The Development and Evaluation of an Innovative Knowledge Translation Tool about Pediatric Concussion

by

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Abstract

Background: Pediatric concussion is a common, yet complex injury caused by a direct or indirect blow to the head. Pediatric concussion places considerable burdens on children, families, and the healthcare system. To minimize this burden, it is essential that patients and families are connected to evidence-based child health information. Despite the plethora of educational resources available about pediatric concussion, uncertainty in how to manage them prevails, particularly among families, and knowing which resources are relevant and accurate is often unclear. This suggests an urgent need for evidence-based strategies that align what is known from research with what is done in health care practice, referred to as knowledge translation strategies. Actively involving patients and families in health care has the potential to optimize knowledge translation. Research indicates that patients and families look for health information online, thus; digital knowledge translation tools are a promising approach to provide complex, child health information.

Purpose: The purpose of this dissertation is to understand the information needs and preferences of children who have experienced a concussion and their parents and use these data to develop and evaluate a novel, innovative knowledge translation tool about pediatric concussion.

Methods: This dissertation is a multi-phase, multi-method project consisting of four phases and three related papers: (1) an environmental scan to identify and describe Canadian-developed, publicly available Internet resources and Apps about pediatric concussion, (2) a qualitative description study on the experiences, information needs and preferences of children who have experienced a concussion and their parents, and (3) the development and evaluation of a novel, digital knowledge translation tool (interactive infographic) about pediatric concussion.

Findings and Conclusions: This dissertation addressed current knowledge gaps in pediatric concussion education tools and actively involved children and parents in the development and evaluation of a digital knowledge translation (KT) tool about pediatric concussion. Results of this research have widespread applications in three key areas.

First, the current state of Canadian-developed resources for pediatric concussion found on the Internet and in Apps is described. In paper one, an environmental scan of 600 websites and 200 Apps was conducted. Sixty-seven resources (64 Internet, 3 Apps) met the inclusion criteria. Information gaps in relation to the content, format and target audience of these resources was identified. Most significantly, this scan determined that few resources targeted children and were most commonly available in PDF format. Recommendations for the future development of pediatric concussion resources are provided.

Second, this research informed the development of a novel, digital knowledge translation tool (an interactive infographic), about pediatric concussion through integrated knowledge translation methods. In paper two, a qualitative description study interviewing children who have had a concussion, and their parents, was conducted. Four major themes were identified from these interviews: 1) mechanism of injury and concussion symptoms experienced by children, 2) parent concerns, emotions, and health care experience with child's concussion, 3) concussions affect more than just your head and, 4) health information seeking, and preferences of parents and children related to concussion. Overall, this study demonstrated that children and their parents have unique experiences, information needs and preferences regarding concussion.

Third, knowledge translation science was enhanced in terms of the development and testing of a novel, knowledge translation intervention (interactive infographic) for children and parents and building KT research capacity through collaborations with patients, families, and key stakeholders. Paper three describes the development of the interactive infographic, and our findings suggest this infographic was viewed positively by parents and significantly improved parents self-reported confidence in their knowledge of pediatric concussions. The findings of this research make substantial contributions to pediatric concussion research, knowledge translation intervention development and evaluation and patient engagement in research.

Preface

This dissertation is an original work by Alyson Louise Campbell. The research project, of which this dissertation is a part, received research ethics approval from the University of Alberta Research Ethics Board, Project Name "Developing and Evaluating a KT tool on Pediatric Concussion", Pro00096202, December 13, 2019.

One paper within this dissertation has been published, one has been submitted for publication and one is in preparation for publication. Paper one is under review as Campbell, A., Plourde, V., Hartling, L., Bains, A., and Scott, S.D. (2021) "An environmental scan of Canadian Internet resources and Apps about pediatric concussion." *CMAJ Open*. I was responsible for the environmental scan search, data extraction and analysis, manuscript composition, writing, submission and response to edits from peer reviewers. Mr. Bains assisted with data extraction and analysis. Drs. Plourde and Hartling contributed to conceptualizing the study, manuscript composition and edits at various stages of manuscript construction. Dr. Scott was the supervisory author on this manuscript and contributed to the overall concept formation, composition and edits of this manuscript.

Paper two is published as Campbell, A., Plourde, V., Hartling, L., & Scott, S. D. (2021). "You Can't Fix Your Brain": Exploring Concussion Experiences of Children and Parents. *Journal for Specialists in Pediatric Nursing*, e12357. https://doi.org/10.1111/jspn.12357. I was responsible for participant recruitment, data collection, data cleaning and analysis, manuscript composition, writing, submission and response to edits from peer reviewers. Dr. Scott was the supervisory author on this manuscript, contributing and overseeing data analysis and manuscript writing. Drs. Hartling and Plourde oversaw data analysis and contributed to manuscript composition and edits at various stages of manuscript construction. All authors contributed to conceptualization and defining methods for this study.

Paper three is in preparation for publication as Campbell, A., Hartling, L., Plourde, V., and Scott, S.D. (2021) "The Development and Parental Evaluation of a Web-Based Infographic for Pediatric Concussion: A Multi-Method Study" *Journal of Medical Internet Research.* I was responsible for data collection, data cleaning and analysis, manuscript composition, writing, submission and response to edits from peer reviewers. Dr. Hartling provided guidance and expertise on quantitative methods and analysis and contributed to manuscript composition and edits. Dr. Plourde provided content expertise on pediatric concussion and contributed to manuscript composition and edits. Dr. Scott was the primary supervisor for this manuscript, contributing to manuscript composition and edits. All authors contributed to conceptualization and defining methods for this study. Drs. Scott and Hartling contributed to the overall concept formation of this dissertation.

The research conducted for this thesis forms part of a research collaboration co-led by Dr. Shannon Scott (supervisor) with Dr. Lisa Hartling (committee member) at the University of Alberta. The methods employed in this dissertation reflect the methodological process to develop a parent knowledge translation tool established by Drs. Scott and Hartling, specifically combining the results of a synthesis work (Paper 1) with the results of a qualitative study (Paper 2) to develop a knowledge translation tool for parents. The knowledge translation tool described in Paper 3 was co-designed by Drs. Scott and Hartling, their research team, and me with feedback received from a Pediatric Parent Advisory Group that informs Drs. Scott and Hartling's research program. The infrastructure required to develop the knowledge translation tool was provided by Dr. Scott's research program and funding awarded to her and Dr. Hartling from the

Canadian Institutes of Health Research and the Stollery Science Lab's Distinguished Researcher funding. I was responsible for contributing to the development and refinement of the tool, interfacing with the Pediatric Parent Advisory Group, as well as leading the interpretation of the data and final reporting. Dr. Scott was the supervisory author of this project and was extensively involved in the development and evaluation of the knowledge translation tool.

Dedication

I dedicate this dissertation to my biggest support, best friend and partner, Steven. Your encouragement, unwavering support, and belief in me, gave me the motivation to push through the most challenging and taxing of times, and enabled me to be successful and find fulfillment throughout this process. Words cannot begin to express my gratitude and appreciation for you. Thank you for all that you are.

Also, to my parents, Barry and Liz, you have always supported and encouraged me to pursue my passions and goals in life. You have both been instrumental to my success. Thank you for all your guidance and unconditional love.

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To my doctoral supervisor, Dr. Shannon Scott, I cannot begin to thank you enough for your continuous support, guidance, and mentorship. I am grateful for each opportunity you have given me, which has allowed me to grow and learn as a student, researcher, and person. Your work was part of my inspiration to pursue a PhD, and I cannot imagine having gone through this journey under the guidance of anyone else. Thank you for everything.

To my supervisory committee, Dr. Lisa Hartling, and Dr. Vickie Plourde, thank you for your support and feedback during this PhD. Your insights, perspectives, and knowledge were deeply appreciated. Thank you for being excellent mentors and colleagues.

Thank you to the many faculty members, administrative and support staff in the Faculty of Nursing who provided me with help and guidance along the way, especially Anita, Tracy, and Janet. Thank you to all the past and present staff and trainees of ECHO research lab I had the pleasure of meeting and working with, especially Anne and Hannah for all their patience and willingness to help!

To my family and friends, both old and new, thank you for always encouraging and supporting me and being so patient and understanding. I am grateful to have such a strong network of people behind me. A special thank you to my dear friend Rachel—thank you for always lending a listening ear, motivating me, and reminding me to laugh, have fun, and enjoy the journey.

The training, mentorship, and financial support I received during this doctoral experience played such an important role in my training and allowed this doctoral experience to be more enriching than I ever imagined. Thank you to the Women and Children's Health Research

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Table of Contents

List of Tables

List of Figures

CHAPTER 1. INTRODUCTION

Background

Clinical Condition

Concussions, also known as mild traumatic brain injuries (mTBI), are complex injuries affecting the brain [1]. The International Conference of Concussion in Sport defines a concussion as a “complex pathophysiologic process affecting the brain, induced by biomechanical forces” due to either a direct or indirect blow to the head, resulting in the impairment of neurologic function with clinical symptoms [2]. Classic clinical symptoms of concussions in children may include headaches, fogginess, transient loss of consciousness, amnesia, balance impairment, drowsiness, or irritability [1]. By the time children reach 10 years of age, 16% will have had at least one head injury requiring medical attention [3]. In Canada, an estimated 250,000 youth will sustain a concussion annually and an estimated 750,000 in the United States [4-6]. Approximately 15-30% of Canadian children and youth who seek medical care for a concussion will have persistent symptoms (symptoms lasting greater than 28 days post injury), including headaches, dizziness, foggy thinking, sleep problems, and emotional distress, which can cause significant disruptions to their daily lives [5-7]. Approximately 25-35% of children will have recurrent concussions, which in rare instances (<5%) can result in acute, life threatening injury with potentially lifelong consequences [8-10]. For the majority (65-75%) however, recovery occurs within 1-4 weeks post-injury [10, 11].

Concussions are primarily functional injuries and rarely result in structural damage to the brain as seen on neuroimaging. Thus, diagnosis is made when typical signs and symptoms are present immediately or within hours following head trauma [10]. However, diagnosis of a concussion may be challenging, as signs and symptoms may change rapidly over time and many symptoms are non-specific. Furthermore, there are no reliable tests or bio-markers currently available to assist with diagnosing concussions in children [10].

Graded symptom checklists may assist in diagnosing a concussion because they measure symptom severity and can be used to monitor recovery [10]. For example, the Sport Concussion Assessment Tool, 5th edition (SCAT5), is a standardized tool for evaluating concussions in children aged 13 years and older and can also be useful for monitoring recovery. For children aged 12 years and younger, the Child SCAT5 is available. Key components of this tool are the Glasgow Coma Scale, the Post-Concussive Symptom Scale, cognitive, balance and co-ordination tests [10].

Children need to be assessed and treated differently from adults for concussions. Children are more prone to head injury for various reasons including their anatomy, development, physical and cognitive recovery, and potential for long-term sequelae from a concussion. [12, 13]. It has been suggested that the impact force required to produce a concussion is greater in children than adults, and the recovery from concussion is generally longer for children [13]. While the long-term effects of concussions in children remain unknown, it is apparent that a child who sustains a concussion at an early age has a greater chance for sustaining further concussions than a person who does not sustain their first concussion until college [13].

In addition to short and long-term sequelae following a concussion, concussions also contribute to major economic burdens including direct medical costs, as well as indirect costs, such as lost work for parents who need to stay home and care for a child who has had a concussion, traveling to/from appointments and tutoring fees to help their youth recover academically. Financial burdens may cause increased stress for families [14, 15].

The prevalence and severity in which children and youth experience concussion coupled with the personal and societal impacts of concussions is concerning [16]. Recognizing the impact of pediatric concussion on children and families, Canadian organizations have developed educational supports and initiatives in an effort to work towards national standardization of concussion response and management including the Pan-Canadian Concussion Strategy, The Canadian Guideline on Concussion in Sport, the Concussion Awareness Training Tool (CATT), and the passing of Rowan's Law [17]. While these efforts indicate progress is being made in Canada in the concussion arena, a clear disconnect remains between concussion knowledge and practice. A 2017 federal survey commissioned by the Public Health Agency of Canada found that approximately half of Canadians reported having little to no knowledge about concussions, and do not know where to find information on how to prevent one [18]. A study by Stoller *et al.* [19] revealed that only some physicians in Ontario are aware that a consensus statement on concussion in sport exists. A 2016 study by Carson *et al.* [20] found that while Canadian sport and exercise medicine physicians are aware of the tools developed by the Concussion in Sport Group, this knowledge did not translate into consistent practice in the clinical setting. Surveys of various athletes have found that continuing to play while symptomatic following a concussion is common, implying athletes are not properly educated about safe and appropriate behavior following a concussion [21, 22]. Research has also found that key messages from published concussion guidelines have not reached many coaches or educators, as they continue to hold misconceptions [23, 24].

Introducing the Problem and Knowledge Gap

Despite the high-quality evidence[1] that exists regarding the recognition and clinical management of concussions, more consistent application of this evidence is required to help reduce the impact of concussions in children. The inconsistent application of this evidence results in a gap between what is known about concussion management and how concussions are being managed, otherwise known as a knowledge translation (KT) problem.

KT is increasingly recognized as a means to bridge the gap between what is known and what is done in clinical practice and is defined by the Canadian Institutes of Health Research as a "dynamic and iterative process that includes the synthesis, dissemination, exchange and ethically-sound application of knowledge to improve the health of Canadians, provide more effective health services and products and strengthen the health care system" [25].

Within academia, peer reviewed publications and formal presentations are the primary means of research dissemination; however, these approaches are less accessible to non-academics [26]. To date, KT efforts have largely focused on ensuring that health care professionals use the latest research to inform their practice; however, emerging evidence suggests that efforts which target health consumers (e.g., patients, parents) can inform their decision making and shape their treatment expectations [27, 28]. While research is beginning to demonstrate that strategies to increase KT to parents by pediatric health care professionals can reduce health care utilization and improve outcomes, more research is required to fully understand the power and impact of these efforts on both children and families [28].

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[1] High-quality evidence refers to knowledge and information derived from a multitude of sources including qualitative and quantitative research, clinical practice guidelines and position statements.

Healthcare requires more integrative, collaborative, and patient-centered strategies to promote knowledge uptake and account for patient preferences and involvement in care provision and decision-making. With the emergence of patient-centered care, patients are assuming a more active role regarding their own health [29]. For patients to effectively participate or take a leading role in their care, they need accessible and reliable information to make their own decisions and implement those decisions themselves [30]. Patient and family centered care in child health is unique given the essential extent of parental involvement in the care of children [31-34]. Families commonly receive information about their children's health condition, medical treatment, or procedure through a combination of verbal and written communication [35]. However, verbal instructions vary extensively, and the stressful context of information delivery in health care settings may contribute to poor parental understanding [36]. Further, commonly used methods of communicating written health information to parents such as standardized information sheets, overuse complex language and medical jargon [37].

Rapid increases in the amount of health research, particularly in pediatric concussion and the increased accessibility to research offered through the Internet, suggests a demand for reliable, evidence-based health information for patients and families that are relevant and easy to understand [38]. Combinations of creative approaches, such as visual art, storytelling, and the application of innovative technologies as KT strategies, are particularly underutilized. When used in conjunction, these approaches may appeal to multiple learning styles. While some research suggests innovative KT tools that present research-based information in user-friendly languages and formats may provide consumers with accurate recommendations while addressing knowledge or information needs, [37, 39-42] this has not been fully explored for children who sustain concussions and their parents.

Furthermore, it has been suggested that the key to addressing the need for standardized concussion care and management in Canada specifically, is through concerted KT efforts [17]. The prevailing knowledge gap across audiences who may be involved with pediatric concussions has made it a challenge to access information that is accurate, reliable, and trustworthy. A lack of knowledge in recognizing concussion is worrisome, despite ongoing efforts to disseminate evidence-based information to families [43]. Furthermore, little information exists to evaluate concussion educational resources with the ultimate goal of better translating concussion knowledge to the general public [44].

In this paper-based dissertation I attend to these gaps by first scanning the Internet and App Stores to discover what current tools exist about childhood concussion. I then explore the experiences, information needs and preferences of children who have sustained a concussion, and their parents and use this information to inform the development of an innovative web based KT tool. Finally, I evaluate the usability and effectiveness of this tool. I incorporate patient engagement and integrated knowledge translation (IKT) approaches, while drawing upon health literacy theories, KT frameworks and a pragmatic paradigm.

Patient Engagement and Integrated Knowledge Translation

Historically, the targets of health research programs have been exclusive to professional scientists. While the knowledge and experience of patients and families have been prioritized in clinical settings, uptake within the research context has been slower. Research programs continue to develop knowledge without patient input, despite efforts to generate research that is relevant and meaningful to patients. Over the past decade, there have been increasing calls for patient and public involvement in health-related research. Patient and public involvement in health-related research allows for more equitable and less hierarchical methods of knowledge generation and increases the usability and relevance of knowledge in clinical practice, ultimately improving patient outcomes [45-47].

In Canada, the term “patient engagement” is defined as “meaningful and active collaboration in governance, priority setting, conducting research and knowledge translation” [45]. The word patient is an umbrella term that includes individuals, groups, communities, caregivers, friends, and families who have personal experience and knowledge of a health issue [45]. Patient engagement in research can range from simply informing stakeholders to giving them complete decision-making autonomy. Within this research, patient engagement aligns with the term collaboration; where a partnership is formed and shared decision making occurs. The knowledge, experience, and preferences of the patient group (children and parents) is fully considered and encompasses the metacriterion of respect, trust, legitimacy, fairness, competence, and accountability in the development of knowledge [45, 48]. Collaborating with children who have experiences with concussion and their parents offers an innovative approach to ensure clinicians, researchers and organizations provide relevant supports, and parents have resources tailored to their needs.

While it has been widely recognized that KT problems are a result of knowledge *transfer* issues, an alternate view suggests this gap is caused by a knowledge *production* issue. Potential users fail to use research results because the research itself does not address the priority questions of its users [49] (Ch, 1.2). In attempts to mitigate this knowledge production issue, a different approach to KT known as, integrated knowledge translation (IKT) was introduced. Within IKT, knowledge users have unique expertise of the research topic, including knowledge of the context and the potential for implementation. Researchers bring methodological and content expertise to the collaboration. Integral to this approach is the sharing of power between researchers and knowledge users, sometimes referred to as the co-production of knowledge [50]. Within the context of my research, an IKT approach was integral to the development of my KT tool. The information needs and preferences as reported by children and parents were essential in determining both the format, and content of the tool to enhance relevance and uptake of the information.

Digital Health Education and Knowledge Translation

Access to the Internet has both accelerated and facilitated the empowerment of health consumers, such as patients and families [51]. A 2013 systematic review found that online KT strategies have the power to connect researchers, practitioners, policymakers, and consumers with the timely and relevant communication of health information across geographical boundaries [52]. However, barriers to effective KT have also been identified including health information overload in Internet searching and the ability to determine quality information online [52]. A 2014 Cochrane review found that multimedia educational interventions (i.e. written information combined with audio, animation or video) for health consumers about medications are superior to no education or usual care for increasing consumer knowledge. This suggests that multimedia interventions should be utilized and made widely accessible, both within and outside of healthcare settings [53, 54].

Theoretical Guidance

The theoretical underpinnings of this work were informed by the philosophical tenets of pragmatism, information literacy and health education theories and the Knowledge to Action (KTA) Framework.

Pragmatism as a Research Paradigm

The philosophy of pragmatism emerged through the works of Charles Sanders Peirce, William James, and John Dewey. A core tenet of pragmatism is seeing the truth as “what works” relative to the current situation [55]. Pragmatism is viewed as having the ability to put theory into practice by selecting and applying functional truths. Pragmatism understands that truth is not absolute, but rather a moveable and usable construct for understanding the nature of reality [55].

Within pragmatism, knowledge is understood to be socially constructed. Individual knowledge is contingent on one’s real work experiences and interests. In pragmatism, knowledge is evaluated on its usefulness within a particular set of circumstances or contexts [56].

As a research paradigm, pragmatism encourages research to use the philosophical and methodological approaches that best address their research problem [57]. Pragmatic research identifies practical and usable solutions to problems [55]. Pragmatic research centralizes the “problem” or research question, and the methods are viewed as tools for addressing the problem or answering the research question [58]. Within pragmatic research, multiple perspectives are required for a robust understanding of the problem and to generate possible solutions [56]. Thus, multi-methods (including qualitative and quantitative) can, and should be used to answer pragmatic research questions [58, 59].

A pragmatic research paradigm was applied to this research, interweaving information literacy theory, patient-engagement research, KT science, qualitative and quantitative methods to explore a complex and real-world problem and evaluate one potential solution. These lenses informed the development and evaluation of an innovative KT tool intended to provide complex child health information about pediatric concussion.

Information Literacy and Health Education

Elements from information literacy and health education shaped my research in various ways. Information literacy theory supports combining text and visuals through multimodal representation, to depict information in emotive and rationale manners [60]. The sheer volume and complexity of health information places a high demand on consumers to navigate this information. Thus, in alignment with information literacy theory and the emergence of visual and innovative media as a favorable communication modality, online arts-based KT tools may be a timely response to navigating this terrain [61].Arts-based KT is referred to as the use of any artistic form (i.e. dance, theatre, visual art, videos) to convey knowledge with the intent of affect a positive change in a health related outcome [42, 62].

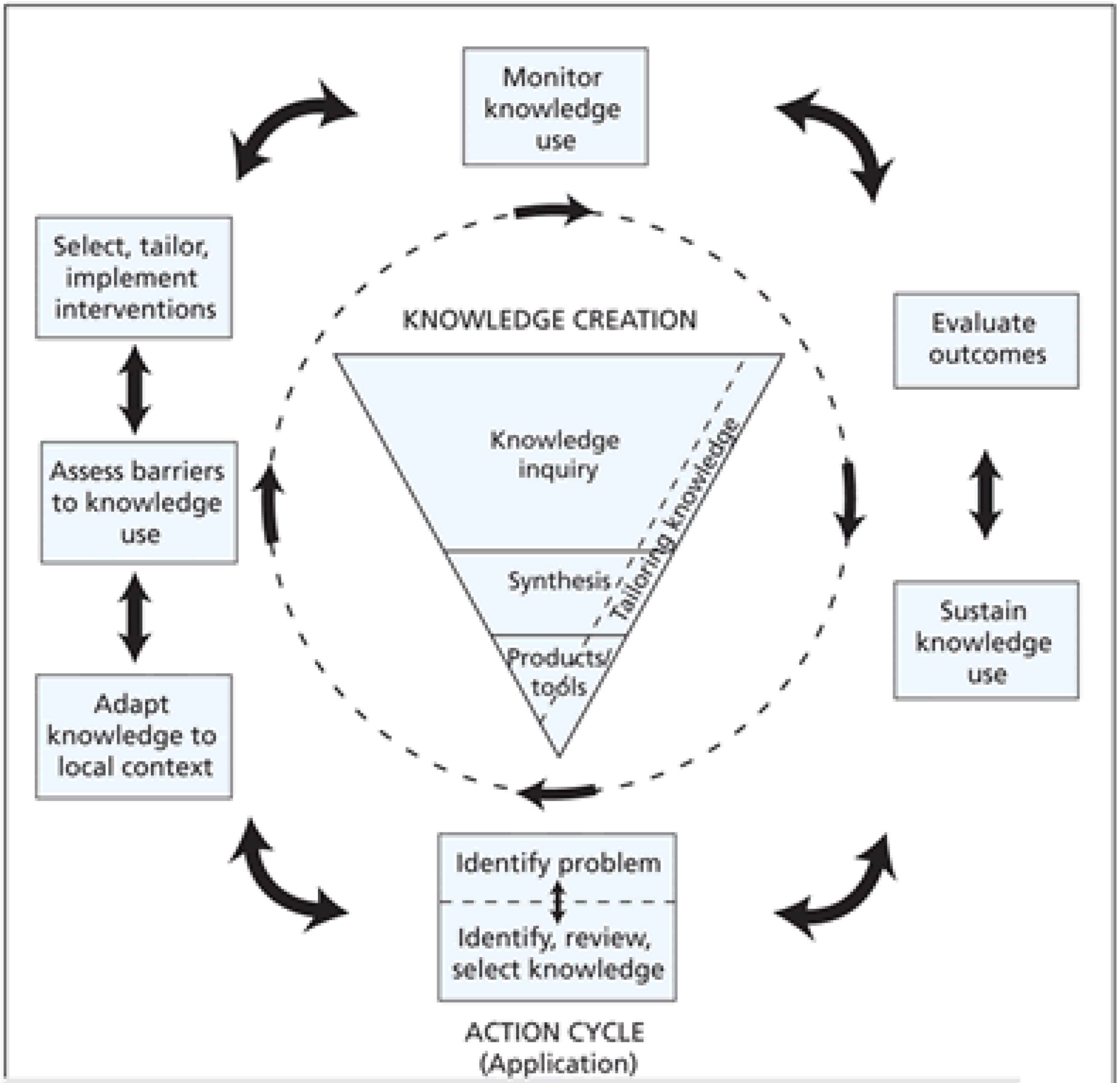
It has been suggested that providing evidence-based child health information to health consumers, such as patients and families has the power to increase effective health decision-making and reduce health system costs [39]. However, there is little guidance on the most effective approach to health education for these diverse populations [63, 64]. Poor comprehension of health information may be due to many factors. For instance, verbal information is typically brief, and written information is often too complex [65-67]. Previous research has found that key health literacy attributes include comprehension, communication, and appropriate health decision-making [68-70]. However, further research is needed on the most effective design and delivery of health education interventions, supporting the need for this work [71].

