Exploring the Organizational Role in Adolescent Health Literacy: A Qualitative Single Case Study

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Preface

Approvals to Conduct Thesis

Ethics approval was obtained from the research ethics board at the organization in which this study took place, as well as from the University of Ottawa.

Statement of Contributions

This thesis represents the original work of Meg Finley and was conducted in partial completion of the Master of Science in Nursing degree at the University of Ottawa. A summary of the authors' contributions is stated below.

1. Meg Finley, RN, BScN, BA

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Meg Finley was the primary author of all chapters of this thesis. Interest in this topic stems both from her career as a pediatric nurse, and from her educational background in linguistics. MF identified the research problem, conducted the literature review, developed the research questions and drafted the thesis proposal as well as the study protocol. MF performed all of the data collection and analysis. Every step of this thesis research was done under the supervision of Dr. Paula Forgeron.

2. Dr. Paula Forgeron, RN, PHD

   Full professor, School of Nursing, Faculty of Health Sciences, and University of Ottawa

The thesis supervisor, Dr. Paula Forgeron, provided guidance and feedback on all aspects of this study, from conception to execution. PF was actively involved in the development of the study design and provided guidance and feedback throughout the research process. All chapters of this thesis were reviewed and approved by PF.

3. Dawn Stacey RN, PhD, FCAHS, FAAN, FCAN, CON(C)

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Thesis committee member, Dr. Dawn Stacey (DS), was involved in the design and methodology of this study, including assisting in refining the research question, and conceptualizing the case study design. DS reviewed and approved the thesis proposal, and participated in committee meetings to analyse results and provided feedback on the thesis.

4. Mwali Muray, RN, BScN, MBA, PhD

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Thesis committee member, Dr. Mwali Muray (MM), was involved in the study design (including refining the research question, methodology), and reviewed and approved all parts of the study, including the study protocol and final chapters.

Abstract

Background: Adolescents need to develop health literacy skills to participate in making decisions about their health care. Organizational health literacy facilitates patient understanding of health information, care access, and self-management.

Methods: A literature review and qualitative case study were conducted to explore adolescent health literacy within an organizational context of an adolescent scoliosis program.

Results: Adolescent health literacy is more nuanced than numeracy and reading levels. Yet, little is known about how organizations (including clinicians) support adolescent health literacy. Interviews with health care professionals in a pediatric tertiary hospital related health literacy to scoliosis patient education but did not address other factors associated with adolescents' ability to navigate health systems. Organizational documents did not adequately support healthcare professionals in promoting the health literacy of adolescent scoliosis patients.

Conclusion: Organizational supports are needed to build health literacy capacity amongst adolescents receiving scoliosis care and clinicians need help to leverage the supports that are in place.

Keywords: *health literacy, adolescents, transition, organizational health literacy, adolescent scoliosis, patient education.*

Dedication

For my mom, for all the things she gave up, all the things she chose not to do, so that I could be anything.

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I need to thank my thesis supervisor, Dr. Paula Forgeron, for all the time and care you put into teaching and raising nurses. You may be the reason that I am a nurse, and there is absolutely no question, that without your support, wisdom, perseverance, and good nature, I would not be at this point of finishing this thesis. To my thesis committee members, Dr. Dawn Stacey, and Dr. Mwali Muray, I am grateful for your time and support, and for your perspectives throughout the research process. Your diverse experience was invaluable. I would also like to thank Tricia Lane, NP, for facilitating this work within the scoliosis program.

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Lastly to my husband Nick, now we know your love is unconditional! Thanks for keeping me alive for the last two years, you can tag me back in now.

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List of Abbreviations

AHLF	Adolescent Health Literacy Framework
CDC	Centers for Disease Control and Prevention
HCP	Health Care Professional
HL	Health Literacy
MF	Meg Finley, masters student and primary investigator
PF	Paula Forgeron, Thesis Supervisor
REB	Research Ethics Board
REDCap	Research Electronic Data Capture
RN	Registered Nurse
WHO	World Health Organization

Chapter 1

Introduction

Introduction

Up to 60% of Canadian adults were found to have low levels of health literacy (HL), resulting in them having trouble understanding provider instructions and lacking the ability to make health related decisions on their own (Canadian Council on Learning, 2008). This leads to system misuse and preventable health issues. Low levels of HL amongst Canadians account for an estimated 3-5% of health care costs (Public Health Association of British Columbia, 2012). More importantly, low HL prevents people from being active in their care and autonomous over their health. In Canada, there is a need to improve people's access to and understanding of health care and health information, and as such, HL is an important topic of research to improve health systems delivery.

Increasing prevalence of health promotion research has led to plenty of literature on the topic of HL, but it is unclear if this has led to health care policy or practice changes (Perry, 2014). As a response to low levels of overall literacy in the population, improving HL has become a major public health goal internationally, as outlined by the World Health Organization (Kickbusch, n.d.). Despite government initiatives prioritizing HL promotion (A Vision for a Health Literate Canada, 2009) there are no policies in Canada with specific strategies for the promotion of HL, leaving the responsibility of access and understanding to individuals (Okan, 2019; Rootman & El- Bihbety, 2008).

Health Literacy

HL is broadly defined as "the degree to which individuals have the ability to find, understand, and use information and services to inform health-related decisions and actions for themselves and others" (Office of Disease Prevention and Health Promotion, 2021). It is a multidimensional construct focused on informed decision making (Bröder et al., 2019). Although there is a correlation between basic literacy and HL, the latter refers to a broader capability to respond to the demands of maintaining and promoting one's health (Liu et al., 2020).

Organizational Health Literacy

"Organizational health literacy is the degree to which health care organizations implement strategies to make it easier for patients to understand health information, navigate the health care system, engage in the health care process, and manage their health" (Brega et al., 2019, p. 128). Organizations have explicit priorities and policies, as well as an embedded culture, which, when they are health literate, promote participation and understanding by patients.

As much as HL is a concern for adults, it is perhaps even more concerning for adolescents and yet, there is a paucity of research on this population. Adolescence is a formative developmental stage of life, characterized by increasing independence and new health concerns (Bröder et al., 2019). A time of life generally characterized by good health, it is easy to overlook the health needs of this age group (Patton et al., 2017). Yet, adolescence is a pivotal stage for neurodevelopment and skills acquired at this age will have an impact across a person's life span. Adolescent HL should be viewed as specific and different from that of adults and will have lasting implications regarding health system usage and overall health status (Patton, et al, 2017; Peralta, et al, 2017).

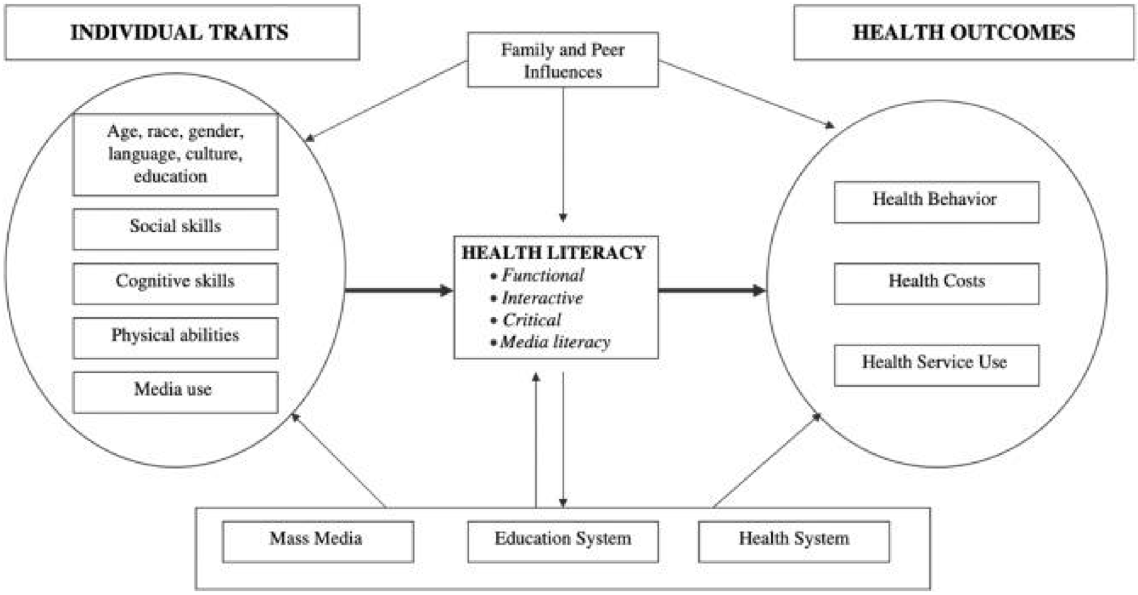
Adolescent HL research stems primarily from the education discipline, where school curriculums are the subject of inquiry (Peralta et al., 2017). However, there needs to be more research from the health disciplines, due to their position within health systems and their goal of promoting the health of individuals. Health related information (e.g., patient education, public health advisories) is disseminated with the perception, that if a message is consumed, its intended outcome will follow. This assumption is problematic, goes against the evidence and has the potential to be dangerous (Brandt et al., 2019; Chisolm et al., 2014; Dharmapuri et al., 2014). The health care system, and the professionals within it, have a responsibility to meet the needs of the population. Acquiring an understanding of adolescent HL, its current organizational and health care professionals (HCP) interpretation, and comparing these to documented best practices, can provide insights to inform strategies for improvement.

Adolescent Health Literacy Framework

HL encompasses knowledge and literacy skills but is more related to these individualistic traits as they interact in relation to social influences and the health care system (Fleary, et al., 2018). Jennifer Manganello (2008) created a framework for adolescent HL (Figure 1), based in ecological theory and Nutbeam's 2000 hierarchy for HL. Manganello's framework demonstrates the complexity of this concept and why it should be studied holistically and is the only framework that is specific to adolescents. In this framework health literacy and its component dimensions (functional, interactive, critical and media HL) are at the centre, with the multitude of upstream influencing factors surrounding. These factors include individual traits (e.g., age, cognitive skills, culture), family and peer influences as well as broader systems of education, health care and media. The framework depicts the downstream health outcomes of HL, including health behaviour, health costs and health service use. In a departure from prior frameworks and those focused on adult populations, the fourth dimension of media HL is emphasized for its relevance to adolescents (Manganello, 2008). Importantly, this framework includes the systems that can impact HL status, including educational, media, and health systems. It identifies these systems in addition to personal traits and social influences as potential intervention points for improving HL status among adolescents (Manganello, 2008). This framework accounts for the specific nuances that influence adolescent HL and was used to inform the literature review and subsequent case study (e.g., semi-structured interview guide).

Figure 1

Adolescent Health Literacy Framework



Taken with permission from: Manganello, J. (2008). Health literacy and adolescents: a framework and agenda for future research. Health Education Research, 23(5), 840–847. https://doi.org/10.1093/her/cym069

Research Purpose

The purpose of this thesis was to investigate how organizational supports within a hospital scoliosis program, in a typical pediatric tertiary care centre, align with how HCPs perceive (e.g., administrator, clinicians) and support adolescent HL to promote adolescents' engagement in their health and health decision making. The specific objectives were 1) to conduct a literature review of adolescent and organizational HL 2) to explore HCP perception of adolescent HL and experiences in supporting adolescent HL and 3) to describe any gaps in organizational HL support for adolescents.

Thesis Layout

This manuscript-based thesis consists of five chapters inclusive of this introductory chapter. Chapter two presents the literature review that was conducted to support the background and justification for the thesis study. Chapter three describes the full methodology, including an explanation of case study and the pragmatic positioning for the study. Chapter four is an unpublished manuscript describing a qualitative single case study prepared for the Journal of Health Communication. The final chapter of this thesis is an integrated discussion bringing together the literature review and the case study, concluding with recommendations for practice, as well as strengths and limitations, along with future research.

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Chapter 2

Literature Review

Literature Review

The purpose of this literature review was to define health literacy (HL) and the types of HL and critically review the literature on adolescent HL and organizational health literacy.

Defining Health Literacy

Nutbeam (2008) first described a hierarchy to define and understand HL, which involves three dimensions of cognitive functioning: functional, interactive, and critical. The functional dimension refers to the basic literacy skills of reading and numeracy and is sometimes conflated with the entirety of the concept. Functional HL is an important foundation upon which to build full HL capacity. Literacy (ability to read and write) is an antecedent to understanding but does not guarantee that one is health literate. The ability to read medication labels and medical instructions for instance, is important to being able to understand them but being overly focussed on reading skills can blind researchers and health care professionals (HCPs) to other factors influencing patients' HL status and therefore leave patients with relative discomfort with situations related to their health (Nielsen-Bohlman, 2004). Overemphasis on functional HL may set the stage for miscommunication due to assumptions of a linear correlation between HL and reading level, especially when it comes to adolescents.

Interactive HL, also known as communicative HL, is the dimension that involves the ability to understand information and communicate effectively about one's health (Nutbeam, 2000). More difficult to measure, this dimension is less easily verified but without comprehension it is impossible to say that a patient is truly informed. A person possessing these skills is able to extract meaning from health information and understand how it applies to their own wellbeing (Fleary et al., 2018). Within this dimension are the skills required to navigate health systems, which involves a level of understanding and an ability to express needs and concerns related to health care (Manganello, 2008).

Critical HL is the dimension that entails the highest degree of cognitive reasoning (Nutbeam, 2000). Critical skills allow patients to locate and identify credible information and apply it to health decision making (Liu et al., 2020). The ability to accurately interpret information and make informed choices is crucial to addressing health goals and concerns independently, yet most Canadians lack the skills to do so (Public Health Association of British Columbia., 2012).

Adolescent Health Literacy

Adolescence is defined by the World Health Organization (WHO) as the stage of life between the ages of 10 and 19 years (WHO, 2023). Erikson describes the developmental stage of adolescence as ‘identity vs. role confusion’ (Ragelienė, 2016). During this time, adolescents are establishing their independence and their identity as separate from their caregivers (Ragelienė, 2016). If adolescents are not given the opportunity and tools to establish this identity, they may be confused regarding their role within systems, and their place in determining their own path (Ragelienė, 2016) including their role in managing their health and interacting with health care systems.

Adolescents are often dismissed as not having the capacity for critical decision making, focussing on parental HL instead, but there is evidence that even young children critically appraise information as it relates to their lives (Fairbrother et al., 2016). When it comes to making health decisions, adolescents may require and indeed prefer to have adults help them with consequential choices (e.g., surgical treatment), but that does not preclude them from wanting to be involved (Coyne et al., 2014). Like anyone, their information needs are closely related to how decisions will impact their lives, but for adolescents these priorities may be different (Bray et al., 2022). Involving adolescents in decision making, even when their desires are not in line with HCP priorities, will help to develop their HL competencies, thereby seizing an opportunity to increase their capacity over the course of their development. Doing so, should be a formal goal of health care organizations.

Cognitive capacity is on the rise during adolescence (Patton et al., 2017). The issue is not that adolescents lack capacity, it is that researchers (and clinicians) may fail to consider their capacity within the context of their development, and growing autonomy (Bröder et al., 2017; Fleary et al., 2018). A health-literate adolescent understands not only the health information related to their wellness, but also their rights, resources, and choices (Massey et al., 2012). Studying HL in this population may have lifelong effects, as experiences during this phase set the stage for the way this generation interacts with the health system as they age (Caldwell & Melton, 2020; Fleary et al., 2018). Adolescents' minimal experience with health care is all the more reason to study HL in this population. Poor health care experiences that result from low HL may be difficult to overcome given adolescents' relatively infrequent engagement in health care services. Moreover, their lack of context makes them more vulnerable to misunderstanding and their age and power differential may make them less likely to verbalize their concerns or questions (Raby, 2010). Research in the field of adolescent HL not only serves to reach patients prior to their becoming adults but may also influence the way we communicate with and improve accessibility for patient populations of all ages.

Media Health Literacy

Media HL is a separate dimension of HL that builds on Nutbeam's framework by incorporating all three levels of cognition, and is especially relevant to adolescents (Nutbeam, 2000), and is a distinctive dimension in the adolescent HL framework proposed by Manganello (2008). Referring to the ability to identify, interpret and critically assess media sources of health information (e.g., health messaging via radio, television, newspapers, electronic), this dimension is a common focus in research of adolescents (Levin-Zamir & Bertschi, 2018). The ubiquity of media, omnipresent throughout one's entire life has made it a popular means of distributing health information and is therefore at the centre of many inquiries related to health education and health promotion (Levin-Zamir & Bertschi, 2018). A sub-dimension of media HL, e-HL or digital HL, was presented by Norman & Skinner (2006), and refers specifically to the use of digital media. Media and digital HL are of great relevance to modern health care in general, but especially important to understand as they relate to adolescent health.

Digital Health Literacy

Digital HL, "the ability to seek, find, understand, and appraise health information from electronic sources and apply the knowledge gained to addressing or solving a health problem," is an important aspect of adolescent health, due to the ubiquity of social media in the lives of these young people (Norman & Sinner, 2006, p. 2; Freeman et al., 2018). It is important to understand how this age group differs in their abilities to utilize digital resources as internet and social media usage is at all-time high, including the use of digital health modalities. Adolescents are no exception and are frequent users of the internet, with 75% using at least one social media platform (Jain & Bickam, 2014; The American Academy of Child and Adolescent Psychiatry, 2018). There is little debate that adolescents are active online, and that they are increasingly using web sources to seek out health information (Freeman et al., 2018). Despite a general ease with digital media usage, an adolescent's ability to use the internet as a portal to health knowledge is dependent on their skills in critically assessing the quality, source, and trustworthiness of information (Taba et al., 2022). In their recent study assessing adolescent digital HL, Taba et al. (2022) found that adolescents are overconfident in their digital HL skills, rating their abilities higher than they actually are. When asked to perform a health information search online, adolescents did use the internet to find reassurance for physical symptoms, and as a first line approach to addressing health concerns (Taba et al., 2022). These adolescents admitted to often using the first website in the results, trusting Google to prioritize the higher quality sources. Ironically, an overabundance of available information, is potentially the source of these concerns in the first place (Bray et al., 2022). Identifying ways and reasons that adolescents use online sources of health information is essential to the conceptualization of their HL and highlights the need for adolescent self-efficacy in critical HL skills (Taba et al., 2022).

McKinnon et al. (2020), found that even though adolescents knew there are credibility concerns with web information sources, they did not employ measures to mitigate the issue. When performing online searches, adolescents favoured content based on communication factors (readability, clarity, visual organization) (McKinnon et al., 2020), rather than credibility of the information. However, adolescents in this study did place confidence in sources suggested to them by HCPs, identifying the reasons to prioritize appropriate digital sources in communication with these patients (McKinnon et al., 2020). These recent studies are performance based and rely on the use of controlled tasks to assess a level of skill.

The fact that this generation is under constant exposure to potentially harmful health advice via social media is a concern for HL policy development**.** During the Covid19 pandemic, this was exemplified by the mass distribution of misinformation via social media platforms and the general public's ability to assess its credibility (Bin Naeem & Kamel Boulos, 2021). Thus understanding how adolescents access and engage with health information to make decisions about their health is paramount. The tendency to associate this age group with digital media usage is possibly missing the point and much of HL research related to this concept seems to be skipping a crucial step of understanding what information is relevant and usable for adolescent patients as opposed to only where they find information.

In a world where information is literally at their fingertips, adolescents are vulnerable to overwhelming and often unreliable information (Maitz et al., 2020, Manganello, 2008). New technologies and social media platforms are idealized as efficient and generationally apt means of distributing information, but what if adolescents cannot understand or relate to the message, despite its arriving to them in this format? Health care organizations should play a role in not only helping adolescents distinguish credible sources but also in understanding what the information means.

