ENHANCING PEDIATRIC HOME CARE IN NOVA SCOTIA: RESOURCES FOR HOME HEALTH PROFESSIONALS

by © Sarah T. King (Report) submitted

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Abstract

Background and Purpose: Pediatric patients are a growing population in the home health care sector in Nova Scotia. As a specialty domain of health care, the care of pediatric patients and their families presents challenges to home health professionals with an adult-focused practice. To enhance pediatric home care, it is necessary to identify and develop resources to optimize home care professionals' practice and improve patient outcomes.

Methods: I conducted a literature review to identify recent prescriptive pediatric home care research, then did an environmental scan of pediatric health centers and government home care programs in Canada to identify how pediatric home care education is provided. I also engaged in detailed consultation with home health professionals in Nova Scotia. As I compiled the results of my endeavors, I determined key subjects for pediatric home care resource development and identified relevant theoretical frameworks.

Results: Pediatric home care resources are needed for the care of rare and complex pediatric populations, and for more common home care situations that require a pediatric lens. Specifically, this includes the care of children and youth with complex health conditions, patients receiving palliative and end-of-life care, family assessment, and effective communication. By searching the literature and reputable websites, and by leveraging existing materials, I identified, evaluated, and compiled resources. I also developed several resources where no suitable options existed. All identified resources were evaluated in light of relevant theoretical frameworks.

Conclusion: The development of pediatric home care resources, though challenged by the emerging nature of this population, is essential to optimize care for patients and families.

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Enhancing Pediatric Home Care in Nova Scotia:
Resources for Home Health Professionals

Pediatrics is an established specialty domain of health care, commonly defined as the care of children and youth aged 0 to 19 years, and their families. In home care, pediatrics often comprises a small proportion of patients, so their specialty care may be less familiar to home health professionals (Foster, Agrawal, & Davis, 2019; Smith, 2011). The Canadian Home Care Association (CHCA) has noted needs and gaps for the smaller population of pediatric home care patients, and particularly, for patients with special health care needs (CHCA, 2016b). Pediatric home care is "an emerging need" (Smith, 2011, p. 108), and a realm of care that requires diligent planning and collaborative partnerships between acute and community care to promote ideal outcomes (McCormick et al., 2015; Norman & Crill, 2011). To ensure pediatric patients and their families receive the best home care possible, the health professionals who care for them need targeted education and support. In my position as liaison between acute care pediatrics and pediatric home- and community-based care in Nova Scotia, it is clear that home health professionals need and want to learn more about pediatric care in the home.

In Nova Scotia, the two largest groups of health professionals involved in pediatric home care are care coordinators and home care nurses. Care coordinators are multi-disciplinary health professionals who assess patient and family needs and oversee home care resource distribution based on established policies (Continuing Care, 2013). Home care nurses provide direct care to patients in the home, such as intravenous medication administration, wound care, and respite. Although there are many health professionals who support pediatric home care, I focused on care coordinators and home care nurses for my practicum project. This will allow me to address the learning needs of a large group of home health professionals who see pediatric patients with the greatest frequency.

The overarching goal of my practicum was to develop educational resources on pediatric care to support the practice of home health professionals, which will ultimately enhance pediatric home care experiences and outcomes for patients and families. Within this goal, my specific objectives were: to describe the challenges faced by home health professionals with an adult-focused practice caring for pediatric patients; to identify existing pediatric educational resources for home health professionals with an adult-focused practice; and to compile and/or develop educational resources on pediatrics suitable for home health professionals in Nova Scotia.

In this final report, I will outline the general methods of my practicum project, including summaries of my literature review, environmental scan, and consultations. Next, I will present the pediatric resources that I compiled and developed for home health professionals in Nova Scotia. To reflect on my practicum, I will discuss my work in light of the Canadian Nurses Association (CNA) (2008) competencies for ANP, and I will conclude by presenting future plans related to my practicum.

Overview of Methods

The question of developing resources to support pediatric home care comprises a vast subject area. To ensure I narrowed this subject area to an achievable yet relevant focus, it was clear that I would need to engage in detailed consultation with home health professionals in Nova Scotia regarding their learning needs and preferences. Based on prior experience, I knew that the pediatric home care literature was not abundant, so a literature review on its own would not provide enough guidance to inform my project. As a consequence, in addition to the requisite literature review, I decided to conduct an environmental scan across Canada. The focus of this scan was to determine how pediatric home care education was being provided by pediatric health centers, within provincial home care programs, and from the perspective of national organizations.

Summary of Literature Review

Literature reviews are an important means to systematically search for, assess, and evaluate published scholarly materials in a given subject area (LoBiondo-Wood & Haber, 2013; Polit & Beck, 2017). Although I anticipated a limited scope of pediatric home care literature, it was still important to determine the state of the current literature. The theories of family-centered care (Kuo et al., 2012) and Carper's fundamental ways of knowing (Carper, 1978; White, 1995) were key in framing and interpreting the results of this literature review. Together, these theories represent the family-centered foundation of pediatric care, and the myriad ways that health professionals can gain knowledge to inform practice. The full text of my literature review is included in Appendix A.

For my literature search, I combined broad search terms referencing "home health care" and "pediatrics" to search the Cumulative Index of Nursing and Allied Health Literature (CINAHL) and the Cochrane Library. I searched the most recent literature from 2009 to 2019 to capture the most updated trends in pediatric home care. I retrieved articles from Canada and the United States that were written in English, and I applied exclusion criteria to ensure selection of primary research articles of a prescriptive or directive nature that were focused on pediatric home care. I used established appraisal tools, the Public Health Agency of Canada (PHAC) Critical Appraisal Toolkit (2014) and the Critical Appraisal Skills Programme (2018), to evaluate the articles that passed my initial screening. In total, I included 10 articles in my literature review.

My initial analysis included noting trends in key study information such as the main subject areas, designs and methodologies, and aims. The most prominent pediatric home care subject areas were the care of rare and challenging pediatric patient populations (e.g. patients who depend on medical devices and technology for survival, patients receiving palliative and end-of-life care), and adding a pediatric lens to common home care scenarios (e.g. nasogastric tube care, safety in home care). In terms of designs and methodologies, the literature had an equal proportion of quantitative and qualitative studies, such as interviews and surveys. The authors' prescriptive or directive study aims included improving pediatric home care by establishing best practice guidelines or by using clinical tools such as a discharge checklist.

Next, to engage in more detailed inquiry, I used thematic analysis to distill the most important ideas from the literature, with a focus on individual and collective study results. Six themes were present in the literature. The first theme was the presence of similarities and differences when comparing pediatric and adult home care. Similarities included the importance of the patient's overall health status and recent hospital discharge in determining the allocation of home care resources. Differences included the higher influence of overall family coping and support in the allocation of pediatric home care resources when compared to adult patients. The second theme was the importance of family and health professional experiences with pediatric home care. These experiences represent a valuable data source for informing home care practice. The third theme was the deeply contextual and multi-factorial nature of pediatric home care. Inherent in pediatric home care is the need for particular understanding of the pediatric patient's health condition and home care needs as well as their personality and coping, intertwined with the needs, coping mechanisms, and stressors faced by the entire family. In addition, there is often overlap between pediatric home care planning and the larger community, such as daycares and schools. The fourth theme is that even common home care situations require specialized pediatric advice. Despite having familiarity with a home care situation, such as central line care and use, home health professionals must also understand how a child's or youth's emotional, developmental, and physiological differences affect overall care. The fifth theme is centered on a particular population, namely, pediatric patients with complex medical needs. Home care for patients with rare and complex health conditions and technology dependence presents unique challenges and learning needs for home health professionals. The literature showed that education for home health professionals, standardization of practice, and partnership with families are required to ensure safe and effective care for this vulnerable population. The last theme was the need for close partnership between acute care pediatric experts and health professionals working in home care to provide initial and ongoing support when pediatric patients are discharged from hospital. In summary, the identified themes show a combined need for a standardized or systemized approach to pediatric home care, along with flexibility and openness. Standard care paths and guidelines for complex pediatric situations and systematic partnerships between acute pediatric care and home care are essential, as are openness and flexibility in considering the personal and family context of pediatric patients and unique needs associated with complex pediatric health conditions.

When considering the overall state of the literature, there is not an abundance of prescriptive or directive literature pertaining to pediatric home care. However, the appropriate use of qualitative research to inform an emerging practice domain, along with the richness and rigor of existing qualitative studies, is encouraging. Likewise, the concerted efforts of researchers to use their findings to inform best practice in pediatric home care shows a befitting link between research and practice. An additional key strength of the literature is the use of family and health professional voices to shed light on the realities of pediatric home care. There are a number of weaknesses in the literature as well. Limited reporting of data collection and data analysis in certain studies, limited description of measures of rigor in certain studies, a need to use more valid and reliable tools in quantitative research, and a need for theoretical frameworks to bolster research are noteworthy gaps. Also missing from the literature is the voice of pediatric home care patients themselves, as well as multi-disciplinary home health professionals. The identified weaknesses in the literature could be easily addressed in future research. Fortunately, the need for ongoing pediatric home care research was widely recognized by researchers in this literature review.

