Developing a Patient-Driven Arts-Based Knowledge Translation Tool for Parents of Children with Asthma

by

Mandy Marie Archibald

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Abstract

Background: Family-centered education is critical to managing childhood asthma, the most common chronic disease of childhood in North America. Parents are largely responsible for the day-to-day management of their child's asthma; as such, finding effective ways to educate parents about asthma is essential to improving childhood asthma outcomes. It is known that the information needs of parents of children with asthma are not being met through current educational approaches despite the availability of high quality evidence on childhood asthma management. Patient-driven educational materials that leverage the power of the arts show promise in communicating health information, and may be useful for parents of children with asthma. However, arts-based knowledge translation approaches are in their infancy, and no such strategy has been developed for parents of children with asthma.

Purpose: The purpose of this dissertation is to identify the information needs of parents of children with asthma, use these data to develop an arts-based educational material (i.e., arts-based knowledge translation tool), and thereby contribute to the emerging knowledge base of arts-based knowledge translation.

Methods: This dissertation consists of four prototypes of an arts-based knowledge translation tool and four related papers: (I) a state-of-the- science review of the literature to determine the information needs of parents of children with asthma; (II) an interpretive descriptive qualitative study on the information needs and experiences of 21 parents of children with asthma, representing diverse backgrounds and stages of the illness trajectory; (III) a methods paper which outlines the process and challenges associated with developing a patient-driven arts-based knowledge translation tool; and (IV) a theoretical paper where a classification schema for arts-based knowledge translation strategies is developed.

Findings and Conclusions: The following four knowledge gaps were identified and addressed through this dissertation: (I) knowledge about the information needs of parents of children with asthma was lacking in previous research; (II) the information needs of parents of children with asthma are not being addressed through current educational approaches; (III) innovative educational approaches to knowledge translation, such as arts-based approaches, may hold promise in childhood asthma but have not been developed or discussed; and (IV) the theoretical basis of arts-based knowledge translation approaches is underexplored. In this dissertation I address these limitations by identifying extant research on parents information needs in childhood asthma (paper one), using these findings to inform a qualitative research study of parents' information needs (paper two), developing four prototypes of a patient-driven arts-based knowledge translation tool for parents of children with asthma based on qualitative findings and best evidence about asthma management (paper three; appendices A through E), and developing an arts-based knowledge translation classification schema based on the mechanisms underlying these approaches (paper four).

Through this research, I illustrate that parents of children with asthma have pervasive, unmet information needs and information deficits of varying types, which negatively impacts asthma management, child and family well-being. I demonstrate support for developing the patient-driven arts-based knowledge translation tool and present conceptual and pragmatic complexities associated with this process. These findings contribute to childhood asthma management through a creative and patient-centered approach, while substantively contributing theoretical and procedural knowledge to the growing domain of arts-based knowledge translation.

Preface

This dissertation is an original work by Mandy Marie Archibald. The research project, of which this dissertation is a part, received research ethics approval from the University of Alberta Research Ethics Board, Project Name "Assessing the Informational Needs of Parents with a Child with Asthma", Pro00012779, March 7, 2011.

Three papers within this dissertation have been published, and one paper is in preparation for publication. Paper one has been published as Archibald, M., & Scott, S. (2014). The information needs of North-American parents of children with asthma: A state-of-the-science review of the literature. *Journal of Pediatric Health Care, 12*, 5-13. doi:10.1016/j.pedhc.2012.07.003. I was responsible for the literature search, data extraction and analysis; manuscript composition, writing, submission and response to edits from peer-reviewers. Dr. Scott was the supervisory author on this manuscript and contributed to the research question, and oversaw data extraction and manuscript composition.

Paper two has been published as Archibald, M., Caine, V., Ali, S., Hartling, L., & Scott, S. (2015). What is left unsaid: An interpretive description of the information needs of parents of children with asthma. *Research in Nursing and Health, 38,* 19-28. doi:10.1002/nur.21635. 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, overseeing and contributing to data analysis and manuscript writing. Drs. Caine, Ali and Hartling contributed to manuscript composition and edits at various stages of manuscript construction. Dr. Scott contributed to overall concept formation of the dissertation.

Paper three is in preparation for publication as Archibald, M., Caine, V., Ali, S., Hartling L., & Scott, S. (2016). Developing a patient-driven arts-based knowledge translation tool: A process exemplar. I was responsible for conceptualizing and writing the article. Drs. Caine, Ali, Hartling and Scott contributed to and supported manuscript conceptualization, and provided insightful reviews at various time points, thus helping with manuscript development.

Paper four has been published as Archibald, M., Caine, V., & Scott, S. (2014). The development of a classification schema for arts-based approaches to knowledge translation. *Worldviews on Evidence Based Nursing, 11*, 316-324. doi:10.1111/wvn.12053. This article emerged from a comprehensive exam question regarding the influence of time, location and context on arts-based knowledge translation strategies. I was responsible for writing the manuscript, conceptualizing and developing the classification schema, and responding to all manuscript edits. Drs. Caine and Scott provided formative feedback on the manuscript at various stages of development and assisted with constructing the manuscript.

Dedication

I dedicate this dissertation to my best friend and husband, Bradley Harder. You provided me with the encouragement to pursue graduate studies from the beginning, and your unwavering support enabled my success, enjoyment, and fulfillment during this process. Your steadfast belief in me means more than these words can express. To my sweet baby Maya: you remind me of why it is important to work smarter. Every time I look at you I am reminded of why this work matters.

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I have been blessed with a wonderful family and network of friends. Thanks to my siblings Joey, Carolynn, and Sean and my loving mother in-law Barb and father in-law Vern who have always stood behind me with strong confidence in my ability. To my dear friends Hannah, Jennifer and Kristy—thank you for always lending a listening ear and reminding me of my strengths.

The Canadian Child Health Clinician Scientist Program provided a doctoral award for my doctoral research. The training, mentorship, networks, and financial support provided through this organization were invaluable. I acknowledge the Women and Children's Health Research Institutes and the Faculty of Nursing at the University of Alberta for providing matched funds for this national award; Knowledge Translation Canada for the seed grant that funded the intervention development; and the numerous other organizations whose monetary prizes allowed for conference attendance and travel, enabling this doctoral experience to be more enriching than I thought possible. Thank you for playing such an important role in my training.

Thank you to the many individuals in the Faculty of Nursing and beyond who encouraged me throughout this process. A specific thank you to Dr. Alex Clark for your mentorship. I always look forward to our discussions and to the creative potential that they generate.

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CHAPTER 1: INTEGRATIVE OVERVIEW

Introducing the Problem

Asthma is the most common chronic disease of childhood, affecting approximately 13% of Canadian children (Deis, Spiro, Jenkins, Buckles & Arnold, 2010; Garner & Kohen, 2008; Ismaila, Sayani, Marin & Su, 2013; McMullen et al., 2007). Asthma is characterized by airflow limitations and airway hyper-responsiveness to internal and external stimuli resulting in acute or persistent symptoms (e.g., shortness of breath, wheezing, cough, chest tightness, wheezing, increased sputum production), which vary extensively between individuals (Lougheed et al., 2012). The diverse presentations and trajectories of childhood asthma place unique challenges on parents[1] tasked with the majority of day-to-day asthma care in community settings (Nicholas, Dell, Fleming-Carroll, & Selkirk, 2009).

Asthma management is multifaceted. Identifying and avoiding asthma triggers, maximizing prevention strategies, administering and making adjustments to medications as necessary, recognizing signs of respiratory distress and responding appropriately, managing medical appointments, and seeking emergent care when needed contribute to asthma's disease burden (Brown, Gallagher, Fowler & Wales, 2010). The steady rise in ambulatory care visits for asthma related exacerbations reflects ongoing challenges in managing these complexities outside of ambulatory care settings (Bloomberg et al., 2009; Boyd et al, 2010).

As the majority of childhood asthma management occurs outside of health care settings, equipping parents with the knowledge to manage the complexities of asthma is integral to improving childhood asthma outcomes (Nicholas et al., 2009). Although the importance of parental education is well recognized, the information needs of parents of children with asthma are not fully understood or addressed through existing educational approaches (Canadian

[1] Parents refers inclusively to all caregivers of a child with asthma

Thoracic Society, 2010; McMullen et al., 2007). Childhood asthma research illustrates that high quality evidence[2] exists, but is inconsistently and ineffectively provided to, or used by, parents (Berg, Anderson, Tichacek, Tomizh & Rachelefsky, 2007; Francisco & Rood, 2011; McMullen et al, 2007). This results in a gap between what is known about asthma management and how asthma is being managed, which is in essence, a knowledge translation (KT) problem.

KT is increasingly recognized as a means to bridge the gap between what is known and what is done, and is defined by the Canadian Institutes of Health Research (CIHR, 2014) 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" (para. 1). Despite its practicality, there are epistemological challenges to this predominantly pragmatic definition of KT. Knowledge is commoditized, tacit knowledge is devalued in favor of empirical evidence, the meaning of knowledge itself is unclear, and the linear push-pull of evidence into practice implied through such a definition is simplistic when compared to the complexities of real-life decision-making in context (Greenhalgh, Howick & Maskrey, 2014; Kothari et al., 2012). These simplifications have repercussions for how interventions are designed and evaluated, which types of evidence are included in KT strategies, and may constrain how the relationship between research and practice is conceptualized (Greenhalgh & Wierenga, 2011).

Within academia, peer-reviewed publications and formal presentations are the primary means of research dissemination; however, these approaches are less accessible to non-academics (Bruce et al., 2013). Indeed, affecting change in real-life settings requires KT

[2] I refer to high quality evidence in a pluralistic manner, inclusive of various forms of knowledge, derived from a multitude of sources (e.g., qualitative and quantitative research of various designs, methodologies, professional and personal experiential knowledge), a combination of which is necessary to reflect the complexities of experiences and practices in which individuals and groups engage.

strategies that target a wider-range of decision makers (Kontos & Poland, 2009). To this effect, extensive efforts have been made to translate research findings to health care provider (HCP) groups, mainly through the provision of educational meetings and materials (Thompson et al., 2007; Yost et al., 2014). Despite these initiatives, additional strategies to translate knowledge to non-health care professional groups, such as parents, are needed.

Parents commonly receive information about their children's health condition, medical treatment, or procedure through a combination of verbal and written communication (Johnson, Sandford & Tyndall, 2003). However, verbal instructions vary extensively, and the stressful context of information delivery in health care delivery settings may contribute to poor parental understanding (Tait, Voepel-Lewis, Snyder & Maliyva, 2008). Further, commonly used methods of communicating written health information to parents, such as standardized information sheets, overuse complex language and medical jargon (Scott, Hartling, O'Leary, Archibald & Klassen, 2012). These materials also lack the temporality and humanism needed to contextualize factual information about health and illness, rendering it less meaningful (Czerwiec et al., 2015).

Recently, the potential of arts-based KT approaches to broaden perspectives of knowledge, impart evidence, and affect change necessary to improve health outcomes across diverse stakeholder groups has been acknowledged (Boydell, Gladstone, Volpe, Allemeng, & Stasiulis, 2012; Scott, Brett-MacLean, Archibald & Hartling, 2013). Yet, as an emerging field, the use and understanding of arts-based KT is in the early stages of development. Arts-based KT involves using artistic means such as storytelling or performing arts to disseminate knowledge (Boydell et al., 2012); however, the arts also have the capacity to reveal and generate new understandings (Archibald, Caine & Scott, 2014; Barone & Eisner, 2012; Kontos & Naglie, 2006). Through emotional evocation, a reduced reliance on written text, and increased

accessibility, arts-based KT strategies may benefit diverse populations in myriad contexts (Boydell et al., 2012; Rossiter et al., 2008).

Arts-based strategies may hold particular promise for parents, who can benefit from their engaging and informative powers (Nicholas et al., 2009). Of notable benefit to parents is that storytelling can be a compelling way of communicating complex health information (Hartling et al., 2010; Hartling, Scott, Johnson, Bishop & Klassen, 2013; Scott, et al., 2012). Storytelling can breathe life into facts that otherwise lie dormant, immobilized by a lack of context in their delivery (Abrahamson, 1998). The use of character, plot, and other narrative devices can humanize information about health and illness, evoke emotional responses, and provoke a sense of relatedness to the characters and story (Czerwiec et al., 2015). These reasons contribute to the longstanding history of storytelling as a potent communication instrument, yet one that is underexplored as a KT strategy in health contexts.

Combinations of creative approaches, such as visual art and storytelling as KT strategies, are particularly underutilized. When used in conjunction, these approaches may be synergistic and appeal to multiple adult learning styles. Despite these potentials, the use of art to communicate health messages within a KT framework is in its infancy. As such, the theoretical basis for these approaches is lacking; little has been done to communicate the processes of developing arts-based KT strategies in a patient-driven[3] manner, and a more thorough understanding of the mechanisms and utility of arts-based KT strategies in conveying health information warrants further attention. While some data supports the use of storytelling as a means to deliver information to health care recipients and non-health care professional provider

[3] In this research, patient-driven refers to incorporating the preferences, needs, and experiences of participants into the KT tool. This personalized approach to intervention development may enhance family-centeredness by acknowledging the centrality of parents' experiences and understandings to those health and care experiences of the family unit.

groups (Houston et al., 2011; Hartling et al., 2010; Scott et al., 2012), arts-based KT approaches have not been developed for parents of children with asthma. In this paper-based dissertation, I attend to these limitations by identifying the information needs and information preferences of parents of children with asthma, using these data to inform the development of an arts-based KT tool, and exploring the processes, challenges, and theoretical mechanisms underpinning such approaches.

In this introductory chapter, I begin by explicating my position and motivation as a researcher, artist, and clinician in this dissertation process. I then discuss existing shortcomings in childhood asthma education, and highlight the importance of attending to parents' information needs. I introduce arts-based KT and outline key theoretical influences shaping my research. I provide an overview of each of the four papers included in this dissertation, and demonstrate the sequential and interrelated nature of these inquiries.

Motivation for Research

My motivation to pursue this dissertation stemmed from my experiences as a registered nurse and as a visual artist. As a practicing nurse in pediatrics, I was struck by the abundance of information available on childhood illness. The pressure to stay abreast of, and apply, current evidence to inform my practice decisions often felt at odds with the clinical culture and day-to-day pressures associated with care provision. Skepticism towards research in the clinical milieu was tangible, was exacerbated by structural challenges (e.g., barriers to accessing online resources), and by a lack of familiarity and comfort with pertinent components of research utilization (e.g., critical appraisal). Extensive research exists documenting the profound and persistent contextual barriers (e.g., time, work volume) influencing HCP's use of evidence in

clinical settings (e.g., Dopson & Fitzgerald, 2009; Estabrooks et al., 2008; Thompson et al., 2008).

In light of these reflections, I became increasingly aware of the difficulties that families face in navigating the complex information terrain. Never before in history has information been more abundant or accessible (Levitin, 2014). Yet, with the exception of open-access publishing, research evidence is often embargoed to the public, and many individuals are not trained in research appraisal. Concurrently, there is a growing emphasis on patient self-management, placing increasing responsibilities for community-based care on non-clinical care providers, such as parents. Finding ways to help parents navigate this complex information and illness management terrain became for me, a meaningful endeavor.

I have one caveat. Although self-management reallocates responsibilities to care recipients and non-HCPs, I find it more reasonable to regard this as a renegotiation of partnership; one which mandates that the experiences, knowledge, goals and perspectives of patients are valued and are not subordinated to standards exclusive to the medical model of care (Holm & Severinsson, 2014). In graduate school, I became aware of shortcomings in how information is provided to parents and became immersed in the field of KT. I realized that my skill set as a visual artist enabled a unique perspective on KT and recognized the potential contribution that I may make to the emerging field of arts-based KT. Most importantly, however, is that integrating the arts and parental stories into a KT tool for parents reflects my position that the knowledge, experiences and perspectives of parents is valuable, and should be reflected in educational efforts. Approaching KT from an arts-based perspective enabled this integration.

My involvement in the visual arts commenced far before my interest in health care. I have experienced first-hand the engaging power of the arts; their capacity to provide transcendent

experiences and escape into timeless emersion facilitated through authentic, relational intimacy. Along with the "traditional" caveats of intellectual development achieved through education, I believe that the arts were indispensible to my cognitive and emotive growth as they enabled appreciation of subtlety, complexity, and evocative experiences.

In addition to these benefits, and to the aesthetic literacy cultivated that can be cultivated, artistic engagement can facilitate inquiry into arts' purpose to individuals and society. My previous theoretical musings about the attributes and purposes of art in cognition, emotion, and society, provided a springboard from which to explore how the arts can be understood, and contribute, as KT strategies. To date, this has been an invaluable and exciting cross-pollination and one that I am eager to continue exploring. Within the context of this dissertation, the emotionally challenging and clinically complex domain of childhood asthma coupled with its practical significance as the most common chronic disease of childhood, provided a rich opportunity to develop and explore the potentials of arts-based KT to improve family and child well-being.

Childhood Asthma and Parental Education

Providing comprehensive asthma education to parents of children with asthma is essential to improving asthma management and enhancing child health outcomes (Brouwer & Brand, 2008). Educating parents about the complexities of childhood asthma can benefit the family unit by reducing morbidity (McMullen et al., 2007), hospitalizations and emergency department (ED) visits (Coffman, Cabana, Halpin & Yelin, 2008), and by promoting parental self-efficacy (Berg et al., 2007; Cashin, Small & Solberg, 2008). As asthma knowledge significantly contributes to successful illness management and improved child health outcomes, ensuring that appropriate

education is provided to parents of children with asthma is of central importance (Nicholas et al., 2009).

The Canadian Respiratory Guidelines clearly state that asthma education must be provided to parents of a child with confirmed asthma, yet parents continue to report receiving minimal to no education at the time of diagnosis (Canadian Thoracic Society, 2010; Lougheed, et al., 2012; McMullen et al., 2007). Components of asthma education typically emphasized include the provision of written information, an asthma action plan to aid in self-management, a description of asthma, methods of achieving control, medication adherence, correct inhalation technique, contributing factors and trigger avoidance strategies (Becker et al., 2003; Brouwer & Brand, 2008; Lougheed et al., 2012). Avoiding environmental triggers, inhaler technique, medication adherence, and a written asthma action plan are identified as the four axes of self-management education for childhood asthma in the Canadian Respiratory Guidelines (Canadian Thoracic Society, 2010). Including these essential components in written asthma education for parents may reduce variability in the quality of education provided. Despite this, many parents report receiving no written information during asthma related encounters with HCPs, and unmet information needs are commonly identified (Canadian Thoracic Society, 2010; Hyland & Stahl, 2004; McMullen et al., 2007).

When provided, asthma educational materials are often outdated (Nicholas et al., 2009) and are inconsistent in content, format, and delivery (McMullen et al, 2007; Peterson-Sweeney, McMullen, Yoos & Kitzmann, 2003). Varying combinations of standardized information sheets, verbal instruction, written information, and a written asthma action plan may be included in asthma education (Johnson et al., 2003). These varying combinations, along with the inconstant content contained in educational approaches, contribute to unpredictable and at times suboptimal

asthma education: less than fifty percent of parents report receiving education that is consistent with the National Asthma Education and Prevention Program guidelines (Francisco & Rood, 2011).

The lack of consistent and meaningful education for parents of children with asthma is a persistent and troublesome problem with far reaching implications for both the family and the health care system. Shortcomings in asthma education contribute to poor asthma control in approximately 75% of Canadian children (McGhan, et al., 2006). Further, uncontrolled asthma has far reaching health, quality of life, and fiscal implications. Asthma exacerbations are a leading reason for seeking emergent medical treatment, are the primary cause of missed school days for children, and contribute to workday absences for parents (Coffman et al., 2008; Dean, Calimlim, Kindermann, Khandker, & Tinkelman, 2009; Ismaila et al., 2013). Uncontrolled asthma adversely impacts parents' quality of life (Cano-Garcinuno et al., 2014) and negative emotions of fear, anxiety and uncertainty are common (Berg et al., 2007; McMullen et al., 2007). High health care utilization and indirect costs of asthma extensively burdens the health care system and are projected to rank among the highest for chronic disease (Coffman et al., 2008; Bahadori et al., 2009; Ismaila et al., 2013). Developing meaningful, current, and robust asthma education strategies for parents is of pressing relevance considering these far reaching implications.

Integrating essential elements of asthma education with a patient-driven and arts-based approach to information development and delivery may enhance the relevance and usefulness of asthma education. Tailoring key messages to specifically address parents' information needs and preferences may promote usability and uptake of the educational material and is integral to a patient-driven process of intervention development. This patient-driven approach to developing

KT strategies for non-HCP groups is particularly timely given the enhanced focus on self-management in the Canadian health care climate and the historical focus of KT on HCPs (e.g., physicians, nurses) (Kothari & Armstrong, 2011). As parents, a key knowledge user group in children's asthma care, have received notably less attention in KT, developing meaningful strategies to assist in community based health management are increasingly needed (Kothari & Armstrong, 2011; Nicholas et al., 2009).

Meaningful education provision involves delivering information in appealing, engaging, and relatable formats[4], with particular attention paid to including lower literacy populations (Clark, Mitchell & Rand, 2008). For instance, visual arts can depict aspects of asthma care that are hard to relay through written text, such as correct inhaler technique. Using storytelling to convey health information can help patients relate their own experiences to those of the characters depicted. Enhancing the individualized nature of asthma education through patient-driven and artistically oriented materials may reduce perceptions of education as generic and non-applicable to recipients, foreseeably enhancing its effectiveness (Clark et al., 2008). Given this, integrating arts-based delivery with factual asthma information may facilitate learning, thereby benefiting parents of children with asthma.

Arts-Based Approaches to Knowledge Translation

Arts-based KT can be defined as the use of any artistic form (e.g., dance, theatre, visual art) to convey knowledge with the intent of affecting a positive change in a health related outcome. Artistic modalities can be used to augment the production and translation of knowledge and research findings through various means (Boydell et al., 2012; Fraser & al Sayah, 2011). While arts-based KT strategies capitalize on diverse learning styles, they may also augment the

[4] Incorporating patient preferences and information needs when developing educational materials while attending to aesthetics, language, usability and design features may enhance how patients relate to, and the extent to which they are satisfied with, educational materials.

appeal of educational materials regardless of learning style and preference. Presenting information in alternative ways, such as through accessible and engaging narratives augmented by visual renderings, may promote understandability and actionability – two important considerations in health literacy (Shoemaker, Wolf & Brach, 2014). Families with lower socioeconomic status often exhibit suboptimal asthma management and higher illiteracy rates (Berg et al., 2007), and concerns regarding literacy levels in various population groups have been identified in an intervention review of verbal and written information provision (Johnson et al., 2003). Providing information in a manner that places a low-demand on end-users while appealing to various learning styles is of considerable importance when the diversity of parents and the complexity of asthma education are considered.

Arts-based KT may leverage multiple ways of knowing beyond the explicit, propositional knowledge characteristic of didactic teaching approaches. Artistic form and content can be merged to generate aesthetic understandings (Norris, 2011). The arts can enable absorption in the lives and experiences of others, and promote empathetic understanding not possible through conventional learning approaches (Archibald, 2012; Greenhalgh, 1999). Depending on the genre and method of delivery, the arts can create space for dialogue and new understanding. These merits illustrate the potentials of the arts for inviting reflection, and shifting attitudes, beliefs, and behaviors. The potentials of the arts in KT are influenced not only by the context of their development and application and the characteristics and needs of involved stakeholders, but also by their artistic form and underlying mechanisms of action.

Storytelling is a powerful communication tool capable of promoting memory retention (Slater, Buller, Waters, Archibeque, & LeBlanc, 2003), enhancing problem-solving capacity (Kirkpatrick, Ford, & Castelloe, 1997), creating an emotional connection with readers

(Kirkpatrick et al., 1997), and conveying information in a meaningful manner (Scott et al., 2012). Through storytelling, meaning is re-negotiated via the re-counting and re-living of experiences. This enables shifting depictions of truth that are perhaps more aligned with individuals' experiences of reality than are the impartial facts and portrayals of reality conveyed through traditional scientific and medical discourses (Greenhalgh, 2001).

Although the merits of storytelling are well documented within the disciplines of psychology and education (Abrahamson, 1998; Brandell, 1984; Kirkpatrick et al., 1997), the use of storytelling as a KT strategy within health care contexts has been underexplored. In a randomized trial conducted by Houston and colleagues (2011), storytelling was used as an innovative intervention to reduce hypertension in a low-income African American population. The researchers used patients' voices on an interactive DVD to convey stories to participants and found significant reductions in blood pressure for the intervention group at a three month assessment period in contrast to the comparison group, who received a DVD with non-hypertension related health information. Although notable differences in the population, pathology, and mechanisms of intervention delivery exist, this study represents the potential utility of storytelling in conveying health information to improve patient outcomes.

Similarly, the use of visual art, although present in health care marketing and certain educational materials, has received minimal attention as a KT strategy. In a scoping review on the use of visual arts in pediatric populations with health conditions, Archibald, Scott and Hartling (2014) report that within the child health context, visual arts are most commonly used for assessment, communication, and therapeutic purposes. Most frequently, visual art was used to facilitate communication between health care practitioners and children. No studies used visual art as a method to augment communication with care providers, such as parents. Similarly,

Boydell and colleagues (2012) conducted a scoping review of arts-based health research and found no studies that used visual art alone as a KT strategy. The lack of KT strategies using visual arts alone implies two significant hypotheses. First, potential applications of visual art as stand-alone KT approaches are underexplored. Theorizing the contexts by which such strategies may hold utility is warranted. Second, conveying precise key messages through visual art presents unique challenges, particularly in the context of illness management. Delivering information that is useable for parents in the day-to-day context of their child's asthma requires more precise key message delivery than is enabled through stand-alone visual arts based KT. Multimodal approaches, such as those integrating visual and narrative arts, may leverage the potentials of both forms of representation while communicating clearer key messages to parents. However, further pragmatic and theoretical understandings of arts-based KT strategies and their use with diverse clinical populations (e.g. childhood asthma), are needed.

To date, no multimodal arts-based KT strategies have been developed exclusively for parents of children with asthma. However, insights into the potentials of arts-based approaches can be gleaned from other clinical applications of multimodal arts-based approaches. Nicholas and colleagues (2009) developed and evaluated two content-rich and visually creative educational materials for children with asthma. Through qualitative evaluation the authors revealed the importance of balancing content with interest. Interest in the educational material enhanced engagement with the educational content and was augmented through the use of visual graphics and vivid narrative.

Scott and colleagues (2012) conducted a qualitative study of parents' perceptions of an illustrated storybook for parents of a child with croup. Parents responded favorably to the book's visual and narrative components and the authors found that the storybooks also engaged the

child. Hartling and colleagues (2013) evaluated this storybook using a randomized controlled trial in the ED setting When compared to a standardized information sheet on pediatric croup, Hartling and colleagues (2013) found no difference in the primary outcome (i.e., parental anxiety) between the evaluation time points of recruitment and discharge. Significant differences in some secondary outcomes, such as time to symptom resolution for the intervention versus comparison group, and greater regret regarding the intervention group's decision to seek treatment in the ED, were noted.

While these studies contribute important knowledge regarding developing arts-based KT approaches, neither study conducted a foundational information needs assessment. Conducting an information needs assessment prior to developing an educational material may further enhance the relevance of the educational material for knowledge end-users (e.g., parents), which in turn may result in greater engagement and uptake. Indeed, as Hartling and colleagues (2010) identify, alignment between the educational intervention and the needs of end-users is an essential consideration. The arts-based KT tool developed for this dissertation is aligned with such a patient-driven approach and was further shaped by multiple theoretical influences.

Influence of Theory

Elements from education, arts-based research, information literacy, and KT theory shaped my approach to inquiry in various ways. From education theory, *adult learning* stipulates that motivation to learn is derived largely from the experience of real-life problems (Grol, Wensing & Eccles, 2005). It follows that information delivered in concrete ways, by use of examples rather than abstractions, will aid learning. Personalized information with direct and immediate application is most valuable (Merriam, 1996). Similarly, through *facilitated learning,* reflection, goal setting, and active engagement in learning are emphasized. Strategies that facilitate learners'

ability to link previous experiences and new knowledge are aligned with this approach (Grol et al., 2008; Merriam, 1996). This is consistent with patient-driven, arts-based KT approaches as these draw upon practical problems, appeal to multiple learning styles and leverage diverse forms of knowledge beyond the explicit, propositional knowledge characteristic of didactic teaching approaches.

Information literacy theory supports the utility of combining textual and visual forms through multimodal representation, thereby depicting information in emotive and rationale manners (Hoover, 2012). The abundance and complexity of the contemporary information environment places a high demand on health care users, such as caregivers, to find ways to navigate the information terrain. The rise of the visual image as an augmentative communication modality suggests that multimodal arts-based KT strategies, specifically those integrating visual and narrative components, may be a timely response to the critical juncture of information abundance and the increasing commodity of the visual image noted in information literacy theory (Harris, 2006).

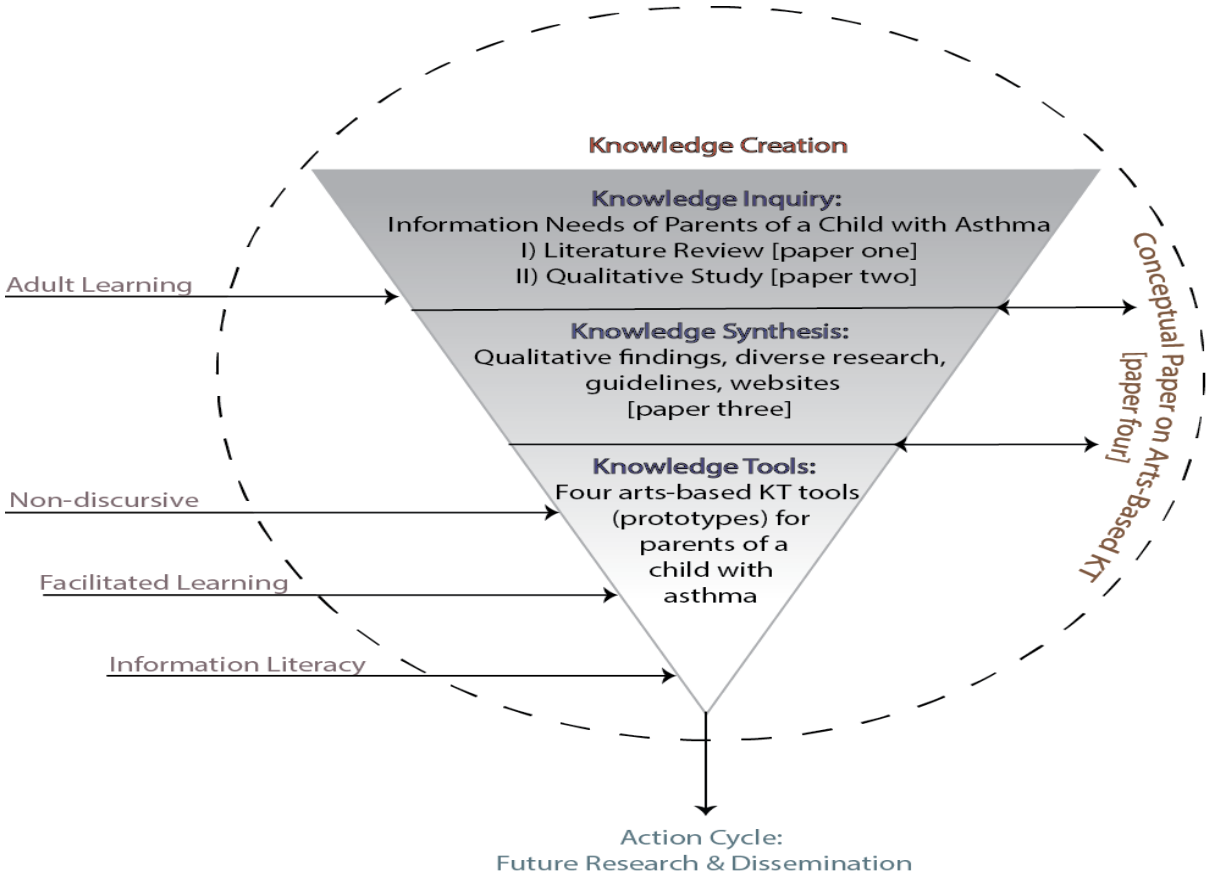
A *non-discursive approach to theory* also informed this dissertation. Different art-based representations enable diverse understandings. Awareness and aesthetic experience can be generated through interacting with non-discursive forms, such as visual arts (Archibald, 2012). This tacit approach to theory provides an "account of" rather than "account for" a particular phenomenon (p. 156); that is, while a generalized explanation of a phenomenon is not offered, an individualized understanding of the particular can be cultivated, reflected upon, and deliberated (Barone & Eisner, 2012). As such, while we can seek to understand how arts-based forms facilitate learning through discourse, there will always be components of artistic experiences that transcend the confines of language, enabling us to "know more than we can tell" (Polanyi, 1966,

p. 4; Kothari et al., 2012). Acknowledging the influence of non-discursive approaches to theory is therefore necessary when using arts-based representations.