Functional Health Literacy

A systematic review of HL studies in adolescence, found that the majority of research in this field is focussed on functional and media HL (Fleary et al., 2018). From this review, there does appear to be a correlation between HL and health promoting behaviours in adolescents, but by using functional literacy as a proxy for overall HL, these studies failed to address factors outside of the ability to read and write. A study by Hoffman is exemplary of the literature and seeks to correlate HL levels to substance use in adolescents in Guatemala, using a functional HL score as the sole variable (2017). The results are consistent with findings in other studies, that low functional HL alone is not predictive of risky health behaviours in this age group (Brandt et al., 2019; Chisolm et al., 2014). Dharmapuri et al. (2014) used a similar measure to assess the relationship of HL to medication adherence in adolescents aged 12-18 years. No correlation was found, and the authors concluded that HL was not predictive of medication adherence, but acknowledge that other cognitive factors have a greater influence on adolescent behaviours (Dharmapuri et al., 2014). This study, like most, used reading as a proxy for HL which is incomplete, so it is unknown how interactive and critical HL contributed to medication adherence.

Functional HL is the easiest to measure and media HL has been popular in studies involving adolescence. However, the ability to interact with health systems (interactive HL) and interpret information for decision making (critical HL) are arguably the more salient characteristics of a health literate individual and have not been robustly studied in this population (Liu et al., 2020).

Nursing and Health Literacy Research

An increasing interest in studying HL is evident in the literature, but there is a conspicuous absence of work from the nursing discipline (Santafé-Madueño et al., 2023). Current literature related to adolescent HL, centres around school health, education, and health promotion. Researchers in the fields of public health are interested in the ways that HL status affect adolescents’ lifestyle choices, but research pertaining to HL practices at tertiary care centres is limited, and studies from the nursing profession are almost nil. Despite being the largest section of the health care workforce and being responsible for much of patient teaching and care, nurses are underrepresented in the research (Santafé-Madueño et al., 2023). Nursing's traditionally holistic models of care would provide important perspectives on HL, a complex and multi-faceted component of health.

Health Literacy: An Antecedent to Health

Health Literacy as an Asset

If HL is conceptualized as antecedent to health outcomes, then there are historically two perspectives from which to view the concept: as an asset or as a risk (Nutbeam, 2008; Broder et al., 2018). Most of the research on HL is from education or public health sources and is focused largely on the concept as a means to describe the state of an issue (Sierra & Cianelli, 2019; Schulenkorf et al., 2022). HL is a priority of the Public Health Agency of Canada and is seen as a critical aspect of health promotion, the assumption being, higher levels of HL will promote a healthier population (Rootman & Gordon-El-Bibehty, 2008). While confounded by a plethora of other determinants of health, there is reason to believe that HL can in and of itself effect outcomes and that interventions targeted to this concept would be impactful (Broder et al., 2018). Public health researchers are interested in how to improve people's ability to make healthy choices, in a way that impacts their overall health, and emphasis is placed on individual traits and skills for decision making to achieve desired outcomes (Fleary et al., 2018).

One focus of research has been the correlation between HL and specific health behaviours, such as substance use (Lindfors et al., 2019; Brandt et al., 2019; Chisolm et al., 2014). Lindfors et al. (2019), found that HL amongst 5,088 adolescents between 14 and 16 years old, was associated with beliefs about smoking consequences but not significantly correlated to smoking behaviours in adolescents across three European cities. Brandt et al. (2019) surveyed 4,219 students (aged 11, 13, 15 or 17 years) and found that overall HL status did not impact participants' alcohol and cigarette use, but that there was a correlation between the ability to understand and appraise health information (interactive and critical HL) and decreased use of both substances. A survey study of 293 adolescents between 14 and 19 years old, assessing the relationship between adolescents' HL status and alcohol use found little significant correlation between the two variables (Chisolm et al., 2014). Only when making choices specifically related to the cognitive impairment risks associated with alcohol use, did HL status affect adolescents' choices (Chisolm et al., 2014). These studies illuminate the nuances of how HL can inform complex health decisions.

The extent to which high HL is predictive of health promoting behaviours in adolescents is debatable and warrants further research. Studies using broad surveys (Lindfors et al., 2019; Brandt et al., 2019; Chisolm et al., 2014) have the advantage of large datasets and robust statistical analysis, but lack the ability to address nuances in the results. In addition, adolescents' ability to make choices or decisions that an adult would be expected to make, (e.g., where long term consequences are considered) should not be seen as a reflection of their HL status. For HL to be seen as unique in this population, research needs to examine age-appropriate factors and motivation for decision making. Contexts of research that do not involve the assessment of stigmatized behaviour (e.g., smoking and substance use) could add to the picture of adolescent HL. Inevitably, questions regarding illegal or risky behaviours amongst youth can be influenced by jurisdictional factors (e.g., legal drinking laws) and may be seen morally as having a right and a wrong answer, which could confound results.

An association with health education means that HL is often seen as being the priority of schools and not health care systems (Hughes & Maiden, 2017). School curriculums include education about health topics (e.g., healthy eating) but do not usually address the skills required to navigate health information and systems (Hughes & Maiden, 2017). While it is a good idea to improve adolescents' health knowledge and to focus on improving competence at an education level, the expectation that everyone will be prepared for unexpected eventualities is impractical. HL must be seen not only from a health knowledge standpoint but also as an asset in navigating health situations and health systems. Thus, understanding from pediatric HCPs how they currently engage with adolescents and how organizations support their work, provides insights into ways to improve their HL and their health outcomes.

Measurements of Health Literacy

To assess an individual's HL status there are a plethora of tools available. Most frequently cited are the Test of Functional Health Literacy in Adults (TOFHLA) and the Rapid Estimate of Adult Literacy in Medicine (REALM), and the Newest Vital Sign (NVS) (Chisolm & Buchanan, 2007; Davis et al., 2006; Warsh et al., 2014). These tools measure basic literacy and numeracy, but they fail to address the complex nature of the concept including interactive and critical domains (Okan, 2019; Brandt et al., 2019). Specific to measuring digital HL (eHL) the eHEALS is a measure of self-perception of skills in using electronic health resources (participants rate themselves out of 5 based on provided statements) (Norman & Skinner, 2006). eHEALS is widely administered in research with adolescents due to the interest in how this age group interacts with online media (Fleary et al., 2018).

All of the above measures have been validated for research with adolescents (Okan, 2019). As an example, adolescents (age 13-17 years) were able to perform the TOFHLA, despite being at an earlier developmental stage, suggesting that reading skills alone are not reflective of cognitive functioning and an ability to read should not be taken as measure of competency in understanding (Chisolm & Buchanan, 2007).

There are several issues with using these tools in a clinical setting (e.g., stress related to test taking, time constraints, cultural context, translation to treatment practices), but even for research data collection these measures are not aligned with accepted definitions of HL, as they focus on the functional skills of reading and numeracy (Pleasant et al., 2011). Acknowledging the inadequacy of these functional measures, researchers have developed several novel tools that attempt to address the other important dimensions of HL (interactive/communicative and critical), but they have not been widely adopted (Massey et al., 2013; McCormack et al., 2010). McCormack et al. (2010) developed a measure that covers a variety of skills and real-world stimuli that achieved adequate validity in testing, but is measured against TOFHLA, which may not be reflective of HL as a latent concept.

As HL encompasses more than an individual’s ability to read, the notion that HL is directly measurable, implies that there is an achievable, acceptable standard that will apply in all settings. HL measures are either cumbersome to administer or overly simplistic, meaning they lack compatibility to many complex circumstances (Pleasant et al., 2011). A person’s agility in making health decisions is not stable and is dependent on situational factors (e.g., fear, fatigue, illness, language of delivery) (Parnell, 2019; Liang & Brach, 2017). The extent to which HL is measurable, is dependent on an assumption that there are decisions that are deemed acceptable and that failure to reach those decisions is a reflection of low HL status. The definition of the concept of HL emphasizes the importance of being informed, not being correct, suggesting that HL is not easily measured by typical factors or even some health-related decisions (Centers for Disease Control and Prevention [CDC], 2020). Therefore, when determining the risk of low HL status, standardized measures only provide a glimpse into the concept.

Organizational Health Literacy

A less individualistic approach seeks to address HL from a systems perspective (Parnell, 2019). HL must be seen as a dynamic construct, one where individual competence exists only in interaction with health information and in the context of health services (Massey et al., 2012). If HL is understood to involve an interaction between patient and health system, it cannot be overlooked that organizations have a responsibility to meet patients' needs (Brega et al., 2019). HL research is largely focused on individual traits and skills, but capacity refers to a person's ability to perform a given task or tasks and therefore implicates health systems (and clinicians) as having a role in ensuring HL (Nielsen-Bohlman, 2004). The extent that health systems are made accessible to patients affects their capacity to function within it, suggesting that health systems need to adjust their HL to be accessible to adolescents (Farmanova et al., 2018).

A study in Istanbul that compared patients' HL scores, hospital organizational HL scores, and patient satisfaction, found a positive association between an organization's HL and that of its patients, resulting in higher patient satisfaction overall (Hayran & Ozer, 2018). Although both HL and organizational HL lack comprehensive measurements, these results are suggestive of the positive impact that health literate organizations can have.

It is difficult to find individual organizational policies that directly reflect a HL mandate. The Plain Language Act in the United States (2010), whereby communications with the public are accessible and readable, would be an example of a literacy focused policy that could be applied in health organizations, but these guidelines do not address many other concerns such as access, ability to navigate the health system, satisfaction and comfort with health care services, all of which are a part of being health literate (Okan, 2019; Wicklund & Ramos, 2009). There is no single set of agreed upon criteria for a health literate organization, but across the literature the most prevalent themes involve appropriateness of communication and access and navigability of services and resources (Bremer et al., 2021).

Applicable to HL is the concept of universal precautions, used in health care to ensure that all people's needs are being met (Parnell, 2019). The recommendation is to assume that all patients experience low HL, thereby meeting the communication needs of a broader group (Dewalt et al., 2011). Liang & Brach (2017) found that specific HL strategies (e.g., help filling out forms, teach back technique) were more likely to be offered by HCPs to patients they perceived to have lower literacy, such as elderly patients or those whose first language differed from that of care delivery. In the United States, where this study took place, this approach would overlook a significant proportion of patients experiencing low HL (Liang & Brach, 2017). In the pediatric realm parents are generally given this role, meaning that adolescents do not have the opportunity to develop the skills and autonomy they will need as young adults.

Point of care assessment of an individual's HL status is not practical, may be stigmatizing and ultimately occurs too late (Pleasant et al., 2011). The Agency for Healthcare Research and Quality in the United States (AHRQ) commissioned a Universal Precautions toolkit for health literate organizations (Dewalt et al., 2011). The toolkit provides document templates, examples, and guidelines for communication with the general population (Dewalt et al., 2011). Notably, and consistent with the adult focus in organizational HL research internationally, the toolkit does not address communication with adolescents (or children) (Okan, 2019).

It is reasonable to assume that adolescents will have different needs than adult patients with regards to their HL, based on developmental stage and increasing independence from parents. (Perry, 2014; Fleary et al., 2018) As such adult studies may not be applicable to this age group and HL should be examined as directly related to the demands that are placed on the individual by the system (Farmanova et al., 2018). An example of a directed HL approach, Bray et al., (2022), used a qualitative participatory research approach to work with adolescent patients with scoliosis to create a communication tool to prepare for clinic visits. Researchers discovered that adolescent patients felt unsure of what questions to ask their HCPs and experienced unmet information needs at appointments (Bray et al., 2022). Adolescents found it helpful when they were spoken to directly, reflecting a desire to be involved in their care despite their young age (13-18 years) (Bray et al., 2022). This study also acknowledged the context of an interaction (health appointment) as having great effect on a person's HL, including adolescents struggling to be involved, which is something that health care organizations need to consider when establishing HL policy.

To understand how health care institutions enact organizational HL, it is necessary to examine the organizational policies that affect the way adolescents interact with and are involved in their health care. As representatives of organizations, as well as the providers of direct patient care, HCPs also need to be aware of the factors affecting the HL of patients and adapt the delivery of care accordingly (Parnell, 2019). While there is reason to aspire to a health system where all people can access individualized care, this may be impractical in terms of HL and taking steps that promote health equity among all service users may have impact (universal precautions), including adolescents who access health care at organizations that serve young populations.

Adolescents with Scoliosis

In HL research with adolescents in a health care context, many studies are situated within chronic or complex medical diagnoses (Caldwell, 2020; Naef et al., 2023). Adolescents in these situations have extensive knowledge and experience with health systems, which may not be representative of a typical adolescent, and therefore these studies may not be as beneficial for creating universal programs.

Adolescent idiopathic scoliosis (AIS) is a curvature of the spine occurring in up to 5% of the population (Choudhry et al., 2016). Diagnosis of idiopathic scoliosis is made by eliminating other medical causes (i.e., neuromuscular disorder) (Weinstein et al., 2008). Patients with AIS are more often female, not only because there is a higher incidence but because they have a greater likelihood of requiring treatment due to greater curve progression (Choudhry et al., 2016; Horne et al, 2014). AIS patients can have poor physical functioning, back pain, body dysmorphia, and social challenges associated with these symptoms (Weinstein et al., 2008). Diagnosis and treatment for scoliosis involves frequent clinic visits, radiology studies, and treatment protocols (Weinstein et al., 2008).

Adolescent idiopathic scoliosis (AIS) patients have relatively low rates of comorbidity, which limits confounding factors; youth who grow up with frequent and varied exposure to the health system may have a higher-than-average level of HL and therefore are not representative of the general population (Bray et al., 2022). Adolescents with scoliosis are generally healthy and are therefore new to encountering health information at the age of diagnosis (usually between the ages of 10-18 years) (Horne et al., 2014). Both the age of onset for AIS and duration of treatment fall within the phase of adolescence (Horne et al., 2014).

Treatment for AIS takes one or more of three paths: monitoring, bracing, or surgery (Choudhry et al., 2016). Over the course of each of these treatments, adolescents have frequent encounters with a variety of clinic settings, health professionals, and information. They are also being treated over a course of several years and so their cognition and independence is actively developing as they progress through their treatment. These scoliosis-related factors situate these adolescents as a group who have some health care experience but confined to the adolescent period and with minimal other co-morbid experiences meaning that they represent a homogenous group enabling a focus on understanding HL needs of adolescents.

Literature Summary

Adolescence is a formative stage of a person’s life, and a time for the acquisition of many cognitive skills. While research has been conducted using quantitative measurements of HL, and with adult populations, the research surrounding adolescents and the organizational strategies to support HL in health care environments are limited. Qualitative research to explore a deeper understanding of the ways organizations and their representatives perceive and support adolescent HL and how this may differ from that of adults, is warranted to develop interventions that support adolescent patients. In tertiary care, there may be a missed opportunity to promote the HL of adolescents, something that is more traditionally associated with the education and primary health care systems. Identifying gaps and facilitators in the organizational support of adolescent HL and exploring the experiences of HCPs, who are the bridge between the organization and its patients, provides insights into what may be needed to make improvements to the care and overall health of this population.

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Chapter 3

Methodology/Methods

Methodology/Methods

To explore the concept of health literacy in adolescence, qualitative methodology was chosen due to the limited research that has been done in health care settings for this population. Specifically, Merriam's (2009) case study methodology was used to guide an investigation of how health care professionals (HCPs) view adolescent health literacy (HL) practices within a real-life setting, and how those views interact with existing organizational supports.

Research Paradigm

Within a pragmatic paradigm, researchers aim to address a problem and through their inquiry offer a solution (Morgan, 2014). Pragmatists focus on problems of human significance, rather than conceptual understanding (Morgan, 2014). As the concept of health literacy has been rigorously described, this study sought to explore its practical implications (Kelly & Cordeiro, 2010). The pragmatic connection between experience and meaning is consistent with the view of health literacy that is used as the basis for inquiry in this study (Kelly & Cordeiro, 2010). Moreover, pragmatism is inclusive of a plurality of methodologies and methods that are best suited to the research question (Mackenzie and Knipe, 2006). Since the interpretation of health information is unique to an individual and based on a variety of factors, a constructivist lens, whereby knowledge is socially constructed and focuses on understanding phenomena through human experiences (Pilot & Beck, 2021), was also adopted to guide this inquiry.

Although a constructivist approach to data collection focuses the research on the experience of participants (Creswell, 2003), within pragmatic inquiry, it was presumed that there may be common, knowable ways to support health literacy functioning that could be illuminated by analyzing organizational practice in a controlled setting (Allemang, 2022). In health care, it is not enough for knowledge to exist, it must be useable, and therefore, the perceptions of HCPs are essential to the translation of knowledge into action.

The assumption that most of the population can digest health information in the same way that it is intended to be by an elite linguistic minority (clinicians), was grounds for this investigation. In the case of the adolescent population, being younger and having less context for decision making, there may be an even greater difficulty to understand language used and meaning intended by clinicians. Qualitative case study methodology allowed for an examination of the non-quantifiable data and resulted in actionable knowledge (Morgan, 2014).

Although, usually associated with mixed methods research, pragmatic inquiry was well suited to this case study approach, where data was collected in different ways to ensure holistic interpretation and triangulation (Harrison, 2017). Methods of document analysis and semi-structured interviews follow from the research question with the goal of describing and understanding the phenomenon and making suggestions for health literacy related strategies, an approach that is supported by pragmatic inquiry.

Research Purpose and Questions

The purpose of this qualitative case study was to investigate how the organizational supports within a hospital scoliosis program align with how organizational stakeholders (e.g., administrator, clinicians) perceive and support adolescent HL to promote adolescents' engagement in their health and health decision making.

Objectives:

1. Explore HCP perception of adolescent HL and experiences in supporting adolescent HL.
2. Describe any gaps in organizational HL support for adolescents.

Study Design

To explore the complex concept of adolescent HL, this study used a single-case study design, informed by Merriam's (2009) qualitative case study approach, and was investigated in the context of adolescent idiopathic scoliosis (AIS). Case study research should be particularistic, heuristic, and descriptive with the purpose of understanding and describing the case (Harrison, 2017). In the realm of HL, qualitative case study research serves to add context to a variety of factors affecting a patient's HL status and how it influences health information interactions for decision making and health system usage (Sibbald, 2021). Exploring interacting influences within a single setting, allows for a more complete picture from which to promote further research. Case study research acknowledges that phenomena exist only within a dynamic context and are best understood as a sum of parts, as opposed to by way of piece meal analysis (Yazan, 2015). A tendency to focus on individual factors in HL research may be a barrier to practice and policy change, but a case study provides a clearer picture for decision makers, one that encompasses the practitioners, and factors in a real-life environment (Sibbald, 2021).

Borne out of the education discipline, Merriam's case study is optimal for health sciences research, in that it emphasizes both personal perspectives and social influences with a goal of program evaluation and development (Merriam, 2016). Merriam's (2016) approach to case study, aligns with both a pragmatic and constructivist approach, with the goal of developing systems that work (Hudon, 2021). This study's goals were related to the practical implementation of HL supports for adolescents which is in keeping with Merriam's approach. The framework for adolescent HL shows a complex interaction of personal, social, and situational factors that can be well demonstrated by a case study (Manganello, 2008). Where the goal of this study was to produce a real-life example of HL as it pertains to adolescents with scoliosis, and with particular interest in the way that health systems can impact HL, Merriam's approach to case study research is ideal and congruous with a pragmatic paradigm and constructivist descriptive approach. Creating a 'picture' of a complex concept, allows for users to derive its meaning and understand how it applies to their practice environment and population (Sibbald, 2021).