Theoretical support from Carper’s fundamental ways of knowing and principles of family-centered care enhanced the findings of this literature review. Carper’s (1978) fundamental ways of knowing include empiric, personal, ethical, and esthetic knowing, with the later addition of sociopolitical knowing by White (1995). Throughout the literature there were many examples of each of the ways of knowing, therefore, these same concepts must be included in the development of educational resources for pediatric home health professionals. In addition, the principles of family-centered care were prominent in the literature. These principles include the essential and central role families play in the care of pediatric patients, acting as collaborative partners and decision-makers with the health care team (Kuo et al., 2012). The development of pediatric home care resources must reflect these foundational ideals of pediatric health care.

When I reflected on the results and analyses of this literature review, along with the noted theoretical frameworks, I was able to identify implications for educational resource development in pediatric home care. First, the experiences of health professionals pertaining to pediatric home care were necessary to inform resource development. This finding underscored the importance of my planned consultation process. Second, two key subject areas for pediatric home care were the care of patients with rare and challenging conditions, and the need for pediatric considerations to frame more common home care scenarios. Third, it was important to leverage existing resources and partnerships between acute care pediatrics and home care to determine possible educational resources and formats. This finding was consistent with my planned environmental scan of pediatric health centers and home care programs across Canada. Lastly, the principles of family-centered care and Carper’s fundamental ways of knowing were clearly identified throughout the literature review, meaning these same principles must inform the development of pediatric resources for home health professionals.

The literature on pediatric home care was limited in quantity and scope, but with diligent analysis, it was possible to identify valuable and relevant information. Importantly, I was able to identify key subject areas and considerations to validate and inform the next steps of my practicum project, an environmental scan and consultation.

Summary of Environmental Scan

An environmental scan is a type of investigation whereby an author reviews programs, practices, regulations, roles, structures, and/or any other factors linked to a particular question, for the purposes of development and strategic planning (Rowel, Moore, Nowrojee, Memiah, & Bronner, 2005; Washington State Department of Health, 2011). The driving question for my environmental scan was, "How is pediatric home health care education being provided across Canada?" To answer this question, I searched for information in the context of pediatric health centers, provincial home care programs, and national organizations. To promote consistency and focus in my data collection, I used a set list of questions to inform conversations with health professionals and searches of relevant websites. My set list of questions reflected my specific objectives, namely, to find examples of pediatric educational programs for adult-focused home health professionals, such as theoretical frameworks, education delivery methods, specific subject areas, means of building confidence in pediatric care, and any other relevant considerations for education within a home-based practice. The full text of my environmental scan is included in Appendix B.

I searched the websites of three Canadian pediatric health centres: The Janeway Children's Health and Rehabilitation Centre in St. John's, Newfoundland and Labrador, The Hospital for Sick Children in Toronto, Ontario, and the British Columbia Children's Hospital in Vancouver, British Columbia. I searched the websites of three Canadian provincial home care programs: The Extra-Mural Program in New Brunswick, Local Health Integration Networks in Ontario, and Continuing Care in Alberta. I also searched the websites of two Canadian national organizations, Children's Healthcare Canada (CHC) and the CHCA. Though I was able to find only limited information pertaining to my questions on the health centre and provincial home care program websites, I was able to find a great deal of relevant information on the national association websites. With this outcome, I needed to speak directly to health professionals at health centres and home care programs to gather more data in these areas. Using my own personal contacts and information online, I was able to set up email or telephone conversations with several health professionals across these various organizations and collect the necessary data to inform my practicum project. I took detailed notes during each conversation to ensure accurate recall of discussion points.

To analyze the data, I identified and catalogued pediatric home care education subjects, frameworks and theories used in home care education, and home care education delivery methods. I then considered overall trends, domains of care, and implications for home care education. In total, I identified 17 pediatric home care education subjects in five overarching domains: technology and medical devices (e.g. home ventilation), skills (e.g. urinary catheterization), health conditions and domains (e.g. children with medical complexity), care and communication approaches (e.g. family-centered care), and other subjects (e.g. vicarious trauma). There were 9 theories or frameworks used within pediatric home care education, the most prominent of which were principles of adult learning, simulation-based education, active and experiential learning, and family-centered care. In terms of education delivery methods, the most common trends were in-person education, written material in paper format, e-learning modules, live webinars or telehealth sessions, recorded webinars or videos, written material available online, phone calls to collaborate with other health professionals, and standardized checklists, policies, and procedures.

Next, I used thematic analysis to consider the data as a whole, and identify overarching implications for pediatric home care education. The results included eleven implications or considerations: (a) pediatric home care education was influenced by the resources and structures inherent to health centers and home care programs, such as whether an educator is available or whether there is a dedicated pediatric home care team; (b) the setting of each home care program and health center was tied to the available pediatric home care education resources with more resources being available in highly-populated areas; (c) the timing of pediatric home care education was predominantly focused on when new patients are coming home from hospital, although continuing competence and other ongoing education initiatives were also present; (d) the role of home health professionals influenced pediatric home care education, with most education being focused on the home care nursing role; (e) pediatric home care education and resources must be customizable to reflect home health professionals' learning needs, and flexible, with a variety of possible education and resource options to reflect different learning preferences and support learning within busy home care practices; (f) partnership between acute care pediatric professionals and home health professionals was essential to support ongoing education; (g) technology such as e-learning and online resources were commonly used to support pediatric home care education; (h) theories and frameworks, particularly adult learning principles, were used to undergird pediatric home care education; (i) more complex pediatric home care education subjects were taught by acute care pediatric specialty health professionals whereas more basic pediatric education such as wound care was more often taught by home care agencies; (j) many discussions of pediatric home care education included overlapping discussions about pediatric health care needs in the school setting; and (k) pediatric home care education had multi-sectoral implications that touch acute care, home care, and educational realms.

The results of my environmental scan showed that there is significant diversity in pediatric home health care education and resource development across Canada, so there must be diversity in associated educational resources. Although my results were not definitive given the limited scope of this scan, I still made relevant conclusions for my practicum project. I was prepared to develop personalized resources that attended to home health professionals' educational needs and preferences, and resources that would be delivered using a variety of flexible methods. It was also encouraging to note similarities in results between my literature review and my environmental scan, such as the prominence of educational needs pertaining to rare and complex pediatric populations, and pediatric considerations for common home care situations. Given the emphasis on personalized education that reflects home health professionals' learning preferences, it was appropriate to move on to a detailed consultation process with home care nurses and care coordinators in Nova Scotia.

Summary of Consultations

To ensure the development of pertinent and impactful pediatric home care educational resources, a consultation to assess learners' needs and learning styles was warranted. As previously outlined, the two groups of home health professionals in Nova Scotia who have the most frequent contact with pediatric patients are care coordinators and home care nurses. In my consultation process, I planned to not only engage in consultation with home health professionals themselves, but also with managers and other leaders for each group of health professionals. The full text of my consultations is included in Appendix C.

The first step in my consultation was conducting focus groups, one for managers of care coordinators and one for managers of home care nurses. If managers were unable to attend the online focus groups, I arranged individual conversations online or by phone. In total, I spoke with seven managers of home care nurses and seven managers of care coordinators from across Nova Scotia. I used a set list of questions to ensure consistent data collection and I took detailed notes to ensure accurate recall. The questions I used for the focus groups had much in common with the questions from my environmental scan, as I continued to seek information about key pediatric home care subjects and educational resource delivery methods. I used thematic analysis to uncover ideas and trends in the data.

The second step in consultation was conducting online needs assessments, one for care coordinators and one for home care nurses. At the end of a two week assessment period, I had responses from 39 care coordinators and 75 home care nurses from across Nova Scotia. The online needs assessment platform provided me with frequencies and percentages of responses to the survey questions, as well as text answers from questions that had a free text option. I used thematic analysis to interpret the free text data.

My consultation process yielded a rich and vast volume of data. The managers of care coordinators said their staff struggle with pediatric patients because they are not always a frequent part of their caseload, and because they present different challenges than adult patients. Examples of these differences included the large and complex care plans for children and youth with complex health conditions and technological dependence, the need for cross-sectoral collaboration with schools and the department of community services, a need for more detailed family assessment and information, and differences inherent to pediatric care, such as the differences between pediatric and adult palliative care. Care coordinators often feel overwhelmed at the prospect of a pediatric patient. Common education and resource delivery methods were identified as quick-reference documents available online, live and recorded videos and webinars, links for online resources, and direct consultation with health professional experts.