Knowledge to Action Framework

It is recognized that theory is necessary for KT to develop useful interventions, and numerous theories and models exist to inform KT science [72]. The Knowledge-to-Action

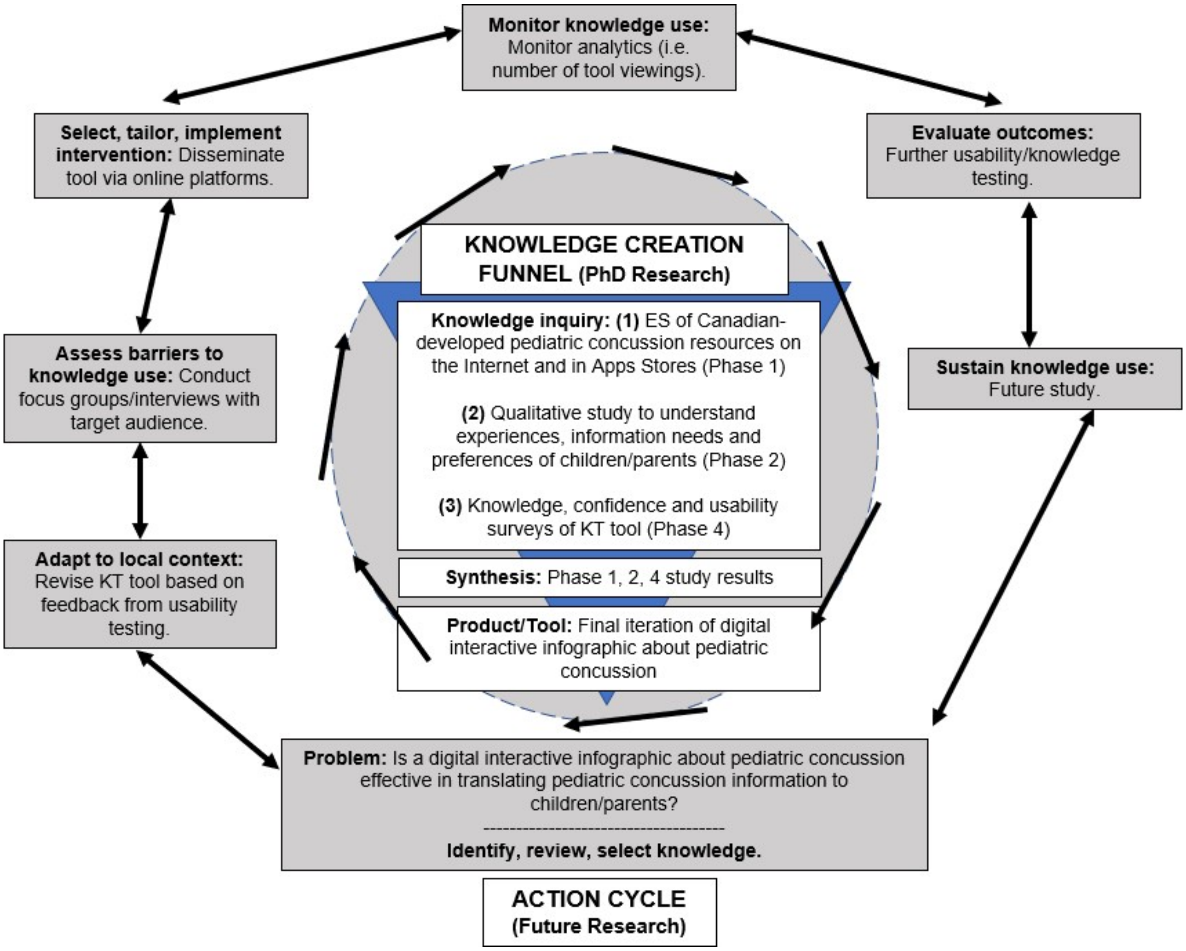
Framework (KTA) is a highly utilized model depicting the iterative process of creating and applying knowledge [49] (Figure 1.1). The KTA framework provides an approach that builds on the commonalities found in 31 interdisciplinary planned action theories. The KTA cycle within the KTA framework has been adopted by the Canadian Institutes of Health Research (CIHR) as the accepted model for promoting the application of research and a framework for the process of KT and is highly relevant to my dissertation [49]. Knowledge creation is at the center of the framework and is surrounded by an action cycle, comprised of several knowledge application steps. According to the KTA framework, knowledge becomes more useful to end-users as it is "filtered" through three knowledge-tailoring processes of knowledge inquiry, knowledge synthesis and knowledge tools or products. Tailoring and filtering knowledge to enhance relevancy and usefulness to end-users is essential to my research. The KTA Framework functions as a dynamic, iterative and non-linear process to develop, design, deliver and evaluate interventions to implement the knowledge created [73-75]. The entirety of this PhD research is situated within the knowledge creation funnel. Upon implementation of the KT tool developed from this research into practice, the action cycle can be triggered. Figure 1.2 maps this body of work to the Knowledge-to-Action Framework.

Figure 1.1 Knowledge to Action Framework



Graham I, et al. *The Journal of Continuing Education in the Health Professions*, Volume 26, pp. 13–24. 2006

Figure 1.2 PhD Research Mapped to Knowledge to Action Cycle



Research Motivation

My motivation to pursue this dissertation stems from my experience as a registered nurse. As a pediatric nurse, I experienced first-hand the frustration and challenges families faced in finding accurate health information for their children, for even the most common childhood conditions, and in formats and languages they could easily navigate and understand.

Information has never been more abundant or accessible, especially with the rapid increase in the conduct of research and expansion of the Internet [76]. However, the most current research evidence is often inaccessible to the public, and many individuals are not equipped to assess the quality of evidence that is available. Finding ways to help patients and families navigate these complexities became a meaningful endeavor for me. I became aware of the shortcomings in how information is provided to patients and families which led me to an interest in the field of KT. Within the context of this dissertation, the clinical complexity of childhood concussion, coupled with the increased prevalence of the injury, provided a rich opportunity to explore the potential of developing an innovative KT tool to improve the well being of children and families who experience concussions.

Dissertation Overview and Paper Summaries

To address the gap between what is known about childhood concussions and how it is managed by non-health care professionals (i.e., children and parents), I conducted a multi-phase, multi-method research project to develop a patient-driven, arts-based, innovative KT tool[2] for children who sustain concussions and their parents. The overarching purpose of this research was to develop a patient-driven, arts-based, innovative KT tool for children who sustain concussions and their parents based on their experiences, information needs, and preferences, while making substantive contributions to the field of KT interventions for patients and families. The four phases (three papers) of this research are summarized below. These inquiries contribute to understanding the major gaps in current resources for pediatric concussion, understanding the information needs of children who sustain concussions and their parents, and the effectiveness of web and arts based KT tools for families. The results of these inquiries will provide relevant foundational knowledge for future KT studies in related areas and form the basis for my future and emerging program of research. I visually represent these dissertation outputs and their status in Figure 1.3.

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[2] The terms intervention, strategy, tool, approach, and resource are used interchangeable throughout this dissertation in relation to knowledge translation.

The papers have been formatted to the specifications of the peer-reviewed journals in which they have been published or submitted. The first paper (Chapter 2) is the foundational work that formed the basis for the subsequent phases of this doctoral work. The second paper (Chapter 3), a qualitative description study, represents the second phase of this multi-phase study. The final paper (Chapter 4) represents the final two phases of this study (KT tool development and evaluation).

Paper One: Internet resources and Apps about pediatric concussion developed in Canada: An environmental scan

In this environmental scan, I aimed to identify resources developed in Canada, that provide information specific to pediatric concussion. Once these resources were identified I extracted information from each resource to identify common resource gaps. This scan enabled an understanding of what resources are currently available for pediatric concussion and what gaps exist in relation to these resources that could potentially be filled through the development of a new KT tool. This scan was foundational to this dissertation. An environmental scan is a method to organize and collect information about phenomena by checking ("scanning") the environment for existing sources of information [77]. For this environmental scan, three main sources were sequentially searched for Canadian-developed resources on pediatric concussion: publicly indexed websites (found through Google Search Engine) and two App stores (Apple App, Google Play). Six phone consultations with key informants at known concussion organizations were conducted to further inquire about resources meeting the inclusion criteria. Resources were assessed using the Suitability Assessment of Materials (SAM) scoresheet which systematically scores the readability, usability, and suitability of health information [78]. Three hundred websites and two hundred Apps were searched. Fifty-three resources meeting pre-determined inclusion criteria were included in the scan. The findings of this scan illustrated gaps in relation to the main audiences these tools target, the main formats these tools are available in and the main content these tools provide. These gaps informed decisions for the subsequent phases of the research including the target audience for qualitative interviews (paper 2), and the target audience, format, and content for the KT tool (paper 3). While not the focus of this paper, I developed expertise in the methods for conducting environmental scans which are not well established for small-scale research projects in the health sciences.

This paper is under review:

Campbell, A., Plourde, V., Hartling, L., Bains, A., and Scott, S.D. (2021) "An environmental scan of Canadian Internet resources and Apps about pediatric concussion." *CMAJ Open.*

Paper Two: You Can't Fix Your Brain: A Qualitative Study Exploring the Experiences of Children with Concussion and Their Parents

The next step in this dissertation was to conduct a qualitative description study [79] exploring the experiences, information needs and preferences of children who have sustained a concussion, and their parents. The target audience for this qualitative study was informed by the environmental scan, which revealed a gap in resources specifically targeting children and parents. The overarching research questions guiding this inquiry were (I) what are the information needs of children who have sustained a concussion, and their parents? and (II) what are the educational preferences of children who have sustained a concussion and their parents? Along with understanding these information needs and preferences, I was also interested in gaining insight into the broader experiential context of managing a concussion, from the perspective of children and of parents. I used a qualitative description approach [79] to guide this inquiry as this approach allows for rich and literal descriptions of experiences and perspectives from participants.

Due to restrictions because of the COVID-19 pandemic, participants were recruited by self-identifying themselves via social media platforms. I conducted 14 semi-structured interviews via Zoom [80] with children who have sustained a concussion and their parents. Through thematic analysis, four major themes were identified regarding the experiences, information needs and preferences of children who have had a concussion and their parents: 1) mechanism of injury and concussion symptoms experienced by children, 2) parent concerns, emotions and health care experience with child's concussion, 3) concussions affect more than just your head and, 4) health information seeking and preferences of parents and children related to concussion.

To our knowledge, this is the first qualitative study to explicitly research the experiences, information needs and preferences of children who sustain concussions, and their parents. Findings illuminate that children and parents have unique and unmet information needs and information deficits regarding concussion. The findings from this inquiry further informed the content and format of the developed KT tool.

This paper is accepted as:

Campbell, A., Plourde, V., Hartling, L., and Scott, S.D. (29 July, 2021) "You Can't Fix Your Brain: Exploring Concussion Experiences of Children and Parents" *Journal for Specialists in Pediatric Nursing*.

Paper Three: The Development and Usability Evaluation of a Web-Based Infographic for Pediatric Concussion: A Multi-Method Study

Paper three describes the development, usability, and evaluation of the KT tool (phases 3 and 4). In collaboration with a creative team, an arts-based online KT tool (infographic) for children and parents about pediatric concussion was developed. The prototype was developed based on current best practice guidelines for pediatric concussion, and in response to the resource information gaps identified in the environmental scan (phase 1) and the experiences, information needs and preferences identified by children and parents in the qualitative interviews (phase 2). The KT tool prototype underwent revisions based on feedback from parents and youth. Snapshots of the final iteration of the KT tool can be found in Appendix A.

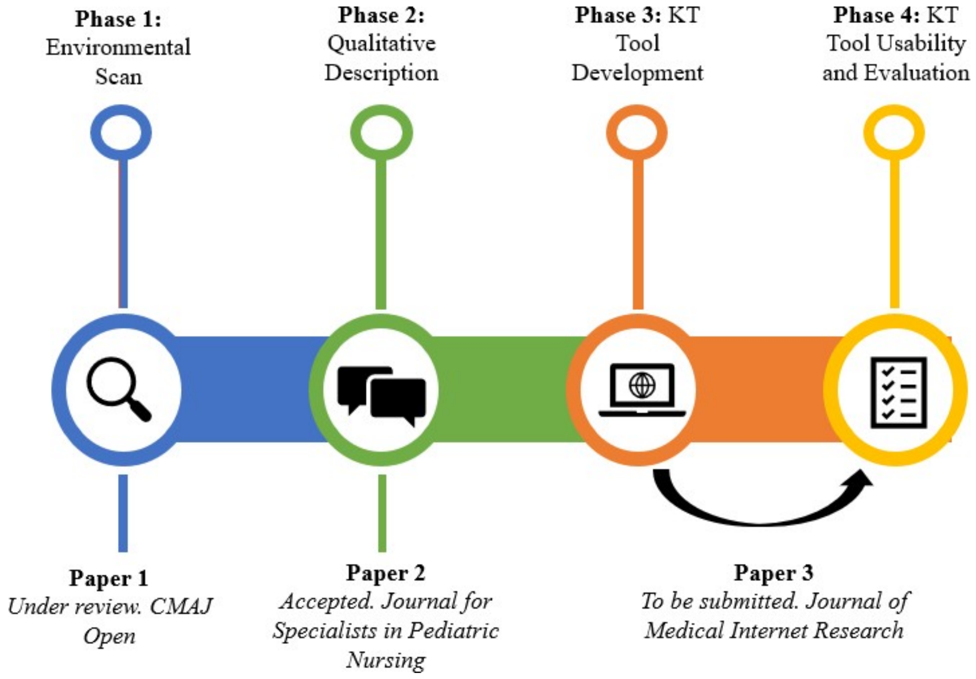
A link to the infographic, usability test, and pre and post knowledge tests were emailed to potential participants. Participants were asked to complete a Web-based survey that assessed their perceptions of the infographic. To evaluate knowledge of pediatric concussion, participants were asked to answer 10 true or false knowledge questions reflecting the most common misunderstandings about concussion and to rate their level of confidence in their responses before viewing the infographic. After completing the baseline knowledge test, participants were invited to read the infographic, and knowledge and confidence questions were answered again to assess short-term knowledge changes. To date, limited research has explored the usefulness and effectiveness of using Web-based infographics as an innovative way to share health information.

The finalized infographic was disseminated through established social media platforms including ECHO Research's Instagram, Twitter, Facebook and website (www.echokt.ca) and TREKK (www.trekk.ca), which is a national network of health professionals whose goals are to improve emergency care for children.

This paper is ready to submit as:

Campbell, A., Hartling, L., Plourde, V., and Scott, S.D. (2021) "The Development and Parental Evaluation of a Web-Based Infographic for Pediatric Concussion: A Multi-Method Study" *Journal of Medical Internet Research.*

Figure 1.3 Overview of Dissertation Phases and Outputs



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CHAPTER 2.

Paper 1: An environmental scan of Canadian Internet resources and Apps about pediatric concussion

This paper is under review as:

Campbell, A., Plourde, V., Hartling, L., Bains, A., and Scott, S.D. (2021) “An environmental scan of Canadian Internet resources and Apps about pediatric concussion.” *CMAJ Open.*

Abstract

Background: Over 100,000 Canadian youth sustain a concussion annually. Resources are available about childhood concussion; however, uncertainty in how to manage them persists, particularly among families. Further, knowing which resources are relevant and accurate is unclear. Internet and smartphone applications are readily accessible to many Canadians, allowing access to health information, including resources about pediatric concussion. Information gaps related to these resources need to be examined to improve knowledge translation surrounding pediatric concussion. The purpose of this environmental scan was to identify Canadian-developed Internet resources and Apps for pediatric concussion, identify resource gaps, and assess resource suitability.

Methods: Environmental scan of Google, Apple App Store and Google Play. Key informants from Canadian concussion organizations were interviewed to further inquire about identified resources. Resources meeting the inclusion criteria were evaluated using the Suitability Assessment of Materials (SAM).

Results: 600 websites and 200 Apps were searched. 67 resources (64 Internet, 3 Apps) were included. Target audiences included parents, health care professionals, teachers, coaches, and youth. Symptoms, treatment, and return-to-play information was the most common content. The most common formats were PDFs and infographics. SAM scores ranged from 36.8% to 97.2%.

Interpretation: Few resources targeted children. Only one resource shared a personal experience with concussion. To enhance relevance, cultural appropriateness and sensemaking the knowledge and perspectives of those using these resources should be incorporated into their development. More creative and innovative formats should also be utilized to enhance the overall usefulness and effectiveness of these resources.

Introduction

Approximately 125,000 Canadian youth will sustain a concussion annually [1-3]. Youth (< 18) account for the highest incidences of concussion in Canada, and that prevalence is rapidly growing. Concussions, (mild traumatic brain injuries) are complex, and may result in non-specific physical, cognitive, sleep and emotional symptoms [4, 5]. Thankfully, most children recover between 1-4 weeks post-injury [1]. Canadian organizations have developed supports and initiatives aimed at national standardization of concussion response and management [6]. While these efforts indicate progress is being made in Canada for concussions, a clear disconnect remains between concussion knowledge and practice. A 2017 survey commissioned by the Public Health Agency of Canada found approximately 50% of Canadians reported having little to no knowledge about concussions, and do not know where to find information on how to prevent one [7]. This is true for physicians, coaches, teachers, athletes, and parents [8-12]. The prevailing knowledge gap across audiences who may be associated with concussion has made it challenging to access information that is accurate, reliable, and trustworthy. Furthermore, little information exists evaluating concussion educational resources with the goal to better translate concussion knowledge to the public [13]. A recent Canadian survey noted approximately half of Canadians use the Internet to help make informed decisions about their health [14, 15]. Additionally, it was noted that 76% of Canadians own a smart phone [14]. These platforms can offer exciting new ways to deliver information pertinent to an individual's health and well-being.

The objective of this environmental scan (ES) was to identify and describe Canadian-developed Internet resources and smartphone applications, providing information specific to pediatric concussion. We identified gaps in these resources (i.e. target audience, content, format) and evaluated them with respect to their readability, usability, and suitability of pediatric concussion information. Telephone interviews with key informants from recognized concussion organizations in Canada supplemented the scan. To date, there is limited research exploring concussion education resources [15, 16]. No research has been conducted exploring both Internet resources and Apps addressing pediatric concussion and developed in Canada. Effectively translating concussion evidence to address knowledge gaps can improve knowledge uptake, concussion care, and outcomes [17]. The information gaps identified will inform the development of new resources.

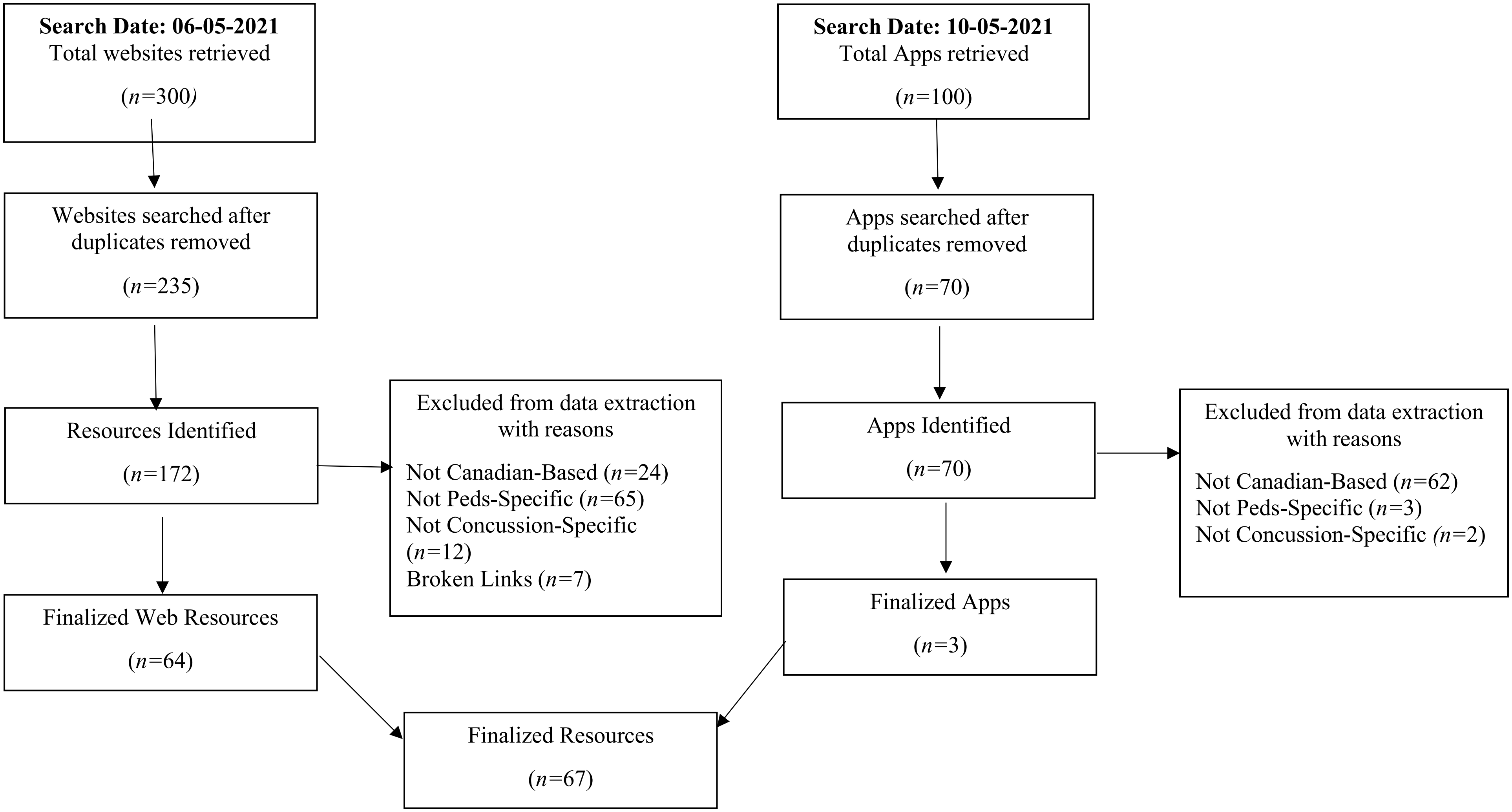
Methods

We conducted an ES to organize and collect information about Canadian-developed pediatric concussion resources, using three main sources: publicly indexed websites, two App stores (Apple App, Google Play) and phone interviews with key informants[18].

Procedures

Phase 1: Webpage and App Store Searches. The searches were conducted by AC (May 2021). Peer-reviewed literature and expert consultation informed the search terms. Using Google's Advanced Search, the following terms were used independently: (i) pediatric concussion information, (ii) pediatric concussion guides, (iii) child concussion. Given the dynamic PageRank algorithm used as the basis for Google's search engine, results of each search were monitored over 24 hours to reduce the chance of changes in findings based on previous searches. The first 100 results from each search string were reviewed for resources [19]. For Apple and Google Play Apps, the search term *"concussion"* was used. The first 50 Apps from each App store were reviewed for resources [19] (Fig 2.1).

Figure 2.1 Flow diagram of search strategy



Selection of Eligible Resources. The following inclusion criteria were applied to resources: (a) Canadian-developed, (b) entire resource (not just a section of a resource) provides any concussion information (i.e. symptoms, management, return-to-learn, etc.) for children under 18 years old, (c) resource targets children/youth, parents/caregivers, teachers, coaches/athletic trainers or health care professionals (HCPs). Resources were excluded if they were not developed in Canada or did not provide information exclusively about pediatric concussion (i.e. entire resource was about "concussion" but not specific to pediatrics). We chose to only look at Canadian-developed resources to maintain consistencies as health practices may differ across health systems [20].

Phase 2: Key Informant Interviews. The Internet and App searches were supplemented by interviewing key informants from organizations identified in our scan. Key informants were identified as those who coordinated research and knowledge dissemination activities. Potential informants were contacted by email through an open letter of invitation and invited to contact AC for more information. An attempt was made to contact a key informant from each organization (n=18), with a follow-up in 1-2 weeks if there was no response.

Data Collection

Phase 1: Internet and App Search. Characteristics of each resource were collected at the time of resource identification by AC into spreadsheets on Excel 2016 [21]. AB confirmed the data extraction. Resource characteristics included resource name, organization, URL, date created/updated, format, target audience, content, and evidence source. Resources were determined to be evidence-based if they directly cited or referred to empirical evidence.

Phase 2: Key Informant Interviews. Interview questions focused on information that could not be obtained by reviewing the resource (i.e., how the resources are developed and by who) (Appendix B). Telephone interviews were conducted by AC. De-identified, detailed field notes were taken. Interviews were not recorded. All informants provided written, informed consent prior to each interview.

Resource Evaluation. Included resources were assessed using the Suitability Assessment of Materials (SAM) scoresheet [22, 23] which assesses readability, usability and suitability of health information and has been used to evaluate online concussion resources [15, 22-24]. The SAM assessed resources on 21 factors within 6 domains [23] *scoring* on a 3-point scale (0=not suitable, 1=adequate, 2=superior) (Table 2.1). Factor scores are then summed, creating a total score reported as percentage, where 0-39% is not suitable, 40%-69% is adequate and 70-100% is superior [22, 23]. Resources were not excluded based on their SAM score. AB scored each resource with AC scoring a random 10% for consistency. Any discrepancies were discussed and determined by a third party (SS).

Table 2.1 Suitability Assessment of Materials (SAM) readability, suitability and usability domains.

SAM Domain	Number of Factors
Content	3
Literacy Demand	5
Graphics	5
Layout and Type	3
Learning Simulation & Motivation	3
Cultural Appropriateness	2

Data Analysis

Phase 1: Web and App Store Searches. Data describing each resource were presented in summary tables. Where appropriate, descriptive statistics were used.