An extensive array of theories and models inform KT science[5] (Estabrooks, Thompson, Lovely & Hofmeyer, 2006). Among them, the knowledge-to-action (KTA) cycle (Graham et al., 2006) is a highly utilized model depicting the iterative processes of creating and applying knowledge. The framework's concision is part of its appeal. Knowledge creation is at the center of the framework and is surrounded by an action cycle, which consists of several knowledge application steps. It is theorized that 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. The concept of tailoring and filtering knowledge in the production funnel to enhance relevancy and usefulness to end-users is highly relevant to my dissertation. These theoretical influences are displayed visually (Figure 1.1) within the knowledge creation component of the KTA cycle.

[5] Models and theories range from prescriptive to explanatory and span many disciplines (e.g., organizational innovation, social sciences, nursing) (Estabrooks et al., 2006; Grol et al., 2005). Examples of influential models and theories include the Diffusion of Innovations Theory which purports that the innovation, time, communication channels and the social system influence the spread of an innovation (Rogers, 1995); the Promoting Action on Research in Health Services Model which emphasizes the interplay between evidence, context and facilitation (Kitson et al., 2008); and attitudinal theories such as the theory of planned behavior, where the attitudes, subjective norms and perceived behavioral control of professionals impact their intention to change behavior (Ajzen, 1991).

Figure 1.1 Overview of Theoretical Influences



Dissertation Overview

In an effort to address the gap between what is known about childhood asthma and how it is managed by non-health care professionals (i.e., parents), I conducted a multi-stage research project to develop a patient-driven arts-based KT intervention[6] for parents of children with asthma based on parents' information needs and educational preferences. The overarching purpose of this process was to develop a patient-driven arts-based KT tool for parents of children with asthma based on their information needs and preferences, while contributing substantively

[6] The terms intervention, strategy, tool, approach, and educational material are used interchangeably throughout this dissertation in relation to knowledge translation.

to the emerging field of arts-based KT. This was accomplished through four interrelated inquiries, which I summarize briefly below.

In paper one, I conduct a state-of-the-science review of the literature to identify what the research literature reflects about the information needs of parents of children with asthma in North America. The findings illustrated a gap in existing knowledge regarding parents' information needs, and thereby underscored the need for an exploratory qualitative study. The findings from this review also informed the development of a semi-structured interview guide for use in the qualitative study. I build directly upon these findings in paper two and conduct an interpretive descriptive study (Thorne, 2008) of the information needs of 21 parents of children with asthma. The information preferences and experiences of parents were also assessed during this study, but were not the focus of paper two; rather, these findings helped inform and direct the development of the KT tool for parents. This process is described in paper three.

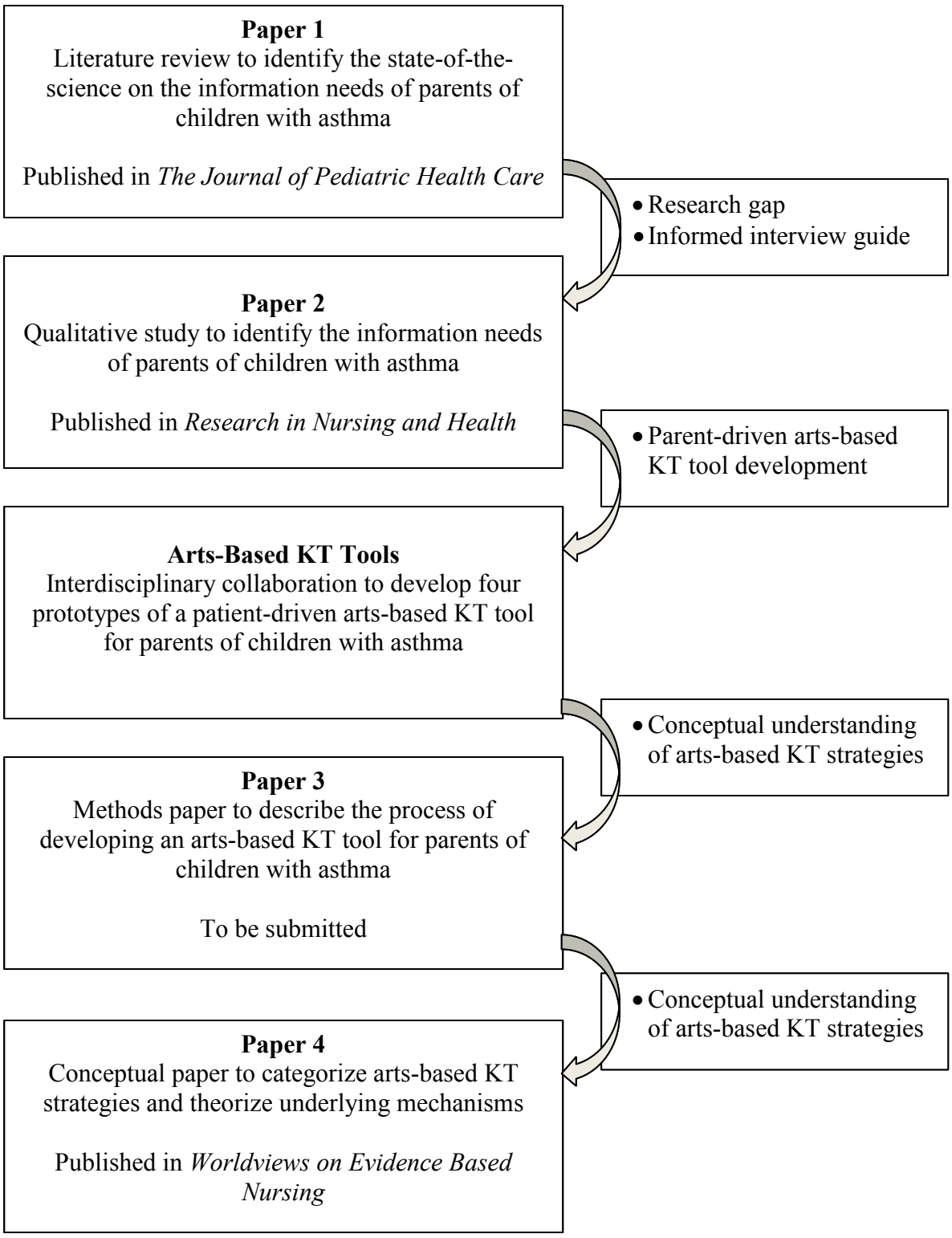
Contextual information about parents' experiences and information preferences justified using an arts-based approach to providing asthma education. Deciding on the form, content and arts-based modalities for the KT tool for parents was greatly influenced by the qualitative research findings (paper two). In paper three, I explore the processes and challenges of developing this innovative tool. The challenges faced during this process were both compounded and overcome by collaborating with an inter-professional creative consulting team. I believe that exploring these methods is a notable contribution to the emerging literature on arts-based KT.

A final and significant contribution to the developing domain of arts-based KT is made in paper four – a conceptual paper that provides the theoretical backbone for my thinking about arts-based approaches to communicating health information. I began this paper as an exploration of how context, time and location influence arts-based KT strategies – integral considerations for

any researcher or practitioner employing arts-based approaches in a health care context. However, early in this theorizing, I realized that discussing these influences requires referral to an organizing framework for arts-based KT based on underlying mechanisms. Discussing arts-based KT in the absence of such a framework would essentially negate the differences and influential roles of precision in key messaging and extent of participation. As such, I developed a classification schema for arts-based approaches to KT, which I then used to theorize the influence of context, time and location on these strategies. This classification promotes discussion of arts-based KT strategies, such as the KT tool developed for this dissertation, based on an understanding of underlying mechanisms.

I visually represent these dissertation outputs and their interrelationships in Figure 1.2. These inquiries contribute to understanding the information needs of parents of children with asthma and patient-driven, arts-based KT strategies. They will provide relevant foundational knowledge for future KT studies in related domains and form the basis for my future and emerging program of research integrating arts-based methods and KT. Following Figure 1.2, I summarize the four dissertation papers, the prototypes of the arts-based KT tool developed, and highlight the sequential and interrelated nature of these inquiries.

Figure 1.2 Dissertation Papers and Outputs



Paper One: The Information Needs of North American Parents of Children with Asthma: A State-of-the-Science Review of the Literature

In this literature review, I identify the information needs of parents of a child with asthma as they have been approached in the research literature. This review enabled an understanding of the current "state-of-the-science" regarding the information needs of parents of children with asthma and was therefore foundational to the dissertation. To gain an understanding of this field, I searched three electronic databases for articles published between 2002 and 2011 that met pre-established inclusion criteria. Eleven of the 164 articles retrieved were included in the review. I classified the findings into four categories of parental information needs: asthma basics, treatment modalities, coping, and medical expectations. Findings from this review illustrated that the information needs of parents of children with asthma are not being met using current educational approaches. Further, despite an emphasis on patient-centeredness, the information needs of parents of children with asthma are not fully understood. As no qualitative study was located which explicitly assessed how parents of children with asthma understand their asthma-related information needs, this review highlighted the need for a qualitative study in this domain. The information needs taxonomy created through this review was used to inform the development of a semi-structured interview guide for use in the follow-up qualitative study (paper two).

This paper is published as:

Archibald, M. & Scott, S. (2014). The information needs of North-American parents of children with asthma: A state-of-the-science review of the literature. *Journal of Pediatric Health Care*, *12*, 5-13. doi:10.1016/j.pedhc.2012.07.003

Paper Two: What is Left Unsaid: An Interpretive Description of the Information Needs of Parents of Children with Asthma

The next step in this dissertation was to build upon the findings from the state-of-the-science review of the literature and conduct a qualitative study of parents' information needs in childhood asthma. The overarching research questions guiding this inquiry were (I) what are the information needs of parents of children with asthma and (II) what are the educational preferences of parents of children with asthma. Along with understanding parents information needs, I was also interested in gaining insight into the broader experiential context of having a child with asthma, including parents' preferences and experiences related to asthma education. From the literature review I realized that relevant information could be gleaned by understanding these broader experiences. I used the applied qualitative approach of interpretive description (Thorne, 2008) to guide this inquiry, as the context of participants' experiences and the application of research findings to practice are emphasized in this approach.

I purposively sampled 21 parents from a pediatric ED and two pediatric asthma clinics in Edmonton, Alberta and conducted 20 semi-structured interviews. Through content and thematic analysis, I glean impactful insights into parents' information needs, information deficits, and management behaviors. Parents' difficulty in identifying their asthma-related information needs impacted their information seeking behaviors and management decisions, and contributed to numerous information deficits. Parents frequently reported receiving little or no education about asthma and its management. Four themes were identified and formed an information needs hierarchy: (I) recognizing severity; (II) acute management; (III) prevention versus crisis orientation; and (IV) knowing "about" asthma. The hierarchy was useful in understanding which information needs generally improved overtime (e.g., recognizing severity) and which did not

(e.g., knowing about asthma). Two dominant factors of interactions with HCPs and perspectives of asthma as an acute condition influenced these themes.

This is the first qualitative study to explicitly research the information needs of parents of children with asthma. Findings illuminate parents' pervasive unmet information needs, information deficits, and the challenges parents face in seeking information during and beyond their interactions with HCPs. While the emphasis of this paper was on understanding the information needs of parents, the contextual information obtained helped inform the subsequent stages of the dissertation. The widespread uncertainty experienced by parents and the need for an engaging and relatable educational resource supported a patient-driven process for developing an arts-based KT tool. The process of using these findings to develop prototypes of an arts-based KT tool for parents is outlined in paper three.

This paper is published as:

Archibald, M., Caine, V., Ali, S., Hartling, L., & Scott, S. (2015). What is left unsaid: An interpretive description of the information needs of parents of children with asthma. *Research in Nursing and Health, 38,* 19-28. doi:10.1002/nur.21635

Arts-Based Knowledge Translation Tools

I developed four prototypes of an arts-based KT tool for parents of children with asthma based on previous research and in response to the information needs and preferences of parents identified in papers one and two. I detail this process of development in paper three. The concept of developing four prototypes emerged largely from a need in the KT literature, particularly in the emerging field of arts-based KT. To date, no research has systematically examined how aesthetic differences in multimodal arts-based KT (e.g., visual art and storytelling) influences usability and ultimately, effectiveness. Although researching the usability and effectiveness of

these KT materials is beyond the scope of this dissertation, I was able to develop the four prototypes with the intent of evaluating these in future research. Examples of prototypes A through C are provided in Appendices A through C. A complete overview of prototype D is provided in Appendix D.

The four prototypes are best described as being modified along the two axes of line and color (Figure 1.3). Color is represented on the vertical axis and ranges from black and white (i.e., superior aspect of continuum) to color (i.e., inferior aspect of continuum). Line weight is represented on the horizontal axis and ranges from light (i.e., left aspect of continuum) to thick / heavy (right aspect of continuum). No other illustration components were modified across the prototypes; for instance, composition, characters and perspective remained consistent, which gives the prototypes a gradated effect. Text font was altered across the line axis.

Figure 1.3 Arts-Based Knowledge Translation Prototypes by Line and Color Axes

Each prototype is formatted as a 28-page asthma diary written in the first person voice of a mother of a child with asthma. Each prototype is web-hosted, which enables linking to existing web-based resources (e.g., Alberta Asthma Centre) and a degree of interactivity. For instance, an information icon is available on most pages. When activated, non story-based information about asthma is made available. A true-and-false quiz is another example of an interactive feature. The process and challenges associated with developing these prototypes are detailed in paper three.

Paper Three: Developing a Patient-Driven Arts-Based Knowledge Translation Tool: A Process Exemplar

Informed by the findings from the qualitative study, I created four prototypes of an arts-based KT tool for parents of children with asthma. The paucity of existing literature on developing and evaluating arts-based KT strategies limits understandings of their utility with diverse populations and contexts. In this paper, I respond to this gap and outline the process and predominant, generalizable challenges associated with this development.

I begin by providing an overview of the sequential stages that informed the tools' development (i.e., literature review; qualitative study; prototype development; and anticipated future research) in order to delineate the complexities of developing an arts-based KT tool in a patient-driven manner. I synthesized information from various sources (e.g., research of various designs; asthma guidelines; reputable websites), combined the information with visual art and storytelling, and used an electronic eBook as the method of delivery. The tool was specifically constructed to address parents' information needs and information deficits identified through previous research and to deliver this information in a manner aligned with parents' preferences. I used a collaborative approach of constructing a creative consulting team involving a visual artist, creative writer, and digital media company and discuss the dynamics of iterative design.

Tensions emerged from the diverse working relationships, multiple perspectives and sources of evidence inputted.

In the second part of the paper, I reflect upon emerging conceptual and procedural challenges. Although the challenges encountered were numerous, I explore four which I believe are likely to be encountered when developing comparable innovations with different populations and contexts: (I) working within an inter-professional team; (II) quantity and ordering of information; (III) creating a composite narrative; and (IV) balancing actual and ideal management scenarios. Through this exploration, I offer a useable resource for practitioners and researchers seeking to develop patient-driven arts-based KT tools; however, the paper does not explore the mechanisms underlying these approaches. I therefore offer a theoretical exploration of the mechanisms by which arts-based KT strategies may exert effect in paper four.

This paper will be submitted for publication as:

Archibald, M., Caine, V., Ali, S., & Hartling L., Scott, S. (2016). Developing a patient-driven arts-based knowledge translation tool: A process exemplar.

Paper Four: The Development of a Classification Schema for Arts-Based Approaches to Knowledge Translation

In this conceptual paper, I offer a classification schema for arts-based KT strategies and use this framework to theorize the influences of context, time and location on arts-based KT. The first of its kind, this schema moves beyond classifying arts-based approaches by form alone (e.g., painting, dance) and draws upon understandings of the underlying mechanisms by which they function: (a) the degree of precision in key message delivery, and (b) the degree of end-user participation. This new way of thinking about arts-based KT represents a significant departure from those of the scarce contemporary musing available.

I conceptualize two continuums of (I) precision-ambiguity in key messaging and (II) passive-active degrees of participation as fundamental axes underlying arts-based KT approaches. Four quadrants are formed when these axes intersect. Briefly, quadrant one strategies convey precise key messages through passive participation; quadrant two approaches deliver precise key messages but through active participation; quadrant three is more ambiguous in key message delivery but maintains active participation, while quadrant four is both ambiguous in key message delivery and passive in participation. I then demonstrate how this classification is necessary to explore how context, time, and location shape arts-based KT and encourage systematic inquiry into the effectiveness of these approaches in diverse inter-professional contexts.

This paper enables discussion of seemingly diverse arts-based KT strategies employed across distinct contexts. For instance, I classify the arts-based KT tool developed for this dissertation as a quadrant one approach. Key messages about asthma are reinforced through explicit non-arts based information. Although parental participation with the KT tool is enhanced through a true-and-false quiz and links to online resources, parents are not involved in shaping the intervention, as would be expected with a quadrant two approach. Amending these core mechanisms in future work will enable cross-comparisons between arts-based KT strategies. This may generate insights into which approaches are effective for which population groups and contexts.

This paper is published as:

Archibald, M., Caine, V., & Scott, S. (2014). The development of a classification schema for arts-based approaches to knowledge translation. *Worldviews on Evidence Based Nursing*. *11,* 316-324. doi:10.1111/wvn.12053

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CHAPTER 2

Paper 1: The Information Needs of North American Parents of Children with Asthma: A State-of-the-Science Review of the Literature

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The Information Needs of North American Parents of Children with Asthma:

A State-of-the-Science Review of the Literature

The high prevalence and disease burden of childhood asthma has prompted extensive research in the area of asthma management, but despite consensus regarding the effectiveness of treatment approaches, asthma management remains suboptimal, and many children exhibit poor asthma control (Peterson- Sweeney, McMullen, Yoos, & Kitzman, 2003; Yoos, Kitzman & McMullen, 2003). Parents typically are the primary care providers for children with asthma and must have sufficient knowledge to effectively manage the illness (Cashin, Small, & Solberg, 2008). Further, a lack of parental knowledge regarding asthma treatment has been associated with poor outcomes for children with asthma, which emphasizes the need for adequate educational provision for parental caregivers (Hyland & Stahl, 2004).

Identifying the information needs of parents of children with asthma is an essential step toward planning and implementing educational interventions (Yoos et al., 2007), and in recognition of the importance of this step, current research is being conducted in the area of asthma education. Further, an increased emphasis on *patient-centered* health care suggests a need for collaborative interventions that attend to both patient and medically identified priorities of care (Yoos et al., 2007). Despite this emphasis, the information needs of parents of children with asthma may not be adequately addressed through current approaches (Hyland & Stahl, 2004). Existing research does not explicitly identify parental information needs but rather focuses on understanding the parental experience of having a child with asthma through exploratory and phenomenological studies (Berg, Anderson, Tichacek, Tomizh, & Rachelefsky, 2007; Cashin et al., 2008; Koenig, 2006). Although these studies have the capacity to provide a rich narrative understanding of "lived experience," they do not provide a comprehensive identification of

parental information needs.

Throughout our search of the literature, no studies were found that offered a comprehensive identification of parental information needs, and few studies differentiated between professionally identified priorities and parent-identified priorities in the information needs assessment. To effectively develop collaborative educational interventions to facilitate evidence uptake in decision-making and to improve the health outcomes of children with asthma, a comprehensive understanding of parental information needs is required. This work may augment current research that examines the differences between medical and lay models of illness representation, providing a more comprehensive perspective of parental needs in asthma management. Therefore the purpose of this state-of-the-science literature review is to: (a) identify, categorize, and critically analyze pertinent research related to parental information needs, and (b) create an inventory of information needs that incorporates parental and medical information priorities.

A state-of-the-science literature review seeks to provide a comprehensive overview of current literature on a topic area (Grant & Booth, 2009). This type of review was selected because, currently, limited literature exists that directly examines the information needs of parents of children with asthma. To conduct a comprehensive review of literature in this area, three databases were searched, broad inclusion criterion were utilized, various research designs were included, and the methodological principle guiding this search was one of inclusion rather than exclusion. Details of the search strategy and inclusion criteria are provided in the following section.

Search Strategy

A standardized search strategy draft was developed in relation to the identified research

question after an information session with a research librarian, and it was modified according to the specific database accessed. The databases of Cochrane Wiley, CINAHL, and Medline were searched using a standardized search strategy with key word combinations and variations of: asthma, child, pediatric, health knowledge, patient education, self-efficacy, and information needs. The detailed search strategy is provided in Appendix F. Articles were included in the review if they were primary research examining parental information needs within the date limiters of 2002-2011 and were conducted in North America. The latter decision was made to reduce the variability in asthma guidelines use and educational practices pertaining to asthma management in the included articles, and thus to provide a more cohesive understanding of parental information needs in North America. Articles were excluded if participants were part of an ongoing education program regarding asthma management.

Results

Of the three databases searched, 164 articles were retrieved, and a preliminary screening of their titles was conducted for relevancy. Of these articles, nine duplicate studies and 20 additional articles were removed because they did not assess parental information needs. The abstracts of the remaining 135 articles were reviewed, and 38 articles were included for full text secondary screening based on the pre-established inclusion criteria. Of these 38 articles, 10 articles assessed the information needs of parents of children with asthma and were included in the state-of-the-science literature review. An additional article (Yoos, Kitzman, McMullen, Sidora-Arcoleo, & Anson, 2005) was later identified as relevant, satisfied all inclusion criteria, was identified as a component of a larger study (Yoos et al., 2007) and was included in the review for a total of 11 articles (Figure 2.1).

[Insert Figure 2.1 about here]

Because a state-of-the-science literature review places less emphasis on quality appraisal (Grant & Booth, 2009), studies were not excluded on the basis of methodological quality. However, the methodological quality of included qualitative studies (n = 8) was assessed using the Qualitative Quality Assessment Tool, developed by Hutchinson et al. (2010), to understand the relative validity and the context in which to interpret the findings from each study. This assessment tool was selected for three reasons. First, the tool is concise, consisting of five questions. Second, although the tool is brief, the questions are comprehensive in that they address essential elements of the research process, such as sampling technique and methods of data analysis. Third, the tool was developed by respected, expert researchers at the University of Alberta who have extensive expertise in conducting and evaluating qualitative research. The Qualitative Quality Assessment Tool and corresponding quality rating of included studies are available in Appendix G. Articles included in the review ranged from moderate (n = 3), moderately high (n = 3) to high quality (n = 2).

The three quantitative studies included in the state-of-the-science literature review were assessed using the QualSyst assessment tool (Kmet, Lee, & Cook, 2004). This tool was developed for and published in an article series endorsed by the Alberta Heritage Foundation for Medical Research and simultaneously assesses the methodological quality of various quantitative study designs. Although it is not validated, the QualSyst tool was developed from existing instruments (e.g., Cho & Bero, 1994; Timmer, Sutherland, & Hilsden, 2003) to assess elements recognized as essential to internal validity. The tool consists of 14 questions, and each item can be rated as "not applicable," "no," "partial," or "yes." Summary scores are then calculated for each research study. The summary scores for the included quantitative studies ranged from 0.875 to 1.00, respectively, indicating moderately high to high methodological quality by study design.

The corresponding quality assessment findings for the quantitative articles are available in Appendix H.

The characteristics of included studies are presented in Table 2.1 to provide a visual representation of the 12 information needs identified in the included 11 studies. These information needs were then collapsed into the following four themes: asthma basics (e.g., basic physiology), treatment modalities, coping, and medical expectations (e.g., when to seek medical attention) (Figure 2.2). The characteristics of included studies and corresponding parental information needs inventory are presented in the following section.

[Insert Table 2.1 about here]

Synthesis and Analysis of the Literature

Upon review of the literature, four predominant parental information needs emerged: asthma basics, treatment modalities, coping, and medical expectations. There was a focus in the literature on the physiologic components of asthma management (e.g., medications), and less emphasis on the non-pharmacologic methods of management that parents often identified as important. This emphasis may reflect an assessment of parental information needs that is more congruent with the biomedical model of asthma management. An exclusive emphasis on these physiological components of asthma education therefore may highlight a discrepancy between what is perceived to be the information needs of parents and what parents identify as their information needs. This finding is consistent with the work of Yoos et al. (2003, 2005, 2007), which illustrates discrepancies between medical and lay models of illness representation. These findings suggest that because medical and parental conceptions of asthma may not align, increased collaboration between parents and health care providers regarding asthma management is needed and may better address parental information needs (Peterson-Sweeney et al., 2003;

Yoos et al., 2005, 2007).

Asthma Basics

Basic knowledge of asthma includes a preliminary understanding of the pathophysiology and the "nature" of the disease as being a chronic illness with a variable degree of acute exacerbation periods (National Heart, Lung and Blood Institute, 2011). Parental understanding in this area provides the foundation for knowledge building in other areas, such as learning how to modify triggers and evaluate the effectiveness of treatment interventions. In nine of the 11 included studies, parental knowledge was prospectively assessed using self-report measures, whereas one study used a cross-sectional design with a retrospective chart review (Yoos et al., 2007). Of the 11 included studies, parents' basic knowledge of asthma ranged from relatively limited (Berg et al., 2007; Navaie-Waliser, Misener, Mersman, & Lincoln, 2004), to having a moderately factual knowledge base (Cashin et al., 2008), with the majority of families possessing good basic knowledge that was deficient in some areas (Peterson-Sweeney et al., 2003; Yoos et al., 2007).

For example, in a cross-sectional, retrospective study of 228 parents conducted by Yoos et al. (2007), parents were found to possess relatively accurate knowledge regarding "asthma facts," including basic pathophysiology and common asthma triggers. Although high ratings on the subscale of basic knowledge were found in this study, negative attitudes and erroneous beliefs regarding the use of anti-inflammatory medications were apparent on a different subscale. This finding suggests that educational interventions need to be tailored to address multiple information needs while challenging erroneous beliefs. In addition, understanding how knowledge is mobilized in decision-making, as well as understanding parental beliefs about asthma as captured through the Asthma Illness Representation Scale that was developed and

used in this study, would provide valuable insight into factors contributing to parental management of childhood asthma.

The concept of how knowledge is mobilized in decision-making may have further implications for information-seeking behaviors. For example, fathers in a phenomenological study conducted by Cashin et al. (2008) were found to possess a high level of basic asthma knowledge and also exhibited proactive information-seeking behaviors to address their identified learning needs. Similar information-seeking behaviors were observed in a qualitative study of Latino immigrant families in America (Berg et al., 2007). A notable difference between the two sample populations is that emotions, specifically fear of death, appeared to prompt the information-seeking behaviors in the Latino families, compared with the curiosity and eagerness to learn that was exhibited by the fathers in the study conducted by Cashin et al. (2008). Further, the immigrant families in the studies conducted by Berg et al. (2007) and Martin, Beebe, Lopez, and Faux (2010) frequently sought information from informal community networks rather than reputable evidence-based sources. This behavior is similar to the behavior of a father in the study conducted by Cashin et al. (2008) who referred to "picking the brains" (p. 377) of others for information on asthma; however, variable information-seeking behaviors also were exhibited in this study. For example, fathers also sought information from their wives or from printed information resources. In reference to information-seeking behaviors, Yoos et al. (2007) found that although formal education is associated with improved health outcomes for children with asthma, informal information-seeking behaviors were found to be associated with a suboptimal medication regime.

Informal information-seeking behaviors also were prevalent in reference to common asthma triggers and prevention approaches. For example, "trigger avoidance strategies" were

underutilized by families in the study by Meng and McConnell (2002, p. 367). Similarly, in a study by Deis, Spiro, Jenkins, Buckles, and Arnold (2010), 68% of parents identified that they would like more information regarding common asthma triggers. These findings may reflect an unmet information need of parents of children with asthma (Berg et al., 2007; Cashin et al., 2008; Koenig, 2006) and an underestimation of the focus on environmental manipulation as a prevention technique in certain populations (Martin et al., 2010).

Informal information-seeking behaviors may further influence parents' perceptions of the nature of asthma, depending on the information solicited through the informal networks (Berg et al., 2007). To effectively address the information needs of parents of children with asthma, consensus regarding the nature of the disease must be reached between parents and health care providers (Yoos et al., 2007). For example, the biomedical model of asthma is that it is both an acute and chronic disease that can be controlled with proper management (National Heart, Lung and Blood Institute, 2011). This model may contrast with various parental views of asthma as a disease that is "episodic, acute, and uncontrollable," (Yoos et al., 2007, p. 171) or "manageable" (Cashin et al., 2008, p. 377). These varying views have implications for illness representation, treatment expectations, and management decisions (Yoos et al., 2003, 2005). For example, if asthma is regarded as uncontrollable, one may anticipate that more frequent exacerbations may be perceived as acceptable. Symptom recognition may be highly variable between parents and contrast with asthma symptoms that are conventionally recognized by the medical community (Yoos et al., 2005). Understanding parental perceptions of the nature of asthma and how these perceptions can influence asthma management decisions is essential to the parental information needs assessment and for reaching common ground regarding the nature of the illness.

Parental information needs regarding symptom recognition generally were difficult to

ascertain in the literature, because parents often expressed these needs in relation to the emotions of fear, uncertainty, or stress (Berg et al., 2007; Koenig, 2006; Navaie-Waliser et al., 2004). Yoos et al. (2005) directly assessed parental perceptions of asthma symptoms, allowing for a clear comparison with medically identified symptoms associated with asthma. In focus group interviews conducted by Meng and McConnell (2002), parents predominantly focused on asthma symptoms in discussing their decision-making, wherein parents identified a wide range of symptoms, including emotional cues and non-pulmonary symptoms, when identifying asthma exacerbations (Yoos et al., 2005). In the study conducted by Cashin et al. (2008), fathers of children with asthma were very proficient at recognizing their child's symptoms, influencing the fathers' perceived ability to manage their child's asthma through the treatment modalities discussed in the following section.

Treatment Modalities

It is recommended that treatment for persistent childhood asthma include a daily dose of inhaled corticosteroids (ICS) and that a "reliever" medication, such as a short-acting beta agonist (SABA), be used as needed (Pharmacotherapy—first line maintenance therapy, 2005). Notably, the daily use of ICS is essential in achieving asthma control and is central to reducing long-term airway inflammation (Yoos et al., 2003). The importance of ICS in the long-term management of childhood asthma suggests that parents be informed regarding the role of ICS in asthma management.

Despite this, the literature reflected a general tendency for parents to use reliever medications (i.e., SABA) more frequently than the preventative "long- term" ICS (Meng & McConnell, 2002). This decision was influenced by concerns and myths regarding medication adverse effects, especially pertaining to ICS (Cashin et al., 2008; Martin et al., 2010; Yoos et al.,

2003, 2007). For example, parents expressed fears that ICS stunt growth (Cashin et al., 2008; Martin et al., 2010; Yoos et al., 2003, 2007), and they often experienced discomfort with the negative connotation or association of steroid use (Cashin et al., 2008; Yoos et al., 2003).

A lack of understanding regarding the mechanism of action of ICS also was present in a study conducted by Deis et al. (2010), where 24% of parents did not know how ICS worked. In this study, only half of children with persistent asthma study received the daily dose of ICS from their parents, suggesting that a lack of knowledge may contribute to a suboptimal medication regime. Further, specific components related to medication administration were not assessed. For example, rinsing of the mouth to prevent thrush following steroid inhalation was not addressed, as was the case in all of the included literature except the study conducted by Peterson-Sweeney et al. (2003).

Misconceptions and a lack of knowledge regarding reliever medications (i.e., SABA) were also present in the literature. For example, in the study by Hyland and Stahl (2004), short-acting medications were "perceived to be more powerful and therefore do more damage" (p. 2145) than ICS because of their rapid onset of action. In two additional studies, parents did not associate an increased use of SABA with poor asthma control, even if the SABA was used to treat nocturnal symptoms (Meng & McConnell, 2002; Yoos et al., 2007). Further, parents in the study conducted by Peterson-Sweeney et al. (2003) found that 50% of mothers of children with asthma did not remember the "actions" of the specific medications, and exercise intolerance was not recognized as a need for reliever medication in Meng & McConnell's exploratory study (2002). These findings are similar to the descriptive statistics reported by Deis et al. (2010), which showed that 6% of parents would not know what to do if their child had an asthma attack. Perhaps more significantly, Navaie-Waliser et al. (2004) found that at "entry to care," 74% of

parents did not know how to act if an asthma attack occurred.

