found that limited GHL was associated with older age (p = 0.004), having lower than ninth-grade reading level (p = 0.001), being publicly insured (p = 0.002) and having limited CHL (p < 0.001). Unadjusted analysis of patient characteristics associated with limited CHL were race other than White (p = 0.008), less educational attainment (p = 0.026), lower than ninth-grade reading level (p = 0.025), having public insurance (p = 0.026), and having limited GHL (p < 0.001) (Table 1).

Adjusted regression analysis demonstrated that limited GHL was independently associated with higher ADI state decile (B = 0.86, [CI 0.27, 1.45], p = 0.004), higher ADI national percentile (B = -0.11, [CI -0.18, 0.03], p = 0.007), and having limited CHL (B = 3.43, [CI 1.62, 5.24], p < 0.001). Adjusted regression analysis found that limited CHL was independently associated with higher ADI state decile (B = -0.61, [CI -1.09, 0.17], p = 0.015), higher ADI national percentile (B = 0.08, [CI 0.00, 0.15], p = 0.041), and having limited GHL (B = 3.17, [CI 1.48, - 4.85], p < 0.001) (Table 1).

Table 1 Patient characteristics (n = 106)

		General health literacy level*			Cancer health literacy level°		
		Adequate (n = 53)	**Limited (n = 53)**	**p value**	**Adequate (n = 53)**	**Limited (n = 53)**	**p value**
Age, median (IQR)	68 (60-75)	65 (57-71)	70 (63-77)	**0.004**	66 (59-70)	73 (63-77)	**0.009**
Female	58 (55)	32 (30)	26 (25)	0.329	33 (31)	25 (24)	0.172
Race				0.680			**0.008**
White	95 (90)	48 (45)	47 (44)		52 (50)	43 (41)	
Black or African American	8 (8)	3 (3)	5 (5)		0 (0)	8 (8)	
Asian	1 (1)	1 (1)	0 (0)		1 (1)	0 (0)	
Hispanic or Latino	2 (2)	1 (1)	1 (1)		0 (0)	2 (2)	
Hispanic or Latino ethnicity	4 (4)	3 (3)	1 (1)	0.610	1 (1)	3 (3)	
BMI, median (IQR)	28 (23-32)	29 (25-34)	27 (22-31)	0.052	29 (25-34)	26 (22-31)	0.059
Native English speaker	99 (93)	50 (47)	49 (46)	0.987	52 (49)	47	0.117
Highest degree obtained				0.075			**0.018**
Less than high school (< 12y)	4 (4)	1 (1)	3 (3)		1 (1)	3 (3)	
High school or GED (12y)	37 (35)	13 (12)	24 (23)		12 (11)	25 (24)	
College bachelors (16y)	34 (32)	20 (19)	14 (13)		23 (22)	11 (10)	
Advanced degree (> 16y)	31 (29)	19 (19)	12 (11)		17 (16)	14 (13)	
≥ 9th grade level reading[†]	86 (81)	50 (47)	36 (34)	**0.001**	48 (45)	48 (45)	**0.025**
Marital status				0.693			0.719
Single	11 (10)	6 (6)	5 (5)		6 (6)	5 (5)	
Married or life partner	67 (63)	33 (31)	34 (32)		31 (29)	36 (34)	
Divorced or legally separated	17 (16)	10 (9)	7 (7)		9 (8)	8 (8)	
Widowed	11 (10)	4 (4)	7 (7)		7 (7)	4 (4)	

Table 1 Patient characteristics (n = 106)

		General health literacy level*			**Cancer health literacy level°**		
		Adequate (n = 53)	**Limited (n = 53)**	**p value**	**Adequate (n = 53)**	**Limited (n = 53)**	**p value**
Employment status				0.123			0.059
Employed	29 (27)	18 (17)	11 (10)		18 (17)	11 (10)	
Unemployed	7 (7)	5 (5)	2 (2)		3 (3)	4 (4)	
Unable to work (disabled)	10 (9)	6 (6)	4 (4)		8 (8)	2 (2)	
Retired	60 (57)	24 (23)	36 (34)		24 (23)	36 (34)	
Private insurance	68 (64)	42 (40)	26 (25)	**0.002**	40 (38)	28 (26)	**0.026**
Social Vulnerability Index				0.630			0.417
Low	63 (60)	34 (32)	29 (27)		33 (31)	30 (28)	
Low-moderate	18 (17)	9 (8)	9 (8)		11 (10)	7 (7)	
Moderate-high	17 (16)	8 (8)	9 (8)		7 (7)	10 (9)	
High	7 (7)	2 (2)	5 (5)		2 (2)	5 (5)	
ADI‡ State, median (IQR)	3 (3-6)	3 (12-6)	4 (2-6)	0.161	3 (2-6)	3 (2-6)	0.161
ADI‡ National, median (IQR)	19 (10-31)	17 (10-28)	21 (11-33)	0.203	19 (10-31)	19 (11-32)	0.426
Charlson Comorbidity Index				0.087			0.074
None (0)	10 (9)	7 (7)	3 (3)		4 (4)	6 (6)	
Mild (1-2)	34 (32)	20 (19)	14 (13)		23 (22)	11 (10)	
Moderate (3-4)	52 (49)	24 (23)	28 (26)		23 (22)	29 (27)	
Severe >5	10 (9)	2 (2)	8 (8)		3 (3)	7 (7)	

Data presented as n (%) unless stated otherwise; boldface type indicates statistical significance ($p < 0.05$); IQR = Interquartile range; *General health literacy level was determined using the Newest Vital Sign. Patients with scores < 4 were considered to have limited health literacy; °Cancer Health Literacy Test (CHLT-6) was used to determine cancer health literacy level. Patients with scores <6 were considered to have limited cancer health literacy; †Rapid Estimation of Adult Literacy in Medicine - Short Form (REALM-SF) score 7: ≥ 9th grade reading level; score < 7: < 9th grade reading level; ‡ADI = Area Deprivation Index

Table 2 Disease characteristics

		General health literacy level*			**Cancer health literacy level°**		
		Adequate (n = 53)	**Limited (n = 53)**	**p value**	**Adequate (n = 53)**	**Limited (n = 53)**	**p value**
Primary cancer type				0.157			0.534
Lung	15 (14)	11 (10)	4 (4)		7 (7)	8 (8)	
Prostate	14 (13)	6 (6)	8 (8)		5 (5)	9 (8)	
Renal	12 (11)	2 (2)	10 (9)		5 (5)	7 (7)	
Skin & Melanoma	2 (2)	2 (2)	0 (0)		1 (1)	1 (1)	
Breast	24 (23)	13 (12)	11 (10)		15 (14)	9 (8)	
Adenocarcinoma unknown[†]	2 (2)	2 (2)	0 (0)		1 (1)	1 (1)	
Multiple Myeloma	11 (10)	4 (4)	7 (7)		6 (6)	5 (5)	
Thyroid	6 (6)	2 (2)	4 (4)		2 (2)	4 (4)	
Liver	3 (3)	1 (1)	2 (2)		1 (1)	2 (2)	
Gynecological	3 (3)	1 (1)	2 (2)		1 (1)	2 (2)	
Osteosarcoma	10 (9)	6 (6)	4 (4)		8 (8)	2 (2)	
Gastrointestinal	4 (4)	3 (3)	1 (1)		1 (1)	3 (3)	
Median days to metastatic bone disease (IQR)	944 (33-2567)	338 (31-2422)	1218 (37 -2917)	0.271	824 (37 -2563)	1009 (17 - 2855)	0.771

Data presented as n (%) unless stated otherwise; IQR = interquartile range; *General health literacy level was determined using the Newest Vital Sign. Patients with scores < 4 were considered to have limited health literacy; °Cancer Health Literacy Test (CHLT-6) was used to determine cancer health literacy level. Patients with scores <6 were considered to have limited cancer health literacy; [†]unknown origin;

DISCUSSION

It has previously been reported that inadequate HL has adverse effects on oncology patients, including increased hospitalization rates and worse clinical outcomes.[23] However, to our knowledge, this is the first investigation of HL in patients with metastatic bone disease that uses multiple validated HL assessments. This study found that half of the patients with metastatic bone cancer presenting at an orthopaedic oncology clinic had limited GHL or limited CHL. Of the 74 patients that had either limited GHL or CHL, over a third had both limited GHL and CHL. The adjusted regression analysis found that a higher ADI, indicative of more social disadvantage, was independently associated with both limited GHL and CHL. An interpretation of these results is that other patient characteristics, such as age, race, reading level, education level, and insurance type, are proxy variables for the true underlying factor associated with poor HL, which is ADI. However, it can be expected that the rate of limited GHL and CHL will be higher in more disadvantaged patient populations, such as those with less education, public insurance, and lower income.[24]

Furthermore, the use of a survey requires that participation bias is considered. Patients with more confidence or those who are more knowledgeable may be more inclined to participate in a HL study and to complete all the required questions.[25] However, this study did have a high response rate. Furthermore, given that educational attainment and grade-level reading were controlled for during analysis, we do not believe participation bias impacted our results. Additionally, it may be argued that the NVS ice cream label assessment falls short of capturing the true complexity of health literacy. However, the NVS has been previously validated and accurately simulates a medical scenario by asking patients to interpret novel information while interacting with a healthcare professional in a clinical setting.[13] Therefore, we find that this form of assessment offers a more realistic impression of a patient's level of HL compared to self-report measures. Finally, selection bias can be a concern in a tertiary orthopaedic oncology clinic. Despite these limitations, this study is the first to report on GHL and CHL in patients with metastatic bone disease, therefore we believe that it provides valuable insights for practicing orthopaedic oncologists.

A previous investigation by Hyatt et al. found that 21% of the 345 oncology patients included in their study had inadequate CHL according to the CHLT-6.[17] This finding stands in stark contrast to our study, which found that 50% of the 106 patients with metastatic bone cancer included in our study had inadequate CHL. One explanation for this discrepancy is that the overall age of our study population was higher, which is known to be associated with limited GHL.[26] This could indicate that limited CHL may also be more prevalent in older patients with metastatic bone disease. This hypothesis is supported by the findings of this study, which suggests that patients who have late-stage cancer, such as metastatic bone disease, are more likely to have inadequate GHL and CHL. Having inadequate HL can inhibit patients' ability to meaningfully discuss their condition and treatment plan with their healthcare provider, which in turn would result in worse disease progression. In hand surgery clinics, it has been reported that patients with limited health literacy ask fewer questions and have shorter consultations with hand surgeons.[15,27] The lack of sufficient information may in turn impact successful treatment adherence. Conversely, patients with adequate HL have been reported to have higher chemotherapy adherence.[28] Our study found that one in three patients who suffer from metastatic bone disease will have inadequate understanding of both general and cancer-specific health information. It is important for clinicians to take this into consideration when discussing treatment options with patients to assure shared decision making.

After controlling for sociodemographic variables such as race, marital status, education level, and type of insurance, this study found that a high ADI remained associated with both GHL and CHL. This suggests that patients who live in disadvantaged neighborhoods and have disadvantaged socioeconomic statuses have a greater risk of limited GHL and

CHL, and consequently, may have worse health outcomes. An independent association between limited HL and higher ADI has previously been reported in orthopaedic spine patients seen in an outpatient clinic.[29] Additionally, in patients with advanced cancer, a higher ADI was reported to be associated with higher levels of anxiety.[30]

The utility of broad area-based measures, such as the ADI, could contribute to efforts of quickly identifying patients who are at risk of inadequate HL without taxing clinical resources. Identifying patients with limited HL can offer opportunities to improve care by providing appropriate resources tailored to a patient's level of HL. Interventional studies would be necessary to determine the most effective strategies to accommodate the level of a patient's HL. Finding effective ways to improve patient HL can improve patient outcomes and treatment experience for oncology patients, as limited HL has been associated with various negative features across different oncologic patient populations.[10] Examples include lower ease of understanding, lower perceived understanding of test results, greater disability, greater baseline cancer related needs, and lower self-efficacy in breast cancer patients. In patients with colorectal cancer, limited HL has been linked to greater financial hardship, higher pain interference, higher sleep disturbance and higher depression scores.[31-36] Other associations between HL literacy in oncologic patient populations that have been drawn include poorer quality of health, lower self-care management, higher treatment regret and, greater number of patient hospital admissions and total number of days hospitalized.[23, 37-40] These findings highlight the importance of finding methods to not only identify patients with inadequate HL, but also to accommodate these patients.

Our investigation is one of few studies that assessed both GHL and CHL, and the first to investigate this in patients with metastatic bone disease. We found that limited GHL and limited CHL were independently associated, suggesting that if a patient has limited GHL, they will likely lack disease-specific HL, and vice versa. This finding is corroborated by a study among breast cancer patients that demonstrated that GHL and CHL are associated.[41]

Conclusion

This study indicates that there is reason for concern with respect to GHL and CHL in patients with metastatic bone disease. Orthopaedic oncologists should be aware that a large proportion of patients they see in daily practice will not have the necessary skills to understand and manage their disease. This calls for further evaluation of how limited health literacy impacts outcomes. Future investigations could prospectively investigate if patients with limited health or cancer literacy are at an increased risk of adverse outcomes such as preventable skeletal related events.

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APPENDICES

Appendix 1 Newest Vital Sign questions in English

Appendix 2 Variables in the Social Deprivation Index

Appendix 3 Variables in the Area Deprivation Index

Chapter 7

Prevalence of- and Factors Associated with Limited Health Literacy in Spine Patients

Amanda Lans, John R. Bales, Daniel G. Tobert, Laura P. Rossi, Jorrit-Jan Verlaan, Joseph H. Schwab

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ABSTRACT

Background: Limited health literacy exacerbates health inequity and has serious implications for patient care. It hinders successful communication and comprehension of relevant health information, which can lead to suboptimal care. Despite the evidence regarding the significance of health literacy, the topic has received little consideration in orthopaedic spine patients. Therefore, the purpose of this study was to investigate the prevalence of- and factors associated with limited health literacy among outpatients presenting to a tertiary urban academic hospital-based orthopaedic spine center.

Methods: Between December 2021 and March 2022, 447 consecutive English-speaking patients over the age of 18 years and new to the outpatient spine clinic were approached for participation in a cross-sectional survey study, of which 405 agreed to participate. Patients completed the Newest Vital Sign Health Literacy Assessment Tool (NVS), the Rapid Estimation of Adult Literacy in Medicine Short Form (REALM-SF), and a sociodemographic survey (including race/ethnicity, level of education, employment status, income, and marital status). The NVS scores were divided into limited (0-3) and adequate (4-6) health literacy. REALM-SF scores were classified into reading levels below ninth grade (0-6) or at least ninth grade (7). Additional demographic data was extracted from patient records. Online mapping tools were used to collect the Social Vulnerability Index (SVI) and the Area Deprivation Index (ADI) for each patient. Subsequently, multivariable regression modeling was performed to identify independent factors associated with limited health literacy.

Results: The prevalence of limited health literacy in patients presenting to an urban academic outpatient spine center was 33% (135/405). Unadjusted analysis found that patients who were socioeconomically disadvantaged (e.g., unemployed, lower household income, publicly insured and higher SVI) and had more unfavorable social determinant of health features (e.g., housing concerns, higher ADI, less years of education, below ninth grade reading level, unmarried) had high rates of limited health literacy. Adjusted regression analysis demonstrated that limited health literacy was independently associated with higher ADI state decile, living less than 10 years at current address, having housing concerns, not being employed, non-native English speaking, having less years of education and below ninth grade reading level.

Conclusion: This study found that a substantial portion of the patients presenting to an outpatient spine center have limited health literacy, more so if they are socially disadvantaged. Future efforts should investigate the impact of limited health literacy on access to care, treatment outcomes and healthcare utilization in orthopaedic patients. Neighborhood social vulnerability measures may be a feasible way to identify patients at risk of limited

health literacy in clinical practice and offer opportunities for tailored patient care. This may contribute to prioritizing the mitigation of disparities and aid in the development of meaningful interventions to improve health equity in orthopaedics.

INTRODUCTION

Health literacy is defined as the ability to obtain, process, and understand health information required to make informed health decisions.[1] Although far from a new concept, health literacy is a mediating factor of health disparities and impacts individual and public health.[2] In 2003 the U.S. Department of Education National Assessment of Adult Literacy survey reported that 87 million adults have basic or below basic health literacy levels, which are considered insufficient to adequately function and participate within a healthcare setting.[3,4] Low health literacy is estimated to account for $100 billion USD in incremental healthcare costs per year.[5]

Patients with inadequate health literacy are less likely to engage in disease management and more likely to misunderstand health information, which can lead to adverse treatment effects and misutilization of medical resources.[6–11] Additionally, patients with limited health literacy are more likely to have worse self-reported heath, increased hospitalizations, longer length of stay after surgical procedures, more emergency room visits, and higher mortality than those with adequate health literacy.[12–16] Determining which patients are at risk of worse health outcomes due to limited health literacy may offer avenues for improving care by aiding the development of effective strategies aimed at greater patient-provider communication. Despite the growing concern for limited health literacy among adults, little is known regarding the prevalence and associated factors in orthopaedic spine patients.[17]

Therefore, the purpose of this study was to investigate the prevalence of- and factors associated with limited health literacy among outpatients presenting to a tertiary urban academic hospital-based orthopaedic spine center.

METHODS

Study Design and Setting

With the approval of our institutional review board, we conducted a prospective single-center cross-sectional study between December 2021 and March 2022 in an outpatient orthopaedic spine center at a tertiary urban academic medical center in the United States of America.

Study Population

Consecutive patients seen by a spine surgeon or a nurse practitioner were approached for participation if they were new to the spine clinic, 18 years or older, fluent English speakers and were able to provide informed consent. Patients were not eligible to participate if they did not consider themselves fluent and literate in English, required a translator, or were visually impaired. Verbal informed consent was obtained from each study participant prior to any study procedures.

Outcome Measures and Explanatory Variables

Eligible patients were approached by either a research fellow or one of three trained research study staff. Consenting participants were asked to verbally complete a sociodemographic survey and two health literacy assessments, namely the Newest Vital Sign Health Literacy Assessment Tool (NVS) and the Rapid Assessment of Adult Literacy in Medicine Short Form (REALM-SF).

The NVS is a health literacy and numeracy tool originally validated against the Test of Functional Health Literacy in Adults (TOFHLA) in a population of primary care patients.[18,19] The assessment incorporates many facets considered vital for adequate health literacy including reading written information, interpreting numbers, and applying basic arithmetic. The NVS is an in-person, verbally administered assessment that utilizes an ice cream nutrition label identical to those found on packaged food in the United States. The research staff asks the subject six questions about the label (Appendix 1). There is only one correct answer per question, and the subject is awarded one point for each question answered correctly. Patients were categorized in the same binary manner as demonstrated in the NVS validation study and as employed in previous orthopaedic populations.[19–21] This categorization considers patients scoring 4-6 points to have adequate health literacy and patients scoring 0-3 points to have limited health literacy. This binary mode of classification achieved a sensitivity of 100% and a specificity of 64% for identifying patients with limited health literacy.[19]

The REALM-SF was administered as a literacy assessment and reflects an individual's grade level reading abilities.[22] The REALM-SF is a validated tool consisting of seven words, which patients are asked to read out loud. Each correct word results in one point. REALM-SF scores reflect the following grade level reading ranges: 0 = third grade and below; 1-3 = fourth to sixth grade; 4-6 = seventh to eighth grade; 7 = ninth to twelfth grade. In the study, REALM-SF scores were categorized into below ninth grade reading level (< 7 correct words) and at least ninth grade reading level (7 correct words).