Phase 2: Key Informant Interviews. After each interview, field notes were reviewed. Phrases in the text were identified and codes were developed to represent key concepts. Codes were then grouped into categories and themes through content analysis by AC. Any missing information about the resources that were noted through key informant interviews were added to the summary tables.

Ethics Approval. Ethics approval was granted by the University of Alberta Health Research Ethics Board (Pro0096202).

Results

Phase 1: Web Search

A total of 300 websites were scanned (100 from each search term). 235 websites were fully scanned once duplicates were removed. From these websites, 172 resources were identified with 64 meeting the inclusion criteria (Fig 2.1). One resource (WEB05) is a group of resources categorized by audience. For this ES, it has been counted as one resource. (Tables 2.2-2.3).

Resource target audience. Twenty-seven resources (42.2%) did not have a specific target audience. However, two of these resources were specific to those involved in hockey or soccer. Parents/caregivers were the most common target audience (n=17, 26.6%), followed by HCPs (n=6, 11.8%), children/youth (n=4, 6.3%), teachers/educators (n=3, 4.7%), and coaches/athletic trainers (n=2, 3.1%). One of the youth resources was specifically for youth athletes. The remaining 5 resources (7.8%) were suitable for more than one audience.

Resource content. Most resources provided a variety of content, not just one specific subject. Over half provided some symptom information (n=40, 62.5%). Treatment (n=29, 45.3%), return-to-play (n=26, 40.6%), return-to learn (n=24, 37.5%), recovery (n=19, 29.7%), assessment (n=17, 26.6%) and when to seek medical attention (n=16, 25.0%), were the most common content. Two resources (3.1%) were about a patient or family experience. Three resources (4.7%) provided information on post-concussion syndrome (PCS). Other information included causes (n=12, 18.8%), prevention (n=14, 21.8%), and general pediatric concussion myths or facts (n=8, 12.5%).

Resource format. The most common formats were handouts (n=26, 40.6%), PDF information booklets (n=9, 14.1%) and infographics (n=9, 14.1%). Five resources were guidelines, or policies specifically tailored for pediatrics (7.8%). Three resources were online learning modules (4.7%). Other formats included assessment tools (n=2), slideshow presentations (n=2), government reports (n=2) and videos (n=2). Podcasts, whiteboard animation videos, online brochures and blog posts were not common with only one resource of each.

Evidence base. Nearly half of the resources (n=31, 48.4%) were evidence-based. For 31 resources (48.4%) it was unclear if the information was evidence-based. The evidence base for two resources was not applicable as they were patient experiences. Of the resources that were clearly evidence based, 16 (51.6%) have not been updated since release of the latest guidelines [5].

Resource evaluation. Total SAM scores varied from 37.5% to 97.2% (M=70.4%) (Table 2). Many of these resources had superior scores in content and layout/type domains. In the content domain, most resources had superior scores for purpose (n=54, 84.4%) and content topic (n=47, 73.4%) factors. In the layout and type domain, many resources had superior scores for typography (n=60, 93.8%) and layout (n=45, 70.3%) factors. The graphics domain consistently had lower scores (i.e. adequate or not suitable), for all six factors, as most resources were text-heavy, with only one or two cover graphics. Additionally, the cultural appropriateness domain often scored “adequate” or “not applicable” for both logic, language, and experience, and cultural image and examples factors. Scores varied for all factors in the literacy demand and learning simulation and motivation domains. (Tables 2.4-2.5).

Table 2.2 Characteristics of web resources

Resource ID	Title	Organization (Province)	Year Updated	Clear Evidence Base	Format	Target Audience£	Target Content¥	SAM Score (%)
WEB01	Bottom Line Recommendations: Concussion	Translating Emergency Knowledge for Kids (TREKK) (Alberta)	2015	Yes	Handout	B	1, 3, 5, 8	47.1
WEB02	Head Injury	HEAL (health education and learning) Alberta Health Services (Alberta)	ND*	Unclear	Handout	A	1, 3, 4	80.6
WEB03	Concussion Among Children and Youth in British Colombia	BC Injury Research and Prevention Unit/ Child Health BC (British Colombia)	2013	Unclear	Report	F	12	41.7
WEB04	Concussion Among Children and Youth: Fraser Health Authority	BC Injury Research and Prevention Unit (British Colombia)	2015	Unclear	Report	F	12	50.0
WEB05	Concussion Awareness Training Toolkit (CATT)	BC Injury Research and Prevention Unit/Child Health BC (British Colombia)	2019	Yes	Online Modules	A, B, C, D, E (module specific)	1, 3, 5, 6	97.2

WEB06	Head Injury-Advice for Parents and Caregivers	BC Children's Hospital (British Colombia)	2014	Unclear	Handout	A	1, 3, 6, 7, 9	81.6
WEB07	Brain Injury Guide for Youth: A Guide to help you understand the effects of brain injury	Teen Mental Health (Sun Life Financial Chair in Adolescent and Teen Mental Health) (Nova Scotia)	ND	Yes	Information Booklet	F	1, 3, 4, 5	76.3
WEB08	What you Need to Know: Concussions	Children's Hospital of Eastern Ontario (CHEO) (Ontario)	2019	Unclear	Handout	F	1, 2, 3, 4, 6, 7, 10	86.8
WEB09	Making Head Way-Concussion eLearning Series (Sport: Generic; Soccer; Snowboard; Speed Skating; Freestyle Ski; Football)	Coaching Association of Canada (Ontario)	2014	Unclear	Online Modules	D	12	88.9
WEB10	Concussion: managing your child's return to everyday activities	Toronto Sick Kids, About Kids Health (Ontario)	2017	Unclear	Handout	A	1, 3, 8, 9	71.1
WEB11	Head injury and concussion	Toronto Sick Kids, About Kids Health (Ontario)	2019	Unclear	Handout	A	1, 3, 9	73.7
WEB12	Two-thirds of children with concussions don't	York University, Institute for Clinical	2017	Yes	Infographic	F	12	61.1

	get recommended follow up care	Evaluative Sciences (ICES) (Ontario)						
WEB13	A Parent's Guide to Dealing With Concussions	Parachute Canada (Ontario)	ND	Yes	Handout	A	3, 12	67.5
WEB14	Concussion Education for Teachers	Ontario Medical Association/OPHEA Healthy Schools, Healthy Communities (Ontario)	ND	Yes	Online Slideshow	C	1, 4, 5, 10	65.0
WEB15	Concussion Children and Youth Mild Traumatic Brain Injury (mTBI)	Ontario Brian Injury Association (Ontario)	2017	Yes	Information Booklet	A	1, 8, 6, 7	65.0
WEB16	Episode 3: Pediatric Head Injury	Emergency Medicine Cases (Ontario)	2010	Yes	Podcast	B	3, 5, 7, 8	38.9
WEB17	Sleep Tips to Recover From a Concussion	Holland Bloorview Kids Rehabilitation Hospital (Ontario)	2015	Unclear	Infographic	F	8	94.1
WEB18	How to Conserve Energy After a Concussion	Holland Bloorview Kids Rehabilitation Hospital (Ontario)	2015	Unclear	Infographic	F	8	94.1
WEB19	Concussion Myths vs Facts	Holland Bloorview Kids Rehabilitation Hospital (Ontario)	2015	Unclear	Infographic	F	12	81.6
WEB20	I think I Have a Concussion? How Can I Get Better?	Holland Bloorview Kids Rehabilitation Hospital (Ontario)	2015	Unclear	Infographic	E	3	89.5
WEB21	Signs of Concussion	Holland Bloorview Kids Rehabilitation Hospital (Ontario)	2015	Unclear	Infographic	F	1	60.5

WEB22	6 Things You Should Know About Concussions	Holland Bloorview Kids Rehabilitation Hospital (Ontario)	2015	Unclear	Infographic	F	12	66.7
WEB23	SCHOOLFirst: Enabling Successful Return-to-School for Canadian Youth Following a Concussion	Holland Bloorview Kids Rehabilitation Hospital (Ontario)	2018	Yes	Information Booklet/ Online Module	F	1, 5, 6, 8	78.9
WEB24	GTHL Concussion Policy	Greater Toronto Hockey League (GTHL)/ Holland Bloorview Kids Rehabilitation Hospital (Ontario)	2019	Yes	Guidelines/ Policy	F (hockey specific)	1, 3, 5, 7	56.3
WEB25	TSA Concussion Policy	Toronto Soccer Association (TSA)/ Holland Bloorview Kids Rehabilitation Hospital (Ontario)	2019	Yes	Guidelines/ Policy	F (soccer specific)	1, 3, 5, 7	38.9
WEB26	Ophea's Concussion Identification, Management and Prevention for Schools 2018/19 e-learning module	Ophea (Healthy Schools, Healthy Communities), Parachute Canada (Ontario)	2018	Unclear	Online Module	C	1, 4, 6, 7	52.8
WEB27	Concussion & You: A Handbook for Parents and Kids	Holland Bloorview Kids Rehabilitation Hospital (Ontario)	ND	Yes	Information Booklet	A, C, D, E	1, 3, 6, 7, 8	94.7
WEB28	Sport-related concussion: Information for	Canadian Pediatric Society/Caring For Kids (Ontario)	2014	Yes	Handout	F	1, 2, 3, 4, 6, 7, 8, 9	72.2

	parents, coaches and trainers							
WEB29	Love Your Brain Like You Love Your Game	CanChild/McMaster University (Ontario)	2019	Not Applicable	Video	F	11	81.8
WEB30	Return to Activity Guidelines for Children/Youth	CanChild/McMaster University (Ontario)	2018	Yes	Handout	F	1, 3, 7	71.1
WEB31	Activity Suggestions for Recovery Steps After Concussion	CanChild/McMaster University (Ontario)	ND	Unclear	Handout	F	7	63.9
WEB32	Mild Traumatic Brain Injury/Concussion-Infants and Toddlers	CanChild/McMaster University (Ontario)	2012	Unclear	Brochure	A	1, 3, 4	50.0
WEB33	Return to School Guidelines for Children and Youth	CanChild/McMaster University (Ontario)	2018	Unclear	Handout	F	1, 6, 7	71.1
WEB34	Understanding and Managing Concussion in Youth (3rd Edition): Concussion KiT	Montreal Children's Hospital, McGill University Health Centre (Ontario)	2018	Yes	Information Booklet	F	1, 3, 6, 7	92.1
WEB35	Pediatric Concussions: Latest Approach to Management	Montreal Children's Hospital, McGill University Health Centre (Ontario)	2013	Yes	Online Slideshow	B	1, 2, 3, 5	45.0
WEB36	Concussions 101, A Primer for Kids and Parents	ReFrame Health Lab (Ontario)	2011	Yes	Whiteboard animation	A, E	1, 2, 6, 7	76.9
WEB37	Strategy for Return to School After a Concussion	Parachute Canada (Ontario)	2019	Yes	Infographic	F	6	84.2
WEB38	Concussion Guide for Athletes	Parachute Canada (Ontario)	2019	Unclear	Handout	E (athlete-specific)	1, 2, 3, 6, 7, 8, 9	84.2

WEB39	Concussion Guide for Coaches and Trainers	Parachute Canada (Ontario)	2019	Unclear	Handout	D	1, 2, 3, 6, 7, 8, 9	84.2
WEB40	Concussion Guide for Teachers	Parachute Canada (Ontario)	2019	Unclear	Handout	C	1, 2, 3, 6, 7, 8, 9	84.2
WEB41	Concussion Guide for Parents and Caregivers	Parachute Canada (Ontario)	2019	Unclear	Handout	A	1, 2, 3, 6, 7, 8, 9	84.2
WEB42	Child Sport Concussion Assessment Tool (SCAT5)	BC Injury Research and Prevention Unit/ Child Health BC/ BC Children's Hospital (British Colombia)	2020	Yes	Assessment Tool	B	5	85.3
WEB43	Sport Concussion Assessment Tool (SCAT5)	BC Injury Research and Prevention Unit/ Child Health BC/ BC Children's Hospital (British Colombia)	2020	Yes	Assessment Tool	B	5	85.3
WEB44	Living Guideline for Diagnosing and Managing Pediatric Concussion	Ontario Neurotrauma Foundation (Ontario)	2019	Yes	Guidelines	B, F	1, 3, 5, 6, 7, 8, 9	52.6
WEB45	Provincial Clinical Knowledge Topic: Concussion, Pediatric Emergency Version 1	Alberta Health Services (Alberta)	2020	Yes	Guidelines	B	1, 3, 5, 6, 7, 8	63.2
WEB46	Kids-Concussions and Head Injuries	Alberta Health Services (Alberta)	2019	Yes	Handout	A	1, 3, 6, 7	64.3
WEB47	Concussion in Sport: Sport and Recreation-Related Traumatic Brain Injuries Among Canadian Children and Youth	Government of Canada (National)	ND	Yes	Infographic	F	12	60.0

WEB48	Concussion in Children Under the Age of 6	Saskatchewan Prevention Institute (Saskatchewan)	2019	Yes	Handout	F	1, 2, 3, 4	56.7
WEB49	Concussion Conversation	Saskatchewan Prevention Institute (Saskatchewan)	2021	Yes	Video	F	1, 2, 4, 5, 9	39.3
WEB50	Return to School	BC Injury Research and Prevention Unit (British Colombia)	2019	Yes	Guidelines	F	6	65.6
WEB51	Head Injury in Pre-School Children (0-5 years)	CHU Sainte-Justine (Quebec)	ND	Yes	Handout	A	1, 3, 4, 9	68.8
WEB52	Concussion (Minor Head Injury) in Children	Fraser Health Authority (British Colombia)	2021	Yes	Handout	A	5, 6, 7, 8, 9	81.6
WEB53	Concussions and Head Injuries in Children: Care Instructions	Maternal Newborn Child and Youth Strategic Clinical Network, Alberta Health Services (Alberta)	2019	Yes	Handout	F	2, 8, 9	58.3
WEB54	Chiropractic: A Piece of The Puzzle In Dealing With Your Child's Concussion	Alberta College and Association of Chiropractors (Alberta)	ND	Unclear	Handout	F	1, 10	37.5
WEB55	Parent's Pathway for Child and Youth Concussion	York Region Public Health (Ontario)	ND	Unclear	Handout	A	1, 5, 6, 7, 8, 9	65.0
WEB56	Concussion Guide for Parents: It's better to Miss One Game Than the Whole Season	Renfrew County District Public School (Ontario)	ND	Unclear	Handout	A	1, 2, 3, 4, 7, 9	81.6

WEB57	Caring For Your Child With A Concussion	McMaster Children's Hospital (Ontario)	2017	Unclear	Handout	A	1, 6, 7, 8, 9	90.0
WEB58	Blog: The Lasting Impact of Childhood Concussions: Harley's Story	Child Safety Link/IWK (Nova Scotia)	2021	Not applicable	Blog Post	F	11	56.3
WEB59	Kids And Concussion: The Facts Every Parent Should Know	BC Parent (British Colombia)	2021	Yes	Handout	A	12	59.0
WEB60	Concussions: Frequently Asked Questions for Parents	Halton Catholic School District Board (Ontario)	ND	Unclear	Handout	A	12	55.9
WEB61	Concussion Protocol: Parent/Guardian Information Package	Halton Catholic School District Board (Ontario)	2014	Unclear	Information Booklet	A	1, 2, 5, 6, 7	55.2
WEB62	Concussion Awareness Resource: Rowan's Law (15 and up)	Government of Ontario (Ontario)	ND	Unclear	Information Booklet	A, E	1, 4, 5, 8	93.0
WEB63	Concussion Awareness Resource: Rowan's Law (11-14)	Government of Ontario (Ontario)	ND	Unclear	Information Booklet	E	1, 4, 5, 8	93.0
WEB64	Concussion Awareness Resource: Rowan's Law (under 10)	Government of Ontario (Ontario)	ND	Unclear	Information Booklet	E	1, 4, 5, 8	93.0

[£] Target audience A: Parent/Caregiver, B: Healthcare Professional, C: Teachers/Educators, D: Coaches/Athletic Trainers, E: Children/Youth, F: General/Not-Specified

[¥] Target content 1: Symptoms, 2: Causes, 3: Treatment, 4: Prevention, 5: Assessment, 6: Return-to-learn, 7: Return-to-play/return-to-sport, 8: Recovery process, 9: When to Seek Medical Attention, 10: Post-Concussion Syndrome, 11: Experience, 12: Other-Myths or General Facts

*ND=no date

Table 2.3 Internet resource title and URL

Resource ID	Title	URL
WEB01	Bottom Line Recommendations: Concussion	https://trekk.ca/system/assets/assets/attachments/257/original/2018-07-25_Concussion_BLR_v2.1.pdf?1535048007
WEB02	Head Injury	https://www.albertahealthservices.ca/assets/heal/heal-handout-head-injury.pdf
WEB03	Concussion Among Children and Youth in British Colombia	https://www.childhealthindicatorsbc.ca/sites/default/files/15%2006%2022%20Concussion%20-%20Children%20and%20Youth%20Supplement%20FINAL.pdf
WEB04	Concussion Among Children and Youth: Fraser Health Authority	https://www.childhealthindicatorsbc.ca/sites/default/files/15%2012%20Concussion%20in%20Fraser%20Health.pdf
WEB05	Concussion Awareness Training Toolkit (CATT)	https://cattonline.com/
WEB06	Head Injury-Advice for Parents and Caregivers	http://www.bcchildrens.ca/Resource-Centre-site/Documents/G-H/BCCH1001_HeadInjury_2014.pdf
WEB07	Brain Injury Guide for Youth: A Guide to help you understand the effects of brain injury	https://www.ontarioshores.ca/UserFiles/Servers/Server_6/File/PDFs/bi_teen_guide_4.pdf
WEB08	What you Need to Know: Concussions	https://www.cheo.on.ca/en/resources-and-support/resources/P5015E.pdf
WEB09	Making Head Way- Concussion eLearning Series (Sport: Generic; Soccer; Snowboard; Speed Skating; Freestyle Ski; Football)	https://coach.ca/making-head-way-concussion-elearning-series
WEB10	Concussion: managing your child's return to everyday activities	https://www.aboutkidshealth.ca/Article?contentid=963&language=English
WEB11	Head injury and concussion	https://www.aboutkidshealth.ca/concussion
WEB12	Two-thirds of children with concussions don't get recommended follow up care	https://www.ices.on.ca/~/media/Images/News_releases/2017/July-Dec/MacphersonConcussion.ashx?la=en-CA

WEB13	A Parent's Guide to Dealing With Concussions	https://www.abipartnership.sk.ca/images/file/A%20parent%EF%BF%BDs%20guide%20to%20dealing%20with%20concussions%20%EF%BF%BD%20Parachute%20Canada.pdf
WEB14	Concussion Education for Teachers	http://sportsandexercisemedicine.ca/wp-content/uploads/2013/09/OPHEA_OMA-Presentation-for-Teachers-revised-Oct-2014.pdf
WEB15	Concussion Children and Youth Mild Traumatic Brain Injury (mTBI)	http://obia.ca/wp-content/uploads/2017/09/Concussion-resource-children-web-rev-Sept-2017.pdf
WEB16	Episode 3: Pediatric Head Injury	https://emergencymedicinecases.com/episode-3-pediatric-head-injury/
WEB17	Sleep Tips to Recover From a Concussion	https://hollandbloorview.ca/Assets/Concussion-center/Infographics.4.pdf
WEB18	How to Conserve Energy After a Concussion	https://hollandbloorview.ca/Assets/Concussion-center/Infographics.1.pdf
WEB19	Concussion Myths vs Facts	https://hollandbloorview.ca/Assets/Concussion-center/Infographics.2.pdf
WEB20	I think I Have a Concussion? How Can I Get Better?	http://hollandbloorview.ca/Assets/Concussion-center/Infographics.6.pdf
WEB21	Signs of Concussion	http://hollandbloorview.ca/Assets/Concussion-center/Infographics.3.pdf
WEB22	6 Things You Should Know About Concussions	http://hollandbloorview.ca/Assets/Concussion-center/Infographics.5.pdf
WEB23	SCHOOLFirst: Enabling Successful Return-to-School for Canadian Youth Following a Concussion	https://www.hollandbloorview.ca/sites/default/files/migrate/files/SCHOOLFirstHandbook-ENG.pdf
WEB24	GTHL Concussion Policy	https://d2pr6pnwfmh0za.cloudfront.net/app/uploads/gthl/2019/10/03141542/GTHL-Concussion-Policy-Full-Version-2019-20.pdf
WEB25	TSA Concussion Policy	http://www.torontosoccerassociation.ca/Content/directors/upimg/dir25854/2019%20tsa%20concussion%20policy.pdf

WEB26	Ophea's Concussion Identification, Management and Prevention for Schools 2018/19 e-learning module	https://www.ophea.net/node/6944
WEB27	Concussion & You: A Handbook for Parents and Kids	http://hollandbloorview.ca/Assets/Concussion-center/Concussion%20handbook%20March%202017%20-no%20crops.pdf
WEB28	Sport-related concussion: Information for parents, coaches and trainers	https://www.caringforkids.cps.ca/handouts/sport_related_concussion
WEB29	Love Your Brain Like You Love Your Game	https://vimeo.com/312201229
WEB30	Return to Activity Guidelines for Children/Youth	https://canchild.ca/system/tenon/assets/attachments/000/002/642/original/Return_to_Activity_Guideline_WEB_1_Reference.pdf
WEB31	Activity Suggestions for Recovery Steps After Concussion	https://canchild.ca/system/tenon/assets/attachments/000/000/287/original/Activity_Suggestion_Post_Brain_Injury.pdf
WEB32	Mild Traumatic Brain Injury/Concussion-Infants and Toddlers	https://canchild.ca/system/tenon/assets/attachments/000/000/290/original/MTBI_Infant_Toddler_Brochure.pdf
WEB33	Return to School Guidelines for Children and Youth	https://canchild.ca/system/tenon/assets/attachments/000/002/575/original/Return_to_School_Guideline_WEB_1_.pdf
WEB34	Understanding and Managing Concussion in Youth (3rd Edition): Concussion KiT	https://www.thechildren.com/sites/default/files/PDFs/Trauma/ConcussionKitInfo/16023-e_concussion_kit-brochure_web.pdf
WEB35	Pediatric Concussions: Latest Approach to Management	https://www.thechildren.com/sites/default/files/PDFs/Trauma/posttraumatic_headache_and_nerve_blocks.pdf
WEB36	Concussions 101, A Primer for Kids and Parents	https://www.reframehealthlab.com/concussions-101-a-primer-for-kids-and-parents/
WEB37	Strategy for Return to School After a Concussion	https://parachute.ca/wp-content/uploads/2019/06/Return-to-School-Strategy.pdf
WEB38	Concussion Guide for Athletes	http://www.parachutecanada.org/downloads/resources/Concussion-Athletes.pdf

WEB39	Concussion Guide for Coaches and Trainers	http://www.parachutecanada.org/downloads/resources/Concussion-Coaches.pdf
WEB40	Concussion Guide for Teachers	http://www.parachutecanada.org/downloads/resources/Concussion-Teachers.pdf
WEB41	Concussion Guide for Parents and Caregivers	https://parachute.ca/wp-content/uploads/2019/06/Concussion-Guide-for-Parents-and-Caregivers.pdf
WEB42	Child Sport Concussion Assessment Tool (SCAT5)	http://childscat5.cattonline.com/
WEB43	Sport Concussion Assessment Tool (SCAT5)	scat5.cattonline.com/
WEB44	Living Guideline for Diagnosing and Managing Pediatric Concussion	https://braininjuryguidelines.org/pediatricconcussion/wp-content/uploads/2019/09/Living-Guideline-for-Diagnosing-and-Managing-Pediatric-Concussion-v09.2019.pdf
WEB45	Provincial Clinical Knowledge Topic: Concussion, Pediatric Emergency Version 1	https://extranet.ahsnet.ca/teams/policydocuments/1/klink/et-klink-ckv-concussion-pediatric-emergency.pdf
WEB46	Kids-Concussions and Head Injuries	https://recoverconcussion.ca/pdf/concussion_handout_2019.pdf
WEB47	Concussion in Sport: Sport and Recreation-Related Traumatic Brain Injuries Among Canadian Children and Youth	https://www.canada.ca/content/dam/phac-aspc/documents/services/publications/diseases-conditions/PHAC-concussion-sport-infographic_may8-eng.pdf
WEB48	Concussion in Children Under the Age of 6	https://skprevention.ca/safety/brain-injury/
WEB49	Concussion Conversation	https://youtu.be/-TzzZ2r9E8s
WEB50	Return to School	https://cattonline.com/wp-content/uploads/2017/10/CATT-Return-to-School-V12-March-2019.pdf
WEB51	Head Injury in Pre-School Children (0-5 years)	https://www.chusj.org/getmedia/e0b2eabc-f101-4054-add4-42c020d3e07b/depliant_F-884A_TC-age-pre-scolaire.pdf.aspx?ext=.pdf
WEB52	Concussion (Minor Head Injury) in Children	https://patienteduc.fraserhealth.ca/file/concussion-minor-head-injury-in-children-3041.pdf