Merriam defines a case study as "an in-depth description and analysis of a bounded system" (Merriam, 2016, p. 39). Important to case study research is defining the case and its boundaries (Merriam, 2009). For this study, the phenomenon itself (adolescent HL) is at the centre of the research and the case was bounded geographically by the scope and location of the hospital, and also clinically within the adolescent scoliosis program. The scoliosis program was selected due to the patient population it serves, being adolescents with minimal previous health care experience and requiring specific and limited treatment options. Adolescents with scoliosis are generally healthy, with few if any comorbidities (Horne et al., 2014; Choudhry et al., 2016). Patients with scoliosis are more likely to be female, given a 1.5 to 3 greater incidence and their greater risk for curve progression requiring treatment (Horne et al., 2014). Included in the case were organizational stakeholders, organizational documents pertaining to HL and patient education materials relevant to scoliosis. This study intended to explore HL within a tertiary health care context and thus school curriculums were outside the boundaries of the case. Individual clinical outcomes, and departments, or hospitals outside the selected program were also not included in this case.

Study Setting

The case consisted of the concept of HL as it applies to adolescent scoliosis patients at a pediatric tertiary teaching hospital serving a population of approximately 370,000 children and youth in the Maritime Provinces (Statistics Canada, 2021). The scoliosis program in the case organization, bridges both the orthopaedic clinic and the inpatient surgical unit for patients that undergo corrective surgery and encompasses an array of professionals.

Data Collection

To explore this phenomenon multiple data sources were collected within the selected scoliosis program (Merriam, 2009). Data to explore HCPs' perception of HL of adolescents was collected via semi-structured interviews (Appendix A) with organizational participants. In qualitative research, document analysis is often used for triangulation and to provide richness to the data, and hence was undertaken in this study (Bowen, 2009). Documents are used to both inform the collection of interview data, and to provide context and comparison to the results (Bowen, 2009). All documents reviewed in this study were publicly available.

Organizational Interviews

Population and Recruitment. A letter of support was received from the Director of Children's Health, and so HCP were purposively selected and invited to participate in individual interviews using their publicly available emails. Purposive sampling is used to direct inquiry, to enhance the usefulness of the data and eliminate non-relevant findings (Polit & Beck, 2021). Typical case sampling is a form of purposive sampling where participants are specifically selected because they are representative of a wider group, which promotes transferability of results (Polit & Beck, 2021). In this case study, the participants were purposively invited to represent a range of HCP disciplines and roles associated with the scoliosis program and the hospital is representative of a typical pediatric tertiary care facility, therefore the procedures and personnel are exemplary of health care organization across Canada.

Interview participants had to be: 1) able to read and speak in English; 2) either a front-line HCP or organizational leader; and 3) associated with the scoliosis program. Sixteen potential interview participants were approached via e-mail with introductory information about the study and the contact information for the primary investigator (Appendix B). They were provided with a link to an online secure information and consent form when they expressed interest in participating (Appendix C).

Ethical Considerations. Ethics approval for this study was received by the University of Ottawa and the case institution's health research ethics boards (see Appendix D & E). The online consent form (see details under Data Management) included the comprehensive study information and explained what their participation would entail. They were also given the opportunity to contact the primary investigator (MF) if they had additional questions prior to signing the online consent. Consent was reaffirmed at the beginning of each interview as well as confirmation of understanding regarding the purpose of the study.

Participants were given the option to opt out of the interview at any time, or to abstain from answering any question that they were not comfortable with. No questions asked participants to break confidentiality or asked about patient outcomes, and the interviews were limited to individual experiences and perspectives on organizational and professional responsibility.

Interview Procedures. Participants were asked to sign the online information and consent form prior to participation in the individual interviews with the option to withdraw at any time from the interview. Signed consent was captured via the hospital's REDCap system, a secure web application for the capture and storage of survey data (Harris et al., 2009). Individual interviews ranged from 10-40 minutes and were conducted using a semi-structured interview guide and were held via a Voice Over Internet Protocol (Microsoft Teams) using the hospital Microsoft account per the preference of the REB. Interviews were recorded, with consent, using the embedded recording and transcription function in the MS Teams platform.

The aim of semi-structured interviews is to elicit subjective responses that reflect the interviewees understanding of the subject matter, while maintaining focus on the study objectives (McIntosh & Morse, 2015). Therefore, the semi-structured interview guide (Appendix A) was developed to explore HCPs perceptions of adolescent HL guided by the adolescent HL framework (Manganello, 2008) and their experiences working with adolescents. For example, interviewees were asked what health literacy means to them, and how they feel adolescent health literacy differs from that of children, parents, or other adults (if at all). They were also asked how they typically engage with adolescents to promote the adolescent's HL. By performing interviews with key HCP and leaders within the organization, an understanding of organizational perspectives on adolescent health literacy can be gleaned and compared with both the existing materials and procedures for communicating with this population and the existing literature.

Organizational Documents

All documents were retrieved from the health centre website. To retrieve patient/caregiver facing information documents the scoliosis page was found by searching 'scoliosis' in the search field. All the hospital resources that were listed (embedded links) on this page were retrieved for analysis. Other documents were identified by searching the health centre website for policies pertaining to HL, as well as those identified by participants during the interview process as being organizational resources for adolescent HL.

Data Management

Consent forms were captured and stored on the hospital's REDCap survey platform (account provided to researcher upon creation of REB file). Therefore, consents are housed separately from the interview transcripts. Transcription of interviews was completed using the imbedded transcription function for Microsoft Teams and compared with recordings for accuracy by the primary researcher. Verbatim transcripts were de-identified immediately after the interview to maintain confidentiality of participants (Polit & Beck, 2019; Canadian Institutes of Health Research, 2018) and stored in a password protected folder on the primary investigators password protected computer during analysis. Once the analysis was completed, interview recordings and transcriptions were stored securely in password protected folders on the case organization's secure server, to which only the primary investigator has access and will be kept for 5 years. De-identified transcripts were transferred to PF (supervisor) securely via uOttawa One Drive account under a data management agreement between the case institution and the University of Ottawa. The primary investigator (MF) and supervisor (PF) are the only people with access to the de-identified transcripts with the other members of the research team (DS and MM) having access to only group level quotes.

Data Analysis

Interview Data Analysis

To address the study objectives, an inductive content analysis approach was used to organize and interpret the interview data. Inductive analysis, where categories are drawn from the data itself, allows for the description of the case as it exists, and to not be pre-determined from *a priori* codes (Merriam, 2016). Elo and Kyngäs (2008)'s descriptive inductive content analysis steps were used to analyze the interviews moving from specific meaning to higher level categories to help understand adolescent HL from an organizational perspective.

During the study the primary investigator (PI) maintained employment as an RN at the organization where the case study took place as the clinical nurse specialist for the Suspected Trauma and Abuse Response Team and former RN on a medical surgical unit. The PI was not associated with the scoliosis program but had an understanding of adolescent HL from 9 years of pediatric nursing. Reflexivity, the identification and awareness of the researcher's values, background, and previous experience that can affect the research (Cope, 2014), was monitored by the writing of field notes and peer debriefing sessions with the supervising researcher (PF).

The preparation phase involves a familiarization with the data and should occur simultaneously with data collection as it helps to determine if gaps may exist in the data prior to the completion of data collection before the full analytical phase (Elo & Kyngäs, 2008). Each transcript was reviewed and continued with a thorough first and second reading of the data, while watching/listening to the recording. The second step involved open coding where initial features are identified and codes written directly in the transcripts. After this, the codes were grouped onto a separate coding sheet, and the codes are grouped into headings. After this step, and all proceeding steps, a debriefing meeting with the supervising investigator of the research team (PF) was undertaken to review, discuss assumptions, refine codes, define and initially name categories and ensure that the findings were grounded in the data. During this step, the primary researcher (MF) sorted the codes into potential main categories and reviewed the results with the entire data set to ensure accuracy in representation. The headings were collapsed further into large (main) categories until no further abstraction was reasonable (Elo & Kyngäs, 2008). The final step involved the reporting of the results to the entire research team (e.g., PF, DS, MM), during which a full peer-debriefing meeting and final refinement of the main categories was conducted.

Document Analysis

Organizational documents and resources retrieved were analyzed depending on the purpose of the document.

Patient/Caregiver Facing Documents. Patient/caregiver facing documents were compared with an institutional policy for the preparation of educational materials.

The Flesch-Kincaid readability scores, was the metric used to analyse the readability of the patient/caregiver facing materials by utilizing the embedded tool within Microsoft Word (Queen's University, 2017). The Flesch-Kincaid is a formula used for English language written information to determine the complexity of a document. There is a score for reading ease (target 60-70 out of 100) and a score for North American grade level (target grade 6-8). The lower the reading ease score and the lower the grade level the easier the document is to read. The scores are generated by measuring average sentence length (ASL) which counts the number of words per sentence, and the average number of syllables per word (ASW) and applying them to a mathematical formula. The formula for grade level is $(.39 \times ASL) + (11.8 \times ASW) - 15.59$ and the formula for reading ease is $206.835 - (1.015 \times ASL) - (84.6 \times ASW)$ (Queen's University, 2017). This method is commonly used to assess readability of patient/caregiver education materials and as such it was an appropriate measure to include in this case.

Patient/caregiver education materials documents also underwent analysis using the Patient Education Materials Assessment Tool for Printable Materials (PEMAT-P) (AHQR, 2020). This tool measures two constructs, understandability and actionability of documents by scoring the document on 24 specific characteristics, as either a 0 (disagree) or 1 agree. The tool examines the document for characteristics such as the use of jargon and plain language, numbers and images, and document layout and clarity of purpose (see Appendix F). Scores are generated as a percentage, and although a score of 70% on either construct has been set for psychometric testing of the PEMAT, this score was somewhat arbitrarily selected as there is no specified target score for understandability or actionability in practice (Shoemaker et al., 2013). The aim is to be able to compare relative scores between documents and to illuminate gaps based on best practice. This score of 70% on either construct has been used by others to indicate acceptable understandability and actionability (Kiss et al., 2023; Muscat et al., 2021) despite Shoemaker et al. (2013) acknowledging that it was not empirically derived. Nevertheless, the PEMAT-P provides a method to analyze documents beyond readability and is the only one that includes actionability as well as understandability.

In addition to readability and PEMAT-P scores, other patient/caregiver facing document characteristics that were noted and tabulated included document length, accessibility, purpose, use of images and publication date.

HL Resources. The documents described by participants in this study were analyzed to compare their content or intended use with their interpreted function of supporting adolescent HL. *A priori* categories that reflect the four domains (functional, interactive/communicative, critical, media) of HL set out by Nutbeam (2000) and Manganello (2008) were used for this content analysis.

Quality Criteria

In keeping with Lincoln and Guba's four criteria to determine trustworthiness in qualitative studies, this study employed several approaches to maintain quality of the qualitative data (Lincoln & Guba, 1995). Multiple data sources were used which creates triangulation (participant interviews, and organizational documents) (Polit & Beck, 2021). With multiple sources and formats of data, it is important to maintain a consistent interpretation of results to ensure credibility. In addition to the coding being reviewed by the supervisor (PF), consistency was maintained by holding regular meetings with the supervisor to audit the data analysis. Additionally, a final review of results with the committee members serve to promote confirmability of the results (Connolly, 2016).

Authenticity is the extent to which the research represents the truth of the data and participants (Connolly, 2016). In this study, the use of exemplar quotes, ensuring that no one voice is dominate (including that of the researcher) allowed for an accurate portrayal of participant experiences with adolescent HL.

To guide the transferability of the results, ample data for rich description was provided (Polit & Beck, 2021; Connolly, 2016) including the context of the case. Selection of a typical case, and the patient population being addressed make the results and recommendations useful to other pediatric health settings serving adolescent patients. Within the Canadian health care system, pre-employment education standards for HCPs are similar, as entry to practice schools for health disciplines undergo national external accreditation. Employees working in other pediatric tertiary care settings will have similar background to the ones in this study. The patient population of focus (adolescents with scoliosis), was chosen specifically for the transferability of the results to a broader adolescent population, given their likelihood of having limited prior exposure to health services. The representativeness of this single case study to similar health centres across Canada, the use of exemplar quotes and the triangulation of data are viewed as strengths towards the transferability of findings.

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Chapter 4

Do Health Care Organizations Support Adolescent Health Literacy?: A Qualitative Case Study of a Pediatric Scoliosis Program

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Abstract

Adolescent health literacy is a complex concept and poorly understood in the tertiary care context. Organizational health literacy is fundamental to patient health literacy and refers to the responsibility of health care organizations to facilitate patient understanding of health information, access to care, and management of their health. However, little is known about how pediatric tertiary care centres operationalize their health literacy. This single case study aimed to explore health care providers' perception of adolescent HL in the context of the adolescent scoliosis program at a representative pediatric tertiary care center and to describe any gaps in organizational HL support for adolescents using a qualitative single case study design.

Eight health care providers were interviewed. They related health literacy to patient education but did not address other factors associated with adolescents' ability to navigate the health care system. The 4 patient/caregiver education documents and 4 organizational resources retrieved, did not adequately support health care providers in promoting all domains of health literacy of adolescent scoliosis patients. Pediatric tertiary care centres could play a leadership role in the development of adolescents' health literacy skills with the appropriate organizational supports.

Keywords: *health literacy, adolescents, transition, organizational health literacy, adolescent scoliosis, patient education.*

Do Health Care Organizations Support Adolescent Health Literacy?:
A Qualitative Case Study of a Pediatric Scoliosis Program

Adolescence is a time where individuals are developing many of the cognitive skills that support health literacy (HL) and establishing themselves as separate from their caregivers, thus HL is essential to their health independence (Ragelienė, 2016). HL is “the degree to which individuals have the ability to find, understand, and use information and services to inform health-related decisions and actions for themselves and others” (Office of Disease Prevention and Health Promotion, 2021). Nutbeam’s (2000) hierarchy of HL, further delineates 3 domains of HL. Functional HL refers to basic literacy skill of reading and numeracy, interactive HL is the ability to understand and communicate health information and critical HL refers to the tasks of locating credible information and using it for decision making (Nutbeam, 2000). Manganello (2008) further expanded upon these domains, introducing media literacy in her framework for adolescent HL.

Adolescents are often dismissed as not having the capacity for critical decision making, focusing on parental HL instead, but there is evidence that even young children critically appraise information as it relates to their lives (Fairbrother et al, 2016). Studies indicate that adolescents may prefer adults to make major decisions (e.g., cancer treatment) but they still want to be included by receiving information and being involved in decision making (Coyne et al., 2014). They desire more information on how treatments will impact all domains of their life and not solely information on the procedure and post operative period (Bray et al., 2012). Not formally involving adolescents in decision making, results in a missed opportunity to support adolescents to develop HL skills. Therefore, adolescents should be formally included in health-related discussions and decisions, with a focus on supporting their access to and understanding of health-related information as well as their ability to communicate and navigate the system.

Most research in adolescent HL focuses on health education and its correlation to health promoting behaviours. Researchers have found that adolescents' perceived HL status did not correlate to decision-making related to smoking or alcohol use, suggesting that factors other than simply understanding information, may be more relevant to these behaviours (Brandt et al, 2019). Instead, HL research is needed on how adolescents are supported to develop their HL is needed, as adolescents with scoliosis have reported that clinicians' use of jargon contributes to unmet information needs after attending specialist appointments (Bray et al., 2022).

Conceptualizing HL as an ongoing competency for individuals, would mean that developing this competency earlier in life may improve health outcomes long-term. Organizational HL has been defined as "the degree to which organizations equitably enable individuals to find, understand, and use information and services to inform health-related decisions and actions for themselves and others" (CDC, 2023). Health care organizations have a responsibility in supporting adolescents to develop HL. However, little is known about how health care organizations support adolescents to develop HL competence.

Examining organizational policies that affect the way adolescents interact with and are involved in their health care is one way to understand how organizations support the development of adolescent HL at an institutional level. However, organizations consist of HCPs who need to adapt their delivery of care to address the factors that affect adolescents' HL (Parnell, 2019). Exploring HCP understanding of HL and the organizational supports to assist

HCPs to build adolescent HL competency, can provide additional insight into how organizations can engage in strategies to enhance adolescent HL.

The purpose of this single case-study was to understand organizational HL of a pediatric tertiary care health centre as it relates to adolescent patients with scoliosis. To accomplish this purpose the specific objectives were to: 1) explore HCP experiences with adolescent HL in the context of the scoliosis program and 2) describe any gaps in organizational HL support for adolescents with scoliosis.

Methods

This qualitative single case study was underpinned within the pragmatic paradigm and approached with a constructivist lens. Pragmatism focuses on supporting researchers to address a problem and through their inquiry offer a solution, (Morgan, 2014) by applying various paradigm approaches and methodologies to understanding the problem (Creswell, 2003). Constructivism, with a view of knowledge being socially constructed, focuses on understanding phenomena through human experiences (Mackenzie and Knipe, 2006). Aligned with both pragmatic and constructivist approaches, Merriam's (2016) case study was used to guide this study, with a description and analysis within a bounded system.

The case consists of the concept of HL as it applies to adolescent scoliosis patients at a Canadian pediatric tertiary hospital serving a general population of approximately 370,000 children and youth. The case is bounded geographically by the scope and location of the hospital, and also clinically within the adolescent scoliosis program. The scoliosis program was selected as its patient population is largely adolescents that undergo limited but defined treatment options.

These patients have few (if any) comorbidities, meaning that they have limited previous experience with tertiary health care, therefore providing a relatively homogeneous population, with limited healthcare exposure, to focus on HL of adolescence as a developmental stage.

Sample

Purposive sampling targeting HCP from a range of disciplines and roles within the scoliosis program was used to recruit study participants and is advised for qualitative descriptive studies (Polit & Beck, 2021). The inclusion criteria were individuals who were: 1) able to read and speak in English; 2) either a front-line HCP or organizational leader; and 3) associated with the scoliosis program. Ranges of one to 15 participants are appropriate for qualitative studies collecting data from interviews and smaller numbers are deemed adequate with homogenous samples (Smith, 2003; Polit & Beck, 2021).

Recruitment

Ethics approval was received for this study from the University of Ottawa and the case hospital's research ethics boards as well as support of organizational executive leadership. Email invitations were sent to potential participants which included introductory information about the study and the contact details of the principal researcher (MF). Consent was obtained via a secure link to online consent form housed on the case study institution's secure online research platform and reconfirmed verbally at the time of interview.

Data Collection

Multiple data sources are recommended in a case study (Merriam, 2016). In this study HCP interviews and organizational documents were used as sources of data. Participants were interviewed over Microsoft Teams with the principal investigator (MF). MF is a part time registered nurse at the case organization but not within the department under study. Interviews were transcribed in real time by the Microsoft Teams software. Interview questions were informed by Manganello's (2008) framework of adolescent HL and related to HCP understanding of HL, communication with adolescents, and how HL is addressed within the program/organization, for example "what does HL mean to you?" and "what is the difference between communicating with adolescents versus adults?" The transcripts were de-identified immediately after the interview by the principal investigator and saved on a password protected computer.

Publicly available organizational documents pertaining to HL in general and patient education materials relevant to scoliosis were obtained via the hospital website. Additionally, documents identified during the interviews as resources for adolescent HL were also retrieved.

Data Analysis

Interviews

Inductive analysis of the transcripts was used, whereby categories are drawn from the data itself which allows for the description of the case as it exists (Merriam, 2009). Data is described not by *a priori* codes but instead grounded in the participants' experiences (Elo & Kyngäs, 2008). Elo & Kyngäs' multi-stepped process to inductive content analysis was used. This was an interactive process that was led by the first author (MF) who started the analysis as the interviews were conducted and familiarized herself with the data by first reading the transcript while reviewing the recordings. Coding commenced by coding words and phrases within the interview data that were descriptive or salient to adolescent HL. Once all interview data was coded, the codes were grouped onto a separate coding sheets to aid in further analysis into categories and further refine into main categories. Each step of the analysis was led by MF and reviewed by PF to ensure analysis was grounded in the data and the entire research team met to review the analysis of the main categories. These peer-debriefing meetings were used as one strategy to support trustworthiness as it assisted with reflexivity, challenged assumptions, and ensured that the findings were grounded in the data (Connelly, 2016).