Variables collected during the verbal sociodemographic survey included native English speaking, race, ethnicity, highest grade or year of school completed, employment status, current marital status, annual household income, and living accommodations ((non-) homeowner, >10 years at current address, number of persons in household, and number of minors in household). Other variables were collected through manual chart review: age, sex, religious affiliation, body mass index (BMI), insurance status, smoking status, and alcohol use. Additionally, the Social Vulnerability Index (SVI) and Area Deprivation Index (ADI) were extracted using online mapping tools and individual patient addresses.[23–25] The SVI is an index created by the Centers for Disease Control and Prevention which utilizes 15 census variables to help identify communities that may need support before, during, or after disasters. The SVI consists of separate scores from four domains, including socioeconomic status, household composition and disability, minority status and language, and housing and transportation. Scores range from 0 (lowest vulnerability) to 1 (highest vulnerability) (Appendix 2). The ADI consists of 17 census variables reflecting socioeconomic status based on income, education, household characteristics, and housing (Appendix 3).[26] ADI scores are presented in state deciles and national percentiles, where higher scores indicate greater deprivation. Both the SVI and ADI have previously been linked to an increased risk of mortality, disability and readmission in various populations.[27–31]

Statistical Analysis

An a priori power analysis was performed to determine an estimated sample size. Due to its ubiquity in medical literature, we chose a Z-score of 1.96, which is the critical value corresponding to a 95% confidence level. The expected prevalence was estimated based on previous studies on health literacy in hand surgery, emergency department, foot and ankle, hand and wrist, and total knee arthroplasty patients, where the reported limited health literacy rates ranged between 33% – 49%.[20,32–34] We averaged these prevalence rates and assumed an expected limited health literacy prevalence of 41%. Precision is dependent upon expected prevalence, and previous literature has found that a precision of 5% is appropriate for studies with an expected prevalence between 10% and 90%.[35] With a Z-score of 1.96, a precision of 5% and an expected prevalence of 41%, a sample of at least 372 patients was needed to draw accurate conclusions from our sample.

Descriptive statistics were used to summarize the data. Continuous variables were tested for normality using histograms, quantile-quantile plots, and Shapiro-Wilks tests. As none of these variables followed a normal distribution, all continuous variables were reported using medians and interquartile ranges. Discrete variables were reported as frequencies and percentages.

Bivariate analysis was conducted to assess differences across demographics and social determinants of health variables between adequate and limited health literacy cohorts. To sample, two-tailed Mann-Whitney U tests were conducted for continuous variables. Discrete variables were assessed using chi-square tests.

Multivariable regression modeling was performed with health literacy level considered as the dependent variable and age, sex, race, ethnicity, native English speaker, home-ownership, persons in household, minors in household, years at current address, ADI state decile, ADI national percentile, SVI, BMI, smoking status, alcohol drinker, years of education, grade-level reading, employment status, annual household income, marital status, religious affiliation and type of insurance as covariates. Adjusted regression coefficients (B) and 95% confidence intervals (CI) were calculated for each variable. A p value < 0.05 was designated a priori as indicative of statistical significance.

RESULTS

Of the 447 eligible patients that were approached, 405 agreed to participate (91%) (Figure 1). The prevalence of limited health literacy among included patients was 33% (135/405). Patients with limited health literacy were more likely to be older (60 years vs. 54 years, p = 0.001), non-native English speakers (19% vs. 8.1%, p = 0.002), a race other than White (23% vs. 11%, p = 0.002) and of Hispanic or Latino ethnicity (8% vs. 3%, p = 0.02). Regarding education and employment factors, patients with limited health literacy were more likely not to have attended college (37% vs. 6%, p < 0.001), less likely to have a reading level above ninth grade (28% vs. 8%, p < 0.001), more likely to not have employment (62% vs. 30%, p < 0.001), have a household income below $75,000 (50% vs. 17%, p < 0.001), be unmarried (58% vs. 34%, p < 0.001), and have public health insurance (62% vs. 32%, p < 0.001) (Table 1).

Table 1 Patient characteristics stratified by health literacy level (n = 405)

		Health literacy level*		
		Limited	Adequate	p value
Total	405 (100)	135 (33)	270 (66)	
Age in years, median (IQR)	57 (43-69)	60 (49-73)	54 (41-66)	**0.001**
Male	203 (50)	67 (50)	136 (50)	0.888
Race				**0.002**
White	345 (85)	104 (77)	241 (89)	
Not White°	60 (15)	31 (23)	29 (11)	
Ethnicity				**0.020**
Not Hispanic or Latino	386 (95)	124 (92)	262 (97)	
Hispanic or Latino	19 (4.7)	11 (8)	8 (3.0)	
Native English speaking				**0.002**
Yes	357 (88)	109 (81)	248 (92)	
No	48 (12)	26 (19)	22 (8.1)	
Education and employment features				
Years of education[†]				**< 0.001**
No college (< 13 years)	66 (16)	50 (37)	16 (5.9)	
College or higher (≥ 13 years)	338 (84)	84 (63)	254 (94)	
Grade level reading[‡]				**< 0.001**
< 9th grade	60 (15)	38 (28)	22 (8.1)	
≥ 9th grade	345 (85)	97 (72)	248 (92)	
Employment status				**< 0.001**
Employed[¥]	241 (60)	51 (38)	190 (70)	
Not employed[^]	164 (40)	84 (62)	80 (30)	
Annual household income[§]				**< 0.001**
< $75,000	88 (28)	53 (50)	35 (17)	
> $75,000	224 (72)	52 (50)	172 (83)	

n (%) unless stated otherwise; IQR = interquartile range; *Health literacy level was determined using the Newest Vital Sign. Patients with scores < 4 were considered to have limited health literacy; boldface type indicates statistical significance ($p < 0.05$); IQR = Interquartile range; °Not white includes American Indian (n = 2), African American (n = 19), Asian (n = 24), Hispanic or Latino (n = 12) and Unknown (n = 3); [†]n = 1 declined to answer; [‡]Grade level reading was determined using the Rapid Assessment of Adult Literacy in Medicine Short Form (REALM-SF) below 9th grade reading level (REALM-SF score < 7) and at least 9th grade reading level (REALM-SF score of 7); [¥]Employed includes employment (n = 204), self-employment (n = 28), or student (n = 9); [^]Not employed includes retired (n = 111), out of work (n = 24), or disabled (n = 29); [§]declined to answer (n = 93)

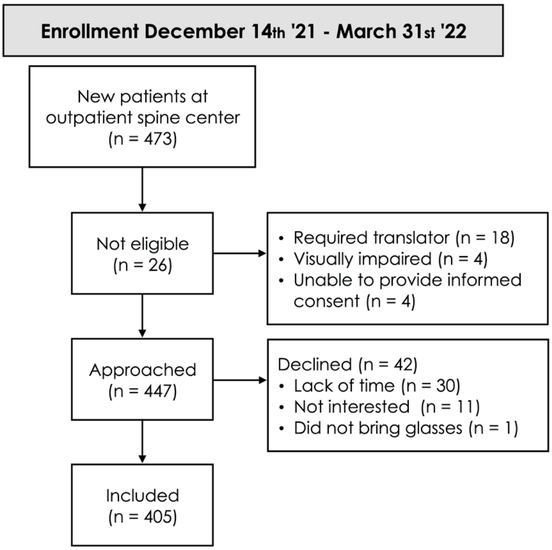

Figure 1 Flow of patient enrollment

Social Determinants of Health and Health Literacy

When considering factors related to living environment and housing, patients with limited health literacy were more likely to be renting a home (47% vs. 24%, p < 0.001), have self-reported housing concerns (14% vs. 4%, p < 0.001), and live in an area with more social vulnerability (SVI: 0.28 vs. 0.26, p = 0.002) as well as a higher deprivation index on both a state (ADI state decile: 4 vs. 2, p < 0.001) and national level (ADI national percentile: 19.0 vs. 11.5, p < 0.001), indicating more neighborhood disadvantage (Table 2). There were no statistical differences in sex (male: 50% vs. 50%, p = 0.888), BMI (28 vs. 27, p = 0.068), or smoking status (current smokers: 14% vs. 16%, p = 0.130) between adequate and limited health literacy groups.

Adjusted regression analysis demonstrated that limited health literacy was independently associated with: higher ADI state decile (B = 0.10, [CI 0.05, 0.20], p = 0.038), living less than 10 years at current address (B = -0.79, [CI -1.48, -0.13], p=0.021), having housing concerns (B= -1.05, [CI -2.11, -0.04], p = 0.045), not being employed (B= 0.81, [CI 0.13, 1.57], p = 0.028), non-native English speaking (B = 1.00, [CI 0.06, 1.97], p=0.038), having less years of education (B = 1.74, [CI 1.05, 2.66], p = < 0.001) and less than a ninth grade reading level (B = 1.03, [CI 0.17, 1.77], p = 0.017).

Table 2 Social determinants of health features stratified by health literacy level (n = 405)

		Health Literacy level*		
		Limited	Adequate	p value
Total	405 (100)	135 (33)	270 (67)	
Living environment and housing°				
Housing				**< 0.001**
Homeowner	275 (68)	71 (53)	204 (76)	
Non-homeowner	129 (32)	64 (47)	65 (24)	
Total persons in household, median (IQR)	2 (2-3)	2 (1-3)	2 (2-3)	**< 0.001**
Persons <18 years in household, median (IQR)	0 (0-0)	0 (0-0)	0 (0-1)	**0.001**
Years at current address				**0.027**
<10 years	208 (52)	59 (44)	149 (56)	
>10 years	196 (48)	76 (56)	120 (44)	
Housing concerns[†]				**< 0.001**
Yes	30 (7)	19 (14)	11 (4)	
No	374 (93)	116 (86)	258 (96)	
Area Deprivation Index, median (IQR)				
State decile	3 (1-6)	4 (2-6)	2 (1-5)	**< 0.001**
National percentile	15 (7-25)	19 (10-27)	11.5 (6-23)	**< 0.001**
Social Vulnerability Index, median (IQR)	0.26 (0.12-0.45)	0.28 (0.13-0.63)	0.24 (0.11-0.39)	**0.002**
Health behaviors				
Body Mass Index[‡], median (IQR)	27 (24-32)	28 (25-33)	26.8 (23-32)	0.068
Smoking status[¥]				0.130
No (former or never)	332 (92)	104 (88)	228 (93)	
Yes (current)	30 (8.3)	14 (12)	16 (6.6)	
Alcohol use[^]				**0.001**
No (former or never)	99 (33)	45 (46)	54 (27)	
Yes (current)	201 (67)	52 (54)	149 (73)	
Social capital				
Marital status[§]				**< 0.001**
Married or life partner	234 (58)	57 (42)	177 (66)	
Not married	171 (42)	78 (58)	93 (34)	
Religious affiliation				**0.044**
Affiliated	243 (60)	89 (66)	154 (57)	
Not affiliated	136 (34)	36 (27)	100 (37)	
Access to care				
Type of insurance[«]				**< 0.001**
Public	171 (42)	84 (62)	87 (32)	
Private	233 (58)	51 (38)	182 (67)	

n (%) unless stated otherwise; IQR = interquartile range; *health literacy level was determined using the Newest Vital Sign. Patients with scores < 4 were considered to have limited health literacy; boldface type indicates statistical significance ($p < 0.05$); °n = 1 declined to answer; [†]Concerned about housing if patient answered yes to: *in the last 6 months, have you been worried or concerned about not having a place to live*; [‡]Unknown Body Mass Index (n = 31); [¥]Unknown smoking status (n = 43); [^]Unknown alcohol use (n = 105); [§]Declined to answer (n = 1); Unknown religious affiliation unknown (n = 26); [«]Public insurance: Medicaid (n = 28), Medicare (n = 123), or MassHealth (n = 20); Private insurance: any other health insurance; No insurance on file (n = 1)

DISCUSSION

Limited health literacy exacerbates health inequity and has serious implications for patient care.[36–39] However, the topic has received little consideration in orthopaedic spine patients. Identifying patients at increased risk for limited health literacy will be imperative for developing more effective communication strategies and may have clinical consequences for the care of spine patients. Therefore, this study sought to investigate the prevalence of limited health literacy in orthopaedic spine patients with a powered sample size and using a validated assessment measure for general health literacy.

Our study is subject to several limitations, and the interpretation of the findings should consider these limitations. First, because this was a survey study, a participation bias must be considered. Patients may be more inclined to participate in a health literacy study if they have more confidence or are more knowledgeable regarding healthcare. Nevertheless, the most predominant reason for declining was lack of time, and given that our response rate was over 90%, we do not believe this has implications for our results. Second, because the patients were seen in a tertiary spine clinic, selection bias should be considered. However, our inclusion criteria allowed for patients to be seen by either a spine surgeon or a nurse practitioner, thereby offering a more diverse spine patient population that includes varying symptom presentations. The generalizability of our results is further increased because patients were evaluated for surgical and nonsurgical interventions. Additionally, patients were only included if they were new to the spine clinic, which mitigates the influence that ongoing treatments or time spent in the clinic may have on their health literacy assessment. A third limitation is the homogenous patient population consisting of predominantly English-speaking, White patients which limits the generalizability of our findings in other populations. Finally, the potential response fatigue caused by the number of questions patients were asked could create a measurement bias. As the survey only takes between five and seven minutes, we believe this had little influence on our findings.

The current study found that the prevalence of limited health literacy in patients presenting at an outpatient spine center was 33% (135/405), which both agrees and disagrees with other health literacy studies among orthopaedic patient populations. For example, Glassman and colleagues reported a limited health literacy prevalence of 45% among 186 patients with degenerative lumbar disease.[40] However, this study was underpowered; the investigators had an insufficient sample size to draw meaningful conclusions. Among 231 foot and ankle and hand and wrist patients, Noback et al. found that 49% of their population had limited health literacy. Unfortunately, this study was also underpowered for prevalence.[33] In another study, total knee arthroplasty patients were retrospectively mailed a survey of which 35% of the 453 respondents were found to have limited health literacy.

Yet, the survey response rate was not recorded, and therefore, the studied sample may not be representative of the population at large.[34] In agreement with the current study, an investigation among 200 hand surgery patients reported the prevalence of limited health literacy to be 33% in their patient population.[41]

Consistent with previous studies in emergency departments, hand surgery patients, surgical patients, and patients seeking general orthopaedic care, lower educational attainment, advanced age, lower income, and being publicly insured or uninsured were also associated with limited health literacy in spine patients.[20,32,42–44] The notion of health literacy deserves further investigation in the field of orthopaedic surgery. Identifying patients with limited health literacy is a necessary step to optimizing patient care among all orthopaedic specialties. After identification, clinicians may offer additional resources or different methods of instruction to those with limited health literacy, thereby ensuring that these patients understand all aspects of their care. However, assessing health literacy of patients within busy clinical settings remains challenging. Although the NVS is accurate, its length and administration method prevent its feasible implementation within clinical workflow. Because our results indicate that the ADI state decile is independently associated with limited health literacy, this metric could be a reliable indicator of limited health literacy in spine patients. Moreover, the ADI can be determined through a patient's address, and thus, it circumvents the necessary survey administration of other health literacy rating obtainment methods. Further studies should assess the ADI and its association with health literacy in other orthopaedic patient populations.

Conclusion

Our study found that a substantial portion of the patients presenting to an outpatient spine center have limited health literacy, more so if they are socially disadvantaged. Future efforts should investigate the impact of limited health literacy on access to care, treatment outcomes and healthcare utilization in orthopaedic patients. Neighborhood social vulnerability measures may be a feasible way to identify patients at risk of limited health literacy in clinical practice. Identifying patients with limited health literacy may contribute to prioritizing the mitigation of disparities and aid the development of meaningful interventions to improve health equity in orthopaedics. By identifying patients with limited health literacy, clinicians can be better prepared to offer additional resources or instructions, even prior to the patients' visit. Furthermore, the identification of patients with limited health literacy may encourage clinicians to spend more time in shared decision-making interactions.

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Part III

Health Literacy in Clinical Practice

Chapter 8

Impact of Health Literacy on Self-Reported Health Outcomes

Amanda Lans, John R. Bales, Pranati Borkhetaria, Joseph H. Schwab, Jorrit-Jan Verlaan,
Laura P. Rossi, Daniel G. Tobert

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ABSTRACT

Background: Patient reported outcome measures (PROMs) are important instruments for assessing symptom severity and treatment success in orthopaedic spine patients. However, the influence of health literacy on PROMs has not yet been given much consideration in spine literature. Therefore, the purpose of this investigation was to determine if health literacy level is associated with differences in baseline PROMs and self-reported health status among patients presenting to an academic outpatient spine center.

Methods: Between December 2021 and March 2022, consecutive English-speaking patients over the age of 18 years and new to our outpatient clinic were approached. The Newest Vital Sign Health Literacy Assessment Tool (NVS) and a sociodemographic survey, including self-reported health status, were verbally administered. Additionally, seven Patient-Reported Outcomes Measurement Information System scores were extracted from patient records. Negative binomial regression modeling was performed with PROMs considered as dependent variables, health literacy level as the primary predictor, and all other factors (age, sex, race, ethnicity, native English speaker, highest educational degree, grade-level reading, marital status, employment status annual household income and type of insurance) considered as covariates.

Results: Three hundred and eighteen patients were included, of which 33% (104/318) had limited health literacy. Adjusted negative binomial regression analysis demonstrated that patients with limited health literacy had worse PROM scores across all seven domains (Physical Function: $p = 0.008$; Depression: $p = 0.015$; Global Health – Physical: $p < 0.001$; Global Health – Mental: $p = 0.003$; Pain Interference Short Form: $p = 0.030$; Pain Intensity Short Form: $p = 0.002$; Anxiety: $p = 0.043$). Additionally, patients with limited health literacy reported worse self-reported health status compared with patients with adequate health literacy ($p < 0.001$).

Conclusion: Spine patients with limited health literacy have worse baseline PROM scores after adjusting for confounding factors and report worse general health. However, further investigations are necessary to elucidate if limited health literacy is a marker or the root cause of these disparities. The findings from this study urge the consideration of patient health literacy when interpreting PROMs as well as the implications for patient assessment and discussion of treatment options.