WEB53	Concussions and Head Injuries in Children: Care Instructions	https://myhealth.alberta.ca/health/AfterCareInformation/pages/conditions.aspx?hwid=custom.ab_concussion_ac_child
WEB54	Chiropractic: A Piece of The Puzzle In Dealing With Your Child's Concussion	https://albertachiro.com/ACAC/Chiropractic_in_Alberta/BLOG/Chiropractic_a_piece_of_the_puzzle_in_dealing_with_your_child_s_concussion_.aspx
WEB55	Parent's Pathway for Child and Youth Concussion	https://www.york.ca/wps/wcm/connect/yorkpublic/3a20174d-a189-4077-b7c8-e8e9cde4658d/Concussion+-+Parent+Pathway.pdf?MOD=AJPERES&CVID=mMGLJKt
WEB56	Concussion Guide for Parents: It's better to Miss One Game Than the Whole Season	http://adm.rcdsb.on.ca/en/resourcesGeneral/newsletter/Concussion-Guide-for-Parents-2.pdf
WEB57	Caring For Your Child With A Concussion	https://www.hamiltonhealthsciences.ca/wp-content/uploads/2019/08/ConcussionCaringForYourChild-lw.pdf
WEB58	Blog: The Lasting Impact of Childhood Concussions: Harley's Story	https://childsafetylink.ca/csl-blog-the-lasting-impacts-of-childhood-concussions-harleys-story/
WEB59	Kids And Concussion: The Facts Every Parent Should Know	https://bcparent.ca/health/kids-and-concussion-the-facts-every-parent-should-know/
WEB60	Concussions: Frequently Asked Questions for Parents	https://www.hcdsb.org/wp-content/uploads/2021/01/Concussion-FAQ-For-Parents.pdf
WEB61	Concussion Protocol: Parent/Guardian Information Package	https://elem.hcdsb.org/holyrosaryburlington/wp-content/uploads/sites/58/2016/07/Parent-Guardian-Concussion-Information-Package.pdf
WEB62	Concussion Awareness Resource: Rowan's Law (15 and up)	https://www2.yrdsb.ca/sites/default/files/migrate/files/mtcs-rowans-law-booklet-ages-15-and-up-en-2019-05.pdf
WEB63	Concussion Awareness Resource: Rowan's Law (11-14)	https://www2.yrdsb.ca/sites/default/files/migrate/files/mtcs-rowans-law-booklet-ages-11-to-14-en-2019-05.pdf
WEB64	Concussion Awareness Resource: Rowan's Law (under 10)	https://www2.yrdsb.ca/sites/default/files/migrate/files/mtcs-rowans-law-booklet-ages-10-and-under-en-2019-05.pdf

Table 2.4 Ratings of individual SAM factors by resource ID

SAM Factor	Resource ID			
	Superior	**Adequate**	**Not Suitable**	**Not Applicable**
Content				
• Purpose	APP: 01, 02, 03 WEB: 01, 02, 03, 04, 05, 06, 07, 08, 09, 10, 11, 12, 13, 14, 15, 17, 18, 19, 20, 21, 22, 26, 28, 30, 31, 33, 34, 35, 36, 37, 38, 39, 40, 41, 42, 43, 44, 45, 46, 47, 48, 50, 51, 52, 53, 55, 56, 57, 59, 60, 61, 62, 63, 64	WEB: 16, 23, 24, 25, 27, 29, 32, 49, 54,	WEB: 58	-
• Content Topics	APP: 01, 03 WEB: 02, 05, 06, 07, 08, 09, 10, 11, 13, 14, 15, 17, 18, 20, 21, 23, 24, 25, 27, 28, 29, 30, 31, 32, 33, 34, 37, 38, 39, 40, 41, 42, 43, 45, 46, 47, 48, 50, 51, 52, 53, 55, 56, 57, 62, 63, 64	APP: 02 WEB: 01, 16, 19, 22, 26, 35, 36, 44, 49, 54, 58, 59, 60, 61,	WEB: 03, 04, 12	-
• Summary & Review	WEB: 03, 04, 05, 07, 09 10, 11, 14, 23, 26, 27, 29, 37, 42, 43, 50, 52, 57, 61, 621, 63, 64,	WEB: 06, 12, 25, 30, 33, 34, 35, 38, 39, 40, 41, 44, 49, 55,	APP: 01, 02, 03 WEB: 01, 02, 08, 13, 15, 16, 19, 21, 22, 24, 28, 31, 32, 36, 45, 46, 47, 48, 51, 53, 54, 56, 58, 59, 60,	WEB: 17, 18, 20
Literacy Demand				

• Reading Grade Level	APP: 02 WEB: 05, 06, 11, 17, 18, 19, 20, 21, 22, 27, 28, 31, 34, 36, 38, 39, 40, 41, 62, 63, 64,	APP: 01 WEB: 02, 04, 07, 08, 09, 10, 12, 13, 14, 23, 24, 26, 30, 32, 33, 37, 42, 43, 56,	APP: 03 WEB: 01, 03, 15, 16, 25, 35, 44, 45, 46, 47, 48, 49, 50, 51, 52, 53, 54, 55, 57, 58, 59, 60, 61,	WEB: 29
• Writing Style	APP: 01, WEB: 02, 05, 06, 07, 08, 09, 10, 11, 13, 17, 18, 19, 20, 22, 23, 27, 28, 29, 34, 36, 38, 39, 40, 41, 42, 43, 51, 52, 56, 57, 58, 59, 62, 63, 67,	WEB: 12, 14, 15, 26, 30, 31, 32, 33, 35, 37, 44, 45, 53, 54, 60, 61,	APP: 02, 03 WEB: 01, 03, 04, 16, 21, 24, 25, 46, 47, 48, 49, 55,	WEB: 50
• Sentence Construction	APP: 01 WEB: 02, 05, 06, 07, 08, 09, 10, 11, 13, 17, 18, 19, 22, 23, 24, 27, 28, 29, 30, 33, 34, 36, 37, 38, 39, 40, 41, 44, 45, 52, 54, 56, 57, 58, 59, 62, 63, 64,	APP: 02 WEB: 01, 04, 12, 14, 15, 20, 25, 26, 42, 43, 46, 48, 49, 50, 51, 53, 60,	APP: 03 WEB: 03, 16, 21, 31, 32, 35, 47, 55, 61,	-
• Vocabulary	APP: 02 WEB: 02, 05, 06, 07, 08, 11, 13, 14, 17, 18, 19, 20, 21, 22, 23, 27, 28, 29, 30, 31, 33, 34, 36, 38, 39, 40, 41, 42, 43, 52, 56,58, 59, 60, 62, 63, 64,	APP: 01, 03 WEB: 04, 09, 10, 12, 15, 24, 25, 26, 32, 37, 45, 46, 48, 49, 51, 53, 57, 61,	WEB: 01, 03, 16, 35, 44, 47, 50, 54, 55,	-
• Learning Aids	APP: 03 WEB: 01, 02, 03, 04, 05, 07, 08, 09, 14, 15, 16, 18, 19, 20, 21, 27, 28, 30, 31, 32, 33, 34,	APP: 01, 02 WEB: 06, 10, 11, 13, 24, 25, 44, 53, 58, 59,	WEB: 12, 22, 26, 49,	WEB: 17, 29, 36,

	35, 37, 38, 39, 40, 41, 42, 43, 45, 46, 47, 48, 50, 51, 5, 54, 55, 56, 57, 60, 61, 62, 63, 64,			
Graphics				
• Cover Graphics	APP: 01, 03 WEB: 02, 05, 06, 08, 09, 15, 17, 18, 19, 20, 21, 22, 27, 30, 33, 34, 36, 37, 38, 39, 40, 41, 42, 43, 46, 47, 55, 56,	APP: 02 WEB: 03, 04, 07, 10, 11, 12, 13, 14, 16, 23, 24, 26, 28, 31, 35, 44, 45, 49, 50, 51, 52, 53, 57, 58, 59, 60, 61, 62, 63, 64	WEB: 01, 25, 32, 54,	WEB: 29, 48,
• Type of Graphics	APP: 01, 02, 03 WEB: 02, 05, 06, 07, 08, 09, 12, 17, 18, 19, 20, 21, 22, 23, 27, 29, 34, 37, 44, 46, 47, 55, 57, 62, 63, 64,	WEB: 10, 11, 13, 14, 30, 32, 33, 36,	WEB: 15, 35	WEB: 01, 03, 04, 16, 24, 25, 26, 28, 31, 38, 39, 40, 41, 42, 43, 45, 48, 49, 50, 51, 52, 53, 54, 56, 58, 59, 60, 61
• Relevance of Graphics	APP: 01, 03 WEB: 05, 06, 12, 17, 18, 19, 27, 34, 36, 37, 47, 55, 57, 62, 63, 64	APP: 02 WEB: 02, 08, 09, 10, 11, 13, 15, 16, 20, 21, 22, 29, 32, 35, 44,	WEB: 01, 03, 04, 07, 14, 23, 24, 25, 26, 28, 30, 31, 33, 38, 39, 40, 41, 42, 43, 49, 50, 51, 52, 53, 54, 56, 58, 59, 60, 61,	WEB: 45, 48
• Graphic Explanation	WEB: 07, 08, 10, 13, 14, 15, 17, 18, 19, 20, 23, 27, 31, 34, 37, 38, 39, 40, 41, 45, 46, 47, 50, 52, 53, 55, 56, 57, 61, 62, 63, 64	APP: 03 WEB: 03, 04, 11, 28, 30, 33, 44,	APP: 01 WEB: 16, 21, 25, 35,	APP: 02 WEB: 01, 02, 05, 06, 09, 12, 22, 24, 26, 29, 32, 36, 42, 43, 48, 49, 51, 54, 58, 59, 60
• Graphic Caption	WEB: 03, 04, 05, 06, 08, 12, 13, 17, 19, 20, 23, 27, 34, 37, 52, 55, 56, 57, 62, 63, 64,	APP: 01	APP: 03	APP: 02

		WEB: 14, 15, 21, 28, 31, 35, 38, 40, 41, 44, 45, 61,	WEB: 22, 25, 26, 30, 33, 46, 47,	WEB: 01, 02, 09, 10, 11, 16, 18, 24, 29, 32, 36, 42, 43, 48, 49, 50, 51, 53, 54, 58, 59, 60,
Layout and Type				
• Typography	APP: 01 WEB: 01, 02, 03, 04, 05, 06, 07, 08, 09, 10, 11, 12, 13, 14, 15, 16, 17, 18, 19, 20, 21, 22, 23, 24, 25, 26, 27, 28, 30, 31, 32, 33, 34, 35, 37, 38, 39, 40, 41, 42, 43, 44, 45, 46, 48, 50, 51, 52, 53, 54, 55, 56, 57, 58, 59, 60, 61, 62, 63, 64	APP: 02, 03 WEB: 47	-	WEB: 29, 36, 49,
• Layout	APP: 01, 02 WEB: 02, 03, 04, 05, 06, 08, 09, 10, 11, 12, 13, 15, 16, 17, 18, 19, 20, 22, 23, 24, 25, 27, 28, 31, 34, 35, 37, 38, 39, 41, 42, 43, 44, 45, 50, 51, 52, 55, 57, 58, 59, 62, 63, 64	APP: 03 WEB: 01, 07, 14, 21, 26, 30, 32, 33, 46, 47, 48, 53, 54, 56, 60,	WEB: 61	WEB: 29, 36, 49
• Subheadings	APP: 01, 03 WEB: 01, 02, 08, 17, 18, 20, 30, 33, 34, 37, 38, 39, 40, 41, 42, 43, 45, 48, 50, 51, 52, 56, 57, 62, 63, 64,	WEB: 05, 12, 15, 19, 21, 27, 28, 31, 32, 35, 46, 47, 55, 60,	APP: 02 WEB: 03, 04, 06, 07, 10, 13, 14, 16, 22, 23, 24, 25, 26, 44, 53, 54, 58, 59, 61	WEB: 09, 29, 36, 49,
Learning Simulation & Motivation				
• Interactions Included	APP: 01	APP: 02	APP: 03	-

	WEB: 05, 09, 16, 23, 24, 26, 27, 30, 33, 42, 43, 57,	WEB: 02, 07, 08, 15, 20, 25, 28, 32, 35, 38, 39, 40, 41, 46, 47, 49, 51, 53, 54, 55, 56, 58, 60, 61, 62, 63, 64,	WEB: 01, 03, 04, 06, 10, 11, 12, 13, 14, 17, 18, 19, 21, 22, 29, 31, 34, 36, 37, 44, 45, 48, 50, 52, 59,	
• Behaviour Changes Modeled	APP: 02, 03 WEB: 02, 05, 06, 07, 08, 09, 10, 11, 13, 14, 15, 17, 18, 19, 20, 21, 22, 23, 24, 26, 27, 28, 29, 30, 31, 33, 34, 36, 37, 38, 39, 40, 41, 42, 43, 45, 46, 47, 48, 50, 51, 52, 53, 56, 57, 58, 59, 60, 61,	APP: 01 WEB: 01, 12, 25, 32, 44, 49, 54, 55, 62, 63, 64	WEB: 03, 04, 16, 35,	-
• Motivation	APP: 01, 02, 03 WEB: 01, 05, 06, 07, 08, 10, 11, 12, 14, 15, 17, 18, 20, 22, 23, 27, 29, 34, 36, 38, 39, 40, 41, 42, 43, 45, 46, 47, 48, 51, 52, 53, 57, 58, 59, 61, 62, 63, 64,	WEB: 02, 03, 04, 09, 13, 16, 19, 21, 24, 25, 26, 28, 29, 30, 31, 32, 33, 35, 37, 44, 49, 50, 55, 56, 60,	WEB: 54	-
Cultural Appropriateness				
• Logic, Language & Experience	WEB: 01, 09, 45, 46, 47, 49, 52, 53, 56, 57, 62, 63, 64,	APP: 02 WEB: 02, 06, 10, 11, 13, 14, 15, 16, 20, 26, 32, 35, 38, 39, 40, 41 42, 43, 55, 59, 60, 61,	-	APP: 01, 03 WEB: 03, 04, 05, 07, 08, 12, 17, 18, 19, 21, 22, 23, 24, 25, 27, 28, 29, 30, 31, 33, 34, 36, 37, 44, 48, 50, 51, 54, 58,

• Cultural Images and Examples	WEB: 09, 46	-	WEB: 47	APP: 01, 02, 03 WEB: 01, 02, 03, 04, 06, 07, 08, 10, 11, 12, 13, 14, 15, 16, 17, 18, 19, 20, 21, 22, 23, 24, 25, 26, 27, 28, 29, 30, 31, 32, 33, 34, 35, 36, 37, 38, 39, 40, 41, 42, 43, 44, 45, 48, 49, 50, 51, 52, 53, 54, 55, 56, 57, 58, 59, 60, 61, 62, 63, 64,

Table 2.5 Rating of individual criterion of SAM factors for all resources (N=67)

SAM Factor	**Number (%)**			
	Superior	**Adequate**	**Not suitable**	**Not applicable**
Content				
• Purpose	57 (85.1)	9 (13.4)	1 (1.5)	0 (0.0)
• Content Topics	49 (73.1)	15 (22.4)	3 (4.5)	0 (0.0)
• Summary & Review	22 (32.8)	14 (20.9)	28 (41.8)	3 (4.5)
Literacy Demand				
• Reading Grade Level	22 (32.8)	20 (29.9)	24 (35.8)	1 (1.5)
• Writing Style	36 (53.7)	16 (23.9)	14 (20.9)	1 (1.5)
• Sentence Construction	39 (58.2)	18 (26.9)	10 (14.9)	0 (0.0)
• Vocabulary	38 (56.7)	20 (29.9)	9 (13.4)	0 (0.0)
• Learning Aids	47 (70.2)	13 (19.4)	4 (6.0)	3 (4.5)
Graphics				
• Cover Graphics	30 (44.8)	31 (46.3)	4 (6.0)	2 (3.0)
• Type of Graphics	29 (43.3)	8 (11.9)	2 (3.0)	28 (41.8)
• Relevance of Graphics	19 (28.4)	16 (23.9)	30 (44.8)	2 (3.0)
• Graphic Explanation	32 (47.8)	8 (11.9)	5 (7.5)	22 (32.8)
• Graphic Caption	21 (31.3)	15 (22.4)	8 (11.9)	23 (34.3)
Layout and Type				
• Typography	61 (91.0)	3 (4.5)	0 (0.0)	3 (4.5)
• Layout	47 (70.2)	16 (23.9)	1 (1.5)	3 (4.5)
• Subheadings	28 (41.8)	14 (20.9)	21 (31.3)	4 (6.0)
Learning Simulation & Motivation				
• Interactions Included	13 (19.4)	28 (41.8)	26 (38.8)	0 (0.0)
• Behaviour Changes Modeled	51 (76.1)	12 (17.9)	4 (6.0)	0 (0.0)
• Motivation	42 (62.7)	24 (35.8)	1 (1.5)	0 (0.0)
Cultural Appropriateness				
• Logic, Language, & Experience	13 (19.4)	23 (34.3)	0 (0.0)	31 (46.3)
• Cultural Image and Examples	2 (3.0)	0 (0.0)	1 (1.5)	64 (95.5)
SAM=Suitability Assessment of Materials				

App Search

One hundred apps were scanned (50 from each App store), with 70 Apps searched after duplicates were removed (Fig 2.1). Of these, only four met the inclusion criteria with one excluded due to the App not launching, leaving three Apps for review (Table 2.6).

App target audience. APP01 was primarily developed for youth, parents, and educators, but could be used by a wide audience. APP02 provides information for parents or children, specifically those who play hockey. When opening APP02, the user can select whether they are an adult or a child, with information then tailored to that audience. APP03 targets HCPs.

App content. All Apps provided symptom information. APP01 also provides content on prevention, assessment and recovery and has a built-in symptom tracker to monitor concussion symptoms overtime. APP02 focuses on prevention, return-to-play guidelines and what to expect during recovery. There is also a video sharing a child's experience after sustaining a concussion through hockey. APP03 is offered in English or French and provides information on assessment, return-to- learn, return-to-play guidelines and clinical decision tools.

Evidence base. APP01 and APP03 provide clear reference to empirical evidence. APP02 provides an explicit statement that the App information has been prepared by Hockey Canada and is to be used as an educational resource only. It is unclear whether this information is evidence-based.

App evaluation. The total SAM scores of each App were 76.3%, 64.7% and 55%, respectively. All Apps scored "not suitable" for the summary and review factor. A "superior" score was given to all Apps for purpose, type of illustrations, and motivation factors. Each App varied for all other factors (Tables 2.4-2.5).

Table 2.6 Characteristics of Apps

Resource ID	Title	Organization (Province)	Year Updated	Clear Evidence Base	Apple/Google Play	Target Audience[£]	Target Content[¥]	SAM Score (%)
APP01	Concussion Ed	Parachute Canada (Ontario)	2019	Yes	Apple and Google Play	A, C, E	1, 4, 5, 6, 7, 8, 13	76.3
APP02	Concussion Awareness	Hockey Canada (Alberta)	2019	Unclear	Apple and Google Play	A, E (hockey-specific)	1, 4, 7, 8	64.7
APP03	TCCL-MTBI	Universite de Montreal/MUHC Research Institute (Quebec)	2019	Yes	Apple and Google Play	B	1, 5, 6, 7, 14	55

[£] Target audience A: Parent/Caregiver, B: Healthcare Professional, C: Teachers/Educators, D: Coaches/Athletic Trainers, E: Children/Youth, F: General/Not-Specified

[¥] Target content 1: Symptoms, 2: Causes, 3: Treatment, 4: Prevention, 5: Assessment, 6: Return-to-learn, 7: Return-to-play/return-to-sport, 8: Recovery process, 9: When to Seek Medical Attention, 10: Post-Concussion Syndrome, 11: Experience, 12: Other-Myths or General Facts, 13: Symptom Tracker, 14: Clinical decision tools

Phase 2: Key Informant Interviews

Eighteen organizations identified in our scan were contacted requesting an interview. Six organizations agreed to participate. The following three themes were common across interviews: 1) resource development process, 2) evidence-base, and 3) perceived resource gaps.

Theme 1: Resource development process. The process was similar across organizations and typically included a comprehensive literature review for the most up-to-date information about pediatric concussion and consultation with content and medical experts. The resource content was generally determined according to what a panel of HCPs perceived to be the most pertinent information for others to know. Interestingly, one informant did speak to a youth advisory group that was consulted for resource appeal and usefulness.

Theme 2: Evidence-base. All six organizations stated looking to the most current consensus statement on concussion in sport and current best practice guidelines as primary sources of evidence for resource content. However, when and how resources were updated varied and ranged from a minimum of every two years, to when someone alerts them about information no longer being relevant. Most organizations admitted that keeping their resources up to date was challenging due to financial and human resource restraints in combination with the ever-evolving evidence base.

Theme 3: Perceived resource gaps. Health care professionals, parents, coaches or educators were the primary target audiences identified by informants. Informants from these organizations identified a lack of resources targeted specifically for children as a gap. Another commonly identified gap was in relation to dissemination of their resources. Informants stated that due to the fast-pace changes in the evidence base of pediatric concussion, and the recent surge in resources and information available, it can be difficult to ensure their resources are being referred to and promoted as the most timely and accurate.

Interpretation

This ES identified critical gaps regarding target audience, content and format of Canadian-developed Internet resources and Apps for pediatric concussion. We discuss the most pertinent gaps identified.

Content Gaps. Few resources provided information about PCS. This is likely due to the limited information on prevalence, incidence and diagnostic criteria of PCS in children [2, 25]. While more conclusive evidence is required in this area, it may be worth noting in resources, especially for parents, coaches and teachers concerned about this subject.

Our key informant interviews revealed that resource content is often determined by HCPs. While HCPs can provide content expertise and ensure the most up-to-date information is provided, consulting end-users to understand what information they want and need is essential for effective knowledge translation [26-29]. Only two resources shared a patient or family experience. One App included an experience video. Sharing illness experiences can have a degree of emotional power that can spark attention, resonance and change [30-32]. Furthermore, patient stories can be used to simplify complex issues and provoke emotional responses that may facilitate enhanced knowledge retention [31, 33]. While the rapid and underdeveloped evidence base in pediatric concussion places restraints on what information can be included, researchers have an opportunity to expand on the evidence being shared by taking a more participatory approach, involving end users in the development of these resources.

Audience Gaps. Similar to Mallory et al. [15] our scan found limited resources designed primarily for children/youth and resources designed for this population tend to focus on sports. This excludes children who may sustain concussions in other ways, such as falls or motor vehicle accidents. According to the Canadian Paediatric Society, sports-related concussions are only one of the common causes of head trauma in children and youth presenting to Canadian emergency departments. Falls, being hit on the head by an object or colliding with an obstacle and injuries involving bicycles are among the most common causes of head trauma in children and youth [34]. Resources should be tailored to be more inclusive beyond those involved in sport.

Format Gaps. Our ES revealed gaps relating to the use of innovative mediums. Handouts or PDFs were the most common resource formats. While time and resource strain often determine how resources are developed, more innovative mediums may be beneficial to evoke relevance, timely accessibility, and engagement. In fact, more innovative media such as cartoons and videos, have been found to be superior to standard medical sheets for transferring information to consumers [31]. While many organizations are moving their educational resources online, it appears they are not optimizing technological potential.

The average SAM score for all resources in our study was 70.2% which is considered “superior material” [22]. This suggests many online resources for pediatric concussion may be useful for their intended audiences. In our scan, resources tended to have lower scores in the graphic domain, especially for the relevance of graphics factor. Our study also found that often few graphics were included and without explanations or captions. Previous studies have found that health education materials with graphics are well received by the target audience, as they can help reinforce messages [35-37]. However, our scan suggests that graphics are not optimally used in concussion education resources. This finding may be related to organizations using more traditional mediums (handouts, PDFs) that tend to be text heavy. Resources in our study were generally scored as “not applicable” or “adequate” for cultural appropriateness. It was often unclear whether different cultural practices or perspectives were considered in the development of these resources. As health practices and access to health resources vary among communities and cultures within Canada, it is essential that health resources be tailored to accommodate this diversity.

Limitations

This ES employed a comprehensive and systematic process, but it is possible a resource was missed. This ES only includes resources which were developed in Canada, excluding resources that may be relevant but developed in other countries.

Conclusions

Our study found gaps in current Canadian pediatric concussion resources. Specifically, few resources target children/youth who sustain concussions, adopt innovative formats, and consider patient experience. Resources aimed at improving knowledge and awareness of pediatric concussions also require inclusivity beyond the athletic community. It is imperative that the knowledge and perspectives of those using these resources are incorporated into their development to enhance relevance, cultural appropriateness, and sense-making. Capitalizing on innovative mediums (such as audio-visuals), using less text, and more graphics may increase patient engagement and usefulness, particularly for those experiencing concussions who may have visual and concentration impairments. Future research is needed to explore what information about concussion should be included in these resources and what information is most helpful and desired by intended end users.

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CHAPTER 3.

Paper 2: “You Can’t Fix Your Brain”: Exploring Concussion Experiences of Children and Parents

This paper is published as:

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Abstract

Purpose: To explore the experiences, information needs and preferences of children who have had a concussion and their parents who have cared for them.

Design: Qualitative description.

Methods: Semi-structured qualitative interviews were conducted via Zoom with children who have had a concussion between ages 5-16 years and parents who have cared for a child with a concussion. Interviews were audio-recorded and transcribed.

Results: Fourteen interviews were conducted with children and parents who have experiences with concussion. Four major themes were identified: 1) mechanism of injury and concussion symptoms experienced by children, 2) parent concerns, emotions, and health care experience with child's concussion, 3) concussions affect more than just your head and, 4) health information seeking, and preferences of parents and children related to concussion. Children and their parents have unique experiences, information needs and preferences regarding concussion.

Practice Implications: This information offers valuable insights about developing resources about childhood concussion that parents and children will find useful and relevant. This research has direct relevance to healthcare professionals who may encounter children with concussion in their daily practice so they can ensure the needs of children and families are being met. Our findings will be used to create the content for an innovative knowledge translation tool about pediatric concussion.

