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Caregiver Literacy in a Pediatric Orthopedic Population: A Cross-Sectional Study

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Abstract

Background: Approximately 33% of Americans have inadequate health literacy, which is associated with increased hospitalization and use of emergency care, poorer control of chronic diseases, infrequent use of preventative measures, and suboptimal treatment outcomes. **Aims and Objectives:** The purpose of this study was to evaluate the general and musculoskeletal health literacy of the parents or guardians (caregivers) of pediatric patients presenting to a general pediatric orthopedic clinic and identify risk factors for limited health literacy. **Study Design:** This cross-sectional study obtained a convenience sample of 200 English speaking caregivers of children presenting with musculoskeletal complaints. Caregivers who were taking their children for either first-time or follow-up visits were included in the study. Participants were excluded if they did not meet the aforementioned criteria, had any cognitive impairment, were unable to read English, or were unable to sign their own consent. **Setting:** The general pediatric orthopedic clinic of a large children's hospital. **Materials and Methods:** Caregivers completed a demographic survey, the Literacy in Musculoskeletal Problems questionnaire, and the Newest Vital Sign to measure musculoskeletal and general health literacy, respectively. **Statistics:** The data was summarized using frequencies and proportions for categorical variables as well as mean and standard deviation for quantitative variables. In the univariate analysis the group comparisons were conducted using the chi-squared test for categorical variables. Multivariable logistic regression was used to model the odds of adequate musculoskeletal health literacy. **Results:** Limited musculoskeletal health literacy was seen in 46.7% of participants. Inadequate general health literacy was observed in 18.0% of participants. Non-Hispanics ($p = 0.0210$), those who worked in a health care ($p = 0.0055$), and those with a level of education of some college or greater ($p = <0.0012$) were more likely to have adequate musculoskeletal health literacy on multivariable logistic regression. Only at least some college experience correlated with adequate general health literacy ($p = 0.003$) upon multivariable logistic regression. **Conclusion:** Almost half of all caregivers who bring their children to a pediatric orthopedic clinic have limited musculoskeletal health literacy and may lack the necessary comprehension required for making informed decisions about their child's care. Limited musculoskeletal health literacy is more prevalent than limited general health literacy.

Keywords: Musculoskeletal Literacy, Pediatric Orthopedics, Parents, Guardians, Caregivers.

INTRODUCTION

For appropriate health care delivery and outcomes, compliance with and understanding of treatment plans is crucial. Most, if not all, health care decisions in children are made by their parents or guardians (caregivers). Thus, for pediatric patients it is the health literacy of the caregiver that is significant. It is estimated that there are currently 74.0 million children living in the United States, and of this population there were 60,008 pediatric orthopedic-related inpatient discharges in 2012, and approximately 2.24 million orthopedic office visits for patients 15 years of age and younger in 2015 [1-3]. This is a significant percentage of the United States population that relies on the health literacy of their caregivers to make appropriate health care decisions.

Per the Institute of Medicine, general health literacy is "the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions" [4]. Those with limited general health literacy have limited medical knowledge and comprehension, and are more likely to skip important preventive measures and have poorer control of chronic diseases, higher rates of health care utilization, and worse health care outcomes [5-7]. In addition, the cost of health care has been shown to be higher in these patients as compared to those with adequate general health literacy [8, 9]. Therefore, health literacy is an important indicator of a person's health status.

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In the United States, studies have estimated that between 33% and 48% of Americans possess inadequate general health literacy [6, 7]. Populations identified at risk are those with less than a high school degree or GED certificate, those with low income levels, non-native English speakers, and those with compromised health status [10–12].

Despite the high prevalence of inadequate general health literacy, health care providers find it difficult to identify these patients [9, 13]. Over the last two decades, several instruments have been designed to evaluate health literacy based on reading and numeracy skills. Most of these measure general health literacy, while very few assess disease or specialty specific literacy [14–17]. To address this deficiency Rosenbaum *et al.* created the Literacy in Musculoskeletal Problems (LiMP) survey, a validated nine-question instrument for measuring musculoskeletal health literacy in adults [17]. While this survey has been used extensively in adult orthopedics, there are few studies of musculoskeletal health literacy as it pertains to the care of pediatric orthopedic patients [11, 12, 17, 18]. Caregiver decisions can have a significant impact on a child’s health care outcomes and thus it is crucial to identify caregivers who possess limited musculoskeletal health literacy [19].