The managers of home care nurses noted a variety of common home care scenarios for which their nurses might need pediatric advice and education, as well as the more anxiety-provoking situations of caring for a child or youth with medical complexity and technological dependence, or a child or youth receiving palliative care. Managers also said their nurses sometimes struggled to conduct family assessments using existing adult-focused tools, or to communicate with families when difficult conversations were needed. Some nurses told their managers they worried that families did not have confidence in them, and their own worries and anxieties sometimes clouded their problem solving abilities. However, home care nurses did benefit from contacts in pediatrics they can call for advice, structured guidelines for pediatric home care, and online resources that are quick and easy to access a mobile phones during their work day.

Care coordinators provided direct feedback via an online needs assessment, beginning with the identification of pediatric home care subject areas they wanted to learn about. These most prominent subject areas included pediatric family assessments, communicating with and building rapport with pediatric patients and families, children and youth with medical complexity, and pediatric palliative and end-of-life care. Care coordinators preferred to learn by accessing videos, self-directed learning such as exploring a website, or reading a guide or pamphlet. Some also expressed preferences for webinars, standardized checklists, or policies.

Home care nurses were also interested in a variety of pediatric home care subjects, such as pediatric family assessments, communicating with children and families, pediatric palliative and end-of-life care, children and youth with medical complexity, in-home medical technology, pediatric enteral tubes, and pediatric medication management. Their preferences for resources and learning included in-person training on pediatric skills, as well as videos, self-directed learning, reading a guide or pamphlet, exploring a website, watching webinars, using case studies, and having standard checklists and policies.

When I considered the data from the entire consultation process, a number of themes were evident: (a) a lack of consistent exposure to pediatric patients in the home care sector created professional challenges for learning as well as emotional challenges around confidence and even anxiety; (b) learning needs had some connection to individual roles, with care coordinators having a greater interest in system navigation and cross-sectoral partnerships and home care nurses having a greater interest in skills and tasks; (c) although there was some variation in specific subject areas between the two groups, several broad subject areas were of interest to both groups -- children and youth with medically complex health conditions, children and youth receiving palliative and end-of-life care, enhancing communication with pediatric patients and families; and pediatric family assessments; and (d) given the autonomous and time-limited practices of both groups of home health professionals, it was important to have a variety of quick-reference resources to support pediatric home care learning.

The consultation process served to confirm and focus my findings from the literature review and environmental scan, so that I was prepared to move forward with the development of a resource repository to support best practice in pediatric home care. It is essential to note that the consultation has helped ensure that the resources will be in keeping with learning needs and preferences of home health professionals in Nova Scotia.

Resource Development

My resource is entitled “Pediatric Resources for Home Health Professionals in Nova Scotia”, and its full text and accessory documents are contained in Appendix D and Appendix E, respectively. This document is a resource repository designed to be applicable to the busy and autonomous practices of home health professionals in Nova Scotia who often have minimal pediatric backgrounds, and encounter pediatric patients on an infrequent basis. The resource repository itself was developed as a PDF document so that it can be easily uploaded to websites accessible to home health professionals, downloaded to a mobile device, or printed in paper form. The resource repository has six sections, reflecting the subject areas of greatest interest to home care nurses and care coordinators. The sections are: (a) Pediatric Communication Basics: Building Rapport and Explaining Health Information; (b) Pediatric Communication: Patients with Neuro-Developmental Challenges; (c) Procedures and Distraction in Pediatrics; (d) Pediatric Palliative and End-of-Life Care; (e) Children and Youth with Medical Complexity; and (f) Pediatric Family Assessment Resources. Each section contains an introductory paragraph followed by multiple resources, such as links to online documents and videos, webinars and podcasts, and resource websites to explore. The resource listings in each subject section are housed in a simple table that lists the resource title, a brief description of the resource, instructions on how to access the resource, and best uses for the resource, such as a 5 minute review, a 10 to 15 minute refresher, or 30 to 60 minute in-depth learning.

The majority of the resources identified in the resource repository were leveraged from existing reputable sources, such as the literature, pediatric health center websites, and established resource websites. However, several resources required to support pediatric home care practice in the Nova Scotia context were not available. Either resources were not available in a specific subject area, the format was not conductive to being easily accessible to busy home health professionals, or the content or format was focused on hospital or specialty pediatric domains rather than home care. For this reason, I developed five accessory documents, included in Appendix E. These documents are contained within the larger resource repository, in the form of hyperlinks to these documents, which have been posted online. The five documents I developed are: (a) Tips for Building Rapport with Children and Youth; (b) Practicing Building Rapport with Children and Youth; (c) Communicating with Children and Youth with Neuro-Developmental Challenges; (d) Tips for Procedures and Distraction in Pediatrics; and (e) a Pediatric Family Assessment Tool, which is available in tabular format for ease of charting, or as a list of questions to guide home health professionals' conversations.

In the following pages, I will outline how the resources I developed reflect the theories of family-centered care (Kuo et al., 2012), Carper's fundamental ways of knowing (Carper, 1978; White, 1995), and adult learning theory (Candela, 2016). I will also explain how the resources reflect the findings of my literature review (Appendix A), environmental scan (Appendix B), and consultations (Appendix C).

Family-Centered Care

Family-centered care is a foundational theory in pediatric health care, as evidenced by its prominence within my literature review and environmental scan. At its core is the knowledge that the family is the context for every pediatric patient, and that to know and care for the patient in an effective and relevant way, the health care team must know and care for the family as well. In practice, family-centered care includes open information sharing, respect for diversity and preferences, honoring differences, partnership and collaboration with families at their level of choosing, negotiable or flexible outcomes of care plans, and decisions and care plans that reflect the child in the context of their family, community, home, school, and other activities (Kuo et al., 2012).

In the pediatric resource document, an entire section was devoted to pediatric family assessments in the home care setting, reflecting the centrality of family-centered care in this project. Without effective resources to assess and support families, home health professionals will simply not be able to provide optimal care for pediatric patients, a need that was identified by Nova Scotia home health professionals in the consultation process. In addition, the principles of family-centered care were represented in every section of the resource document. For example, in the section on children and youth with medical complexity, I included videos that explore the experience of a family with a medically complex child (Open Pediatrics, n.d.). These videos will help home health professionals appreciate the context of such families, promoting a greater understanding of pediatric patient diversity and differences, realizing the need to negotiate flexible outcomes given the complex care needs at play, and learning how to partner with these families in a meaningful way. Input from and partnership with families is also woven throughout the supplemental documents I developed. Partnership with families is necessary to build rapport with pediatric patients, communicate with children and youth with neuro-developmental challenges, and use effective distraction during a procedure. An example of partnership is noted when a home care nurse needs to do a procedure. One of the initial steps in preparation is to elicit feedback from the family about what has worked well or not worked well with past procedures, and to determine specific roles for family members to support the patient during the procedure. Thus the home care nurse partners with the family to plan for the procedure and the distraction needs for the patient.

One of the most important family-centered components of the pediatric resource repository for home health professionals is the pediatric family assessment tool. Although many family assessment tools and frameworks are in existence, most are meant for specialty situations, such as health professionals who work in family therapy or with families in the inpatient oncology setting. Such tools are detailed and often lengthy, and do not focus on the types of information that a home health professional requires to build a relationship with pediatric patients and families in their home environment. A home health professional needs an efficient, effective, and customizable way to elicit contextual patient and family information relevant to building a relationship while providing care and support to the patient at home. Despite concerted searching, I could not find a relevant tool. Instead, I used templates and information from existing Nova Scotia home care assessment tools, along with relevant research, to develop a new tool.

The pediatric family assessment tool consists of a single-page assessment that should be used for all home care patients to obtain basic information and determine the impact of the illness on the patient and family. Instead of adult-focused questions, “Does the patient have a spouse or children?”, “What is the patient’s employment?”, and “How is the patient coping with their illness?”, the questions have a pediatric family-centered lens. “Who lives in the home with the patient?”, “Does the patient have siblings?”, and “Does the patient attend daycare, preschool, or school?” are more pertinent questions for young patients. Also, many of the questions prompt the home health professional to ask the patient the question if they are developmentally able to respond, as well as asking a parent or guardian. This simple step reflects family-centered principles of open information sharing and partnership. It is important to involve children in their care plans even from a young age, and to realize that in a family-centered context there may be differing opinions between pediatric patients and their parents or guardians. It is not always enough to ask only the parent how the child is coping, as even a 4 year old child could respond to a simple question of, “What was it like when you were in the hospital?” or “What was it like to have nurses come to your house to check the bandage on your leg?”. The family assessment tool also includes sub-sections, one recommended for all patients to assess family coping and functioning, and sub-sections for specific scenarios of pediatric patients with chronic illnesses, children and youth with medical complexity, children and youth receiving palliative care, and children and youth receiving end-of-life care. The impacts of these situations on the patient and family require careful assessment to ensure the home health professional understands patient and family wishes, and that care planning and outcomes of care reflect mutual understanding and partnership.