Keywords: concussion; mTBI; pediatrics; qualitative research; parent experiences

What is currently known?

Concussions are complex brain injuries affecting millions of children worldwide. Few studies have qualitatively explored the concussion experience from child perspectives in addition to the parental experience.

What does this article add?

Our study explores the concussion experience from onset of injury through recovery from the unique perspectives of parents, and children themselves. Our study moves beyond objective knowledge and attitudes towards concussion by understanding first-hand experiences, information needs and preferences about this condition. Our findings will inform the development of an innovative knowledge translation (KT) tool that addresses the unique experiences and information needs of children who have had concussions and those who care for them.

“You Can’t Fix Your Brain”: Exploring Concussion Experiences of Children and Parents

Concussions are complex injuries affecting the brain caused by direct or indirect blows to the head (McCrory et al., 2017). An estimated 125,000 children in Canada and 750,000 in the United States will sustain a concussion annually. An estimated 33% of children who seek medical care for a concussion will have persistent symptoms (symptoms occurring beyond 28 days post-injury) including headaches, dizziness, foggy thinking, sleep problems, and emotional distress, which can cause significant disruptions to their daily lives (Barlow et al., 2010; Yeates et al., 2012; Zemek et al., 2016). Previous studies have found that children with prior concussions are at risk for recurrent concussions which, in rare instances, can result in acute life-threatening injury with potentially lifelong consequences (Collins et al., 2002; Manley et al., 2017; Marshall, Guskiewicz, Shankar, McCrea, & Cantu, 2015; Meehan, D'Hemecourt, & Comstock, 2010; Swaine et al., 2007; Tator et al., 2019). For the majority however, recovery occurs within 1-4 weeks post-injury (Davis et al., 2017). The prevalence and severity in which children experience concussions, coupled with the personal and societal impacts of concussions is concerning (Government of Canada, 2018). Recovering from a concussion can be emotionally draining for children and their families (Graves et al., 2020). To fully understand the impact of this common injury we conducted a qualitative study to explore the experiences and information needs of children who have had a concussion, and their parents. Previous research has examined knowledge and attitudes of concussion among parents, coaches and athletes through surveys, which fail to capture rich perspectives and experiences (Bloodgood et al., 2013; Kay, Register-Mihalik, Ford, Williams, & Valovich McLeod, 2017; Rice & Curtis, 2019; Ritter et al., 2018; Stein et al., 2016). Few studies have qualitatively explored the concussion experience from child perspectives and tend to focus specifically on those in sport (Bloodgood et al., 2013; Choudhury, Kolstad, Prajapati, Samuel, & Yeates, 2020; Stein et al., 2016; Valovich McLeod, Wagner, & Bacon, 2017). Sports-related concussions are only one of the common causes of head trauma in children presenting to Canadian emergency departments (EDs) (Canadian Pediatric Society, 2014). As a result, children who sustain concussions in other ways (i.e., falls, accidents) may have different experiences regarding recovery and management. Our study is unique in that we explore the concussion experience from onset of injury through recovery from two unique perspectives: parents, and children. Our study aimed to recruit participants who sustained a concussion by any mechanism. Few studies have explored the information needs and preferences of parents and children who sustain concussions, which our study explores explicitly (Minney, Roberts, Mathias, Raftos, & Kochar, 2019).

The objectives of this qualitative study were to describe the common experiences of parents looking after a child with concussion and the common recovery experiences of children who have sustained a concussion to better understand their information needs regarding concussion, where they look for information and how they prefer information to be provided. This study adds to previous work by capturing the diverse experiences of parents caring for a child with a concussion, and children themselves who experience concussions. Our study moves beyond objective knowledge and attitudes towards concussions by understanding first-hand experiences, information needs and preferences. This exploration will help inform the development of an innovative knowledge translation (KT) tool that addresses the unique experiences and information needs of children who have had concussions and those who care for them.

Methods

This study was conducted using qualitative description methods (Sandelowski, 2000, 2010). The Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist for reporting qualitative research interviews was followed (Tong, Sainsbury, & Craig, 2007) (See supplemental file).

Participants and Recruitment

Participants were recruited by self-identifying themselves, from May-August 2020, via our research group's (ECHO KT) social media platforms (Twitter, Facebook, Instagram) and website (www.echokt.com). Although purposive sampling is more likely to yield information-rich cases, to progress with this research amidst a global pandemic, we used convenience sampling, recognizing there are limitations to this approach (Patton, 2015). Recruitment ads and standardized messages were developed and shared via these online venues and were open to public viewing. All recruitment postings explicitly instructed individuals interested in participating to privately contact the lead author (AC) via email or telephone. AC provided potential participants with a study information letter and determined participant eligibility. Eligibility included: 1) parent with experience caring for a child 16 years old or younger, and/or 2) children who had experienced a concussion between the ages of 5-16 years (those older than 16 at the time of recruitment were eligible if they had a concussion at age 16 years or younger).

In Canada, the definition of a child varies provincially, ranging from a person under 16 years in some provinces to under 19 years in others (Government of Canada, 2013). We chose to define a child as a person 16 years or younger to capture a younger perspective, as limited research in this area targets younger children. We chose children as young as 5 years as research has shown children this young can provide important insights into their daily lives and health experiences (Irwin & Johnson, 2005). All participants were required to be able to communicate in English. Data collection and analysis occurred concurrently until no new information emerged from the interviews, suggesting data saturation (Sandelowski, 1995b).

Data Collection

The lead author followed up with eligible participants by email or telephone to schedule an interview via Zoom at a convenient time for participants (Archibald, Ambagtsheer, Casey, & Lawless, 2019; Zoom Video Conferencing Inc, 2020). Two interview guides (one for parents, one for children) were developed by the lead author in consultation with the research team. Interview topics included mechanism of injury, symptom experience, experience with the healthcare team, recovery and follow-up, and concussion information needs and preferences (See supplemental file). Written consent forms were emailed to all participants and returned prior to the interview. Children provided assent and consent was obtained from the parent.

Both parents and children were interviewed, to capture independent versions of the joint experience of concussion (Reczek, 2014). Two interview guides were used (one for parents, one for children). The lead author followed the recommendations of Irwin and Johnson as a guide for interviewing children (Irwin & Johnson, 2005). Parents and children were given the choice to interview in private, or in the presence of the other. Irwin and Johnson (2005) suggest that having parents present during interviews with children may contribute to the interview in a positive way. Only two parent/child dyads chose to interview separately, due to scheduling conflicts where they could not be interviewed at the same time. All interviews were digitally recorded via Zoom and transcribed verbatim by a professional transcription service.

Data Analysis

Inductive thematic approaches guided analysis (Braun & Clarke, 2006). Analysis was conducted by the lead author (AC) trained in qualitative content analysis and comprehensively reviewed and confirmed by the research team (Sandelowski, 1995a). Transcripts were analysed separately by participant group (parents, children) following the same approach. We wanted to understand the overall, joint experience of concussion from the perspective of parents and children. We then looked at what similarities and differences were present across these two populations. First, transcripts were read in detail several times, and compared against the recordings, ensuring accuracy. Second, open coding was done on each transcript to identify data patterns. Third, codes across transcripts were grouped into emergent and recurring themes. Detailed field notes documented impressions and decisions. We used NVivo 12 for data management (QSR International Pty Ltd, 2018). Demographic data were analysed using measures of central tendency. Ethics approval for this study was obtained from the University of Alberta Health Research Ethics Board (Pro00096202).

Rigor

Analytic rigor was enhanced throughout the research process through strategies proposed by Morse (Morse, 2015). One member of the research team (AC) conducted all interviews to maintain consistency. Data were analysed and findings were collaboratively critiqued by the research team with the intent to develop integrity, representative credibility, analytic logic, and interpretive authority. Reflexive journaling and field notes were used during data collection and analysis to examine potential biases and their potential influence on the research process, build an audit trail, and support rigor.

Results

Demographics

Twenty-nine parents contacted AC about participation on behalf of themselves and their child. Eleven parents could not be reached for follow-up, three parents refused participation after receiving the study information letter and one parent did not meet the inclusion criteria. A total of fourteen interviews were conducted (n=11 parent/child dyads, n=1 child only, n=2 parents only). The demographic characteristics of participants are presented in Tables 1 and 2. Interviews with parent/child dyads ranged from 36:06h -1:22:47h (*M*=1:00:34), parent-only interviews ranged from 26:07h-47:40h (*M*=36:19), and child-only interviews ranged from 15:25-26:27h *(M*=20:47). Five children experienced a concussion for the first time and seven had multiple concussions. The average age of their first concussion was 8.7 years and the average length of time since their last concussion was 2.9 years. Despite seeking to recruit participants irrespective of how they sustained a concussion, most children in our study sustained a concussion through sport. Additionally, seven of the 12 children who participated were teenagers. Teens can often articulate their experiences in more detail; thus, many of the accompanying quotes are from teens. The quotes were strategically chosen to capture the essence of each theme in the most descriptive way possible. All parent participants in our study were mothers, therefore the data does not reflect fathers' experiences.

Table 3.1 Demographic characteristics of sample of parents of children with concussion (N=13)

Baseline characteristic	Total	
	N	%
Gender		
Female	13	100
Age		
21-30 years	1	7.7
31-40 years	2	15.4
41-50 years	7	53.8
50 years and older	3	23.1
Marital Status		
Married/Partnered/Common-Law	13	100
Education		
Completed community college	1	7.7
Completed bachelor's degree	4	30.8
Completed post-graduate training	8	61.5
Work Status		
Not working	1	7.7
Student	1	7.7
Working for pay part-time	1	7.7
Working for pay full-time	9	69.2
Prefer not to answer	1	7.7
Worked for Pay in Healthcare		
Yes	6	46.2
No	6	46.2
Prefer not to answer	1	7.7
Annual Household Income ($CAD)		
40,000-60,000	1	7.7
80,000-100,000	1	7.7
Over 100,000	9	69.2
Prefer not to answer	2	15.4
Number of children		
1	2	15.4
2	8	61.5
3	3	23.1
Current age of concussed child		
0-5 years old	1	7.7
6-11 years old	4	30.8
12-17 years old	7	53.8
18 years and older	1	7.7

Table 3.2 Demographic characteristics of sample of children with concussion (N=12)

Baseline characteristic	Total	
	N	%
Gender		
Boy	4	33.3
Girl	8	66.7
Age at Time of Interview		
5-10 years old	4	33.3
11-15 years old	3	25.0
16-20 years old	4	33.3
21 years and older	1	8.3
Grade at Time of Interview		
Elementary school	4	33.3
Junior high school	2	18.2
High school	4	33.3
Graduated high school	1	8.3
Number of concussions		
1	5	41.7
2	3	25.0
3	3	25.0
Greater than 3	1	8.3
Age of first concussion		
0-2 years old	1	8.3
3-5 years old	2	16.7
6-9 years old	4	33.3
10-12 years old	3	25.0
13-15 years old	1	8.3
16 years or older	1	8.3
Time since last concussion		
Between 0-6 months	2	16.7
Between 6 months-1 year	1	8.3
Between 1-2 years	4	33.3
Between 2-3 years	1	8.3
Between 3-4 years	1	8.3
Over 4 years	3	25.0
Considered recovered from last concussion		
Yes	11	91.7
Still experiencing symptoms	1	8.3

Thematic Discoveries

Analysis revealed four major themes: (1) mechanism of injury and concussion symptoms experienced by children, (2) parent concerns, emotions and health care experience with child's concussion, (3) concussions affect more than just your head, (4) and health information seeking, and preferences of parents and children related to concussion. The child's age as depicted in the quotes reflects their current age at the time of interviews, not their age when they had a concussion, and not necessarily their first concussion.

Theme 1: Mechanism of Injury and Concussion Symptoms Experienced by Children

The majority of children in our study (n=10) got concussions playing sports, namely hockey, soccer, basketball, figure skating and flag football. Three children got a concussion from falling (stairs, furniture, play-structure) and one child got a concussion after being hit in the head during play or "rough-housing" with friends. The most common symptoms reported by children were dizziness/headache (n=9), photosensitivity (n=8), nausea/vomiting (n=5) and balance/gait disturbances immediately following injury (n=5). Other ongoing symptoms children reported were difficulty concentrating (n=3), lethargy (n=2) and sensitivity to noise (n=1). For instance, one child described their symptoms as, "It was a lot of issues with noise and lights. It felt like my head was ringing…it made everything hard to think and concentrate because my brain kept, like going off and being, like no this hurts, stop" (Child, age 17 years).

Two parents reported emotional changes in their child after having to quit participating in activities they enjoyed and being frustrated with their recovery. One parent said, "he was so frustrated with the rate of progress. And I think [he was] scared too that it wasn't going to get better because it was lasting so long. And so…we had him see a psychologist." (Parent of child age 14 years).

Children reported a wide range of symptom duration lasting from a few days to months. All children who experienced more than one concussion (n=7) described the subsequent concussions as “worse” with symptom onset occurring sooner and lasting longer. Children reported experiencing similar symptoms with each concussion.

Theme 2: Parent Concerns, Emotions and Healthcare Experience with Child’s Concussion

When children sustained a concussion for the first time, the majority (n=10) were taken to the emergency department (ED) immediately (within hours) after injury. Four parents reported not taking their child to the ED until the following day. For children experiencing repeat concussions, parents still reported taking their child to the ED within hours of injury. When asked what influenced their decision to take their child to the ED, parents noted two main factors: symptom presentation and fear of “missing something” serious, such as a brain bleed and the desire for documentation with a head injury. As one parent said, “I just want to make sure I’m not missing something. You know…she’s got a concussion but what if there’s other elements there…I’m not a health care professional. I may not be able to identify those kinds of things” (Parent of child age 16 years).

Most children seen in the ED followed up with their family doctor within days. This was often a personal choice of parents, not a recommendation by the ED doctor. When asked what influenced their decision to follow-up with their family doctor, parents reported the desire for documentation and symptom monitoring. As one parent expressed, “I wanted to see him [family doctor] just to keep him in the loop...” (Parent of child age 17 years). While most parents understood symptom management was the cornerstone of concussion care, they were surprised that “more was not done” in the ED, such as computed tomography (CT) scans. Parents felt they did not receive all the information they needed about their child’s concussion in the ED. As one parent stated,

> Maybe it was just because it was my kid and she was bleeding and her head hurt…but I expected a little bit more… like a scan…you know, a kid falls and hurts their arm and they get an x-ray. I kind of thought the same idea was going to happen, but it didn't. I felt they didn't give me very much information. They handed me a pamphlet" (Parent of child age 7 years).

One parent, despite being a healthcare professional, expressed how confusing and misleading concussion management guidelines were. This parent felt the "step-by-step" approach for return to learn and return to sport, with their associated timelines were not applicable to all children as her son was taking much longer to proceed through each recovery step. However, for the three parents who saw a concussion specialist, they were very satisfied with the experience and information they received due to the individualized and specialized care. One parent described matter-of-factly:

> I think that we got everything that we needed from the concussion clinic, especially. They had paper handouts that we went home with, with a plan of action. I knew what to do, I knew when to do it and who to call if it wasn't going as planned (Parent of child age 9 years).

The "concussion specialist" was described as a health care professional (either a physician or physiotherapist) who specialized in treating concussions and worked at a designated concussion clinic with a multi-disciplinary team. All three children who were referred to these specialists were referred by their family physician.

Parents expressed feeling worried over their child's concussion. Many were concerned about the long-term impacts on their child's quality of life and what lasting effect concussions had on their child's brain stating, "you can't fix their brain…it can be permanent and long-lasting and have such implications for them" (Parent of child age 15 years).When their child got one concussion, parents worried about their child getting another. Parents also expressed a tension between wanting to protect their children from getting more concussions, and "letting kids be kids." As one parent said,"you just kind of get worried and you don't want them to have any brain damage, and you don't want to also not allow them to do things" (Parent of child age 2 years).This was particularly prevalent among parents of children who sustained their first concussion at a young age (less than 10 years old). Parents expressed feeling guilty about their child's concussion, feeling responsible for letting them play sports with high concussion risk, or feeling like a bad parent for not protecting their child from getting injured. As one parent said,

> There's guilt because I know he wanted to play hockey (parent getting emotional and choked up) and we wanted him to do that, but if we hadn't let him play…because every parent knows that concussions are a risk of sports, so if we had said no to hockey, what would that have meant for him (very emotional) on a longer term basis?" (Parent of child age 14 years).

Parents also felt stressed and helpless because they could not make their child immediately feel better and could not provide answers as to how long recovery may takeParents expressed concern about everyone in their child's life "not being on the same page" with their child's concussion (i.e. teachers, coaches, other parents, child's friends). Parents worried that not everyone had the same information regarding concussion management and recovery guidelines. One parent expressed:

> One of the things that I have always struggled with… is that it's fine if your doctor reviewed that [concussion information] with you and you understood it and you had time to ask questions…but it's the other people in their world…it's their coach, their

> teacher…all the other people that you now either have to educate them and advocate for your child, or you have to hope that they're educated (Parent of child age 15 years).

Theme 3: Concussions Affect More Than Just Your Head

Children expressed how difficult it was to reconcile with being unable to do what they had normally done, when they did not have a concussion, such as play sports, study, look at their phones, play video games, etc. without getting headaches or other symptoms. Many expressed frustrations such as, "the fact that even if I wanted to do something, I couldn't do it" (Child age 17 years). In contrast to parents, most children were not worried about getting another concussion, but were worried about potentially being unable to play sports or do things they enjoyed because of the concussion. This worry made some children more timid during sports and play. Children in our study admitted to knowing little information about concussions before they got one, stating "that was the first I really heard about it [when I got a concussion]" (Child age 17 years) and "I thought it was just a bad headache. At the time, I didn't really have a good understanding of what a concussion was" (Child age 15 years). Most children could recognize that a concussion was something traumatic or "bad" for your brain but were often unaware of lasting effects or recovery.

The most common adjustment for children in our study after a concussion was easing back to sports and recreation. Children often weren't allowed to play sports or participate in physical activity for a certain period, followed by a gradual return to play regimen. One child said, "I think getting back to sports was the hardest part of having a concussion because I would show up and I knew I can't do contact, I can't do this or this…" (Child age 17 years). For younger children, being unable to play at recess or gym class was disappointing and made them feel "left out". Some children struggled with being unable to return to sport at the same level they were at prior to getting a concussion stating, “I was a lot more cautious about things” (Child age 23 years speaking to concussion sustained at 14 years). Two children admitted that having a concussion changed the way they played their sport, as they were more timid or nervous about getting another concussion and being unable to play once again.

Some children in our study who sustained a concussion through sport were forced to practice an alternate, less risky sport, or stop playing sports all together. For most of these children, the inability to practice the sport they loved was disheartening. As one child said, “I mainly just play basketball now but it is hard to leave hockey behind because I was always a really big fan of hockey growing up in general… I had mixed feelings about it.” (Child age 14 years).

Another adjustment for children was regarding school and learning. All children in our study missed some school ranging from a few days to a few months, regardless of whether it was the child’s first or subsequent concussion. Like return to play, return to learn was also gradual with children returning for half days to start and working their way up to full days. School absenteeism meant children were at home, separated from their peers. This meant children often missed important socialization with friends. One child described how she could not always participate in regular activities with her friends that she enjoyed in case her symptoms exacerbated. Some parents reported how their child’s friends did not always understand the severity of concussions or what they could do with and for their friend experiencing a concussion, resulting in social isolation. As one parent described, “her friends were scared, like one of the mom’s had said her friends are scared because she’s not feeling well, they’re hesitant to [do things with her] … she just wasn’t the same” (Parent of child age 17 years).

Two parents expressed needing to take time off work to care for their concussed child and another mentioned having to drive long-distances for concussion care. Many parents in our sample worked from home or were on leaves of absence from their job at the time their child had a concussion, making it easier to care for their child at home.

Theme 4: Health Information Seeking and Preferences of Parents and Children Related to Concussion

Parents reported a variety of preferences regarding concussion information for their child. In general, parents prefer information that is available in multiple formats, which appeases different learners. Parents turned to the Internet to look for child concussion information, stating "I tend to stick to government websites or…different health education resources from different hospitals that are uploaded online (Parent of child age 9 years)". Despite parents turning to the Internet for information, many recognized the Internet was often a source of confusion, as different websites presented different information. Other parents preferred to receive health information directly from a healthcare professional, either verbally, written down, or a combination of both. As one parent said, "my preference in terms of receiving information is health care professional first. That's why I like my doctor to give me something because I'm getting it from a health care professional. I already know it's okay" (Parent of child age 16 years).

Parents also reported wanting pertinent information in bullet-form and laymen's terms. Few parents reported that video formats would be helpful. Parents recognized that concussions are very individualized and learning about other parents' experiences with their kids is not necessarily helpful. When asked what information parents search for about concussions, common responses included symptoms, long-term complications, sport-specific information, and treatment. Parents reported they would often look up more information after their child had been seen by a healthcare professional for clarification. One parent recognized the need for concussion information pertinent to children who do not participate in sports.

Of the parents who did receive information in the ED or from their family physician, it was either verbal or a “brief” information sheet with return to learn and return to play guidelines. Many parents admitted to not remembering exactly what was on the information sheets, and that they were not necessarily helpful. In contrast, parents who saw the concussion specialist felt the handouts they were given were helpful and pertinent to their child’s specific needs.

In contrast to parents, who acknowledged that hearing from other parents about their child’s concussion would not necessarily be helpful or preferred, children reported that hearing from peers who experienced a concussion is how they would like to learn about concussions and would turn to their friends who had a concussion for advice. As one child said, “yeah, I definitely did ask a bunch of my friends who had concussions. I have a friend who has had maybe three and all three of them were really, really bad. I asked him for tips” (Child age 17 years). One child suggested that having a speaker, such as a professional athlete, talk about the dangers of concussion may be engaging for children. Children also reported preferring to watch a video or see a visual to learn about concussions stating, “it [videos] just makes you feel like you’re actually learning from it… and soaking all of the information in because sometimes books can be a little bit slow and boring” (Child age 13 years) and “definitely some visual where you can maybe see the impact of what happens…. I think that kind of… makes it more realistic in your mind” (Child age 23 years, sustained concussion at 14 years). Despite most children indicating videos would be helpful, one child suggested that videos were sometimes difficult to watch with a concussion and that a webpage they could refer to would be preferred.

When asked what information children wanted to know about concussions, common questions were, “What does a concussion mean for me?” Children wanted their concussion care and recovery to be tailored to them. Children also wanted to know how long they would have a concussion for, what the lasting effects may be, when they could return to sports and how many concussions was too many.

Discussion

Our findings provide critical insight for researchers seeking to explore the experiences, challenges and needs of children and families regarding concussion management. This research highlights the differences in the information parents and children want about concussion and how they prefer to receive this information. We have organized our discussion in relation to two key findings: (1) impacts of concussion on the lives of children and parents, and (2) information needs and preferences of parents and children about concussion.

Impact of Concussion on the Lives of Children and Parents

Perhaps one of our most significant findings was how concussions can impact a child’s life, even after the acute phase of injury. Other studies have shown the cognitive, emotional, and social life of children can be adversely affected for five years after injury, even in mild and moderate cases. However, prolonged recovery is only experienced by a minority of children post-concussion (Choudhury et al., 2020; Daneshvar et al., 2011; Limond, Dorris, & McMillan, 2009).

For children in our study, failure to meet their own expectations and having to accept new limitations regarding sports, academics and screen time was challenging. Having to reconcile with the sense of performing ‘less than’ their pre concussion state coupled with the fear of exacerbating symptoms if they pushed themselves too far resulted in feelings of stress and frustration. Children felt disappointed and excluded if they had to stop activity, like sports or spending time with friends all together. These findings mirror those of Choudhury et al.,(2020) who noted more consideration needs to be given to the cognitive and emotional impact of concussion. Stein et al.,(2016) reported the loss of participation in activity as the worst thing for children about having a concussion.

The emotional strain experienced by parents and children may result from receiving inadequate information about concussions and where this information comes from. For instance, those who saw a concussion specialist felt more reassured. The fear, worry and uncertainty parents feel is often related to not knowing what lasting effects one or multiple concussions may have on their child. The long-term impacts of concussions in children is still a phenomenon not well understood (Davis & Purcell, 2014).

Information Needs and Preferences of Parents and Children About Concussion

Studies have shown that many misconceptions and inaccurate beliefs about concussion persist and although individuals may have basic knowledge of concussion, there is confusion surrounding the consequences of brain injury including misconceptions about memory problems, unconsciousness, and recovery time (Bloodgood et al., 2013). This was echoed among parents in our study who admitted to being especially surprised by the recovery time for their child and their symptoms that seemed to linger months after injury.

Parents in our study were also left with questions about their child’s concussion and felt as though they did not receive all the information they wanted from the ED. In part, this may be due to the lack of research evidence in this area (Reed, Zemek, Dawson, & Ledoux, 2019). While research has informed the imaging decisions that physicians make during the acute care period (<4 days post injury) and guidelines for concussion management, there is a significant lack of research to inform other aspects of care, including the amount and type of information that children and families require, as well as the follow-up services most needed. Furthermore, there is limited research to guide the development of effective evidence-based resources to optimize recovery in the short term (4 days-4 months) and long term (> 4 months) (Lumba-Brown et al., 2018; Minney et al., 2019).

A systematic review on parent concussion knowledge identified a common source for parents was physicians and other medical professionals (Feiss, Lutz, Moody, & Pangelinan, 2020). This preference is also indicated with other childhood illnesses (Albrecht, Hartling, & Scott, 2017; Campbell, Hartling, Louie-Poon, & Scott, 2019; Gates et al., 2019; Meherali, Campbell, Hartling, & Scott, 2019). Parents in our study expressed wanting information from medical professionals. Despite this preference, parents felt they did not receive all the information they desired, aside from those who saw a concussion specialist. As concussions are complex injuries and the experience is unique to everyone, health professionals must be aware of where and when they can refer children to seek more specialized, individualized care regarding concussions.