This study aims to investigate the musculoskeletal health literacy of caregivers of pediatric orthopedic patients regarding the anatomy, terminology, diagnosis, and treatment of common musculoskeletal conditions and its correlation with both general health literacy and caregiver demographic characteristics.

MATERIALS AND METHODS

This cross-sectional study obtained a convenience sample of 200 English speaking caregivers of children presenting with musculoskeletal complaints to the general pediatric orthopedic clinic of a large children’s hospital. Caregivers who were taking their children for either first-time or follow-up visits were included in the study. Participants were excluded if they did not meet the aforementioned criteria, had any cognitive impairment, were unable to read English, or were unable to sign their own consent.

The authors’ Institutional Review Board classified the project as exempt from review as no identifiable information was collected from patients. A written consent was obtained from all willing participants. In addition, an informed consent factsheet containing a study summary, risks and benefits, and contact details for the research personnel was provided to each participant. The health literacy surveys, consent forms, and fact sheets were available in English. The physician was blinded to the responses of the participants and to the completeness of the questionnaires.

All participants first completed a three-minute demographic questionnaire, in which they were asked to identify their age, gender, race, highest level of education, whether or not they had ever worked in a health care field previously, and their child’s musculoskeletal complaint. The caregiver’s classification as having worked in a healthcare field was of their own subjective designation.

Next, the caregiver’s general health literacy was assessed using the Newest Vital Sign (NVS), a validated general health literacy instrument in which the caregiver answered six questions pertaining to an ice-cream label [20]. Adequate general health literacy was considered present when ≥ 4 questions were answered correctly. Those participants with NVS scores of < 4 were determined to have limited general health literacy [20]. To administer the NVS a standardized nutrition label was given to each participant, followed by a research assistant verbally asking the participant each question. The NVS took less than five minutes to complete. Permission to use the NVS was obtained from Pfizer, Inc.

The validated, self-administered LiMP survey was then given to participants to assess musculoskeletal health literacy, which took five

minutes to complete [17, 18]. The survey’s nine multiple-choice questions were based on the most commonly emphasized themes (anatomy, terminology, diagnosis, treatment) found in the patient education section of the American Academy of Orthopedic Surgeons (AAOS) website. The LiMP scores ranged from 0 to 9, with scores ≥ 6 indicating adequate musculoskeletal health literacy. Those with scores ≤ 5 were determined to have limited musculoskeletal health literacy. Cutoffs were based on a previous validation study based on the methods described by Pendlimari *et al.* [10]. It was written at a Flesch-Kincaid grade level of 4.2 as the readability of patient education materials is generally recommended to be no higher than a sixth-grade level [21].

Statistical Analysis

The data was summarized using frequencies and proportions for categorical variables as well as mean and standard deviation for quantitative variables. In the univariate analysis the group comparisons were conducted using the chi-squared test for categorical variables. Multivariable logistic regression was used to model the odds of adequate musculoskeletal health literacy (LiMP score ≥ 6). The results were summarized using the odds ratio, corresponding 95% confidence interval and the p-value. The binomial distribution was used to compute the precision or margin of error of the 95% confidence interval for the sensitivity, positive predictive value (PPV), negative predictive value (NPV), and specificity of the NVS survey in predicting limited musculoskeletal health literacy. The significance level was set at 0.05. Statistical Analyses were performed using the statistical software packages SAS 9.4 (SAS Institute, Cary, NC).

RESULTS

A total of 200 participants completed the NVS instrument, and 199 completed the LiMP questionnaire. Table 1 summarizes the demographic and baseline characteristics of the study participants. Participants were predominantly Caucasian (68.7%), female (77.4%), and had at least some college education (70.9%). In addition, 32.0% reported that they were currently or previously employed in a health care setting.