Documents

Documents were analyzed depending on the intended audience of the document by the first author (MF), such that patient/caregiver educational documents underwent analysis separately from organizational resources intended for use by HCP. However, a policy offering instructions to HCP on development of patients/caregivers HL materials was compared to the patient/caregiver scoliosis educational materials retrieved to determine the alignment of these materials with the policy.

Patient/Caregiver Educational Documents. These were analyzed in three distinct steps. One step was to compare patient and caregiver educational materials with the institutional policy on the development of patient and caregiver information to determine alignment with the policy. The other two steps used specific instruments designed to assess patient and caregiver health information.

The Patient Education Materials Assessment Tool for Printable Materials (PEMAT-P). This tool was selected for its intended usefulness in appraising the understandability/actionability of printed patient-facing information (Shoemaker et al., 2013). Understandability is achieved when people (patients) of diverse backgrounds are able to explain the critical content of the information (Shoemaker et al., 2013). Actionability is achieved if people know what they should do based on the information (Shoemaker et al., 2013). The scores are percentages derived by summing the item scores for each of the constructs separately, dividing by the total possible score for that construct and multiplying by 100. A score of 70% on either construct was set for psychometric testing of the PEMAT, but Shoemaker et al. (2013) acknowledge that this score was not empirically derived suggesting that the tool is designed to make comparisons between documents and not against any particular ideal. Nevertheless, this score of 70% has been used by others to indicate acceptable understandability and actionability (Kiss et al., 2023; Muscat et al., 2021).

The Flesch-Kincaid Reading Ease and Grade level scoring system. This tool measures words-per-sentence and syllables-per-word to produce scores that reflect the reading levels associated with successfully completing the typical North American secondary grade levels (Queen's University, 2017). This score is the recommended metric to assess readability by the organization and provides an assessment parameter that is intended to equate adolescent educational development. The scores for grade reading level and reading ease were calculated using the software embedded in Microsoft Word.

Organizational Documents Intended for HCP. The documents for HCP were analyzed depending on the objective of the document. Policy documents were used to compare alignment with the patient/caregiver educational documents described above. Other documents were analyzed to determine congruency between what the participants had voiced in the interview and the documents actual intent. If appropriate, these organizational documents were also analyzed by determining if they helped HCP address the four domains of adolescent HL described by Manganello (2008), functional, interactive, critical, and media.

Approach to Enhancing Trustworthiness

Lincoln and Guba's criteria guided the approach to trustworthiness (Lincoln & Guba, 1985). Triangulation with multiple data sources (participant interviews, and organizational documents) and prolonged engagement with the data were used to support credibility of the findings (Polit & Beck, 2021; Lincoln & Guba, 1985). Confirmability, the extent to which findings are confirmed by other researchers, was supported by frequent peer-debriefing (Connolly, 2016). Authenticity is the extent to which the research represents the truth of the data and participants (Connolly, 2016). In this study, the use of exemplar quotes, ensuring that no one voice is dominant (including that of the researcher) allowed for an accurate portrayal of participant experiences with adolescent HL. Document analysis and interview results serve to provide ample data for rich description to guide the transferability of the results (Polit & Beck, 2021; Connolly, 2016).

Results

HCP Interviews

Out of 16 invitations sent to eligible participants, eight participants representing five disciplines (nursing, medicine, physiotherapy, social work, child life) and seven roles (surgeon, staff nurse, staff physiotherapist, transition coordinator, bilingual coordinator, child life specialist, institution executive) within the broad interprofessional scoliosis team were interviewed (see Table 1). All but one of the participants were female.

Table 1

Characteristics of Participants

	Years of Experience	Level of Education
Participant 1	23	Graduate degree
Participant 2	18	Graduate degree
Participant 3	8	Bachelor's degree
Participant 4	15	Bachelor's degree
Participant 5	15	Bachelor's degree
Participant 6	6	Graduate degree
Participant 7	25	Graduate degree
Participant 8	8	Graduate degree

From the analysis of the interview data, three main categories that encompass factors for adolescent HL within the organization were derived. The categories are: *Our Patients are all Different: Individual Factors*, *It's Our Job to Teach Them: HCP Factors*, and *We Need More Help: Organizational Factors*.

Our Patients are all are Different: Individual Factors

This main category describes HCPs perspectives on the individual factors for adolescents' HL. An adolescent's capacity to understand health information and their health depends on cognitive development during adolescence, parental literacy and parent involvement in health management, a deference to media and technology use, growing autonomy, and their ability to access appropriate information. Participants recognized that this developmental period required nuanced understanding inclusive of the individuality of each adolescent.

Overall, the ability to understand health information and individual health circumstances was voiced by participants to be the main outcome of addressing adolescent's HL and an adolescent's level of HL was seen as a factor that should affect the way HCPs communicate with patients. However, HL was further described by participants as an individual characteristic, with influencing factors, including developmental age, parental literacy level, language fluency, and experience within the health care system as noted by Participant 2 who stated, "It all depends on the age." Most participants agreed that HL would be lower for younger children and should increase throughout the lifespan and most acknowledge variability within an adolescent's developmental trajectory. Adolescents were described by all participants as having a greater autonomy in decision-making than younger patients, but less interest in their health and information than adults. Participant 6 illustrated that adolescents are "starting to kind of create their own idea of themselves and their own understanding of their health condition," acknowledging this developmental stage as unique but challenging, especially when it comes to an interest in their health.

Not all adolescents are the same, and variation within this population was noted by many. Participant 3 was representative of how participants viewed HL amongst adolescents, "Not everybody's at the same level. So… not every 16-year-old would have literacy at the same capacity." However, it was more than literacy that influenced HL variation amongst adolescents. Personal interest had a role as voiced here by Participant 2 as they describe this unpredictability, "You know our patients, are quite variable in their level of interest in their health conditions."

The intersection between adolescents' HL and parents as proxy decision-makers was thought by HCPs to be a complicated space for communication. Several participants were discouraged by how adolescents are spoken over and around in conversations about their health, and wondered if this was a habit generated in pediatric practice. Participant 4 saw this as an area for improvement: “Um, often I see people talking to parents and not teenagers, so I think we can do better there.” Although parents were primarily seen as facilitators to adolescent health, it is noted that parents can equally be a barrier to the development of independence which may put the adolescent at a disadvantage as voiced here by Participant 8. “And then that kind of gives them a little bit of a deficit just because then they don’t get the opportunity to build those skills and build that education themselves.”

Two participants acknowledged that the context of communication can influence a person’s HL status. Participant 8 stated “It really depends on the parent and the child’s coping in terms of how much health literacy they have,” referring to the challenge of digesting information when dealing with stressful diagnoses or environment. Due to stress or time constraints, the healthcare environment can act to take away a person’s usual functioning and skills, as described by Participant 4.

> So, it’s literacy and then it’s health literacy, which is using bigger words that they don’t understand. Often I think everyone Googles things, but in a conversation or a document, I don’t know how often you have the time to Google it [meaning of medical terms]. So, I think you’re [HL] level is lower.

Although other HCPs understood that taking extra time with patients was important, they did not acknowledge the way circumstances can affect one’s ability to digest information.

Digital media technology was thought by many of the participants to be a facilitator to communicating with adolescents. That adolescents are “always on their phones,” as mentioned by Participant 4, was representative of participants’ feelings that adolescents preferred to engage with technology over interacting with HCPs or traditional documents, but no one was able to articulate examples of successes in this approach. Participant 6 expressed concern related to the safety of online information, and “Dr. Google”, acknowledging the unreliable information accessible to adolescents on the internet. Indeed, a general bewilderment regarding the best application of digital media was perceptible across interviews, and an inability to keep up was illustrated by participant 1, “So I laugh about the TikTok and our lack of ability to use TikTok, when that might be the platform. But again, … as soon as we’re on TikTok, they’re not going to be on TikTok.”

Absent from most interviews was discussion of challenges related to access to health services or information. Some participants described adolescents as not having the knowledge of how to adequately find health information, as stated by Participant 8 “And part of it would be access. So how would they access those things and how do they typically look for support and or resources?”, but only two participants brought up concerns of inequity which speaks to the individuality of adolescent patients. Participant 2 addressed this, “We don’t necessarily ask patients and families if they have access to your computer and reliable Internet, so we may be giving them these resources and they may not have the means to actually follow up with them and learn,” Participant 3 raised the challenges of language barriers “also language, of course needs to be considered. So what’s their first language?”

It’s Our Job to Teach Them: HCP Factors

This main category encompasses HCPs perceptions of how their role influences or is influenced by adolescents’ HL, which was supported by participants description of their role in educating and communicating and their difficulty in engaging adolescents to participate in their care. An adolescent’s HL was described as a fixed status to which HCP needed to adapt. Overwhelmingly, they struggled with engaging adolescents in their health care.

All participants described some type of patient education as part of the HCP role in HL. They shared a focus on providing information to adolescents to increase their knowledge of their specific condition (e.g., scoliosis), and many spoke to the different communication strategies utilized with adolescents, particularly the need to make things simpler, and more relatable to this population. They provided examples of pamphlets or reliable external internet resources that scoliosis patients receive and emphasized taking more time to ensure patients’ understanding. Overall, participants were satisfied that the education they provided to patients was appropriate, and that adolescent HL was being addressed in this way.

Across interviews, participants were explicit about the need to engage adolescents in conversations about their health care. Specifically, it was seen as an aspect of their HL that differed from adults and as a specific challenge. Several participants mentioned difficulty getting adolescents’ attention and using techniques to make the interaction more “fun” as expressed here by Participant 4, “Engaging them, I think. It’s tough to get people’s attention these days. So, [using] something that they can relate to.” Participants mentioned that adolescents lack forward thinking, resulting in less interest in activities that promote recovery and creating a barrier to engagement and communication. Participant 6 agreed, and spoke of trying to leverage the adolescent’s own interests as opposed to notions of long-term health as an engagement strategy, “so trying to relate something to an interest that they have. So we have to do this [physio] so that you can do this [basketball] again.”

Establishing trust was thought by one participant to be a particular challenge with adolescents, making it more difficult to build rapport. “I think a lot of young people don’t automatically trust health care workers. You almost have to spend a little bit more time” (Participant 5). Building rapport and making connections were common topics across the interviews and are seen as important factors in HL of adolescent patients. Participant 6 explains that with younger patients this may take more time, “I mean you have to build rapport with everybody but, you might have to spend some more time with it with an adolescent than you do with like an adult, I would say.” Illustrating an understanding that relationship building, key to engagement and communication, was not only part of improving a patients’ HL but was also their responsibility as HCPs.

We Need Help: Organizational Factors

We Need Help speaks to the need for strategies and supports at the institutional level that would help adolescents and HCP in building the HL capacity of adolescents. HCPs described barriers to promoting adolescent HL as well as additional HL resources that could be beneficial at the organizational level. The most significant organizational role presented was the provision of oversight and resources. Specifically, educational documents are put through an approval process (existing policy) prior to being distributed (see document analysis), and although the frontline HCPs were aware of this process they either were unclear on its details and/or found it to be a barrier. Those who were well acquainted with the process voiced frustration. The purpose of this policy was noted by participants to be an assurance that patient education was at the appropriate reading level. “We also have somebody who reviews all of our stuff to see what kind of [grade reading] level we’re at. And if we’re at like a grade 6, I think is what it’s supposed to be" (Participant 5). Although only Participant 2 stated that, "I can't say we've received any kind of feedback, you know, advice in terms of how to deliver a better [patient education document] or you know to improve our writing style and level of writing," when speaking of this process, the other participants did not describe benefits outside of a ensuring the reading level was in keeping with the policy.

Participants described adolescents as preferring non-traditional delivery of health information, favouring digital resources. Participant 6 explains, "written communications aren't always helpful, especially for adolescents. Um, who may need some visual feedback as opposed to just a phone call or just an in-person assessment or written information, that sort of thing." Other participants echoed this sentiment but as Participant 4 states, the examples they provided of patient education materials available include only pamphlets or websites with written information. "We've got information, booklets, handouts in various languages and they're all, I believe at a certain base reading level." This illustrates a disconnect between organizational resources and what HCPs need to support adolescent HL.

Other organizational resources mentioned, were those that support adolescent HL more broadly (e.g., across health care conditions and programs). One was the Youth Advisory Council (YAC) which is a group of volunteer youth who serve on a hospital level committee about and for youth. Although few participants were familiar with the function of the YAC, they were aware of their existence and thought they were relevant to HL. Participants voiced that patients with lived experience could be valuable in supporting HL amongst adolescents, but these comments were general and unspecific as exemplified here by Participant 3 "[for material] specifically directed to youth or teenagers, maybe the [Youth] Advisory Council would be involved." There was one mention of direct peer education as a potential organizational resource, but this participant was not specific about how this would occur.

Although adolescents with scoliosis will inevitability transition to adult services, and participants identified transition tools as organizational HL resources (e.g., Readiness Checklist and 3 Sentence Summary), no participants expressed having used these documents. Participant 1 confirmed that they are not broadly accessed,

> Our hope is that our health care providers would do that [use the checklist]. But we also know from our research and from scanning the readiness checklist on Meditech [electronic patient record] that we don't have huge uptake on the use of that readiness checklist.

In two of the interviews, participants queried whether the organization should have an active role in supporting HL of adolescents in the broader community.

Participant 1 asked,

> So what is our role? In terms of that health literacy piece on an individual patient basis, but also sort of more broadly as a trusted voice in pediatrics. And what's our role sort of more broadly in terms of adolescent health literacy? And I don't know that we've, stamped that as something that is our role.

Participant 7 articulated a similar question, related to the organizational role,

> For me, the only thing I would probably say is. We should probably do a better job at partnering with our provincial stakeholders … because we don't see all adolescents. So, I do think that we should … be more partnered and uniform in what we're doing [about HL in general]. Like what I think are we doing well? Probably we're doing well, but could

> we be helping them [provincial stakeholder] being advocates and leaders in it, probably we could be doing that better.

Compared with other participants who were directly on the scoliosis care team, these two participants had roles that crossed programs, requiring them to reflect on programs across the organization and beyond. As such, they articulated a broader conceptualization of HL to include some navigational factors.

Document Analysis

In total, eight documents from the organization's public facing website were reviewed. (Table 2) Four were patient/caregiver education materials, of which two were education about scoliosis for adolescents (Patient Passport and Physiotherapy guidelines) and two were education materials for caregivers (Scoliosis pamphlet and Scoliosis webpage). The other four documents were intended for HCP and thus analyzed as organizational level documents. Of these four, one was the organizational policy on development of patient information materials and three were identified by participants during the interviews (two were tools for HCPs to use with adolescents transitioning to adult care, and one was the 'about us' webpage for the Youth Advisory Council)..

The two documents targeted at adolescent patients, had multiple versions each (postoperative timing of activities varies based type of procedure and surgeon preference). The wording, formatting, and presentation amongst versions were the same, resulting in identical readability, understandability, and actionability scores. As such, these documents (Patient Passport, which has 2 versions, and the post-operative physiotherapy guidelines, which has 5 versions) were analysed as one.

Table 2

Documents Included

Title of document	Type of document
Scoliosis (downloadable pamphlet)	Caregiver education
Scoliosis (webpage)	Caregiver education
Physiotherapy after surgery (5 versions)	Patient education
Patient passport: scoliosis surgery (2 versions)	Patient education
How to create patient/family learning resources (patient guides): Criteria for staff	Policy
Readiness Checklist	Chart form (transition tool)
My Health 3 Sentence Summary	Patient education transition tool
About Us: Youth Advisory Council	Website

See table 3 for the readability, understandability, and actionability analysis of the scoliosis patient and caregiver educational materials. Two patient educational materials scored within the grade 6 level and were rated as more understandable (PEMAT-P score 71-77%), when compared with the two materials for a caregiver audience which were grade 6-10 level and PEMAT-P understandability scores of 66-69% (see Table 3). The post-operative resource(s) by physiotherapy had high actionability PEMAT-P scores (90%).

The PEMAT-P analysis also found that language was easy to read but sometimes lacked clarity of content. For example, the Passport (which is a document that provides information to adolescents with scoliosis on what to expect) refers to "lines and tubes" but does not always make explicit what these could be or where they would be in one's body post operatively. Despite scoring well on all metrics, the physiotherapy pamphlets state that 2 kilograms is the maximum weight to be lifted after surgery, but it is unclear if most adolescents can imagine how much weight this represents or what they would be lifting in their everyday lives that would be approximately 2 kilograms.

Organizational Documents for HCP

The organizational policy outlines the procedure for submission and approval of patient targeted educational materials, and mainly addresses details related to format or process. It provides examples of plain language, active voice, medical jargon, and recommends use of instructive images. It does not address specific considerations for young audiences, nor does it explicitly refer to HL. It recommends a Flesch-Kincaid score of grade 6 to 8 reading grade level but it does not mention any other structured assessment such as PEMAT-P scores for patient and caregiver materials. In terms of the alignment of the patient and caregiver scoliosis educational documents with the organizational policy, the two parent targeted documents were above the recommended grade 6 to 8 reading level (see Table 3) and only one of these contained one informative image. The text for the adolescent materials was lengthy with one document being 11 pages, and no use of informative imagery. All of the documents were text heavy. See table 3 for details of the patient and caregiver education and alignment with the organizational policy.

Table 3

Patient and Caregiver Educational Documents

	Purpose	Targets	Length (pages)	Visual Cues	Imagery	Access	Version Date	Flesch-Kincaid Scores		PEMAT-P Scores	
								Reading Ease *	Grade Level	Understandability %	Actionability %
Recommendations of Policy			**N/R**	**N/R**	**Only if relevant**	**N/R**	**Review every 3 years**	**N/R**	**6-8**	**N/R**	**N/R**
Scoliosis Website	A	Caregivers	1	Headings, Bullets	None	online	2023	59.5	9.9	66.7	40
Scoliosis Pamphlet	A	Caregivers	2	Headings, Bullets	1 image, illustrative	clinic handout, hospital website	04/2021	52.7	9.9	68.75	0
Patient Passport	B	Adolescents	11	Tables, section headings, text boxes, bolded text	None	clinic handout, hospital website	01/2022	60.4	6.6	71.4	40
PT Post-operative	B	Adolescents	4	Headings, bullets, bolded text	2 images, decorative	clinic handout, hospital website	2019-2020	67.7	6.4	76.5	90

A = Information on diagnosis
B = What to Expect
N/R = No recommendation

The other three organizational resources intended to be used by HCP and identified by participants in the interviews, were assessed for congruency between the resource's content or intent and the participants voiced beliefs representing the 4 domains of adolescent HL described by Manganello (2008), functional, interactive, critical, and media. One of these was a 17-item, 'readiness checklist' (identified by participants as being a resource for HL) is a patient chart form, designed to be completed by HCPs with adolescent patients. Of the readiness checklist items, 1 addressed functional HL, 11 addressed interactive HL, 4 addressed critical HL, no items addressed digital or media HL, and 1 item did not directly address HL. The second resource was the 3-Sentence Summary tool which addresses interactive HL. The third resource, the Youth Advisory Council webpage described 'what we do' and was consistent with HCPs interpretation, that they (the Youth Advisory Council) could (not should) consult on a number of issues including patient education resources.

Discussion

This single case qualitative study captured data from interviews with HCPs and documents to gain insight into organizational HL in the context of adolescents with scoliosis. Findings from interviews suggest that frontline HCPs see the topic of HL for adolescents as it relates to patient education. These clinicians traditionally see patient education as part of their role in the provision of health care, and although all participants describe patient understanding as the primary feature of HL, their comments about the topic were largely limited to the unidirectional delivery of disease or situation specific information. A focus on disease knowledge as the essence of HL, speaks to a traditional worldview from within a medical model of care, where patients are more passive participants. The document review supported the focus on disease knowledge as the scoliosis patient fronting information did not address additional aspects of HL.