In addition to health professionals, the Internet, specifically Google or health-related websites (i.e. WebMD) are common sources parents use to obtain concussion information (Bloodgood et al., 2013; Feiss et al., 2020). In our study, parents turned to the Internet (mainly Google) for concussion symptoms, management and return to play and learn information despite recognizing Internet sources cannot always be trusted. This finding is not surprising given that parents are increasingly using the Internet to access health information (Campbell et al., 2019; Khoo, Bolt, Babl, Jury, & Goldman, 2008). Thus, providing parents with credible information online, in understandable formats is essential to ensuring they are making well-informed decisions about their child's health.

Younger children in our study (under 13 years), admitted to knowing little about concussions before they sustained one. Older children (>13 years) also admitted to limited knowledge of concussion, aside from common symptoms, despite some of these children playing competitive sports where the risk for concussion is high. Similarly, other studies have reported limited concussion knowledge particularly among younger youth and adolescents (Bloodgood et al., 2013; Choudhury et al., 2020). Similar to Gagnon et al., (2008) children in our study were left with questions about concussions and what having a concussion meant for them. This knowledge deficit demonstrates more action must be taken to educate this population about concussions and their severity. Increasing knowledge and awareness among children is especially important because research suggests younger brains are more susceptible to concussions due to greater head-to-body ratio, weaker neck musculature, and undeveloped cranial bones (Cook, Schweer, Shebesta, Hartjes, & Falcone, 2006). Children's' desire to understand what a concussion means for them further emphasizes the recommendation for more specialized and individualized care, with information tailored to each child's unique needs.

Children in our study expressed a preference of learning about concussions from others who have had concussions, either face-to-face or via video. In many conditions, peer support and the sharing of experience is often recognized as vital among pediatric populations (Gagnon et al., 2008; Kita et al., 2020). Sharing experiences with illness can have a degree of emotional power that can spark attention, resonance, and change (Charon, 2012; El-Farargy & Walker, 2017; Scott, Hartling, & Klassen, 2009). Furthermore, patient stories can be used to simplify complex issues, capture the attention of others and provoke emotional responses that may facilitate enhanced knowledge retention (Scott et al., 2009). Thus, developing educational interventions that promote the sharing of experience among peers may be beneficial to increasing concussion awareness and education among youth populations. Additionally, while time and resource allocation often determine how resources are developed, more innovative mediums for health education may be beneficial to evoke relevance, meaning and engagement for children with concussion. In fact, more innovative media such as cartoons and videos, have been found to be superior to standard medical sheets for transferring information to consumers (Scott et al., 2009). However, important considerations need to be taken when developing electronic resources for children with concussion such as reducing the visual and cognitive demands of screen time that may exacerbate concussion symptoms.

Limitations

We relied on parent and child self-report of their experience with concussion. In attempts to capture a broad and diverse sample, we recruited children who sustained a concussion at any point during childhood. For some participants, it had been months or years (see Table 2) since their concussion, therefore recall bias is possible. All parents in our study were mothers; hence, fathers are not represented in this study. Despite extensive effort to ensure variation in parent demographics, our participants consistently possessed high levels of education. As a result, our findings cannot be extrapolated to all parents, including those who may have more pronounced information needs and deficits. Additionally, we analysed all child data together and did not investigate differences by age or gender. Recruitment and data collection for this study occurred during the COVID-19 pandemic, thus; in adherence to government guidelines, recruitment occurred online through convenience sampling, which may not provide the most information-rich sources.

Conclusion

Our study provided an exploration of the unique experiences, information needs and preferences of children and parents regarding concussion. Our results show that concussions can have considerable negative impacts on the lives of children and families. Our study found that children and parents have unique information needs regarding concussions and how they prefer to acquire this information. This is valuable in developing resources about childhood concussion that parents and children will find useful and relevant. The findings from this study will be used to create the content for an innovative KT tool about pediatric concussion. Specific experiences of children and families will be included in the tool to enhance relevance and meaning. Providing timely, appropriate, and engaging concussion information, tailored to the needs and preferences of children and families may alleviate feelings of fear and uncertainty.

How might this information affect nursing practice?

Our exploration of children and parent experiences with concussion provides important insights toward improving clinical care for this complex condition, making significant contributions to nursing practice. The results of this study are an important foundation for creating resources that directly address children and parents' experiences and self-identified needs for managing concussion. Developing supports, such as digital KT tools, that target the information needs of children and parents may improve families' experiences of concussion recovery. Creating resources that validate concerns and experiences for both children and their parents can make an important contribution to meeting their support needs and epitomizes the essence of patient and family cantered care, an important aspect of nursing practice. Nurses are in an ideal position to educate and support families through their healthcare encounters and the uptake of these findings will guide nurses, and other health care providers, to improving care provision of children and families managing the complex condition of concussion.

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CHAPTER 4.

Paper 3: The Development and Parental Evaluation of a Web-Based Infographic for Pediatric Concussion: A Multi-Method Study

This paper is ready to submit as:

Campbell, A., Hartling, L., Plourde, V., and Scott, S.D. (2021) “The Development and Parental Evaluation of a Web-Based Infographic for Pediatric Concussion: A Multi-Method Study” *Journal of Medical Internet Research.*

Abstract

Background: Concussions, known as mild traumatic brain injuries, are complex injuries caused by direct or indirect blows to the head and are increasingly being recognized as a significant public health concern for children and their families. Previous research has identified few studies examining the efficacy of educational interventions on parental concussion knowledge.

Objective: The aim of this research was to actively work together with children who have experienced a concussion, and their parents, to develop, refine and evaluate the usability of a digital infographic for pediatric concussion. We also aimed to assess parental knowledge and self-confidence of pediatric concussion before and after exposure to the infographic.

Methods: A multi-phase, multi-method research design employing patient engagement techniques were used to develop a digital interactive infographic. Parents who were able to communicate in English were recruited via social media platforms and invited to complete online questionnaires. Electronic pre/post questionnaires were administered to parents to assess changes to concussion knowledge and confidence after viewing the infographic. A usability questionnaire with 11 items was also completed.

Results: A digital, interactive infographic was developed. The interactive infographic is intended for parents and children and incorporates information parents and children identified as both wants and needs about concussion alongside the best-available research evidence on pediatric concussion. N=31 surveys were completed by parents. The average scores for each item on the usability surveys ranged from 8.03 to 9.26 on a 10-point Likert scale, indicating the usability components of the infographic were largely positive. There was no statistically significant difference between pre (M=9.1/10; SD=0.75) and post (M=9/10; SD=0.76) knowledge scores ($t(30)=0.619$, $p=0.540$). In contrast, there was a statistically significant difference between pre

(M=3.9/5; SD=0.56) and post (M=4.4/5; SD=0.44) confidence in knowledge scores ($t(30)=-5.083$, $p<0.001$).

Conclusions: Our results demonstrate that parents rated a digital, interactive infographic for pediatric concussion, positively. In addition, while there was no statistically significant difference overall in parents’ knowledge scores before and after viewing the infographic, their confidence in their knowledge did significantly increase. These results suggest that a digital, interactive infographic as a knowledge translation intervention may be useful in increasing parents’ confidence to manage their child’s concussion.

Keywords: *concussion; mTBI; usability evaluation; knowledge assessment; knowledge translation; parent knowledge; parent confidence; patient engagement; educational tool*

Introduction

Concussions, known as mild traumatic brain injuries, are complex injuries caused by direct or indirect blows to the head (1). An estimated 125,000 youth in Canada, and 750,000 in the United States will sustain concussions annually (2, 3). Typical signs and symptoms of a concussion include headaches, nausea, dizziness or “fogginess” and sensitivity to light or noise (4). For most children, recovery occurs within 1-4 weeks post-injury (5). An estimated one third of children and youth will have persistent symptoms, occurring beyond 28 days. Persistent symptoms may include headaches, sleep problems and emotional distress (2, 3, 6).

Rapid increases in the amount of health research, particularly in pediatric concussion, and the increased accessibility to research offered through the Internet, suggests a demand for reliable, evidence-based health information for patients and families that is relevant and easy to understand (7). Innovative mediums have been shown to be superior to traditional methods (e.g. handouts) for transferring health information to consumers (8). Our research team conducted an environmental scan of pediatric concussion resources found on the Internet and in App stores. Despite innovative mediums being superior to traditional methods for transferring health information, our scan revealed that the majority of pediatric concussion resources are PDF documents, suggesting organizations struggle to optimize the use of innovative mediums (e.g. infographics, videos, narratives) when sharing health information. Our environmental scan also found many resources are not developed in collaboration with health consumers. Employing patient engagement approaches to involve end-users (i.e. parents and children) in the development of educational resources is key to effective knowledge translation (9).

A 2020 systematic review (10) evaluating the effectiveness of concussion education programs for coaches and parents of youth athletes found a limited number of studies examining the efficacy of educational interventions on parental knowledge of concussion and a lack of interventions designed specifically for parents. This suggests additional research is necessary to investigate changes in parental knowledge following education interventions and a need for more interventions specifically intended for parents and families. Furthermore, while studies have been conducted assessing parental knowledge of concussion, most focused on sport-related concussions (11-16). Few studies have evaluated changes in concussion knowledge after exposure to an educational intervention (14), and no known studies have assessed changes in self-confidence. Confidence is an important construct for behavioral change. Higher levels of confidence increase the likelihood an individual will change a health behavior when faced with obstacles (17). Understanding how confident parents are in their knowledge and abilities to parent is an essential component of the quality and sustainability of parenting behaviors (18). In the context of our research, understanding how confident parents are in their knowledge of concussion and if an increase in confidence pre-post intervention is observed, may provide critical insight into their health decision making for their child such as when to seek emergency care, and at home recovery.

To date, knowledge translation (KT) efforts have largely focused on ensuring that health care professionals use the latest research to inform their practice; however, emerging evidence suggests that efforts which target health consumers (e.g., patients/families) can inform their decision making and shape their treatment expectations (19-22). While research is beginning to demonstrate that strategies targeting parents for KT can reduce health care utilization and improve outcomes, more research is required to fully understand the power and impact of these efforts on both children and families (23-25).

Developing innovative KT tools that present research-based information in user-friendly languages and formats provides consumers with accurate recommendations while addressing knowledge or information needs. Additionally, these tools may foster and empower consumers to make informed decisions about healthcare for themselves and their families. To date, limited research has explored the usefulness and effectiveness of Web-based infographics as an innovative way to share health information with patients and families. The purpose of this research was to actively work together with children who have experienced a concussion, and their parents, to develop, refine and evaluate the usability of a digital infographic for pediatric concussion. We also aimed to assess parental self-confidence and knowledge of pediatric concussion before and after exposure to the infographic. This paper reports on the infographic prototype development and the results of parental usability and knowledge and confidence testing.

Methods

A four phase, multi-method study employing patient engagement techniques was used to develop, refine, and evaluate the usability of a digital infographic for pediatric concussion to promote knowledge translation. Changes in concussion knowledge and confidence in responses were also evaluated through pre/post-tests. Ethics approval was received from the University of Alberta Health Research Ethics Board (Pro0096202).

Exploring Gaps in Current Concussion Tools (Intervention Development, Phase 1)

An environmental scan (ES) was conducted by the first author (AC) to identify publicly available Canadian-developed resources providing information on pediatric concussion found on the Internet and in Apps. Information gaps in these resources were extracted and used to inform the subsequent phases of this research including the target audience for semi-structured interviews (Phase 2), and elements of the infographic, including target audience, content, and format (Phase 3). Full results of this environmental scan are reported elsewhere (26).

Compilation of Child and Parent Narratives (Intervention Development, Phase 2)

Phase 2 of this multi-phase study was a qualitative description (27, 28). The first author (trained in qualitative methods and supervised by the senior author and principal investigator [PI]) conducted semi-structured interviews with a convenience sample of children who have experienced a concussion, and their parent. Children and parents were recruited online through our research group's (ECHO KT) social media platforms (Twitter @echoktresearch, Facebook ECHO Research, Instagram echoktofficial) and website [www.echokt.ca]. The overarching purpose of these interviews was to explore the concussion experience of children and parents to understand their information needs and preferences regarding concussion. For children, questions focused on the concussion experience from the child's perspective and for parents, questions focused on the experience of caring for a child with concussion. Interview topics included mechanism of injury, symptom experience, experience with the healthcare team, recovery and follow-up, and concussion information needs and preferences. The interviews were recorded and transcribed verbatim. The findings from these interviews informed the content and format of the web-based infographic. Full results of this qualitative study are reported elsewhere (29).

Prototype Development (Phase 3)

The development of the infographic prototype involved first creating a composite infographic "skeleton", which integrated the information needs and preferences of parents and children (as reported in the qualitative interviews) with the best available research on pediatric concussion management (30, 31). This integration determined the content for the infographic. AC lead the development of the infographic with ongoing input and feedback from all authors.

We then worked with a graphic design team who assisted with developing the accompanying artwork that would coincide with the content for the infographic.

Parent, Youth and Expert Feedback and Prototype Refinement

Upon completion of the infographic prototype, it was vetted for content accuracy by VP (content expert). VP is ideally suited for this assessment as she is well abreast of the best available research evidence in this specialized field. All authors provided extensive input and feedback on each iteration of the prototype until a finalized version was agreed upon to be disseminated for user feedback and evaluation. The prototype was then shared with a group of parents from the Pediatric Parent Advisory Group (P-PAG). The P-PAG is a group of parents, legal guardians and grandparents who serve as advisors to the ECHO Research and ARCHE programs (SDS and LH's research programs) by providing advice and feedback on research aimed at improving child health outcomes (32). Finally, the prototype was shared informally with a diverse group of youth for further advice and feedback. Based on the recommendations and feedback from content experts, parents and youth, changes were made to the infographic.

Prototype Usability Evaluation and Knowledge Change

We collected a convenience sample of participants to complete our online surveys. Collaborating clinicians from across Canada emailed potential participants with links to the infographic, usability test and pre and post knowledge and confidence tests. Potential participants included any parent, legal guardian, or grandparent. Participants were required to read and understand English. We asked for assistance from clinicians with known connections to concussion clinics as potential participants from these clinics would be best suited to assess the relevance of the infographic and are more likely to seek out similar resources. Parent participants who previously participated in the qualitative interview portion of this research were also contacted via email with links to the infographic and surveys. Additionally, we recruited participants via advertisements on our research group's social media platforms (Twitter, Facebook, Instagram) with a link to the surveys.

A link to the infographic, usability test, and pre and post knowledge and confidence tests was made available to all potential participants. Consent was implied if the Web-based survey was completed and submitted. Completion of the survey was completely voluntary. Participants were asked to complete a Web-based survey that assessed their perceptions of the infographic using an adapted version of the User Experience Questionnaire (UEQ) (33, 34). The adapted UEQ contained 11-items, rated on a 10-point Likert scale ranging from 1 (least favorable answer) to 10 (most favorable answer) (Appendix E). Participants had the opportunity to provide free text feedback on areas that required revisions or more information.

To evaluate knowledge of pediatric concussion, participants were asked to answer 10 true or false questions reflecting the most common misunderstandings about concussion. The true or false questions were adopted from a questionnaire developed by McKinlay et al. (35). Participants rated their level of confidence in their response to each question using a 5-point Likert scale (very sure to very unsure) (Multimedia Appendix A). After completing the baseline knowledge test, participants were to read the infographic, and knowledge questions were answered again to assess short-term knowledge changes. Participants were again asked to rate their confidence. The UEQ was also completed following post knowledge and confidence testing.

Survey data was collected from May 6, 2021 to June 14, 2021 through the Canadian online electronic platform, SimpleSurvey™. SimpleSurvey™ is secure protected by several firewalls and layers of security in alignment with Canadian privacy laws. Data collected through

SimpleSurvey is completely anonymous and cannot be traced back to any individual. We followed the Checklist for Reporting Results of Internet E-Surveys (CHERRIES) (Appendix F).

Data Analysis

Data were entered into Statistical Package for the Social Sciences (SPSS) version 26 (36) and descriptive statistics (e.g. frequencies), measures of central tendency, as well as tests of statistical significance were completed. To assess knowledge change, we statistically compared pre and post knowledge and scores overall as well as pre and post scores for each individual topic. To assess knowledge change in each topic, items on the knowledge questionnaire were scored as one for correct, and zero for incorrect. The percentage of correct answers for each item and overall were then calculated. The average knowledge scores for both pre and post questionnaires were compared using paired *t*-tests.

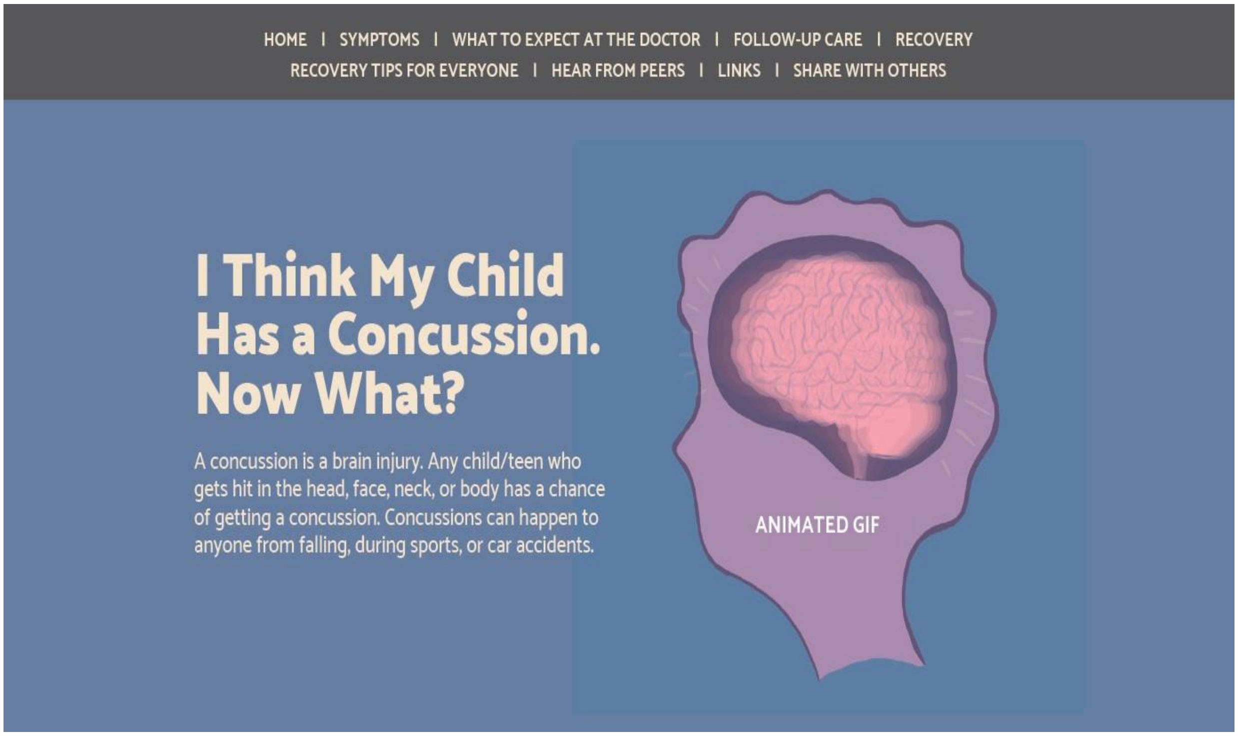
To assess change in confidence, we statistically compared pre and post confidence scores overall as well as pre and post scores for each individual topic. Likert-scale scores were averaged and differences in pre and post test scores were compared using paired *t*-tests. Free text data was analyzed using content analysis (28). We conducted sample size calculations based on change in overall knowledge score; to achieve a power of 80% and a level of significance of 5% (two-sided) with a 1-point difference (on a 10-point scale) between knowledge scores pre and post-intervention (correlation estimate 0.6), a total sample size of 28 participants was required.

Results

The Tool (Digital Interactive Infographic)

In collaboration with a creative design team, we developed a digital, interactive infographic based on 14 interviews with children and parents who have had experiences with concussion. The interactive infographic targets parents and children and was designed to incorporate information parents and children identified as both wants and needs about concussion including symptoms, when to go to the emergency department, return to play and learn guidance, and recovery tips. Interactive elements of the infographic include an animated GIF (Graphics Interchange Format) depicting what happens to the brain inside the skull after a direct or indirect blow to the head, drop down lists, horizontal scrolling, audio clips of children telling their story and experience with concussion, and downloadable PDF information sheets targeting teachers, coaches, and family/friends that can be shared (Fig.4.1-4.4). Modifications to the infographic were also made in careful consideration of those suffering from concussions. For example, we opted to make the font size larger than average, and ensured the colors used throughout the infographic were "less bright" (softer or "dull") to accommodate the visual disturbances and sensitivity to light often experienced with concussions (37, 38). We ensured the characters used throughout the infographic were representative of a diverse population. On average, the infographic takes approximately 5-10 minutes to read and review from beginning to end.

Figure 4.1 Sample page from infographic



I Think My Child Has a Concussion. Now What?

A concussion is a brain injury. Any child/teen who gets hit in the head, face, neck, or body has a chance of getting a concussion. Concussions can happen to anyone from falling, during sports, or car accidents.

Figure 4.2 Sample page from infographic

Recovery

After a short time (24-48hrs), of rest “return to play” and “return to learn” should be slow and follow step-by-step recommendations

Below shows the expanded version of drop-downs

Figure 4.3 Sample page from infographic

Below shows the expanded version of drop-downs

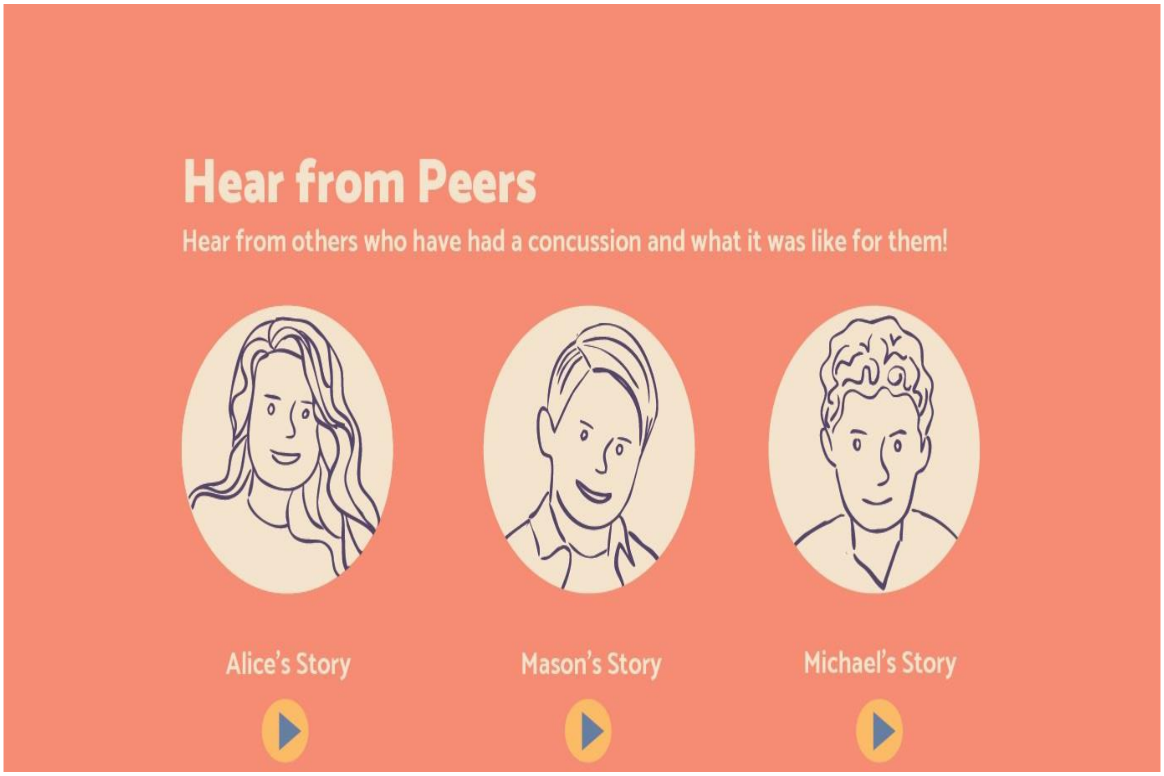
Return to Play (sport or recreation): 6 Steps and Activity Suggestions

No new or worsening symptoms for 24 hours?

Yes: move to next step.
No: move back a step.

STEP 6	FULL RECOVERY.	Normal game play.
STEP 5	FULL-CONTACT ACTIVITY.	Full contact sport practices or play.
STEP 4	MORE COMPLEX ACTIVITY. NON-CONTACT.	Passing drills, jungle-gyms, resistance training.
STEP 3	MODERATE ACTIVITY. NON-CONTACT.	Skating, running, simple sport drills.
STEP 2	LIGHT ACTIVITY. INCREASE HEART RATE.	Walking, jogging, swimming, no resistance training.
STEP 1	RECOVERY. NO SPORTS.	Rest. Walking.

Figure 4.4 Sample page from infographic



Hear from Peers

Hear from others who have had a concussion and what it was like for them!

Usability Testing Results

Forty-three surveys were started, and 31 were fully completed (72.1%). Table 4.1 describes the demographics of the study population.