Although they are valid, the parental concerns and misconceptions present in the literature may highlight a need for further education regarding the function, benefits, and adverse effects of both SABA and ICS. The findings further suggest that "myth dispelling" should be a component of asthma teaching. This suggestion is additionally supported by findings from a study conducted by Peterson-Sweeney et al. (2003), in which a family that had experienced ICS-associated apprehension expressed that their apprehension dissipated when information from a specialist was provided. Although this study provided rich and diverse data regarding elements of the parental experience of having a child with asthma and delineated clear methods used by the researchers, the particular framework (e.g., grounded theory) directing the study was not explicitly identified.

Another parental information need related to treatment modalities was the "how to" or the technique of medication administration. Despite recognition that the technique of SABA and ICS administration is essential to the effective short-term and long-term management of asthma, only 60% of included articles addressed this technique as a component (Cashin et al., 2008; Deis et al., 2010; Meng & McConnell, 2002; Navaie-Waliser et al., 2004; Peterson-Sweeney et al., 2003; Yoos et al., 2007). Among these studies, parental experiences regarding information provision regarding technique were variable.

For example, parents were asked by the health care provider if they preferred to use a metered dose inhaler (MDI) or "spacer" (Deis et al., 2010); however, no reference by the health care provider was made to the advantages or disadvantages of these approaches. In one study, parents were provided with an inhaler but did not know how to use it (Peterson-Sweeney et al., 2003). In contrast, one group of fathers and another set of parents were shown "how to use the

puffers" by a health care provider, but technique was not discussed further (Cashin et al., 2008; Peterson-Sweeney et al., 2003). For example, the benefits of using high-flow versus low-flow breathing with MDI use were not addressed.

Similarly, in a study conducted by Meng and McConnell (2002), more than 25% of parents used direct observation as an approach to promoting medication adherence. Although a strength of this study is that parents were directly asked "how do you know your child is taking his/her medication correctly," (p. 366) a weakness is that the responses to this question were not discussed in detail. The use of direct observation may potentially function more as a strategy to promote adherence and does not necessarily ensure adequate technique in medication administration.

Coping

The theme of coping includes the concepts of self-perceived efficacy, confidence, and sorting through the emotions of having a child with asthma. It is conceptualized as an information need because it is closely linked with both information provision and perceived management abilities. In the literature, "self-perceived efficacy" is seen as related to the type of information provided and to parental level of understanding (Berg et al., 2007) and was positively correlated with the acquisition of experiential and factual knowledge (Cashin et al., 2008).

The concept of coping with the emotional experience of having a child with asthma was observed in the majority of studies included in our review (Berg et al., 2007; Cashin et al., 2008; Koenig, 2006; Martin et al., 2010; Meng & McConnell, 2002; Yoos et al., 2007). For example, the concept of vigilance emerged when discussing symptom recognition and asthma management in two of the included studies (Cashin et al., 2008; Koenig, 2006). The fathers in

the study conducted by Cashin et al. (2008) credited effective asthma management, in part, to vigilance, and the concept was recognized as necessary to asthma management in Koenig's study (2006). The concept of vigilance illustrates that a close relationship between symptom recognition, emotional response, and subsequent management may exist.

The close relationship between symptom recognition, emotional response, and asthma management is further supported by findings in the study by Meng and McConnell (2002) that explored factors influencing parental decision-making about asthma management. In this study, anxiety related to asthma was found to correlate with poor decision-making, and "learning to remain calm resulted in better decision-making" (p. 364). This report is similar to parental reports that emphasize the importance of "life management" following asthma diagnosis (Hyland & Stahl, 2004).

Despite the importance of developing strategies to cope with the diagnosis and management of asthma, coping strategies were not routinely addressed by health care providers during diagnosis or subsequent treatment visits (Koenig, 2006; Martin et al., 2010). At times, the ability to cope appeared to be related to the amount of information provided, with less knowledge being related to high levels of fear and anxiety (Berg et al., 2007) and learning how to effectively manage asthma symptoms being related to level of confidence (Peterson-Sweeney et al., 2003).

A method to facilitate asthma management that may also foster self-efficacy and was found to significantly increase parental confidence in one study is the use of a written action plan (Deis et al., 2010). The use of such an approach is recognized as a component of preventative asthma care and thus may be correlated with improved asthma management (Deis et al., 2010); however, fewer than half of included studies addressed this component as related to parental

information needs (Cashin et al., 2008; Deis et al., 2010; Meng & McConnell, 2002; Peterson-Sweeney et al., 2003). Because important asthma management information can be embedded in a treatment plan and may enhance parents' confidence in asthma management, it may provide an effective approach to addressing the information needs of parents of a child with asthma (Martin et al., 2010).

Medical Expectations

Recognizing when to seek medical care is a concept that typically is central to discharge teaching; however, when to seek medical attention was rarely emphasized in the literature. Parents generally sought medical attention when they felt unable to adequately manage the situation (Berg et al., 2007) or as a means of coping with the crises of exacerbation (Koenig, 2006). Illness representation and perspectives on asthma control may further implicate when medical care is sought, as demonstrated in the analyses provided by Yoos et al. (2005, 2007), which examined how parental illness representation influenced health care seeking behaviors. In these studies, discrepancies between parental perceptions and the National Heart, Lung and Blood Institute's guidelines (1997, 2002) for asthma symptom recognition and treatment were revealed, specifically regarding when to contact a health care provider to modify treatment for worsening symptoms. According to these guidelines, medications should be adjusted in a "stepwise" fashion in accordance with changing symptom severity. For parents to be aware of this national guideline, they must be informed regarding this approach to asthma management. The discrepancies revealed in the studies by Yoos et al. (2005, 2007) demonstrate a lack of understanding between health care providers and parents, compounded by differences in the language used to describe asthma symptoms, and suggests that the appropriate time to contact a health care provider be included in parental asthma education plans so that medication regimes

can be adjusted accordingly.

An additional medical expectation that surfaced in the literature was the concept of consistency, as was apparent in the study by Hyland and Stahl (2004), in which parents exhibited dissatisfaction with seeing different physicians during medical visits. Similar findings were reported in the study conducted by Peterson-Sweeney et al. (2003), in which parents expressed frustration when their primary physician was not available during acute exacerbations. Although achieving consistency with health care providers may be difficult, specific approaches that can be used by health care providers also were identified in the literature.

For example, parents felt a desire to be "acknowledged for their own assessments" (Peterson-Sweeney et al., 2003, p. 121). This desire is supported by parental reports of the importance of feeling validated during asthma-related encounters with health care providers (Koenig, 2006). Acknowledging parental assessments may be further recognized as central to the parent-health care provider partnership (Institute of Medicine, 2002), which is an important component in improving disease management for children with asthma (Peterson-Sweeney et al., 2003). The information needs of parents of children with asthma are summarized in Figure 2.2.

[Insert Figure 2.2 about here]

What We Already Know About This Topic

- Parents often experience fear and uncertainty regarding management of their child's asthma.
- Information needs of parents may not be adequately addressed through current educational approaches.

What This Article Adds

- Comprehensive identification of parental information needs through a state-of-the-science

review of the literature

- Creation of a parental information needs taxonomy classifying four predominant parental information needs (asthma basics, treatment modalities, coping, medical expectations)

Conclusion

Despite the emphasis on patient collaboration in health care, the information needs of parents of children with asthma may not be adequately addressed by health care providers. This situation is due, in part, to a lack of solicitation and identification of the needs of parents in the literature. Unaddressed parental information needs contribute to parental fear and anxiety, suboptimal asthma management, and inappropriate utilization of health care services, and subsequently have far reaching negative effects on the family unit and health care system.

The four parental in formation needs identified through this state-of-the-science literature review provide a preliminary inventory of parental needs with which to integrate evidence-based information for educational purposes and future intervention studies. Findings from this review illustrate the importance of addressing issues relevant to parents, such as learning methods to cope with a child's chronic illness, which may not be addressed when education is provided based predominantly on a medical representation of asthma. Incorporating parental information needs into health care assessment and educational planning are essential steps toward improving parental competency in asthma management and to enhancing health outcomes for children with asthma.

Table 2.1 Characteristics of Included Studies

Author (year)	Journal	Sample size / subjects	Purpose of study (re: asthma)	Methods to assess information needs	Information needs identified
Berg et al. (2007)	*Journal of Pediatric Healthcare*	*n* = 8; families in East Los Angeles	Explore the experiences, issues and needs of Latino families regarding asthma management	Ethnographic groups and individual interview techniques	A B C D H P Q S
Cashin et al. (2008)	*Journal of Pediatric Nursing*	*n* = 8; fathers of children ages 7-11 y	Explore the lived experiences of fathers of children with asthma	Phenomenologic interviews	A B C D E H G P Q R
Deis et al. (2010)	*The Journal of Asthma*	*n* = 229; parents of children ages 2-18 y	Assess parental knowledge of use of prevention strategies in managing childhood asthma	38-item questionnaire and quantitative analyses	B C D G P R
Koenig (2006)	*Journal of Family Nursing*	*n* = 11; families with children < 4 y	Discover the earliest experiences of families of children (< 4 y) hospitalized for severe-persistent asthma	Home interviews and home observation	D Q S
Martin et al. (2010)	*Journal of Health Care for the Poor & Underserved*	*n* = 32 parents and children grades 4-8 and grades 9-12	Describe the asthma self-management behaviours Puerto Rican children in the U.S.A	Focus group interviews	B C D E Q S
Meng & McConnell (2002)	*Journal of the American Academy of Nurse Practitioners*	*n* = 28; school-age children and their parents	Learn how parents of children with asthma, and children, make decisions regarding asthma treatment	Focus group interviews	A B C D E G R S Q
Navaie-Waliser et al. (2004)	*Public Health Nursing*	Chart review *n* = 1007	Examine risks, characteristics and needs of children and improve parental / family knowledge	Retrospective chart review	A B C D E G
Peterson-Sweeney et al. (2003)	*Journal of Pediatric Healthcare*	*n* = 18; parents of children ages 2-18 y	Report parental experiences and concerns regarding asthma management	One-on-one semi-structured qualitative interviews	A B C E F G P R S
Yoos et al. (2003)	*Ambulatory Pediatrics*	*n* = 21; parents	Identify parental barriers to medication use	Qualitative interviews	A B C E F
a. Yoos et al. (2007)	*Nursing Research*	*n* = 228; parents	Compare parental and health care practitioner representation of asthma	Semi-structured interviews	A B C D E F G H Q
b. Yoos et al. (2005)	*Journal of Pediatric Healthcare*	*n* = 228; parents	Identify parental perceptions of asthma symptoms; in illness representation, describe proposed action to symptoms	Qualitative interviews, Likert scale	E F H

A, Basic asthma knowledge (frequency: 7); B, short-term medications (frequency: 9); C, long-term medications (frequency: 9); D, triggers and prevention (frequency: 8); E, symptom recognition and management (frequency: 8); F, when to seek medical care/contact HCP (frequency: 4); G, technique (frequency: 6); H, prognosis/meanings of "control" (frequency: 4); P, self-perceived efficacy (frequency: 4); Q, coping (frequency: 6); R, "action" or "treatment" plan (frequency: 4); S, other (non-drug, myths; frequency: 5).

***The diagnosis of asthma is present in all children in all included studies; included parents are parents of children with asthma.*

†Coding schema adapted from Irvine, L. Waiting to exhale (unpublished work).

‡Yoos et al. (2007) and Yoos et al. (2005) are part of a larger study and are counted as one study.

Figure 2.1 Decision Tree for Study Inclusion

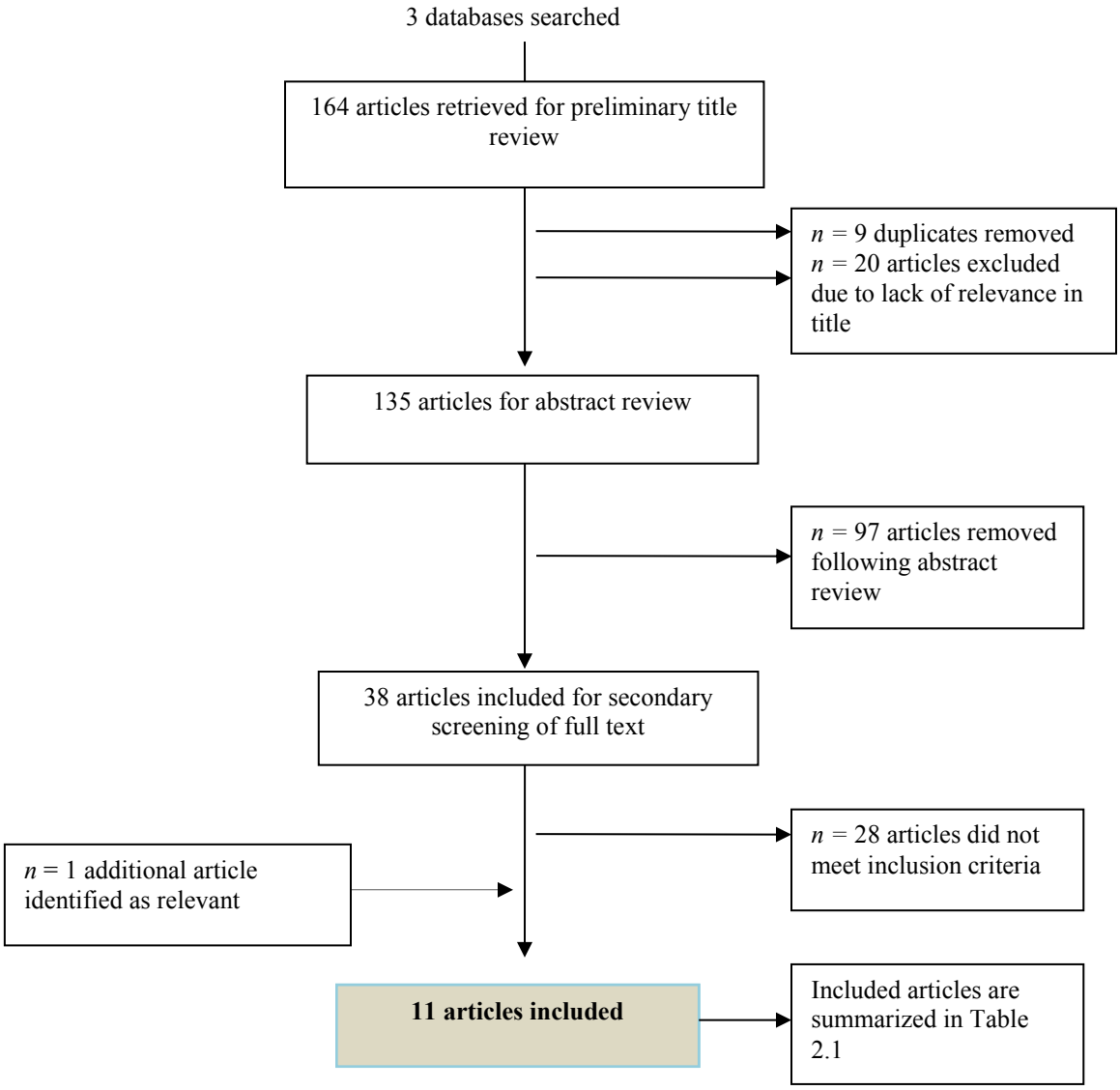

Figure 2.2 Box- Parental Information Needs Inventory

Information needs identified through state-of-the-science review of the literature

1. Asthma Basics
Basic pathophysiology, nature of disease
Symptom recognition (e.g., basic physiology; nature of disease)
Triggers and prevention (environmental modification)

2. Treatment Modalities
Short-term "reliever" medications (short-acting *B*-agonists): mechanism of action, adverse effects, when to use it, technique of administration
Long-term medications (inhaled corticosteroids): mechanism of action, adverse effects, when to use it, technique of administration, myth dispelling

3. Coping (including self-efficacy)
How to deal with emotions, worry, and uncertainty
Developing an action plan/treatment plan

4. Medical Expectations
When to seek medical care/contact health care provider

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CHAPTER 3

Paper 2: What is Left Unsaid: An Interpretive Description of The Information Needs of Parents of Children with Asthma

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What is Left Unsaid: An Interpretive Description of the Information Needs of Parents of Children With Asthma

Over the past twenty years, substantial strides have been made in understanding childhood asthma, including its pathophysiology and effective therapies (Clark, Mitchell, & Rand, 2009). However, this progress has inconsistently resulted in improvements in children's asthma management or reduction in health care utilization or disease prevalence (Clark et al., 2009; Nicholas, Dell, Fleming-Carroll, & Selkirk, 2009; Toole, 2013). The prevalence of childhood asthma continues to rise globally, and the associated disease burden for asthma is increasing (Centers for Disease Control and Prevention, 2011; Garner and Kohen, 2008).

The trajectory of childhood asthma is one of sub-acute chronicity, interspersed with acute exacerbations of variable severity (Swerczek et al., 2013). Asthma management in children remains suboptimal (Peterson-Sweeney et al., 2007; Stewart, Letourneau, Masuda, Anderson, & McGhan, 2011; Swerczek et al., 2013) and poor control has been reported in up to 75% of cases (McGhan et al., 2006). Exacerbations associated with inadequate at-home asthma management are a primary reason for emergent medical treatment and school absenteeism and place financial burden on the family and health care system (Bloomberg et al., 2009; Stewart et al., 2011; Toole, 2013).

Asthma exacerbations can be mitigated by minimizing exposure to allergen or irritant triggers, maximizing preventative measures, recognizing asthma-related signs and symptoms, and knowing how to manage acute exacerbations. For families of children with asthma, these complex aspects of management, as well as integrating asthma into the family context and understanding asthma as a chronic illness, are considered necessary components of

comprehensive parental education (Brown, Gallagher, Fowler, & Wales, 2010). Parents[1] often serve as proxies for their children and assume responsibility for their care, and education therefore should follow a family-centered approach (Kumar, Edelman, & Ficorelli, 2005), but inadequate family-centered asthma education continues to hamper management efforts (Cleveland, 2012; Peterson-Sweeney et al., 2007; McMullen et al., 2007).

The majority of childhood asthma management is done by families outside of hospital settings, so optimizing parents' capacity to manage asthma day-to-day is essential. Evidence to date on information needs of North American parents of children with asthma (Archibald & Scott, 2014) indicates a pervasive need for education, but little is known about parents' perceptions of their knowledge gaps. This study was designed to identify parents' self-identified information needs.

Education of Parents of Children With Asthma

Education improves asthma management (Boyd et al., 2010; Nicholas et al., 2009; Cleveland, 2012), including knowledge, self-efficacy, and medication adherence (Toole, 2013). Conversely, lack of knowledge is linked to poorer child health outcomes, parental fear, anxiety, and uncertainty (Berg, Anderson, Tichacek, Tomizh, & Rachelefsky, 2007). Anxiety and uncertainty are common at the time of asthma diagnosis and, in the absence of appropriate education, may persist due to the complexity and variability of the disease trajectory (Berg et al., 2007).

The focus of qualitative research to date on families of children with asthma has been on experiences of caring for a child with asthma (e.g., Peterson-Sweeney, McMullen, Yoos, &

[1] Adults who defined themselves as parents of children with asthma, whether biological parents, step-parents, foster parents, guardians, or adoptive parents, were eligible to participate in this study and are described as parents in this report.

Kitzman, 2003; Berg et al., 2007), symptom and illness representation (e.g., Peterson-Sweeney et al., 2007; Yoos, Kitzman, McMullen, Sidora-Arcoleo, & Anson, 2005; Yoos et al., 2007), and the effectiveness of educational initiatives (e.g., Brouwer & Brand, 2008; Clark et al., 2009; Nicholas et al., 2009). When provided, parental education often reflects the medical priorities of health care providers (HCPs) and may not incorporate parental perceptions and priorities (Yoos et al., 2007; Nicholas et al., 2009). For instance, education based on guidelines for asthma management "represents the professional model for asthma management" (Yoos et al., 2007, p. 168). Parents and HCPs use different words to describe symptoms, and how these symptoms are identified and interpreted may differ (Yoos et al., 2005). Understandings of asthma control also conflict; parents may overestimate the degree of their child's asthma control (Davis, DiSantostefano, & Peden, 2011).

Although the views and priorities of HCPs and parents differ, they can be further aligned through the provision of family-centred asthma education (Peterson-Sweeney et al., 2007). Thus, the purpose of this study was to explore how parents of children with asthma understand their asthma-related information needs, and to identify areas where further information about asthma is needed (information deficits).

Methods

Study Design

Interpretive description (Thorne, 2008) guided this qualitative study. This applied qualitative approach is intended to foster understanding of a clinical phenomenon in relation to its context. In our review of previous research, we identified a need to more thoroughly understand the information needs of parents of children with asthma (Archibald & Scott, 2014). In response to this practice-oriented problem, we aimed to gain insight into how parents

understand their asthma-related information needs and identify lingering information deficits relevant to childhood asthma management. We adopted the role of learners situated within the health disciplines (i.e., nursing, medicine) during this process.

Recruitment and Sample

An eligible participant had a child with any form of asthma (e.g., mild episodic or severe persistent) and spoke English. Data collection and analysis occurred iteratively over the year from September 2011 to August 2012 to capture seasonal variations in pediatric asthma. Ethics approval was received prior to recruitment.

Purposive and convenience sampling approaches were used. Two pediatric asthma clinics and one pediatric emergency department (ED) in a large Canadian urban center (population 1,159,869) were purposively selected to reflect the diverse patient demography in the area and to capture families expected to have greater knowledge deficits and unmet information needs than in other health care sites. Pediatric asthma clinic C1 was located in a lower-income area and served a larger number of immigrants than the other recruitment sites, a pediatric ED and a second asthma clinic (C2) on the opposite end of the city. We theorized that this combination of sites would enable access to parents of diverse income brackets and socioeconomic status, given that disparities in asthma management have been documented (Bloomberg et al., 2009).

In the ED, clinical team members located eligible participants via the ED Information System and notified the researcher so that potential participants could be approached after triage. At one pediatric asthma clinic (C1), asthma nurses distributed brochures to potential participants, and the researcher was on-site during clinic days to discuss the study with parents directly after their appointments. In the central pediatric clinic (C2), the asthma nurse educator distributed brochures to potentially eligible participants, who could then contact the research team.

We intentionally maximized variation in the recruitment process to achieve diversity in time since diagnosis and parental education level. The sample consisted of 20 families, including 20 mothers and one father of 23 children with asthma. Parents' education and income levels, and length of time since receiving their child's asthma diagnosis were diverse. The demographic characteristics of participants are presented in Table 3.1.

[Insert Table 3.1 about here]

Data Collection

Parents completed demographic information forms after consenting to participate. The first author conducted 20 semi-structured interviews, each lasting approximately 25 minutes. Interview duration was not predetermined and was guided by parents' willingness and ability to participate.

The semi-structured interview guide was based on a literature review (Archibald & Scott, 2014) and designed to capture data in two main domains. First, we explored how parents expressed and understood their information needs. We inquired into the information they received at the time of diagnosis and in subsequent health care encounters, how information was provided, what information they found important to asthma management, and their knowledge about childhood asthma. Second, we explored each parent's experiences of caring for a child with asthma (e.g., at the time of diagnosis, asthma exacerbations, health care encounters). Data from the second domain provided contextual understanding of the parents' information needs. Interviews were audio-recorded, and field notes were taken.

Data Analysis

All interviews were transcribed verbatim and uploaded to NVivo data management software. Data analysis followed four steps and involved two authors. First, transcripts were read

in detail several times. Second, the first author conducted open coding of all transcripts and then grouped codes into preliminary categories to facilitate within-case understanding. Third, preliminary categories across cases were grouped into a beginning organizational framework according to explicit information needs (e.g., asthma triggers; medications), while writing analytic memos and summary notes to capture impressions and decisions. Fourth, data were classified by "time since diagnosis," which enabled comparison across cases in the following three categories: inexperienced (2.5 years or less), moderately experienced (2.5 – 5 years) and experienced (5 years or more). Throughout the analysis process, analytic rigor was enhanced by discussions between the first and fifth authors, in which the coding framework, analytic procedures, preliminary findings, and interpretations were reviewed. Particular attention was paid to the disciplinary and pragmatic relevance of the findings to practice settings (Thorne, 2008).

This analytic approach enabled us to differentiate between parents' description of their information needs and our interpretation of these information needs. In reporting this interpretive study, we discuss these descriptive and interpretive levels of analysis in tandem. The descriptive level of analysis refers to parents' self-described information needs. The interpretive level refers to the information deficits perceived by the research team. These often reflected a professional standard of what parents ought to know, and frequently related to aspects of asthma care unrecognized by parents but important to a child's well-being.

Results

For many parents, the information they felt they needed and the gaps identified during the research teams' interpretation were not the same. Some gaps in knowledge were long-standing, in some cases persisting for years following diagnosis.

Parent-identified and clinician-identified lack of knowledge fell into a hierarchy of four areas. The most foundational was recognizing severity, followed by acute management, prevention versus crisis orientation, and knowing "about" asthma (Figure 3.1). Parents were more likely to identify a need for procedural knowledge (e.g., how to use an inhaler) than for propositional knowledge (e.g., asthma facts). Parents' ability to recognize their information needs was mediated by their interactions with HCPs, as discussed below, and their beliefs about the nature of asthma, which were a pervasive influence on their approach to asthma management.

[Insert Figure 3.1 about here]

I. Recognizing Severity

Many parents had difficulty interpreting the meaning and severity of asthma symptoms. This was most common immediately following diagnosis but for some parents persisted for years. Recognizing severity was interpreted as the foundational information need (Figure 3.1) because without it, parents' ability to manage an asthma attack and employ preventative measures was hindered.

Recognition of symptom severity generally improved over time (e.g., participants 3 and 4), but initial deficiencies placed the child at significant risk. For instance, one mother reflected on a frightening incident that occurred three years earlier:

> He just kind of laid around. He didn't *do* anything . . . that night . . . he was breathing so hard that his body was shaking my bed . . . his stomach like he was sucking it in and I didn't know anything. I was like stop it (participant 14).

Similarly, another parent stated,

> We weren't really informed of the severity of her condition . . . we brought her home and said well we'll rest her, it's nothing . . . until the doctor said, you know, we need to get

her uh, to get her to the hospital *right away* (participant 15).

Parents discussed not knowing hallmark symptoms of an asthma exacerbation or how to interpret a low oxygen saturation level. Often, hallmark asthma symptoms were attributed to non-asthma causes or regarded as normal. Some parents had noticed black circles under the child's eyes (e.g., participants 4 and 17), or lips turning blue (participant 13) but did not view them as symptoms of concern. Peri-orbital dark circles can be indicative of allergies and fatigue in children with asthma (Canadian Lung Association, 2014; Jacobson, 2010), problematic as the former is an asthma trigger. In the more severe cases, parents did not recognize severity until they were told that the child was "close to having cardiac arrest" (participant 9) or they were urgently instructed to seek emergent medical care.

II. Acute Management and Inhaler Use

Many parents lacked confidence in their ability to manage acute exacerbations. They described not knowing what to do during an asthma attack, panicking in the moment, not having the inhaler on-hand, and being unsure of proper inhaler technique. When asked what she would do if her child had an attack, one mother responded, "I'd probably just panic and take her to the emergency . . . like I don't have a clue" (participant 4). Similarly, another parent stated, "I don't know, I don't have his Ventolin . . . I'm a panicker" (participant 14).

The majority of parents reported that at some point since diagnosis they had not known when or how to properly use an inhaler. One parent whose child was diagnosed five years earlier confessed, "I still don't know how to use an inhaler" (participant 10). This was commonly attributed to not being instructed on technique. As one parent stated during an ED visit, "They say, here's a pump, here's a chamber, she needs to take, you know four times day of whatever it is, um, but no one actually stops to show you how to use it" (participant 15).

Participants expressed that HCPs used different inhaler techniques and infrequently assessed parents' inhaler techniques. Parents were confused because "every practitioner does it differently." Other parents felt that they would have benefited from hands-on learning with HCPs. As one mother stated after unsuccessfully managing in the community for over five years, "They gave her . . . these inhalers which we didn't know how to use," (participant 4) an information need that persisted until the family attended a pediatric asthma clinic.

III. Prevention Versus Crisis Orientation

A crisis orientation to asthma management was common and placed near the top of the "levels" of knowledge types represented in Figure 3.1. Emergency-focused management, misguided beliefs about the nature of asthma, and a lack of preventative strategies characterized this orientation. Parents who did not know what to do in case of an asthma exacerbation generally did not know how to prevent exacerbations either. In this way, acute management was the foundation for preventive management.

For instance, eight years after her child was diagnosed with asthma, one mother proclaimed,

> Basically emergency stuff, that's what we had been doing . . . that worked out well because you know when stuff like that happens they take you in right away, so we didn't have to stress out about waiting to see the doctor (participant 5).

Use of an inhaler was equated with asthma management by some parents, to the exclusion of other approaches to management and prevention.

The belief that asthma is an acute rather than chronic condition was reflected in a crisis orientation to asthma management, and for these parents, approaches to prevention were rarely pursued. Some parents were aware of particular asthma triggers but did not prevent exposure to

allergens or irritants, believing that a physical barrier, like a door, offered sufficient protection. A common strategy for family pets was to "limit the pets in the room" (participant 4). Another mother expressed "I do have a lot, quite a few animals. I raise animals . . . but nothing in the room with them . . . nothing sleeps with them in bed" (participant 19). Another parent's view of asthma as an acute condition was supported by her observation that they "got rid of the cat . . . (and now) he's cured" (participant 14).

Some parents who were aware of triggers to asthma exacerbation offered rationalizations for not eliminating them or identified incomplete efforts. As one mother confessed, "smoking can make it worse, I know . . . I never smoke in my house ever. Um, I have to quit smoking in my vehicle" (participant 19). This mother recognized the need to quit smoking, particularly around her child with asthma, but had not yet changed this behavior. Other parents rationalized their lack of prevention or planning by referring to a child as being tough or a trooper. For instance, when asked if he kept an inhaler at his child's school and daycare, a parent proclaimed, "Well we haven't done that because . . . she's just a spry little girl and um, she's also very tough" (participant 15).

Many parents said they often "forgot" aspects of their children's asthma management, such as to take rescue inhalers with them on walks or administer preventative medications. Regarding bronchodilators, a mother "didn't think of it . . . but I think that it should be probably have it with me . . . I always forget it" (participant 14). Later, the same mother recalled,

> We just went on a walk, uh a long walk, it was like three hours out in the park . . . near the end, we're slowing down, 'cause he just wasn't keeping up anymore . . . I guess in that sense I should have had his inhaler, because it might have probably helped him. But I'm really not smart to plan ahead.

Consistently administering daily preventative medications such as inhaled corticosteroids was even more challenging for parents and particularly so during periods of symptom remission. As one mother, whose child was diagnosed with asthma five years before, said,

> They were meant to be supposedly on the daily medications . . . then they'd go through a time where they were symptom-free . . . you're meant to carry on and we get carried away with life and the asthma inhalers have fallen under their beds (participant 10).

Similarly, one mother lamented that "the hardest thing for me is keeping up the regular twice daily preventative, because I'm dealing with my own stuff" (participant 11).

IV. Knowing "About" Asthma

While recognizing severity and managing in acute scenarios gradually, albeit unpredictably, improved over time, propositional knowledge, such as what asthma is, generally did not improve in the absence of education. Many parents were unable to describe what many HCPs consider basic asthma knowledge. Some parents recognized this as an information need, with statements like, "I don't even know what asthma is," (participant 10, five years after diagnosis), or "side effects, I have no idea" (participant 15, one year after diagnosis). When asked, they said this information was relevant, but parents were less likely to express a need for this knowledge type than for procedural knowledge about asthma care (e.g., how to use an inhaler). One mother did identify a need for both: "I need to be comfortable with myself to know at least what is going on with him . . . and what can help him" (participant 1).

Participants with information deficits from a HCP's perspective would readily admit they knew "nothing really" (participant 20) but only when asked pointed questions (e.g., "How important is it to know what asthma is?"). When questioned, many parents' knowledge about asthma, including what asthma is, medication side effects, or how medications work in the body,

was absent or incomplete. They sought information only when they identified a gap. As one mother exclaimed, “I don’t really look up information . . . everything I need to know I can find it if I need to find it, I just don’t really know everything I need to know” (participant 1). Conversely, parents who recognized their information needs generally had more experience with asthma and took an active role in seeking information, both during and beyond visits with HCPs (e.g., participants 3, 7, and 8). This information-seeking was often motivated by a change in clinical status or by an emotional motivator, such as a desire to be comfortable with an aspect of asthma management.