INTRODUCTION

A patients' understanding of their disease and treatment is a fundamental component of ensuring proper care. Results from a national survey suggest that only twelve percent of adults have sufficient health literacy skills to manage their health care and navigate the complexities of the current health care system.[1] Health literacy is commonly defined as the "ability to obtain, process, and understand health information needed to make appropriate health decisions".[2]

Limited health literacy is linked to many disparities and is associated with increased risks of illness and poor treatment outcomes.[3–7] Patients with limited health literacy often struggle with important decisions about how to seek care and make informed decisions about treatment.[8] As a result, healthcare utilization and related expenditures for higher readmissions and longer length of hospital stay are often increased. The impact of limited health literacy has typically been a concern in the self-management of chronic illness although it is increasingly recognized as a risk for surgical patients.[9,10] It has previously been demonstrated that patients with limited health literacy have more emergency room visits but less self-directed care and healthcare engagement.[11–14]

Health literacy may also directly impact clinically important metrics such as patient-reported outcome measures (PROMs). PROMs have become a central tool in assessing symptom severity and treatment success in patients presenting to orthopaedic spine clinics.[15,16] Orthopaedic surgeons generally endorse the concept of patient-centered measures to guide patient management. However, health literacy may influence PROM scores in unknown ways as question comprehension and accurate response are vital to PROMs utility. Despite the established importance of health literacy, a paucity of literature regarding health literacy and PROMs in spine patients remains.[17] Therefore, the objectives of this investigation were to evaluate the impact of health literacy on baseline 1) Patient-Reported Outcomes Measurement Information System scores and 2) self-reported health in patients new to an outpatient spine center.

METHODS

Study Design and Setting

After approval of our institutional review board, we conducted a single-center, cross-sectional study among consecutive patients seen at an urban academic medical outpatient orthopaedic spine center. Enrollment took place between December 2021 and March 2022. Study data were collected and managed using REDCap electronic data capture tools hosted at Mass General Brigham.[18,19] REDCap (Research Electronic Data Capture) is a secure, web-based software platform designed to support data capture for research studies.

Patients were considered eligible if they were new to the outpatient clinic, 18 years or older, self-proclaimed fluent in speaking and reading English, and capable of providing informed consent. Patients were ineligible if they denied fluency in English, required a translator, or were visually impaired.

Data Collection and Clinical Outcome Measurements

Eligible patients were approached for participation by a research fellow or trained research study staff. Verbal informed consent was obtained from each study participant prior to any study procedure. Consenting patients verbally completed a sociodemographic survey, which included variables for race, ethnicity, native English speaker, highest educational degree, marital status, employment status, annual household income, and self-reported health status. On average, each patient interview took five to seven minutes and was integrated into the normal clinic workflow. Additional variables were collected through manual chart review, namely: age, sex, type of insurance, and PROMIS scores.

Health Literacy Assessment

<u>Newest Vital Sign Health Literacy Assessment Tool (NVS):</u> The NVS is a six-item questionnaire that assesses numeracy and literacy. Each correct response results in one point. The tallied NVS scores were divided into limited (0-3 points) and adequate (4-6 points) health literacy. Previously, the NVS has been validated with the Test of Functional Health Literacy in Adults (TOEFLA).[21] The questions are based on a nutrition label identical to those found on packaged food containers in the United States.[22] The NVS has previously been used in various orthopaedic subspecialties, including hand, foot and ankle, arthroplasty, and spine.[23–26]

<u>Rapid Estimation of Adult Literacy in Medicine Short Form (REALM-SF):</u> The REALM-SF is a validated tool which consists of seven words that patients are asked to read out loud and was administered as literacy assessment.[20] Each correct word results in one point. REALM-SF scores were divided into below ninth grade reading level (< 7 correct words) and at least ninth grade reading level (7 correct words).

Patient-Reported Outcome Measures

<u>Patient-Reported Outcomes Measurement Information System (PROMIS</u>) scores were collected by chart review. Patients are asked complete questionnaires online prior to their appointment through an online portal or with a tablet while in the waiting room prior to their clinic visit. PROMIS scores were collected for the following forms: Physical Function,

Depression, Global Health – Physical, Global Health – Mental, Pain Interference Short Form, Pain Intensity Short Form and Anxiety.

Self-reported health status: Patients were verbally asked to grade their general health status with a self-rated health question, namely, "How would you finish the following sentence: *In general, my health is…*". Possible responses were excellent, very good, good, fair, or poor. Self-rated health is an easy to administer measure of general health and a valid measure among patients without cognitive impairment.[27]

Statistical Analysis

Data analysis was completed using RStudio Version 2021.09.1. Wilcoxon rank-sum test, and chi-squared test were utilized for descriptive non-adjusted comparisons of means and proportions of demographic variables and self-reported health status responses. PROMIS scores were the primary outcome measures in regression analysis that was subsequently performed. When analyzing PROMIS scores, regression model was constructed with level of health literacy as the primary predictor. Age, sex, race, ethnicity, native English speaker, highest educational degree, grade reading level, marital status, employment status, annual household income, and type of insurance were included as covariates in all regression models. Adjusted regression coefficients (B) and 95% confidence intervals (CI) were calculated for each PROMIS domain. A p value < 0.05 was designated a priori as indicative of statistical significance.

RESULTS

Overall, 318 patients were included, of which a slight majority (52%; 164/318) was male, with a mean age of 55 years (Figure 1). Among the included patients, 33% (104/318) were found to have limited health literacy (Table 1). Eighty-seven patients did not complete one or more PROMIS questionnaires and were excluded from the regression analysis. No association found between health literacy or grade reading level and PROMIS completion rate (p = 0.825).

Table 1 Patient characteristics

	Health literacy level*		
	Adequate (n = 214)	Limited (n = 104)	p value
Age, mean (SD)	53 (17)	58 (16)	**0.005**
Male	114 (53)	50 (48)	0.453
Race			**< 0.001**
White	194 (91)	79 (76)	
Black or African American	3 (1)	11 (11)	
Hispanic or Latino	4 (2)	6 (6)	
Asian	2 (1)	6 (6)	
American Indian	0 (0)	2 (2)	
Ethnicity			**0.043**
Non-Hispanic or Latino	208 (97)	95 (91)	
Hispanic or Latino	6 (3)	9 (9)	
Native English Speaker	199 (93)	82 (79)	**< 0.001**
Highest degree obtained			0.864
Less than high school (<12y)	5 (2)	2 (2)	
High school or GED (12y)	31 (15)	12 (12)	
Some college (13-15y)	44 (21)	20 (19)	
College bachelors (16y)	68 (32)	32 (31)	
Advanced degree (>16y)	66 (31)	38 (37)	
≥ 9th grade reading level°	196 (92)	74 (72)	**< 0.001**
Marital status			**0.005**
Single	54 (25)	39 (38)	
Married or life partner	137 (64)	44 (42)	
Divorced or legally separated	15 (7)	12 (12)	
Widowed	8 (4)	8 (8)	
Employment status			**< 0.001**
Employed	150 (70)	42 (40)	
Unemployed	11 (5)	9 (9)	
Unable to work (disabled)	7 (3)	17 (16)	
Retired	46 (22)	36 (35)	
Annual household income			**< 0.001**
$0 - $35,000	9 (4)	22 (21)	
$35,000 - $74,999	17 (8)	17 (16)	
$75,000 - $149,999	61 (29)	25 (24)	
$150,000 or more	76 (36)	17 (16)	
Declined	51 (24)	23 (22)	
Type of insurance			**< 0.001**
Private	148 (69)	45 (43)	
Public	66 (31)	59 (57)	
Medicare	58 (27)	33 (32)	

Table 1 Patient characteristics

	Health literacy level*		
	Adequate (n = 214)	Limited (n = 104)	p value
Medicaid/MassHealth	7 (3)	12 (12)	
Medicare & Medicaid/MassHealth	1 (1)	14 (14)	

Values are stated as number and percentage (%) unless stated otherwise; boldface type indicates statistical significance ($p < 0.05$); SD = Standard deviation; *Health literacy was determined using the Newest Vital Sign. Patients with scores < 4 were considered to have limited health literacy; °Rapid Estimation of Adult Literacy in Medicine - Short Form (REALM-SF) score 7: ≥ 9th grade reading level; < 7: < 9th grade reading level

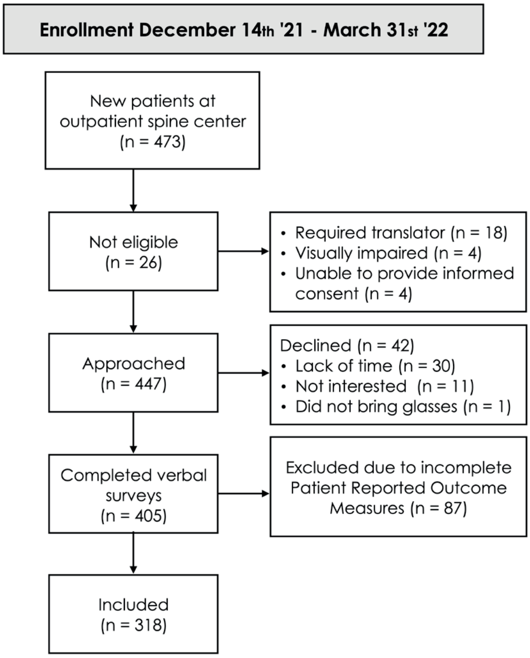

Figure 1 Flow of patient enrollment

When controlling for potential confounding factors such as age, sex, race, ethnicity, native English speaker, highest educational degree, grade level reading, marital status, employment status, annual household income and type of insurance, adjusted regression analysis demonstrated that patients with limited health literacy had worse PROMIS scores across all seven domains: Physical Function (B = -0.29, [CI -0.55, -0.03], p = 0.028); Depression (B = 0.27, [CI 0.02, 0.52], p = 0.035); Global Health – Physical (B = -0.42 [CI -0.68, -0.17]; p = 0.001); Global Health – Mental (B = -0.36 , [CI -0.61, -0.10]; p = 0.007); Pain Interference Short Form: (B = 0.29, [CI 0.02, 0.56], p = 0.036); Pain Intensity Short Form (B = 0.37, [CI 0.11, 0.63]: p = 0.002), Anxiety (B = 0.26, [CI 0.00, 0.51], p = 0.047) (Figure 2; Table 2).

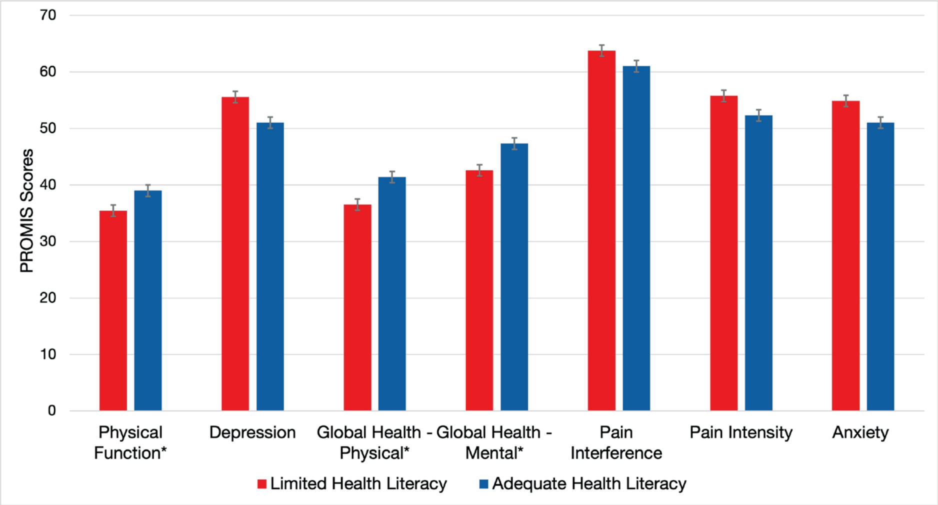

Figure 2 Mean Patient-Reported Outcomes Measurement Information System scores by health literacy level; *indicates that a higher score is favorable for the domain, for the remaining domains a lower score is favorable

Table 2 PROMs by health literacy level

	Health literacy Level*				
	Unadjusted mean ± SD		Adjusted difference		
	Adequate (n = 214)	Limited (n = 104)	Regression coefficient	[95% CI]	p value
PROMIS° Score					
Physical Function Score†	39.0 ± 8.3	35.5 ± 8.4	-0.29	[-0.55, -0.03]	**0.028**
Depression Short Form‡	51.0 ± 9.2	55.6 ± 10.4	0.27	[0.02, 0.52]	**0.035**
Global Health – Physical†	41.4 ± 8.5	36.5 ± 8.6	-0.42	[-0.68, -0.17]	**0.001**
Global Health – Mental†	47.3 ± 9.8	42.6 ± 9.5	-0.36	[-0.61, -0.10]	**0.007**
Pain Interference Short Form‡	61.0 ± 8.4	63.8 ± 9.3	0.29	[0.02, 0.56]	**0.036**
Pain Intensity Short Form‡	52.5 ± 6.9	55.7 ± 8.6	0.37	[0.11, 0.63]	**0.002**
Anxiety‡	51.0 ± 9.7	54.9 ± 10.3	0.26	[0.00, 0.51]	**0.047**

Boldface type indicates statistical significance ($p < 0.05$); CI = confidence Interval confidence interval; SD = standard deviation; *Health literacy was determined using the Newest Vital Sign. Patients with scores < 4 were considered to have limited health literacy; °PROMIS indicates Patient-Reported Outcomes Measurement Information System; †Higher score is considered favorable; ‡Lower score is considered favorable

Half of the patients with limited health literacy described their health as fair or poor (50%; 52/104), whereas this was only true for a minority of patients with adequate health literacy (22%; 46/214) (Figure 3). Unadjusted analysis showed that patients with limited health literacy were more likely to report worse self-reported health status than those with adequate health literacy ($p < 0.001$) (Table 3).

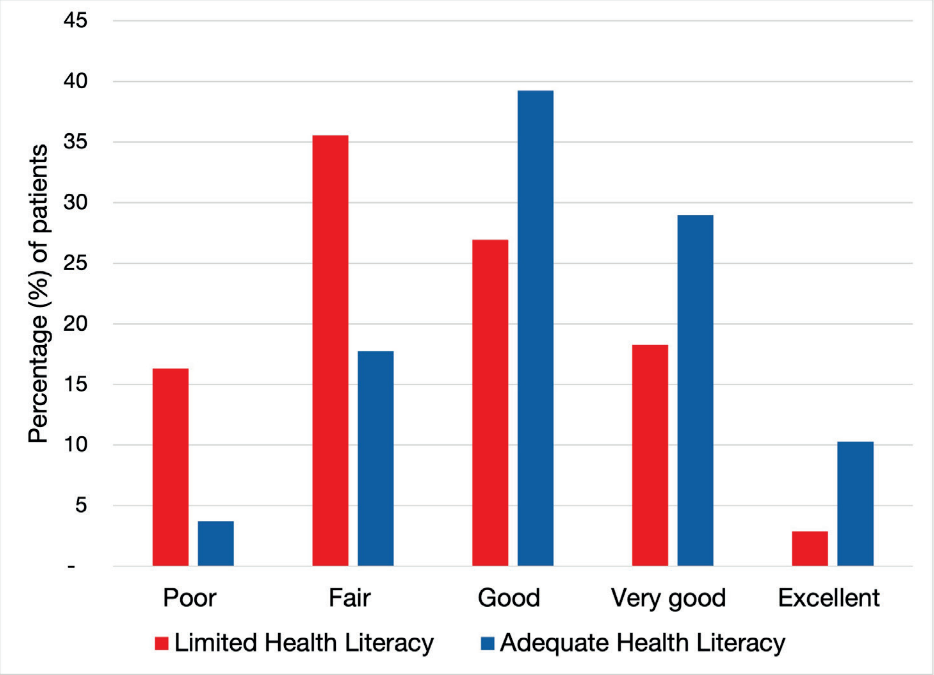

Figure 3 Distribution of self-reported health status responses by health literacy level

Table 3 Self-reported health status by health literacy level

	Health Literacy Level*				
	Adequate (n = 214)		Limited (n = 104)		p value
Self-reported health					**< 0.001**
Excellent	22	(10%)	3	(3%)	
Very good	62	(29%)	19	(18%)	
Good	84	(39%)	28	(27%)	
Fair	38	(18%)	37	(36%)	
Poor	8	(4%)	17	(16%)	

Values are presented as n (%); boldface type indicates statistical significance ($p < 0.05$); *Health literacy was determined using the Newest Vital Sign. Patients with scores < 4 were considered to have limited health literacy

DISCUSSION

Over the last decades, PROMs have become a central tool in assessing patients presenting to spine clinics.[15,16] However, inadequate health literacy may influence patient understanding of these items and, subsequently, the reliability of this important measure reflecting patient evaluations of health and effective treatment.

The current study used a validated health literacy assessment in new patients presenting at an outpatient spine center and demonstrated a relationship between level of health literacy and patient-reported outcome measurement scores when adjusting for confounding variables. Patients with limited health literacy had worse PROMIS scores across all collected measures (Physical Function, Depression, Global Health – Physical, Global Health – Mental, Pain Interference Short Form, Pain Intensity Short Form and Anxiety). Additionally, when asked during the verbal survey, patients with limited health literacy reported worse self-reported health. These findings persisted after adjusting for confounding factors and are consistent with results from previous investigations. For example, a study by Glassman et al. of 201 patients with degenerative lumbar spine disease reported that patients with limited health literacy had worse PROMs regarding back and leg pain.[24] This is further corroborated by investigations in rheumatology patients, who also report lower PROMs scores in patients with limited health literacy.[28] This pattern across different populations offers avenue to tailor care effectively for the individuals and assure essential health information is appropriately accessible.[29]

To a certain degree, health literacy is correlated with level of education.[30] However, this investigation found that only a minority of patients had less than high school education. This implies that level of education is not an absolute reflection of heath literacy, which is consistent with prior studies.[31,32] Within this subset of patients, those with limited health literacy but more than high school education may be at particular risk because healthcare providers may be more inclined to overestimate their level of comprehension. This further solidifies the notion that health literacy is more complex than general literacy skills such as readability. If not identified and addressed, patients with limited health literacy will continue to have poor health outcomes, such as an increased risk of hospitalizations and higher mortality.[5]

This study is not without limitations. The use of a survey requires that participation bias is considered. Patients who are approached and have more confidence or be more knowledgeable may be more inclined to participate in a health literacy study and complete all PROMs.[33] Nevertheless, given that level of education and grade-level reading was controlled for during analysis, we do not believe this had implications for our results. Furthermore, it may be argued that the NVS ice cream label assessment falls short of capturing the true complexity of health literacy. However, the validated NVS assessment simulates a situation in which patients are asked to interpret new information on the spot whilst interacting with a healthcare professional in a clinical setting. We believe that this reflects a more realistic impression of a patient's true level of health literacy compared self-reported skills. Additionally, selection bias can be a concern in a tertiary spine clinic. However, patients were included if they saw a spine surgeon or nurse practitioner, offering a more heterogeneous population of spine patients with varying presentation of symptoms. Patients included in this study were evaluated for both surgical and nonsurgical interventions increasing the generalizability of our results. Furthermore, to mitigate the influence that ongoing treatment may have on PROM scores, only patients new to the spine clinic were included. However, the study is limited by its homogenous patient population consisting of predominantly White patients and native English-speaking patients. Finally, the possibility of measurement bias through response fatigue due to the number of questions patients were asked to answer may have limited our findings. Despite these limitations, the current study offers meaningful insights regarding spine patients and emphasizes that health literacy is undervalued component in the evaluation and treatment of this patient population.