In summary, family-centered care is inseparable from all aspects of pediatric care. It is therefore suitable that the principles of this theory are present within each saubject domain of pediatric resources for home health professionals, and that family-centered assessment comprises an entire subject area of focus for pediatric home care resources.

Carper’s Fundamental Ways of Knowing

Carper’s (1978) fundamental ways of knowing is a well-established nursing theory that outlines four domains of knowledge required for an informed and holistic practice:

empiric, personal, ethical, and esthetic knowing. A later addition to Carper's work is the domain of sociopolitical knowing (White, 1995). Although this is a nursing theory, its principles focused on acquiring and developing a full and complete knowledge base to inform and plan patient care are compatible with the multi-disciplinary home care environment. Home care is a particularly contextual domain because health professionals are working within the patient's own home as the care setting, therefore, developing myriad ways of knowing is well-suited to this type of practice. In addition, the focus of my practicum project is growing and enhancing the pediatric knowledge of Nova Scotia home health professionals, so a focus on knowledge acquisition is an ideal theoretical base. I used Carper's fundamental ways of knowing to frame my literature review and clearly identified examples of each way of knowing despite a small body of pediatric home care literature. In order to respond appropriately to this degree of theoretical support, I knew it would be essential to represent the ways of knowing in the pediatric resources I compiled and developed for home health professionals.

Empiric knowing reflects scientific facts, principles, laws, and any information that is designed to explain or control (Carper, 1978). A number of resources in the resource repository reflect scientific facts and principles that are not subject to negotiation, such as the videos that reflect aseptic technique for tracheostomy changes or principles of air flow in home mechanical ventilation (Open Pediatrics, n.d.). Even the more contextual resources contact factual information, such as questions in the pediatric family assessment tool that note what grade the patient is in and whether a parent is employed outside the home. Tips and resources on communication with pediatric patients are based on principles of healthy child development, a series of principles that are designed to explain, predict, and guide communication. Finally, information websites like Orphanet (2019) contain factual information on rare health conditions and drugs that a home health professional may encounter when caring for the population of children and youth with medical complexity. The scientific principles and laws of anatomy, physiology, pathophysiology, and pharmacology are important to ensure full knowledge and understanding for home health professionals caring for pediatric patients.

Personal knowing includes the health professional's self-awareness and capacity for genuine interaction with and acceptance of the patient and family as their true selves (Carper, 1978). Self-awareness is a key starting point in the tip sheet on procedures and distraction in pediatrics that I developed. Home health professionals must be aware of their own learning needs and their own worries and anxieties before they can proceed in planning for a procedure in the home. Their learning needs must be addressed, and they must be able to either remedy or set aside their anxieties to allow a true focus on the patient and family. Without this specific attention to self-awareness, the chances of an optimal experience for in-home procedures is certainly reduced, as the home health professional can be overcome by the thought of "doing something unpleasant to a child", as opposed to focusing on how to support the child and family during an important and necessary task. Knowing the patient and family as their true selves and in their personal context is the purpose for the pediatric family assessment tool I developed. In the sub-section on pediatric patients with chronic illness, I included a comment that family patterns that might be considered less-than-ideal or even dysfunctional in an average family, such as a strict daily schedule, can actually be functional in a family whose child has a chronic illness. This is because the strict schedule may help promote the child's best health, such as a child with diabetes who requires predictable meal times to promote blood sugar control, or a teenager with ulcerative colitis, whose medications needs to be taken at a consistent time of day.

Ethical knowing includes an awareness of values, motives, and intentions inherent to a situation, and a sense of right and wrong in a situation (Carper, 1978). Values and intentions are particularly present in the domains of palliative and end-of-life care. The importance of assessing values during palliative and end-of-life care is noted both in the associated sub-sections of the pediatric family assessment tool, as well as in the resources in the associated section of the pediatric resource repository. The values of the home health professional may or may not match those of the patient or family, but it is incumbent upon the professional to be aware of any differences and to keep the patient's and family's values and motives at the forefront of care. Resources such as the video case study on pediatric palliative care help home health professionals appreciate how one family's values and motives both evolve and remain the same over the course of their child's three-year involvement with the palliative care service (Children's Hospital of Philadelphia, 2019). A sense of values and of right and wrong are also part of how health professionals communicate with pediatric patients. In the not-too-distant past, children and youth were often kept in the dark about their own health care situations, such as the nature of upcoming procedures or even their disease prognosis. It is now an ethical value of pediatric health care that children and youth should be involved in every aspect of their health care and have a clear understanding of their health situation, according to their level of developmental understanding (Kuo et al., 2012). It is not considered ethical to withhold information from a pediatric patient as this can actually add to their distress. The ethical principles of involvement and clear communication with all children and youth is noted in the extensive focus on communication with children and youth in the pediatric resource repository, such as the tip sheet on building rapport with children and youth, and the tip sheet on communicating with children and youth with neuro-developmental challenges. The information in these tip sheets I developed reflects the central importance of engaging with children and youth of all ages and all levels of understanding, and knowing how to communicate with them as a foundation to effective practice for all home health professionals.

Esthetic knowing builds upon and synthesizes the prior ways of knowing, so that the health professional has a contextual understanding of each situation, making them able to use creativity, discovery, imagination, and empathy to find and promote meaning and wholeness for patients (Carper, 1978). In my personal experience, esthetic knowing that uses contextual understanding along with creativity, imagination, and empathy is central to much of pediatric health care. In the resource repository, the section on procedures and distraction reflects esthetic knowing in a variety of ways. One video shows ways parents and health professionals can work together to help a pediatric patient cope during a procedure (University of Illinois Children’s Hospital, 2017). The ways chosen to support and distract the children in the video reflect a contextual understanding of that patient and their health situation, including their response to prior procedures. Health professionals and parents are often using creativity and imagination during the distraction process as they use books, toys, and videos that capture the child’s attention to allow the procedure to take place. Importantly, this video and others such as The Power of a Parent’s Touch (IWK Health Centre, 2014) show how central a parent’s involvement is during painful or uncomfortable procedures. The ability of parents to contribute to their child’s care and comfort is an important way to promote meaning and wholeness for the parent, for the child, and within the patient-parent-provider relationship. Another way esthetic knowing is reflected in the pediatric home care resources document is in the section regarding children and youth with medical complexity. This population of patients and their families face a reality that is incomprehensible to most others, and that requires a special type of contextual knowledge and empathy from the health professionals who support them. The resources in this section are designed to help home health professionals gain knowledge about what it is like to have a child or youth who has complex and far-reaching health needs, including the associated impact on parents, caregivers, siblings, other family, and the larger community. This knowledge must include understanding of the patient’s unique context, empathy for the challenges of care that the family has taken on, as well as a willingness to discover what is helpful and meaningful for the patient and family. Creativity and imagination are also essential to meet the care needs of these patients and their families, which by definition, are care needs that are outside the realm of the usual in any domain of the health care system. For example, there are two series of videos, one from Open Pediatrics (n.d.) and one from Children’s Healthcare Canada and

In-Gauge (2017) that include personal insights from the families of children and youth with medical complexity and show the realities of their daily life at homes.

Sociopolitical knowing involves an awareness of the sociopolitical context of the nurse-patient relationship and the nursing profession (White, 1995). For the purposes of my practicum, I would rephrase this type of knowing as the context of the professional-patient relationship and the home health profession. The home health profession is in a difficult position with extensive challenges in resources and staffing, and a shift from hospital-based to home-based care without proportional increases in funding and resources (CHCA, 2016a). As a result, home health professionals are pressed for time as they take on larger caseloads and more complex patient care. A consequence of this reality in practice is that these professionals have an increased need for readily-available and quick learning resources, as confirmed by the findings of my literature review, environmental scan, and consultation. The entire design of my pediatric home care resource repository is in response to this need, presenting Nova Scotia home health professionals with a variety of resources at their fingertips that are largely quick reference and high-impact learning documents, videos, and guidelines. Therefore, sociopolitical knowing had a very global influence on how and why I developed pediatric resources for home health professionals. Sociopolitical knowing is also an important part of the care of children and youth with medical complexity. The care of these children, by definition, far exceeds the usual resources allocated in pediatric health care, such as visits to primary care providers, visits to the emergency department, frequency and length of hospital admissions, number and costs of medications and other treatment regimes, and amount of formal home care supports required (Cohen et al., 2011). The sociopolitical context is that the usual resources allocated for home care are often inadequate for these patients and their families. Home health professionals can sometimes be pressed for time as it takes much longer to complete basic assessments and care tasks in the face of such complex care needs, or home health professionals can face questions and pressure to justify why these patients and families require so much more support than the average home care patient. A number of resources in the pediatric resource repository give evidence to support the extensive care needs of children and youth with medical complexity and support the work of home health professionals. For example, Children's Healthcare Canada (formerly the Canadian Association of Pediatric Health Centres [CAPHC]) developed a national guideline on the care of these patients and families (CAPHC, 2018). Using evidence from this national document, home health professionals have access to information and guidelines to support the home care needs of children and youth with medical complexity and their families. The need for systems-level change to support care needs, including home care needs, of children and youth with medical complexity and their families is noted in the literature (Foster et al., 2019), and underscores the need for an informed sociopolitical knowledge of this unique pediatric population.