Table 4.1 Demographic characteristics (N=31)

Variable	**n (%)**
Sex	
Female	**28 (90.3)**
Male	**3 (9.7)**
Age (years)	
20-29	**7 (22.6)**
30-39	**10 (32.3)**
40-49	**5 (16.1)**
50-59	**6 (19.4)**
≥60	**3 (9.7)**
Marital Status	
Married/Partnered/Common-Law	**28 (90.3)**
Single/Separated/Divorced/Widowed	**2 (6.5)**
Prefer not to answer	**1 (3.2)**
Education	
Post-secondary certificate/diploma	**6 (19.4)**
Post-secondary degree	**9 (29.0)**
Graduate degree	**15 (48.4)**
Other	**1 (3.2)**
Prefer not to answer	**1 (3.2)**
Annual Household Income ($CAD)	
$40,000-59,000	**1 (3.2)**
$60,000-79,000	**1 (3.2)**
$80,000-99,000	**4 (12.9)**
≥$100,000	**22 (71.0)**
Prefer not to answer	**3 (9.7)**
Number of Children	
0	**2 (6.5)**
1	**12 (38.7)**
2	**15 (48.4)**
3	**1 (3.2)**
4	**1 (3.2)**
Age of children (years)	
<1	**4 (12.9)**
1-5	**14 (45.2)**
6-10	**2 (6.5)**
11-15	**6 (19.4)**

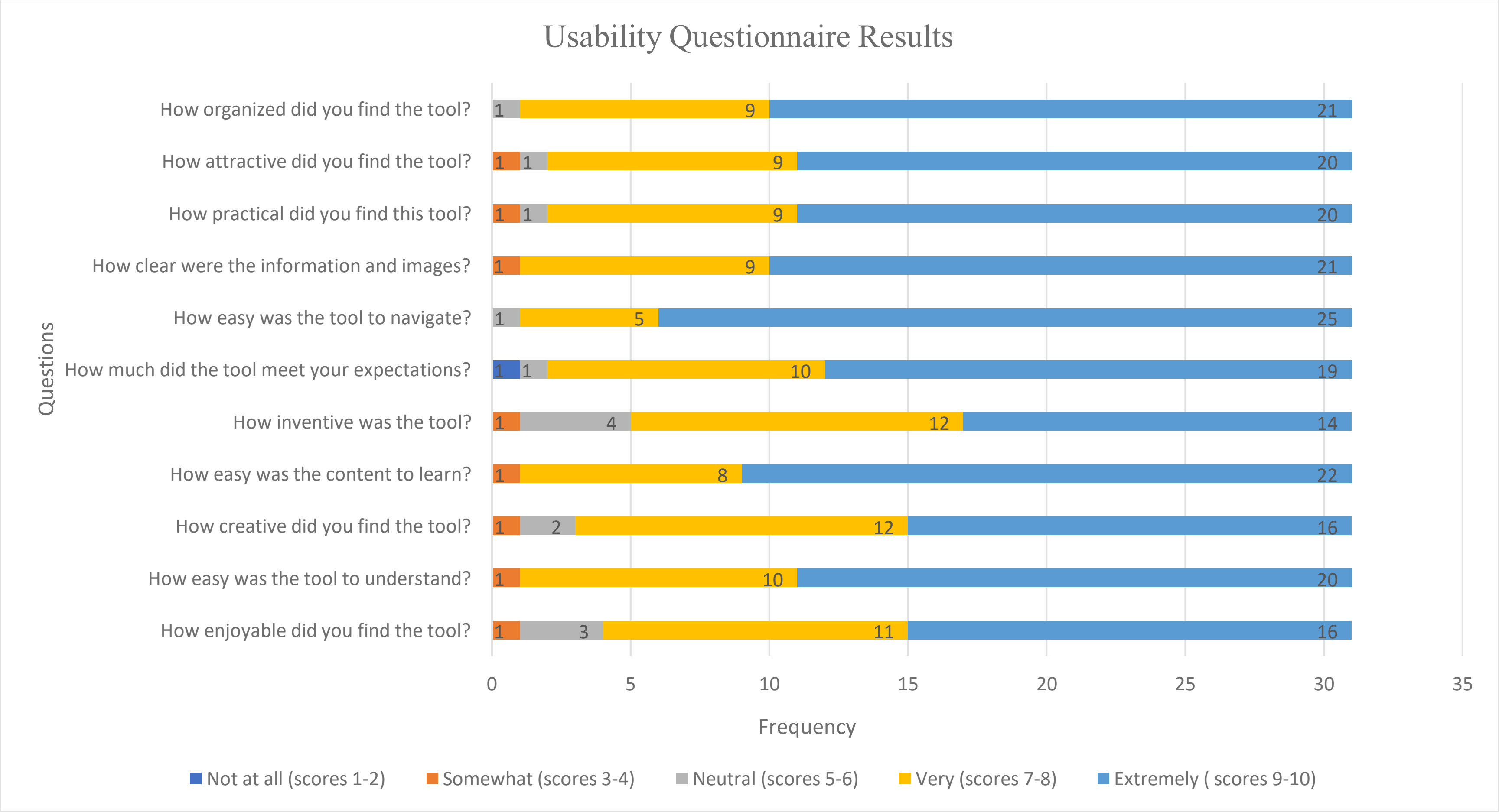
16-20	**11 (35.5)**
21-25	**3 (9.7)**
>25	**9 (29.0)**
N/A	**2 (6.5)**
Has your child ever had a concussion?	
Yes	**14 (45.2)**
No	**17 (54.8)**

In general, parental reaction to the infographic was positive. The average scores for each item of the usability scale ranged from 8.03 to 9.26 out of 10 (Figure 4.1). Only one parent indicated the infographic did not meet their expectations and one parent commented that they would not recommend this tool to other families managing a child's concussion. Common comments on the usability survey indicated parents felt the infographic was "simple and easy to follow", "user friendly", and "concise". Other comments on the most positive aspects of the infographic included, *"Good layout and flow to answer questions, easy to navigate, and flow chart easy to follow on next steps"* (Participant 14). Another parent said, *"The points were well highlighted. Easy to follow. Informative, quick to look at for what to do or watch for. Not too overwhelming. Touched the most important information."* (Participant 23). Another parent alluding to the simplicity of the infographic said, *"It did not overwhelm with information"* (Participant 8).

Some parents felt the infographic colors were "dull" and "sometimes hard to view" (i.e. Participants 26, 29). For instance, one parent said,

> *"Mostly blocks of words, not unlike a pamphlet. Colours somewhat dull and lacking contrast between text and background. May be difficult for people with low vision or differences in colour perception."* (Participant 11).

Figure 4.5 Usability Questionnaire Results



Knowledge Evaluation and Confidence in Response

The average pre-knowledge score across the 10 knowledge topics was 9.1/10 (91%; SD=0.75) and the average post-knowledge score was 9/10 (90%; SD=0.76). A paired *t* test showed no statistically significant difference in average knowledge scores before and after viewing the infographic (*t*(30)=0.619, *p*=0.540). Individually, an overall knowledge gain was observed for topics 2, 7 and 10 and an overall knowledge loss was observed for topics 1, 6, 8, and 9, but none of these changes pre- post-intervention were statistically significant (Table 4.2). In the remaining three topics (topics 3, 4, 5) 100% of parents successfully identified the correct response before viewing the infographic and this was retained post.

The average pre-confidence score across the 10 knowledge topics was 3.9/5 (78%; SD=0.56) and the average post-confidence score was 4.4/5 (88%; SD=0.44). A paired *t* test showed a statistically significant difference in average confidence scores before and after viewing the infographic (*t*(30)=-5.083, *p*=<0.001). Across each knowledge topic, paired *t* tests showed a statistically significant difference in confidence in answering the true or false questions for seven of the 10 topics (topics 2, 3, 5, 6, 7, 9, 10) (Table 4.3).

Table 4.2 Changes in knowledge before and after exposure to the intervention

Table 2. Changes in parental knowledge before and after exposure to the intervention (N=31)

Question/Topic (correct answer)		**Scenario**		**Frequency, n (%)**	**% correct Pre**	**% correct Post**	**P-value**
		Pre	**Post**				
1	A concussion only occurs when there is loss of consciousness (false)	T	F	0 (0.0)	100%	96.8%	0.325
		F	T	1 (3.2)			
		T	T	0 (0.0)			
		F	F	30 (96.8)			
2	A concussion only occurs after a blow directly to the head (false)*	T	F	4 (12.9)	87.1%	96.8%	0.325
		F	T	1 (3.2)			
		T	T	0 (0.0)			
		F	F	26 (83.9)			
3	Confusion is not a sign of concussion if it clears within 5 minutes (false)	T	F	0 (0.0)	100%	100%	--
		F	T	0 (0.0)			
		T	T	0 (0.0)			
		F	F	31 (100.0)			
4	It is safe to return to playing sports as soon as the child is no longer confused (false)	T	F	0 (0.0)	100%	100%	--
		F	T	0 (0.0)			
		T	T	0 (0.0)			
		F	F	31 (100.0)			
5	Concussion symptoms are only apparent at the time of injury (false)	T	F	0 (0.0)	100%	100%	--
		F	T	0 (0.0)			
		T	T	0 (0.0)			
		F	F	31 (100.0)			
6	Being "knocked out" is not the same as a concussion (true)†	T	F	6 (19.4)	77.4%	64.5%	0.161
		F	T	2 (6.5)			
		T	T	18 (58.1)			
		F	F	5 (16.1)			
7	Someone with a concussion should be kept awake for the first 24 hours after injury (false)	T	F	1 (3.2)	90.3%	93.5%	0.325
		F	T	0 (0.0)			
		T	T	2 (6.5)			

		F	F	28 (90.3)			
8	There are no longer term effects of a concussion (false)	T	F	0 (0.0)	96.8%	93.5%	0.325
		F	T	1 (3.2)			
		T	T	1 (3.2)			
		F	F	29 (93.5)			
9	Children will recover better from a concussion than adults (false)	T	F	1 (3.2)	61.3%	58.1%	0.572
		F	T	2 (6.5)			
		T	T	11 (35.5)			
		F	F	17 (54.8)			
10	Sometimes, concussion symptoms can take hours or days to show up (true)	T	F	1 (3.2)	90.3%	96.8%	0.325
		F	T	3 (9.7)			
		T	T	27 (87.1)			
		F	F	0 (90.0)			
	Overall score	n/a	n/a	n/a	90.3%	90.0%	0.540

Table 4.3 Confidence in knowledge responses

Table 3. Confidence in Knowledge Responses by Question/Topic										
Question/Topic (correct answer)		**Pre/Post-test**	**Confidence**					***M***	***SD***	***P* value**
			Not at all confident n (%)	**Somewhat confident n (%)**	**More than somewhat, but not very confident n (%)**	**Very confident n (%)**	**Extremely confident n (%)**			
1	A concussion only occurs when there is loss of consciousness (false)	Pre	0 (0.0)	0 (0.0)	2 (6.5)	9 (29.0)	20 (64.5)	4.58	0.62	0.057
		Post	0 (0.0)	0 (0.0)	1 (3.2)	6 (19.4)	24 (77.4)	4.74	0.51	
2	A concussion only occurs after a blow directly to the head (false)	Pre	1 (3.2)	1 (3.2)	5 (16.1)	9 (29.0)	15 (48.4)	4.16	1.04	**0.020***
		Post	0 (0.0)	0 (0.0)	2 (6.5)	7 (22.6)	22 (71.0)	4.65	0.61	
3	Confusion is not a sign of concussion if it clears within 5 minutes (false)	Pre	0 (0.0)	1 (3.2)	12 (38.7)	10 (32.3)	8 (25.8)	3.81	0.87	**0.004***
		Post	0 (0.0)	1 (3.2)	3 (9.7)	8 (25.8)	19 (61.3)	4.45	0.81	
4	It is safe to return to playing sports as soon as the child is no longer confused (false)	Pre	0 (0.0)	10 (32.3)	5 (16.1)	0 (0.0)	16 (51.6)	4.35	0.76	0.059
		Post	0 (0.0)	1 (3.2)	0 (0.0)	8 (28.8)	22 (71.0)	4.65	0.66	
5	Concussion symptoms are only apparent at the time of injury (false)	Pre	0 (0.0)	0 (0.0)	4 (12.9)	11 (35.5)	16 (51.6)	4.39	0.72	**0.031***
		Post	0 (0.0)	0 (0.0)	1 (3.2)	7 (22.6)	23 (74.2)	4.71	0.53	
6		Pre	0 (0.0)	2 (6.5)	14 (45.2)	10 (32.3)	5 (16.1)	3.58	0.85	

	Being “knocked out” is not the same as a concussion (true)	Post	0 (0.0)	2 (6.5)	6 (19.4)	12 (38.7)	11 (35.5)	4.03	0.91	**0.008***
7	Someone with a concussion should be kept awake for the first 24 hours after injury (false)	Pre	1 (3.2)	4 (12.9)	10 (32.3)	10 (32.3)	6 (19.4)	3.52	1.06	**0.001***
		Post	1 (3.2)	1 (3.2)	3 (9.7)	9 (29.0)	17 (54.8)	4.29	1.01	
8	There are no longer term effects of a concussion (false)	Pre	0 (0.0)	0 (0.0)	5 (16.1)	14 (45.2)	12 (38.7)	4.23	0.72	0.071
		Post	0 (0.0)	0 (0.0)	3 (9.7)	9 (29.0)	19 (61.3)	4.52	0.68	
9	Children will recover better from a concussion than adults (false)	Pre	3 (9.7)	6 (19.4)	14 (45.2)	5 (16.1)	3 (9.7)	2.97	1.08	**0.004***
		Post	2 (6.5)	1 (3.2)	11 (35.5)	12 (38.7)	5 (16.1)	3.55	1.03	
10	Sometimes, concussion symptoms can take hours or days to show up (true)	Pre	2 (6.5)	1 (3.2)	8 (25.8)	12 (38.7)	8 (25.8)	3.74	1.09	**0.000***
		Post	0 (0.0)	0 (0.0)	3 (9.7)	11 (35.5)	17 (54.8)	4.45	0.68	

*=statistically significant *p*<0.05

Discussion

Principal Results

This study evaluated the usability of a novel, digital and interactive infographic for parents who have experiences managing a child with a concussion in addition to parental knowledge about pediatric concussion and confidence in their responses. Previous research has explored student and parent knowledge and perceived confidence about brain injury and concussion, but did not assess changes in knowledge or confidence before and after exposure to an educational intervention (39). Our study is the first to examine how digital and arts-based media impact parental knowledge and confidence about pediatric concussions.

Parental concussion education is critically important, as many concussion signs and symptoms may not appear until hours, or even days, following the incident. As such, the onus falls on parents to identify signs and symptoms to ensure prompt and proper diagnosis, treatment, management, and ensure safe return to play/school (10, 15). Previous studies on parental concussion knowledge have found that parents are generally knowledgeable about concussion signs, symptoms, and recovery time even prior to exposure of an educational intervention with small improvements in knowledge following exposure (14, 15). Parents in our study were also found to be generally knowledgeable about concussion prior to exposure of our infographic. Overall, results in the current study have shown no significant increase overall in concussion knowledge. This may be due to the fact that most parents in our study had previous experience with concussion and possessed high levels of concussion knowledge at baseline. A more diverse sample (particularly those without previous concussion experience) and more pronounced knowledge deficits at baseline may have yielded more significant knowledge changes.

Unique to our study was the evaluation of not only parental knowledge changes, but changes in confidence in their responses. After exposure to the infographic, parents' confidence in their responses significantly increased in seven of ten content areas. This suggests that our infographic was effective in helping parents feel more confident in their knowledge about pediatric concussions. Increasing parental confidence in knowledge of their child's illness or injury may positively influence their child healthcare decision making (such as when to seek medical attention, homecare and recovery) ultimately improving child health outcomes (17). This phenomenon has been observed in a previous study conducted by our research team in the area of pediatric chronic pain (24).

Overall, results on the usability of the infographic were positive, with most parents rating each aspect of the tool as very or extremely favorable. Our study, and others, have demonstrated that innovative media, using narrative and artistic elements, is a promising approach for communicating complex health information to parents and families (20, 21, 24, 40). While time and resource strain often determine how resources are developed, more innovative mediums may be beneficial to evoke relevance, timely accessibility, and engagement. In fact, more innovative media such as cartoons and videos, have been found to be superior to standard medical sheets for transferring information to consumers (8). Our chronic pain study yielded similar results to our current study, suggesting innovative, digital and arts-based interventions (i.e. e-Books, infographics) are viewed positively by parents and may increase parental confidence in their knowledge of pediatric conditions (24).

Feiss et al's (2020) systematic review found only three concussion education programs to be evaluated in the literature (10). Furthermore, while these programs include written content directed towards parents, there are no programs specifically designed for parents. Our infographic is unique in that it was designed specifically for parents based on their information needs and preferences and parents were involved throughout the tool development process. Furthermore, our infographic was designed to be "safe" or "comfortable" for youth with concussions to view, as we carefully considered elements such as font size and colors that would not cause eye strain, and potentially exacerbate concussion symptoms. While the rapidly developing evidence base in pediatric concussion places increased demands on updating information that is included in educational interventions to ensure they are timely and relevant, researchers have an opportunity to expand on the evidence being shared by taking a more participatory approach, involving end users in the development of these interventions.

Upon finalization of the infographic, it will be disseminated through established social media platforms including ECHO Research's Instagram, Twitter, Facebook and website (www.echokt.ca) and TREKK (www.trekk.ca), which is a national network of health professionals and parents whose goals are to improve emergency care for children.

Limitations

We relied on parent self-report data. Parents in our study consistently possessed high levels of education, and our findings cannot be extrapolated to all parents, including those with more pronounced information deficits or poor health literacy. Our study evaluated short-term changes in knowledge and confidence. Future research should examine changes in knowledge and confidence over time, as well as whether this change affects decisions made in regards to the care and outcomes of the child. Additionally, approximately half the parents in our study had prior experience with concussions and may have received information about concussions via other sources. This may confound our results in terms of the effectiveness of the infographic on knowledge and confidence. Further the baseline knowledge score was very high, leaving little room to see an effect in terms of knowledge change. Our study did not ask about previous education sources, training, or exposure about pediatric concussions. Better understanding about the impact of various forms of education on knowledge and confidence will help improve the design and format of future educational interventions.

Conclusions

Our results demonstrate that parents positively rated a digital, interactive infographic about pediatric concussion and this infographic increased their confidence in knowledge of pediatric concussion. These findings hold promise for future development, application, and effectiveness testing of digital, arts based KT interventions for transferring complex health information to parents. Future research employing innovative digital media for knowledge transfer with different clinical conditions and participant demographics (i.e., children, different parents) should be explored as well as the effectiveness of different formats (i.e., videos, e-books, standard information sheets).

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CHAPTER 5. CONCLUDING CHAPTER

Overview of Findings

My research situates pediatric concussion as a complex, yet common injury experienced by Canadian families and places considerable burden on children, parents, and our healthcare system. Understanding the experiences and information needs of children and parents in relation to pediatric concussion and connecting them to evidence-based information about pediatric concussion was deemed as one solution to minimize the burden of this complex injury. Patient-engagement, IKT and the KTA Framework were integrated throughout this research [1-3]. Specifically, within the KTA Framework, the knowledge funnel process identified and refined relevant knowledge about pediatric concussion into a useful tool, which is a digital interactive infographic designed for children and parents managing pediatric concussion. The KTA action cycle informed the refinement, evaluation and future implementation of the KT tool.

Three main phases were conducted and mapped into the KTA Framework. The first, was an ES aimed at identifying resources developed in Canada, that provide information specific to pediatric concussion and extracting information about each resource to determine information gaps (Chapter 2). The contribution of this ES was a comprehensive list of Canadian-developed educational resources about pediatric concussion available on the Internet and in App stores. Gaps in these resources with respect to target audience, content, and format were identified, and these gaps informed the subsequent phases of this work including the target audience to interview in the qualitative description study (Chapter 3) and elements of the KT tool (i.e., format, content). The gaps identified in this ES also provided guidance for the future development of novel educational resources about pediatric concussion.

Phase two was a qualitative study to explore and describe the experiences and information needs of children who have experienced a concussion, and the experience and information needs of their parents in caring for them (Chapter 3). The contribution of this study was the identification of key child and parent information preferences and needs about pediatric concussion. Additionally, this study provided insight into the overall experience of having a concussion from the unique perspective of children, and the emotional impact on parents caring for a child with a concussion. These findings, alongside the findings from the ES (phase 1) informed the content of the digital interactive infographic. The infographic was designed to meet the information needs and preferences of children and parents managing concussions as unveiled in the interviews and provide specific recommendations on identifying signs and symptoms of concussion, evidence-based management tips at home, when to seek emergency care and navigating the safe return to play and learn.

The third study (phases 3 and 4) was the development and evaluation of an innovative KT tool about pediatric concussion (Chapter 4). The contribution of this study was the development of a novel and innovative, digital interactive infographic for children and parents about pediatric concussion. Additionally, this study evaluated the usability of the infographic and compared parental knowledge of concussions and confidence in their knowledge before and after viewing the infographic. This evaluation determined that the infographic was viewed positively by parents and increased parental self-reported confidence in their knowledge of pediatric concussion.

Collectively, this body of work provides an example of the detailed and pragmatic application of the KTA Framework within a multi-phase, multi-method KT study. This research makes substantial contributions to the complex fields of pediatric concussion, KT science, IKT and patient engagement research, and KT intervention design and evaluation. Additionally, the methods employed in phase 1 (ES) make novel contributions to the limited methodological guidance for conducting ESs.

Relevance to Nursing

Developing an emotionally and communicatively responsive solution for childhood concussion for children and families reflects a patient-centered approach to research and care provision. Exploring the lived experiences of children with concussion and their parents provides important insights toward improving clinical care for this complex condition, making significant contributions to nursing practice. Creating resources that validate the concerns and experiences for both children and their parents can make an important contribution to meeting their support needs and epitomizes the essence of patient and family centred care, a fundamental component of nursing practice. Nurses are in an ideal position to educate and support families through their healthcare encounters and the uptake of these findings will guide nurses, and other health care providers (HCPs), to improving care provision of children and families managing the complex condition of concussion. Clinically, this work has the capacity to inform nursing and health care practices in childhood concussion in a patient-centred manner. The digital infographic that was developed as a result of this work may be a useful resource for HCPs working with patients and families experiencing concussions across diverse practice settings.

Relevance to Knowledge Translation Science

This research contributes to KT science in terms of the development and testing of a novel, KT intervention for patients and families and building KT research capacity through collaborations with patients, families and key stakeholders. This research contributes to the emerging field of KT efforts targeting health consumers and advances the science on the best mode of patient education for pediatric conditions, such as concussion. Additionally, this work builds KT research capacity through collaborations with patients, families and key stakeholders and makes important contributions to theoretical and methodological domains by means of novel and collaborative approaches (environmental scan, IKT). Furthermore, the evaluation of the KT tool contributes to the emerging science on the potential effectiveness that online, arts based KT tools have on transferring complex and essential health information to consumers [4-6]. This research provides an opportunity for future studies to assess these approaches to KT with different clinical conditions, and tailor to different audiences. Furthermore, this research demonstrates the practical applicability of the KTA Framework to multi-phase, multi-method research. Collectively, my research illuminates a detailed example on the process of conducting an IKT study within the knowledge creation funnel of the KTA Framework. Traditionally, KT efforts have often targeted health professionals however, an emerging area in KT is developing and implementing interventions targeting health consumers. My research makes critical contributions to this emerging focus through the development and evaluation of a KT tool for patients and families.

Relevance to Patient Engagement Research

The collaborative nature of this research provided an important theoretical lens to enhance engagement with parents and children. The Canadian Institutes of Health Research (CIHR) identifies KT as a fundamental component of their mandate. Central to KT, is the exchange of knowledge between researchers and knowledge users, including decision makers and health consumers. To facilitate this exchange with patients and families, CIHR has established the SPOR Patient Engagement Framework. Co-building is a guiding principle of this framework, which suggests that Canadian health research should be patient informed and/or directed to enhance future uptake and success [7]. This means that patients, families, and researchers must work together from the identification of a research idea through data collection, and dissemination. Despite this framework, and emerging research supporting patient engagement, research often continues to be conducted in isolation from patient input. In part, this may be due to the limited evidence base on the processes and outcomes of patient engagement in research [8-10]. Little is known about how effective patient collaborations in research are built, maintained, or improved. While patients and families were engaged throughout this body of research, formal evaluations on the patient engagement processes are needed. Additionally, to ensure future interventions, like the interactive infographic featured in this body of research, are optimized to the needs of patients and families, patient engagement and IKT is necessary at all stages of intervention design, development, and evaluation.

Overall Implications for Research and Practice

Pediatric concussion is becoming increasingly prevalent and represents a large burden to children, families, and our healthcare system [11, 12]. Connecting families to effective, evidence-based patient education is key to effective decision-making and therapeutic management of pediatric concussion.

My research makes unique contributions to understanding the information needs and experiences of children and families managing concussion. My research resulted in the co-creation of a novel, innovative KT tool about pediatric concussion. The development of practice relevant knowledge and a novel resource are substantive contributions to the field of pediatric concussion. The results of this study are an important foundation for creating resources that directly address children and parents' experiences and self-identified needs for managing concussion and can be applied to other populations and other conditions. Developing supports, such as the KT tool developed from this body of work, that target the information needs of children and parents may improve families' experiences of concussion recovery.

The findings of this work support current evidence that multimedia patient education may improve patient confidence in knowledge, which may be a precursor to behaviour change and behaviour outcomes [13]. However, to capitalize on the use and benefit of these resources we must ensure they are accessible, compatible across multiple devices, and the content is easy to understand, meaningful and credible. Collaborating with pre-existing organizations that already share and promote trusted sources of health information (i.e., children's hospitals, TREKK) will ensure access and reach to a broad and diverse audience.