It is becoming evident that the integration of health literacy assessment should be considered as a component of surgical practice. In particular, the heterogenous population of patients seeking care for spine concerns as they will often require detailed instructions about activity, use of medications as well as pre- and postoperative care. In clinical practice, health literacy can be assessed using tools such as the NVS but alternative strategies that are less taxing for clinical workflow may be considered. One example is the four question Brief Health Literacy Screening Instrument (BRIEF) which determines the subject's self-reported ability to understand health information.[34] However, self-reported skill levels may not accurately reflect actual abilities. If the health literacy assessment is recorded in the electronic medical record and readily available, health care providers will be aware of patients with limited health literacy for whom they can accommodate when communicating. Health literacy assessment can also help interpret severe PROM scores and may offer insight if the clinical presentation does not reflect patient-reported symptoms.

This study demonstrates that spine patients with limited health literacy have worse baseline PROM scores on adjusted analysis and report worse general health. However, further investigations are necessary to elucidate whether limited health literacy is a marker or the root cause of these disparities. The findings from this study urge the consideration of patient health literacy when interpreting PROMs as well as the implications for patient assessment and discussion of treatment options.

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Chapter 9

Health Literacy and Quality of Life

Dylan Koole[*], Amanda Lans[*], Julian H. Lang, Tom M. de Groot, Pranati Borkhetaria,
Jorrit-Jan Verlaan, Joseph H. Schwab

Submitted

ABSTRACT

Background: Spinal conditions impact health-related quality of life (HRQoL). Patient education and counseling improve HRQoL, yet the effects may be limited for patients with inadequate health literacy (HL). Despite the established relationship between HRQoL and HL in other fields, research in the orthopaedic spine population is lacking. Therefore, the goal of this study was 1) to evaluate if limited HL results in lower HRQoL and 2) which other factors are associated with HRQoL in patients seen at an outpatient orthopaedic spine center.

Methods: Between October 2022 and February 2023, consecutive English-speaking patients over the age of 18 and new to the outpatient spine clinic were approached for participation in this cross-sectional survey study. Patients completed a sociodemographic survey, EQ-5D-5L HRQoL questionnaire, and Newest Vital Sign Health Literacy Assessment Tool (NVS). The EQ-5D-5L yields two continuous outcomes: an index score ranging from below 0 to 1 and a visual analog scale (EQ-VAS) score ranging from 0 to 100. The NVS scores were divided into limited (0-3) and adequate (4-6) HL. Multivariate linear regression with purposeful selection of variables was performed to identify independent factors associated with HRQoL.

Results: Limited HL was independently associated with lower EQ-5D-5L index scores (B = 1.07 [95% CI 1.00, 1.15], p = 0.049). Other factors associated with lower EQ-5D-5L index scores were being obese (body mass index (BMI) ≥ 30), having housing concerns, and being an active smoker. Factors associated with lower EQ-VAS scores were being underweight (BMI < 18.5), obese, having housing concerns, and higher updated Charlson Comorbidity Index scores. Being married was associated with higher EQ-VAS scores.

Conclusion: Limited HL is associated with lower EQ-5D-5L index scores in spine patients, indicating lower HRQoL. To effectively apply HL-related interventions in this population, a better understanding of the complex interactions between patient characteristics, social determinants of health, and HRQoL outcomes is required. Further research should focus on interventions to improve HRQoL in patients with limited HL and how to accurately identify these patients.

INTRODUCTION

Lower back and neck pain are among the leading causes of disability worldwide, collectively accounting for approximately 11% of all years lived with disability.[1] Demographic projections indicate an increasing prevalence of spinal disorders, particularly in middle and low-income countries.[2] These conditions limit daily activities and impact health-related quality of life (HRQoL).[3,4]

HRQoL reflects an individual's subjective assessment of their well-being and ability to participate in social roles.[5] Over the past decades, healthcare focus has shifted towards emphasizing patient HRQoL.[6] The addition of patient education and counseling to medical treatment has demonstrated to be effective in improving HRQoL.[7,8] However, for patients with limited health literacy (HL), the effectiveness of these methods may be limited and require additional effort to ensure patient comprehension.[9]

HL refers to a person's ability to obtain, understand, and comprehend information about their health, medical conditions, treatments, and long-term care.[10] Patients with low HL often experience poor health outcomes and psychological stress associated with healthcare interactions and decision-making.[11–13] Previous work by our study group demonstrated that 33% of patients presenting to an outpatient spine center exhibit limited HL.[14] These patients consistently reported worse baseline patient-reported outcome measurement scores and worse general health.[15] In other populations, limited HL has been linked to lower HRQoL and other adverse health outcomes through poor access and utilization of care, challenges with self-care, unsuccessful patient-provider interactions, and difficulty with health-related problem-solving.[16–20] Conversely, adequate HL has been associated with greater patient empowerment and more involved healthcare decision-making.[21]

Despite the established relationship in other fields of research, there is a paucity of literature on the impact of HL on HRQoL in orthopaedic spine patients. Since a substantial part of this population possesses limited HL and consistently reports worse outcomes, a broader understanding of this subject is essential to improve HRQoL. Therefore, the goal of this study was 1) to evaluate if limited HL results in lower HRQoL and 2) to evaluate the factors associated with HRQoL in patients seen at an outpatient orthopaedic spine center.

METHODS

Study Design and Setting

With IRB approval, patients who were over 18 years of age and new to the outpatient spine clinic at an urban tertiary referral center were approached to participate in this cross-sectional study. Patients were excluded if they did not consider themselves fluent in English, were visually impaired, or were unable to provide informed consent. Between October 2022 and February 2023, consenting patients' data were prospectively collected during their first visit to the outpatient spine clinic. Consecutively, a sociodemographic survey, HRQoL questionnaire, and HL assessment were administered by one of two trained research study staff.

Reporting of Outcomes

The primary outcome, HRQoL, was measured with the five-level EQ-5D (EQ-5D-5L) questionnaire, the improved version of the original, three-level EQ-5D.[22,23] The EQ-5D-5L is one of the most widely used HRQoL measures and is a reliable and valid instrument that can be applied to a broad range of settings and populations.[24,25] The first element comprises five dimensions (health states): mobility, self-care, usual activities, pain/discomfort, and anxiety/depression. Each dimension has five response levels: no problems, slight problems, moderate problems, severe problems, and unable to/extreme problems (Appendix 1A). An index value can be derived by applying a formula that attaches values to each level based on societal preferences for the health state. These values may vary between countries and therefore a valuation of EQ-5D-5L health states with a representative sample of the general population of the United States was used to calculate index scores.[26] EQ-5D-5L index scores can range from less than 0 (health state equivalent to dead; negative values represent a state worse than dead) to 1 (full health), with higher scores indicating higher perceived health.[27] The second element is the EQ-5D Visual Analog Scale (EQ-VAS), which records the patient's overall current perception of their perceived health. The endpoints range from 0 to 100 and are labeled "*The worst health you can imagine*" and "*The best health you can imagine*", respectively (Appendix 1B).[27]

The primary exposure was HL measured by the Newest Vital Sign Health Literacy Tool (NVS), a validated tool for assessing HL and numeracy.[28] The NVS consists of a nutritional label accompanied by six questions (Appendix 2). Scores may range from 0 (no correct answers) to 6 (all answers correct). A score of 0-1 indicates a high likelihood (≥ 50%) of limited HL, whereas a score of 2-3 indicates a possibility of limited HL. A score ranging from 4-6 corresponds to adequate HL. To optimize sensitivity and specificity, these groups were reduced to two: limited HL (score 0-3) and adequate HL (score 4-6).[28] This categorization has previously been used in orthopaedic patient populations, including spine and hand patients.[29,30]

Variables collected in the sociodemographic survey were race, ethnicity, educational attainment, employment status, marital status, annual household income, house ownership, and household composition. Other variables collected through manual chart review were: age, sex, body mass index (BMI), insurance status, smoking status, alcohol risk, and previous spinal surgery at date of enrollment. The updated Charlson Comorbidity Index (uCCI) was used to classify and index comorbidities.[31] BMI was categorized into four categories: underweight (BMI < 18.5), healthy weight (BMI ≥ 18.5 – < 25.0, overweight (BMI ≥2 5.0 – < 30.0), and obese (BMI ≥ 30.0). Housing concerns were defined as: "*Being worried or concerned about not having a place to live in the past six months*." Alcohol risk was defined as >2 alcoholic drink equivalents in a day for men or >1 in a day for women.[32] Furthermore, the area deprivation index (ADI) and social vulnerability index (SVI) were obtained using online mapping tools for patient addresses.[33,34] The ADI is based on census variables that reflect socio-economic status through measures of income, education, household characteristics, and housing. ADI scores are represented in state deciles and national percentiles, with higher scores indicating higher levels of deprivation.[34] The SVI scores range from 0 (lowest vulnerability) to 1 (highest vulnerability) and consist of scores from four domains, including socio-economic status, household composition and disability, minority status and language, and housing and transportation.[33] These scores can be categorized into four categories: low (< 0.25), low-medium (≥ 0.25 – < 0.50), medium-high (≥ 0.50 – < 0.75), and high (≥ 0.75). Higher ADI and SVI scores have been associated with an increased risk of mortality, disability, and readmission in multiple populations.[35,36]

Statistical Analysis

Due to the lack of available literature regarding HRQoL outcomes in the orthopaedic spine population, a statistician was consulted to calculate the sample size required for this investigation. Sequentially, a pilot study (n = 124) was performed to allow for a more accurate sample size estimation. To reach a power of 0.8, and with a Z-score of 1.96, the minimal sample size was estimated to be 228 patients. However, due to high variance and small sample size, and considering the sparse literature available in the orthopaedic spine population, a decision was made to aim for a minimum of 300 patients.

Descriptive statistics were used to summarize the data. Shapiro-Wilks tests were used to check for normality. Since all continuous variables did not follow a normal distribution, they were reported using medians and interquartile ranges (IQR). Categorical variables were reported as frequencies and percentages. Mann-Whitney U tests were performed on continuous variables to evaluate differences in patient characteristics and demographics between patients with adequate and limited HL. For categorical variables, chi-square and Fisher's exact tests were conducted. To reduce collinearity, variables with a correlation of ≥ 0.8 were removed from further analysis.

Purposeful selection of variables was performed to prevent overfitting of the adjusted multivariate linear regression model. By iteratively adding and removing variables based on statistical significance, a model was created that contains significant covariates and confounders while also identifying variables that make an important contribution in the presence of other variables. This process helps improve the model's interpretability and generalizability and works well in identifying and retaining confounders for samples of 240-600 patients.[37] To optimize this process, a p-value cut-off point of 0.25 was used since more traditional levels, such as 0.05, can fail in identifying variables known to be important.[38] Subsequently, an adjusted multivariate linear regression model was fitted to identify variables associated with EQ-5D-5L index scores and EQ-VAS scores. Adjusted regression coefficients (B) and 95% confidence intervals (CI) were calculated for each variable. A p value of < 0.05 was considered statistically significant.

Missing data

Missing data were imputed using the MissForest package in Python software. This package is a non-parametric imputation method that uses a random forest algorithm to estimate missing values based on observed values in the dataset. The imputation was performed separately for all variables with missing data: BMI (n = 19 [56%]), insurance (n = 3 [1%]), smoking status (n = 22 [6%]), and alcohol use (n = 60 [17%]). The resulting imputed variables were then used for all subsequent analyses. Statistical analysis was performed using Python version 3.9.12 (Python Software Foundation, Wilmington, DE) programming language.

RESULTS

Of the 451 approached patients, 54 (12%) were ineligible because they were not fluent in English, were visually impaired, or needed a sign language interpreter. Of the remaining 397 eligible patients, 49 (12%) declined to participate due to lack of time or no interest. Ultimately, 348 (88%) patients were included for statistical analysis (Figure 1). Of this group, 124 (36%) had limited HL.

The univariate analysis showed that patients with limited HL had lower EQ-5D-5L index scores (0.56 [IQR 0.26 – 0.75] vs. 0.71 [IQR 0.52 – 0.82], p < 0.001) and EQ-VAS scores (70 [IQR 50 – 80] vs. 75 [IQR 62 – 85], p < 0.001). Patients with limited HL were more likely to be older (68 years vs. 51 years, p < 0.001), be Black or African American (11% vs. 2%, p < 0.001), be Hispanic or Latino (7% vs. 1%, p = 0.020), have Hispanic or Latino ethnicity (7% vs. 2%, p = 0.016), and be married or with a partner (61% vs. 47%, p = 0.013). Patients with adequate HL were more likely to be White (87% vs. 73%, p = 0.001). Additionally, patients with limited HL were less likely to have attended college (51% vs. 72%, p < 0.001), be currently employed (40% vs. 63%, p

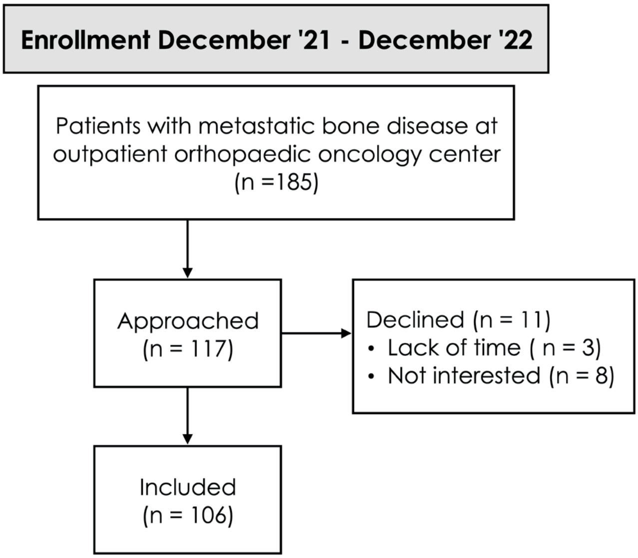

Figure 1 Flow of patient enrollment

< 0.001), and have private health insurance (33% vs. 71%, p < 0.001). Patients with limited HL were more likely to have an annual household income below $75,000 (31% vs. 15%, p < 0.001), live in an area with high social vulnerability (26% vs. 14%, p = 0.008), have higher ADI scores on both a state (4 [IQR 2 – 6] vs. 3 [IQR 1 – 5], p = 0.002) and national level (17 [IQR 8 – 25] vs. 12 [IQR 6 – 23], p = 0.010), and have self-reported housing concerns (14% vs. 3%, p < 0.001). Furthermore, patients with limited HL had fewer other people (1 [IQR 0 – 2] vs. 1 [IQR 1-3], p < 0.001) and minors (0 [IQR 0 – 0] vs. 0 [IQR 0 – 1]) in their households. Regarding health behavior and comorbidities, patients with limited HL were more often active smokers (17% vs. 9%, p = 0.036), and had higher uCCI scores (3 [IQR 1 – 4] vs. 1 [IQR 0 – 2]). There were no statistical differences in sex, BMI, language other than English, house ownership, alcohol risk, and previous spine surgery (Table 1).

Table 1 Patient characteristics stratified by health literacy level (n = 348)

		Health literacy level*		
		Limited	Adequate	p value
		124 (36)	224 (64)	
EQ-5D-5L index, median (IQR)	0.68 (0.40-0.79)	0.56 (0.26-0.75)	0.71 (0.52-0.82)	**< 0.001**
EQ-VAS, median (IQR)	74 (50-80)	70 (50-80)	75 (62-85)	**< 0.001**
Age in years, median (IQR)	58 (41-69)	68 (56-75)	51 (36-65)	**< 0.001**
Male	251 (45)	52 (42)	103 (46)	0.500
Body Mass Index[‡]				0.735
Underweight (< 18.5)	8 (2)	4 (3)	4 (2)	0.463
Healthy weight (≥ 18.5 – < 25.0)	116 (33)	44 (36)	72 (32)	0.554
Overweight (≥ 25.0 – < 30.0)	135 (39)	46 (37)	89 (40)	0.648
Obese (≥ 30.0)	89 (26)	30 (24)	59 (26)	0.702
Race				**< 0.001**
White	285 (82)	90 (73)	195 (87)	**0.001**
Black or African American	17 (5)	13 (11)	4 (2)	**< 0.001**
Hispanic or Latino	11 (3)	8 (7)	3 (1)	**0.020**
Asian	22 (6)	7 (6)	15 (7)	0.820
American Indian or Alaska Native	3 (1)	2 (6)	1 (0)	0.290
Other	10 (3)	4 (3)	6 (3)	0.749
Ethnicity				**0.016**
Not Hispanic or Latino	335 (96)	115 (93)	220 (98)	
Hispanic or Latino	13 (4)	9 (7)	4 (2)	
Native English speaker	266 (76)	89 (72)	177 (79)	0.147
Area Deprivation Index, median (IQR)				
State decile	3 (1-6)	4 (2-6)	3 (1-5)	**0.002**
National percentile	14 (6-24)	17 (8-25)	12 (6-23)	**0.010**
Social Vulnerability Index				**0.015**
Low (< 0.25)	121 (35)	34 (27)	87 (38)	0.035
Low-Medium (≥ 0.25 – < 0.50)	97 (28)	31 (25)	66 (30)	0.386
Medium-High (≥ 0.50 – < 0.75)	67 (19)	27 (22)	40 (18)	0.396
High (≥ 0.75)	63 (18)	32 (26)	31 (14)	**0.008**
Insurance status[°‡]				**< 0.001**
Public	148 (43)	83 (67)	65 (29)	
Private	200 (58)	41 (33)	159 (71)	
Educational attainment				**< 0.001**
College education or more	224 (64)	63 (51)	161 (72)	
No college education	124 (36)	61 (50)	63 (28)	
Employment status[†]				**< 0.001**
Employed	207 (60)	50 (40)	157 (70)	

Table 1 Patient characteristics stratified by health literacy level (n = 348)

		Health literacy level*		
		Limited	Adequate	p value
Not employed	141 (40)	74 (60)	67 (30)	
Marital status				**0.013**
Married or with partner	194 (56)	58 (47)	136 (61)	
Not married or with partner	154 (44)	66 (53)	88 (39)	
Annual household income				**< 0.001**
< $75,000	71 (20)	38 (30)	33 (15)	**< 0.001**
≥ $75,000	174 (50)	39 (32)	135 (60)	**< 0.001**
Prefer not to answer	103 (30)	47 (38)	56 (25)	**0.014**
Homeowner	226 (65)	75 (61)	151 (67)	0.199
Housing concerns	24 (7)	17 (14)	7 (3)	**< 0.001**
Household composition, median (IQR)				
Others in household	1 (1-2)	1 (0-2)	1 (1-3)	**< 0.001**
Minors in household	0 (0-0)	0 (0-0)	0 (0-1)	**0.047**
Smoking status[‡]				**0.033**
Never smoked	204 (59)	63 (51)	141 (63)	**0.031**
Former smoker	103 (30)	40 (32)	63 (28)	0.462
Active smoker	41 (12)	21 (17)	20 (9)	**0.036**
Alcohol risk[‡]				0.753
Yes	11 (3)	3 (2)	8 (4)	
No	337 (97)	121 (98)	216 (96)	
uCCI[‡], median (IQR)	2 (0-3)	3 (1-4)	1 (0-2)	**< 0.001**
Previously had spine surgery	69 (20)	30 (24)	39 (17)	0.160

n (%) unless stated otherwise; Boldface type indicates statistical significance ($p < 0.05$); IQR = interquartile range; *Health literacy was determined using the Newest Vital Sign. Patients with scores < 4 were considered to have limited health literacy; [°]Public insurance: Medicaid, Medicare, or MassHealth; Private insurance: any other health insurance; [†]Employed includes being self-employed (n = 191) or student (n = 16); Not employed includes retired (n = 98), unemployed (n = 21), or unable to work/disabled (n = 22); ‡ Imputed missing values: BMI (n = 19), insurance (n = 3), smoking status (n = 22), and alcohol risk (n = 60); [‡]Updated Charlson Comorbidity Index.