Table 1: Demographic characteristics of study participants

Demographics		N(%)
Age	18 to 24	22(12.0)
	25 to 34	59(32.2)
	35 to 44	73(39.9)
	45 to 54	23(12.6)
	55 to 64	3(1.6)
	65 to 74	3(1.6)
Gender	Male	44(22.9)
	Female	148(77.1)
Race	Hispanic	49(26.1)
	Not Hispanic	139(73.9)
Health care employee/profession	Yes	63(32.0)
	No	134(68.0)
Highest level of education completed	8th grade or less	3(1.6)
	Some high school	11(5.9)
	High school or GED	31(16.7)
	Some college of 2-year degree	57(30.6)
	4-year college graduate	46(24.7)
	More than 4-year college degree	38(20.5)

The mean LiMP score was 5.49 +/- 1. The prevalence of inadequate musculoskeletal health literacy among participants was 46.7%. Questions evaluating knowledge of musculoskeletal conditions were correctly answered by 57.8% of respondents (95% CI 54.3%-61.2%), while diagnosis and treatment questions were correctly answered by 36.4% (95% CI 31.9%-41.3%), and those pertaining to anatomy and terminology by 55.4% (95% CI 52.4%-58.3%).

The mean NVS score was 4.75 +/- 1.5. Limited general health literacy, as defined by a score of <4 on the NVS, was present in 18.0% (95% CI 13.3%-23.9%) of participants. There was a statistically significant association between general health literacy as measured by NVS and musculoskeletal health literacy as measured by the LiMP (p<0.001). The sensitivity, specificity, positive predictive value and negative predictive value of the NVS in predicting inadequate musculoskeletal health literacy were 31.2% (95% CI 22.0%-41.6%), 92.5% (95% CI 85.7%-96.7%), 78.4% (95% CI 63.6%-88.3%), 60.5% (95% CI 57.0%-64.0%), respectively.

In the univariate analysis there was a significant association between the prevalence of adequate musculoskeletal health literacy and gender, race, level of education, and history of health care employment (Table 2). Specifically, participants who were female (p = 0.033), had at least some college experience (p = <0.001), were non-Hispanic (p = <0.001), or held a current or prior position in health care (p = 0.001) experienced higher rates of adequate musculoskeletal health literacy as compared with the other study participants. On multivariable logistic regression there was no difference in adequate musculoskeletal health literacy between male and female caregivers (p = 0.062), however, a statistically significant difference existed between Hispanic versus not (OR 0.38 (95% CI 0.16-0.86), p = 0.021), health care employee versus not (OR 2.96 (95% CI 1.37-6.36), p = 0.006), and at least some college versus not (OR 3.43 (95% CI 1.62-7.25), p = 0.001) (Table 3).

Table 2: Risk Factors for limited musculoskeletal health literacy

Demographics		Inadequate ML N(%)	Adequate ML N(%)	P-value
Age	18 to 24	14(63.6)	8(36.4)	0.0581
	25 to 34	(25)43.1	33(56.9)	
	35 to 44	30(41.1)	43(58.9)	
	45 to 54	8(34.8)	15(65.2)	
	55 to 64	0(0)	3(100)	
	65 to 74	3(100)	0(0)	
Gender	Male	26(59.1)	18(40.9)	0.0326
	Female	60(40.8)	87(59.2)	
Race	Hispanic	33(67.3)	16(32.7)	0.0001
	Not Hispanic	49(35.5)	89(64.5)	
Health care employee/ profession	Yes	19(30.2)	44(69.8)	0.0012
	No	73(54.9)	60(45.1)	
Highest level of education	8th grade or less	1(33.3)	2(66.7)	0.0031
	Some high school	7(63.6)	4(36.4)	
	High school or GED	21(67.7)	10(32.3)	
	Some college or 2 year associates	28(50.0)	28(50.0)	
	4 year college graduate	13(28.3)	33(71.7)	
	More than 4 years college	11(28.9)	27(71.1)	

ML = musculoskeletal health literacy

Table 3: Multivariable logistic regression for adequate musculoskeletal health literacy

Risk Factor	OR (95% CI)	P-value
Care giver age >=35 vs not	0.88 (0.42,1.840)	0.7371
Female vs Male	2.21 (0.96,5.09)	0.0622
Hispanic vs not	0.38 (0.16,0.86)	0.0210
Health care employee vs not	2.96 (1.37,6.36)	0.0055
At least some college vs not	3.43 (1.62,7.25)	0.0012

CI = confidence interval

In the univariate analysis there was a significant correlation between the prevalence of adequate general health literacy and race, level of education, and history of health care employment (Table 4). Specifically, participants with a current or prior occupation in health care (p = 0.029), at least some college experience (p = <0.001), or who were non-Hispanic (p = <0.001) experienced higher rates of adequate general health literacy, as compared with other study participants. However, upon multivariable logistic regression only at least some college experience correlated with adequate general health literacy (OR 5.77 (95% CI 1.8-18.1), p = 0.003) (Table 5).