Methodologically, this research makes substantial contributions to environmental scans. Given the lack of quality standards and methodological guidance for conducting environmental scans, the methods employed in this work are widely applicable, meaning others can use the methods to guide them in conducting an environmental scan in a variety of contexts. Additionally, this work illuminates the development of an accessible, digital knowledge translation tool created *with* and *for* children who have had a concussion and their parents. This process helps to build upon the science of patient engagement in concussion research and can also be applied to patient engagement in research more broadly.

Strengths and Limitations

A strength of my dissertation is the overall contribution to understanding the experiences and information needs of children and parents who have experienced the complex injury of concussion. My dissertation makes unique contributions to the areas of pediatric concussion and KT science, specifically KT intervention development and evaluation for patients and families. The strengths and limitations of this dissertation by phase are discussed.

Phase 1. The nature of this research being multi-phase and multi-method, with each phase building upon the subsequent phase is a strength of this work. The results of each phase provided strong rationale for decisions made in the subsequent phases and different methods allowed for robust data. For phase 1, limited research or quality standards exist for conducting ESs and the nature of Google's search engine ranks pages based on a personalized sorting algorithm, meaning results can be ordered differently when different users enter the same search term. To mitigate this, multiple searches were conducted, returning more results than a typical user would see "above the fold" (results that do not require a click to see) [14]. This would hopefully capture more resources that would be returned in a broad range of personalized searches, in real-world scenarios. However, while the ES employed a comprehensive and systematic process, it is possible that a resource was missed, particularly due to the rapid pace in which pediatric concussion information is being updated and distributed. Despite a lack of quality standards for conducting ESs, this method was the best approach for answering the research question and is the first ES to be conducted on this topic.

Phase 2. I collected data at one point in time, using one method, limiting my ability to determine how children and parents' information needs changed over time. Due to the global COVID-19 pandemic and government restrictions in place, recruitment for qualitative interviews of this study occurred online through convenience sampling. Convenience sampling may not result in the most information-rich sources [15]. Furthermore, recruiting participants online may have impacted the ability to recruit a more diverse sample, as we relied on participants who had access to the Internet. However, we used social media venues to recruit participants, which proved to be a novel and effective way to recruit participants for qualitative research studies.

In attempts to capture a broad and diverse sample for phase 2, we recruited children who sustained a concussion at any point during childhood which meant, for some participants, it had been months or years since their concussion, therefore recall bias was possible. Additionally, recall and self-report bias is always possible when relying on participant self-report. All parents in our study were mothers; hence, fathers were not represented in this study. However, mothers often assume the role of primary caregiver for their child, suggesting the underrepresentation of fathers may reflect a common experience in the everyday management of child illness and injury. Furthermore, despite extensive efforts to ensure variation in parent demographics for phase 2, parents consistently possessed high levels of education. As a result, the findings cannot be extrapolated to all parents, including those who may have more pronounced information needs and deficits.

The participation of both parents and children in this research is a considerable strength. Limited research has been conducted to date in this area with children, and research that has focuses on teens and athletes. This research is unique in that our sample of children is diverse in age and not limited to those only in sport. Secondly, interviewing parents and children together offers a way to capture unique and independent versions of the joint experiences of concussion. This offers a more robust perspective of the entire concussion experience from patient and caregiver perspectives.

Phases 3 and 4. For phases 3 and 4, we evaluated the short-term changes in knowledge and confidence as reported by parents. Evaluating changes in knowledge and confidence over a longer period may have resulted in more profound changes However, no known studies have assessed changes in self-confidence in addition to changes in knowledge of concussion after exposure to an educational intervention. As confidence is an important construct for behavioral change, understanding how confident parents are in their knowledge of concussion and if an increase in confidence pre-post intervention is observed, may provide critical insight into their health decision making for their child such as when to seek emergency care, and at home recovery. Thus, assessing changes in self-confidence in addition to changes in knowledge is both unique and a considerable strength of this work.

As with phase 2, recruitment for phase 4 occurred during a global pandemic. Due to government restrictions in place, recruitment occurred online through convenience sampling, which may have impacted the ability to recruit a more diverse sample, as we relied on participants who had access to the Internet. Furthermore, we relied on participant self-report for knowledge and confidence surveys, therefore self-report bias may be a possibility.

Considerations for Future Research.

Future research should evaluate the long-term effectiveness of the KT tool on knowledge and confidence and whether this tool results in behavior changes and/or improved health outcomes. Additionally, the infographic was developed for both children and parents, and we only evaluated the usability and knowledge of one population. Understanding how children perceive this tool and whether this tool influences the self-reported knowledge and confidence of children and youth may provide valuable insights. Future research may also consider how children and parents' information needs change over time and what factors influence their information needs and care behaviors. Understanding the best methods to get evidence-based information into the hands of consumers is another future area of exploration.

Research Reflections and Implications During a Global Pandemic

The end of this PhD was conducted amidst a global pandemic of the highly infectious disease, COVID-19. Strict public health measures have been implemented locally, including physical and social distancing measures, mandatory work from home orders, school, and business restrictions and at times, complete closures. These unprecedented events have caused our healthcare systems to be under a tremendous amount of strain. Thankfully, in Canada, after over a year and a half, it appears as though the rigorous public health measures, coupled with the development of a vaccine has proven to “bend the curve” on the rate of infections resulting from COVID-19, and a return to a sense of normalcy is on the horizon. Experiencing such an extreme circumstance has given me an opportunity to reflect on the implications and impact of this work in such a unique and unprecedented circumstance.

Witnessing the pandemic unfold, it became clear that the public has had great difficulty navigating the abundantly available health information and differentiating between reliable evidence and misinformation. Various organizations and levels of government have attempted to educate the public on basic infectious disease prevention, including basic hand hygiene and distancing practices and symptom recognition and management. In response to this, numerous education and awareness tools were rapidly developed targeting health consumers. Strategies to share the best and most up-to-date research evidence with the public regarding COVID-19 is essential, however careful consideration of how these tools are developed, and delivered is necessary to build public trust. This pandemic has solidified the importance of collaborating with patients, families, and various levels of stakeholders to ensure research evidence is presented in meaningful and useful ways. The findings from this PhD work contribute to this critical need. Although this dissertation specifically focused on pediatric concussion, fundamental learnings can, and should, be considered for different conditions, and across different health settings.

Many learnings can be gleaned from this pandemic about the health information needs and preferences of the public, the types of interventions that support successful communication and knowledge uptake, and how we can work towards combating the spread of misinformation. Now, more than ever, we recognize the importance of working collaboratively with patients, families, health-care providers, and decision makers at all levels to maximize health service interventions and delivery, for conditions like pediatric concussion, COVID-19, and beyond.

Next Steps: Program of Research

This research provides various avenues and opportunities for future research. I have determined clear next steps from which to build a program of research integrating patient engagement and KT principles for other audiences (i.e., children, youth) and conditions (i.e., mental health, COVID-19). I intend to directly build upon my dissertation research in these areas in a tenure-track faculty position. My program of research will be focused on involving children and youth throughout each aspect of the research process (beginning with setting research questions and aims), developing, and evaluating health education resources, and empirically testing them through pragmatic trials. Another area for future research consideration is evaluating children and youth engagement in research to understand what represents meaningful engagement and how does engagement influence or impact research outputs.

Conclusion

My dissertation contributes to understanding the information needs and preferences of children who experience concussion, and their parents, and to the emerging fields of KT science and patient engagement research. This sequential, multi-phased, multi-method study has practical implications for both childhood concussion research and practice as well as KT science. I found all current, Canadian-developed, health education resources for pediatric concussion that are publicly available online and in App stores, and identified what gaps exist among these resources. This informed decisions for the subsequent phases of the research, including the target audience for a follow-up qualitative study. This ES and qualitative study were the first of their kind and highlighted shortcomings pertaining to education, knowledge, and management in childhood concussion. This data was then used to develop a novel and innovative digital, interactive infographic for children and parents about pediatric concussion. The usability and knowledge evaluation of this tool shows promise for this emerging field of digital and arts based KT interventions.

The research findings, methodological, and theoretical contributions of this dissertation have the potential to stimulate further research and impact health care practices. This research will conceivably generate new insights and research directions for KT intervention development and evaluation and patient engagement processes. The digital, interactive infographic will be made publicly available on www.echokt.ca and www.trekk.ca following final revisions based on the feedback received through the usability testing conducted in this work. This comprehensive, contextually relevant, and clinically accurate resource may assist children and parents through the management of childhood concussions.

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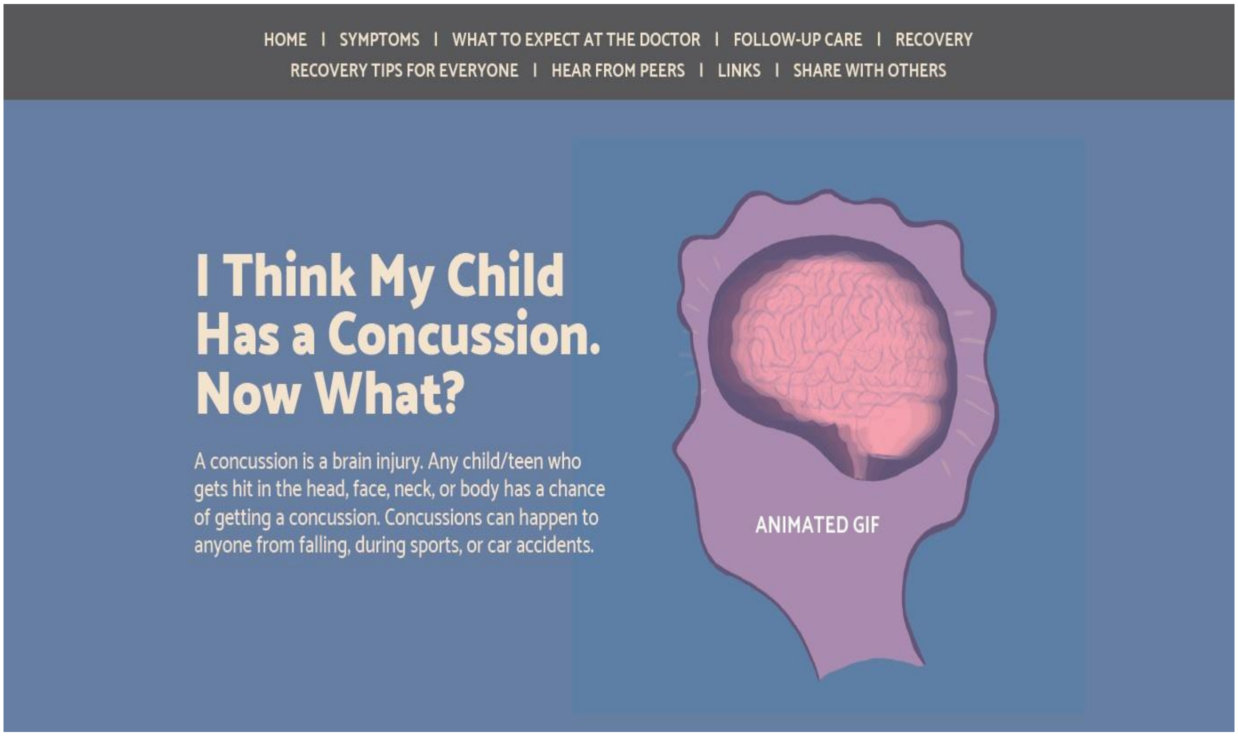
Appendix A. Snapshots from final infographic iteration.



I Think My Child Has a Concussion. Now What?

A concussion is a brain injury. Any child/teen who gets hit in the head, face, neck, or body has a chance of getting a concussion. Concussions can happen to anyone from falling, during sports, or car accidents.

Recovery

After a short time (24-48hrs), of rest “return to play” and “return to learn” should be slow and follow step-by-step recommendations

Below shows the expanded version of drop-downs

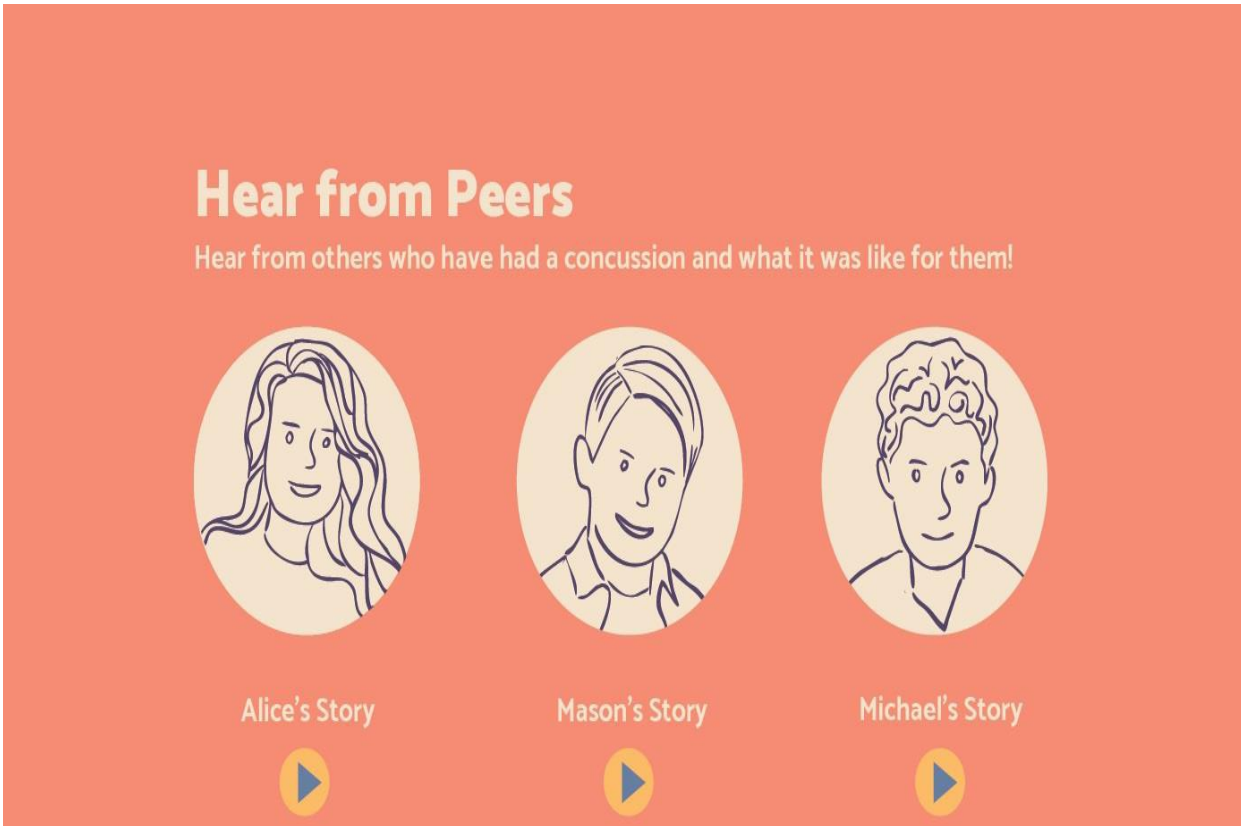
Below shows the expanded version of drop-downs

Return to Play (sport or recreation): 6 Steps and Activity Suggestions

No new or worsening symptoms for 24 hours?

Yes: move to next step.
No: move back a step.

STEP 6	FULL RECOVERY.	Normal game play.
STEP 5	FULL-CONTACT ACTIVITY.	Full contact sport practices or play.
STEP 4	MORE COMPLEX ACTIVITY. NON-CONTACT.	Passing drills, jungle-gyms, resistance training.
STEP 3	MODERATE ACTIVITY. NON-CONTACT.	Skating, running, simple sport drills.
STEP 2	LIGHT ACTIVITY. INCREASE HEART RATE.	Walking, jogging, swimming, no resistance training.
STEP 1	RECOVERY. NO SPORTS.	Rest. Walking.



Hear from Peers

Hear from others who have had a concussion and what it was like for them!

Appendix B. Environmental Scan Key Informant Interview Guide

Environmental Scan: Pediatric Concussion KT Tools

Key Informant Interview Guide/Data Extraction Questions

1. How many information tools does______(organization) have about pediatric concussion?
2. In what format(s) are the tools available?
3. Are the tools accessible online or physical copies only?
4. For physical copies, who distributes these tools (i.e. doctors, nurses, physiotherapists, patients have to ask for them, etc.)
5. What information/content do the tools provide?
6. What audience do the tools target?
7. Are the tools available in different languages? What languages?
8. When are these tools meant to be shared/used? (i.e. pre-injury, post-injury, acutely, long-term)
9. Is the tool evidence-based? What evidence source does the information come from? (e.g. research, systematic review, expert opinion) How are these sources accessed?
10. Who develops these tools? How are the tools developed (e.g. what is the process?) Are end-users involved in the tool development?
11. How often are the tools updated? Is there a formal process to update any information tools? What does this process entail?
12. Are there any perceived information gaps in these tools? If so, what gaps? (i.e. what steps are taken to ensure accessibility of these tools? What challenges do you encounter with health literacy?)

Appendix C. Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist

Developed from:
Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

No. Item	**Guide questions/description**	**Reported on Page #**
Domain 1: Research team and reflexivity		
Personal Characteristics		
1. Inter viewer/facilitator	Which author/s conducted the interview or focus group? AC conducted all interviews	Methods: Data collection
2. Credentials	What were the researcher's credentials? E.g. PhD, MD PhD candidate trained in qualitative data collection.	Methods: Data collection
3. Occupation	What was their occupation at the time of the study? PhD candidate	Methods: Data collection
4. Gender	Was the researcher male or female?	N/A
5. Experience and training	What experience or training did the researcher have? PhD candidate trained in qualitative data collection.	Methods: Data collection
Relationship with participants		
6. Relationship established	Was a relationship established prior to study commencement?	N/A
7. Participant knowledge of the interviewer	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	N/A
8. Interviewer characteristics	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests	N/A

	in the research topic	
Domain 2: study design		
Theoretical framework		
9. Methodological orientation and Theory	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis Qualitative description	Methods
Participant selection		
10. Sampling	How were participants selected? e.g. purposive, convenience, consecutive, snowball Convenience sampling	Methods: Participants and Recruitment
11. Method of approach	How were participants approached? e.g. face-to-face, telephone, mail, email Recruitment ads and standardized messages were developed and shared via online platforms and were open to public viewing. All recruitment postings explicitly instructed individuals who were interested in participating to privately contact the lead author via email or telephone.	Methods: Participants and Recruitment
12. Sample size	How many participants were in the study? 25	Results: Demographics
13. Non-participation	How many people refused to participate or dropped out? Reasons? 11 parents could not be reached for follow-up contact, 3 parents refused participation after receiving the study information letter and 1 parent did not meet the inclusion criteria.	Results: Demographics
Setting		
14. Setting of data collection	Where was the data collected? e.g. home, clinic, workplace	Methods: Data Collection

	Online, via Zoom	
15. Presence of non-participants	Was anyone else present besides the participants and researchers? No	Methods: Data Collection
16. Description of sample	What are the important characteristics of the sample? e.g. demographic data, date See demographic tables.	Results/Tables 1 and 2
Data collection		
17. Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested? Two interview guides (one for parents, one for children) were developed by the lead author in consultation with the research team. Interview topics included mechanism of injury, symptom experience, experience with the healthcare team, recovery and follow-up, and concussion information seeking needs and preferences.	Methods: Data collection/Supplemental Material
18. Repeat interviews	Were repeat inter views carried out? If yes, how many?	N/A
19. Audio/visual recording	Did the research use audio or visual recording to collect the data? Audio recording	Methods: Data collection
20. Field notes	Were field notes made during and/or after the inter view or focus group? Detailed field notes documented impressions and decisions.	Methods: Data analysis
21. Duration	What was the duration of the inter views or focus group? Interviews ranged from 30-60 minutes	Results
22. Data saturation	Was data saturation discussed? Data collection and analysis occurred concurrently until no new information emerged from the interviews, suggesting	Methods: Data collection

	data saturation	
23. Transcripts returned	Were transcripts returned to participants for comment and/or correction?	N/A
Domain 3: analysis and findings		
Data analysis		
24. Number of data coders	How many data coders coded the data? Analysis was conducted by the lead author (AC) trained in qualitative data analysis and reviewed by the research team.	Methods: Data analysis
25. Description of the coding tree	Did authors provide a description of the coding tree?	N/A
26. Derivation of themes	Were themes identified in advance or derived from the data? Codes across transcripts were grouped into emergent and recurring themes	Methods: Data analysis
27. Software	What software, if applicable, was used to manage the data? NVivo 12	Methods: Data analysis
28. Participant checking	Did participants provide feedback on the findings?	N/A
Reporting		
29. Quotations presented	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number Quotes to support each theme can be found in Tables 3 to 8	Results/Tables 3-8.
30. Data and findings consistent	Was there consistency between the data presented and the findings? Relationship to existing knowledge was presented throughout the discussion.	Discussion
31. Clarity of major themes	Were major themes clearly presented in the findings? Analysis revealed six major themes: (1)	Results

	mechanism of injury and concussion symptoms experienced by children, (2) healthcare experience reported by parents, (3) parent concerns and emotions over child's concussion, (4) child thoughts, feelings and questions about their concussion, (5) concussions affect more than just your head, and (6) health information seeking and preferences related to concussion. Some themes contain subthemes	
32. Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	N/A

Appendix D. Interview Guide for Parents/Caregivers and Children

Interview Guide for Parent/Caregiver

Study Title: The development and evaluation of an innovative knowledge translation (KT) tool about pediatric concussion.

1. Tell me about your experiences caring for your child with a concussion.
    a. What were the symptoms? How was your child behaving? How did you know something was wrong?
    b. Has this happened before? If so, how many times? Were the symptoms/behaviours of the child the same or different? In what ways?
2. Tell me about your child who had a concussion.
    a. How old is your child? What were they doing when a concussion was suspected (i.e. playing with friends, playing sports, a fall, an accident)?
3. What information did you know about concussion before your child was diagnosed?
4. What made you decide to take your child to see a health care provider?
5. Tell me about your thoughts and feelings when your child was injured.
    a. Did you feel confident in knowing what to do for your child? Did you seek any information or advice before seeing a health care provider?
6. Tell me about your experience with the health care provider. Overall, was it positive or negative? Why?

    a. How long did you have to wait to see a health care provider?

    b. How did they determine your child had a concussion? What tests/procedures were performed?

    c. What information did the health care provider give you? Was it helpful? When did they give you this information? How was this information delivered to you? (i.e. written, verbal).

7. How do you prefer to receive health information?

8. How did the information you received influence your experience with your child? (i.e. more prepared, confident, overwhelmed).

    a. Do you feel as though you received all the information on your child's concussion that you wanted? Is there anything else you would have liked more information on? Did you seek more information after seeing a health care provider? Where did you seek out this information (i.e. friends, family, online)?

9. How did you manage your child's concussion symptoms at home?

    a. How long were symptoms present? How long did you monitor symptoms for? What sort of follow-up, if any, was advised? Any return visits to the ED?

10. If your child got another concussion, what would you do differently, if anything?

11. In your opinion, what is the best way to make parents/caregivers aware of reliable concussion information? Where would you first go to get concussion information?

Interview Guide for Child:

1. Can you tell me about your overall experience having a concussion? What was it like for you having a concussion? What happened when you got a concussion?

2. What is a concussion to you? What were you told about concussions? How do you treat a concussion? Who told you this?

3. How many concussions have you had? Tell me what happened when you got a concussion.

    a. What were you doing when you got a concussion? (i.e. sports, playing with friends, and accident, etc)

    b. What did it feel like when you got a concussion? What symptoms did you have?

    c. Did you go to the doctor?

4. If you went to the doctor, tell me about that.
    a. What happened at the hospital, clinic, sports medicine clinic, etc.? Did you have to wait a long time? How long? What happened while you waited? How were you feeling? Were you scared, sick, nervous?
    b. What did the doctor say? How did he/she know you had a concussion?
    c. What did the doctor tell you to do now that you had a concussion? How did you get better after a concussion? What things did you do to deal with your concussion?
    d. How did you feel after you saw the doctor? What did you think about what he/she had to say/told you to do?
    e. Did you still have questions after you had seen the doctor?
    f. Thinking back, was there anything you wish the doctor/nurse would have told you about concussions and how to manage them in the days/weeks to come?

5. Did you look for any information about concussions once you knew you had one?

    a. Did you look up any information online? If so, where did you look? What information did you look up? (i.e. signs/symptoms, recovery, return to sports/play, etc.)

    b. Did you ask any friends about concussions? Teammates? Coaches?

6. How long did it take you to feel better, or are you still having symptoms?

7. What happened after you knew you had a concussion?

    a. Were you scared or worried about that?

    b. Did you miss any school, sports or times with friends? If so, how much time? How did you feel about that?

    c. Was school more difficult for you? If so, how was it more difficult (i.e. trouble concentrating, reading, writing). How long did this difficulty last?

    d. Was playing sports more difficult for you? If so, how was it more difficult? (i.e. balance, endurance, fear). How long did this difficulty last?

    e. Did you feel “normal” or the same or did you feel “different” or funny? If you felt different, how so? How long did that last?

8. Were you scared or worried about getting another concussion? If so, how did this change how you acted or what you did? (i.e. more cautious, stopped playing sports/activity, more anxious)

9. Do you think it would help you if you had information to watch, read or listen to about concussions? For example, would a book, a pamphlet or a video be helpful?

10. What do you think is a good way to teach kids about concussions or help kids feel better about having a concussion?