Since ethnicity and ADI state level showed a correlation of ≥ 0.8 with other variables, they were not included in multivariate regression analysis. Adjusted multivariate regression analysis demonstrated that adequate HL was independently associated with higher EQ-5D-5L index scores (B = 1.07 [95% CI 1.00, 1.15], p = 0.049). Other variables that were associated with higher EQ-5D-5L index scores were Asian race (B = 1.16 [95% CI 1.02, 1.32], p = 0.026) and college education (B = 1.07 [95% CI 1.00, 1.15], p = 0.044). Variables that were associated with lower EQ-5D-5L index scores were being obese (B = 0.90 [95% CI 0.84, 0.98], p = 0.013), having housing concerns (B = 0.88 [95% CI 0.78, 1.00], p = 0.048) and being an active smoker (B = 0.88 [95% CI 0.80, 0.98], p = 0.014) (Table 2).

Table 2 Adjusted multivariate analysis with purposeful selection of variables, EQ-5D-5L index score

	EQ-5D-5L Index						
					95% CI		
	B	SE	t-statistic	p value	0.025	0.975	VIF
[constant]	1.47	0.053	7.274	0.000	1.32	1.62	
Health literacy, adequate	1.07	0.035	1.975	**0.049**	1.00	1.15	3.237
Body Mass Index[‡]							
Overweight	0.96	0.036	-1.157	0.248	0.89	1.03	2.075
Obese	0.90	0.040	-2.499	**0.013**	0.84	0.98	1.734
Asian race	1.16	0.065	2.236	**0.026**	1.02	1.32	1.176
Social Vulnerability Index							
Low-medium	1.05	0.036	1.383	0.167	0.98	1.13	1.516
High	1.07	0.043	1.498	0.135	0.98	1.16	1.307
Private insurance[°‡]	1.06	0.041	1.433	0.153	0.98	1.15	4.058
College education or more	1.07	0.035	2.023	**0.044**	1.00	1.15	3.259
Employed[†]	1.07	0.038	1.776	0.077	0.99	1.15	3.662
Married or with partner	1.06	0.037	1.500	0.134	0.98	1.14	3.423
Homeowner, yes	1.07	0.037	1.759	0.080	0.99	1.15	3.465
Housing concerns, yes	0.88	0.064	-1.988	**0.048**	0.78	1.00	1.139
Others in household	0.98	0.017	-1.480	0.140	0.94	1.01	1.232
Active smoker[‡]	0.88	0.050	-2.469	**0.014**	0.80	0.98	1.247
Previous spine surgery, yes	0.94	0.039	-1.555	0.121	0.87	1.02	1.252
R-squared	0.232						
Adj. R-squared	0.198						
F-statistic	6.703						
Prob (F-statistic)	0.000						

Boldface type indicates statistical significance ($p < 0.05$); B = regression coefficient; CI = confidence interval; SE = standard error; VIF = variance inflation factor; ; °Public insurance: Medicaid, Medicare, or MassHealth; Private insurance: any other health insurance; [†]Employed includes being self-employed (n = 191) or student (n = 16); Not employed includes retired (n = 98), unemployed (n = 21), or unable to work/disabled (n = 22); ‡ Imputed missing values: BMI (n = 19), insurance (n = 3), smoking status (n = 22).

Variables that were associated with lower EQ-VAS scores were being underweight (B = 0.47 [95% CI 0.24, 0.90], p = 0.022), being obese (B = 0.69 [95% CI 0.55, 0.86], p = 0.001), having housing concerns (B = 0.52 [95% CI 0.35, 0.78], p = 0.001), and higher uCCI score (B = 0.90 [95% CI 0.81, 1.00], p = 0.048). Being married was associated with a higher EQ-VAS score (B = 1.30 [95% CI 1.06, 1.58], p = 0.011) (Table 3).

Table 3 Adjusted multivariate analysis with purposeful selection of variables, EQ-VAS score

	EQ-VAS						
					95% CI		
	B	SE	t-statistic	p value	0.025	0.975	VIF
[constant]	0.94	0.111	-0.542	0.588	0.76	1.17	
Health literacy, adequate	1.23	0.113	1.823	0.069	0.98	1.54	2.128
Body Mass Index‡							
Underweight	0.47	0.333	-2.299	**0.022**	0.24	0.90	1.045
Obese	0.69	0.115	-3.272	**0.001**	0.55	0.86	1.349
Race							
Asian	0.72	0.207	-1.560	0.120	0.48	1.09	1.086
Other	0.62	0.263	-1.805	0.072	0.37	1.04	1.060
ADI°, national percentile	0.92	0.051	-1.643	0.101	0.83	1.02	1.074
Married or with partner	1.30	0.101	2.564	**0.011**	1.06	1.58	1.914
Housing concerns, yes	0.52	0.203	-3.209	**0.001**	0.35	0.78	1.109
Active smoker‡	0.74	0.158	-1.926	0.055	0.54	1.01	1.177
Alcohol risk, yes‡	1.63	0.284	1.721	0.086	0.93	2.85	1.058
uCCI†	0.90	0.054	-1.983	**0.048**	0.81	1.00	1.156
R-squared	0.192						
Adj. R-squared	0.165						
F-statistic	7.247						
Prob (F-statistic)	0.000						

Boldface type indicates statistical significance ($p < 0.05$); CI = confidence interval; B = regression coefficient; SE = standard error; VIF = variance inflation factor; ‡Imputed missing values: BMI (n = 19), smoking status (n = 22), and alcohol risk (n = 60); °ADI = Area Deprivation Index; †Updated Charlson Comorbidity Index.

DISCUSSION

This study found that limited HL is associated with worse HRQoL scores in spine patients, suggesting limited HL has a negative effect on HRQoL in this population. Of the two dimensions of HRQoL that were assessed, the EQ-VAS did not show a statistically significant association with HL in multivariate analysis. Nevertheless, patients with limited HL did report lower EQ-VAS scores than patients with adequate HL. A possible explanation could be that this study was powered based on the EQ-5D-5L index score, as it assesses different aspects of HRQoL in more detail compared to the EQ-VAS score and a bipolar scale such as the EQ-VAS is more difficult for subjects to comprehend.[39] Obesity and housing concerns were independently associated with a lower HRQoL on both the EQ-5D-5L index and EQ-VAS score. These findings are corroborated by existing literature.[40,41] Variables independently associated with higher EQ-5D-5L index scores were Asian race and college education. Being an active smoker was associated with lower EQ-5D-5L index scores. On the other hand, being married or with a partner was associated with higher EQ-VAS scores, while being underweight and having a higher uCCI score was associated with lower EQ-VAS scores. Using purposeful selection of variables for the multivariate regression analysis, there is evidence suggesting that selected factors are associated with HRQoL, albeit solely in the presence of one another.

A study on patients with degenerative lumbar disease found EQ-5D index scores were lower in patients with limited HL, yet the results were not statistically significant.[42] This may be attributable to the small sample size (n = 186) and the use of three levels of HL (limited literacy likely, possible, or adequate literacy) instead of two. Research in other populations and across multiple geographical locations supports our findings and suggests HL is associated with HRQoL across populations.[13,18–20,43] This is the first adequately powered study linking HL and HRQoL outcomes in orthopaedic spine patients. Therefore, it provides the field with valuable insights into the importance of HL in mediating HRQoL in spine patients.

However, there are several limitations to consider. First, as with all HRQoL measures, the patient's perspective is subjective. This could make outcomes more difficult to compare and should be considered in all quality-of-life research. Second, purposeful selection of variables for multivariable analysis can result in omitted variable bias. To minimize this bias and provide a more complete overview of the variables associated with HRQoL we used a p value cutoff of 0.25 instead of 0.05. This technique selects only the most important variables for a model and included HL, which further supports the finding that HL is an important factor in mediating HRQoL outcomes, regardless of statistical significance. Third, participation bias is possible as patients may be more inclined to participate in a HL study if they have more confidence regarding their healthcare knowledge. However, almost 90% of eligible patients agreed to participate, which minimizes the possibility of significant contribution. As a tertiary spine center, there is potential selection bias. Yet, we believe this bias was adequately mitigated by adhering to the inclusion and exclusion criteria, the random selection of patients, and controlling for relevant patient characteristics through multivariate regression analysis. Additionally, patients were evaluated for surgical and nonsurgical interventions, increasing the generalizability of our findings. Another limitation is the homogenous patient population of predominantly White and well-educated patients with an above-average household income. Although this limits the generalizability of our findings, it does reflect the patient population seen in our clinic. Finally, response fatigue should be considered. Given that the questionnaire only took 5-7 minutes to administer, we do not believe this impacted our results.

Conclusion

This investigation demonstrated that HL is independently associated with aspects of HRQoL in spine patients. To effectively develop interventions aimed at improving HRQoL in patients with limited HL, we must gain a deeper understanding of the complex interactions between patient characteristics, social determinants of health, and HRQoL outcomes. Additional research is warranted to explore effective methods for identifying patients with limited HL and consequently developing meaningful interventions to improve their HRQoL.

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APPENDICES

Appendix 1A EQ-5D-5L questionnaire, descriptive segment

Appendix 1B EQ-5D-5L questionnaire, Visual Analog Scale

Appendix 2 Newest Vital Sign nutritional label and accompanying questions

Chapter 10

Reliability of Self-reported Health Literacy

Amanda Lans, John R. Bales, Mitchell S. Fourman, Daniel G. Tobert, Jorrit-Jan Verlaan, Joseph H. Schwab

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ABSTRACT

Background: Limited health literacy has previously been associated with increased healthcare utilization, worse general health status and self-reported health, and increased mortality. Identifying and accommodating patients with limited health literacy may offer an avenue towards mitigating adverse health outcomes and reduce unnecessary healthcare expenditure. Due to the challenges associated with implementation of lengthy health literacy assessments, the Brief Health Literacy Screening Instrument was developed. However, to our knowledge, there are no reports on the accuracy of this screening questionnaire, with or without the inclusion of sociodemographic characteristics, when predicting limited health literacy in orthopaedic spine patients. Therefore, the purpose of this study was to evaluate the reliability and predictive accuracy of self-reported health literacy screening questions with and without the inclusion of sociodemographic variables in orthopaedic spine patients.

Methods: Between December 2021 and February 2022, consecutive English-speaking patients over the age of 18 presenting as new patients to an urban, hospital-based outpatient spine clinic were approached for participation. A sociodemographic survey, the Brief Health Literacy Screening Instrument (BRIEF), and the Newest Vital Sign Health Literacy Assessment Tool (NVS) were administered verbally. Simple and multivariable logistic regression were utilized to assess the accuracy of each BRIEF question individually, and collectively, at predicting limited health literacy as defined by the NVS. Further regression analysis included sociodemographic variables (age, body mass index, race, ethnicity, highest educational degree, employment status, marital status, annual household income, insurance status, and self-reported health).

Results: A total of 262 patients [mean age (years), 57 ± 17] were included in this study. One hundred thirty-four (51%) were male, 223 (85%) were White, and 151 (58%) were married. Patient BRIEF scores were as follows: 23 (9%) limited, 43 (16%) marginal, and 196 (75%) adequate. NVS scores identified 87 (33%) patients with possible limited health literacy. BRIEF items collectively demonstrated fair accuracy in the prediction of limited health literacy (area under the receiver operating characteristic curve (AUROC), 0.76; 95% CI 0.70, 0.82). Individually, the fourth BRIEF item (“How confident are you in filling out medical forms by yourself?”) was the best predictor of limited health literacy (AUROC, 0.67; 95% CI 0.60, 0.73). The predictive accuracy of the BRIEF items, both individually and collectively, increased with the inclusion of sociodemographic variables within the logistic regression. Specific characteristics independently associated with limited health literacy were self-identified Black race, retired or disabled employment status, single or divorced marital status, high school education or below, and self-reporting “poor” health.

Conclusion: Limited health literacy has implications for patient outcomes and healthcare costs. Our results show that the BRIEF questionnaire is a low-cost screening tool that demonstrates fair predictability in determining limited health literacy within a population of spine patients. Self-reported health literacy assessments may be more feasible in daily practice and easier to implement into clinical workflow.

INTRODUCTION

Limited health literacy has previously been associated with increased healthcare utilization, worse general health status and self-reported health, and increased mortality.[1–6] A national survey indicated that approximately one-third of US adults have basic or below basic health literacy, costing the United States economy up to an estimated $238 billion every year.[7,8] However, to date, health literacy has received little attention in the field of orthopaedic surgery.[9] A previous study in spine patients reported patients with limited health literacy report worse PROM scores across several domains, indicating that limited health literacy likely affects individual's perception of health or the ability to answer screening questions.[10] Additionally, other studies in various patient populations indicate worst post-operative outcomes in individuals with limited health literacy.[11,12] Identifying and accommodating patients with limited health literacy may offer an avenue towards mitigating these adverse health outcomes and reduce unnecessary healthcare expenditure.

Several validated assessment tools have been developed to assess health literacy. For example, the Test of Functional Health Literacy in Adults (TOFHLA) and the Newest Vital Sign Health Literacy Tool (NVS) have both been shown to accurately reflect patient relative health literacy.[13,14] However, due to their length and the required in person administration, these questionnaires are difficult to implement in busy clinical settings. Patients may also harbor humiliation associated with perceived deficiencies in health literacy and, understandably, may attempt to hide these shortcomings.[15,16] To address these concerns, a four-question screening questionnaire—the Brief Health Literacy Screening Tool (BRIEF)—was developed. BRIEF has been shown to predict limited health literacy in a relatively innocuous manner.[17–19] To our knowledge, there are no reports on the accuracy of this screening questionnaire, with or without the inclusion of sociodemographic characteristics, when predicting limited health literacy in orthopaedic spine patients. Therefore, to assess the potential clinical utility of the BRIEF, evaluation of these screening questions in the spine patient population is warranted.

Therefore, within a population of spine patients, we evaluated the reliability and accuracy of self-reported health literacy screening questions with and without inclusion of sociodemographic variables at predicting possible limited health literacy defined by NVS.

METHODS

Study Design and Setting

We performed an institutional review board-approved cross-sectional survey study at an outpatient orthopaedic spine clinic of an academic urban medical institution. Enrollment occurred between December 2021 and February 2022. Patients who were scheduled to see one of seven orthopaedic spine surgeons, two orthopaedic spine fellows, one nurse practitioner, or one physician assistant were approached and enrolled. Patients were considered eligible if they were new to the clinic, at least 18 years of age, and fluent in English. Patients were excluded from the study if they did not report fluency in English or could not provide informed consent.

Outcome Measures and Explanatory Variables

After consent was obtained, research staff verbally administered three surveys in the following order: a sociodemographic survey, the Brief Health Literacy Screening Tool (BRIEF), and the Newest Vital Sign Health Literacy Assessment Tool (NVS). Data collected from the sociodemographic questions included race, ethnicity, highest educational degree, employment status, marital status, annual household income, and self-reported health. Variables collected from the electronic health record included age, sex, body mass index, type of insurance, and spine pathology.

The BRIEF is a questionnaire that assesses the subject's self-reported ability to understand health information (Appendix 1). We utilized the same BRIEF questions and scoring system used by Haun and colleagues in previous studies in veterans attending ambulatory clinics.[18,19] The questionnaire includes four multiple choice questions. The answer choices for each question reflect that of a five-point Likert scale. Each question is scored from one to five points depending on the response; total scores may range from 4 to 20 points. Participants are considered to have limited, marginal, and adequate health literacy if their BRIEF score ranges from 4-12 points, 13-16 points, and 17-20 points, respectively. In this study, the test administrators verbally asked each question and stated the five answer choices for the participant to choose from.

The NVS is a verbally administered questionnaire assessing both health literacy and numeracy (Appendix 2) which has previously been validated against the Test of Functional Health Literacy in Adults (TOFHLA).[14] The NVS assesses a participant's ability to understand written information and apply basic calculations based on their interpretation of an ice cream nutrition label. Participants are asked a total of six questions about the label, and each correctly answered question earns one point. In the original validation study of this metric, Weiss and colleagues found that an NVS score of less than 4 indicated possible limited health literacy with a sensitivity of 100% and a specificity of 64%. Other studies in orthopaedic populations have also utilized this threshold.[10,20,21] Because of its previous usage, as well as for the purpose of logistic regression, we used the binary outcome of NVS scores 0-3 and 4-6 indicating possibly limited and adequate health literacy, respectively. Furthermore, the NVS was considered the ground truth that objectively reflects health literacy rating, and the categorical arrangement between the BRIEF and NVS assessments have been shown to be comparable in previous studies.[22,23]

Statistical Analysis

All statistical analyses were performed using RStudio Version 2021.09.1 (Boston, MA). Previous studies using the NVS in English-speaking hand and spine patients found a limited health literacy prevalence of 33%.[20,21] With this estimated prevalence, a priori power analysis indicated a needed sample size of at least 197 patients. Descriptive statistics were conducted to present sociodemographic characteristics and health literacy assessments based on BRIEF and NVS scores. Continuous variables were reported using means and standard deviations. Discrete variables were reported using frequencies and percentages.

Simple and multivariable logistic regression models were used to assess the accuracy of the BRIEF screening items in predicting NVS-based health literacy assessments. Receiver operating characteristic (ROC) curves were calculated for each individual BRIEF item, as well as for all BRIEF items collectively. Subsequently, we determined whether the inclusion of sociodemographic factors increased the predictive accuracy in predicting limited health literacy. Multivariable logistic regressions to assess predictive accuracy across all BRIEF items (individually and collectively) were repeated with the inclusion of sociodemographic variables. The ROC curves calculations were repeated, and all results were reported using accuracy, sensitivities, specificities, and area under the receiver operating characteristic curve (AUROC) with 95% confidence intervals (CI). Odds ratios (OR) with a 95% CI and p values were calculated to determine which sociodemographic characteristics were associated with increased odds of limited health literacy. P values were considered significant if less than 0.05.