Mediator: Interactions with health care providers. Parents expressed that their asthma knowledge was affected by how and whether asthma education was provided by HCPs. Most parents reported receiving little to no education at time of diagnosis or during subsequent visits to the ED. Most made comments such as, “I can’t say anyone came out and did any teaching” (participant 18), “I know from using it but they don’t explain” (participant 19), and “He never explained to us what the medications do, what the side effects were . . . it was just ‘here, give this medication to her’” (participant 21). In contrast, one mother proclaimed that while she knew very little about asthma at the time of diagnosis, she “knows a whole lot now” (participant 3), which she attributed largely to interactions with a HCP through the asthma clinic.

The reported lack of education by HCPs hampered parents’ ability to identify their information deficits and limited the information they sought during interactions with HCPs. As one parent stated, “The thing is, what questions do you ask?” (participant 15). When asked if they had sufficient information about childhood asthma, others responded “I think so, but it’s hard to know what you don’t know” (participant 1); “I just don’t really know everything I need to know” (participant 13); or, “I can’t even articulate what I think I should know right now . . . or

what I would like some help with" (participant 20).

Parents' ability to recognize their information needs generally improved with experience over time. Some parents became aware that they needed to direct their interactions with HCPs or specifically ask for more information. As one participant stated, "I have to do a lot of thinking before we come to make sure that I have all my questions ready to go" (participant 6). Another mother of a child with uncontrolled asthma proclaimed that "(HCP) provided me with the information that I wanted and, yeah it's been good so far" (participant 2). Only the few parents who were able to identify their information needs were able to formulate and ask questions during HCP visits.

Misconceptions about asthma were prevalent and at times reinforced by HCPs. For example, many parents viewed asthma as an acute condition, and approximately half believed that their children would grow out of asthma, a misconception reinforced through interactions with HCPs who were not asthma specialists. Seven years after diagnosis, one participant said she had previously thought of asthma as a lifelong, chronic condition, but her doctor said that her daughter might grow out of it. "I think the biggest awareness for me was that I didn't know if it was childhood asthma or a big deal. No one made that clear*"* (participant 11).

Impact of asthma clinic education. All parents who had received referrals to asthma clinics commented on the impact or quality of the education received, although information deficits were still evident for some to varying degrees. Their core knowledge of "recognizing severity" and intermediate knowledge of "acute management" improved over time if they practiced careful observation, which generally was enhanced by these referrals. Parents said their inhaler administration technique and related confidence improved following asthma clinic attendance. For instance, one mother realized she had been using inhalers incorrectly for five

years: “We didn’t know how to use (the inhalers) until we went to the asthma clinic” (participant 4).

Parents provided testimonies to the power of education received there. One mother realized that she had “no idea, no clue, none at all” (participant 13) what her child’s medications were for, despite administering them for three years. Another parent said, “Until we came to the children’s asthma clinic after those bad attacks we didn’t know much. They just said it was bad . . . we didn’t understand how it worked until the asthma clinic showed us the models where you can see the difference” (participant 11). Parents valued the personalized nature of the visits and the follow-up they received, and they described increased confidence in their asthma knowledge. This positive effect was linked to receiving information tailored to the child in a non-emergency context in which the child’s particular presentation and treatment responses were evaluated by consistent HCPs.

Discussion

Findings from this study are congruent with the major components of the Health Belief Model (Janz & Becker, 1984) used extensively since the 1950s to explain individual health behaviours (Stretcher & Rosenstock, 1997). In this model, perceived susceptibility (belief about vulnerability to a health condition), perceived severity (belief in the seriousness of the condition), perceived benefits of engaging in health recommended behaviors, and perceived barriers to participating in the associated health initiative are the dominant dimensions influencing health behaviors. Cues to action are often included in the model but have not been extensively studied, and perceived self-efficacy was later included when the model’s use extended to situations where long-term behavior change was required (Stretcher & Rosenstock, 1997). In the present study, participants’ underlying beliefs related to illness susceptibility and

perceived seriousness of asthma, as well as benefits and barriers to information seeking and management decisions influenced parents' ability to successfully manage their child's asthma. These findings both reinforce and add to existing literature on childhood asthma management and education. Parents' information deficits were evident in their comments and the self-reported frequency of ED visits for acute asthma exacerbations. Their perspective that asthma was an acute and episodic condition and their reported lack of asthma education at critical time points (e.g., diagnosis) were particularly worrisome. Previous experiences, such as having another family member with asthma, enabled a few parents to manage at home as soon as they received the diagnosis. More commonly, however, parents did not know what to do in the event of an asthma exacerbation, and this deficit persisted for years. Education had a positive impact for those parents who received it but was not consistently provided to parents in our sample.

Learning through trial and error enabled some parents to improve their management of acute asthma exacerbations. In contrast, knowledge about asthma (e.g., propositional knowledge) did not consistently improve over time. HCPs may use time since diagnosis to predict clients' level of knowledge, but the present findings suggest that this may be problematic and contribute to failure to provide necessary education. Similar findings have been reported in previous studies assessing asthma knowledge (e.g., knowledge about asthma medications; Deis, Spiro, Jenkins, Buckles, & Arnold, 2010). Although Deis and colleagues (2010) reported that parents' confidence in managing asthma exacerbations improved over time, our findings suggest that confidence may at times be misplaced and at other times may be developed only after unnecessary periods of trial and error.

Recognizing Symptom Severity

Parents felt that they received insufficient education on how to recognize symptom

severity, and this was most pronounced in participants who had not received referrals to asthma clinics. Classic symptoms of asthma, such as night-time cough, and other signs of respiratory distress were often overlooked by parents until an emergency occurred. Similarly, in previous qualitative research, parents expressed inadequacy and uncertainty in the acute aspects of asthma management, which they attributed to a lack of asthma knowledge and education (Berg et al., 2007). Parents also overestimated the degree of asthma control and underestimated symptom severity in children, despite regularity of symptoms and unscheduled health care use (Davis et al., 2011). Similarly, HCPs have been found to underestimate at-home symptom severity (Halterman et al., 2006), which may further reduce the quality of asthma education provided.

Inaccurately estimating asthma symptoms and severity is a barrier to appropriate asthma care and a significant threat to a child's well-being. Consistent with the Health Belief Model (Janz & Becker, 1984), the extent to which parents perceived symptoms as threatening a child's well-being may be compounded by underestimating a child's susceptibility to harm. Working with parents to promote an aligned interpretation of asthma symptoms may promote parental understanding and self-efficacy in asthma management and decrease the use of rescue medications and ED visits.

The Nature of Asthma

The perception that asthma is an acute condition resulted in a crisis orientation to asthma management. The other misconception of "growing out of asthma" common in these findings has been widely reported (Berg et al., 2007; Toole, 2013). These beliefs may negatively affect follow-up and medication adherence by deemphasizing asthma's chronicity (Bloomberg et al., 2009). For instance, the inconsistent use of inhaled corticosteroids in this sample was concerning, as this significantly decreases their effectiveness (Klok, Kaptein & Duiveiman,

2014). Reorienting parents to the chronic nature of asthma may have a positive impact on these asthma management behaviors.

Highlighting the benefits of a specific action can positively influence outcome expectations and contribute to greater self-efficacy, according to the Health Belief Model (Janz & Becker, 1984). Reinforcing why preventative medications should be administered daily as prescribed, even in the absence of symptoms, may be particularly beneficial to parents who are concerned about administering "unneeded" medication to a child who appears healthy. Collaboratively developing strategies to promote these behaviors and attending to underlying concerns regarding medications are particularly important. For instance, understanding of asthma triggers and developing a written asthma action plan can aid in understanding asthma symptoms and contribute to parents' self-efficacy while improving their asthma care (Klok et al., 2014).

Impact of Asthma Clinic Attendance

Although discrepancies, inconsistencies, and shortcomings in the provision of asthma education and adherence to asthma guidelines and recommendations continue to be reported in the literature (Lob, Boer, Porter, Nunez, & Fox, 2011; McGhan et al., 2006), findings from the present study shed new light on the impact of attending a pediatric asthma clinic on parents' knowledge and perceived management ability. Parents regarded the comprehensiveness of education provided, the commitment of providers to work with the family, and the continuity of care enabled through seeing a consistent team of practitioners as having a positive impact on their ability to manage asthma. Meaningful HCP-client partnerships and individualized education has been emphasized in previous research (Swerczek et al., 2013; Yoos et al., 2007). Unfortunately, awareness of and referral to these resources was inconsistent for parents in this study and did not follow a discernible pattern.

Many parents may have benefited from an asthma clinic referral. This finding was particularly troublesome when viewed in the context of the pervasive lack of awareness of the seriousness of their children's condition at some point during participants' asthma trajectories, and the striking information needs and deficits that persisted over time and often threatened the well-being of the child. As similar gaps in accessing needed asthma education have been reported recently (e.g., Stewart et al., 2011), the present findings highlight a troublesome and persistent challenge in this area.

Application of Information Needs Hierarchy

The hierarchy of information needs provides a pragmatic and problem-based orientation to identifying information needs, enabling parent education to be motivated by the real-life challenges of facing and avoiding asthma attacks. Parents' ability to recognize the severity of asthma symptoms and identify exacerbations formed the foundation of their learning needs. Without it they were unable to respond appropriately. Over time, as their ability improved to recognize severity and manage acute exacerbations, some moved on to identify a need for information about prevention-focused aspects of care, but knowing about asthma was infrequently seen as an information need. The pervasive influence of interactions with HCPs and beliefs about the nature of asthma also are emphasized in the model.

Information categories for parental education have been identified in previous research as summarized in our initial review (Archibald & Scott, 2014), and the present model offers a preliminary understanding of how these information needs are understood by parents. The evidence in the present study for a hierarchical view of learning priorities supports a problem-based approach to learning and identifying learning needs as a fruitful approach to providing asthma education.

Future Interventions

The findings from this study will inform the development of an educational material for parents of children with asthma. Parental experiences from this current study will be used to create the context for the educational material, and specific examples of care experiences will be included. Foundational asthma education will be embedded throughout, to target the information deficits and information needs identified in this study. In this way, the educational intervention will integrate the information needs identified by parents as well as those information deficits identified by the research team as relevant to childhood asthma management.

Limitations and Recommendations

Fathers are underrepresented in this study. We wanted to capture common management scenarios with parents, and in our recruitment sites, mothers most often brought their children with asthma to appointments and emergency visits, perhaps reflecting some commonality in day-to-day management scenarios. We conducted interviews at a single point in time and only with parents who were seeking asthma care. As the majority of parents reported receiving little or no asthma education from HCPs, other forms of data collection (e.g., observation) and a broader participant base inclusive of HCPs might have enhanced our understanding of information needs and how they are assessed and addressed by HCPs. Further, because we sampled from EDs and asthma clinics, our sample may reflect parents with more pronounced information needs and information deficits than those parents successfully managing in the home environment.

This study raised questions regarding provider-patient interactions. An ethnographic study of how information needs are assessed and addressed during ED visits may be fruitful. Because education can be provided in myriad ways by any one or a combination of individuals, further understanding is needed of which HCPs are involved in asthma education and the

potential benefits of team approaches. Given that parents reported that HCPs reinforced the notion of asthma as an acute condition, understanding HCPs' knowledge and discourses related to asthma may be informative. Finally, educational approaches for parents that target their information needs and information deficits are warranted if parental self-efficacy and childhood asthma outcomes are to improve.

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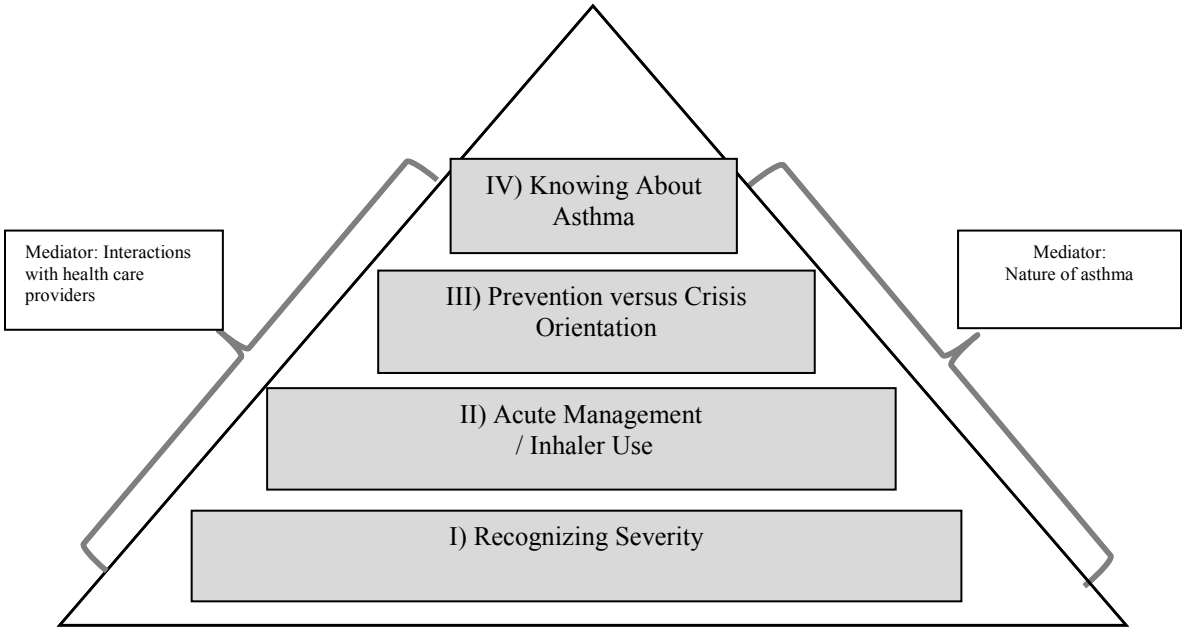
Table 3.1 Demographic Characteristics of Sample of Parents of Children with Asthma ($N = 21$)

Variable	*n*	%
Age		
20-30	6	28.6
31-40	9	42.9
>41	6	28.6
Current age of child with asthma		
< 1 year	1	4.3
1-2 years	1	4.3
>2 years	4	17.4
> 5years	7	30.4
> 10 years	10	43.5
Age of child with asthma at diagnosis		
< 1 year	7	30.4
1-2 years	4	17.4
>2years	7	30.4
>5years	3	13
>10years	2	8.7
Years since diagnosis		
<1 year	1	4.7
1-2 years	4	19
>2 years	3	14.2
>5 years	6	28.6
>10 years	7	33.3
Household Income		
$20,000 – $39,999	3	14.2
$40,000 – $59,999	6	28.6
$60,000 – $79,999	2	9.5
$80,000 – $99,999	3	14.2
$100,000 and up	7	33.3
Marital Status		
Married	14	66.7
Single	3	14.2
Divorced	2	9.5
Separated	2	9.5
Highest level of education		
Did not finish high school	2	9.5
Completed high school	4	19
Attended college or technical school	3	14.2
Graduated from college or technical school	5	23.8
Attended university	2	9.5
Graduated from university (bachelor's degree)	5	23.8

Figure 3.1 Hierarchy of Parental Information Needs



CHAPTER 4

Paper 3: Developing a Patient-Driven Arts-Based Knowledge Translation Tool: A Process Exemplar

Manuscript to be submitted: Archibald, M., Caine, V., Ali, S., Hartling L., & Scott, S. (2016). Developing a Patient-Driven Arts-Based Knowledge Translation Tool: A Process Exemplar.

Developing a Patient-Driven Arts-Based Knowledge Translation Tool: A Process Exemplar

Educating parents about the complexities of childhood asthma is foundational to effective asthma management (Boyd et al., 2010). However, parents continue to struggle with fear and uncertainty about childhood asthma care, a problem compounded by inconsistent and often ineffective provision of asthma education (Archibald, Caine, Ali, Hartling & Scott 2015; Archibald & Scott, 2014). The paradoxical existence of high quality research evidence about asthma and continued deficiencies in parental knowledge, self-efficacy and suboptimal at-home asthma management is a knowledge translation (KT) problem. As such, finding effective ways to deliver asthma education to parents is essential as asthma prevalence and childhood asthma morbidity continue to rise globally.

KT is an iterative process of synthesizing, disseminating and ethically applying knowledge to improve health, health services, and health systems globally (Canadian Institutes of Health Research, 2014). Yet, mobilizing knowledge for use by health care professionals in isolation is insufficient to affecting change in real-life settings (Kontos & Poland, 2009). KT strategies targeting the wide-range of stakeholders (e.g., parents, non-health care professionals) who mobilize knowledge in decision-making are necessary, particularly in light of the growing emphasis on patient-centeredness, shared-decision-making, and community-based health management of, for example, childhood asthma.

Arts-based approaches to KT offer viable ways of engaging diverse knowledge-users, such as parents, in a meaningful manner. Arts-based KT, defined here as the use of any art form to communicate knowledge (e.g., research from various sources) and promote empathetic understanding to affect attitudinal, knowledge or behavioural change, is gaining momentum across health disciplines concerned with mobilizing knowledge to improve health outcomes

(Archibald, Caine & Scott, 2014a; Parsons & Boydell, 2012). Arts-based approaches enable a human relationship to form with otherwise impersonal information by using artistic techniques, such as plot, characters, and specific vernacular (Barone & Eisner 2012; Leavy, 2013). The use and evaluation of arts-based KT is in its infancy; as such, few examples of how to create arts-based KT strategies exist in the literature (e.g., Hartling et al., 2010).

We address this gap by offering an account of how a multimodal, visual art and story-based KT tool for parents of children with asthma was developed, while highlighting challenges encountered during this process. Although we developed this tool for parents of children with asthma, we believe our process can serve as a guide for others conducting similar work with different populations. Through describing this process we also explore tensions related to the field of arts-based KT more generally.

Arts-Based Knowledge Translation

Different artistic representations convey various expressive qualities and as such, foreseeably impact viewers in distinct ways (Barone & Eisner, 2012). Visual representations may foster more emotive than rational responses compared with text (Lafreniere, Hurlimann, Menuz, & Godard, 2014). Music ignites the imagination and fosters the development of mental models to help make sense of the world (Perlovsky, 2013). Theatre promotes engagement and renders abstract concepts, concrete (Mason, 2008). The selection of an arts-based approach should be informed by an understanding of the form; the population, context, and location of use; the desired outcome of interest (e.g., attitude); and the degree of precision in key messages and the extent of participation enabled through each form of representation (Archibald et al., 2014a).

Indeed, considering how faithfully to represent data and how precisely to convey key messages are paramount considerations in arts-based KT. These considerations should occur in

tandem with the extent of participation enabled through the selected strategy; for instance, audience members can, through participation, shape the outcome of forum theatre. As such, what is *revealed* through theatre (e.g., the key messages) will differ somewhat between productions. Conversely, factual health information interwoven into a printed story has less variability in its delivery; the precision in its key messages and the extent of participation with the art form are more consistent. Archibald et al. (2014a) explored these mechanisms (i.e., extent of participation and precision in key message delivery) and how they influence time, context, and location of KT strategies. This exploration culminated in the creation of the Archibald Classification Schema for arts-based approaches to KT (Archibald et al., 2014a). Researchers and practitioners seeking to develop, understand, or classify arts-based KT strategies may find this schema to be a useful tool for considering factors beyond the artistic form.

The practicalities of how the selected artistic modality affects delivery of the arts-based KT strategy are also imperative to consider. For instance, ethnodrama, a theatrical-dissemination modality gaining traction in health research (Rossiter et al., 2008), requires considerably more resources to deliver than would a recorded rendition of the same theatrical performance; however, the latter requires playback equipment that may not be readily available in all settings. Vital aspects of the performance, such as audience engagement, staging, and embodiment, may be lost or abated through video-based delivery. Contrarily, visual and text-based representations are highly portable and accessible, particularly if made digitally available; however, these forms lack the interactivity made possible through particular performance modalities. Artistic form and method of delivery thereby constrain and liberate aesthetic effects through dialogical tension.

KT tools that utilize visual art alone are absent in the literature (Archibald, Scott & Hartling, 2014b; Scott et al., 2015; Fraser & al Sayah, 2011). Textual representation is a

necessary complement to visual form if some precision in information delivery, a critical aim of much KT, is to be attained (Archibald et al., 2014a). Information literacy theory supports the utility of combining textual and visual forms, thereby depicting information in emotive and rational manners (Hoover, 2012); however understandings of these approaches is limited by their complexity and by the paucity of literature on the design and effectiveness of visual art and text-based approaches to KT (Lafreniere et al., 2014).

Yet, visual and text-based representations are not homogenous. For instance, photographs, abstract paintings, cartoons, poetry and storytelling can produce myriad combinations. Stylistic rendering, aesthetic appeal, interplay between visual and text, and the extent of abstraction shape the KT strategy and foreseeably its impact on intended outcomes. The form of the arts-based approach, although relevant, should be considered in reference to its underlying mechanisms (i.e., precision in key message delivery; degree of participation) (Archibald et al., 2014a). Given these complexities, identifying arts-based KT strategies with comparable attributes and purposes is particularly challenging.

Some quality examples of visual and textual arts-based KT for non-health care provider stakeholder groups can be found in the literature. Hartling and colleagues (2010) developed paper-based storybooks for parents to communicate health information about childhood croup, in conjunction with a creative writer and an illustrator. Parents' feedback was used to revise the storybooks (Hartling et al., 2010). Parents' perceptions of the storybooks were assessed using qualitative methods and a randomized controlled trial (RCT) was conducted (Scott, Hartling, O'Leary, Archibald & Klassen, 2012; Hartling, Scott, Johnson, Bishop & Klassen, 2013). Although no change on the primary outcome of parental anxiety was identified in the RCT, parents receiving the storybook intervention experienced greater decisional regret and reported

faster resolution of croup symptoms in their children than parents in the comparison group (Hartling et al., 2013). From the qualitative data, the authors (2012) conclude that "the storybook format is a useful KT device" (p. 162) and the findings support a user-centered development process.

Lafreniere and colleagues (2014) combined visual and text-based representations. They used web-based cartoons with text to disseminate project findings from nutrigenomics/nutrigenetics research. Each cartoon illustrated a research theme and reinforced textual data. The authors report that the approach was effective in conveying findings from the larger study, highlight pertinent procedural challenges to KT intervention development, and consider the impact of these challenges on effectiveness (e.g., simplification, aesthetics). Finally, in a recent synthesis of arts-based KT strategies, Scott and colleagues (2015) located numerous multimodal visual and text-based KT strategies; reporting of the characteristics of arts-based strategies was generally lacking.

Process of Developing the Arts-Based Knowledge Translation Tool

The development of the arts-based KT tool occurred over four stages (Figure 4.1). We have detailed stages one and the interpretive description component of stage two in previous manuscripts (Archibald & Scott, 2014; Archibald et al., 2015) and therefore only briefly describe these stages here. We provide additional, previously unpublished data on parent's information preferences and how this helped inform the development of the KT tool. We then focus on stage three—the process of developing the arts-based KT tool. Stage four will involve usability testing of the arts-based KT tool and will be discussed in a forthcoming manuscript.

[Insert Figure 4.1 about here]

Stage 1: Literature Review

We conducted a state-of-the-science literature review of the information needs of parents of children with asthma (Archibald & Scott, 2014). This review illustrated a need to explicitly assess the information needs of parents of children with asthma. Based on findings from the 11 included articles, we constructed a parental information needs taxonomy. We then used this to inform the development of a semi-structured interview guide for use in the qualitative study.

Stage 2: Qualitative Study

Interpretive description of information needs. We conducted an interpretive descriptive study (Thorne, 2008) of the information needs of 21 parents of children with asthma from diverse backgrounds and stages of asthma illness in an urban centre in Western Canada (Archibald et al., 2015). Our research questions focused on parents' information needs and the general experiences of having a child with asthma. These data were foundational to developing the arts-based KT tool. For instance, parental uncertainty surrounding day-to-day asthma management enabled integration of "real-life" examples into the tool.

Through thematic analysis we identified four themes: (I) recognizing severity, (II) acute management and inhaler use, (III) prevention versus crisis orientation to asthma management, and (IV) knowing about asthma (Archibald et al., 2015). We identified interactions with health care providers (HCPs) (e.g., how education was provided) and beliefs about asthma (e.g., acute or chronic) as two factors influencing these themes. These themes formed an information needs hierarchy and influenced which information to include in the KT tool.

Topical survey of information preferences. Information about the format and perceived relevance of asthma education was essential to developing the KT tool. While we depicted findings from the interpretive descriptive study largely at the level of thematic description (e.g.,

reflecting latent patterns), here we augment these previously unpublished findings and discuss the informational preferences of parents in a more concrete manner through topical survey (Thorne, 2008). During the interviews, we inquired about the information parents received, its effectiveness, and how they would like to receive information in the future. Parents generally felt they received insufficient information about asthma. Parents had difficulty identifying their information needs and numerous information deficits were present. This limited parents' information seeking behaviours at home and during interactions with HCPs. Many parents were overwhelmed by the abundant asthma information available online, and had difficulty determining its reputability (Archibald et al., 2015).

When discussing their preferences about formats of information delivery, parents identified web-based information (44%) followed by pamphlets (33%) and face-to-face or verbal information (33%) as most desirable. Parents often had multiple preferences (e.g., discussing written educational materials with HCPs). Parents valued personalized information and reassurance provided by HCPs. Approximately 25% of participants commented that visuals, illustrations, or animation would be helpful ways of receiving information. Illustrating how an inhaler "works" on respiratory muscles or animating inhaler technique were examples of potentially useful visuals.

Emotionally sensitive information delivery was important to parents. Parents used the words "supportive," "compassionate," and "validation" to reference these emotions and at times desired more emotional support than they currently were receiving. As one parent stated "one thing I'd like . . . I don't think I got much support . . . for the emotional side of it" (participant 18). Other participants emphasized the emotionally laden nature of having a child with asthma. As one mother stated, "it's the emotional part that is the worst of it —it really is" (participant 7).

Based on this, as well as the pervasive uncertainty, fear and anxiety expressed by parents during the interviews, we were attentive to the emotional sensitivity of the KT messaging. The emphasis on the emotional aspects of having a child with asthma, the desire for reputable web-based written information with visual components and the value placed on personalized information reinforced that an arts-based approach to KT may be a useful and effective method of delivering asthma education to parents.

Stage 3: Arts-Based KT Tool Development

We combined storytelling and visual art in an online format to deliver asthma education to parents. This decision was influenced by the stage two findings and the degree of ambiguity in key-message delivery permissible in this context of illness management (Archibald et al., 2014a). For example, managing childhood asthma is a complex process involving viewing asthma as a chronic illness while responding appropriately during acute exacerbation periods. Integrating asthma into family life, identifying and monitoring symptoms, and employing preventative measures are integral to asthma management. Factual and procedural knowledge related to asthma care are needed, which requires that information be provided in a non-ambiguous manner. Yet, changes in attitudes and beliefs about the nature of asthma are also necessary and may be less responsive to non-arts based information provision. The need to attend to knowledge, beliefs and attitudes reinforces the potential merits of using a story and visual arts-based KT approach. Using the Archibald Classification Schema (Archibald et al., 2014a), we therefore categorized this strategy as a multimodal quadrant one intervention due to the presence of precise key messaging and relative passive involvement with its use.

Determining the voice and presentation format were key considerations. A first-person, diary-format was selected for the following reasons. First, participants emphasized the

importance of personalized and compassionate education during the stage two interviews. A first-person narrative promotes resonance and authenticity in the reader, and is more personalized than a third-person approach. Second, in previous research, parents expressed a preference for the first-person over the third-person narrative (Hartling et al., 2010; Scott et al., 2012). Third, the diary-format is aligned with the rise of the "reality phenomenon" prevalent in social cultures which leverages the concept of connectedness between viewers and characters (Tran & Strutton, 2014). A diary-format provides an insider's perspective into the life of another family living with asthma.

Constructing interdisplinary teams. We constructed two interdisciplinary teams to assist with developing the arts-based KT tool: (I) a review committee, and (II) a creative consulting team. The review committee consisted of five individuals with expertise in arts-based KT [M.A; L.H; S.S], visual arts [M.A], KT science [M.A; L.H; S.S], narrative methods [V.C], pediatrics [M.A, L.H, S.S, S.A], and emergency medicine [S.A]. The team provided email feedback at various time points, and provided in-person feedback on early versions of the illustrations and narrative. The in-person meeting was inspiring; there was palpable excitement regarding the KT approach and although conflicting perspectives arose, they generated important considerations about individual aesthetic preferences. In addition to the core review committee, a registered nurse at a participating pediatric asthma clinic provided clinical feedback when needed.

The creative consulting team was assembled to enable a mosaic of innovative ideas, capitalize on expertise in different styles of visual and narrative arts, and allow enough distance from the research team so that objective feedback could be provided. The first author (M.A) advertised for a creative writer and illustrator on two freelancer forums, screened applications,

and invited five visual artists to provide artistic samples based on an asthma-case scenario. One visual artist with experience in character development and diverse illustration styles was contracted. Similarly, M.A reviewed the curriculum vitae and writing samples of the creative writers; one writer was hired based on her extensive experience, enthusiasm for the topic, and perceived "fit" with the project and team. Confidentiality, work agreements, and terms-of-payment were agreed upon and signed. A digital media company was hired to digitize the KT tool for web hosting.

M.A developed an outline of significant and common events in the experience of having a child with asthma, based on the frequency or impact of their occurrence during the stage two interviews. For instance, because receiving an asthma diagnosis was a noteworthy and anxiety-provoking event for most participants, M.A noted these events for the creative writer to include. M.A included "illustration ideas" in the outline when appropriate but deliberately avoided prescriptively directing the illustrator, as this would be antithetical to the creative generation possible through such a partnership.

The outline also included an "evidence insertion opportunities" column which listed information identified as important to parents and to the successful management of childhood asthma. For instance, participants had concerns surrounding diagnosis (Table 4.1). Similarly, parents had information deficits regarding the signs of asthma exacerbation (Archibald et al., 2015). Such incidences were classified as important educational opportunities based on their relevance to asthma management and the child's well-being.

[Insert Table 4.1 about here]

The creative writer then crafted story entries to align with the outline and M.A ensured that evidence was included. The process of evidence insertion involved iteratively synthesizing

and compiling diverse research (e.g., systematic reviews, qualitative studies, reputable websites, asthma guidelines) into a readable format to correspond with the emerging story framework. M.A refined the "key items for narrative" column and the creative writer drafted story segments that M.A reviewed to ensure the events, tone, and spirit of the participants' experiences was reflected. Consulting with the review committee (i.e., paediatrician (S.A); asthma clinic nurse) assisted when specific clinical questions arose.

In addition to synthesizing information, five links to existing educational online and community resources were provided. The host organizations were contacted in August 2014, and processes for requesting permission of content were completed. Linking to resources was important because locating and assessing information reputability is challenging (Archibald et al., 2015; Harrison, 2007). Additionally, parents felt that a list of resources would be useful during the previous information needs study and qualitative evaluation of croup storybooks (Archibald et al., 2015; Hartling et al., 2010).

Although M.A and the creative writer did not pre-determine the number of story entries, we did attempt to limit these to fewer than 25 for time and usability considerations. We felt that limiting the number of story entries prematurely could restrict the creative process. By entry number 18 we could foresee a natural end to the story and began tying together extraneous details. Once complete, the review committee ensured all textual information was clinically accurate, relevant, and readable.

The story segments were then provided to the illustrator who constructed visuals through a multi-stage process. First, she drafted an illustration to align with each story entry. M.A reviewed these drafts, suggested revisions, and consulted with other members of the review committee as needed. The illustrator revised all illustrations once the composition, feeling, and

scene were agreed upon. M.A then compared all illustrations to ensure internal consistency and requested further revisions. An average of three to four revisions per illustration was required before the final output was achieved. M.A noted that examining how parents respond to different illustration styles would be a fruitful and unexplored avenue for research. As such, four distinct illustration styles were requested from the illustrator. The illustration styles differed by color and line; all other illustration components were unchanged across the prototypes (e.g., composition).

Challenges in KT Tool Development

We faced numerous challenges while developing the arts-based KT tool that may likely be encountered in future efforts. We highlight four of these considerations, including: (I) working within an inter-professional team; (II) quantity and ordering of information; (III) creating a composite narrative, and (IV) balancing the actual with the ideal.