Table 4: Risk factors for limited general health literacy

Demographics		Limited GHL N(%)	Adequate GHL N(%)	P-value
Age	18 to 24	8(36.4)	14(63.6)	0.0873
	25 to 34	7(11.9)	52(88.1)	
	35 to 44	9(12.3)	64(87.7)	
	45 to 54	5(21.7)	18(78.3)	
	55 to 64	1(33.3)	2(66.7)	
	65 to 74	1(33.3)	2(66.7)	
Gender	Male	8(18.2)	35(81.8)	0.8902
	Female	26(17.6)	122(82.4)	
Race	Hispanic	17(35.7)	32(65.3)	0.0001
	Not Hispanic	15(10.8)	124(89.2)	
Health care employee /profession	Yes	6(9.5)	57(90.5)	0.0293
	No	30(22.4)	104(77.6)	
Highest level of education	8th grade or less	0(0.0)	3(100)	0.0001
	Some high school	4(36.4)	7(63.6)	
	High school or GED	14(45.2)	17(54.8)	
	Some college or 2 year associates	9(15.8)	48(84.2)	
	4 year college graduate	2(4.3)	44(95.7)	
	More than 4 years college	2(5.3)	36(94.7)	

GHL = general health literacy

Table 5: Multivariable logistic regression results for adequate general health literacy

Risk Factor	OR (95% CI)	P-value
Hispanic vs not	0.43 (0.18, 1.07)	0.0684
Health care employee vs not	2.05 (0.73, 5.72)	0.1720
At least some college vs not	5.77 (1.8, 18.1)	0.0027

CI = confidence interval

DISCUSSION

Overall, despite exposure to the musculoskeletal problems of their children, almost half of the caregivers of pediatric orthopedic patients sampled had inadequate musculoskeletal health literacy. This far exceeds the level of inadequate general health literacy sampled in the same population at almost 20% of caregivers. Non-Hispanics, those with at least some college education, and those who had worked in health care were more likely to have adequate musculoskeletal health literacy. As our patient population was predominantly Caucasian with at least some college education, it is likely that the actual rate of limited musculoskeletal health literacy among all caregivers of pediatric orthopedic patients is even higher.

The level of inadequate musculoskeletal health literacy and associated risk factors seen in this study are similar to that seen in the adult orthopedic population. Rosenbaum *et al.* found limited musculoskeletal health literacy in 69% of adult orthopedic patients presenting to the emergency department of an academic medical center and limited general health literacy in 48% [17]. Non-Caucasians and those with lower levels of education were risk factors [17]. A follow-up study examining only patients presenting to the ED with foot and ankle complaints found a limited musculoskeletal health literacy of 32%, with the risk factors for limited musculoskeletal health literacy once again being non-Caucasians and those with a lower education level [12]. Limited musculoskeletal health literacy in those presenting for elective carpal tunnel release was found to be 34% by Rosenbaum *et al.*, while Noback *et al.* found limited musculoskeletal health literacy of in 49% of patients presenting to either

a foot and ankle or hand and wrist surgeon at an urban medical center [11, 22].

This study also demonstrates that instruments made to assess general health literacy run the risk of not detecting inadequate musculoskeletal health literacy. When the NVS is used to predict inadequate musculoskeletal health literacy it has a sensitivity of approximately 1/3rd and thus is not a reliable screening test. However, it has a specificity of over 90% and as such if the patient has limited general health literacy is it very likely that they have limited musculoskeletal health literacy as well. Therefore, if the patient has adequate general health literacy further testing is required to assess their musculoskeletal health literacy, but if the patient has inadequate health literacy it can be reasonably assumed that they likely have limited musculoskeletal health literacy as well. This indicates the need for dedicated instruments to measure musculoskeletal health literacy such as the LiMP.