Adult Learning Theory

Adult learning theory is a well-known cognitive development theory of teaching and learning (Candela, 2016). The importance of this theory for informing pediatric home care resource development was noted in my literature review, environmental scan, and consultation. Hallmarks of adult learning theory include the knowledge that adults are motivated to learn about problems that are personally relevant or impactful to their life or profession, and that adults have experiences from their personal and professional lives that should be taken into account to support their learning. Adults are self-directed in their learning and like to be involved in the learning process, and each adult has unique learning style preferences that should be accommodated to optimize learning (Candela, 2016). These principles are inseparable from many components of my practicum project, most importantly, the consultation process and the overall approach to developing and designing the pediatric home care resource repository.

From the outset, I knew that conducting a needs assessment-style consultation to ascertain home health professionals’ learning subject and learning style preferences would be necessary to develop relevant and impactful pediatric resources. The importance of this consultation process was underscored when the literature review and environmental scan findings revealed that principles of adult learning are inherent throughout the literature and in current pediatric home care education across Canada. The consultation results confirmed the need to develop a resource repository that covered a variety of subject areas and that included diverse resources that home health professionals could quickly and easily access. Such an approach would enable home health professionals to self-identify topics that were relevant to their practice in general, or in relation to a particular patient and family situation. In addition, a variety of resources would be required to reflect the varying learning preferences of home health professionals, not limited to written material, guidelines, and videos. This knowledge served as the design framework for the final pediatric home care resource repository.

Consistent with adult learning, I ensured the self-directed nature of the pediatric resource document by designing the table of contents to be a quick-reference overview of the document in its entirety, facilitating home health professionals' ability to easily locate a pertinent subject area and resource. The design of resource tables within individual subject areas also fosters self-directed learning by briefly outlining essential information for each resource. The best uses column is a very important part of the design because it provides a time estimate for the home health professional to consider in deciding if that resource is suitable for the learning time they have available. The accessory documents I developed also included principles of self-directed adult learning. The design of my tip sheets on building rapport with children and youth and communicating with children and youth with neuro-developmental challenges consist of direct, straightforward, and high-impact information that has a direct bearing on clinical practice. It is easy for home health professionals to hone in on particular tips or points within these documents that reflect what they need and want to learn about.

A central adult learning theme from the literature review, environmental scan, and consultation was the need for home care resources to be easy to access and generally of a short duration in terms of learning time commitment. I accounted for this theme by creating the resource document and accessory documents as PDF files – not only are such files very easy to post online to make them accessible, but they are also easy to download to smart phones used by most home health professionals. Importantly, for areas of Nova Scotia that do not have reliable internet access, and for professionals who prefer paper copies, the document is also printable, as are many of the resources in the repository itself.

Further ease of access is part of the design in terms of colors and tables used to organize the information by subject area. A final key consideration is that most of the resources included in the repository do not require an extensive time commitment from home health professionals. Most of the documents and videos can be read or watched in less than 15 minutes, while the remaining resources of a moderate or longer length were included for situations where more in-depth learning was required due to a complex subject area, or when dedicated learning time was possible through organized education days, lunch and learn sessions, or other educational opportunities.

The final component of adult learning theory that I will highlight is the use of a variety of resource and learning formats to support the different learning style preferences of home health professionals in Nova Scotia. The consultation results showed that the learning preferences of home health professionals were indeed diverse. For this reason, I was mindful to include many different types of learning resources. I included brief research articles, checklists, guidelines or policies, quick-reference documents such as tip sheets, instructional videos, tool kits, websites to explore, recorded webinars in seminar style, and videos of a documentary style about particular patient and family experiences. I am hopeful that with this variety of options, every home health professional will be able to access resources that reflect their personal learning preferences.

Resource Development Conclusions

The results from my literature review, environmental scan, and consultation truly served as the foundation and guide for the development of my practicum project. In the preceding paragraphs, I have discussed how many of these influences came to the forefront of my pediatric home care resources within the context of my theoretical frameworks. However, additional aspects of my research must be highlighted separately.

First, the consistency in subject themes across all domains of research was quite striking, especially given the limited scope of my research. For example, the theme of pediatric palliative care and end-of-life care was noted throughout my research. In the literature, extensive data were presented about priorities and areas of focus for pediatric palliative and end-of-life care at home (Thienprayoon, Alessandrini, Frimpong-Manso, & Grossoehme, 2018). The environmental scan results also highlighted the importance of pediatric palliative care as a subject area in two hospitals and one provincial home care program. In my consultation, pediatric palliative and end-of-life care was a subject of interest to home health professionals in Nova Scotia, specifically, 77% of home care nurses and 81% of care coordinators. One home care nurse described an experience surrounding the death of a child as “heart wrenching”, which reflects the added emotional toll associated with the death of a child. Such consistency in themes helped me narrow my resource development to the subjects that were likely to have the greatest impact on home health professionals and the patients and families they care for.

In addition, the use of theory to bolster the knowledge and information in my research was indispensable. As I have outlined, family-centered care, Carper’s fundamental ways of knowing, and adult learning theory all informed my research and subsequent resource development. Theory and philosophy are the foundation of nursing knowledge, and the nature of nursing knowledge is what distinguishes our profession and practice from other health professionals. Noting clear and consistent theoretical principles inherent to the research, and then using reflection and analysis to draw these principles into the forefront of resource development has added a deeper quality to my practicum project. This practice has helped me determine what was the most important, namely, the development of a pragmatic and focused resource repository to support best practice in pediatric home care, and optimal outcomes for patients and families.

Advanced Nursing Practice Competencies

The goal and objectives for my practicum are closely linked to the Canadian Nurses Association's (CNA) Advanced Nursing Practice (ANP) competencies (2008). As noted in the introduction, the main goal of my practicum has been to develop educational resources on pediatric care to support the practice of home health professionals, which will ultimately enhance pediatric home care outcomes for patients and families. Within this goal, I also had specific objectives, namely, to describe the challenges faced by home health professionals with an adult-focused practice caring for pediatric patients, identify existing pediatric educational resources for home health professionals, and compile and/or develop educational resources on pediatrics suitable for home health professionals in Nova Scotia. I am confident that my goal and objectives have been addressed within my literature review, environmental scan, consultation, and resource development. In the following paragraphs, I will outline how my work reflects each domain of ANP, which will demonstrate an established foundation for my forthcoming independent ANP career.

Clinical Competencies

Clinical ANP competencies reflect expertise in a specialized area of nursing, in my case, pediatrics and home care (CNA, 2008). Clinical expertise includes an integrated and multi-disciplinary team approach to patient care, along with the use of theory, research, and in-depth knowledge to inform practice. During the course of my practicum project, I have developed and utilized qualitative and quantitative data in complex situations to develop assessment and intervention strategies to support multi-disciplinary pediatric home care. My review of the literature and the data generated from my environmental scan and consultation have served to inform the clinical practice of pediatric home care, which by definition is complex and contextual. In addition, by focusing on the care of rare and challenging populations of children and youth with medical complexity and children and youth receiving palliative and end-of-life care, I am guiding decision-making in complex situations, considering patients' lived experiences, and managing a wide range of responses inherent in these patients' health problems. Also in keeping with clinical ANP competencies, I have generated new resources and uncovered new knowledge that will enhance the standard of pediatric home care in Nova Scotia, such as the new pediatric family-centered assessment tool for use in home care. I have also provided access to an extensive repertoire of educational resources based directly on the needs and priorities of multi-disciplinary home health professionals.

Research Competencies

The CNA (2008) outlines research competencies for ANP as centered on the generation, synthesis, and use of research evidence to inform practice. My literature review included an extensive examination and critique of the literature, along with careful analysis to interpret the results in the challenging and emerging domain of pediatric home care. I also conducted an environmental scan and consultation, which were necessary to build knowledge to bolster this lesser-known domain of care and ensure an evidence-informed project. My combined research efforts were evaluated in light of established theoretical frameworks and literature appraisal tools, and in light of the learning needs expressed by home health professionals in Nova Scotia. This detailed synthesis allowed me to compile and develop resources that are now being disseminated through my provincial role at the IWK Health Centre as I formally present and share these resources with home health colleagues across the province.