(I) Working within an Inter-Professional Team

Collaboration has the potential to foster innovation and enable creative approaches to research problems, yet its success is greatly influenced by communication dynamics, mutual understanding, and the characteristics of individual collaborators (Archibald, 2015; Lunde, Heggen, & Strand, 2013). Challenges such as communicating across disciplines may be proportionate to the diversity of collaborating professionals. The unique inter-professional team assembled in this study consisted of a nurse academic, a creative writer, an illustrator, and a digital media company.

An unanticipated challenge we encountered was the perceived appropriateness of feedback. Researchers may be accustomed to a high volume of feedback because of the culture surrounding grantsmanship, co-authorship, and peer-review. Artists may be less accustomed to this type of exchange. During our process, a collaborating artist expressed that her creative

process was hampered by the detailed feedback received. Communicative openness and a willingness to receive feedback were imperative to overcome this challenge. M.A also restricted feedback to those of a substantive nature and made editorial adjustments independently. These challenges were not encountered between the researchers and the digital media company.

(II) Quantity and Ordering of Information

Information sequencing was an ongoing challenge. At times a concept (e.g., asthma action plan) was introduced in one diary entry but was not explained until later. Explaining each concept as it was introduced was not always feasible, particularly for recurring concepts (e.g., triggers) because other concepts (e.g., emergency asthma kits) were only present in one story segment and therefore took precedence. The challenge of information ordering raised potential issues for parents navigating the KT tool; the table of contents created did not align seamlessly with the information provided. Information was matched to the diary-entries wherever possible.

Balancing information comprehensiveness with length was an ongoing consideration. Hartling and colleagues (2010) encountered similar struggles; parents generally desired abundant information about croup but some found the storybooks to be too lengthy. This challenge extends beyond the technical into the realm of aesthetics, highlighting a fundamental tension of using arts-based approaches for KT. Specifically, any extraneous inclusion detracts from the concision of the artistic rendering, reduces its aesthetic appeal, and foreseeably hinders its effectiveness (Barone & Eisner, 2012; Leavy, 2013). We mitigated this by limiting each diary-entry to approximately 90 words (a common length for a short paragraph), providing information in point-form when possible, externally linking to supplemental content, and eliminating content not immediately reflective of asthma priorities, parents' information needs, and information deficits as identified in our previous research.

(III) Creating a Composite Narrative

Amalgamating the experiences of multiple participants into a single story (e.g., composite narrative) while maintaining resonance, appeal, and authenticity for the reader was one of the most profound challenges encountered. In previous work, participants' ability to relate to characters was a recurring theme (Hartling et al., 2010; Scott et al., 2012). We contend that this challenge of verisimilitude (Leavy, 2013) is not unique to arts-based representations but reflects the crisis of representation more generally; there is a longstanding tension between representing individual cases alongside a shared reality. The tension between general knowledge and shared experience and between the individual experience and experience *applied* to the individual has also been illuminated by others exploring research methods (e.g., Denzin, 2014; Thorne, 2008).

We recognized that we could not resolve this tension, yet we strived to create a narrative that reflected some aspect of the majority of parent's experiences. To assist with this, we examined our data for negative cases / outliers. We determined that narrative examples from these cases were less likely to resonate with the majority of parents and as such, were less likely to be reflected in the composite. To honor individual narratives, we selected real-life examples from the lives of our participants and used their own words to convey these experiences. This reflects Denzin's (2012) perspective that "our texts must always return to and reflect the words persons speak as they attempt to give meaning and shape the lives they lead" (p. 5).

Aligning terminology. Terminology considerations were ongoing when developing the composite narrative. We strived for relatability and aimed to use parents' words whenever possible; however, parents used various terms to refer to health related concepts. For instance, parents referred to the emergency department as the emergency, emergency room/ department/ clinic/ facility/ ward and "ER," with "emergency" being the most common term. The reviewing

paediatrician (S.A) preferred the term "emergency department"; as such, we had to balance parents' terminology with that of practitioners who may be endorsing the tool. Ultimately, we decided to use the term "emergency department" given the diverse terms used by parents.

Parents also used different terms to describe HCPs. The vast majority (86%) referred generically to "doctor" multiple times during an interview. Nurses were referred to less frequently (38%). No parent mentioned nurse practitioners or health care *professionals*. Emergency professional and HCPs were referenced by 5% of participants. We were alerted to the merits of specificity and consistency in terminology when the same parent would use multiple terms to describe the same concept.

We grappled with using specific, consistent terminology that is valued in research or the diverse and often, nonspecific terms used by parents. Unfamiliar terms may lack appeal and alienate parents from diverse backgrounds. Specificity may be undesirable when parents possess low baseline knowledge about asthma. For example, parents generically referred to "pulmonary tests." The reviewing paediatrician (S.A) questioned how specific terminology should be when providing information about this content area: "*there are pulmonary function tests . . . there are peak flow tests . . . do you want to label it more specifically, or are you being purposefully vague?"* M.A referred back to the participant interviews to address this question and found that 29% of participants referred to "pulmonary tests" in any capacity. Participants most often referred to "a test," or, a "breathing" or "capacity" test. Only 10% of participants referred to a pulmonary function test and never to peak flow. Given this, the decision was made to use general terminology.

The issue of voice extended beyond using parents' terminology in the diary entries. We questioned whether to present evidence as personal (e.g., "your child may . . .") or impersonal

(e.g., "common symptoms include . . ."). This was a challenge of evocation; that is, ensuring the work can reach the reader to arouse feeling, and therefore meaning (Barone & Eisner, 2012). A personal presentation of evidence was generally adopted for this reason.

(IV) Balancing the Actual with the Ideal

We grappled with authentically portraying parents' experiences of care when they did not reflect ideal medical practices. For instance, some parents reported that HCPs reinforced the notion of growing out of asthma (Archibald et al., 2015). This reinforced beliefs about asthma as an acute condition and undermined the importance of prevention. To address this, characters in the KT tool discussed their hopes about growing out of asthma but chronicity was reinforced.

As another example, mothers represented 95% of parents presenting for asthma related care in this sample. We reflected this in the storyline but not without hesitancy. We recognized that our sample might not represent the wider population of parents of children with asthma. Further, one parent found the overrepresentation of mothers in the croup storybooks to be an inaccurate depiction of real-life management scenarios (Hartling et al., 2010). We decided to portray a mother as the primary character in our story and included the father in the text and illustrations.

Balancing the ideal and the actual also related to the emotions of parents. Parents in stage two commonly experienced panic, anxiety, fear, and uncertainty. We needed to convey these experiences to enhance relatability but did not want to reinforce that parents should panic during asthma exacerbations. We were cognizant that doing so may contradict messages conveyed in the KT tool. This tension was captured in the comments of one expert reviewer: "*ran suggests urgency and panic . . . I would like to relay some comfort and decrease the panic . . . if the point is to mirror what a 'real parent' might feel at home, then the word is exactly right*!" Recognizing

that different terminology serves different purposes, we felt compelled to stay true to the data in our narrative; parents in the qualitative study expressed urgency and we mirrored this through our selected terminology.

Conclusions

There is a need to learn about the processes and potential challenges associated with developing patient-driven arts-based KT tools, particularly as these strategies continue to emerge. Gaining familiarity with the stakeholder group (e.g., through qualitative research) is necessary to identify the need for, and appropriateness of, an arts-based strategy. Foundational research can help identify which knowledge sources the target audience uses; preferences held about information delivery, and pervasive information and emotional needs. Fluency with the artistic form(s) and information literacy within the creative team are required to construct a meaningful and aesthetic artistic output with merit as a KT strategy. Establishing a review committee of individuals with clinical, content and methodological expertise is recommended to ensure accuracy and relevancy of the KT approach. We believe that collaboration within a diverse inter-professional team, considerations related to the quantity and ordering of information, representation issues encountered through creating a composite narrative, and harmonizing actual and ideal management scenarios reflects common challenges when developing patient-driven arts-based KT tools. Suggestions for linking evidence into action are provided in Figure 4.2. Highlighting these considerations may help prepare investigators seeking to conduct comparable work.

[Insert Figure 4.2 about here]

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Table 4.1. Example of Asthma Diary Outline

Page #	Key Items for Narrative	Evidence Insertion Opportunities	Illustration Ideas
2	• Child showing asthma symptoms • Mother reflects on child's frequent illness, including Emergency Department (ED) visits • Visits ED for respiratory illness • Multiple diagnostic procedures; experiences uncertainty • Receives asthma diagnosis	Asthma symptoms Incidence of viral infections Process of asthma diagnosis	Child in respiratory distress Child visiting ED with mother

Figure 4.1 Four-Stage Process of Developing an Arts-Based KT Tool

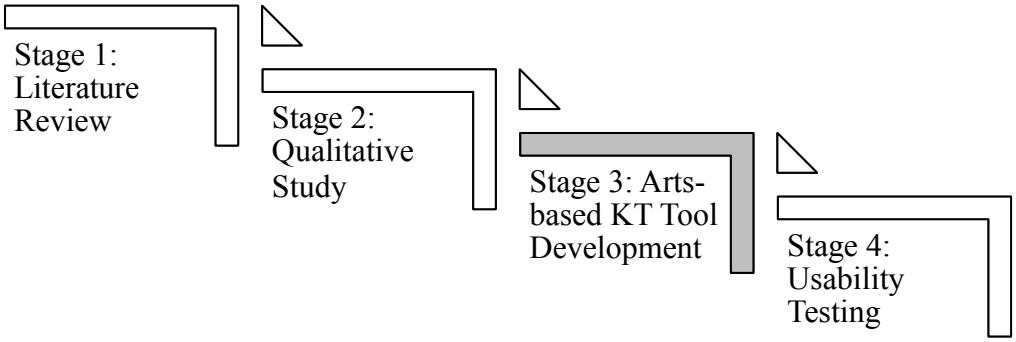

Figure 4.2 Box – Linking Evidence to Action

- Developing arts-based KT strategies that reflect participants' experiences is a costly, labour intensive, and challenging process. Tensions related to representation, voice, and interplays of and between artistic and non-artistic forms must be addressed to facilitate understanding and appropriate development of these tools.
- Integrating diverse information sources and stakeholder experiences may enhance the meaningfulness and effectiveness of arts-based KT approaches. Strategies should be developed to reflect understandings of the needs of, and knowledge sources used by, specific stakeholder groups.
- Inter-professional collaboration across the arts and health-science sectors can facilitate development of evidence-informed, arts-based KT tools with aesthetic appeal. Researchers considering the utility of arts-based strategies should reflect upon the diverse skills and expertise required to render such an undertaking successful.
- There is a paucity of literature on developing and evaluating patient-driven, visual and text-based KT strategies. Further research is needed to understand how various stakeholder groups perceive the attributes of arts-based KT strategies across diverse contexts, and which attributes influence effectiveness.

CHAPTER 5

Paper 4: The Development of a Classification Schema for Arts-Based Approaches to Knowledge Translation

Archibald, M., Caine, V., & Scott, S. D. (2014). The development of a classification schema for arts-based approaches to knowledge translation. *Worldviews on Evidence Based Nursing*. *11*, 316-324. doi:10.1111/wvn.12053

The Development of a Classification Schema for Arts-Based Approaches to Knowledge Translation

The emergence of the Evidence Based Medicine Working Group in the 1990s contributed to the formation of an evidence culture within health care settings (Guyatt, Drummond, Meade, & Cooke, 2008; Sackett, Rosenberg, Gray, Haynes, & Richardson, 1996). Since this time, extensive effort has been exerted to develop strategies, often termed interventions, to facilitate the use of knowledge, evidence or research to guide the professional practices of health care practitioners. Such knowledge translation (KT) interventions (e.g., educational meetings, audit and feedback, and clinical practice guidelines) have inconsistently affected change as desired (Wensing, Bosch, & Grol, 2009). Recognizing the significant challenges in translating evidence into health practices globally (World Health Organization, 2010), it is important to develop KT interventions that are robust, and call forth innovative methodological approaches that speak to a wide variety of professional perspectives.

Arts-based KT is an emerging field. Arts-based KT approaches are increasingly being investigated as viable and effective strategies to reduce the knowledge-to-action gap (Archibald, Scott & Hartling, 2014; Scott, Brett-MacLean, Archibald & Hartling, 2013). As with KT generally, the primary objective of arts-based KT is the "dissemination and communication of knowledge" (Parsons & Boydell, 2012, p.170). However, arts-based strategies, specifically those employing literary, visual, and performing arts, offer opportunities for participant engagement and embodiment beyond those available with traditional approaches (Lafreniere & Cox, 2012). Arts-based KT relies on some similar (e.g., communication), and some distinct (e.g., embodiment), processes compared to their non arts-based counterparts. Anchored on these processes and by their inherently constructivist leanings, arts-based approaches have potential to

expand the at times narrow views of evidence that permeate the political discourse dominant within the evidence-based practice (EBP) movement (Denzin, 2009). However, as arts-based approaches to KT are neophyte in status, little has been done to explicate the mechanisms by which these approaches function; create common language for classifying arts-based KT approaches, or to develop criteria for assessing arts-based approaches (Lafreneire & Cox, 2012). Furthermore, because of their emergence as KT approaches, how context, time and location influence arts-based strategies in health disciplines, such as nursing, has not yet been theorized or studied.

A key feature of this paper is the creation of a classification schema for arts-based KT approaches, based on two core attributes. These attributes of (a) precision in key message delivery and (b) degree of end-user participation with the KT strategy are integral to theorizing how context, time, and location shape the use of such approaches. As the first of its kind, this classification schema will enable comparisons of arts-based KT interventions in syntheses studies designed to assess the effectiveness and utility of utilization strategies. It extends existing approaches to classification which have been limited to art form alone (e.g., drawing) or a process versus product orientation (Boydell et al., 2012). It is not our intention to over simplify the inherent complexity of arts-based approaches. Rather, we encourage that key attributes and mechanisms of arts-based approaches be considered to enable the guidance and assessment of arts-based approaches across diverse settings. This classification schema will be increasingly needed as arts-based approaches to KT proliferate in diverse inter-professional settings and across cultural and geographic contexts.

Defining Knowledge Translation

Similar terms are used to describe processes of translation and utilization of evidence (e.g., knowledge utilization, dissemination, research utilization). These vary by use geographically and by discipline (Estabrooks, Scott-Finlay, & Winther, 2004), and carry implicit assumptions about the nature of knowledge (Graham et al., 2006). Notions of knowledge as research evidence are commonly implied, and often favor objectivity, rationality, and linear decision-making. While many have favored explicit knowledge in discussions of KT, this has been problematized more readily by those in non-medical disciplines such as sociology and philosophy (Greenhalgh & Wieringa, 2011). Others still have questioned the appropriateness of "translation" metaphor altogether (e.g., Davies, Nutley & Walter, 2008).

Limited views of knowledge not only constraint what "counts" as knowledge, but undermine the utility of forms which leverage other ways of knowing (i.e., arts based strategies) (Archibald, 2012). A broader view of knowledge includes personal practical knowledge and experience, as well as knowledge gained through research and professional domains. Declaring what is meant by KT is essential to promoting clarity and to delineating the boundaries of what qualifies as knowledge in translational processes, a step too often missed in discussions related to dissemination (Estabrooks, Thompson, Lovely, & Hofmeyer, 2006). Here, we refer to KT as the "dynamic and iterative process that includes synthesis, dissemination, exchange, and ethically-sound application of knowledge" (Canadian Institutes of Health Research, 2013). However, like others (e.g., Graham et al., 2006; Greenhalgh & Wieringa, 2011), we include other forms of knowledge, such as experiential, procedural, and personal knowledge in our conception and view translation as a non-linear and co-creative or transformative process (Davies et al., 2008). These

inclusions align with the underlying mechanisms of arts-based KT strategies and their constructivist natures.

Schematic Classification of Arts-Based Knowledge Translation Strategies

Arts-based KT comprises a broad range of forms (e.g., literary, dance), mechanisms of delivery (e.g., passive viewing, active participation), and identified outcomes (e.g., knowledge gain, promoting dialogue). As with traditional interventions, arts-based strategies cannot be treated as homogenous (Improved Clinical Effectiveness through Behavioural Research Group, 2006). Frequently, arts-based approaches are classified by form (e.g., drawing, dance); however, this alone is insufficient. Rather, arts-based strategies may be better classified by how they interact with the local context—specifically, the degree of precision in key message delivery and the degree of end-user engagement required (e.g., passive, active) in their use.

Ambiguity and the individual nature of interpretation are fundamental components of engagement with the arts. Contrarily, standardization and precision of key messages underlie many traditional KT strategies (Guyatt et al., 2008). Consequently, there is an innate tension between the goals and mechanisms of art and the intent of many traditional KT strategies. For instance, the predominant mechanism of art entails its capacity to elicit cognitive and emotive abstractions entrenched with meaning for the individual (Rand, 1971). Ambiguity and uncertainty are part-in-parcel with art and the artistic process (Boydell et al., 2012; Eisner, 1997). As such, a central attribute of arts-based KT is that interpretation exists on a continuum, ranging from precise to ambiguous key message delivery. Within this interpretation-continuum, attributes of the intervention and context interact to create ambiguity and uncertainty, creating space for dialogue and change in the end-user. Tensions emerging from the arts and KT intersect differ depending on the context of their implementation. Theorizing how context, time, and location

shape the appropriateness, uptake, and effectiveness of arts-based KT strategies is foundational to their development.

The degree of end-user participation with the KT strategy can also be viewed on a continuum. The usefulness of this continuum to classifying arts-based KT strategies is illustrated by considering the differences between audience participation in a research-based theatre (active engagement) versus viewing the same production (a more passive endeavour). The active-passive continuum has been used to classify art in general (Dileo & Bradt, 2009). Active and passive participation has been alluded to through process (e.g., participant involvement) and product (dissemination) references (Boydell et al., 2012). However, a more nuanced classification is needed to theorize contextual influences and facilitate comparisons of interventions across studies.

The degree of participation with an arts-based strategy can obscure the notion of audience. In this work, we conceptualize audience as any group for whom arts-based strategies are intended to affect a particular outcome (e.g., attitude change). As such, the "audience" of passive arts-based strategies favors dissemination (e.g., families reading a storybook about diabetes). In contrast, the audience of highly participatory arts-based strategies often involves the audience in the co-creation of the artwork, which shifts the passive notion of "end-user" (e.g., persons with dementia participating in a co-creative theatre production).

To conceptualize the relationships between the precision-ambiguity continuum and the passive-active continuum, Archibald developed a classification schema of their relationship (Figure 5.1). The precision-ambiguity continuum is represented on the vertical axis. The passive-active continuum is represented on the horizontal axis. The result of this intersect is a

representation of four quadrants of arts-based KT strategies, necessary to theorize how context, time and location influence such strategies.

[Insert Figure 5.1 about here]

Arts-based KT strategies in quadrant one convey precise messages but end-user involvement is passive in nature. An example of a quadrant one strategy is graphic storyboards with explicit key messages. Arts-based KT strategies in quadrant two convey precise messages but through active participant involvement. A quadrant two example includes participatory theatre with key message summaries. Quadrant three strategies have ambiguous key messages that are not explicitly conveyed. Their purpose may be to foster critical dialogue or elicit an embodied experience to provoke questioning of assumptions, such as through research-based dance productions. Like quadrant three, quadrant four is characterized by ambiguous key messages but participation is passive in nature. Viewing a research based abstract art installation is an example of a quadrant four strategy.

These categories are not absolute. For instance, quadrant one strategies may incorporate elements of participation, such as components of role-play during a health theatre production. Such a strategy would trend towards the participation axis, but would lack the embodiment that full participation would enable (quadrant two). Yet, in recognizing the complexity and diversity of arts-based strategies, the quadrants facilitate theorizing of how each broad category may interact with contexts of their delivery, and in some cases, their creation.

How Context, Time and Location Shape Arts-Based Knowledge Translation Strategies

Existing research syntheses of arts-based approaches tell us little about the influences of context, time and location on arts-based KT strategies (e.g., Boydell et al., 2012; Fraser & al Sayah, 2011). This may be attributed, in part, to insufficient reporting of these components in

primary research studies. Other contributing factors include a lack of attention to these details when extracting data from primary research studies and deficient reporting in synthesis efforts.

For example, Boydell and colleagues (2012) conducted a scoping review of arts-based health research and included arts-based KT and dissemination studies. Although a useful contribution, the authors do not describe the context, time, or location of the primary studies using arts-based KT strategies. They provide scant information about audience, and although this is a central component of dissemination activities, it is alone insufficient (Canadian Institutes of Health Research, 2013). Similarly, in their systematic review of arts-based methods in health research, Fraser and al Sayah (2011) identified seven studies that used arts-based dissemination approaches, but did not attend to issues of context, time or location. Notably, Fraser and al Sayah (2011) include a section on context in their findings; however, only audience and disciplines were mentioned in this section (p. 138).

Interestingly, neither Boydell and colleagues (2012) or Fraser and al Sayah (2011) identified a need to better understanding how context, time, or location shape arts-based KT strategies—core elements of non-arts-based KT. Instead, the authors identified a need to attend to ethics and evaluation in arts-based research, which we suggest is intimately related to contextual influences. Both reviews focused extensively on the artistic form used in producing or disseminating knowledge. An over emphasis on artistic form at the neglect of participant engagement (i.e., passive or active) and interpretive ambiguity (i.e., precise or ambiguous) may hinder understandings of how context, time and location shape arts-based KT strategies. Notably, similar issues are encountered with "traditional' KT interventions," evidenced by such statements as "passive educational interventions, such as written guidelines, lectures, and conferences, are unlikely to change behaviour" (Wensing et al., 2009, p. 95). The form of

guideline, lecture, or conference is suggested to be less important than the degree of participation with such an intervention. Similarly, classifying arts-based KT strategies by form alone risks that approaches within a particular genre will be "grouped together" or synonymised without acknowledging important differences.

The Influence of Context on Arts-Based KT

The context in which KT strategies are employed is profoundly influential, yet the mechanisms by which context exerts its influence has historically received little attention (Dopson & Fitzgerald, 2009; McCormack et al., 2002). Recent advancements have been made to explicate the interrelationships between aspects of context; however, the very concept of context varies extensively (Dopson & Fitzgerald, 2009; Kitson, Harvey, & McCormack, 1998). As such, how context is conceptualized changes perceptions of its influence.

From a health care professional oriented perspective, culture, leadership, and measurement are three elements characteristic of the complexity of context (Kitson et al., 1998). Culture is something that an "organization is" (p. 97) rather than something that it possesses (McCormack et al., 2002). Scott-Findlay and Golden-Biddle (2005) differentiate between culture as organization and organizational culture as a variable influencing organizational effectiveness. Leadership relates to a leader's "transformational capacity, role clarity, teamwork, democratic decision-making and empowering approach to teaching, learning, and management" (McCormack et al., 2002, p. 99). Measurement, or evaluation, refers to feedback on performance using multiple methods and information sources. Importantly, the three components of context (culture, leadership, and measurement) identified by Kitson and colleagues (1998) and extended by McCormack and colleagues (2002), are conceptualized within an institutionalized framework consistent with the historical focus of traditional KT efforts (Kothari & Armstrong, 2011). As

such, scant research or dialogue exists on the influence of these elements on KT in non-institutionalized settings or of an arts-based nature. The potential influences of select meso (e.g., hospital organization) and micro levels (e.g., clinical settings) on arts-based KT strategies warrant investigation.

Organizational features such as formalization, interconnectedness, size and centralization (Rogers, 1995) influence innovativeness and plausibly the use and effectiveness of arts-based KT strategies. Care unit complexity and volume of clinical work relate to these elements (Dopson & Fitzgerald, 2009). From a structural perspective, how particular units are organized to attend to complexities of care, the resulting hierarchies and communication patterns, and staff compositions may significantly influence the use and effectiveness of arts-based KT.

For instance, hierarchies and communication patterns reflect existing power relations which exert stifling or empowering effects on individuals wishing to use "novel" strategies (Dopson & Fitzgerald, 2009). Alternatively, there may be utility for arts-based approaches in contexts with rigid hierarchical structures or suboptimal communication patterns, as these entrenched behaviors and social structures may be difficult to recognize and illuminate using non-emotive KT strategies. Extrapolating from literature on organizational barriers to change, institutionalized settings characterized by highly routinized behaviors and rigid hierarchal structures and communication patterns may be less open to arts-based KT interventions that disrupt these practices, such as the participatory strategies located in quadrants two or three (Figure 5.1) (Straus, Tetroe & Graham, 2009). Social structures assumed by professional groups, specifically hierarchal nursing structures and autonomous physician practices, and work structures, specifically continuous nursing care versus episodic physician care, are contextual factors influencing the use of research in particular (Thompson, Estabrooks, Scott-Finlay,

Moore, & Wallin, 2007). Such features may also shape the use and effectiveness of arts-based KT strategies.

Beyond organizational features of context, individual barriers to behavior change, disciplinary variations related to KT strategies and characteristics of intended end-users may shape arts-based KT. Individual barriers to behavior change and individual determinants of KT have been studied extensively from a clinician-oriented perspective (Estabrooks et al., 2004; Straus et al., 2009). Knowledge, attitudes, and skills of clinicians are commonly identified determinants that could influence the use and effectiveness of arts-based KT strategies.

Attitudes towards arts-based KT are influenced by the EBP movement that emerged in the 1990s (Guyatt et al., 2008). EBP critics often concede that evidence is narrowly conceived of as research and that other forms of evidence and knowledge, such as those derived from qualitative inquiry, are devalued (Holmes, Perron, & O'Byrne, 2006; Wall, 2008). As such, the EBP movement influences the attitudes of health care professionals and the general public towards evidence and research. Such influences foreseeably inhibit or enhance the perceived acceptability of arts-based strategies.

For instance, EBP proponents focusing predominantly on research utilization may be less likely to use, or accept, ambiguous arts-based KT strategies (e.g., quadrants three or four strategies closest to the *y* axis). This is because precise delivery of research evidence is difficult to accomplish through such approaches. However, they may regard arts-based strategies with precise messaging (e.g., quadrants one or two closest to the y axis) more favorably. Alternatively, health care professionals who interpret the EBP movement as unnecessarily constraining, offering a limiting view of evidence, may regard arts-based KT strategies positively and be motivated to employ them in practice. Indeed, "arts-based dissemination strategies are

driving an important shift in our understanding of what counts as evidence" (Boydell et al., 2012 p.2). Such a statement suggests positive regard for arts-based KT strategies in relation to broader issues, such as dominant views of evidence that shape health research and evaluation behaviors.

The selection and effectiveness of KT strategies differs by profession (Scott et al., 2012; Thompson et al., 2007). Outcome selection differs by discipline, with particular professions (e.g., occupational therapy) favoring process variables to determine intervention effectiveness (Scott et al., 2012). As such, there is a strong basis to infer that the extent of interdisciplinary team involvement (a component of context) will shape the use and evaluation of arts-based KT strategies.

Historically, the majority of KT interventions have targeted health care professionals in institutions (Wensing et al., 2009); however, arts-based KT may be useful for non-clinician groups in non-institutional settings. For instance, participatory community-based research and integrated KT may be well suited for non-institutions. The Canadian Institutes of Health Research (2013) defines integrated KT as those dissemination activities involving end-users throughout the entire process. The context of certain non-institutionalized settings, such as community-based support groups, may enable participatory strategies, such as those in quadrants two and three (Figure 5.1). This may be related to organizational features, such as decentralized decision-making or reduced role formalization (Rogers, 1995). Furthermore, the degree of interpretative ambiguity deemed acceptable is intimately linked with characteristics of the end-user group. As non-institutionalized settings are more likely to target non-clinician groups, the intended outcome of arts-based strategies will likely differ.

For instance, consider that community members desire to challenge stigma surrounding mental illness. This may be achieved through challenging community assumptions or "opening

up space for dialogue," best accomplished through arts-based KT strategies (Boydell et al., 2012). "Space for dialogue" can be leveraged through participatory approaches that foster ambiguous interpretations (e.g., quadrant three strategies with no key message summaries). In contrast, ambiguity in interpretation is likely less acceptable in institutionalized settings where precise key messaging is required (e.g., targeting prescribing behaviors). Selection of quadrant and arts-based KT attributes need to be outcome dependent.

The Influence of Time on Arts-Based KT

Time is integral to the diffusion process and is an acknowledged barrier to the knowledge and research utilization behaviors of health care professionals (Legare, 2009; Rogers, 1995). As a concept however, time is rarely described in the KT literature (Nilsson Kajermo et al., 2010). Clarifying what is meant by time, and differentiating between physical and perceived time has been suggested, as these differ and influence research utilization behaviors in distinct ways (Estabrooks et al., 2008; Nilsson Kajermo et al., 2010). Relatedly, time pressure and organizational slack significantly influence research utilization behaviors and likely, arts-based KT strategies (Legare, 2009; Thompson et al., 2008). Time pressure is a perceived lack of time to complete tasks. Organizational slack relates to "uncommitted resources available to an organization" (p. 412) and is a component of organizational innovativeness (Rogers, 1995). As such, time is viewed as a resource in this discussion.

Time is a dominant factor influencing nurse's research use (Thompson, et al., 2008). Time has consistently been identified as a barrier to nurse's research utilization behaviors in studies conducted over various time periods and regardless of geographic location (Nilsson Kajermo et al., 2010). Although the influence of time on arts-based KT strategies has not yet

been explored, evidence of its profound bearing on the research utilization behaviors of professional groups provides insight into its potential power.

For example, highly collaborative arts-based dissemination strategies (i.e., quadrants three or four) may require more time and engagement than non-collaborative approaches. As such, one might postulate a directional relationship between perceived slack time, time pressure, and uptake of arts-based strategies. For instance, institutional settings with high time pressure and low organizational slack may favor less participatory and prescriptive arts-based interventions (i.e., quadrant one) over ambiguous, participatory strategies (i.e., quadrant three). Time of day, intensity and duration of delivery are important factors influencing KT interventions as seen in the WIDER recommendations for reporting of behavior change interventions (Michie, Fixsen, Grimshaw, Eccles, 2009; Albrecht, Archibald, Arseneau & Scott, 2013); however, as little is known of their direct influence, exploring how time can constrain the form and delivery of arts-based dissemination strategies warrants investigation.

Final time related considerations pertain to evaluation, sustainability, and reporting of arts-based KT strategies. Indeed, *how* to evaluate these approaches and using which criteria are perennial issues in the field of arts-based research more generally (Barone & Eisner, 2012; Leavy, 2009). The time points at which to evaluate and "scale up" traditional KT interventions require further investigation (Davies & Edwards, 2009, p. 168), additional research is needed to determine the appropriate time points to deliver, evaluate, and "scale up" arts-based KT strategies to maximize their effectiveness with various end-users in diverse settings. Regarding KT intervention reporting, the relevance of time is implied within the WIDER recommendations (Michie et al., 2009). Here it is recognized that time related concepts of intensity and duration

influence KT intervention integrity. Similarly, reporting intensity and duration of arts-based interventions is necessary to promote understanding of their influence.

The Influence of Location on Arts-Based KT

Location impacts KT intervention adoption and effectiveness (e.g., Michie et al., 2009). Hospitals commonly are complex institutions characterized by centralized decision-making structures that can impede innovation. Specific hospital units or departments vary extensively, demonstrating the power of context. Generally, arts-based KT strategies of a passive and precise nature (quadrant one) are most likely to align with values of EBP that permeate 21st century medical ideals. As many traditional KT strategies have inconsistently achieved intended results pertaining to professional behavior change (Straus et al., 2009), this may negatively influence the development, use and acceptance of arts-based KT strategies in hospital settings.

Community-based KT refers to those strategies occurring outside of the hospital context. Comparatively, community-based KT has received little attention and more work is needed to determine if processes related to institutional KT are applicable to non-institutionalized settings (Kothari & Armstrong, 2011). Non-hospital and community-based facilities are more common locations for arts-based KT implementation (e.g., Boydell et al., 2012; Fraser & al Sayah, 2011). However, the influence of location on the development, implementation, or effectiveness of arts-based strategies is impossible to determine due to deficient reporting of these details in primary research and syntheses studies. In studies where arts-based KT strategies were used and evaluated in diverse settings, such as inpatient units or universities, data were not analyzed independently (e.g., Colantonio et al., 2008). As such, existing research does not enhance understanding of how location shapes arts-based KT. As with non-arts-based KT, locations with high patient acuity as encountered in intensive and acute care units may frequently possess

centralized decision-making, routinized behavior practices, and frequent change, all of which can hinder receptiveness to innovations (Rogers, 1995).