RESULTS

Of the 291 patients who were approached, 262 (90%) agreed to participate (Table 1). Eligible patients declined due to lack of time (n = 22, 8%) or lack of interest (n = 7, 2%). The age of enrolled subjects ranged from 18 to 95 years (mean, 57 ± 17). A total of 134 (51%) patients enrolled were male, and 224 (85%) patients self-identified as White. One hundred forty-nine subjects were employed (57%), and 151 (58%) subjects were married or living with a partner. One hundred and four (40%) subjects had Medicare, 17 (7%) had Medicaid, and 140 (53%) had private insurance. Health literacy assessments according to BRIEF scores were as follows: limited (n = 23, 9%), marginal (n = 43, 16%), and adequate (n = 196, 75%). Health literacy assessments according to NVS scores were as follows: limited (n = 87, 33%) and adequate (n = 175, 67%). Figure 1 and Figure 2 show the distribution of BRIEF scores and NVS scores, respectively.

Table 1 Patient characteristics (n = 262)	
Mean age, in years (SD)	57 (17)
Male	134 (51)
Self-reported race	
White	223 (85)
African American	14 (5)
Asian	15 (6)
Hispanic or Latino	5 (2)
Other or declined	5 (2)
Hispanic or Latino ethnicity	12 (5)
Mean body mass index (SD)	28 (6)
Highest degree obtained	
Did not finish high school	4 (2)
High school or GED*	34 (13)
Some college/associate degree	53 (20)
College bachelors	86 (33)
Graduate, postgraduate	85 (32)
Employment status	
Employed	149 (57)
Unemployed	14 (5)
Retired	76 (29)
Disabled	17 (7)
Student	6 (2)
Marital status	
Single	72 (27)
Married or living with partner	151 (58)
Divorced or legally separated	24 (9)
Widowed	15 (6)
Type of insurance	
Medicare	104 (40)
Medicaid	17 (7)
Private	140 (53)
No insurance	1 (0)
Annual household income	
≥ $75,000	143 (55)
< $75,000	56 (21)
Declined	63 (24)
Self-reported health	
Excellent	23 (8.8)
Very good	69 (26)
Good	90 (34)
Fair	53 (20)
Poor	27 (10)

Table 1 Patient characteristics (n = 262)

Spine pathology	
Degenerative°	217 (83)
Scoliosis/sagittal plane imbalance	22 (8)
Bone lesion	7 (3)
Trauma	15 (6)
Infection	1 (0)
BRIEF[†] scores	
Limited (4-12)	23 (9)
Marginal (13-16)	43 (16)
Adequate (17-20)	196 (75)
NVS[‡] scores	
Limited (0-3)	87 (33)
Adequate (4-6)	175 (67)

Numbers are stated n (%) unless stated otherwise; *General Educational Development diploma; °Degenerative pathologies include stenosis, spondylolisthesis, radiculopathy, myelopathy, or chronic pain; [†]BRIEF Health Literacy Screening Tool [‡]Newest Vital Sign Health Literacy Assessment Tool.

Figure 3 and Figure 4 show the ROC curves for each individual BRIEF item and the collective BRIEF items predicting limited health literacy, respectively. Collective BRIEF scores, compiled from responses to all BRIEF items, showed the greatest ability to predict limited health literacy (AUROC, 0.76; CI 0.70, 0.82).

As for the individual BRIEF items, the first BRIEF item ("How often do you have someone help you read hospital materials?") was the least accurate in predicting limited health literacy (AUROC, 0.58; CI 0.52, 0.65) (Table 2). Conversely, the fourth BRIEF item ("How confident are you in filling out medical forms by yourself?") was the most accurate screening item in predicting limited health literacy (AUROC, 0.67; CI 0.60, 0.73).

Figure 5 and Figure 6 display ROC curves of individual and collective BRIEF items, both with the inclusion of the following demographic variables: age, race, ethnicity, highest degree obtained, employment status, marital status, type of insurance, annual household income, self-reported health, and spine pathology. All BRIEF items, individual and collective, displayed larger predictive accuracy with the inclusion of these characteristics (Table 3). The first BRIEF item with sociodemographics was the worst individual screening item in predicting limited health literacy (AUROC, 0.85; CI 0.81, 0.90). The fourth BRIEF item with sociodemographics was the best individual screening item at predicting limited health literacy (AUROC, 0.87; CI 0.83, 0.92). The collective BRIEF with sociodemographics showed the highest predictive accuracy among all situations (AUROC, 0.89; CI 0.85, 0.93).

Concerning OR calculation, reference groups were chosen based on the most common patient response within each characteristic domain: White race, not Hispanic or Latino

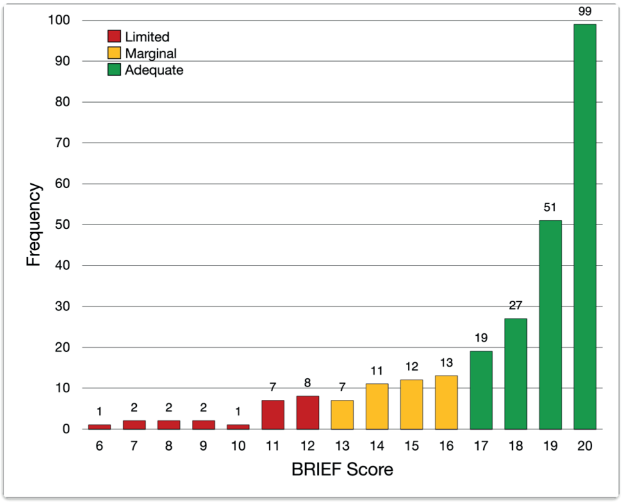

Figure 1 Distribution of BRIEF Scores

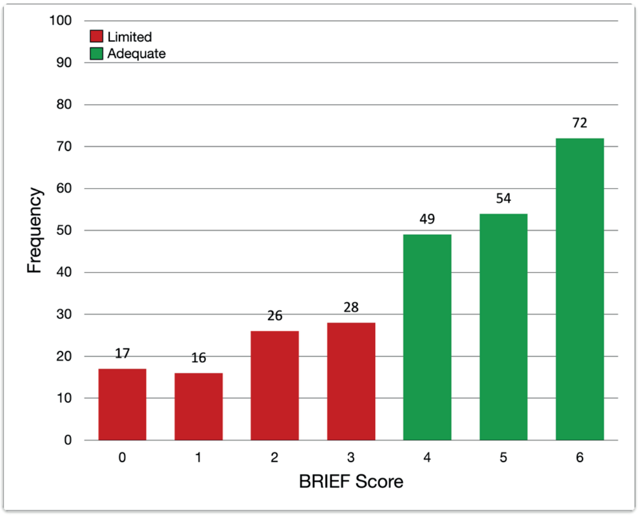

Figure 2 Distribution of NVS Scores

ethnicity, College bachelor's degree obtainment, currently employed, currently married or with a life partner, current private health insurance, current income ≥ $75,000, and good self-reported health. Several characteristics were found to have increased odds of limited health literacy including self-identified Black race (OR, 8.55; CI 1.21, 60.14), having a high school or equivalent education (OR, 10.83; CI 2.66, 44.09), being retired (OR, 3.64; CI 1.14, 11.67) or disabled (OR, 9.65; CI 1.21, 77.29), being single (OR, 3.76; CI 1.29, 10.90) or divorced (OR, 4.75; CI 1.31, 17.17), and having poor self-reported health (OR, 10.92; CI 2.33, 51.19) (Table 4).

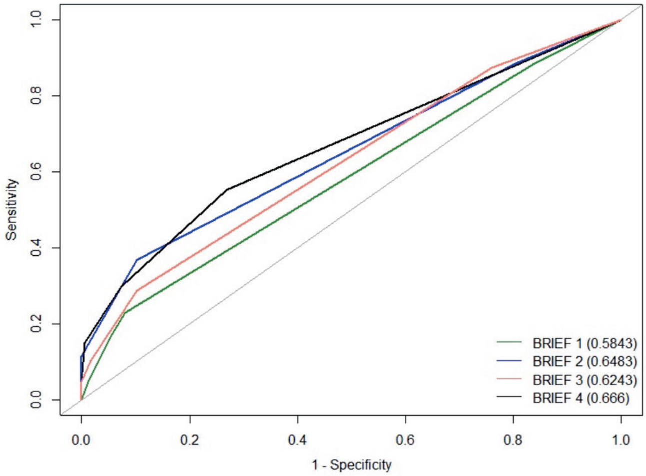

Figure 3 ROC and AUROC of individual BRIEF items

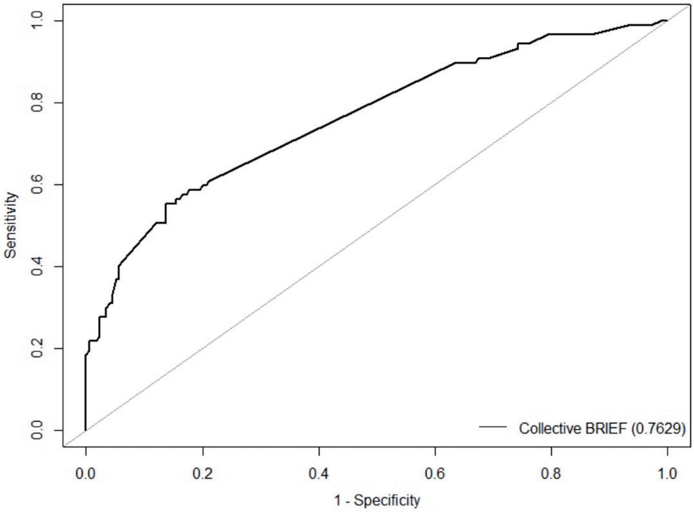

Figure 4 ROC and AUROC of all BRIEF items collectively

Table 2 Predictability of only BRIEF Health Literacy Tool on limited health literacy

BRIEF* Question	Accuracy (95% CI)	Sensitivity	Specificity	AUROC (95% CI)
BRIEF 1	0.69 (0.63, 0.75)	23.0%	92.0%	0.58 (0.52, 0.65)
BRIEF 2	0.72 (0.66, 0.77)	36.8%	89.7%	0.65 (0.58, 0.71)
BRIEF 3	0.69 (0.64, 0.75)	28.7%	89.7%	0.62 (0.56, 0.69)
BRIEF 4	0.72 (0.66, 0.77)	30.0%	92.6%	0.67 (0.60, 0.73)
BRIEF Collective	0.76 (0.70, 0.81)	36.8%	94.9%	0.76 (0.70, 0.82)

*BRIEF Health Literacy Screening Tool; CI = confidence interval; AUROC = area under the receiver operating characteristic curve.

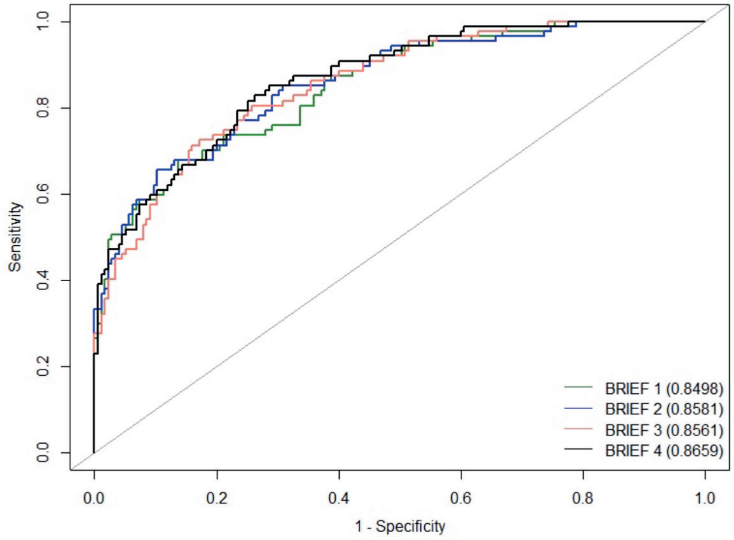

Figure 5 ROC and AUROC of individual BRIEF items with sociodemographic variables

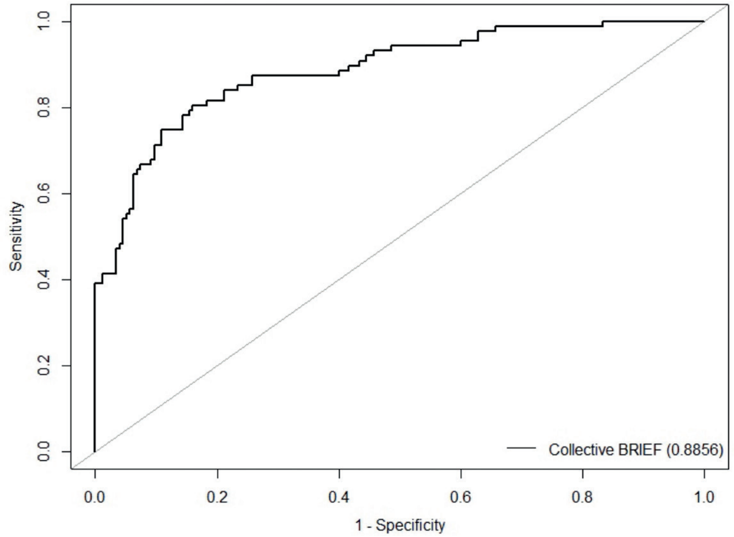

Figure 6 ROC and AUROC of all BRIEF items collectively with sociodemographic variables

Table 4 Predictability of both BRIEF Health Literacy Tool and sociodemographic variables on limited health literacy

BRIEF° Question	Accuracy (95% CI)	Sensitivity	Specificity	AUROC (95% CI)
BRIEF 1	0.79 (0.74, 0.84)	58.6%	89.7%	0.85 (0.81, 0.90)
BRIEF 2	0.81 (0.76, 0.86)	62.1%	90.9%	0.86 (0.82, 0.91)
BRIEF 3	0.80 (0.74, 0.84)	58.6%	90.3%	0.86 (0.82, 0.91)
BRIEF 4	0.80 (0.72, 0.82)	57.4%	90.9%	0.87 (0.83, 0.92)
BRIEF Collective	0.84 (0.79, 0.89)	66.7%	93.1%	0.89 (0.85, 0.93)

°BRIEF Health Literacy Screening tool; CI = confidence interval; AUROC = area under the receiver operating characteristic.

DISCUSSION

Limited health literacy can hinder optimal patient care and impact outcomes. Many questionnaires that identify limited health literacy in patients are too lengthy to be practically implemented in a clinical setting and are prone to measurement bias. In this study, we assessed the accuracy of a short, validated self-reported health literacy screening tool for predicting limited health literacy in spine patients. The results of this study indicate that BRIEF is a fair predictor of limited health literacy in an outpatient spine population and improves considerably with the inclusion of sociodemographic variables. Sociodemographics specifically associated with limited health literacy included race, education level (high school or equivalent), employment status (retired or disabled), marital status (single or divorced), and self-reported health (poor).

The BRIEF screening tool has been used in several institutions and has been shown to reliably predict health literacy assessments in other patient populations.[24,25] This is corroborated by the current study, which shows that the BRIEF screening tool can adequately predict the risk of limited health literacy in patients seen at an outpatient spine center. Similar to our findings, Stagliano and Wallace previously found that all four BRIEF items accurately predicted limited health literacy in a family medicine patient population, with the fourth BRIEF item as the best predictive individual screening question.[22] Similarly, in a vascular surgery patient population, Wallace et al. also demonstrated the predictability of limited health literacy using the BRIEF questionnaire, where the fourth BRIEF item also proved to be the best individual item at predicting limited health literacy.[13] However, this study utilized a different instrument as the ground truth in defining limited health literacy: the Rapid Estimate of Adult Literacy in Medicine (REALM).[26] Unlike the NVS, the REALM does not include a numeracy assessment.

Although the BRIEF showed an acceptable predictive accuracy of limited health literacy alone, incorporating sociodemographic characteristics within the logistic regression considerably improved performance. Multiple sociodemographic characteristics were found to be

Table 4 BRIEF collective with demographics: odds ratios and p values by characteristic

	Odds Ratio (95% CI)	p value
Age	1.03 (0.99-1.07)	0.09
Race (ref.* = White)		
African American	8.55 (1.21-60.14)	**0.03**
Asian	2.48 (0.59-10.40)	0.21
Hispanic or Latino	9.26 (0.18-474.62)	0.27
Other or declined	1.2 (0.00-285.13)	0.95
Ethnicity (ref. = Not Hispanic or Latino)		
Hispanic or Latino	3.48 (0.40-30.52)	0.39
Highest degree obtained (ref. = College bachelors)		
Did not finish high school	>50 (0.00-Inf)	0.99
High school or GED°	10.83 (2.66-44.09)	**< 0.01**
Some College or associate degree	1.60 (0.54-4.8)	0.40
Graduate, postgraduate	1.19 (0.42-3.32)	0.75
Employment status (ref. = Employed)		
Unemployed	0.18 (0.00-2.14)	0.17
Retired	3.64 (1.14-11.67)	**0.03**
Disabled	9.65 (1.21-77.29)	**0.03**
Student	2.34 (0.20-27.83)	0.50
Marital status (ref. = Married or life partner)		
Single	3.76 (1.29-10.90)	**0.01**
Divorced	4.75 (1.31-17.17)	**0.02**
Widowed	2.92 (0.62-13.65)	0.17
Type of insurance (ref. = Private)		
Medicare	0.61 (0.18-2.01)	0.42
Medicaid	1.63 (0.27-9.78)	0.60
Annual household income (ref. = ≥ $75,000)		
< 75,000	0.39 (0.12-1.32)	0.13
Declined	0.36 (0.12-1.10)	0.07
Self-reported health (ref. = Good)		
Excellent	0.57 (0.10-3.12)	0.52
Very good	1.56 (0.57-4.29)	0.38
Fair	1.75 (0.54-5.62)	0.35
Poor	10.92 (2.33-51.19)	**< 0.01**
Spine pathology (ref. = Degenerative[†])		
Scoliosis/sagittal plane imbalance	0.96 (0.27-3.50)	0.95
Bone lesion	0.03 (0.00-161.65)	0.43
Trauma	0.55 (0.01-5.08)	0.60

Boldface type indicates statistical significance ($p < 0.05$); CI = confidence interval; *The most common response among patients was utilized as a reference standard within each characteristic domain; °General Educational Development diploma; [†]Degenerative pathologies include stenosis, spondylolisthesis, radiculopathy, myelopathy, or chronic pain.

associated with increased odds of having limited health literacy. These results are consistent with other orthopaedic studies that evaluated sociodemographic factors independently associated with limited health literacy. Menendez et al., for example, found that age, years of education, insurance status, and income are associated with limited health literacy in a population of patients with hand pathologies.[21] In the context of orthopaedic trauma, Kadakia et al. also found an independent association between limited health literacy and educational level.[27]

Our study should be viewed with caution considering its limitations. First, the study was conducted in a single institution with a cohort of patients who had, on average, a relatively high income and educational level. Although this is reflective of the specific sociodemographics of the patient population seen at our spine clinic, our results may not be generalizable to other institutions with more diverse patient populations. Validation of this correlation can only be achieved with a multicenter analysis across a broad geography. Second, our study may be subjected to selection bias, as patients who believe they could do well on a health literacy assessment may be more inclined to complete study procedures. However, given our high participation rate (90%), we believe this is unlikely. Third, this health literacy study only assessed those who were fluent in the English language. A previous study of patients seeking care for hand pathologies demonstrated that Spanish-speaking patients are more likely to have limited health literacy than their native English-speaking counterparts.[21] This calls for further investigation of health literacy in diverse patient populations and across different orthopaedic specialties. Lastly, all questionnaires were administered verbally, which may be a less burdensome experience for patients, and ensures completion and accuracy of questionnaire administration and responses. It is possible that patients may respond differently to the BRIEF items if taken online or on paper.