Leadership Competencies

An ANP leader is one who is not afraid of change, seeking new ways to practice, improve care, and shape organizations (CNA, 2008). I have a passion for developing and improving the way pediatric home care is provided in Nova Scotia, and this passion and desire to help patients, families, and home health professionals is what prompted me to undertake this project. By its very nature, this project was designed to propose new ways to practice and improve care by sharing information that is reputable, reliable, and relevant to home health professionals' practice in Nova Scotia. My hope is that in time, and with ongoing conversations and ongoing development of resources to support pediatric home care, that the organizational approach to pediatric home care in Nova Scotia will be better informed and provide even greater supports to patients and families. My leadership in pediatric home care is inseparable from my efforts to advocate for this group, as a small proportion of the home care population that both merits and requires a unique approach to care coordination and provision. By identifying the learning needs of home health professionals in relation to pediatric home care, and then developing resources that are suited to their practice and learning preferences, I am acting as a mentor and leader to address a gap in their learning. In addition, I am fortunate that within the scope of my role, I have the opportunity to be a leader in ongoing conversations and plans about pediatric home care across the province, using the information from my practicum project to foster greater understanding of the needs and trends inherent to this population.

Consultation and Collaboration Competencies

Consultation and collaboration in ANP involves multi-disciplinary and cross-sectoral collaboration at multiple levels of influence to inform patient care (CNA, 2008). By focusing on pediatric home care, I am inherently creating a partnership between the acute care and home care sectors. I have not only collaborated with and consulted multi-disciplinary home health professionals across the province, but I considered international literature in my literature review, and national practices in my environmental scan. I also elicited feedback from colleagues in pediatric acute care and home care on the draft versions of my pediatric home care resources as part of my ongoing consultation. The premise of my role as a liaison between acute care pediatrics and home care in Nova Scotia has required me to build relationships of trust and partnership over many months, respecting the rules and limitations of collaborating roles and organizations while also being mindful to show consideration and empathy for the experiences and needs of others, and respond with the necessary supports to enhance pediatric home care. I see this practicum project as a significant and impactful milestone in my professional role, giving me the opportunity to leverage my consultation and collaboration competencies to develop informed and relevant pediatric home care resources. I hope the development of these resources will set the stage for a larger-scale move toward greater empowerment of home health professionals to provide the best pediatric home care possible, and in turn, have far-reaching positive impacts on patients and families.

Future Plans

The repository of pediatric resources for home health professionals in Nova Scotia has only recently been made publicly available. An important part of my ongoing work will be to conduct an evaluation of these resources in the coming year. I plan to evaluate how home health professionals access the resources (i.e. on a website, by downloading the document to a computer or smart phone, by printing the resources), in which situations they access the resources (i.e. planned learning or "just in time" learning), how frequently they access the resources, and which resources have been the most or least helpful. I will ascertain feedback on the subject matter and the format of the resource itself, and request any suggestions for improvement in content or format.

The resource repository itself is also meant to grow and change over time and in response to the needs of home health professionals, the needs of pediatric home care patients and their families, and the ongoing development and availability of information and resources pertaining to pediatric home care. I anticipate ongoing revisions and additions in the months and years to come for this reason as well.

In the pediatric home care literature and in terms of practical pediatric home care resources, there is a good deal of room for growth and development. As noted in my literature review, a broader literature base would be welcome, one that builds upon and diversifies existing subjects, includes more rigor such as theoretical frameworks, and utilizes more varied study designs such as before-after research and outcomes-focused research. Clearly, given my need to develop several pediatric home care resources in the scope of this project, there will be room for the development of additional resources in future. I was certainly not able to address every subject area identified in the literature, in the environmental scan, and in the consultation process. I am fortunate to have ongoing opportunities in my current position to pursue the development of further resources as well as the publication of my current work, and perhaps even engage in related research.

Conclusion

During the course of my practicum, I have compiled and developed a suite of educational resources within the broad yet specialized domain of pediatric home care. These resources will support the practice of multi-disciplinary home health professionals who have a generally adult-focused practice. This project was informed by a three-fold data collection and analysis approach involving a literature review on pediatric home care, an environmental scan of pediatric home care education across Canada, and a consultation to ascertain the pediatric home care education subjects of interest to home health professionals in Nova Scotia. In addition, a framework of theoretical support from family-centered care, Carper's fundamental ways of knowing, and adult learning theory informed my project as I compiled existing reputable pediatric home care resources, and developed new and necessary resources. The output of my project is a document that comprises a repository of easily-accessible pediatric home care resources in six subject areas, as well as five new accessory documents to supplement these subject areas. The key subject areas relate to effective communication with pediatric patients and families, pediatric family-centered assessment in the home, and the care of rare and challenging pediatric populations.

By using a comprehensive research-informed process to plan my project and frame my search for and development of pragmatic educational resources, I have now designed and built an important resources to address a gap in the learning needs of home health professionals. It is my sincere hope that these resources will augment the quality of home care for pediatric patients and families and generate new and sustained momentum of optimal pediatric home care in Nova Scotia.

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Appendix A: Literature Review

Literature Review: Multidisciplinary Education in Pediatric Home Health Care

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Abstract

Background: In Nova Scotia, home health professionals who work with pediatric patients and families need education and supports to foster optimal care for this specialty population.

Purpose: By determining the state of the literature on pediatric home health care, I identified important subject areas, best practices, and resource formats to use in enhancing home health professionals' learning in pediatric care.

Methods: Using search terms "home health care" and "pediatric", I retrieved primary research studies from Canada and the United States published from 2009 to 2019. All articles were English-language and had a prescriptive or directive focus. Ten articles were identified and analyzed using critical appraisal tools, followed by in-depth thematic analysis and comparison to principles of family-centered care and Carper's fundamental ways of knowing.

Findings: Implications for education and resource development for pediatric home health professionals included: integrating home health professionals' pediatric experiences within educational initiatives; addressing the care of rare and challenging populations in pediatrics; adding tailored pediatric advice for common home care scenarios; promoting acute care pediatric and home care partnerships to support education; using a variety of flexible education delivery and resource formats; and incorporating principles of family-centered care and Carper's fundamental ways of knowing in pediatric home care education.

Conclusion: Despite a limited body of literature, I have identified relevant considerations for home health professional education to enhance the care of pediatric patients and their families at home.

Keywords: home health care, pediatrics, health professional education, resource development, family-centered care, Carper’s fundamental ways of knowing.

Literature Review: Multidisciplinary Education in Pediatric Home Health Care

Home health care is a fast-growing sector in Canada, and improving access to this care is a current national priority (Canadian Institute for Health Information [CIHI], 2019). It is estimated that one million Canadians receive government-funded home care each year, and another 500 000 access home care services not funded by the government (Canadian Home Care Association [CHCA], 2016a). Pediatric home health care (PHHC) represents a relatively small proportion of home health care, but has been recognized as "an emerging need" (Smith, 2011, p. 108), particularly for children with complex chronic health conditions (CHCA, 2016b; Mendes, 2013; Nageswaran & Golden, 2017). PHHC is most commonly defined as home care for patients less than 19 years of age; it may involve nursing support for medication administration or wound care, in-home respite, multi-disciplinary consultation from physiotherapy or occupational therapy, home support for activities of daily living, or other services (CHCA, 2016b).

Pediatrics is a specialty area of health care centered on the philosophy of family centered care (FCC), in which families are collaborative partners and decision-makers who are essential to all aspects of their child's care plan (Kuo et al., 2012). Pediatric health care includes unique considerations for interacting with babies, children, and teenagers in health situations, working with patients solely within the context of their family, and building pediatric skill sets such as assessing developmental milestones (LeGrow, Hubley, & McAllister, 2010). Not only are general pediatric competencies important in PHHC, but PHHC in itself presents special challenges for home- and community-based health care professionals, some of which include the care of medically complex and technology-dependent children (McCormick et al., 2015; Mendes, 2013; Nageswaran & Golden, 2017), unique pediatric considerations within common home care scenarios (Northington, Lyman, Guenter, Irving, & Duesing, 2017), and intrapersonal challenges of home-based palliative care in pediatrics (Thienprayoon, Alessandrini, Frimpong-Manso, & Grossoehme, 2018).

In Nova Scotia, there are two main groups of health professionals who provide specialized home care to pediatric patients within the provincial home care program: care coordinators and home care nurses (Continuing Care, 2013). Care coordinators are multi-disciplinary health professionals who assess patients and families and allocate home care resources to meet their needs, including networking with professionals throughout the system to support patients, families, and direct home health care providers. Home care nurses provide direct patient care in homes, such as medication administration, tube feeding, wound care, and respite. Based on my professional experience, I know these two groups of health professionals in Nova Scotia are seeking to increase their knowledge and skills in the care of pediatric patients and their families – they need relevant educational resources to support their practice.