Although general health literacy and musculoskeletal health literacy have been studied in the adult orthopedic population, there are very few studies which have examined the general and musculoskeletal health literacy of caregivers of pediatric orthopedic patients [23–27]. This is problematic as adequate health literacy allows caregivers to comprehend the medical knowledge needed to make informed decisions regarding the care of their children, and caregiver health literacy has been shown to directly impact pediatric outcomes in a variety of conditions [19, 28–32].

Su *et al.* reported significant disparities in musculoskeletal health literacy in pediatric sports medicine patients and caregivers [33]. They reported Caucasian guardians with private insurance as well as English-speaking and highly educated guardians were associated with higher directly assessed musculoskeletal health literacy. However, there are some differences between our two studies. Their study included patients age 10 to 17 years old presenting for sports-related musculoskeletal injuries and validated instruments of general health literacy or musculoskeletal health literacy were not used, but rather they developed their own questionnaire for direct assessment of musculoskeletal literacy. In our study, all patients presenting to a

general pediatric orthopedic clinic were included and validated instruments of general health literacy and musculoskeletal health literacy were used [16, 17, 20]. However, despite these differences, their findings are ultimately consistent with our own.

In the United States, health literacy has been identified as a significant area for improvement and policy innovation. In 2010 the United States federal government outlined *The National Action Plan to Improve Health Literacy* [34]. This plan provides a blueprint for efforts to improve health literacy and calls for a response from all sectors involved in health information and services to provide equal access to accurate and actionable health information, deliver person-centered health information and services, and support life-long learning and skills to promote health. As the first step of this plan, it is crucial that patients who possess limited general and musculoskeletal health literacy be identified so clinicians are aware of the need to reinforce health information and confirm understanding at the patient's visit, and at a systems level appropriate health education materials can then be targeted towards at-risk populations [35, 36]. Other potential interventions include simplifying health information in educational materials, electronic interventions such as computers and tablets with videos & interactive self-help tools, and group training sessions [30, 37, 38]. In regard to pediatrics, one study had success with providing personalized robots to children with type 1 diabetes, resulting in higher scores on diabetes knowledge and motivation for self-management as compared to the control group [39]. There is some evidence that these interventions addressing limited health literacy result in increased health-related knowledge and comprehension as well as improved adherence to treatment; however, robust large-sampled randomized control trials are lacking in the literature [29, 36–38, 40–44]. Future studies will be needed to see if these interventions correlate with improved health outcomes in the pediatric orthopedic population. As the first step of this process, our study is one of the first to identify caregivers of pediatric orthopedic patients with both limited general and musculoskeletal health literacy.

This study has several limitations. First, this was a single-center study in the pediatric orthopedic outpatient clinic of a large children's hospital, and thus the results may not be generalizable to other pediatric orthopedic populations such as private practice. In addition, some caregivers left certain demographic questions blank, such as their age or level of education, which lowered the power of the subsequent analysis. Furthermore, this study was conducted with English speaking participants only and the results may have differed if non-English speaking participants were included in the study. Finally, the effects of other social determinants of health such as socioeconomic status, living environment, and insurance type on health literacy were not examined.

CONCLUSION

Overall, this study suggests that almost half of all caregivers of pediatric orthopedic patients may lack the necessary knowledge and comprehension for making informed decisions regarding the musculoskeletal care of their children, which may leave their children at a higher risk for sub-optimal outcomes. Those who had at least some college experience, were non-Hispanic, or held current or prior positions in health care were more likely to possess adequate musculoskeletal health literacy. Furthermore, the prevalence of limited musculoskeletal health literacy is far greater than that of limited general health literacy. Interventions to improve health literacy in caregivers of pediatric orthopedic patients would benefit from a focus on musculoskeletal education.

Conflicts of Interest

Dr. Rachel Garfinkel, Dr. Ian Singleton, Dr. Jason Malone, Dr. M'Hamed Temkit, and Dr. Mohan Belthur have no conflicts of interest to declare.

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Rachel J Garfinkel, MD (Contribution: data collection, manuscript preparation)

Ian M Singleton, BS (Contribution: data collection, manuscript preparation)

Jason B Malone, DO (Contribution: study design, manuscript preparation)

M'hamed H Temkit, PhD (Contribution: statistical analysis, manuscript preparation)

Mohan V Belthur, MD (Contribution: study design, manuscript preparation)

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