Conclusion

Limited health literacy has implications for patient outcomes and healthcare costs and should therefore be considered by clinicians when providing care. Our results show that the BRIEF questionnaire is a low-cost screening tool that demonstrates fair predictability in determining limited health literacy within a population of spine patients. Moreover, predictive accuracy increased with the inclusion of sociodemographic variables. Spine patients screening positive for limited health literacy may be offered additional resources, assistance or follow-ups to ensure adequate care is provided. Future studies should aim to assess the feasibility of incorporating screening questions into clinical care and evaluate the impact of subsequent interventions aimed at accommodating patients with limited health literacy.

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APPENDICES

Appendix 1 BRIEF Health Literacy Screening Assessment Tool questions

Appendix 2 Newest Vital Sign Questions in English

Part IV

Summary &
General Discussion

Chapter 11

Summary

SUMMARY

This thesis conducts a thorough exploration of the complex social determinants of health that affect orthopaedic patients, with a specific emphasis on health literacy. Through rigorous analysis and examination, it provides valuable insights into the prevalence of limited health literacy and the significant risk factors associated with it. Through the investigations in this thesis, a new understanding of the dangers posed by limited health literacy emerges, underscoring the critical importance of early identification of patients with low health literacy to improve health outcomes. Moreover, by evaluating the impact of limited health literacy on patient-reported outcome measures, it offers a vital perspective on how to improve aspects of patient-centered care that optimizes health outcomes. Furthermore, an evaluation of a self-reported health literacy screening measure is presented that offers potential for identifying patients with limited health literacy while being mindful of clinical resources. This screening tool can aid health care providers in personalizing patient care to meet the unique needs of those with low health literacy, thereby improving overall health equity. Overall, this thesis provides a wealth of information and insights into the social determinants of health and health literacy among orthopaedic patients, emphasizing the urgent need to identify and address these critical factors to achieve optimal health outcomes.

PART I – SOCIAL DETERMINANTS OF HEALTH

Chapter 2 – Social Determinant of Health Factors Associated with Physical Function and Mental Health among Patients with Orthopaedic Conditions

Patient-reported lack of reliable transportation, difficulty paying for medications and having Medicaid or workers compensation insurance, were associated with worse presenting physical function at initial presentation. Worse mental health at presentation was associated with patient-reported trouble paying for medication and having Medicaid or workers compensation insurance. Even after controlling for these specific socioeconomic factors, being publicly insured was still associated with both worse presenting physical and mental health. Although traditional patient variables still hold importance, our findings show that additional factors have implications for presenting physical and mental health.

Chapter 3 – Social Determinants of Health in Prognostic Machine Learning Models for Orthopaedic Outcomes: A Systematic Review

The current reporting and consideration of various social determinants of health for the development of prognostic ML models for orthopaedics is limited. ML-based prediction models may support clinical decision making, but health care providers should be aware of the models they consider using based on what data was used to develop them. Knowledge regarding the quality of model development, such as adherence to recognized methodological standards, should always be considered. ML is useful in orthopaedic surgery, however, if these models are integrated into clinical care, they should consider reporting SDOH factors. Future efforts should aim to avoid bias and disparities when developing machine learning driven applications for orthopaedics.

Chapter 4 – Health Literacy in Orthopaedics

Health literacy is a dynamic, multifaceted skill set that carries serious implications for overall health and safety, expectations, treatment outcomes and healthcare costs in patients who require orthopaedic care. Orthopaedic surgeons should be aware of the large proportion of patients who have inadequate health literacy and great difficulty understanding health-related information, particularly with respect to their diagnosis, treatment, and prognosis. It is crucial to identify patients at risk of poor health literacy and use appropriate assessment tools to measure the patient's true understanding of their diagnosis and supplement their education when necessary.

Chapter 5 – Systematic Review of Health Literacy and Orthopaedic Surgery Outcomes

This systematic review found a paucity of appropriately designed studies that used validated measures of health literacy in the field of orthopaedic surgery. Out of 616 studies that were identified, nine studies met the inclusion criteria. Among these studies, the majority focused on arthroplasty (44%) or trauma (33%) patients. Only four of the included studies utilized validated health literacy assessments, and just three studies reported the prevalence of limited health literacy, which ranged from 34% to 38.5%. It remains unclear how health literacy may affect orthopaedic patients and their outcomes, highlighting the need for thoughtful, high-quality trials across diverse demographics and geographical locations.

PART II – ASSESSMENT OF PATIENT HEALTH LITERACY

Chapter 6 – General Health Literacy and Cancer Health Literacy in Patients with Metastatic Bone Disease

Over the course of one year 106 patients with metastatic bone disease were enrolled in a cross-sectional survey study. Half of the included patients were found to have limited health literacy (50%) or limited cancer health literacy (50%) and 32% were found to have both limited health and cancer health literacy. Adjusted regression analysis found that limited health literacy was independently associated with a higher Area Deprivation Index, indicating more social disadvantage. Limited cancer health literacy was also independently associated with a higher Area Deprivation Index.

Chapter 7 – Prevalence of- and Factors Associated with Limited Health Literacy in Spine Patients

This cross-sectional survey study of 405 patients presenting to an academic outpatient spine center found that the prevalence of limited health literacy was 33%. Limited health literacy was independently associated with factors such as a higher Area Deprivation Index, having housing concerns, non-employment, non-native English speaking, less years of education, and below ninth grade reading level. These findings demonstrate that a large proportion of spine patients have limited health literacy and that neighborhood measures of social vulnerability may be a feasible manner of identifying patients at risk of limited health literacy. This may contribute to prioritizing the mitigation of disparities and development of meaningful interventions to improve health equity in orthopaedics.

PART III – HEALTH LITERACY IN CLINICAL PRACTICE

Chapter 8 – Impact of Health Literacy on Self-Reported Health Outcomes

This study evaluated if health literacy (HL) level is associated with patient-reported outcome measure (PROM) scores and self-reported health status among patients newly presenting to an academic outpatient spine center. A total of 318 patients were included, and regression analysis demonstrated that patients with limited HL had worse scores across all seven PROM domains that were evaluated (physical function, mental health, depression, anxiety, pain intensity and pain interference). Additionally, patients with limited HL reported worse self-reported health status. The study highlights the importance of considering patient health literacy when interpreting patient-reported outcomes and discussing treatment options.

Chapter 9 – Health Literacy and Quality of Life

This cross-sectional survey study evaluated the relationship between health-related quality of life (HRQoL) and health literacy (HL) in patients seen at an outpatient orthopaedic spine center. The EQ-5D-5L (EuroQol 5-dimension 5-level) is a standardized instrument and was used to measure HRQoL. The study found that limited HL was independently associated with lower EQ-5D-5L index scores, indicating lower HRQoL in spine patients with limited HL. Other factors associated with lower HRQoL were being obese, having housing concerns, and being an active smoker. Additional research is warranted to explore effective methods for identifying patients with limited HL and consequently develop meaningful interventions to improve their HRQoL.

Chapter 10 – Reliability of Self-Reported Health Literacy

This study aimed to evaluate the reliability and predictive accuracy of a self-reported health literacy screening questionnaire called the Brief Health Literacy Screening Instrument (BRIEF) with and without the inclusion of sociodemographic variables in orthopaedic spine patients. A total of 262 patients were included in the study, and the BRIEF questionnaire demonstrated fair predictability in determining limited health literacy within this population. The fourth BRIEF item ("How confident are you in filling out medical forms by yourself?") was the best predictor of limited health literacy. The inclusion of sociodemographic variables increased the predictive accuracy of the BRIEF items, and specific characteristics that were independently associated with limited health literacy were identified. The study suggests that self-reported health literacy assessments may be more feasible and easier to implement into clinical workflow.

Chapter 12

General Discussion and Future Perspectives

Social determinants of health

Despite significant efforts to improve healthcare in the United States, disparities in access and outcomes persist, with socioeconomic factors playing a crucial role in their perpetuation. The social determinants of health (SDOH) framework encompasses several critical factors, including economic stability, living environment, education, access to healthcare, and social support, all of which play a crucial role in determining health outcomes. Research indicates that lower levels of education and income are associated with higher rates of musculoskeletal conditions, such as osteoarthritis, and delayed healing after orthopaedic surgeries.[1] In addition, patients living in impoverished neighborhoods or with limited access to healthcare facilities may encounter greater challenges accessing timely orthopaedic care and follow-up.[2] Studies have suggested that addressing SDOH may have a more profound impact on healthcare outcomes than direct medical care, with SDOH being linked to patient symptoms, access to care, and clinical outcomes.[3] Therefore, it is crucial for healthcare providers, including orthopaedic surgeons, to understand and address the social determinants of health when treating patients to improve patient satisfaction, increase trust in the healthcare system, and ultimately reduce inequities and improve health outcomes.

Healthcare inequity is a complex issue that affects a significant portion of the population.[4] To address this problem, it is important to examine the underlying factors that contribute to disparities in SDOH. By better understanding the various SDOH, policymakers can develop targeted interventions to reduce inequity between populations, including racial, geographic, gender and income-based disparities. Moreover, healthcare providers can use this information to guide clinical research and enhance healthcare value. In **Chapter 2**, we found that several unfavorable SDOH, such as inadequate access to reliable transportation and difficulties paying for medication, were linked to worse physical function at presentation. Similarly, difficulties in paying for medication and having Medicaid or workers compensation insurance were associated with worse mental health at the time of presentation. These findings highlight the need to consider the broader social context of patients when evaluating their health status and implementing targeted interventions to address the underlying social needs that contribute to health disparities. The social context of an individual encompasses a diverse range of social factors that significantly influence their behavior, beliefs, attitudes, and experiences. As such, culture and social norms have a profound impact on people's perceptions, opportunities, and decision-making processes.[5,6] It is imperative to understand the social context of a patient to develop strategies that effectively address the root causes of social issues such as inequality and discrimination. Strategies could include providing access to education and training programs, increasing awareness of available resources, and working with community organizations to address social needs. Furthermore, patient education materials can be adapted to be more accessible to patients with lower health literacy levels by using simplified language and visual aids.

Given the relevance of SDOH, it is important to consider how they are currently represented in orthopaedic literature. In a world where we are increasingly relying on new technological strategies to facilitate how we deliver care, such as machine learning (ML) based algorithms that assist with clinical decision-making, it is useful to know how SDOH are being accounted for. This evaluation can identify areas for meaningful improvements. **Chapter 3** evaluates one of these aspects, namely how SDOH are considered in prognostic ML models in orthopaedic surgery. The study found that the current level of reporting SDOH during the development of prognostic ML models was poor. This suggests that there may be notable biases in existing ML models described in the available orthopaedic literature. Orthopaedic outcomes are affected by several components of the SDOH, including race/ethnicity, educational attainment, socioeconomic status and social context. Studies have found that the afore mentioned factors impact length of stay, patient-reported outcome measurement scores, and revision surgery.[7–12] Therefore, lack of reporting of basic demographic characteristics or inability to justify why certain factors are excluded during model development may limit the quality and impact of these models. Arguably, some SDOH indicators may not be appropriate for the intended use of a ML model or simply not be independent predictors. Yet, without transparent reporting, it will be challenging for readers to fairly evaluate the quality and usability of ML models. Moreover, the addition of SDOH indicators to risk adjustment models has been shown to reduce disparities in several vulnerable populations.[13]Additionally, being unaware of the possibility that data is biased can cause an unintended propagation of existing systemic inequalities. Although the concept of inequity in healthcare is not novel or unique to the prognostic modeling for orthopaedic surgery, it should still be deemed important to aim at minimizing biases, regardless of which approach is used. If we are to rely on ML driven algorithmic decision aids in clinical practice, it is vital that these models are held to a high, equitable standard and implemented into practice with caution. There are existing guidelines for ML model development studies such as the transparent reporting of a multivariable prediction model for individual prognosis or diagnosis (TRIPOD).[14] A notable limitation of the TRIPOD guideline is the absence of any evaluation of how researchers have considered SDOH or acknowledge its absence as a constraining factor. Journal editors should recognize this gap and the potential implications of perpetuating biases in research. To address this, the PROGRESS+ framework can be incorporated alongside existing guidelines to provide comprehensive guidance on SDOH reporting and support researchers in addressing this critical issue. PROGRESS + stands for: Place of Residence, Race/Ethnicity, Occupation, Gender/sex, Religion, Education, Social capital, Socioeconomic status, "Plus+" age, disability, and sexual orientation.[15,16]

Health literacy

As the importance of SDOH in orthopaedic care becomes evident, there is a growing need to translate this knowledge into practical strategies that can be implemented at the bedside. Health literacy may be a potent marker for unfavorable SDOH making it a good candidate for mitigating SDOH disparities in practice. Health literacy refers to an individual's ability to obtain, process and understand health information in order to make informed health-related decisions about.[17] By assessing health literacy and addressing limited health literacy, healthcare providers can gain insights about how they can influence this vulnerability in a positive way. These insights are essential for developing targeted interventions that address social vulnerabilities in a meaningful way. Incorporating health literacy into clinical practice has the potential to serve as a valuable mediator in the effort to improve health equity and achieve optimal health outcomes for all patients.[18] **Chapter 4** highlights the critical implications of limited health literacy for orthopaedic patients, including compromised health and safety, suboptimal treatment outcomes, unrealistic expectations, and higher healthcare costs.[19–22] This may in part be due to the fact that patients often do not understand the "one-size-fits-all" information or instructions they receive. To enhance the delivery of care, it is crucial to assess the effectiveness of patient instructions that are conveyed through various mediums, such as verbal, written, or online resources. The process of auditing patient instructions can provide valuable insights into identifying areas of improvement. Combining health literacy assessments, auditing existing patient resources, and evaluating if information is successfully relayed to patients can pave the way to improving how we provide care.

Orthopaedic surgeons must recognize that a considerable proportion of their patients struggle to understand health-related information, especially regarding their diagnosis, treatment, and prognosis.[23–25] It is important to identify patients at risk of poor health literacy using appropriate assessment tools to measure their understanding and supplement their education when necessary. Despite this, **Chapter 5** highlights the lack of appropriately designed studies with validated measures of health literacy in the field of orthopaedic surgery. Besides using validated health literacy measures, health literacy investigations should be conducted across multiple institutions and include patients from diverse backgrounds. Furthermore, exploratory studies evaluating what is important from a patient's perspective can contribute to developing meaningful interventions. Building a robust body of literature enables physicians to target specific aspects of health-related education during the preoperative and postoperative stages of care, promote patient-physician collaboration, and provide high-quality, patient-centered care while minimizing resource utilization.

Scope of the problem; assessing health literacy in orthopaedic patients

It is crucial to acknowledge the prevalence of limited health literacy among orthopaedic patients in order to tackle the disparity they encounter as a result of inadequate health literacy skills. In **Chapter 6**, the levels of general health literacy and cancer health literacy among patients with metastatic bone disease was investigated. Astonishingly, half of the patients in the study had limited health literacy in either general or cancer health literacy, and almost a third had limited literacy in both areas. Our findings revealed that a higher Area Deprivation Index (ADI), which considers socioeconomic factors such as income, education, household characteristics, and housing, was independently associated with limited general health literacy and cancer health literacy.[26,27] Furthermore, in **Chapter 7**, we assessed the health literacy of patients visiting an outpatient orthopaedic spine center and found that over a third of the patients had limited health literacy. Factors linked to limited health literacy included having housing concerns, being unemployed, being a non-native English speaker, less educational attainment, lower reading levels, and a higher ADI. These results present an opportunity to identify patients at risk of limited health literacy. Since both studies demonstrated an association between the ADI and limited health literacy, this metric could prove to be a useful indication of limited health literacy in these patient populations. The ADI has previously been shown to predict rehospitalization and is considered a reasonable measure of social deprivation that should be considered when conducting clinical research.[28,29]

However, the investigations conducted in **Chapter 6** and **Chapter 7** have limiting factors that should be considered. First, because these were survey studies, participation bias must be considered. Patients may be more inclined to participate in a health literacy study if they have more confidence or are more knowledgeable regarding healthcare. Nevertheless, the participation rate in both studies were at least 90% and patients most frequently declined to participate due to lack of time. Therefore, the samples were likely representative of our populations. Another limitation is the homogenous patient demographic seen at our institution. In both studies, the majority of patients were White, non-Hispanic, native English speaking and privately insured. Although this is representative of the patients seen in our clinic, it limits the generalizability of our results. Arguably, one can expect the prevalence of limited health literacy to be higher at institutions where patients with more social vulnerability are seen. This would mean that the findings in **Chapter 6** and **Chapter 7** under-represent the incidence of limited health literacy.

Further investigation is needed to determine the feasibility and reliability of using neighborhood social vulnerability measures to identify patients at risk of limited health literacy in clinical practice. However, neighborhood measures present an accessible approach for clinicians to consider the barrier patients face when it comes to understanding what they say. Although there are limitations to using a proxy for health literacy, any consideration is better than no consideration at all. By focusing attention on patients who face inherent challenges in navigating and managing healthcare, clinicians have the opportunity to adjust how they communicate and direct additional resources to those who need it most. It is imperative that health care providers understand this issue in the context of their practice.

Health literacy; from bench to bedside

The impact of health literacy can extend to important clinical metrics like patient-reported outcome measures (PROMs). In orthopaedic spine clinics, PROMs have emerged as a critical tool for evaluating symptom severity and treatment efficacy among patients.[30,31] **Chapter 8** demonstrated that patients with limited health literacy had poorer scores across all PROM domains that were evaluated (Physical Function, Depression, Global Health—Physical, Global Health—Mental, Pain Interference Short Form, Pain Intensity Short Form, and Anxiety). Besides that, patients with limited health literacy had worse self-reported health when asked during the survey component of the study. These results remained consistent after adjusting for confounding factors and are in agreement with previous investigations.[32] This urges the consideration of patient health literacy when interpreting PROMs, as well as the implications limited health literacy has for patient assessment and discussing treatment options.