The focus of my practicum project is to develop resources for PHHC professionals as a means to support best practice, which will ultimately improve experiences and outcomes for PHHC patients and their families. Caring for the child in the context of their family and community is a key component of the FCC principles that undergird pediatric health care, yet FCC is not fully integrated within non-inpatient pediatric care delivery such as home care. FCC has been shown to support optimal health outcomes in pediatrics, so my consideration of such principles will be important to further enhance positive patient and family outcomes as I develop PHHC resources (Kuo et al., 2012). To begin my practicum project, I will conduct a literature review to determine the state of the literature regarding PHHC. This will help me identify best practices, available resources, learning resource formats to use in the home health care setting, and key subject areas to consider for PHHC resource development.

Literature Review & Theoretical Framework

I conducted a literature review of the Cumulative Index of Nursing and Allied Health Literature (CINAHL) database using the CINAHL heading for "home health care" in combination with the term "pediatric". I also searched the Cochrane Library using the term "home care" and adding the filter for child health. I narrowed my search to the last ten years, 2009 to 2019, to obtain the most recent results in the evolving domain of PHHC. I retrieved articles written in English, and articles from Canada and the United States. To ensure a clear focus on the pediatric population, I excluded perinatal subjects such as well-baby and well-mother care, and public health and wellness-based initiatives. It was important to retrieve articles relevant to best practices and education in PHHC, so I excluded articles that only described or reported information about PHHC. Instead, my focus was on prescriptive and directive articles for multi-disciplinary health professionals in the home care setting. Within these parameters, I retrieved a total of 17 articles.

The next step in my literature review was to critically appraise the articles I retrieved. I excluded two articles that were not of an adequately scholarly nature, and five articles that were not primary research studies. Of the remaining 10 articles, five were quantitative and five were qualitative. I evaluated the quantitative articles using the Public Health Agency of Canada (PHAC) Critical Appraisal Toolkit (2014), and they all achieved a moderate rank in overall quality (see Appendix). I evaluated the qualitative articles using the Critical Appraisal Skills Programme (CASP) qualitative checklist (2018), and they all achieved satisfactory ratings. The qualitative research on PHHC provided valid results because the researchers focused on relevant and important subjects and sought to illuminate experiences using established methods such as guided interviews. However, added detail about data collection methods and consideration of the researcher-participant relationship would bolster the quality of the research. The data from the five qualitative research studies showed evidence of ethical consideration and clear statements of findings, though triangulation, credibility, and validation were not always discussed. Articles with stronger data analysis included techniques such as coding and an inductive thematic analysis verified independently by another researcher, while other research lacked a certain degree of detail in outlining the data analysis process. Although the results of the research vary in scope and in the nature of overall strengths and weaknesses, they can be used to inform the lesser-known and emerging domain of PHHC, including the care of specialty subpopulations and obscure health professional roles and processes.

During the literature analysis phase, I noticed that best-practice guidelines and prescriptive articles in the literature are not easily evaluated using the existing appraisal tools. These types of articles combine features of a literature review and a descriptive study such as a case study or survey, but may not have all established characteristics for one type of study. An appraisal guide for best-practice guidelines and prescriptive articles would be a welcome addition to any literature appraisal repertoire.

When conducting a literature review, a theoretical framework can add insight and perspectives to findings. To guide my literature review, I will draw on Carper's (1978) theory regarding the fundamental patterns of knowing in nursing. In her seminal work, Carper outlined four domains of knowledge that are essential for informed, effective, and holistic nursing practice. *Empiric knowing* includes scientific principles, laws, facts and information designed to explain or control. *Personal knowing* combines a nurse's self-awareness with knowing and accepting patients as their true selves. Nurses must be genuine and accepting in their interactions to demonstrate personal knowing. *Ethical knowing* refers to examining what is right or just in a situation, and examining the values, character, motives, and intentions of self and others. *Esthetic knowing,* the most challenging domain to describe and learn, can be understood as a synthesis of all the patterns of knowing. Esthetic knowing is a contextual understanding of each unique patient situation, including the nurse's efforts to use creativity, discovery, imagination, and empathy to promote meaning and wholeness in patient situations (Carper, 1978; Jacobs-Kramer & Chinn, 1988). A later addition to Carper's work is *sociopolitical knowing,* which involves consideration of the sociopolitical context of the nurse-patient relationship and of the nursing profession (White, 1995). Since the purpose of my practicum project is to provide education and resources for home health professionals in PHHC, a theoretical framework that focuses on knowledge is appropriate. In addition, the fundamental patterns of knowing have been shown to have particular usefulness and applicability within the context of pediatrics (Lee, 2002). I anticipate that Carper's theory will help me gain a more profound understanding of ways to increase my own knowing, and the knowing of other health professionals, in PHHC.

Literature Review Findings

Study Subject Areas, Designs and Methodologies, and Aims

To understand the state of the literature on PHHC, I first considered subject areas, study designs and methodologies, and overall study aims. The 10 articles included in this literature review span a broad range of topics, but can be grouped into two subjects: rare and challenging patient populations, and pediatric considerations for more common home care scenarios. Rare and challenging populations include patients with complex chronic health conditions (Fraser, Lisa, Laing, Lai, & Punjani, 2018; Mendes, 2013; Nageswaran & Golden, 2017), patients who depend on devices such as a tracheostomy (McCormick et al., 2015) or ventilator (Sterni et al., 2016), patients who require special treatments such as home parenteral nutrition (Norman & Crill, 2011), and patients receiving palliative and end-of-life care (Thienprayoon et al., 2018). More common home care scenarios with a pediatric viewpoint include nasogastric (NG) tube care (Northington et al., 2017), the care of international patients (Shesser, 2017), and safety in home care (Shesser, 2014).

The studies in this literature review were equally divided between quantitative and qualitative methodologies. In the quantitative research, literature reviews and surveys were predominant, such as McCormick et al.'s (2015) survey about life after having a tracheostomy. In the qualitative research, qualitative descriptive designs with interviews were common, and in one study (Fraser et al., 2018), an ethnoscience method with interviews was used to explore resource allocation and decision-making in home care. The aims of these studies centered on describing and understanding key phenomena, such as Northington et al.'s (2017) study describing current in-home NG tube care by families and home health nurses. Often the aim of description went one step further, with specific goals of guiding or improving care. In McCormick et al.'s (2015) study, they not only described the experiences of parents taking their child home with a new tracheostomy, but they also developed a checklist for engagement of families and discharge preparation. Literature reviews such as those of Norman and Crill (2011) and Sterni et al. (2016) had aims not just of describing patient populations but establishing best practice guidelines for care, in these cases for home parenteral nutrition and home ventilation, respectively.

Study Results and Overall Themes

The results of the studies in this literature review contained recurring themes, which was notable given the diverse subjects of individual studies. One theme was the presence of *similarities and differences when comparing adult and pediatric home care*. Fraser et al. (2018) noted this situation when comparing decision making practices of home care case managers. There was a similar degree of influence in adult or pediatric home care when case managers considered factors such as a patient's recent hospital discharges or the patient's health status to decide about home care resources. However, with PHHC, case managers' decisions about home care were more heavily influenced by factors such as overall family coping and supports. Another article that demonstrated co-existing similarities and differences between adult and pediatric home care was Thienprayoon et al.'s (2018) discussion of home palliative and end-of-life care. This domain of home care has great importance and similar guiding principles in the adult and pediatric world, but one difference in PHHC was the added emotional distress when parents and families are facing the death of a child. The added emotional distress families face when their child has a health problem and needs home care was also noted by McCormick et al. (2015), Nageswaran and Golden (2017), and Sterni et al. (2016).

A second theme in the review results was the *importance of individual home care experiences* of family members and health professionals. Study authors often elicited or described the perspectives and experiences of individuals directly involved in home care, which was a rich and valuable source of data. Nageswaran and Golden (2017) spoke with family caregivers and home health nurses caring for children with complex medical needs, which enabled them to identify barriers and solutions to improving home care for this population of children. Most of the articles that incorporated health professional experiences obtained information from home care nurses; a notable exception is Fraser et al. (2018), who spoke with home care case managers, a role that has much in common with Care Coordinators in Nova Scotia's home care program.

A third theme was a sense of the particularly *contextual and multi-factorial nature of PHHC*. From decision making regarding home care resources (Fraser et al., 2018), to planning home care for a pediatric patient on parenteral nutrition (Norman & Crill, 2011), context is everything in PHHC, and it is an elaborate context. Not only is it essential to know about the pediatric patient's health condition, but care providers must also know and respect the child as a person (Mendes, 2013) and work closely and collaboratively with the family, respecting their needs and challenges (Nageswaran & Golden, 2017).

Care providers must be mindful to foster connections with the patient's community and social supports (Fraser et al., 2018) and support the patient in their school, play, and social life (Thienprayoon et al., 2018). The contextual possibilities are endless and evolving.

A fourth theme in the results of this literature review was a need for *tailored pediatric home care advice* in certain scenarios. Several authors outlined how physiological, developmental, and emotional differences in pediatrics necessitated different approaches to home care or different tools to use in home care (Shesser, 2017; Shesser, 2014; Sterni et al., 2016). One example is an initiative to reduce central line-associated blood stream infections, which included a tailored pediatric approach of educating siblings, teachers, and others who are unique to the child's environment (Shesser, 2014).