Consistent with the literature was the finding that social media and media literacy are viewed as particularly relevant to an adolescent population but participants in this study viewed leveraging adolescent smartphones as an out-of-reach portal to connect with them. This notion that social media is relevant to adolescents seeking health information is not new, and there is consensus that adolescents seek health information via online sources (MacKinnon et al., 2020) A study of late-adolescents’ (18-21years of age) eHL found that although 94.6% of participants used their smartphone to access health information, the majority did not use health specific applications to engage with their health; instead they used search engines like Google (Masilamani et al, 2020). Moreover, these researchers found that even older adolescents have trouble discerning the credibility of online sources, making it unclear how helpful social media is to supporting HL of adolescents (Ghaddar et al, 2012). In our study, HCPs were unsure of how to reach adolescents via social media platforms and were concerned about how to harness these resources to deliver information. As other studies have suggested, a change of focus to the promotion of HL behaviours, including the discernment of source credibility, could result in adolescents being better able to use and navigate health information (Freeman et al., 2020). Freeman et al. (2018) described adolescents as lacking the skills to formulate appropriate searches and being wary of the overwhelm of information and also unskilled in the ability to assess sources, often favouring relevance of content (closeness of information to their own concerns) over accuracy. Freeman and colleagues found that adolescents do not necessarily trust internet sources, but are likely to use them anyway, and so like the participants in our study expressed, it is important to address this aspect of HL with this population. It was unclear from our study if there are organizational supports is in place for HCPs who want to promote these skills in adolescent patients.

This study provides insight into the organizational gaps between frontline providers and HL resources available to support their patients. Many of the participants described adolescents as having different communication needs than adults. They proposed visual or digital methods of teaching, suggesting that too much reading could be cumbersome for young patients. Yet research identifies that all demographics benefit from lower text volumes, instructive imagery, and the use of plain language, and so this is not what makes adolescents a unique population (Liang & Brach, 2017). Even so, the resources available within the scoliosis program are incongruous with these observations from HCPs as well as with the policy from their organization. Although the adolescent resources scored above 70% for understandability, they are long, text heavy, and lack instructive images, requiring readers to be self-directed. Minimally, making adjustments to these documents to follow a universal precautions approach (meaning that it is assumed that all patients may have difficulty understanding), could benefit patients, and organizational resources ought to facilitate that (Liang & Brach, 2017). From the interviews conducted, it is apparent that the organizational oversight (e.g., policy on developing patient information) of this issue is seen as a barrier, not a facilitator of patient HL given the minimal development support provided with this resource.

HCPs in this study wanted their adolescent patients to understand about their health condition and participate in their care but felt that their developmental age made them difficult to engage. The emphasis on the need to spend more time with these patients, and the importance of finding ways to engage them in their care speaks to an understanding of this population even where the nuances of adolescent HL are not expressly articulated. This is important, as the current research in adolescent HL, often focuses on health behaviours as measurable outcomes of HL (Brandt et al, 2019; Lindfors et al., 2019), and while it is a goal to have adolescents make healthier choices, HL is about the ability to manage health decisions and navigate health systems (Nutbeam, 2000). This study instead highlights a need to have adolescents actively engaged in their health care, which can be seen as both a sign of increased HL, and as a means to develop it.

Participants aptly identified HL resources related to transition, two closely correlated concepts. Findings in this study echo others, that found that well-intentioned HCPs are not skilled at assessing adolescents' HL or transition readiness and may not have a fulsome understanding of these concepts (Huang et al., 2012). Huang et al (2012) found that HCP over estimated HL-related transition readiness of adolescent patients by 37%. HCP on the scoliosis team did not utilise the transition resources to promote the HL of their patients, despite their knowledge of them, possibly because they did not adequately assess the need. Chisolm et al. (2021) found that HL was independently associated with transition readiness in adolescent patients and correlated with appropriate use of medical services. The concept of transition readiness is generally associated with highly medicalised, chronically ill patients, but all adolescents, will be required to navigate adult health systems at some point. Adapting HL focussed transition theory and tools to the general population could promote a more health literate generation overall, and patients with scoliosis are a good example of a missed opportunity to develop these skills.

Health literate organizations are those that implement strategies to make it easier for patients to understand and navigate their health care needs (CDC, 2023). Bray et al, 2022 described several ways to facilitate HL for patients coming to scoliosis clinic appointments. Their findings indicated that having resources available to prepare adolescents for clinic prior to their visit would facilitate participation and communication. An approach to HL that is pre-emptive focusses on building skills and empowering patients to ask the questions that are important to them. This is consistent with findings from the current study, where participants placed emphasis on the challenge of engaging adolescents in conversations about their health, and also that developmentally these patients may require more time to process information.

Findings from this study suggest that specific organizational resources directed at fostering HL, in addition to the need for understanding disease related information of patients, across the adolescent population is needed by organizations interested in improving their organizational HL. For example, in this study the hospital website provides information about scoliosis etiology, and links to other credible online sources, but could provide interactive resources related to a clinic visit and preparing questions and concerns. This study suggests that organizational support be implemented to assist frontline HCPs in promoting the HL of adolescent patients and ensure they are well informed about organizational resources (e.g., how to use transition tools for all adolescents, consulting with YAC) that already exist. Ongoing HCP education about HL is also warranted given the focus on patient education as the main component of HCP role in supporting HL of adolescents.

Limitations and Strengths and Future Research

One limitation of this study was that it did not include adolescent patients within the scoliosis program due to the focus on organizational level HL factors. However future research should harness an adolescent perspective for their broader HL needs (apart from health condition education) that could be supported by an organization. However, a strength of this study was the detailed description of the case and the patient population being addressed to make the results and recommendations more transferable to other pediatric health settings serving adolescent patients with scoliosis. For example, within the Canadian health care system, pre-employment education standards for HCPs are similar, as health disciplines undergo national external accreditation and thus HCPs working in other pediatric tertiary care settings will have similar background to the ones in this study. Future studies should explore differences across programs at the same institution to have a more comprehensive understanding of how adolescent HL is actioned within an organization. In this pediatric health care institution, HCPs were versed on patient education as it relates to HL but limited in their broader understanding. Thus, research that links organizational strategies to support HCPs in their work with adolescents is needed to determine content and process of effective strategies.

Conclusion

Although HCPs in this study had a limited view of what HL entails, they wanted to engage adolescents with scoliosis in their health care. They focus on disease specific education but struggle with having the resources to promote a more fulsome HL development in their patients. There is an opportunity to support HL amongst adolescents with health care conditions so that they can fully engage in their health care throughout their lives. Organizational supports are needed to build HL capacity amongst adolescents and clinicians need help to leverage the supports that are in place. Future research should explore differences across programs within the same institution and the perspectives of adolescents themselves.

Declaration of Interest Statement

The authors of this study have no conflicts of interest to declare.

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Chapter 5

Integrated Discussion

Integrated Discussion

This thesis consisted of a literature review and single qualitative case study design to explore adolescent health literacy within an organizational context of an adolescent scoliosis program. The Adolescent Health Literacy Framework (AHLF) was used to inform the literature search and the case study as it includes individual factors that impact four domains of adolescent HL (functional, interactive, critical and media), and acknowledges that societal systems factors (e.g., education, health care) have a role. The literature review revealed that adolescents want to understand their health and treatment and to have an active role in their health-related decisions. However, this inclusion is seldom accomplished or is implemented in a superficial manner. The literature review revealed a gap in research, where studies mostly captured data reflective of functional HL (literacy and numeracy) without as much attention to interactive or critical HL. Adolescent research also tends to focus on media (digital) HL with studies revealing that despite the ubiquity of health information on the Internet and the frequency of engagement with online environments and social media, adolescents were not savvy consumers of the plethora of information. These findings suggest that organizations that specialize in pediatric care could and should play an active role in building HL capacity amongst adolescents.

Using a single qualitative case study design, this thesis sought to explore health literacy (HL) of adolescents from the perspectives of health care professionals (HCPs) within a pediatric health care setting, and the organizational resources available to support them. Organizational health systems, similar to educational systems, need to support the development of the four domains of adolescent HL. The case was bound by both organization (representative of a typical Canadian tertiary pediatric health care centre) and specific health care program (adolescents with scoliosis) representing a more homogenous adolescent population to focus on the concept of adolescent HL within a pediatric health care centre. Documents that support adolescent HL as well as individual organizational HCP interviewers formed the modes of data collection. Eight documents were retrieved and analyzed, and eight HCPs participated in the individual interviews. HCPs are the implementers of health resources and thus this study adds to the literature by illuminating some ways that HCP are well positioned to promote the HL of adolescents as well as how organizations can improve structures and processes to support HCPs in this work with adolescents, in light of the literature.

Based on the findings from the literature review and the case study, this chapter will present several points for discussion. First that HCPs are clear that their role in the provision of care includes providing education to patients, but they lack a depth of understanding of the complex concept of adolescent HL. Second, patient education materials do not meet best practice standards, despite HCP being able to identify certain characteristics that would improve them. This points to a disconnect between HCP values and organizational supports to address them. Third, HL should be seen as more than an ability to understand health information, but as a capacity that can be actively supported and developed in adolescence. Finally, that there is an organizational responsibility to promote the HL of patients, including adolescent patients in health care settings. This chapter will also present recommendations for future research, implications for practice, and for nursing.

Main Case Study Findings

All eight participants in this study defined HL as an ability to understand health information and circumstances. A few participants expanded this definition to include other aspects of HL including, navigation, access, and participation in care, but broadly, HL was seen in terms of patient education of disease specific information and experiences. This is consistent with the aspect of interactive dimension of Nutbeam's (2000; 2008) HL model, that pertains to comprehension, but not communication. The critical dimension of HL, which is involved in using information for decision making, was addressed mostly in terms of adolescents' ability to find information in a safe manner, and only by two participants. Manganello's (2008) addition of media (digital) HL to Nutbeam's (2000) HL model was discussed by most participants, focusing mostly on the challenge of harnessing digital platforms to support adolescent HL. Interviews with HCPs addressed three main categories related to adolescent HL in the health care setting: (1) the individual factors for HL, (2) HCP factors for HL, and (3) the organizational factors for HL.

Individual Factors

Overall, participants in this study see HL as an individual characteristic, one that is largely related to developmental age, and personal interests. Individual factors for HL of adolescents included personal characteristics including patients' developmental age and capacity for understanding, use of digital media, and overall interest in their health. They described caregivers as proxies for adolescent communication and noted that this can both facilitate and hinder a patient's HL. The stage of adolescence was identified as being an important time for establishing personal autonomy, which HCPs described in terms of individual development.

HCP Factors

It was in relation to patient education that participants described professionals' involvement in adolescent HL. They agreed that communication styles may be different for this population compared to adult populations and that they may use simpler words or images to help explain conditions or situations for patients. There was relative consensus that engaging adolescents to participate in their care was both necessary and challenging for HCPs, noting that adolescents were not always interested in the information they needed to share with them. HCPs noted that adolescent HL levels were affected by this perceived disengagement. Many participants thought that social media or digital media could be utilized to reach adolescents, through means that were relevant to them, but a palpable bewilderment was present throughout interviews as to how to implement these technologies.

Organizational Factors

Participants in this study had limited knowledge of organizational resources for HL. Particularly frontline providers stated that the supports in place for developing patient education materials (organizational policy) were more of a barrier than a facilitator, and reported having received no feedback from this process in terms of best practice or opportunities for improvement. Participants were able to identify a variety of resources they felt promoted adolescent HL, such as the Youth Advisory Council (YAC), transition tools, and collaborating with patient advisors, but few were able to describe the practical function of or ways to access these resources.

Document Findings

There was one overall organizational policy on developing patient and caregiver facing documents. The policy focused mainly on the process for registering the education material, as well as having some suggestions on how to achieve the appropriate reading level for patients (or caregivers (North America grade 6-8 reading level). Four patient education materials (two for patients and two for caregivers) for the scoliosis program were collected and found to have varying reading ease and grade-level scores, with those aimed at adolescent patients scoring around a North American grade 6 reading level. The PEMAT-P analysis found that while the patient educational materials were easy to read, they were not necessarily easily understood and lacked illustrative images to promote comprehension and actionability. Participants identified several transition tools as resources of organizational supports for adolescent HL and these documents did address interactive and critical HL as well as functional, but did not address media HL. However, these tools were not broadly utilised in practice and thus their usefulness in building adolescent HL is limited.

Adolescent Health Literacy

Findings from this study show that frontline providers equate HL with health education and the delivery of information to patients. Despite this, they acknowledge that spending more time with adolescents and engaging them in their health are important factors in providing them education, which in turn addresses HL. Taking into account the accepted definitions from the literature, and these observations related to adolescent development, it may be beneficial for organizations and HCPs to reframe their conceptualization of HL for adolescents (Peralta et al., 2017). HL should be seen not as a static state, or an individual characteristic, but rather a capacity that can be progressively developed. For adult patients there may be greater value in point of care adaption to HL status, but adolescent patients are primed for skill building due to their developmental stage, and the backup of presumed caregiver support, so that should be the goal (Bray et al, 2022).

Health Education and Health Literacy

It is not unique to the participants in this study to conflate health education with HL. Indeed, much of the literature relating to adolescent HL comes from the education discipline (Peralta et al., 2021; Smith et al., 2021; Khanal et al., 2023). There is certainly a link that has been well demonstrated, where efforts to address HL in education settings, have made a perceptible difference to HL skills of adolescent students (Peralta et al., 2021; Hughes & Maiden, 2018). It is also true that patient education and an adolescent's ability to understand disease specific information will be affected by their HL. However, HL is a complex concept, that has many influencing factors and outcomes, and this study demonstrates that HCP may have a limited understanding of this concept. HCPs could benefit from HL focused professional education strategies to support them in their care of adolescents' health. This type of education has been poorly investigated, and there are few examples of professional development that aims to improve patient HL (Connell et al., 2023). A preliminary study involving a small cohort of occupational therapists, revealed that direct workshops to improve HL efficacy amongst HCP was useful in improving self-perception of skills amongst the participants (Koenig & Provident, 2019). Notably, this study was based on self-report measure and used a pre-test post-test approach to assess knowledge improvement. It is unclear if a more comprehensive understanding of HL results in HCP practices that increased HL capacity building with patients. Although more research is needed, it is likely that a more informed workforce, could benefit outcomes as without awareness of the need for change, change is unlikely to occur. HCP participants from the scoliosis team in this study, did not know of any professional development available to improve their efficacy in addressing patients' HL suggesting an area where organizations can take leadership and first steps at improving organizational HL.

Engaging Adolescents in their Health

Building rapport and making connections, both thought to be important by HCPs, are factors that are suggestive of a holistic understanding of HL that goes beyond basic functionality. Participants cited difficulty engaging youth in conversations about their health as a major feature of adolescent HL and a subsequent barrier to health communication with this population. They were clear that maintaining trust and attention from adolescents was important and their responsibility, but struggled with describing strategies that work to achieve this goal. Interestingly, there are examples from the literature that suggest that adolescent patients value HCPs who support their independence more than attempts at engaging them in their care (Siembida et al., 2018). The difference between these two concepts is certainly nuanced, and perhaps adolescents in the Siembida et al. study did not interpret 'engagement' in the same way as HCPs. However, the message is clear: adolescents value their developing autonomy, and HCPs should promote that. These findings support a shift to focus on adolescent HL capacity building, to foster independence in managing health issues and away from solely educating them about their condition. They felt that adolescent patients may have less inherent interest in health information. However, the important point may not be to have adolescents interested in their health condition, but rather to address the things that they are interested in, in order to build a capacity for decision making and navigating the health system, thereby fostering independence.

Appropriately, participants defined HL as a capacity to understand health information and having knowledge of one's health overall. Interestingly, no participants in this study correlated

HL to patient health outcomes, even though previous researchers have used adolescent health behaviours as a means of measuring the effect of HL on health (Fleary et al., 2018). This suggests these HCPs may not associate HL competencies as important to one's overall health status, at least not for patients at a young age. The association between HL and health outcomes is not well established in the literature, where varying degrees of influence have been found (Lindfors et al., 2019; Brandt et al., 2019; Chisolm et al., 2014). As such HL ought to be considered an outcome, in and of itself, where informed decision making is the goal.

Adolescents and Media Literacy

Participants in this study described social media as being ubiquitous with this young generation, which has been a consistent theme in HL literature over the past two decades (Manganello, 2008; Levin-Zamir et al, 2011). They suggested that adolescents primarily retrieve information from their mobile devices and that learning to connect with them in this way may be the most beneficial way to provide health information. Adolescents' skill in using online modalities may be seen as greater than that of their adult HCPs, which presents a barrier to communication with this population. Participants in this study expressed difficulty in knowing how to overcome this challenge. This dilemma may have multiple facets, because while it is important to address the technology used by this generation, it may distract from the fact that the HL of adolescents is not adequately supported in the first place.

HCPs in the current study were unsure of how to reach adolescents via social media platforms and were concerned about how to harness these resources to deliver information. As other studies have suggested, a change of focus to the promotion of HL behaviours, including the discernment of source credibility could result in adolescents being better able to use and navigate health information (Freeman et al., 2018; McKinnon et al., 2020). Freeman et al. (2018) described adolescents as lacking the skills to formulate appropriate searches. They were described as being wary of the overwhelm of information but unskilled in the ability to assess sources, often favouring relevance of content over accuracy (Freeman et al., 2018). Taba et al. (2022) found that adolescents do not often discuss their own search results (internet searches), with their HCP. This suggests that HCPs ought to include this in their assessments, if HL is to be considered part a person's overall health status.

The notion that social media is relevant to adolescents' health information seeking behaviour is not new, and there is consensus that adolescents seek health information via online sources (MacKinnon et al., 2020). Although many health specific applications have been developed, in an attempt to improve self-management for individuals, adolescents broadly employ simple search engines, like Google to access health information (Masilamani et al., 2020). Indeed, in their study of late-adolescents' (18-21years of age) Masilamani et al. (2020) found 94.6% of participants used their smartphone for this purpose. Moreover, other researchers have found that even older adolescents have trouble discerning the credibility of online sources, making it unclear how helpful social media is to supporting HL of adolescents (Ghaddar et al., 2012). Taken together with our findings that HCPs are unsure of how to leverage social media, an over reliance on social media and technology by health care organizations may not be as effective as desired in improving adolescent health outcomes. An assumption that adolescents are media literate, could lead health care organizations to waste resources on unused social media, and media applications.

Websites recommended by trusted professionals were found to be more highly considered by adolescents in some studies (Holmberg et al., 2019). Therefore, HCPs in tertiary centres are well positioned to be promoting this aspect of adolescent HL. Participants in our study acknowledged the issues related to online safety and the vast array of unregulated information available on the internet, and so it should be seen as HCP responsibility to promote adolescents' skills in managing this resource and suggesting a selection of credible sources. Furthermore, organizations may have an opportunity to set standards for such recommendations and include this in the orientation for their employees. That all people, including adolescents, will gather health information from internet sources, is a reality that ought to be factored into health care delivery.

A general bewilderment with ever-changing technology was apparent in our study, as one participant aptly described the inability to keep up. It is possible however that the issues professionals have in communicating with adolescents predates modern social media applications. It is clear from HCPs that they are interacting with a wired generation, but it seems likely that an approach to adolescent HL that promotes two-way communication and critical thinking, will translate to whatever methods patients use to find the information they require and that it may be less important that providers try to master the technology themselves.