Health literacy has been associated with health-related quality of life (HRQoL) in various populations around the world.[33] HRQoL pertains to an individual's personal assessment of well-being and capacity to participate in social roles. Over the past few decades, the principal goal of healthcare has transitioned from solely extending lifespan to emphasizing patient HRQoL, as research has shown its significance.[34] Incorporating patient education and counseling into medical treatment has demonstrated efficacy in improving HRQoL.[35,36] For patients with limited health literacy, the effectiveness of these interventions may be reduced and necessitate extra effort by health care providers, such as avoiding medical jargon, speaking slowly, and ensuring patient comprehension. **Chapter 9** establishes that the relationship between health literacy and HRQoL also exists in spine patients. Health literacy was found to be independently associated with HRQoL and limited health literacy was shown to negatively impact HRQoL.

Clinicians are beginning to recognize the impact of health literacy on patient outcomes, but there is still a gap in the implementation of health literacy interventions in clinical practice. Addressing health literacy in orthopaedic patients can be a daunting challenge for health care providers, but successful interventions require a multifaceted approach that involves collaboration from all levels of society. By engaging patients, caregivers, clinicians, and community organizations, a supportive environment can be established that promotes health literacy and empowers patients to make informed decisions about their health.

Simplifying healthcare services and improving health education lie at the heart of such interventions. Health care professionals should assume that patients may have a poor level of comprehension and take steps to ensure clear, concise, and informative communication that can improve doctor-patient relationship and facilitate informed consent. In order to provide targeted guidance and selecting appropriate materials for patient education and health counseling, we need to be able to identify patients who are likely to have limited health literacy. This identification can also help clinicians tailor preoperative education and postoperative instructions to patient health literacy levels, which can have a positive impact on treatment outcomes.

Several validated measures, such as the Test of Functional Health Literacy in Adults and the Newest Vital Sign Health Literacy Assessment Tool, have been developed to assess health literacy.[37,38] However, the utility of these measures is limited by their length and in-person administration. Instead of this, a simpler four-question screening questionnaire, the Brief Health Literacy Screening Tool (BRIEF), has been developed and demonstrated fair accuracy in predicting limited health literacy in spine patients (**Chapter 10**).[39] The BRIEF is a multiple-choice questionnaire that assesses the subject's self-reported ability to understand health information and takes about two minutes to administer. Of the four questions, the fourth item ("How confident are you in filling out medical forms by yourself?") most accurately screened for limited health literacy. However, implementing an additional step, in this case, a health literacy assessment, into an already taxed clinical workflow can be challenging for healthcare providers. Another issue that arises is that the results need to be recorded and readily available for the provider to interpret and respond to in a meaningful way. Consequently, this will require the allocation of resources, which is not always possible.

What we can do right now is audit the available resources we provide our patients with, whilst keeping health literacy in mind. As we rely predominantly on written information, one thing that can be simply assessed is the readability of the materials we present to our patients. Although there has been some progress towards improving the readability of orthopaedic patient education materials, there is still room for improvement.[40,41] Readability can easily be assessed using the Flesch-Kincaid formula which is built into Microsoft Word. The Flesch-Kincaid formula is a widely used algorithm that measures the readability of a text based on the average number of syllables per word and the average number of words per sentence. It produces a score that represents the minimum educational level required to understand the pertaining text.

In the exam room, demonstrating and illustrating how an intervention will take place will improve understanding. Research has indicated that patients who receive visual aids along with written or spoken instructions demonstrate improved recall and comprehension compared with those who receive only written or spoken instructions.[42,43] Incorporating visual aids could be particularly advantageous for individuals with limited health literacy. Especially because patients with limited health literacy seeking orthopaedic care in emergency departments and those who are admitted to orthopaedic wards have difficulty comprehending orthopaedic terminology, particularly anatomical terms.[44,45] Moreover, the use of visual aids can decrease the likelihood of misinterpretation or confusion regarding medication regimens or other self-care instructions. Using illustrations or diagrams can be especially helpful in orthopaedic care, where visual representation of anatomy or exercises can be crucial for patient understanding and adherence to treatment plans. Ultimately, improving treatment adherence will increase the likelihood of treatment success.

It is important to note that some components of health literacy, such as understanding or remembering specific health information, may fluctuate over time and may be affected by the complexity of the medical information presented or the circumstances under which it is delivered. Health literacy is associated with age and may also decline as we get older or when general cognitive function decreases. It should be noted that health literacy can be dynamic and influenced by environment, age, and emotions. Reassessment or annual screening of patient health literacy can offer early identification of arising risks, such as loss of self-efficacy, before this can have damaging consequences or unnecessary healthcare expenditures. Screening positive for limited health literacy may prompt offering additional resources, assistance, or follow-ups to ensure adequate care is received.

Finally, we should handle health information the way we handle medication. We must administer the *correct medication*, at the *appropriate dosage*, in a *suitable form*, to the *right patient* at the *right time*. The same concept applies to health information, if we fail to execute this correctly it will render ineffective or, in a worst-case scenario, have damaging consequences.

CONCLUSION

This thesis demonstrates that limited health literacy is prevalent in orthopaedic patient populations. It highlights the fact that a significant portion of patients lack the essential skills necessary to manage their health and navigate the complex healthcare system. Failing to recognize the profound impact of health literacy on the demand and delivery of orthopaedic care represents a missed opportunity to optimize treatment outcomes and patient satisfaction. The findings reported in this thesis should inspire a renewed commitment to improving the delivery of care and developing effective interventions for patients with limited health literacy. This requires multidisciplinary collaboration among healthcare providers, social workers, policy makers, and patients. Moreover, it is a call to action for healthcare providers and medical researchers to explore the impact of health literacy on access to care, treatment outcomes, and healthcare utilization in orthopaedic patients. Finally, this thesis underscores the urgent need for policy makers to prioritize health literacy as a critical public health and safety issue.

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Part IV

Appendices

DUTCH SUMMARY – NEDERLANDSE SAMENVATTING

Steeds vaker wordt erkend dat sociale gezondheidsdeterminanten en gezondheidsgeletterdheid een grote invloed hebben op de uitkomsten van medische behandelingen. Zo associëren we sociale gezondheidsdeterminanten zoals huisvestingsinstabiliteit en voedselonzekerheid met verminderde therapietrouw en dat is belangrijk bij de behandeling van chronische aandoeningen. Bovendien kunnen de sociale gezondheidsdeterminanten – denk aan sociaaleconomische status, opleidingsniveau of arbeidsstatus – bepalend zijn voor het gebruik van en de toegang tot de benodigde medische zorg.

Gezondheidsgeletterdheid definiëren we als het vermogen van een individu om diensten en informatie op het gebied van gezondheid te verkrijgen, te verwerken en te begrijpen, om vervolgens adequate en gezondheid bevorderende beslissingen te kunnen nemen. Beperkte gezondheidsgeletterdheid kan leiden tot een verhoogd risico op ziekte en slechtere uitkomsten van de gekozen behandeling.

In dit proefschrift worden sociale gezondheidsdeterminanten en gezondheidsgeletterdheid bij orthopedische patiëntenpopulaties onderzocht. Door gebruik van nauwgezette analyse en onderzoek biedt dit proefschrift waardevolle inzichten over de prevalentie van beperkte gezondheidsgeletterdheid en de significante risicofactoren die daarmee samenhangen. Daarnaast wordt de invloed van beperkte gezondheidsgeletterdheid op patiënt gerapporteerde uitkomstmaten onderzocht. Deze evaluatie biedt een perspectief op de verbetering van patiëntgerichte zorg. Ook wordt een zelf-gerapporteerde screeningmaat voor gezondheidsgeletterdheid onderzocht. Dit deelonderzoek richt zich op de herkenning van patiënten met beperkte gezondheidsgeletterdheid. Een dergelijke screeningstool kan zorgverleners helpen bij het personaliseren van patiëntenzorg en zo tegemoetkomen aan de unieke behoeften van deze kwetsbare patiëntengroep.

Dit proefschrift biedt nieuwe inzichten in de sociale gezondheidsdeterminanten en gezondheidsgeletterdheid bij orthopedische patiënten en benadrukt de noodzaak om deze kritieke factoren te identificeren en op te volgen om optimale behandeluitkomsten te bereiken.

DEEL I - SOCIALE GEZONDHEIDSDETERMINANTEN

Hoofdstuk 2 - Sociale gezondheidsdeterminanten geassocieerd met fysieke functie en mentale gezondheid bij patiënten met orthopedische aandoeningen

Een gebrek aan betrouwbaar vervoer, moeite met betaling van medicatie en publieke verzekeringen werden geassocieerd met een slechtere fysieke functie bij aanvang van de behandeling. Verder werd een slechtere mentale gezondheid bij aanvang geassocieerd met moeite met betaling voor medicatie en publieke verzekeringen. Ook na controle van deze specifiek sociaaleconomische factoren, is een publieke verzekering geassocieerd zowel met een slechtere fysieke als mentale gezondheid bij aanvang van de behandeling. Hoewel traditionele patiëntvariabelen nog steeds van belang zijn, tonen onze bevindingen aan dat aanvullende factoren ook gevolgen hebben voor fysieke en mentale gezondheid.

Hoofdstuk 3 - Sociale gezondheidsdeterminanten in prognostische machine learning-modellen voor orthopedische resultaten: een systematische review

Sociale gezondheidsdeterminanten worden tot op heden beperkt gerapporteerd en meegenomen bij de ontwikkeling van prognostische machine-learning (ML) modellen voor orthopedie. Op ML gebaseerde voorspellingsmodellen kunnen de klinische besluitvorming ondersteunen. Kennis over de kwaliteit van modelontwikkeling, zoals van erkende methodologische normen, is van groot belang. ML is nuttig in de orthopedische chirurgie, maar als deze modellen worden geïntegreerd in de klinische zorg, moeten we rekening houden met sociale gezondheidsdeterminanten. Bij de ontwikkeling van ML gedreven toepassingen voor orthopedie moeten we ongelijkheden zoveel mogelijk vermijden.

Hoofdstuk 4 - Gezondheidsgeletterdheid in de orthopedie

Gezondheidsgeletterdheid is een dynamische, veelzijdige vaardigheid met belangrijke implicaties voor de algehele gezondheid, veiligheid, verwachtingen, behandeluitkomsten en zorgkosten van orthopedische patiënten. Orthopedisch chirurgen moeten zich realiseren dat de meeste patiënten beschikken over beperkte gezondheidsgeletterdheid en daardoor veel moeite hebben om gezondheid gerelateerde informatie te begrijpen. Het gaat dan vooral om informatie over hun diagnose, behandeling en prognose. Het is cruciaal om patiënten die mogelijk beperkte gezondheidsgeletterdheid hebben, te identificeren met passende beoordelingstools en de voorlichting voor deze patiënten hierop aan te vullen of aan te passen indien nodig.

Hoofdstuk 5 - Systematische review van gezondheidsgeletterdheid en operatieve uitkomsten in de orthopedie

Deze systematische review toonde aan dat er een gebrek is aan goede studies die gevalideerde evaluatietools voor gezondheidsgeletterdheid gebruiken binnen de orthopedische zorg. Van de 616 geïdentificeerde studies voldeden negen studies aan de inclusiecriteria. Van deze studies richtte de meerderheid zich op patiënten binnen de prothesiologie (44%) of traumazorg (33%). Slechts vier van de geïncludeerde studies gebruikten gevalideerde methodes voor de beoordeling van gezondheidsgeletterdheid en slechts drie studies rapporteerden de prevalentie van beperkte gezondheidsgeletterdheid die varieerde van 34% tot 38,5%. Het blijft onduidelijk welke invloed (beperkte) gezondheidsgeletterdheid heeft op orthopedische patiënten en de resultaten van hun behandeling. Dit bevestigt de behoefte aan gedegen, volwaardige studies, uitgevoerd over verschillende bevolkingsgroepen en geografische regio's.

DEEL II – BEOORDELING VAN GEZONDHEIDSGELETTERDHEID BIJ PATIËNTEN

Hoofdstuk 6 – Algemene gezondheidsgeletterdheid en oncologie-specifieke gezondheidsgeletterdheid bij patiënten met gemetastaseerde botziekte

Gedurende één jaar werden 106 patiënten met gemetastaseerde botziekte geïncludeerd in een enquête studie. Bij de helft van de geïncludeerde patiënten werd beperkte gezondheidsgeletterdheid (50%) of beperkte oncologie-specifieke gezondheidsgeletterdheid (50%) vastgesteld, en bij 32% werd zowel beperkte gezondheids- als oncologie-specifieke gezondheidsgeletterdheid vastgesteld. Een gecorrigeerde regressieanalyse toonde aan dat beperkte gezondheidsgeletterdheid onafhankelijk geassocieerd was met een hogere ‘*Area Deprivation Index*’, wat wijst op een grotere sociale achterstand. Beperkte oncologie-specifieke gezondheidsgeletterdheid was ook onafhankelijk geassocieerd met een hogere ‘*Area Deprivation Index*’.

Hoofdstuk 7 – Prevalentie van - en factoren geassocieerd met beperkte gezondheidsgeletterdheid bij patiënten met wervelkolomproblematiek

Van 405 poliklinische patiënten die zich presenteerden bij een academisch centrum voor wervelkolomproblematiek, had 33% beperkte gezondheidsgeletterdheid. Beperkte gezondheidsgeletterdheid werd onafhankelijk geassocieerd met factoren als een hogere *Area Deprivation Index*, problemen met huisvesting, werkloosheid, Engels als tweede taal, minder onderwijs (in jaren) en een leesniveau lager dan middelbaar. Deze bevindingen tonen aan dat een groot deel van de patiënten met wervelkolomproblematiek beperkte gezondheidsgeletterdheid heeft en dat het beoordelen van de *Area Deprivation Index* (een indicatie van sociale kwetsbaarheid) een geschikte methode kan zijn om patiënten te identificeren die risico lopen op beperkte gezondheidsgeletterdheid. Dit kan bijdragen aan de ontwikkeling van bruikbare interventies om de gelijkheid in de orthopedische zorg te verbeteren.

DEEL III – GEZONDHEIDSGELETTERDHEID IN DE PRAKTIJK

Hoofdstuk 8 – Impact van gezondheidsgeletterdheid op zelf-gerapporteerde gezondheidsuitkomsten

Dit onderzoek evalueerde of het niveau van gezondheidsgeletterdheid verband houdt met patiënt-gerapporteerde uitkomsten en zelf-gerapporteerde gezondheidsstatus bij patiënten die zich voor het eerst (poliklinisch) presenteerden in een academisch centrum voor wervelkolomproblematiek. Er werden 318 patiënten geïncludeerd en een regressieanalyse toonde aan dat patiënten met beperkte gezondheidsgeletterdheid slechtere scores hadden op alle zeven geëvalueerde domeinen van patiënt-gerapporteerde uitkomsten (fysieke functie, geestelijke gezondheid, depressie, angst, pijnintensiteit en pijnbelemmering). Bovendien rapporteerden patiënten met beperkte gezondheidsgeletterdheid een slechtere zelf-gerapporteerde gezondheidsstatus. Dit onderzoek benadrukt het belang van de aandacht voor de gezondheidsgeletterdheid van de patiënt bij de interpretatie van door de patiënt gerapporteerde uitkomsten en bij de bespreking van behandelopties.

Hoofdstuk 9 – Gezondheidsgeletterdheid en kwaliteit van leven

Deze studie evalueerde de relatie tussen gezondheids-gerelateerde kwaliteit van leven (GGKvL) en gezondheidsgeletterdheid bij patiënten die gezien werden op een polikliniek voor wervelkolomproblematiek. De EQ-5D-5L (EuroQol 5-dimensie 5-niveau) is een gestandaardiseerd instrument en werd gebruikt om GGKvL te meten. Beperkte gezondheidsgeletterdheid was onafhankelijk geassocieerd met lagere EQ-5D-5L-indexscores. Dit geeft aan dat wervelkolompatiënten met beperkte gezondheidsgeletterdheid een lagere GGKvL hebben. Andere factoren die geassocieerd waren met lagere GGKvL waren obesitas, huisvestingsproblemen en roken.

Hoofdstuk 10 - Betrouwbaarheid van zelf-gerapporteerde gezondheidsgeletterdheid

Dit onderzoek evalueerde de betrouwbaarheid en voorspellende waarde van een zelf-gerapporteerde gezondheidsgeletterdheid-screening vragenlijst genaamd de *Brief Health Literacy Screening Instrument* (BRIEF), met en zonder de inclusie van sociodemografische variabelen, bij patiënten met wervelkolomproblematiek. In totaal werden 262 patiënten in het onderzoek opgenomen. De BRIEF-vragenlijst had een redelijk voorspellende waarde bij de vaststelling van beperkte gezondheidsgeletterdheid bij deze populatie. Het vierde BRIEF-item (“Hoe zeker voelt u zich bij het alleen invullen van medische formulieren?”) was de beste voorspeller van beperkte gezondheidsgeletterdheid. Met de inclusie van sociodemografische variabelen werd de voorspellende waarde van de BRIEF-items vergroot, en specifieke kenmerken die onafhankelijk geassocieerd waren met beperkte gezondheidsgeletterdheid werden geïdentificeerd. Het onderzoek suggereert dat zelf-gerapporteerde beoordelingen van gezondheidsgeletterdheid mogelijk haalbaarder en gemakkelijker te implementeren zijn in de klinische workflow.

REVIEW COMMITTEE

Prof. T. Gosens
Professor of Quality of Life in a Medical Setting
Tilburg University, the Netherlands

Prof. dr. L.M.O. de Kort
Professor of
University Medical Center Utrecht, the Netherlands

Prof. dr. L. van Rhijn
Professor of Orthopaedic Biotechnology
University Medical Center Utrecht, the Netherlands

Dr. T.J. Snijders
Department of Neurology
University Medical Center Utrecht, the Netherlands

Prof. dr. H.M. Verkooijen (Committee chair)
Professor of Evaluation of Image-Guided Treatment
University Medical Center Utrecht, the Netherlands

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CURRICULUM VITAE AUCTORIS

Amanda Lans was born on November 8th, 1992 in Blaricum, the Netherlands. She grew up outside of Amsterdam, where she attended the International School of Hilversum and completed her international baccalaureate. In 2011 Amanda began her academic career at University College Utrecht, University Utrecht. Here she completed her Bachelor of Science and graduated with honors.

In 2015, she worked as a graduate research assistant (extra-curricular internship) at the Massachusetts General Hospital – Harvard Medical School, Boston, United States, Orthopaedic Spine and Oncology Department, supervised by dr. J.H. Schwab. During her time in Boston, she developed her interest in medical research leading her to pursue a dual degree in medicine and clinical research. In 2019 she completed the Selective Utrecht Medical Master (SUMMA) and obtained her Medical Degree and Master of Science in clinical research.

With the support of prof. dr. J.J. Verlaan, Amanda returned to the Massachusetts General Hospital in the fall of 2020. Amid the COVID-19 pandemic, under the guidance of J.H. Schwab, she completed the clinical research for her dissertation.