Context and location should be considered active ingredients that influence arts-based KT. We agree that "any useful interpretation . . . must be responsible to . . . interplay between the empirical elements within the composition . . . as well as the context in which it is displayed" (Barone & Eisner, 2012 p.113). Assumptions and experiences of individuals, previous organizational and institutional practices, and broader contextual influences shape the interpretation and ultimate acceptance of arts-based KT strategies. As such, discussions of arts-based KT should occur in tandem with the context, time, and location in which they are developed and implemented.

Effectiveness and Future Considerations

The notion of effectiveness can be particularly problematic as it relates to arts-based strategies. The degree of expertise required when using arts in research and which criteria, if any, should be used to evaluate arts-based strategies is a contested issue in the field of arts-based research (Lafreniere & Cox, 2012). As with arts-based research, the integrity and soundness of the artistic aspects of KT strategies exert a foreseeable impact on the potential of given strategies to affect change as desired. It is therefore prudent to consider the quality of the arts-based approach when considering the effectiveness of the strategy.

Effectiveness cannot be regarded in isolation of context, socio-cultural factors, mechanisms (e.g., passive, precise, etc.), or end-user characteristics. Exploring the interplay between these elements can provide insight into if and how complex strategies (i.e., arts based KT) affect change (or not) or call forth the intended outcomes (Clark, MacIntyre & Cruickshank, 2007). This interplay may be particularly relevant to strategies with pronounced co-creative

components, such as participatory approaches. Assessing the processual nature of arts-based strategies is an integral aspect of their evaluation (Pawson, 2012) and may foster understanding of processes and outcomes unique to arts-based strategies (e.g., empathetic understanding).

[Insert Figure 5.2 about here]

Conclusions

Arts-based KT is rapidly gaining momentum across disciplines and in diverse settings. With this growing popularity, there is a need to understand which arts-based KT strategies are effective for whom and in which settings if these strategies are to affect changes in behavior, knowledge and attitude as desired. However, current approaches to classifying arts-based KT strategies are insufficient, which hinders comparisons across interventions and evaluations of effectiveness. Classifying arts-based KT strategies by the degree (a) of precision in key message delivery and (b) active or passive participation may foster more robust comparisons and understandings, a necessary foundational step for this emerging field. Extrapolating from the broader literature base on KT, arts-based research, and arts-based KT, we identify core underlying mechanisms of arts-based KT, which the first author (M. Archibald) classifies into four quadrants using a visual schematic. This classification system may be useful for categorizing arts-based strategies, ranging from those focused on dissemination to those incorporating more co-creative processes; facilitating comparison across studies in relation to contextual, time and location related influences; furthering emerging discussions pertaining to assessing arts-based dissemination and co-creative strategies; and contributing to a common language needed to advance these methods (Lafreneire & Cox, 2012). Existing evidence syntheses on arts-based KT insufficiently report and explore how context, time, and location shape such approaches. However, as context, time, and location shape traditional KT approaches,

these influences warrant equal attention in the context of arts-based KT. Further research and reporting is needed in this area.

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Figure 5.1 Classification Schema of Arts-Based Knowledge Translation Strategies

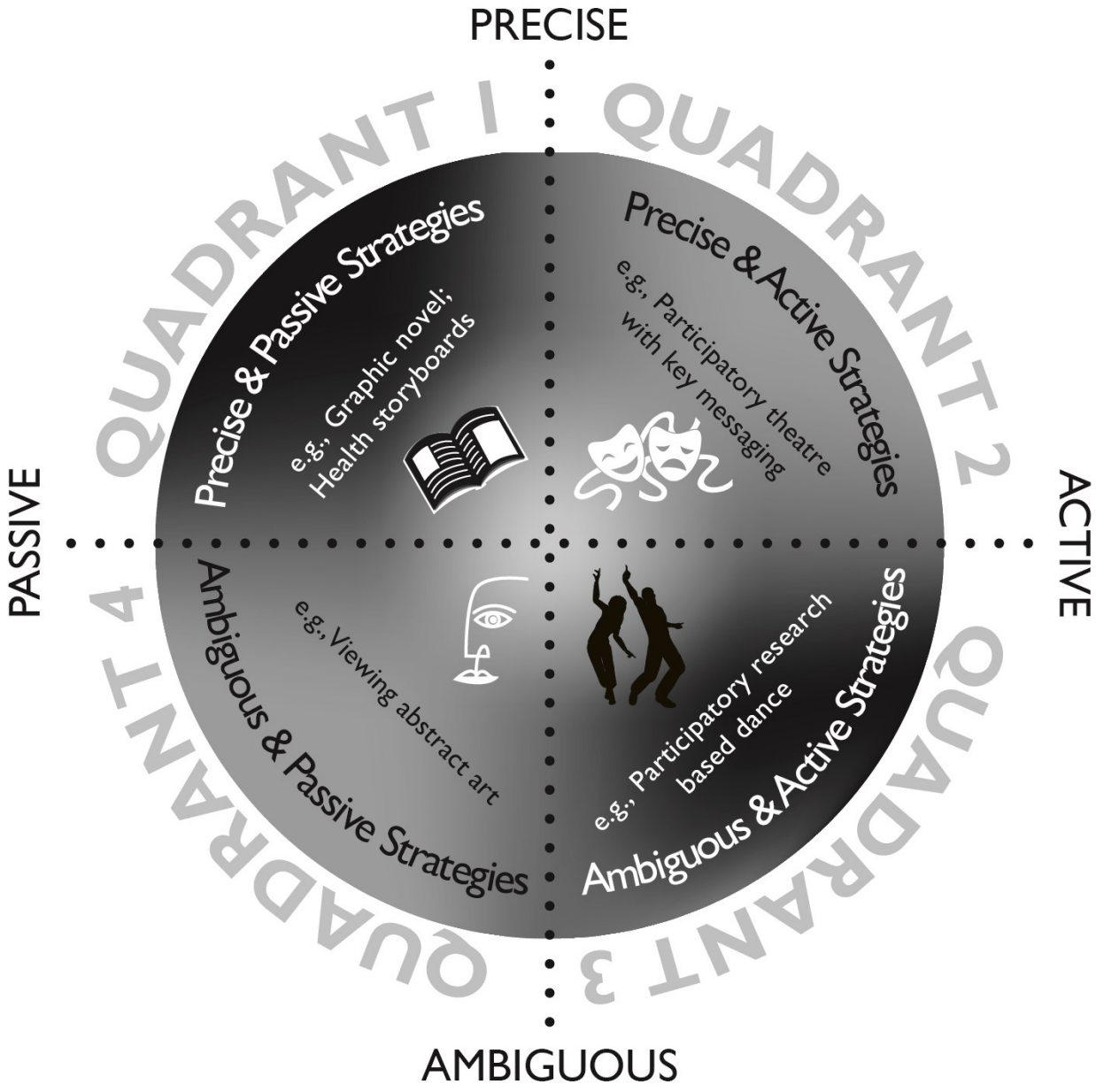

Figure 5.2. Box- Linking Evidence to Action

- Arts-based approaches to KT have potential to expand what counts as evidence, a discourse that permeates KT and EBP. Design and evaluation of arts-based approaches to KT should therefore consider the range of knowledge and evidence leveraged by such approaches, and report and reflect upon whose evidence is captured through these strategies.
- Although many health interventions and translational efforts are highly context dependant, the complex interplay between arts-based KT, context and user characteristics is particularly pronounced. Arts-based KT should be considered in relation to these factors, and not treated as homogenous strategies with inherent power to affect change a-contextually.
- Understanding the mechanisms of arts-based strategies is in many ways contingent on detailed reporting of their core mechanisms and attributes. As such, individuals conducting research in this domain are encouraged to report how precisely key messages are delivered and the degrees of audience-participation enabled through the approach. Further research is needed in this area.
- Degree of precision in key message delivery and extent of participation with an arts-based strategy is highly context dependant and likely to affect identified outcomes. For instance, highly participatory strategies may promote empathetic understanding and embodiment and may be more aligned with attitudinal change than knowledge gain. As such, outcomes should be considered in relation to context, but also to the mechanisms underlying arts-based approaches.

- Assessing the quality of arts-based strategies is difficult and contested in the field of arts-based research more generally. However, the quality of an arts-based approach is likely to impact its outcome. Although the meta-framework developed by Lafreniere and Cox (2012) may provide some insights, more research in this area, specific to arts-based KT, is needed.
- Further research is needed to understand how arts-based KT affects change in particular audiences and contexts. Research into which process outcomes and pathways are pertinent for specific strategies, populations and contexts is needed, using a variety of research methodologies and designs.

CHAPTER 6: CONCLUDING CHAPTER

Overview of Findings

My dissertation focused on developing a patient-driven arts-based knowledge translation (KT) tool to address the information needs of parents of children with asthma. In my work, I uncovered two current limitations in the research literature, namely the need to (I) better understand and address the information needs of parents of children with asthma and (II) develop a stronger procedural and theoretical basis for arts-based KT approaches, particularly for communicating health information to non-health care professionals such as parents. The combined findings from this dissertation contribute substantively to these domains. In this concluding chapter, I provide an overview of the knowledge contributions that emerged from the four dissertation papers in relation to these areas. I further discuss the relevance of this dissertation to nursing and KT science and describe associated strengths and limitations of the dissertation. I conclude by highlighting areas for future inquiry.

(I) Information Needs of Parents of Children with Asthma

Understanding how the information needs of parents of children with asthma are approached in contemporary literature was foundational to the knowledge contribution provided through this dissertation. As such, conducting a state-of-the-science review of the literature to ascertain how parents' information needs have been understood within the context of childhood asthma was an essential step; no previous literature review had been conducted in this content area. Through this work (paper one: Archibald & Scott, 2014), I discovered rigorous research relevant to parents' experiences and management of childhood asthma (e.g., Berg et al., 2007; Halterman et al., 2006; Yoos, Kitzman, McMullen, Sidora-Arcoleo, & Anson, 2005; Yoos et al., 2007). I extracted and synthesized information pertaining to the information needs of parents,

many of which reflected health care provider (HCP) and medical orientations aligned with the professional model of asthma management. At times, authors acknowledged potential differences between lay and professional models of asthma management in important areas such as symptom representation (e.g., Yoos et al., 2005). This was infrequent and explicit research on parents' understandings of their information needs was lacking.

I attended to this knowledge gap in paper two and conducted the first qualitative study on parents' information needs in childhood asthma (Archibald, Caine, Ali, Hartling & Scott, 2014). Findings from this paper illustrated that parents found it challenging to identify what they did not know about childhood asthma. As a result, parents expressed both unmet information needs (i.e., information deficits identified by parents) and demonstrated pervasive information deficits (i.e., areas where further learning was needed but was not recognized by parents).

While the information needs reflected parents' perspectives, the information deficits reflected a more professional perspective of asthma management, suggesting that a tension may exist between these two perspectives. This aligns with previous research demonstrating the differences between HCP and parents' illness representations in childhood asthma (Ducharme, 2012; Yoos et al., 2007). Similar misalignments between lay and medical models of asthma management (as captured through national guidelines et cetera) have been documented (Yoos et al., 2005) and may be reflected in parents' accounts of learning about and managing childhood asthma. Erroneous beliefs about the nature of asthma (e.g., the absence of symptoms equates to the absence of disease) may compound potential misalignments (Ducharme, 2012). The tensions between parents' knowledge levels and insights into their learning needs, underlying parental beliefs about asthma as an acute condition which conflict with medical views of chronicity, and parents desire for emotional support beyond that received during many HCP visits underscores

that a more holistic approach to communicating health information to parents may be warranted. These findings shed new light on existing literature and suggest that educational approaches that integrate parents' and HCPs' perspectives may foreseeably bring these into closer alignment. Embedding research evidence with concrete examples from parents' experiences in a manner aligned with adult learning principles may also enhance the problem-centered and personalized nature of the evidence presented, thereby increasing its perceived relevance and usefulness for parents (Merriam, 1996).

One key finding from this research was that the information needs and deficits of parents often persisted over time. How parents learned about childhood asthma was at times haphazard, mirroring the findings from the literature review (paper one). Recognizing information needs was frequently prompted by day-to-day situations and associated emotions (e.g., needing to feel comfortable), and parents infrequently identified gaps in propositional knowledge until they were explicitly asked. These findings led me to reflect that not all information is regarded as equal in the everyday management of childhood asthma and particular information deficits were less identifiable. For instance, using an inhaler was a necessary and recognizable information need for most parents, likely facilitated by the real-life challenges of managing asthma day-to-day. While this underscores the influence of adult learning, it also reinforces the cyclical relationship between tacit, experiential knowledge and propositional forms of evidence (Fitzgerald & Dopson, 2009).

Another key finding from this work is that many parents struggled with the education received from HCPs, which negatively impacted their management ability. Asthma was commonly regarded as an acute rather than a chronic, respiratory condition, which reinforced findings from paper one. This perspective mediated parents' information seeking behaviours and

management decisions, and highlighted that childhood asthma management extends beyond the realm of propositional and procedural knowledge. Addressing parents' beliefs about the nature of asthma through education is also needed.

Comparing the major findings from the literature review (i.e., information needs taxonomy) and the qualitative study (i.e., hierarchy of information needs) with dominant perspectives from the research literature generated important insights into the evolution of my thinking on parents' information needs, and the higher degree of inclusivity forwarded through the patient-driven approach taken in this dissertation (Table 6.1). The initial information needs taxonomy created through the literature review is comprehensive and broad; the hierarchy of information needs derived from the qualitative study can be effectively mapped against these categories. However, the initial taxonomy does not reflect parents' capacity to identify their needs and/or deficits over time and in comparison to the information needs hierarchy, it is generally less specific, process oriented, and parent-focused.

Table 6.1 Comparison and Evolution of Parental Information Needs

Categories of Information Needs from Literature Review	Subcategories of Information Needs from Literature Review	Corresponding Information Needs from Qualitative Study	Canadian Pediatric Asthma Consensus Guidelines & Summary (Becker et al., 2003; Lougheed at al., 2010)	Analysis of Cochrane Systematic Reviews & Meta Analyses (Brouwer & Brand, 2008)
Asthma Basics	Pathophysiology	Knowing about asthma (Level IV)	Description of asthma	Description of asthma & causal mechanisms Contributing factors
	Nature of disease	Mediating Factor: Beliefs about the nature of asthma	-	-
	Symptom recognition	Recognizing Severity (Level I)	-	-
Treatment Modalities	ST & LT medications Mechanisms	Prevention versus crisis orientation (Level III)	Methods of control	Treatment & adherence
	Adverse effects	Knowing about asthma (Level IV)	Description of asthma	Description of asthma
	Administration technique	Acute Management/ Inhaler Use (Level II)	Inhalation technique	Inhalation technique
	Myths	Mediating Factor: Beliefs about the nature of asthma	-	-
	When to use	Acute management/inhaler use (Level II); Mediating Factor: Beliefs about the nature of asthma	Medication Adherence	-
Coping (including self-efficacy)	Dealing with emotions, worry & uncertainty Written asthma action plan	Mediator: Interactions with HCPs Prevention versus crisis orientation (Level III)	Continuity of care Avoiding triggers Written Asthma Action Plan	-
Medical Expectations	When to seek treatment	Recognizing severity (Level I) Acute management (Level II)	-	Treatment

Comparing the educational emphases of quality asthma resources (e.g., asthma consensus guidelines; meta analyses of Cochrane reviews) with the dissertation findings underscores the

comprehensive understanding of parents' information needs generated through this research. While existing asthma guidelines and reviews (e.g., Becker et al., 2003; Brouwer & Brand, 2008) highlight many foundational components of asthma education, important information needs and deficits related to the nature of asthma, acute versus preventative aspects of management, and recognizing the severity of asthma symptoms are underemphasized. The mediating potentials of HCP interactions, including supportive aspects, are more thoroughly reflected in the present research.

Terminology is an important component of educational KT interventions (O'Connor, 2009). While the information needs taxonomy (paper one) is less reflective of parents' terminology than is the hierarchy of information needs (paper two), the language employed in the asthma consensus guidelines is particularly medical and unreflective of parents' terminology. The initial taxonomy (paper one) was created from a research synthesis of authors' descriptions of participants' information needs from both qualitative and quantitative data. In contrast, the information needs hierarchy (paper two) was derived directly from parents' descriptions and researchers interpretations stemming from these descriptions. Efforts were taken to ensure parents' terminology was used to describe the information needs; this may enhance the personalized nature of the KT intervention, promote alignment between HCP and parents' understandings, and heighten resonance with the arts-based approach (Barone & Eisner, 2012; O'Connor, 2009).

(II) Procedural and Theoretical Basis for Arts-Based Knowledge Translation

The tensions discussed in papers one and two (e.g., lay versus medical perspectives on asthma) were reflected in the arts-based KT tool developed. By integrating quality evidence about childhood asthma management from various sources (e.g., systematic reviews, randomized

controlled trials, national asthma guidelines, reputable websites) with parents' knowledge, experiences, information needs and deficits, my intent was to create a resource that is usable, accurate, and relatable for parents. Independently, health research may not align with parents' beliefs, needs and perspectives about asthma and its management. Artistic methods of representing experiences and communicating information can mitigate some of these tensions by validating parents' perspectives and beliefs while providing information aligned with medical convention. The approach taken in this dissertation is an innovative and new way of providing information to parents; no comparable tool has been developed in this population.

My research advances arts-based KT through procedural and theoretical knowledge contributions. At the procedural level, my work provides needed information about the process of developing a patient-driven multimodal arts-based KT intervention. Leveraging the communicative power of the arts is a particularly underexplored avenue for relaying health information. To date, processes associated with developing such a tool, including the requisite skills and potential challenges associated with inter-professional collaboration, are relatively new and emerging. I add substantially to this emerging knowledge base in paper three (Archibald, Caine, Ali, Hartling & Scott, 2016). The procedural guidance offered, including the exploration of challenges faced and resulting strategies employed, can be adapted for use in various contexts, and represents a significant contribution to the emerging field.

In addition, I provide a substantive theoretical contribution to the field in paper four (Archibald, Caine & Scott, 2014), which signifies the theoretical backbone for my thinking around arts-based KT. In the early stages of this conceptualization, I focused on (I) the artistic form employed to (II) communicate evidence that included, but was not limited to, research findings. However, I began realizing that discussing arts-based KT by artistic form alone is too

coarse a classification; it fundamentally negated important component parts of an intervention (i.e., those aspects which are distinct from but contribute to the whole of an intervention) (Clark, 2013). Reflecting upon which aspects of an arts-based approach contribute to its totality assisted in theorizing how the degree of participation and extent of precision in key message delivery, as two components, underpin arts-based KT interventions. Based upon this thinking, I offer a conceptualization of the mechanisms underpinning arts-based KT. The classification schema produced significantly extends current thinking, which is generally limited by form-based classifications alone (e.g., drawing, theatre), and conflates non-arts based and arts-based components of the interventions (e.g., Rieger & Shultz, 2014). While there has been comparatively little theoretical development in the arts-based domain of KT, this dissertation contributes by challenging emerging mainstream conventions and offering a unifying perspective for developing and categorizing arts-based approaches based on meaningful criteria. Distinguishing the components (e.g., participatory, non-participatory) contributing to arts-based KT interventions renders these aspects researchable; as such, this work may assist in future theoretical development and research regarding the use and effectiveness of arts-based strategies.

Relevance to Nursing

My dissertation reflects a creative and holistic response to a practice problem that is relevant to but not limited to nursing. Identifying the misalignment between parents' needs and current educational approaches and developing an emotionally and communicatively responsive method with the aim of addressing this misalignment reflects a patient-centered and whole-person orientation to research and care provision. The interpretive description (Thorne, 2008) approach (paper two) and the arts-based orientation (papers three and four) reflect a methodological alignment with these perspectives and values. That my dissertation resulted in an

intervention with a high likelihood of being clinically useable is an important contribution to knowledge guided by this interpretive methodology.

Clinically, my work has the capacity to inform nursing and health care practices in childhood asthma in a person-centered manner. Understanding parents' information needs provides needed insights for HCPs working with these populations and is an integral component of providing safe, ethical, and competent care. Developing the arts-based KT tool based on an understanding of parents' perspectives and experiences provided a strong foundation for an accessible, engaging, and relatable educational intervention for parents. Once evaluated in future research, this intervention may be a useful resource for HCPs working with parents of children with asthma in diverse practice settings.

Nursing has a long history of alignment with the arts and artful practice, including valuing knowledge beyond propositional, codified forms (Archibald, 2012; Cloutier, Duncan & Bailey, 2007; Darbyshire, 1994). The understanding that various knowledge forms (e.g., empirical, aesthetic, ethical, and personal) inform nursing has been foundational to much theorizing and nursing scholarship (Archibald, 2012; Carper, 1978). Arts-based approaches are well aligned with nursing's affiliation with holistic practices and valuing of multiple forms of knowledge. Developing a patient-driven arts-based KT tool represents a synergistic integration of these knowledge forms and signifies a holism of knowing in nursing (Archibald, 2012). This educational approach focuses on personalizing and facilitating learning rather than didactically teaching a-contextual information and is therefore consistent with these tenets.

Relevance to Knowledge Translation Science

The arts-based and patient-driven approach I undertook in this dissertation makes a notable contribution to KT science. First, this dissertation makes a substantive methodological

contribution to developing and understanding arts-based KT strategies. Paper three outlines the process of developing an arts-based KT tool for parents based on two previous stages of research (i.e., literature review and qualitative study). This approach reflects the orientation necessary to establishing a community of scholars in this field, while promoting scientific discourse through non-proprietary sharing of methodological innovation. The inter-professional perspective employed provided needed dimension to the study of KT, which has historically focused on HCPs in institutionalized settings (Kothari & Armstrong, 2011) while offering little procedural guidance for developing arts-based KT approaches. The theoretical contribution provided in paper four, namely, the creation of the Archibald Classification Schema (Archibald et al., 2014), enables a new perspective on arts-based approaches that can stimulate further theorizing and cross-comparison of arts-based interventions as they continue to emerge.

Arts-based approaches to KT can challenge epistemological hegemony and extend perspectives of what counts as knowledge. Patient-driven approaches may be particularly effective at re-distributing the emphasis from empirically rooted sources of knowledge to those sources valued and used by patients. Communicating health information is democratized when individuals' perspectives and personal knowledge are legitimized, and when knowledge sources not generally regarded as scientifically rigorous but are useful to stakeholders (e.g., experiences, websites) are integrated. These perspectives may encourage questioning of power imbalances embedded in discourses of knowledge, enticing questions such as who decides what knowledge is valued in KT.

Strengths and Limitations

A significant strength of my dissertation is the breadth of contribution to understanding parents' information needs in childhood asthma, and to the procedural and theoretical basis of

arts-based and patient-driven KT strategies for non-HCPs. Strengths and limitations related to representation, methodology and design are also discussed.

Representation

Sampling. In the qualitative study (paper two), I sampled from three diverse recruitment sites in order to access a range of participants with various information needs, experiences, and stages of the asthma trajectory. This contributed to robust data and allowed for comparisons of parental groups, based on time since diagnosis. However, as I was using these data to inform the development of an arts-based KT tool for parents beyond those who participated in the qualitative study, I encountered a tension between representing the experiences of a few in a way that would resonate with many.

I combined purposive and convenience sampling techniques to access diverse participants for the qualitative study (paper two), giving rise to potential sampling bias. The numerous factors influencing parents' decisions to seek treatment are not captured in the qualitative study. I collected data at one-time point and using one method, which limited my ability to ascertain how parents' information needs changed over time and the scope and depth of data. Using observation and HCP interviews for instance would have provided a more contextual understanding of parents' information needs and how they are addressed by HCPs. However, the study highlighted these relevant domains for future inquiry while substantially contributing knowledge to understanding parents' information needs.

Fathers are underrepresented in the qualitative study (paper two). However, the intent of the sampling strategy and study was to capture real-life management scenarios of parents, and mothers dominated this sample. It is common for mothers to assume the role of primary caregiver for a child and as such, the underrepresentation of fathers may reflect a common

experience in the everyday management of childhood asthma (Borhani, Asadi, & Mohsenpour, 2012). As I discuss in paper three, I grappled with how to represent fathers when developing the arts-based KT tool given their underrepresentation. Committing to *staying-true* to the data helped to reconcile this challenge. Investigators exploring performance based dissemination strategies have reported similar considerations (Rossiter et al., 2008). Although there is no clear way to address these tensions, they serve an integral purpose in arts-based KT: namely, to critically examine what is being represented and omitted through the artistic form.

Artistic Form. Form and representation are inseparable and invariably influence communication and understanding (Barone & Eisner, 2012). Using narrative and visual arts-based forms of representation simultaneously liberates and constrains meaning. Emotive capacity and resonance are enhanced through various artistic devices used in the arts-based KT tool in this dissertation, such as first-person narrative, character development, and semi-realistic character portrayals. The use of these creative devices to extend representation, aid communication and understanding is a notable strength of this study. However, given the complex context of childhood asthma management, I used artistic representation in a manner that promoted clear messaging of health information and reduced ambiguous interpretation. This precise key message delivery may be considered "low dose" art. As such, those seeking to develop or understand more interpretative art forms, such as dance or theatre-based KT (e.g., quadrants three or four, Archibald et al., 2014), may find that aspects of this dissertation are less relevant, given the extensive variation between these artistic modalities.

Methodology and Design

Notable strengths of this work are the pronounced methodological alignment and the generative interplay between the substantive and methodological aspects of the dissertation. For

instance, using qualitative data to inform the development of the arts-based KT tool is well aligned with the clinical orientation emphasized in interpretive description (Thorne, 2008). Considerations related to the context of childhood asthma management influenced thinking about the mechanisms of arts-based KT more generally, facilitating conceptualizing and refining the classification schema (paper four). This clinical-methodological interplay is akin to the double helix analogy (Medlinger & Cwikel, 2008) wherein two diverse research perspectives contribute synergistically to new understandings and research directions, while diverging and intersecting at different time points.

I did not evaluate the usability or effectiveness of the arts-based KT tool, which may be considered a limitation. However, the extensive process of intervention development and theoretical exploration executed in this dissertation rendered such an evaluation unfeasible for the proposed timeframe of this work. Further, the four papers presented here form the foundation for a program of research integrating patient-driven interventions and arts-based approaches. In the section that follows, I outline subsequent areas for future research building on this dissertation, including plans to evaluate the arts-based KT strategy using a step-wise approach.

Implications for Research and Practice

Childhood Asthma

Numerous areas for future research and theoretical development were generated throughout this multi-phased dissertation. First, while this work contributes to understanding parents' information needs in childhood asthma, many questions were generated regarding the nature of patient-HCP interactions; discourses during asthma education; and the relationships between asthma management, asthma control, and information needs. Whether systematic differences exist in the information needs and information deficits of parents receiving education

according to context remains unanswered. While I did inquire into the information preferences of parents in the qualitative study (paper two), a more thorough investigation into the nuances of education in reference to content, form, and methods of delivery would provide further insight into addressing the information needs of parents in this context of illness management. As such, this dissertation has strong potential to generate several relevant practice-oriented research questions.

There is also great potential for the arts-based KT tool developed for this dissertation to positively affect clinical practice in a family-centered manner. The need for an accessible, engaging, comprehensive, and relatable educational resource was demonstrated through participant testimonies obtained in the qualitative study (paper two). Participants frequently reported receiving insufficient education at the time of asthma diagnosis and emphasized the value of personalized information delivered in an emotionally sensitive manner. Contextual factors related to clinical structure and knowledge, such as busyness, time-pressure, and continuity of care, impact the extent and quality of professional education provided (Goeman et al., 2005). As such, equipping HCPs and families with the KT tool developed for this dissertation may foreseeably promote consistent and comprehensive educational provision in a manner consistent with parents' information needs and asthma related experiences.

Arts-Based Knowledge Translation

There is much to be understood about developing and testing arts-based and patient-driven KT strategies for various populations and contexts. In paper four, I extend contemporary theoretical thinking surrounding the mechanisms of arts-based KT by creating the Archibald Classification Schema (Archibald et al., 2014). Building upon this framework through further theoretical and empirical inquiries is a robust domain for future research. Such inquiry may

facilitate understanding of how arts-based KT affects change in particular audiences and contexts.

The framework used for my dissertation research and the subsequent step-wise evaluation proposed below could be modified and applied to different populations and settings to facilitate systematic comparisons of KT intervention effectiveness. Interventions developed for diverse health conditions and population groups can be compared so that characteristics of the intervention, participant sample, context of delivery (or development), and other components related to intervention implementation can be hypothesized, and future research can be designed to test these hypotheses. This is important because presently, how content, individual intervention components, and intervention delivery influence effectiveness is poorly understood (Brouwer & Brand, 2008). Evaluating which components of educational interventions contribute to their success may promote understanding of *what works* for particular health conditions and settings, thereby reducing haphazard approaches to educational provision in needed contexts such as childhood asthma (Squires, Estabrooks, Wallin, & Gustavsson, 2011).

Next Steps: Establishing a Program of Research

By carefully crafting my dissertation research I have established clear next steps from which to build a program of research integrating the axes of KT for non-HCP groups and artistic forms of research and representation. I intend to build directly upon my dissertation research in these two domains commencing with my graduation and carrying through my postdoctoral training and tenure track faculty position. Drawing upon the double helix analogy (Medlinger & Cwikel, 2008), I will integrate, at different time points, arts-based approaches with clinical foci to address patient needs and perspectives while synergistically gaining methodological and theoretical understandings.

Usability and Effectiveness

Although this dissertation extended the procedural and theoretical basis of patient-driven arts-based KT from a purely form based orientation to conceptualizing underlying components of arts-based interventions (e.g., precision in key message delivery; degree of participation), it did not contribute to understanding the effectiveness of these approaches. This is a critical avenue for future research, particularly in the domain of community-oriented KT (Kothari & Armstrong, 2011). The UK Medical Research Council guidelines promote a step-wise approach to evaluating interventions and advocates for a pilot evaluation prior to extensive evaluation, such as randomized controlled trials (Craig et al., 2008). I plan to design and implement the following step-wise evaluation approach: (I) usability testing using a explanatory sequential mixed methods research design, and a (II) mixed methods embedded design (e.g., randomized trial with an embedded qualitative component) to evaluate the effectiveness of the arts-based KT strategy (Creswell & Plano Clark, 2011).

Following defense of my PhD research, I will conduct mixed-methods usability testing of the arts-based KT prototypes developed for the dissertation using an explanatory sequential design (phase I). Participants will review the arts-based KT tool, complete a usability questionnaire, and be provided the opportunity to consent to a follow-up focus group interview. Focus group participants will be purposively selected from the quantitative sample to maximize diversity, and data will be linked to promote complementarity (Greene, Caracelli, & Graham, 1989). These pilot data will be foundational to future evaluative research of the effectiveness of the arts-based KT tool. During my postdoctoral research, I will design a mixed-methods evaluation of the arts-based KT prototypes (phase II), which I will submit to a tri-council grant-

funding agency (e.g., Canadian Institutes of Health Research) following completion of my postdoctoral training.

Theoretical Development

In future research, I intend to cross-compare types of arts-based KT strategies developed for various health conditions (e.g., acute or chronic). Such work could help identify attributes of arts-based KT amendable for use with chronic versus acute conditions. I will also inquire into which process outcomes and pathways of arts-based KT approaches are pertinent for specific strategies, populations, and contexts. These inquiries may extend understandings of the mechanisms by which arts-based KT approaches function; thereby assisting in further developing the Archibald Classification Schema (Archibald et al., 2014) conceptualized during this dissertation.

In previous work, I identified that "understanding the mechanisms of arts-based strategies is in many ways contingent on detailed reporting of their core mechanisms and attributes*"* (Archibald, Caine & Scott, 2014, p. 7). As such, a component of my future work will involve developing reporting guidelines that reflect essential attributes of arts-based approaches. This may include for example the degree of precision in key message delivery, the extent of audience participation enabled through the artistic approach, the artistic form(s) employed, characteristics of those delivering and developing the intervention, the rationale for the arts-based approach, and relevant aspects of context.

Reporting is intimately related to assessing the quality of, and establishing evaluative criteria for, arts-based KT strategies. This is "a difficult and contested in the field of arts-based research more generally" (Archibald et al., 2014, p. 7). Recent inquiries (e.g., Lafreneire & Cox, 2012; Norris, 2011) provide useful insights relevant to evaluation but are not specific to arts-

based KT. I will provide a theoretical contribution to this domain by synthesizing and extending these existing criteria in my future work.