Resources Do Not Reflect Health Care Professional Values

Across interviews, participants of this study identified ways in which communicating with adolescents ought to differ from communications with adults. They recommended simpler language, and the use of images as important for adolescents' understanding as well as lower text volumes, suggesting that too much reading could be cumbersome for young patients. We know from the research, that these are strategies, long established, that should be employed for communications with all populations (Safeer & Keenan, 2005; Liang & Brach, 2017). In fact, these best practices were outlined in the policy that was reviewed as a part of this study, one that most participants were able to identify. However, patient education materials fell short of meeting these standards, despite what appears to be broad acknowledgement of the necessity of doing so. This is an indication that the organizational resources in place for maintaining best practices (e.g., policies) may be ineffective at supporting frontline providers in their delivery of patient education if no additional organizational resources (e.g., training, editing, feedback) are available. This challenge is not unique, as others have found that HCPs and organizations are both likely to misinterpret the reading level and accessibility of patient education materials (Hadden et al., 2017). Moreover, over reliance on grade level reading scores of materials (based on syllables and word count) is not an assurance that one understands unfamiliar content.

The education materials available within the scoliosis program are incongruous with these observations from participants. The documents are long, text heavy, and lack imagery that promotes understanding, requiring readers to be self-directed. Minimally, making adjustments to these documents to follow a universal precautions approach (meaning that it is assumed that patients will have difficulty understanding), could benefit patients, and organizational resources ought to facilitate that (Liang & Brach, 2017). From the interviews conducted, it is apparent that the organizational involvement (e.g., policy on developing patient information) of this issue is seen as a barrier, not a facilitator of patient HL, so either there is a lack of support provided in using this resource or HCP have an incomplete understanding of the process and best practices. Either way, there is clearly a disconnect.

Building Capacity

As we know from HL literature, an emphasis on reading and comprehension dominates both the research and the focus of health care interventions (Fleary et al., 2018). Interactive HL, which includes both understanding and communicating, and critical HL, which involves using health information to make decisions, are underdeveloped areas in the adolescent population. Additionally, although media HL is promoted amongst this population, adolescents have been found to be naive in their use of online resources to find health information (Ghaddar et al., 2012). Developing these cognitive skills, would undoubtedly improve patients' ability to manage their health long term. However, HCPs and organizations need to make deliberate choices to assist adolescents in doing so.

Bray et al. (2022) described several ways to facilitate HL for patients coming to scoliosis clinic appointments. Their findings indicated that having resources available to prepare adolescents for clinic appointment prior to their visit would facilitate participation and communication. An approach to HL that is pre-emptive focusses on building skills and empowering patients to ask the questions that are important to them (Bray et al., 2022). This is consistent with findings from the current study, where participants placed emphasis on the challenge of engaging adolescents in conversations about their health partially due to adolescents not being concerned about the long-term outcomes, and that developmentally these patients may require more time to process information. As such, specific resources directed at fostering HL, in addition to the need for understanding disease related information of patients across the adolescent population is recommended.

Transition Readiness

It could be argued that the concepts of transition readiness (transition to adult care from pediatrics) and HL, are nearly interchangeable, so it is not surprising that when asked about HL resources within their organization, most participants in this study identified transition tools. Findings from this study suggest that HCPs do not have a fulsome understanding of either concept, which is in keeping with results from other studies (Huang et al., 2012). Huang and colleagues' (2012) findings, that HCPs overestimate patients' transition readiness by 37%, could be related to the underuse of transition tools identified in our study. These tools are not broadly utilised at the case organization, and not in the scoliosis program specifically, which may reflect an inability to accurately assess patients' HL or transition needs.

The correlation between HL and transition readiness was studied by Chisolm et al (2021), who found an independent association between the two concepts for adolescents. Higher HL was positively correlated with appropriate use of medical services, demonstrating not only a readiness for more independence for these patients, but incidentally, a reduced burden of the health system as well. Although transition readiness programs and tools are generally reserved for patients with chronic medical needs, as exemplified by the case institution from our study, it should be acknowledged that all adolescents will graduate from pediatric care, whether they were frequent users of the system or not. HL focussed transition theory and tools should be adapted to meet the needs of the general population, to promote a more health literate generation overall. Patients with scoliosis represent a missed opportunity to promote these skills.

Organizational Responsibility

Health literate organizations are those that implement strategies to make it easier for patients to understand and navigate their health care needs (CDC, 2023). With an ongoing crisis of primary health care in this country, more than ever opportunities to improve access and health promotion need to be seen as the responsibility of all HCPs and organizations, including those in tertiary centres. Situated in a pediatric centre, the participants in this study are the local experts in adolescent health, as they identified in their interviews. As such, they queried what position they should have organizationally to promote adolescent HL not only in the hospital but in the broader community.

Experts in Adolescent Health

In health care, there are lessons from the education discipline that can be applied to adolescent HL. Peralta et al (2021), provides an example of a school health curriculum (grades 7-10) designed to promote HL. These researchers used case study methods to assess curriculum activities related to three traditional dimensions of HL (media literacy was not included). The case in their study illuminated the need for teachers to be educated in HL. With the appropriate resources, they describe a staged approach to skill development, across several grade levels, that if implemented would positively impact adolescent HL levels. Hughes & Maiden (2018) conducted a multi-school intervention study, where a HL specific education unit was tested for its ability to improve adolescents' navigational knowledge of health systems. Their study showed that providing all adolescents, regardless of health status, with HL skills improved students' confidence and knowledge of health-related tasks.

Examples of activities included are strategies that centred on self-advocacy, understanding one's medical history, and administrative tasks such as filling forms (Hughes & Maiden, 2018). These studies set in educational settings, provide evidence for the benefit of a standardized approach for developing HL competencies and autonomy in all adolescents, which should be seen as a health care priority as well as an educational priority. The Adolescent Health Literacy Framework illustrates an approach where systems work together and towards shared goals of improving adolescent HL competencies (Manganello, 2008). HL policies that involve collaboration amongst sectors could benefit adolescents where, HCPs have expertise in adolescent health, and educators have greater knowledge of teaching skills and self-sufficiency. Additionally, findings from our study did not adequately address socioeconomic factors for HL, something that could be more thoroughly addressed by an intersectoral approach. Interprofessional collaboration across sectors to promote adolescents HL warrants future study.

Universal Precautions

Significant effort has been made to create screening tools for use in health care settings, but their clinical implementation is impractical. Screening measures, for example the TOFHLA, tend to be long and cumbersome, unrealistic for time constrained medical appointments (Chisolm & Buchanan, 2007). Firstly, even validated tools aimed at assessing adolescent HL are unable to thoroughly address the non-functional (beyond literacy and numeracy) dimensions of HL, and secondly, an in-person clinical setting is far from the first interaction a person will have with the health care system and therefore they will have already come up against several HL challenges. While HCPs believe it is important to address individual HL needs, a universal precautions approach is favored in the literature for organizations to use for its efficiency in helping the majority of people.

There is evidentiary support for a universal precautions approach to HL, and even a toolkit specifically made for use in health care settings (Brega et al., 2015). The concept is simple, people with high HL are not disadvantaged by an assumption that they may have difficulty understanding health information but, people with low HL are disadvantaged by the assumption that they do understand. The toolkit provides guidelines for communication, templates for forms, etc., and assumes that all people will experience low levels of HL (Brooks et al., 2020). It does not provide specific tools or guidance for adolescent HL approaches, nor is there any presence in the literature related to a universal precautions approach for adolescents. This is a concerning gap in the research, as the participants in our study voiced a great deal of variation amongst their adolescent patients, supporting the need for a broader strategy.

From the adult literature there are examples of universal precautions in practice. A study that observed primary care interaction with adult patients, found that despite an awareness of the importance of plain language and HL universal precaution techniques, physicians practiced these strategies inconsistently (Byrne et al., 2021). This illustrates that HCPs perception of what constitutes plain language may differ from basic literacy standards, as was demonstrated by the patient education materials in the scoliosis program in this study. Within the health care professions, there may also be a lack of conviction when it comes to these communication practices, where HCPs are aware of the techniques but may not have full belief in their necessity or efficacy (Byrne et al., 2021). Establishing an organizational culture where HL is considered a core value, could promote a change in the way HCPs approach patient communication (Koh et al., 2013).

Brooks, and colleagues (2020) found that HCPs often rely on intuition and context clues as indicators of low HL when working with adult patients. Similar to participants in our study, these HCPs found that more time spent with a patient allowed them a greater sense of the patient's abilities, and that building rapport and trust meant patients were more vocal about their

HL (Brooks et al., 2020). However, HCPs' overreliance on individual instincts, was seen in our adolescent study as well, where they felt they addressed patients' understanding of health information, despite voicing the challenges related to other HL factors. Although universal techniques for adolescent HL do not currently exist, when the factors associated with this population are understood, standardized approaches can be established.

Recommendations

Implications for Practice

While HL development may have been traditionally seated within the education or primary care environment, the changing public services landscape in Canada means that changes may be needed to adequately address this aspect of development. Fewer Canadians have access to consistent primary care, and so specialists, such as those on the scoliosis team, would be advised to see HL as an aspect of adolescent health that falls into their domain of responsibility (Duong & Vogel, 2023). An appointment in the clinic is an opportunity to build skills and develop self-management as well as to assess spinal health and deliver treatment plans. Pediatric health care organizations should be at the forefront of integrating tools and policy to promote adolescent HL, and modelling strategies for community organizations that are not specialized in this stage of development (e.g., community or regional hospitals, primary care clinics). HCPs want to help adolescents improve their HL, and organizations need to have the supports in place to foster this priority. Teaching hospitals, have an even greater responsibility to this effect, as was the case for this case institution.

Implications for Nursing

The Canadian health care system is deeply rooted in a medical model of care, and that was apparent in interviews with HCPs. Participants described HL in relation to a unidirectional exchange of information, whereby HCPs are the gatekeepers of health knowledge and need to find a way to deliver this to their patients, in this case adolescents with scoliosis. Nurses represent the largest discipline amongst HCPs and operate within a more holistic model, where patients' coping and social factors are considered clinically relevant. Additionally, they are involved in almost all patient encounters within the pediatric tertiary care environment and have constant interactions with adolescents when they are in hospital receiving treatment as well as outpatient clinics. Therefore, nurses have multiple opportunities to use strategies to help build functional and non-functional domains of adolescent HL. However, they need organizational commitment (e.g., resources, education, time) to support integrating strategies into their practice. Advanced practice nurses are well positioned to provide leadership in this endeavor, by modelling HL focussed practices that take into account the context of adolescent health encounters and the developmental stage of these patients. Pre-licensure, nursing students need to be educated on the broader understanding of HL for all patients and given opportunities to practice their skills beyond a focus on patient teaching. Of note, neither the Canadian Nurses Association nor the Canadian Association of Schools of Nursing have explicit positions or standards regarding HL.

Implications for Future Research

With this young population it is essential to understand the construct of HL as experienced by them, in order to reach them in a way that is meaningful. Future study should explore adolescents' experience of HL both for those in specific programs (e.g., scoliosis) but also more broadly to understand the differences that health conditions, age, timing, and durations of health care interactions have on their HL needs. A broader examination of HL in this population is necessary to address the factors that influence adolescents' capacity to interact with health systems, beyond the context of an initial consult.

Studies are needed to illustrate effectiveness of organizational strategies in supporting adolescent HL. It is not clear which strategies are most effective with this population. Patient partnering in research approaches, such as completed by Birnie et al. (2019) could be used to investigate this gap in knowledge. Birnie et al. (2019) used such partnering to set a pediatric pain research agenda in Canada. This approach could be used to adapt strategies advocated by Brooks and colleagues (2020) in their adult focused universal toolkit to meet adolescent needs. Once developed, these toolkit strategies could be deployed by organizations and examined for their effectiveness at improving adolescents HL competencies.

This study identified the close relationship between transition readiness and HL. It could be argued that these two concepts are nearly interchangeable when broken down to their component parts. Because of this, it is recommended that research be carried out to expand transition interventions to address a broader population of adolescents beyond those with chronic illness. For example, interventional studies exploring the outcomes of modified transition tools as a strategy to build adolescent HL amongst those who receive health care for non-chronic conditions is warranted. In addition, and in a departure from much of the current literature on adolescent HL, studies involving non-stigmatised health decisions may be more illuminating. To study the effects of HL status or HL interventions, the outcomes measures should not be decisions that are likely to be influenced by peer pressure, and developmentally inappropriate expectations (e.g., alcohol use).

Conclusion

Adolescents are traditionally viewed as being unable to fully engage in their health care, with a deference to caregivers as recipients of health-related information. Yet adolescence is an opportunity to support the development of HL. Adolescents with health care conditions, such as scoliosis, are primed to learn these skills, as they are being introduced to health care systems in a controlled manner. HCPs and adults in general have long struggled to engage adolescents in conversations about their health, yet a focus on supporting capacity so that adolescents are able to find their own way, may have a greater long-term effect on patients' lives.

This study found that HCPs clearly have an interest in connecting with these young patients and are invested in their well-being. However, organizational supports are needed to build HL capacity amongst adolescents and clinicians need support to leverage the resources that are in place. Organizational culture that values HL is needed to promote self-efficacy amongst adolescent patients, not only in those with chronic conditions but in every adolescent, in every health care encounter (clinic or in-patient), every time.

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Appendices

Appendix A

Organizational Interviews

Introduction:

Interviewer: Thank you for agreeing to participate in this study about adolescent health literacy and structuring it within the AIS program at the [case organization]. This interview will take approximately 20 -60 minutes.

If there are any questions that you do not want to answer, or if you want to stop at any time, please feel free. This interview is being recorded and transcribed but your name and anything that can identify you will be removed before sharing with others. If you are not sure about what I am asking you, please do not hesitate to ask me any questions. Before we begin, I want to confirm your understanding: are you able to tell me what the purpose is of this interview and research project? And do you still agree to participate in the interview?

Are you ready to start?

1. What is your professional discipline?
2. How long have been working in this capacity?
3. What is your level of education?

4. When I say, ‘health literacy’, what does that mean to you?

5. Please tell me how health literacy is addressed within the hospital?
    Probes: What about in staff training, communications, patient/family resources or facility design

6. What is the difference between adults, children and adolescents when it comes to health literacy?
    Probes: What is different about communicating with adolescents vs adults?
    What about adolescents vs. children?

7. What factors are important to consider when creating communications or information for adolescents?

    Probes: Do you think that those factors are being considered for communication at the IWK?

8. Do you know of any IWK policies that are designed to promote health literacy of adolescents?

9. What is the IWK process for creating health information materials for adolescents?

10. Is there anything about adolescent health literacy that we have not discussed that you think is important for me to know?

Appendix B

Invitation to Participate

Study Title: Do You Understand Me? A Case Study Exploring the Health Literacy of Adolescents with Scoliosis

We are conducting a study to explore the concept of health literacy as it relates to adolescents in tertiary care. We want to understand how adolescents are experiencing and interacting with health information and how healthcare providers and hospital administrators promote and support health literacy in adolescents. Given the transitional stage of development, adolescents are developing skills and knowledge that they will use lifelong.

This research is using a qualitative case study approach and exploring not only adolescent perspectives but those of organizational stakeholders as well as an analysis of organizational documents. Thus, we are inviting you to take part in an interview as you are healthcare provider or hospital administrators who plays a role in the development of health information for adolescents. We are framing the study within the context of adolescents with scoliosis given that they generally do not have significant co-morbidities, a relatively similar age of onset, and therefore may have a more uniform trajectory through their treatment course and health information requirements. However, the research is not focused on the specifics of scoliosis treatment but rather health literacy experience.

We will also be gathering information from adolescents with scoliosis who receive care at the IWK as we want to know what is important to adolescents and what things affect their ability to understand information about their health.

Due to your position at the IWK, you have an important perspective on adolescent health information and resources, and the policies and procedures involved in communicating with adolescents at the health centre. We would like to conduct a short semi-structured interview with you over Microsoft Teams as a part of our data collection for this qualitative study. The interview will take 20-60 minutes.

If you are interested in learning more about the study and or taking part, please reply to Meg Finley, at meghan.finley@iwk.nshealth.ca.

Thank you,

Meg Finley

Appendix C

Information and Consent

Confidential

Page 1

Welcome!

IWK Health

uOttawa

Information and Consent Form for Stakeholders

Study title: Do You Understand Me? A Case Study Exploring the Health Literacy of Adolescents with Scoliosis

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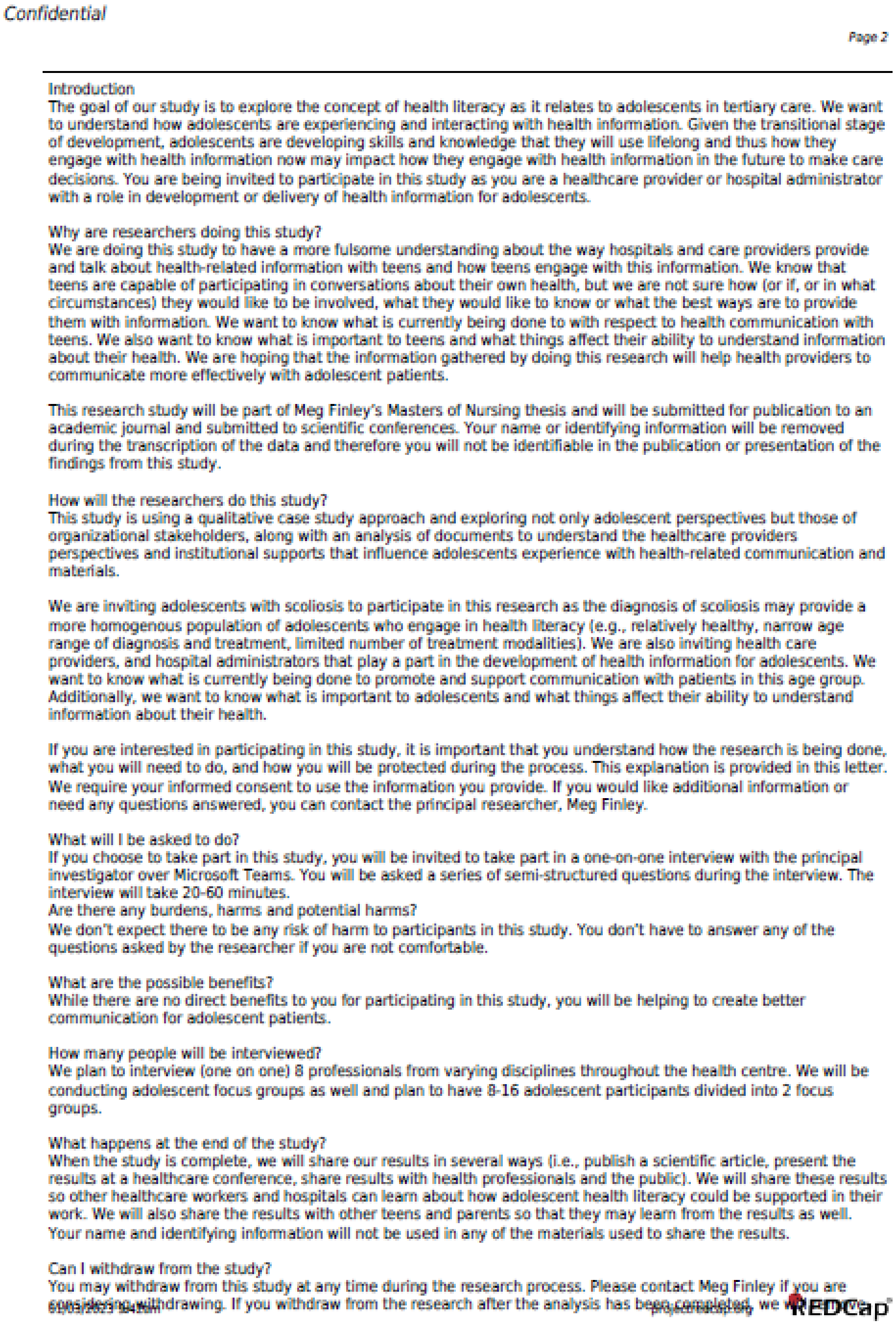


Introduction

The goal of our study is to explore the concept of health literacy as it relates to adolescents in tertiary care. We want to understand how adolescents are experiencing and interacting with health information. Given the transitional stage of development, adolescents are developing skills and knowledge that they will use lifelong and thus how they engage with health information now may impact how they engage with health information in the future to make care decisions. You are being invited to participate in this study as you are a healthcare provider or hospital administrator with a role in development or delivery of health information for adolescents.