Conclusion

My dissertation contributes to understanding the information needs of parents of children with asthma and to the emerging field of arts-based KT. I conducted a sequential, multi-phased study with practical implications to the contexts of childhood asthma and translational research, and with theoretical implications to arts-based KT. I synthesized contemporary asthma research to classify the information needs of parents of children with asthma, which informed the development of a semi-structured interview guide for use in a follow-up qualitative study. This literature review and information needs study were the first of their kind and highlighted alarming shortcomings pertaining to education, parental knowledge, and management in childhood asthma. I then used these data to develop four prototypes of a web-hosted, visual art and story-based KT tool for parents using highly innovative and uniquely inter-professional methods. By describing this patient-driven process and associated challenges in detail, I provide a needed methodological contribution to this emerging and promising field. The conceptual underpinnings of this dissertation are reflected in paper four where the mechanisms underlying arts-based KT and the complex interplay between intervention components and time, location and context are theorized.

The research findings, methodological, and theoretical contributions of this dissertation have the potential to stimulate further research and impact health care practices. The creative methods and alternative conceptualizations of arts-based KT may conceivably generate new insights and research directions at a critical early juncture of arts-based KT theory development. The arts-based and patient-driven KT tool developed will be made available to HCPs and parents

of children with asthma following evaluation in future research. This comprehensive, contextually sensitive, and clinically accurate resource may assist parents during the day-to-day management of their child's asthma. The power of this resource to affect health care outcomes for parents and children will be one aspect of my future program of research incorporating systematically developing, evaluating, and concurrently theorizing arts-based and innovative methods to understand and communicate health information to non-HCP groups.

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Appendices

Appendix A

Arts-Based Knowledge Translation Tool Example Prototype A

November 15

Poor little Sammy is sick AGAIN! His coughing woke me around 2 a.m. His breathing was super-fast. I took him to the hospital while Tahir stayed home with Nila. No sense getting the baby sick, too!

The emergency department doctor asked if Sammy has asthma!? I mentioned the lung infections he had as a baby. They gave him oxygen, something called Ventolin, and did some tests. So scary! They think it's another lung infection, but this time, we didn't get antibiotics.

Thankfully, Sammy seemed better and we were discharged. He's sleeping soundly now. It's good to be home.

important

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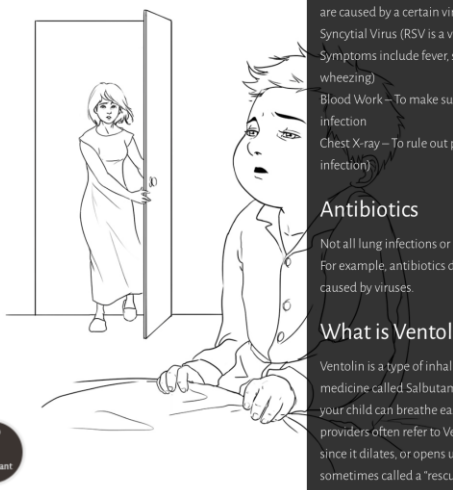

important

What kind of tests did they run on Sammy?

Nasopharangeal Swab – To figure out if his symptoms are caused by a certain virus, such as Respiratory Syncytial Virus (RSV is a very contagious viral infection. Symptoms include fever, stuffy or runny nose, and wheezing)
Blood Work – To make sure he doesn't have a blood infection
Chest X-ray – To rule out pneumonia (a kind of lung infection)

Antibiotics

Not all lung infections or pneumonias need antibiotics. For example, antibiotics do not work for infections caused by viruses.

What is Ventolin?

Ventolin is a type of inhaler that contains a fast-acting medicine called Salbutamol. It quickly opens airways, so your child can breathe easier. That is why health care providers often refer to Ventolin as a "bronchodilator", since it dilates, or opens up, the airways. Ventolin is also sometimes called a "rescue inhaler", since you use it when your child needs immediate relief.

Asthma Fact!

Did you know that childhood asthma occurs more often in boys than girls?

4 / 28

April 11

Sammy is constantly coughing … at night, when he plays, even when he's watching TV! He's also started wheezing! I thought of Mrs. Lim's son. Could Sammy have asthma, too?

I was so worried, I called Health Link. They asked a lot of questions . . . Is he working hard to breathe? Does he seem panicked? I told them Sammy was really struggling to breathe and looked very pale. They said we should get to the hospital. We are in the emergency department as I write this. It was great to be told what to do.

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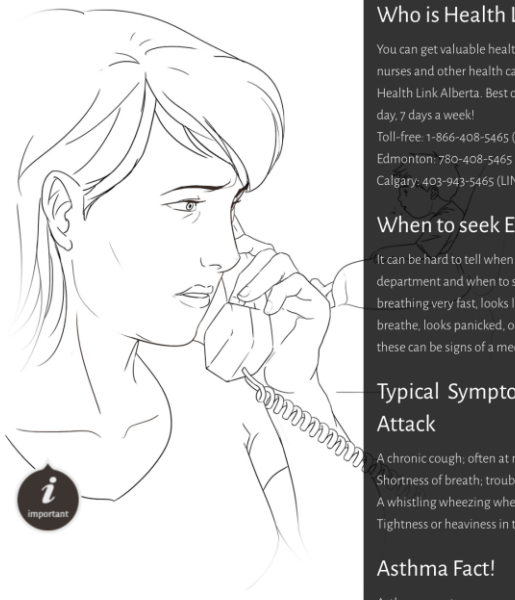

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When to seek Emergency Care

It can be hard to tell when to go to the emergency department and when to stay at home. If your child is breathing very fast, looks like he or she is struggling to breathe, looks panicked, or is getting tired breathing, these can be signs of a medical emergency.

Typical Symptoms of an Asthma Attack

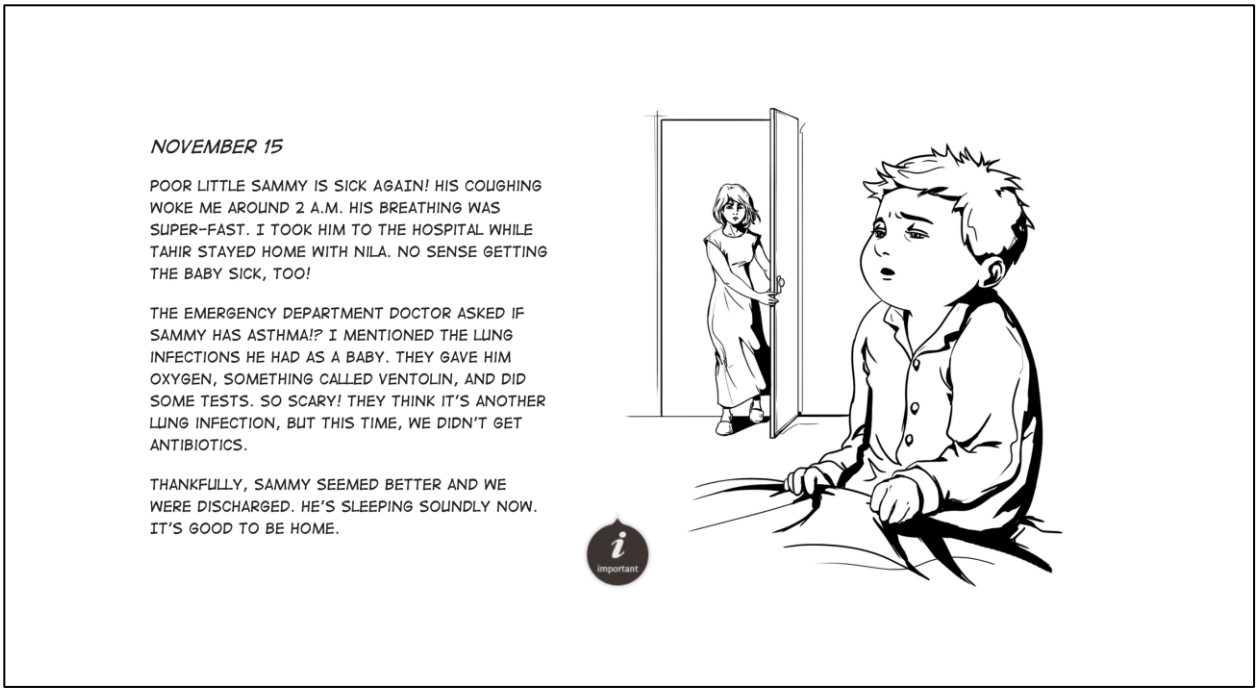
A chronic cough, often at night.
Shortness of breath; trouble breathing.
A whistling wheezing when breathing out.
Tightness or heaviness in the chest

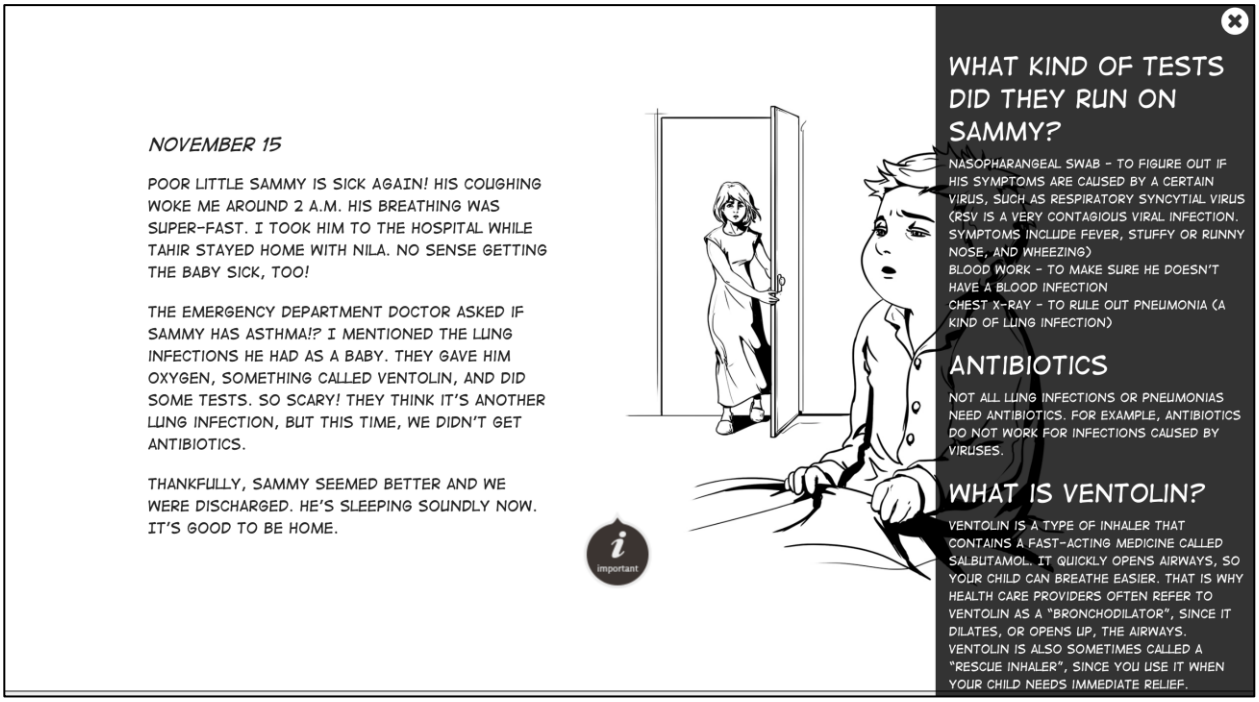
Asthma Fact!

Asthma symptoms can vary from child to child. A person with only one symptom (like wheezing) can still have asthma.

Appendix B

Arts-Based Knowledge Translation Tool Example Prototype B





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SAMMY IS CONSTANTLY COUGHING ... AT NIGHT, WHEN HE PLAYS, EVEN WHEN HE'S WATCHING TV! HE'S ALSO STARTED WHEEZING! I THOUGHT OF MRS. LIM'S SON. COULD SAMMY HAVE ASTHMA, TOO?

I WAS SO WORRIED, I CALLED HEALTH LINK. THEY ASKED A LOT OF QUESTIONS . . . IS HE WORKING HARD TO BREATHE? DOES HE SEEM PANICKED? I TOLD THEM SAMMY WAS REALLY STRUGGLING TO BREATHE AND LOOKED VERY PALE. THEY SAID WE SHOULD GET TO THE HOSPITAL. WE ARE IN THE EMERGENCY DEPARTMENT AS I WRITE THIS. IT WAS GREAT TO BE TOLD WHAT TO DO.

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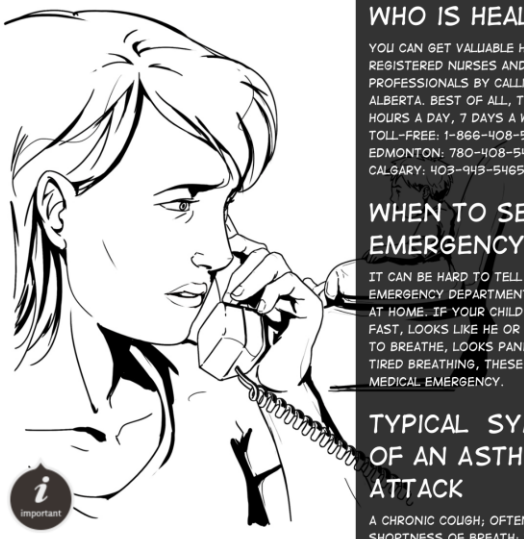

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WHEN TO SEEK EMERGENCY CARE

IT CAN BE HARD TO TELL WHEN TO GO TO THE EMERGENCY DEPARTMENT AND WHEN TO STAY AT HOME. IF YOUR CHILD IS BREATHING VERY FAST, LOOKS LIKE HE OR SHE IS STRUGGLING TO BREATHE, LOOKS PANICKED, OR IS GETTING TIRED BREATHING, THESE CAN BE SIGNS OF A MEDICAL EMERGENCY.

TYPICAL SYMPTOMS OF AN ASTHMA ATTACK

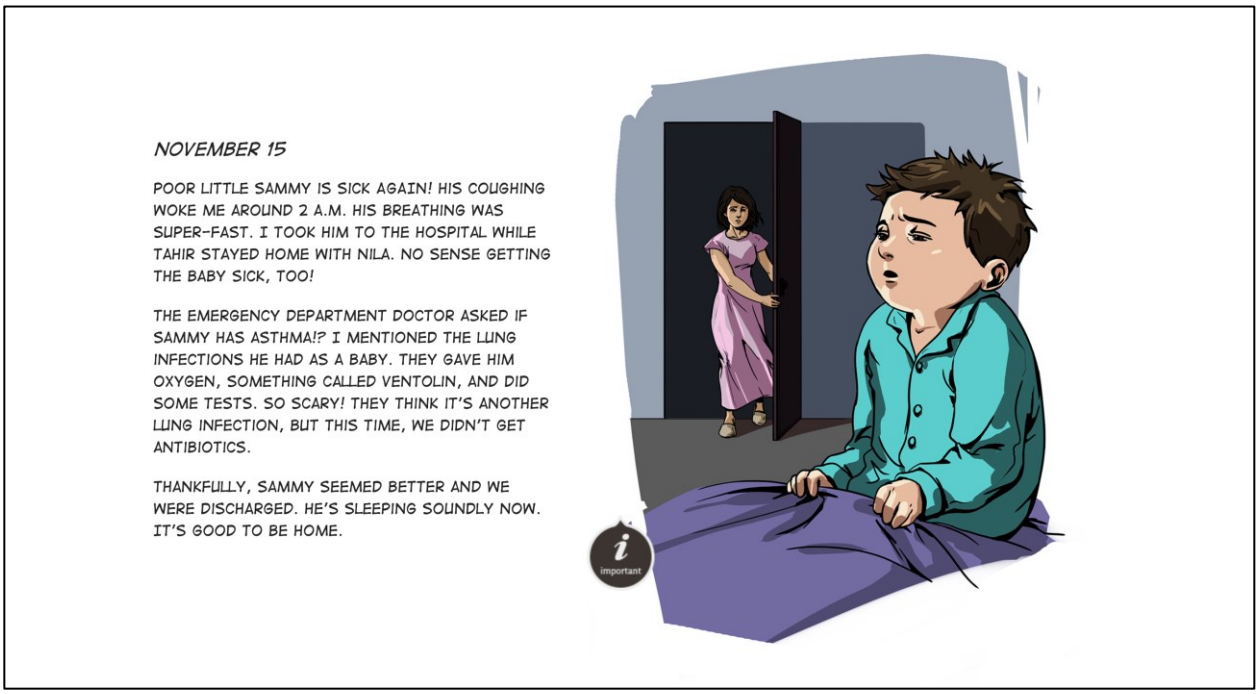
A CHRONIC COUGH; OFTEN AT NIGHT.
SHORTNESS OF BREATH; TROUBLE BREATHING.
A WHISTLING WHEEZING WHEN BREATHING OUT.
TIGHTNESS OR HEAVINESS IN THE CHEST

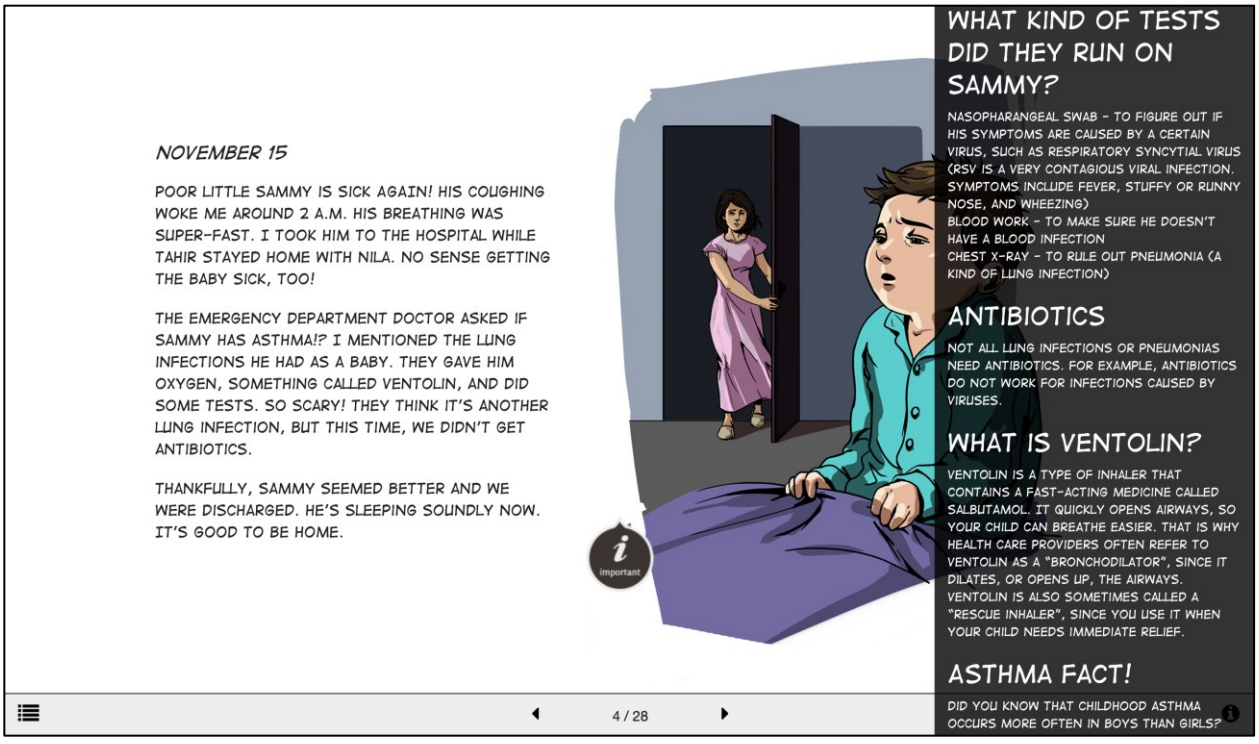
ASTHMA FACT!

ASTHMA SYMPTOMS CAN VARY FROM CHILD TO CHILD. A PERSON WITH ONLY ONE SYMPTOM

Appendix C

Arts-Based Knowledge Translation Tool Example Prototype C





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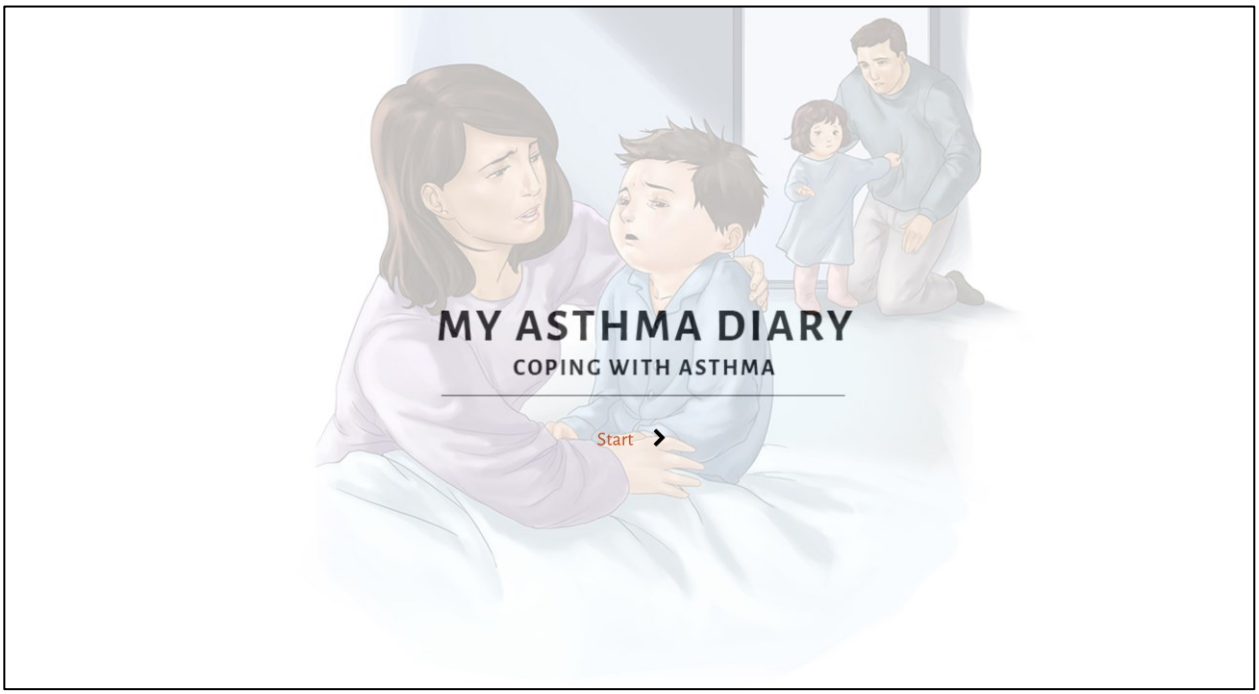
Appendix D

Arts-Based Knowledge Translation Tool Prototype D



Welcome

Whether your child has just been diagnosed with asthma or has had asthma symptoms for years, this book is designed to provide helpful information for you and your family. Its purpose is to answer common questions about childhood asthma. It explains many of the common terms, medications, and treatment options in an easy-to-understand way. Don't worry if you don't understand all of the information in this book. Be sure to make a list of your questions and bring them to your next visit with your health care provider.

This book should not be used to diagnose or treat any medical or health condition. Please talk to your doctor or health care provider about your health concerns.

Winter

It is common for asthma symptoms to get worse in winter. Cold air is often a trigger for asthma. A trigger is something that makes asthma symptoms worse. More time indoors also means more contact with indoor allergens, such as pets, dust mites, germs. Even that cozy, wood-burning fire could cause problems.

During the winter months, children can wear a neck warmer across their noses and mouths when going outdoors, wash their hands frequently to avoid flu and cold germs, and avoid other personal asthma triggers like smoke or mold. Make sure to keep the house nice and clean to lessen you child's exposure to dust and other irritants!

November 15

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The emergency department doctor asked if Sammy has asthma!? I mentioned the lung infections he had as a baby. They gave him oxygen, something called Ventolin, and did some tests. So scary! They think it's another lung infection, but this time, we didn't get antibiotics.

Thankfully, Sammy seemed better and we were discharged. He's sleeping soundly now. It's good to be home.

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Asthma Fact!

Did you know that childhood asthma occurs more often in boys than girls?

November 17

I took Sammy back to school today. Luckily, he only had to stay home for one day. After school, we ran into Sammy's teacher, Mrs. Lim. She was on her way to the doctor's with her toddler. Apparently, he also has really bad coughing and wheezing attacks.

Mrs. Lim said he's just been diagnosed with asthma! I had no idea children so young could get asthma. It made me think, "How do they know for sure?" Now, I'm worried about Sammy.

Gotta go! Time to pick up Nila from daycare.

What is asthma?

Asthma is the most common chronic disease of childhood. This means that asthma is a long-term disease that will last throughout your child's life. The small airways in the lungs get tight and clogged because of constriction (tightening and narrowing), inflammation (swelling) and extra mucous production. This brings on coughing, wheezing, shortness of breath, and tightness in the chest. The cause of asthma is unknown and right now, there is no cure. The good news is asthma can be managed so that your child can enjoy his or her normal daily activities.

How is asthma diagnosed?

Sammy's mom didn't realize young children can get asthma. That's because it is very difficult to diagnose in children under the age of six. Asthma diagnosis can vary from person to person, but usually includes:

- A family history of asthma
- Childhood history of allergies
- History of coughing, difficulty breathing, wheezing, or frequent lung infections
- Doing some breathing tests (like spirometry or pulmonary function tests)
- A 'test period' of trying out asthma medications to see if they help your child

Asthma Fact!

According to Statistics Canada, more than 13% of Canadian children have asthma.

April 11

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A chronic cough; often at night.
Shortness of breath; trouble breathing.
A whistling wheezing when breathing out.
Tightness or heaviness in the chest

Asthma Fact!

Asthma symptoms can vary from child to child. A person with only one symptom (like wheezing) can still have asthma.

April 12

Yesterday's trip to the hospital is still a blur! The nurse said I did the right thing to bring Sammy in. They gave Sammy oxygen and more Ventolin right away. Then they did something called a 'pulmonary function' test. The nurse and doctor asked a million questions about Sammy's symptoms and whether our family has asthma, allergies, or eczema. Isn't that a skin rash?

The doctor said that Sammy has asthma! I can't believe it! We were sent home with a Ventolin inhaler and a prescription for steroids. I'm worried. Aren't steroids dangerous?

important

Steroids and Asthma

The steroids used to manage asthma help reduce the swelling (inflammation) in the lungs. Steroids in liquid or pill form are sometimes given at the hospital during an asthma attack and your child may need to take them at home for a few days (usually 3-5 days). Steroids that you breathe in are called inhaled steroids. These are taken the same way as Ventolin, and are an important part of day-to-day asthma care for many children. Inhaled steroids should be taken as prescribed, even if your child isn't showing asthma symptoms.

Pulmonary test

This test measures how well a person can take air into the lungs and how well he or she can push the air out. To complete the test, a person must be able to use a special mouthpiece and follow instructions. That's why it is usually only given to adults and children over the age of six. Ask your health care provider for more information about the different kinds of pulmonary tests available.

Eczema

Eczema is a skin disease that causes a red, itchy rash and inflammation (swelling). It does not cause asthma but many children with eczema also have asthma. That's why doctors or nurse practitioners often ask about it when diagnosing asthma.

Asthma fact!

The steroids used to treat asthma are not the same as the illegal steroids that some athletes use to build muscle. Asthma treatment steroids help control symptoms and improve how the lungs work.

April 13

I kept Sammy home from school today. He seemed okay this morning, but I wanted him close.

I guess I have to tell his teachers that Sammy has asthma, but what if he has an asthma attack at school? Should I put his inhalers in his backpack?

I read through the pamphlets from the hospital and that helped a bit. Maybe I should have asked the doctor and nurses more questions, but I didn't even know what to ask. Maybe there's something online? Surely other parents have gone through this.

Some questions you might want to ask your health care provider

What does having asthma really mean for my child?
Will he / she have asthma forever?
Will he / she always need to take medication?
How do the inhalers work to help him / her breathe better?
What if he/she has allergies? Will this affect his/her asthma? How will we know?
Are there things I should do differently at home now that my child has asthma?
What can I do to help my child now that he/she has asthma?
Can my child still run and play like he/she used to?

Attack at school

Your child can still go to school even if they have asthma, but to prevent emergencies, you must plan ahead. Follow this checklist to make sure your school is informed about your child's asthma:

- Notify the school of your child's asthma
- Make sure you fill out any needed forms to allow your child to have medications, like inhalers, at school
- Make sure your child has his/her medication and knows how to use it
- Remind your child to wash his/her hands with soap regularly
- Inform your child's teacher of what makes your child's asthma worse (triggers) so that these can be avoided. Have a meeting, if needed
- Consider an annual flu shot since children with asthma are at higher risk of lung infections, such as the flu

Asthma Fact!

Asthma is the number one reason why children miss school due to chronic (long-term) illness!

April 24

Sammy had another attack today. Thankfully it wasn't too bad. He was playing in the yard when I heard him wheezing and coughing. I grabbed his inhaler and ran to him.

I made sure to give Sammy the blue Ventolin inhaler since it is supposed to open the airways. I think I did it right, but who knows if any of the medicine got in! After watching the nurse give Sammy the inhalers at the hospital I thought I knew how to do it, but now, as I worry, I'm not so sure. Thankfully, Sammy seemed better.

How to use an inhaler and spacer

Metered dose inhalers or 'MDIs' (sometimes called puffers) may appear tricky at first, but with proper instruction and a bit of practice, they can be used quite easily and effectively. It can be hard to breathe in at the exact moment you push down on the canister. That's why a "spacer" is used with many inhalers. This long tube (spacer) traps the medicine, so you can breathe it in at your own pace.

Follow these basic steps to use your MDI and spacer correctly:

1. Get your medication (MDI) and spacer. Make sure the medication canister is snug in the MDI tube and remove the plastic cap.
2. Fit the MDI snugly into the opening of the spacer. Make sure your child is sitting up straight or standing. Shake the medication about 5 times.
3. Place the mask of the spacer firmly over your child's nose and mouth.
4. Use one hand to hold the mask in place. Use the other hand to firmly press the MDI to release 1 puff into the spacer. Hold this position for 10 -15 seconds, or until your child takes 5-6 breaths. Repeat these steps until you have delivered all the puffs needed/prescribed (usually 2 puffs).
5. Have your child drink or rinse his or her mouth with water to prevent thrush (a mouth infection).

If your child can follow instructions, breathe through his or her mouth, and hold his or her breath for ten seconds, you may have been given a spacer with a mouthpiece. In this case, your child will need to breathe out fully before breathing in the medication and holding his or her breath for 10 full seconds.

Click to see a quick (2 minute) video of this technique

Asthma Fact!

"Toughing it out" and not taking asthma medications makes it harder for the lungs to handle an asthma attack. Taking medication as prescribed and needed is important!

May 15

Tonight was family movie night. Tahir made some popcorn and we all got comfy on the sofa. Then Sammy started coughing. Next the wheezing. I thought, poor Sammy can't even watch TV with his family and his cat. And then it hit me! Our cat Bailey was sleeping on Sammy's lap. What if Sammy's allergic to him??

We just can't get rid of Bailey. We love him! Doesn't Sammy deserve a normal childhood? Will asthma run our entire life? Maybe I should keep Bailey out of Sammy's bedroom?? I'm not sure what to do.

What triggers asthma?

There are many different 'triggers' that can cause asthma symptoms. Although these differ from person to person, many people have allergic-type triggers such as:

- Dust
- Pet hair or dander (tiny flecks of skin)
- Pollen from plants
- Mold
- Food allergies (especially in babies)

Other common asthma triggers include

- Smoke
- Exercise
- Weather (e.g, cold)
- Infections from viruses

Asthma Fact!

About 80% of children with asthma have some allergic triggers! Ask your health care provider if allergy testing is right for your child.

May 17

I just can't stop thinking about Bailey. What if he's making Sammy's asthma worse? I even went online to see what I could find. Oh, my goodness! There is so much on the Internet about asthma. It's hard to know what to do, or what information is correct!

I did find some good tips on how to "asthma-proof" our home. I also read it's best not to have pets. But, if you do already have one, they suggested keeping your pet off the furniture, out of the bedrooms, and clean. Looks like it's bath time for Bailey!

How do I find information online?

There is a lot of information about asthma available online, but some is better quality than others. When looking up information, stick to websites of well-known organizations such as the Alberta Asthma Centre, The Canadian Lung Association, or the Asthma Society of Canada and check the date to make sure the information is current.