Why are researchers doing this study?

We are doing this study to have a more fulsome understanding about the way hospitals and care providers provide and talk about health-related information with teens and how teens engage with this information. We know that teens are capable of participating in conversations about their own health, but we are not sure how (or if, or in what circumstances) they would like to be involved, what they would like to know or what the best ways are to provide them with information. We want to know what is currently being done to with respect to health communication with teens. We also want to know what is important to teens and what things affect their ability to understand information about their health. We are hoping that the information gathered by doing this research will help health providers to communicate more effectively with adolescent patients.

This research study will be part of Meg Finley's Masters of Nursing thesis and will be submitted for publication to an academic journal and submitted to scientific conferences. Your name or identifying information will be removed during the transcription of the data and therefore you will not be identifiable in the publication or presentation of the findings from this study.

How will the researchers do this study?

This study is using a qualitative case study approach and exploring not only adolescent perspectives but those of organizational stakeholders, along with an analysis of documents to understand the healthcare providers perspectives and institutional supports that influence adolescents experience with health-related communication and materials.

We are inviting adolescents with scoliosis to participate in this research as the diagnosis of scoliosis may provide a more homogenous population of adolescents who engage in health literacy (e.g., relatively healthy, narrow age range of diagnosis and treatment, limited number of treatment modalities). We are also inviting health care providers, and hospital administrators that play a part in the development of health information for adolescents. We want to know what is currently being done to promote and support communication with patients in this age group. Additionally, we want to know what is important to adolescents and what things affect their ability to understand information about their health.

If you are interested in participating in this study, it is important that you understand how the research is being done, what you will need to do, and how you will be protected during the process. This explanation is provided in this letter. We require your informed consent to use the information you provide. If you would like additional information or need any questions answered, you can contact the principal researcher, Meg Finley.

What will I be asked to do?

If you choose to take part in this study, you will be invited to take part in a one-on-one interview with the principal investigator over Microsoft Teams. You will be asked a series of semi-structured questions during the interview. The interview will take 20-60 minutes.

Are there any burdens, harms and potential harms?

We don't expect there to be any risk of harm to participants in this study. You don't have to answer any of the questions asked by the researcher if you are not comfortable.

What are the possible benefits?

While there are no direct benefits to you for participating in this study, you will be helping to create better communication for adolescent patients.

How many people will be interviewed?

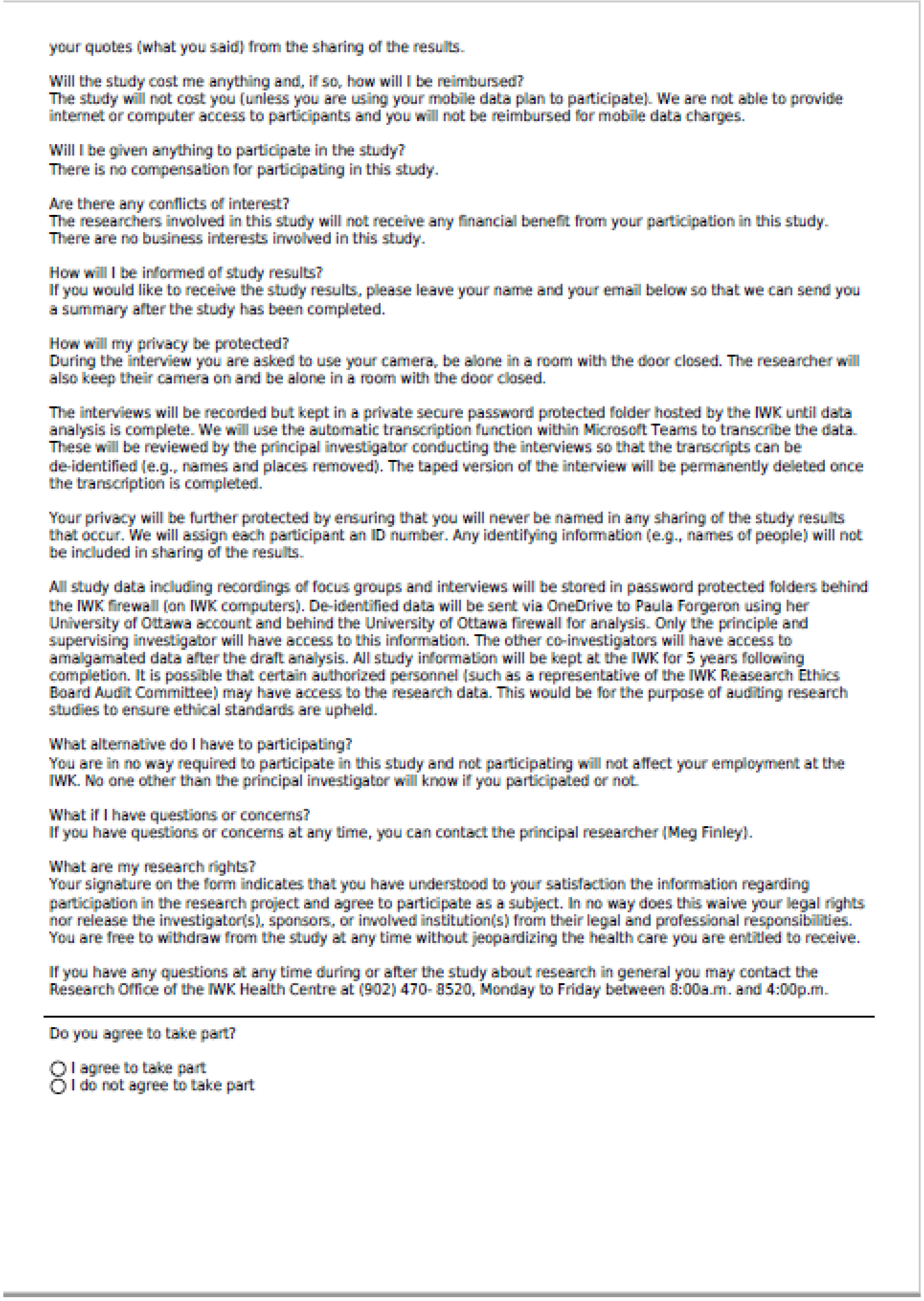
We plan to interview (one on one) 8 professionals from varying disciplines throughout the health centre. We will be conducting adolescent focus groups as well and plan to have 8-16 adolescent participants divided into 2 focus groups.

What happens at the end of the study?

When the study is complete, we will share our results in several ways (i.e., publish a scientific article, present the results at a healthcare conference, share results with health professionals and the public). We will share these results so other healthcare workers and hospitals can learn about how adolescent health literacy could be supported in their work. We will also share the results with other teens and parents so that they may learn from the results as well. Your name and identifying information will not be used in any of the materials used to share the results.

Can I withdraw from the study?

You may withdraw from this study at any time during the research process. Please contact Meg Finley if you are considering withdrawing. If you withdraw from the research after the analysis has been completed, we



your quotes (what you said) from the sharing of the results.

Will the study cost me anything and, if so, how will I be reimbursed?
The study will not cost you (unless you are using your mobile data plan to participate). We are not able to provide internet or computer access to participants and you will not be reimbursed for mobile data charges.

Will I be given anything to participate in the study?
There is no compensation for participating in this study.

Are there any conflicts of interest?
The researchers involved in this study will not receive any financial benefit from your participation in this study. There are no business interests involved in this study.

How will I be informed of study results?
If you would like to receive the study results, please leave your name and your email below so that we can send you a summary after the study has been completed.

How will my privacy be protected?
During the interview you are asked to use your camera, be alone in a room with the door closed. The researcher will also keep their camera on and be alone in a room with the door closed.

The interviews will be recorded but kept in a private secure password protected folder hosted by the IWK until data analysis is complete. We will use the automatic transcription function within Microsoft Teams to transcribe the data. These will be reviewed by the principal investigator conducting the interviews so that the transcripts can be de-identified (e.g., names and places removed). The taped version of the interview will be permanently deleted once the transcription is completed.

Your privacy will be further protected by ensuring that you will never be named in any sharing of the study results that occur. We will assign each participant an ID number. Any identifying information (e.g., names of people) will not be included in sharing of the results.

All study data including recordings of focus groups and interviews will be stored in password protected folders behind the IWK firewall (on IWK computers). De-identified data will be sent via OneDrive to Paula Forgeron using her University of Ottawa account and behind the University of Ottawa firewall for analysis. Only the principle and supervising investigator will have access to this information. The other co-investigators will have access to amalgamated data after the draft analysis. All study information will be kept at the IWK for 5 years following completion. It is possible that certain authorized personnel (such as a representative of the IWK Reasearch Ethics Board Audit Committee) may have access to the research data. This would be for the purpose of auditing research studies to ensure ethical standards are upheld.

What alternative do I have to participating?
You are in no way required to participate in this study and not participating will not affect your employment at the IWK. No one other than the principal investigator will know if you participated or not.

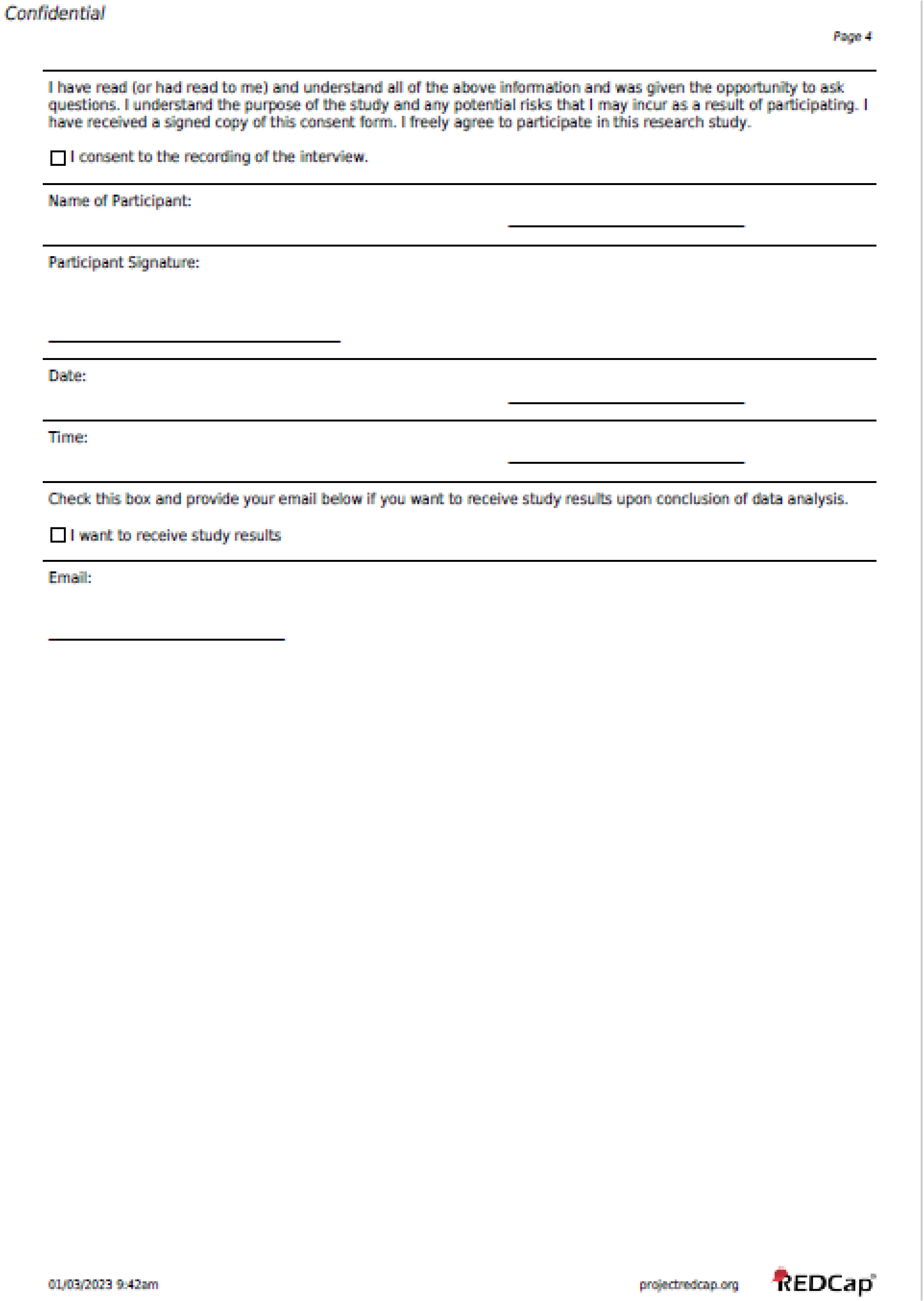
What if I have questions or concerns?
If you have questions or concerns at any time, you can contact the principal researcher (Meg Finley).

What are my research rights?
Your signature on the form indicates that you have understood to your satisfaction the information regarding participation in the research project and agree to participate as a subject. In no way does this waive your legal rights nor release the investigator(s), sponsors, or involved institution(s) from their legal and professional responsibilities. You are free to withdraw from the study at any time without jeopardizing the health care you are entitled to receive.

If you have any questions at any time during or after the study about research in general you may contact the Research Office of the IWK Health Centre at (902) 470- 8520, Monday to Friday between 8:00a.m. and 4:00p.m.

Do you agree to take part?

○ I agree to take part
○ I do not agree to take part



Confidential

Page 4

I have read (or had read to me) and understand all of the above information and was given the opportunity to ask questions. I understand the purpose of the study and any potential risks that I may incur as a result of participating. I have received a signed copy of this consent form. I freely agree to participate in this research study.

☐ I consent to the recording of the interview.

Name of Participant:

Participant Signature:

Date:

Time:

Check this box and provide your email below if you want to receive study results upon conclusion of data analysis.

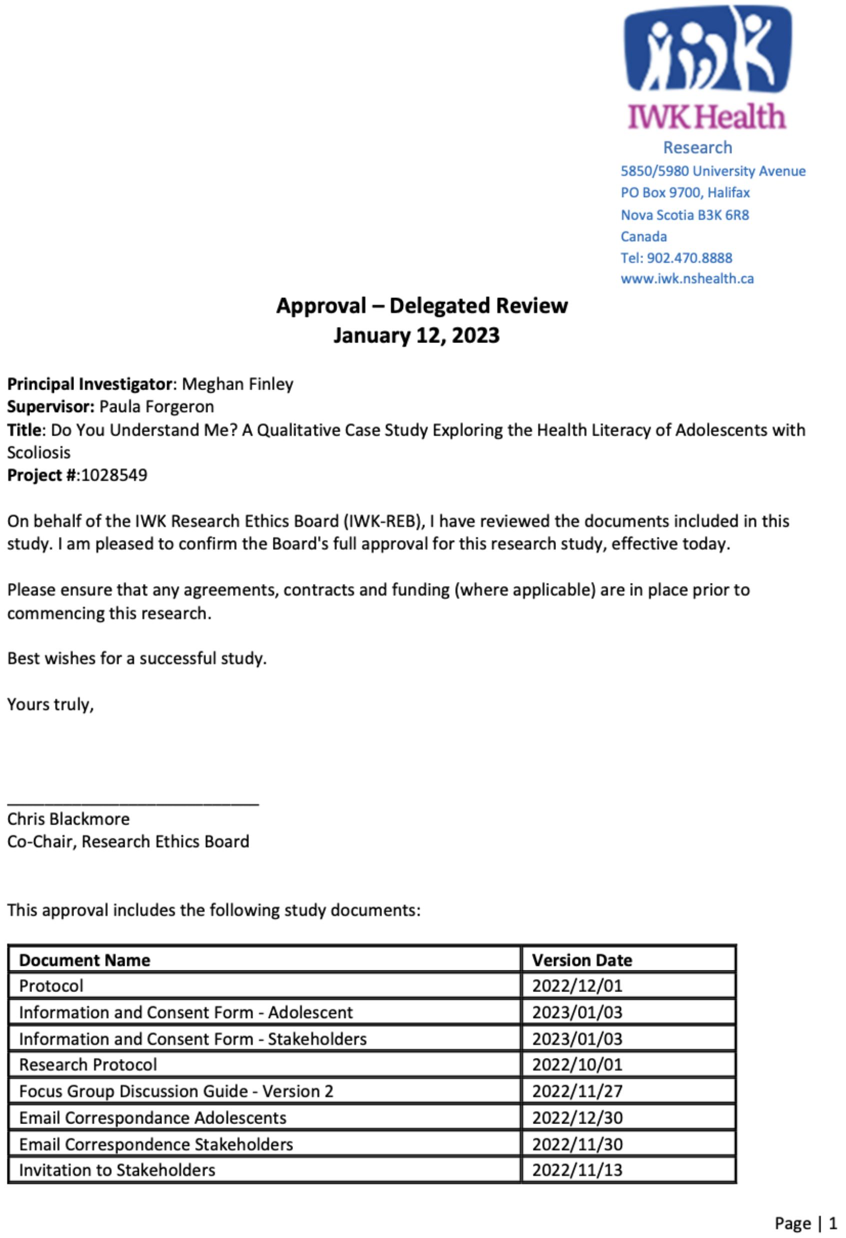
☐ I want to receive study results

Email:

01/03/2023 9:42am projectredcap.org REDCap

Appendix D

Research Ethics Board Approval – IWK



IWK Health
Research
5850/5980 University Avenue
PO Box 9700, Halifax
Nova Scotia B3K 6R8
Canada
Tel: 902.470.8888
www.iwk.nshealth.ca

Approval – Delegated Review
January 12, 2023

Principal Investigator: Meghan Finley
Supervisor: Paula Forgeron
Title: Do You Understand Me? A Qualitative Case Study Exploring the Health Literacy of Adolescents with Scoliosis
Project #:1028549

On behalf of the IWK Research Ethics Board (IWK-REB), I have reviewed the documents included in this study. I am pleased to confirm the Board's full approval for this research study, effective today.

Please ensure that any agreements, contracts and funding (where applicable) are in place prior to commencing this research.