Asthma proof

You can make changes to your home that may help reduce your child's asthma symptoms. For example:

- Bathe your pet
- Keep all animals out of your child's bedroom at all times
- Wash bedding every week
- Use waterproof covers on all bedding
- Don't use fans
- Replace furnace filters often
- Consider using a High Efficiency Particulate Air (HEPA) furnace filter in your furnace or vacuum.
- If possible, replace carpet with linoleum, tile, or hardwood and get rid of upholstered furniture
- Wash your child's stuffed toys often and limit how many your child has.

Asthma Fact!

Unfortunately, the allergens from cats are very hard to remove with regular cleaning.

Summer

Summer is here! For many children, asthma symptoms like coughing and wheezing can get better over the summer, but every child is different. For others, breathing is not as easy. Higher temperatures can bring more humidity and smog. Pollen may still be an issue with certain trees and grasses. The best way to treat asthma any time of year is to avoid your child's known asthma triggers.

Other tips to help make your summer safer and more enjoyable include keeping windows and doors shut, using an air conditioner at home and in the car, turning off fans, staying indoors on high-pollen days, and using a dryer to dry your clothes.

July 1

What an amazing day! Tahir and I took the kids to the Canada Day parade. We walked around for hours and then joined some neighbours for a barbeque. The kids had a blast! It was great to see.
At first, I was worried all the excitement and activity would be too much for Sammy, but he was great! In fact, it's been weeks since his last asthma attack.

Tahir hopes Sammy is outgrowing it. I suspect it has more to do with the changes we made at home. Either way, it's been a welcome break.

Will my child grow-out of asthma?

Asthma is a life-long (chronic) condition with no cure. Sometimes asthma symptoms go away for a period of time – even years. This is called remission. Sometimes these symptoms return during teenage years or early adult life. It is normal for asthma symptoms to get better or worse throughout the year and as your child grows.

Sometimes in children, asthma-like symptoms like wheezing and coughing are not actually asthma but something else, like a lung infection (e.g., bronchiolitis). Conditions like this tend to get better as the child grows older.

There are also many different types of asthma. Asthma symptoms can be mild, moderate, or severe. Some children have symptoms that go away, sometimes for long periods of time (intermittent) while others have persistent asthma.

Asthma Fact!

In Canada, the number of childhood asthma attacks (flare-ups or exacerbations) is highest in the fall and lowest in the summer.

August 8

Sammy hasn't had an asthma attack since May! What a relief! I am starting to think Tahir could be right. Maybe Sammy doesn't have asthma anymore. I wonder how long before a doctor could confirm that?

Now I keep forgetting to give him his orange inhaler. I know it's preventative, but it just seems wrong to pump Sammy full of medicine when he has no symptoms. Plus, I'm worried about the side effects. Will it stunt Sammy's growth?? I actually found it under Sammy's bed yesterday. I feel so guilty. How many doses did he miss?

important

Daily "preventative" medication

Although it can be hard, giving preventative medication to your child when he or she seems healthy is an essential part of controlling asthma symptoms and improving lung function. Not all children need to take a daily inhaled corticosteroid (ICS)—these are usually needed for children who need a bronchodilator (like Ventolin) more than once a week. Make sure you check with your health care provider before changing your medication plan or if you have questions or concerns.

True or False?

1. Research shows that inhaled corticosteroids (ICS) can stunt (slow) growth
   Click here to view the answer:

2. Most ICS are prescribed at a low dose which has very few side effects
   Click here to view the answer:

3. ICS are only helpful when used continuously and regularly
   Click here to view the answer:

4. The risks of taking a ICS as prescribed are higher than the risks of NOT taking it
   Click here to view the answer:

5. ICS can cause a funny taste in the mouth
   Click here to view the answer:

6. Your child should rinse his or her mouth after taking an ICS to prevent thrush, a mouth infection that more often occurs with higher doses
   Click here to view the answer:

7. Short-lived hoarseness of the voice can occur with higher doses of ICS
   Click here to view the answer:

Fall

Often with the return of school comes the return of asthma symptoms. Children may have more sneezing, wheezing and coughing. They may complain of itchy, watery eyes. You may even start to notice dark circles under their eyes.

Not only has the cold and flu season begun, it's fall allergy time. In fact, ragweed pollen and mold spores peak in late summer and early fall. Mold can form in piles of rotting leaves or on damp soil. Pollen travels easily on a windy fall day. The best prevention is to keep your doors and windows closed and stay indoors on high pollen days. Fall is also the perfect time to get an annual flu shot.

important

Annual flu shot

The flu (influenza) is a dangerous infection caused by a virus. It can be very serious for children with asthma or other long-term health conditions. The best way to protect your child is to take him or her for a flu shot every year, starting at 6 months old. At first, your child may need two doses to be protected from the flu.

September 20

I completely messed up today! I took Sammy to his friend Jacob's house for a play date after school. Nila and I barely arrived back home when I got a frantic phone call from Jacob's mom. Sammy was having an asthma attack! Jacob's mom was panicked! I hadn't given her an inhaler or provided any instructions. I hadn't even told her that Sammy had asthma! I raced over, helped Sammy, and then apologized to Jacob's mom. I felt like the world's worst mother. What if his asthma attack had been more serious?

Finding a balance

Balancing asthma care with other family and work responsibilities can be hard. It is easy to forget that everyone caring for your child (like extended family, daycare and camp workers, teachers, and parents at play-dates) should be informed that your child has asthma. This includes giving information about the signs of an asthma attack, what to do if an attack happens, and when medical help is needed.

Asthma Fact!

Keeping yourself and your child as calm as possible and talking you child through an asthma attack are essential parts of managing asthma.

September 27

It's been a week since Sammy's attack at Jacob's and things still aren't great. I gave him his Ventolin, but I'm not sure it helped. We had to rush to the hospital twice! Yesterday, I admitted to the emergency department nurse I've been forgetting to give Sammy his orange inhaler. I felt terrible, but I'm glad I told him. The nurse was understanding, but stressed I must be more consistent. Then the doctor prescribed Sammy an oral steroid and referred us to an asthma clinic. Maybe they can help me get into a better routine.

Are "preventative" medications needed every day?

Preventative medication (inhaled steroids, like Pulmicort / budesonide or Flovent/ fluticasone) does not work right away. In fact, it may take weeks to lessen the swelling (inflammation) in the lungs and to make a positive difference for your child. That is why it is so important to remember to use it as prescribed, even if you don't notice a change right away.

Asthma Fact!

Research has shown that children often avoid physical activity and experience more asthma symptoms than parents expect!

October 8

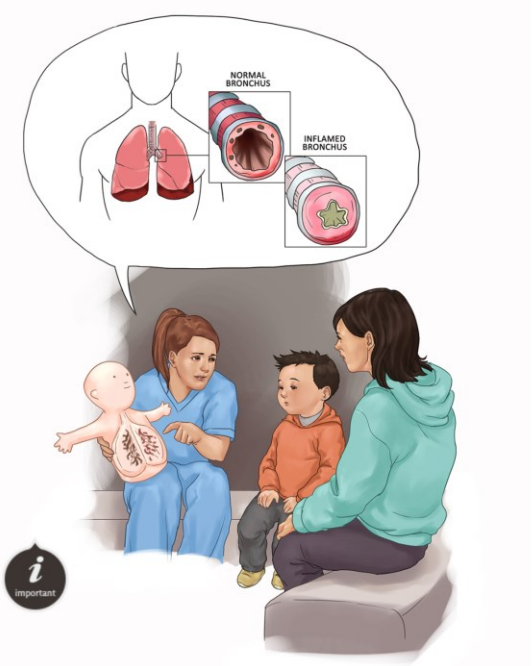
Sammy and I visited the asthma clinic this afternoon. We spent a full hour with the nurse. We talked about everything – our family medical history, our home environment, Sammy's asthma triggers, his symptoms, and his inhalers. I told her how Sammy's symptoms seem to get worse when he plays outside or with our cat, Bailey. I even told her about misplacing Sammy's inhaler and his attack at Jacob's house. It was such a relief to review it all with the expert health care provider. She was so reassuring and knowledgeable.

Asthma clinic

Asthma clinics provide specialty education about asthma and asthma management to you and your child. Not everyone is referred to an asthma clinic. You can ask your health care provider about an asthma clinic in your area and whether this is right for you.

I learned so much during the visit. The nurse made sure we were using the inhalers properly and gave us tips on how to avoid Sammy's triggers. She helped us create a step-by-step action plan to follow at home and gave me a bunch of information to read. Best of all, she used a model of the lungs to show us how the airways work and what happens during an asthma attack. It's going to take time to process all of this information!

We're going to keep in touch by phone. If all goes well, we will have our next appointment in six months.



What is a written asthma action plan?

A written asthma action plan is a key part of your child's asthma management and there are different types. Some are based on asthma symptoms and others are based on measures of lung function (how well the lungs work), like peak flow (a measure of the flow of air from your child's lungs).

A written asthma action plan can help you:

- Record important information and communicate with your health care provider
- Know when to give more or less medication
- Know which medications to use
- Know when to seek medical treatment

Asthma Fact!

Peak flow meters can be purchased over-the-counter at a pharmacy. These can help detect early changes in your child's lung function – even before you notice asthma symptoms! Ask your health care provider if this is a good choice for your child, before purchasing.

November 6

It's been about a month since our visit to the asthma clinic but I already notice a difference. Tahir and I both read the information the nurse gave us and I even posted an information sheet on the fridge. I'm starting to use the asthma action plan to track Sammy's symptoms – it's becoming routine! Plus, whenever Sammy goes to a friend's house, we give the "asthma emergency kit" I created to the parents.

Asthma may be part of our lives, but I'm starting to realize it doesn't have to be our life.

Asthma emergency kit

An asthma emergency kit includes items needed to help your child in the case of an asthma attack at school or in the community. It should include a:

- Rescue inhaler (like Ventolin)
- Spacer device
- Instructions on how to use the medication
- What to do in case of a severe attack
- A place to record what medications were given and when

You may also want to include a copy of your child's asthma action plan.

Asthma Fact!

A person with asthma that is well managed can accomplish a lot. Did you know that more Olympic athletes have asthma than any other chronic disease?!

December 8

Using the asthma action plan is helping. By tracking Sammy's symptoms, I can see they are definitely worse when Sammy and Bailey are together. I was hoping that extra vacuuming and keeping Bailey out of Sammy's room would be enough, but clearly they are not. Being inside thanks to the cold weather doesn't help, either. Tahir and I talked last night about taking Bailey to my sister's place for a few weeks as a test. It's upsetting to even think about it. Bailey has been with us since he was a kitten!

important

How do asthma medications work?

Breathing becomes harder when the muscles around the airways tighten during an asthma attack and extra sticky mucous is produced. "Rescue" medications, like Ventolin, relax these muscles and make it easier to breathe. These medications don't prevent asthma attacks or flare-ups. That is why "preventative" medications (like inhaled corticosteroids) are needed. When used regularly, these prevent the swelling from happening in the first place.

Asthma Fact!

The most common side effects of bronchodilator medication (like Ventolin) are tremors, shakiness, nervousness, and an increased heart rate. These can cause trouble sleeping for some children. Talk to your health care provider if you need help to manage these side-effects.

January 20

I got a call from Sammy's teacher today. He's coughing a lot during gym class, but says he feels fine. I remember reading that this can be a common sign for poorly controlled asthma. It makes me wonder if Sammy's medications need adjusting. Maybe he's outgrown his dosage? Or is it just that he's more active? Soccer season is just around the corner. I don't have time today, but I'm going to see if I can find some answers online. In the meantime, I think we better take Bailey to my sister's.

Can my child still be active?

Exercise can cause asthma attacks in some children. If exercise is a trigger for your child's asthma, you can safely use either short or long-acting bronchodilator medications (like Salbutemol / Ventolin or Formoterol / Foradil) as prescribed, before exercise.

Asthma Fact!

Canadian asthma guidelines state that as long as asthma is properly managed, children do not need to avoid or limit their physical activity, even if their asthma is severe!

February 19

Sending Bailey to my sister's house wasn't easy. We all miss him. Especially Sammy. After Bailey left, we cleaned the house from top to bottom. Sammy suggested if we kept the house super clean, maybe we could keep Bailey. Poor little guy. I wish it was that simple.

I've been giving Sammy his orange inhaler faithfully and tracking his progress on the asthma action plan. There's no denying it. Without Bailey, Sammy is improving, and he doesn't need his rescue inhaler as often. Tonight Tahir and I are taking him to the movies while my mother watches Nila. Some special time with us might help him miss Bailey a little less.

Monitoring symptoms

Sammy's mom is using the asthma action plan to monitor symptoms, inhaler use, and to identify asthma triggers. This is important since every child's asthma is unique in its type, pattern of symptoms, and triggers.

Asthma Fact!

Sometimes parents and children don't agree about what triggers an asthma attack or how often asthma symptoms happen. This makes is very important to talk with your child about asthma.

February 28

This afternoon the most amazing thing happened. I actually got a moment to myself. Tahir took the kids out and the house was mine for two whole hours. Although I was tempted to invite my friend, Amy, over for lunch, I went online instead and visited the asthma websites the clinic recommended. The information was so helpful and I even found websites made just for kids! Much better than the stuff I used to get "googling". I jotted down some great follow-up questions for the clinic. Plus, I even squeezed in a quick chat with Amy!

important

Is it okay to have these feelings?

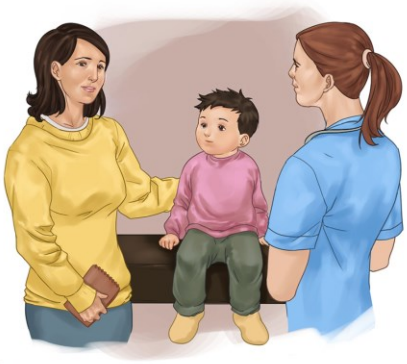
Many emotions and changes come with having a child with asthma. These emotions range from fear, anxiety, guilt and uncertainty to feeling happy, confident, and balanced. All of these feelings are normal and may change as asthma becomes a part of your family routine and everyday life.

Asthma Fact!

The Asthma Society of Canada has a website just for kids! Find it at asthmakids.ca

March 15

We had a follow-up appointment at the asthma clinic yesterday. This time I felt much more prepared! I had a list of questions for the nurse and took lots of notes when she explained how we should adjust Sammy's medicines based on his symptoms. I couldn't thank her enough for her help. We've all learned so much this past year. Even Sammy is getting used to his inhalers- he doesn't fight with me when I try to give them like he used to. Sure, we had to make some changes at home, but now things are really good. I know we can manage this.



important

Should I involve my child in asthma care?

Involving your child in asthma care can help him or her cooperate and take responsibility. You can try to:

- Start a routine: Give medication at the same time and place every day
- Give choices: Like giving medication before or after getting dressed. Remember, taking the medication is not a choice!
- Teach your child: Explain the medications and how they will help
- Encourage: Give specific praise after your child cooperates

Asthma Fact!

A child as young as 5 years old can become involved in his or her asthma care!

April 10

Today we went on a family bike ride. Sammy has become quite the speed demon. Tahir and I could barely keep up! When we got home, Amy called. They just found out her niece has asthma. Amy was hoping I could help. I told her that although I'm no expert, I do know where to get advice. I gave Amy a list of asthma websites and recommended that she talk to her health care provider about getting a referral to the asthma clinic that we go to. I said there's lots of professional help out there. You just have to ask!

There are resources to help you and your child manage asthma in your area. Going to see your family doctor or asthma clinic regularly is important, as the health care provider will know your child, their symptoms, and their medical history.

Asthma Fact!

Learning the ins-and-outs of asthma management can help you prepare your child to live with asthma - symptom-free!

MY ASTHMA DIARY

COPING WITH ASTHMA

Read Again Trekk.ca

This asthma book was made possible through the generous support of:

CCHCSP PCCCSE women & children's health research institute echo

Knowledge Translation Canada / Applications des Connaissances Canada trekk Translating Emergency Knowledge for Kids

Developer: Mandy Archibald, RN, PhD Candidate
Faculty of Nursing, University of Alberta
mma@ualberta.ca

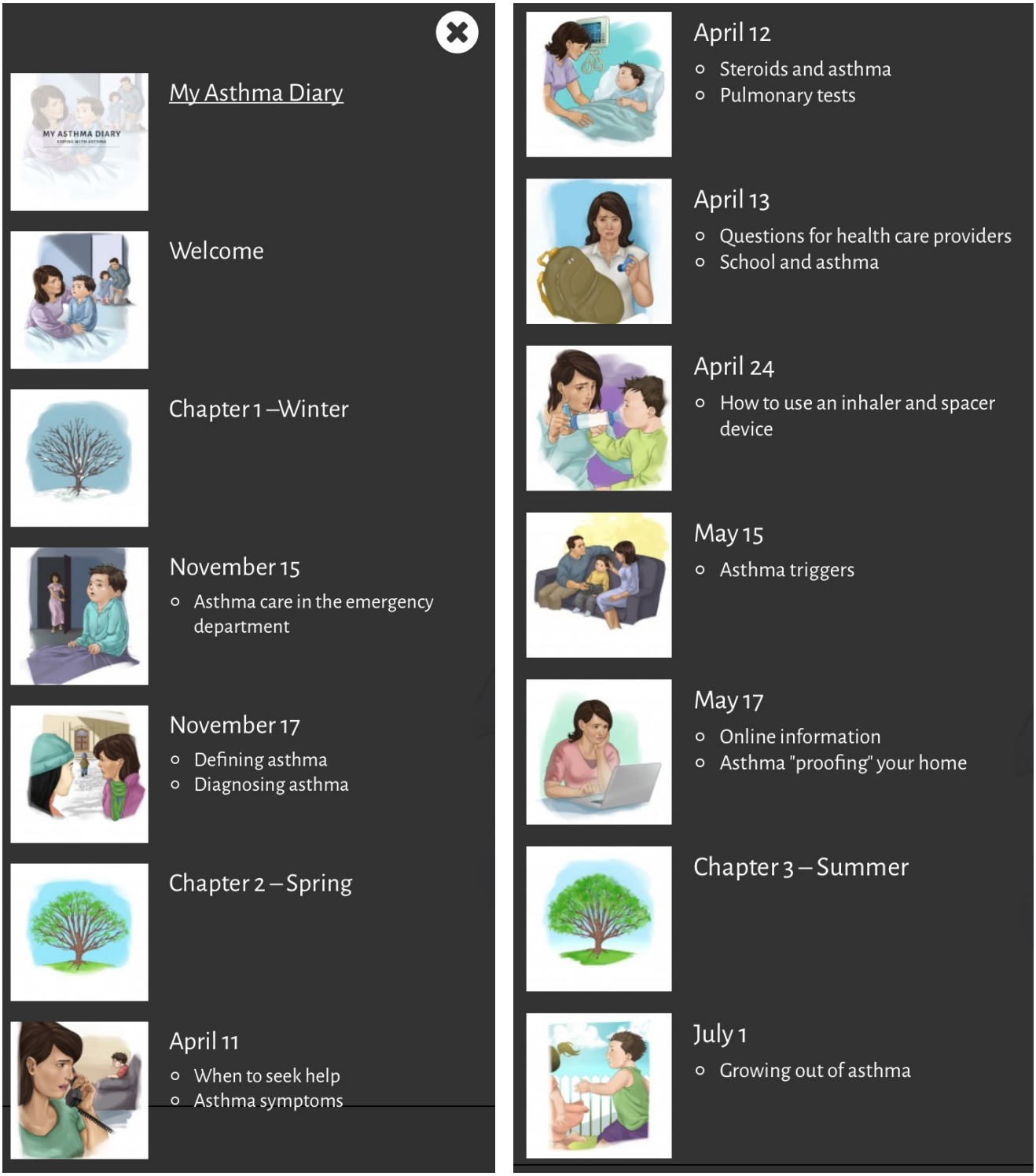
Illustrator: Lea Ragos Segarra

Creative Writer: Tina Marie-Powell

M. Archibald gratefully acknowledges the feedback received from her dissertation committee: Drs. Shannon Scott (RN), Lisa Hartling, Samina Ali (MD) and Vera Caine (RN)

Appendix E

Example of Table of Contents for Arts-Based Knowledge Translation Tool



Appendix F

Detailed Search Strategy

Database (date)	Key terms (limiters)	Total Results (*n* =)	Further Limiters (*n* =)	Preliminary Title Review
Cochrane Wiley (12/01/2011)	Asthma AND [chil* OR pediatri*] (reviews)	*n* = 221	2000-2011	*n* = 5
	'Health knowledge', 'patient education as topic', 'self-efficacy' AND 1 (2000-2011) *including all combinations of all above terms*	*n* = 1	None	*n* = 1
CINAHL (13/01/2011)	Needs AND paren* AND asthma	*n* = 91	None	*n* = 91
CINAHL (01/02/2011)	"information needs" (suggest terms)	*n* = 7189	AND paren* (*n* = 577) AND asthma	*n* = 13
Medline (29/01/2011)	"information needs" (suggest search terms)	*n* = 601868	AND "patient education as topic" *n* = 305 > title review> *n* = 54	*n* = 54
				Total *N* = 164

Appendix G

Methodological Quality of Included Qualitative Studies

Author (year)	Journal	Question 1	Question 2	Question 3	Question 4	Question 5	Total
Berg et al., (2007)	*Journal of Pediatric Health Care*	Y	Y	Y	Y	Y	5
Cashin et al., (2008)	*Journal of Pediatric Nursing*	Y	Y	Y	Y	N	4
Deis et al., (2010)	*The Journal of Asthma*	Quantitative	-	-	-	-	-
Koenig, K. (2006)	*Journal of Family Nursing*	Y	Y	N	Y	N	3
Martin et al., (2010)	*Journal of Health Care for the Poor & Underserved*	Y	Y	Y	Y	N	4
Meng & McConnell (2002)	*Journal of the American Academy of Nurse Practitioners*	Y	Y	Y	N	Y	4
Navaie-Waliser et al., (2004)	*Public Health Nursing*	Quantitative	-	-	-	-	-
Peterson-Sweeney et al., (2003)	*Journal of Pediatric Health Care*	Y	Y	Y	N	N	3
Yoos et al., (2003)	*Ambulatory Pediatrics*	Y	Y	Y	Y	Y	5
Yoos et al., (2007)	*Nursing Research*	Quantitative	-	-	-	-	-
Yoos et al., (2005)	*Journal of Pediatric Health Care*	Y	Y	Y	Y	N	4

Questions from Hutchinson, A. M., Mallidou, A. A., Toth, F., Cummings, G. G., Schalm, C., & Estabrooks, C. (2010). Review and synthesis of literature examining characteristics of organizational context that influence knowledge translation in healthcare: Technical report (10-01-TR). Edmonton, Alberta, Canada: University of Alberta, Faculty of Nursing.

[a]The screening tool utilizes the following five questions to assess for methodological quality:

1. Are the aims of the research stated clearly?

2. Is the research method appropriate for the research question?

3. Is the sampling appropriate and adequate?

4. Was an iterative process of collecting and analyzing data used? 5. Did the outcomes go beyond data description to substantive theory or conceptual framework?

[b]Instrument development.

Appendix H

Methodological Quality of Included Quantitative Studies

Question No.	Deis et al. (2010) *The Journal of Asthma*	Navaie-Waliser et al. (2004) *Public Health Nursing*	Yoos et al (2007) *Nursing Research*
1	Yes	Yes	Yes
2	Partial	Yes	Yes
3	Yes	Partial	Yes
4	Yes	Yes	Yes
5	n/a	n/a	n/a
6	n/a	n/a	n/a
7	n/a	n/a	n/a
8	n/a	Partial	Yes
9	n/a	n/a	Yes
10	Yes	Yes	Yes
11	Yes	Yes	Yes
12	n/a	n/a	n/a
13	yes	Yes	Yes
14	Partial	Yes	Yes
Summary Score	0.88	0.89	1.00

n/a, not applicable
Instructions for calculating summary score:
Total Sum= (number of "yes" x 2) + (number of "partials" x 1)
Total possible sum= 28 – (number of "N/A" x 2)
Summary Score: total sum / total possible sum
From Kmet, L., Lee, R. & Cook, L. (2004) Standard quality assessment criteria for evaluating primary research papers. www.ihe.ca/documents/HTA-FR13.pdf

Standard quality assessment criteria for evaluating primary research papers
Criteria
1. Question/objective sufficiently described? 2. Student design evident and appropriate? 3. Method of subject/comparison group selection or source of information/input variables described and appropriate? 4. Subject (and comparison group, if applicable) characteristics sufficiently described? 5. If interventional and random allocation was possible, was it described? 6. If intervention and blinding of investigators was possible, was it reported? 7. If interventional and blinding of subjects was possible, was it reported? 8. Outcomes and (if applicable) exposure measure(s) well defined and robust to measurement/misclassification bias? Means of assessment reported? 9. Sample size appropriate? 10. Analytic methods described/justified and appropriate? 11. Some estimate of variance is reported for the main results? 12. Controlled for confounding? 13. Results reported in sufficient detail? 14. Conclusions supported by the results?

Appendix I

Notification of Approval from Health Research Ethics Board

Health Research Ethics Board

308 Campus Tower
University of Alberta, Edmonton, AB T6G 1K8
p. 780.492.9724 (Biomedical Panel)
p. 780.492.0302 (Health Panel)
p. 780.492.0459
p. 780.492.0839
f. 780.492.9429

Notification of Approval (Renewal)

Date:	March 4, 2014
Amendment ID:	Pro00012779_REN5
Principal Investigator:	Shannon Scott
Study ID:	MS17_Pro00012779
Study Title:	Narratives for knowledge translation in child health: Assessing the informational needs of parents with a child with asthma (Stage 1)
Sponsor/Funding Agency:	Stollery Children's Hospital Request Fund
Approval Expiry Date:	April 7, 2015

Thank you for submitting this renewal application. Your application has been reviewed and approved.

This re-approval is valid for another year. If your study continues past the expiration date as noted above, you will be required to complete another renewal request. Beginning at 30 days prior to the expiration date, you will receive notices that the study is about to expire. If you do not renew on or before the renewal expiry date, you will have to re-submit an ethics application.

All study related documents should be retained so as to be available to the Health REB upon request. They should be kept for the duration of the project and for at least 5 years following study completion.

Sincerely,

Anthony S. Joyce, Ph.D.
Chair, Health Research Ethics Board - Health Panel

Note: This correspondence includes an electronic signature (validation and approval via an online system).

UNIVERSITY OF ALBERTA   Alberta Health Services   Covenant Health

Appendix J

Information Letter and Consent Form

UNIVERSITY OF ALBERTA

INFORMATION SHEET

Title of Research Study: Narratives for knowledge translation in child health: Assessing the informational needs of parents with a child with asthma

Background:
The goal of this research study is to identify the informational needs of parents with a child with asthma. The information that we acquire will help us develop and test resources for parents with a child/children with asthma. These resources have the potential to improve clinical outcomes and facilitate more selective and appropriate health-care utilization.

Purpose: You are being asked to take part in a study to help us find out the information needs of parents with a child with asthma are.

Procedures: *Participating in this study will involve:*
Either an individual interview that will last no longer than 60 minutes *or* a focus group interview lasting no longer than 90 minutes and conducted with 6-8 other parents. The interviews will be chaired by a researcher with experience in focus groups and qualitative methods. In either interview method you will be encouraged to express your views about what you want to know about asthma**. An individual will be present to record the interviews verbatim using specific equipment. We would like to tape record the interviews so we can look at your answers later. You will be asked for permission to do this at the beginning of the interview**. Answering the study questions are your choice. You do not have to answer any questions you do not want to.

Benefits and Risks: This study has no direct benefits to you. We hope the information you give will help us give the best information to parents of children with asthma. There are no expected risks from participating in the study. We may use this information in other studies. However, we will get ethics approval first.

Your privacy:

- Your name will not appear in any research data collected about you during this study, only your initials and a coded number.
- Your name will not be shared outside the research clinic.
- Any report published will not identify you by name.
- All information in this study will be kept for at least 7 years in a secured area. It will not be destroyed. The information may be looked at again in the future to help us answer other study questions. If so, the ethic board will first review the study to make sure that the information is used ethically.
- All information will be held private, except when professional codes of ethics or the law requires reporting (i.e. child abuse)

Voluntary participation

- You are free to choose not to participate and may withdraw from the study at any time without consequence

Questions: If you have questions or concerns about this study at any time, you may contact:

Mandy Archibald, Faculty of Nursing, (780) 982-8115, mma@ualberta.ca

PhD Student: Mandy Archibald, RN
Principal Investigator: Dr. Shannon Scott, RN
Study coordinator: Kathy O'Leary

Concerns: Please contact the **University of Alberta Health Ethics Board** at **(780) 492-0302** should you have any questions regarding your right as a participant in a research study.

CONSENT FORM

Part 1 (to be completed by the Principal Investigator):

Title of Project: Narratives for knowledge translation in child health: Assessment of the informational needs of parents with a child with asthma

Principal Investigator(s): Dr. Shannon Scott Phone Number(s): 780-492-1037

Project co-coordinator(s): Kathy O'Leary Phone Number(s): 780-492-2126

Part 2 (to be completed by the research subject):

	Yes	No
Do you understand that you have been asked to be in a research study?	☐	☐
Have you read and received a copy of the attached Information Sheet?	☐	☐
Do you understand the benefits and risks involved in taking part in this research study?	☐	☐
Have you had an opportunity to ask questions and discuss this study?	☐	☐
Do you understand that you are free to withdraw from the study at any time without having to give a reason and without affecting your future medical care?	☐	☐
Has the issue of privacy been explained to you?	☐	☐
Do you understand who will have access to your records?	☐	☐
Do you want the investigator(s) to inform your family doctor that you are taking part in this research study? If so, give his/her name _____	☐	☐

Who explained this study to you? _____

I agree to take part in this study: YES ☐ NO ☐

Signature of Research Subject _____

(Printed Name) _____

Date: _____

I believe that the person signing this form understands what is involved in the study and voluntarily agrees to take part in the study.

Signature of Investigator or Designee _____ Date _____

THE INFORMATION SHEET MUST BE ATTACHED TO THIS CONSENT FORM AND A COPY GIVEN TO THE PARENT

Appendix K

Interview Demographics Sheet

Study Title: Narratives for Knowledge Translation in Child Health: Assessing the Informational Needs of Parents with a Child with Asthma

Please Tell Us About Yourself. Place A Checkmark In the Box For Your Answer.

1) What is your gender? Male ☐ Female ☐

2) What is your relationship to the child with asthma?
Please circle one answer.
a. Parent b. Grandparent c. Other family member
d. Foster parent e. Adoptive parent

3) What is your Age?
a. Less than 20 years old b. 20-30 years c. 31-40 years d. 41 and up

4) What is your Marital Status?
a. Married b. Single c. Divorced d. Separated e. Widowed

5) What is your annual household income? (before taxes)
a. $20, 000 – $39, 999 b. $40,000-59,9999 c. $60,000 – $79,999
d. $80,000 – $99,999 e. 100,000 and up

6) What is your highest level of education?

- Did not finish High School ☐
- Completed High School ☐
- Attended College/Technical School ☐
- Graduated From College/Technical School ☐
- Attended University ☐
- Graduated from University with Bachelor's Degree ☐
- Graduated from University with a Graduate Degree ☐
- Other (Please Specify) ☐

7) How many children do you have? _____

8) What is the current age of your child with asthma? _____

9) How old was your child when they were diagnosed with asthma? ____

10) How long has your child had asthma? _____ months

Appendix L

Semi-Structured Interview Guide

Title of research study: Narratives for knowledge translation in child health: Assessment of the informational needs of parents with a child with asthma

1. Can you start by telling me about your experiences of having a child with asthma?
2. What did you understand about asthma when your child was first diagnosed?
    - What information were you provided with from health care providers when your child was first diagnosed? What, if anything, was helpful about this information?
    - When did they give you this information?
    - In what format did the health care providers give you this information? Written, verbal, demonstration, combination?
3. How would you have liked to receive this information?
4. How did this information influence your experience with your child's illness?
5. If your friend's child had asthma and she asked you for information, what would you teach her about it?
    - When would you give her this information?
6. Today, do you feel you have enough information about your child's asthma?
    - If no, what would you like more information on?
7. How has your learning needs changed over time (comparison between time of diagnosis and now?)
    - Better access to information?
    - Trusting partnership with health care personnel?
8. How has your confidence to manage your child's illness changed over time? What has influenced you confidence level over time?
9. What was your biggest fear for your child at time of diagnosis? How has that changed, when reflecting upon your fears of today?
10. What is one thing that you would like health providers to know about your experiences of living with a child who has asthma?
11. What is important to you in terms of your child's health outcomes?
12. How do you "define" when your child has a good day? E.g. Number of puffs per day? Parents being able to go to work? Child participating in sports?