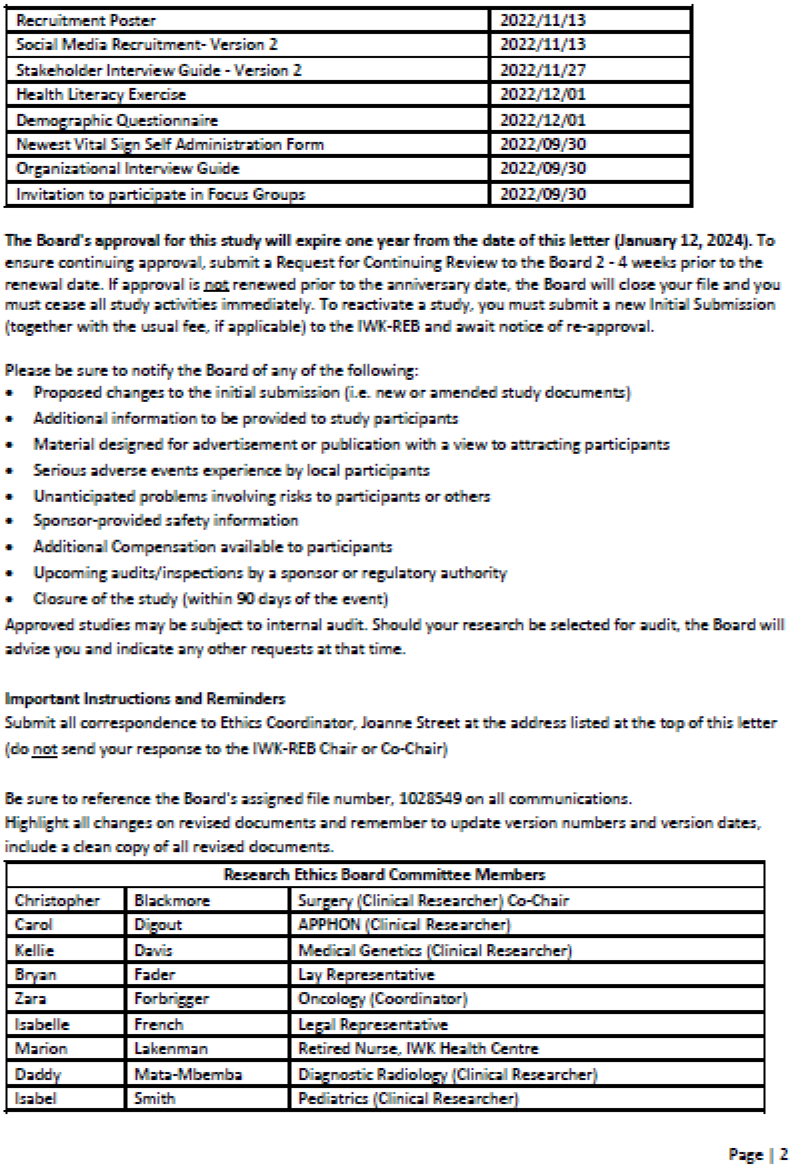
Best wishes for a successful study.

Yours truly,

Chris Blackmore
Co-Chair, Research Ethics Board

This approval includes the following study documents:

Document Name	Version Date
Protocol	2022/12/01
Information and Consent Form - Adolescent	2023/01/03
Information and Consent Form - Stakeholders	2023/01/03
Research Protocol	2022/10/01
Focus Group Discussion Guide - Version 2	2022/11/27
Email Correspondance Adolescents	2022/12/30
Email Correspondence Stakeholders	2022/11/30
Invitation to Stakeholders	2022/11/13



Recruitment Poster	2022/11/13
Social Media Recruitment- Version 2	2022/11/13
Stakeholder Interview Guide - Version 2	2022/11/27
Health Literacy Exercise	2022/12/01
Demographic Questionnaire	2022/12/01
Newest Vital Sign Self Administration Form	2022/09/30
Organizational Interview Guide	2022/09/30
Invitation to participate in Focus Groups	2022/09/30

The Board's approval for this study will expire one year from the date of this letter (January 12, 2024). To ensure continuing approval, submit a Request for Continuing Review to the Board 2 - 4 weeks prior to the renewal date. If approval is not renewed prior to the anniversary date, the Board will close your file and you must cease all study activities immediately. To reactivate a study, you must submit a new Initial Submission (together with the usual fee, if applicable) to the IWK-REB and await notice of re-approval.

Please be sure to notify the Board of any of the following:

- Proposed changes to the initial submission (i.e. new or amended study documents)
- Additional information to be provided to study participants
- Material designed for advertisement or publication with a view to attracting participants
- Serious adverse events experience by local participants
- Unanticipated problems involving risks to participants or others
- Sponsor-provided safety information
- Additional Compensation available to participants
- Upcoming audits/inspections by a sponsor or regulatory authority
- Closure of the study (within 90 days of the event)

Approved studies may be subject to internal audit. Should your research be selected for audit, the Board will advise you and indicate any other requests at that time.

Important Instructions and Reminders

Submit all correspondence to Ethics Coordinator, Joanne Street at the address listed at the top of this letter (do not send your response to the IWK-REB Chair or Co-Chair)

Be sure to reference the Board's assigned file number, 1028549 on all communications.

Highlight all changes on revised documents and remember to update version numbers and version dates, include a clean copy of all revised documents.

Research Ethics Board Committee Members		
Christopher	Blackmore	Surgery (Clinical Researcher) Co-Chair
Carol	Digout	APPHON (Clinical Researcher)
Kellie	Davis	Medical Genetics (Clinical Researcher)
Bryan	Fader	Lay Representative
Zara	Forbrigger	Oncology (Coordinator)
Isabelle	French	Legal Representative
Marion	Lakenman	Retired Nurse, IWK Health Centre
Daddy	Mata-Mbemba	Diagnostic Radiology (Clinical Researcher)
Isabel	Smith	Pediatrics (Clinical Researcher)

Megan	Thomas	Developmental Pediatrics (Clinical Researcher) Co-Chair
Francois	Tremblay	Pediatric Ophthalmology (Clinical Researcher)

* REB members are not in attendance during the review of their own proposed research involving human subjects or where there is a conflict of interest with the proposed research

This statement is in lieu of Health Canada's Research Ethics Board Attestation: *the Research Ethics Board for the IWK Health Centre operates in accordance with:*

- Part C Division 5 of the *Food and Drug Regulations* or with the definition in the *Interim Order Respecting Clinical Trials for Medical Devices and Drugs Relating to COVID-19;*
- *Natural Health Products Regulations, Part 4 "Clinical Trials Involving Human Subjects"*
- *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS 2)*
- *ICH Good Clinical Practice: Consolidated Guideline (ICH-E6)*
- *FWA #: FWA00005630 / IORG #: IORG0003102 / IRB00003719*

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Appendix E

Research Ethics Board Approval – University of Ottawa

02/02/2023

Université d'Ottawa
Bureau d'éthique et d'intégrité de la recherche

University of Ottawa
Office of Research Ethics and Integrity

Lettre d'approbation administrative | Letter of administrative approval

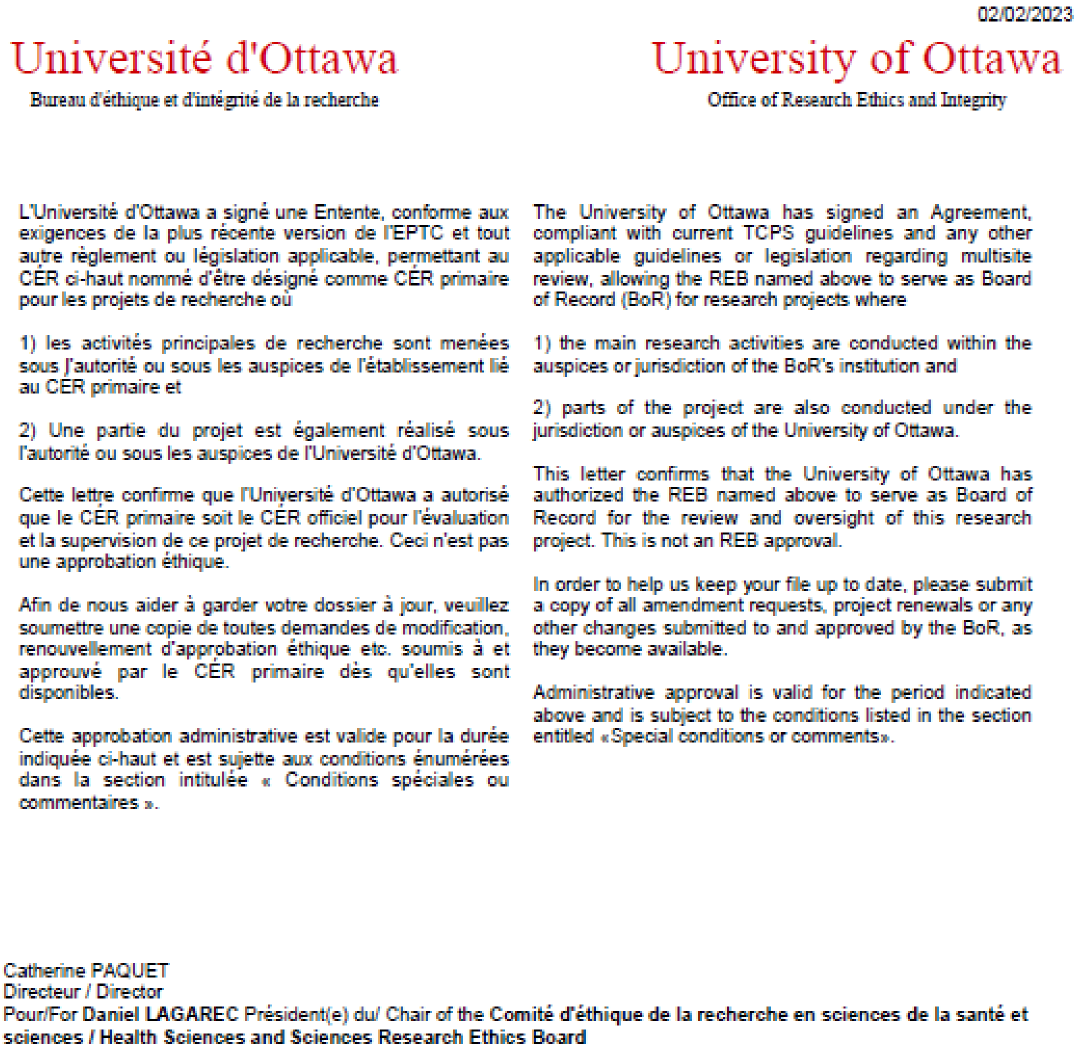
Numéro de dossier / Ethics File Number	H-01-23-8568
Titre du projet / Project Title	Do You Understand Me? A Qualitative Case Study Exploring the Health Literacy of Adolescents with Scoliois
Type de projet / Project Type	Thèse de maîtrise / Master's thesis
CÉR primaire / Primary REB	IWK Health Centre, Halifax, Nova Scotia
Statut du projet / Project Status	Approuvé / Approved
Date d'approbation (jj/mm/aaaa) / Approval Date (dd/mm/yyyy)	02/02/2023
Date d'expiration (jj/mm/aaaa) / Expiry Date (dd/mm/yyyy)	12/01/2024

Équipe de recherche / Research Team

Chercheur / Researcher	Affiliation	Role
Meghan FINLEY	École des sciences infirmières / School of Nursing	Chercheur Principal / Principal Investigator
Paula FORGERON	École des sciences infirmières / School of Nursing	Superviseur / Supervisor
Mwali MURAY	École des sciences infirmières / School of Nursing	Co-chercheur / Co-investigator
Dawn STACEY	École des sciences infirmières / School of Nursing	Co-chercheur / Co-investigator

Conditions spéciales ou commentaires / Special conditions or comments:

IWK-REB Project #:1028549



02/02/2023

Université d'Ottawa
Bureau d'éthique et d'intégrité de la recherche

University of Ottawa
Office of Research Ethics and Integrity

L'Université d'Ottawa a signé une Entente, conforme aux exigences de la plus récente version de l'EPTC et tout autre règlement ou législation applicable, permettant au CÉR ci-haut nommé d'être désigné comme CÉR primaire pour les projets de recherche où

1) les activités principales de recherche sont menées sous l'autorité ou sous les auspices de l'établissement lié au CÉR primaire et

2) Une partie du projet est également réalisé sous l'autorité ou sous les auspices de l'Université d'Ottawa.

Cette lettre confirme que l'Université d'Ottawa a autorisé que le CÉR primaire soit le CÉR officiel pour l'évaluation et la supervision de ce projet de recherche. Ceci n'est pas une approbation éthique.

Afin de nous aider à garder votre dossier à jour, veuillez soumettre une copie de toutes demandes de modification, renouvellement d'approbation éthique etc. soumis à et approuvé par le CÉR primaire dès qu'elles sont disponibles.

Cette approbation administrative est valide pour la durée indiquée ci-haut et est sujette aux conditions énumérées dans la section intitulée « Conditions spéciales ou commentaires ».

The University of Ottawa has signed an Agreement, compliant with current TCPS guidelines and any other applicable guidelines or legislation regarding multisite review, allowing the REB named above to serve as Board of Record (BoR) for research projects where

1) the main research activities are conducted within the auspices or jurisdiction of the BoR's institution and

2) parts of the project are also conducted under the jurisdiction or auspices of the University of Ottawa.

This letter confirms that the University of Ottawa has authorized the REB named above to serve as Board of Record for the review and oversight of this research project. This is not an REB approval.

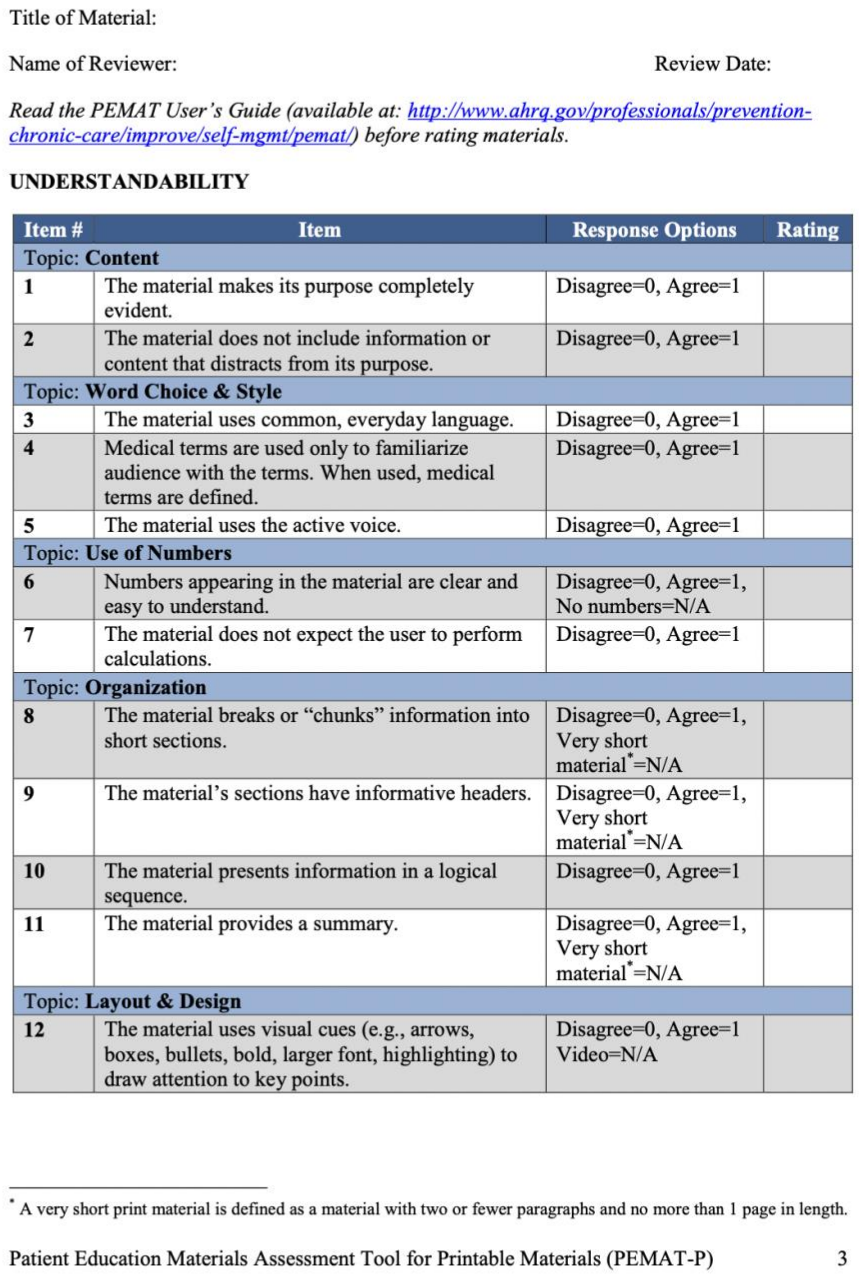
In order to help us keep your file up to date, please submit a copy of all amendment requests, project renewals or any other changes submitted to and approved by the BoR, as they become available.

Administrative approval is valid for the period indicated above and is subject to the conditions listed in the section entitled «Special conditions or comments».

Catherine PAQUET
Directeur / Director
Pour/For **Daniel LAGAREC** Président(e) du/ Chair of the **Comité d'éthique de la recherche en sciences de la santé et sciences / Health Sciences and Sciences Research Ethics Board**

Appendix F

PEMAT-P



Title of Material:

Name of Reviewer: Review Date:

Read the PEMAT User's Guide (available at: http://www.ahrq.gov/professionals/prevention-chronic-care/improve/self-mgmt/pemat/) before rating materials.

UNDERSTANDABILITY

Item #	Item	Response Options	Rating
Topic: **Content**			
1	The material makes its purpose completely evident.	Disagree=0, Agree=1	
2	The material does not include information or content that distracts from its purpose.	Disagree=0, Agree=1	
Topic: **Word Choice & Style**			
3	The material uses common, everyday language.	Disagree=0, Agree=1	
4	Medical terms are used only to familiarize audience with the terms. When used, medical terms are defined.	Disagree=0, Agree=1	
5	The material uses the active voice.	Disagree=0, Agree=1	
Topic: **Use of Numbers**			
6	Numbers appearing in the material are clear and easy to understand.	Disagree=0, Agree=1, No numbers=N/A	
7	The material does not expect the user to perform calculations.	Disagree=0, Agree=1	
Topic: **Organization**			
8	The material breaks or "chunks" information into short sections.	Disagree=0, Agree=1, Very short material[*]=N/A	
9	The material's sections have informative headers.	Disagree=0, Agree=1, Very short material[*]=N/A	
10	The material presents information in a logical sequence.	Disagree=0, Agree=1	
11	The material provides a summary.	Disagree=0, Agree=1, Very short material[*]=N/A	
Topic: **Layout & Design**			
12	The material uses visual cues (e.g., arrows, boxes, bullets, bold, larger font, highlighting) to draw attention to key points.	Disagree=0, Agree=1 Video=N/A	

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[*] A very short print material is defined as a material with two or fewer paragraphs and no more than 1 page in length.

Patient Education Materials Assessment Tool for Printable Materials (PEMAT-P) 3

Item #	Item	Response Options	Rating
Topic: **Use of Visual Aids**			
15	The material uses visual aids whenever they could make content more easily understood (e.g., illustration of healthy portion size).	Disagree=0, Agree=1	
16	The material's visual aids reinforce rather than distract from the content.	Disagree=0, Agree=1, No visual aids=N/A	
17	The material's visual aids have clear titles or captions.	Disagree=0, Agree=1, No visual aids=N/A	
18	The material uses illustrations and photographs that are clear and uncluttered.	Disagree=0, Agree=1, No visual aids=N/A	
19	The material uses simple tables with short and clear row and column headings.	Disagree=0, Agree=1, No tables=N/A	

Total Points: ____________________

Total Possible Points: ____________________

Understandability Score (%): ____________________
(*Total Points* / *Total Possible Points*) × 100

ACTIONABILITY

Item #	Item	Response Options	Rating
20	The material clearly identifies at least one action the user can take.	Disagree=0, Agree=1	
21	The material addresses the user directly when describing actions.	Disagree=0, Agree=1	
22	The material breaks down any action into manageable, explicit steps.	Disagree=0, Agree=1	
23	The material provides a tangible tool (e.g., menu planners, checklists) whenever it could help the user take action.	Disagree=0, Agree=1	
24	The material provides simple instructions or examples of how to perform calculations.	Disagree=0, Agree=1, No calculations=NA	
25	The material explains how to use the charts, graphs, tables, or diagrams to take actions.	Disagree=0, Agree=1, No charts, graphs, tables, or diagrams=N/A	
26	The material uses visual aids whenever they could make it easier to act on the instructions.	Disagree=0, Agree=1	

Total Points: ____________________

Total Possible Points: ____________________

Actionability Score (%): ____________________
(*Total Points* / *Total Possible Points*) × 100