A fifth theme in the literature is the *challenge of home care for pediatric patients with complex medical needs*. Patients with technology dependence (Mendes, 2013; McCormick et al., 2015; Sterni et al., 2016) and rare and complex health conditions (Nageswaran & Golden, 2017; Norman & Crill, 2011; Thienprayoon et al., 2018) present challenges in the acute care sector and the home care sector. Building the competence of home health care professionals and establishing consistency in direct care practices is not to be taken lightly, given the vulnerability this population of patients and families living at home. Multidisciplinary care coordination, capacity building and education for staff, standardized competencies and guidelines, support from home care employers, and close partnership with families can be time-consuming, but they are necessary to establish safe and effective home care for pediatric patients with complex medical needs (Fraser et al., 2018; Mendes, 2013; Nageswaran & Golden, 2017; Norman & Crill, 2011; Northington et al., 2017; Shesser, 2014; Thienprayoon et al., 2018).

The final theme in the results of this literature review was the need for *partnership between acute pediatric care and home care sectors* to provide effective PHHC. This partnership is at its most critical phase when a child is discharged home from hospital for the first time with unique home health care needs (McCormick et al., 2015; Norman & Crill, 2011); yet this partnership must extend beyond the discharge period. Home health care professionals must be able to collaborate with and be supported by pediatric experts whenever questions and needs arise in the home care setting to promote ongoing best practices in PHHC (Norman & Crill, 2011; Sterni et al., 2016; Thienprayoon et al., 2018).

When considering the six overall themes in this literature review, a prevailing idea is present – the simultaneous need for a systemized approach and for customization and openness in PHHC. Certain aspects of PHHC were similar to the systematic approaches to adult home health care, yet the differences of PHHC required health professionals to provide customized care based on individual patient and family needs. A measure of openness in eliciting the home care experiences of families and health professionals is required to uncover their important first-hand perspectives. The contextual and multi-factorial nature of PHHC and the need for tailored PHHC advice both echo the need for customized care, and in the case of tailored PHHC advice, systematic or standardized tools and care approaches could also be appropriate. The challenge of home care for children with complex medical needs also necessitates standardized care paths for complex tasks such as tracheostomy care and home ventilation. At the same time, these children and families require openness to customize care based on rare health conditions and the associated vast challenges families face. Finally, to create partnerships between acute pediatric care and the home care sector, there must be openness on both parts to create the supportive best practice collaboration needed for optimal PHHC. Overall, there is substantial information contained within the six themes of this literature review.

Strengths and Weaknesses in the Literature

A final and necessary consideration is the overall strengths and weaknesses in the literature. The presence of qualitative research was a strength in this literature review, given that this genre of research is a necessary starting point for studying rare and poorly understood phenomena (LoBiondo-Wood & Haber, 2013). Due to the emerging nature of PHHC (Smith, 2011) and the prominence of patients with rare health conditions who need home care (Nageswaran & Golden, 2017), the use of and ongoing growth of qualitative research is vital to build understanding. Another strength was the authors' efforts to maximize rigor within qualitative study designs, using techniques such as purposeful sampling (Mendes, 2013), member checking (Fraser et al., 2018), and independent coding (Nageswaran & Golden, 2017). It is also noteworthy that there was general awareness of the need for future research to better inform care and increase the volume and rigor of literature related to PHHC (Northington et al., 2017; Thienprayoon et al., 2018). Ensuring research had clear implications for clinical practice was another strength. By including resources for clinical practice such as an ethanol lock protocol for patients on home parenteral nutrition (Norman & Crill, 2011) and tracheostomy discharge checklist (McCormick et al., 2015), the authors are fostering the translation of research into practice. An important strength in the very personal domain of home care was eliciting the voices of families and health professionals who experience this aspect of care directly. When McCormick et al. (2015) described families' experiences receiving home care in the context of a new tracheostomy, their perspectives and quotations illustrated gaps and barriers to inform future care. In certain studies, the voices of expert health professionals also served to illuminate important implications for PHHC (Mendes, 2013; Sterni et al., 2016; Thienprayoon et al., 2018). A final strength in the literature was the prominence of collaborative models to support and sustain PHHC. Numerous authors recognized the need for multidisciplinary collaboration and partnerships between acute care and home care as an important way to maximize effective home care for pediatric patients and their families (Fraser et al., 2018; Nageswaran & Golden, 2017; Norman & Crill, 2011; Shesser, 2014; Shesser, 2017; Sterni et al., 2016; Thienprayoon et al., 2018).

Weaknesses in the qualitative PHHC literature included the limited detail in reporting or describing data collection and data analysis in certain studies, and a limited discussion of triangulation, credibility, and validation. In the quantitative PHHC literature, there was a need for reliable and valid tools to inform studies and resultant clinical care. It would also be helpful if researchers shared information about literature evaluation for literature reviews, and used theoretical frameworks to strengthen the quality of their research (LoBiondo-Wood & Haber, 2013; Public Health Agency of Canada, 2014). When considering the entire body of literature in this review, there is an overall paucity of research regarding PHHC, meaning there is limited literature on which to base practice recommendations (Northington et al., 2017; Sterni et al., 2016). A noteworthy gap was the lack of direct patient voices in the literature, which is likely due in part to the number of pediatric patients with limited communication ability due to their young age or neurodevelopmental challenges. That being said, it is a perspective that is essential and possible to obtain in future research by recruiting children and youth who are able to communicate and share their experiences. Another voice that is largely missing from the literature is that of multi-disciplinary health professionals such as occupational therapists, physiotherapists, dietitians, social workers, care coordinators, managers, and decision-makers who are directly or indirectly involved in PHHC. Fortunately, many of these weaknesses in the literature are relatively straightforward to address in ongoing research.

Conclusions about the State of the Literature

Overall, it is worth emphasizing that PHHC is an evolving and heterogeneous domain of home care, as reflected in the state of the literature. The body of literature is very small compared to the adult home health care literature, as evidenced by over 7000 results generated by CINAHL when using the heading for “home health care” in the same 10 year period. Within the available literature, there is appropriate representation from qualitative research using family and home care nurse voices, with a need for more patient and multidisciplinary voices in future studies. There is also a need for more quantitative research including rigorous literature reviews, theory-informed research, cost-analysis research, evaluative or outcomes research, and before-after group comparisons. Many valid and reliable tools exist that can be used in research, such as patient and family health-related quality of life measures, staff satisfaction measures, and organizational quality and safety outcomes such as infection rates and hospital readmission rates (LoBiondo-Wood & Haber, 2013).

In my literature review methodology, I noted that five articles were excluded because they were not primary research studies. Despite their exclusion, these articles contain information and evidence that are part of a broader body of literature. According to Rycroft-Malone et al. (2003), evidence is garnered not just from research, but also from clinical experience, patients and carers, and the local context and environment. In the five excluded articles, the authors framed their discussions of diverse PHHC subjects with literature, clinical experience, feedback from patients and families, and/or local programs and initiatives, making their evidence worthy of consideration. Interestingly, these articles shared much in common with the 10 articles included in this literature review, such as a focus on acute care pediatric and home care partnerships (Smith, 2011; Williams et al., 2011), the use of standardized guides and tools for PHHC (McCaskey et al., 2011; Northington et al., 2018; Smith, 2011), adding tailored pediatric advice to home care issues such as professional boundaries (Petosa, 2018) and preventing skin breakdown (McCaskey et al., 2011), caring for medically complex children (McCaskey et al., 2011), and caring for pediatric patients in a very contextual, family-centered, and multi-factorial environment (Williams et al., 2011). Given the consistency in themes across additional PHHC articles, the stated conclusions in this literature review have greater significance.

Another important consideration regarding the PHCC literature is the presence of direct and indirect evidence of FCC philosophy. Kuo et al. (2012) defined the principles of FCC as: open and unbiased information sharing; respect for diversity and preferences along with honoring differences; partnership and collaboration with families at the level they choose; negotiable or flexible outcomes of medical care plans; and direct care and decision-making that reflects the child within the context of their family, community, home, school, and activities. The parallels of this philosophy when compared to the themes of this literature review are unmistakable. One powerful demonstration of how critical FCC is within PHHC was noted in the study that examined the process and taxonomy of decision-making in home health care (Fraser et al., 2018). In the taxonomy of adult home health care decision making, family was one sub-component of the community resources category, yet in the pediatric taxonomy, family-related factors was its own category with six sub-components including the number of children, beliefs, family supports, coping, risk to the family unit, and socioeconomic status. Family is central to PHHC, and the philosophy of FCC is consistent with, and inseparable from the approaches to PHHC noted in this literature review.

Overall, it is clear that researchers are aware of many of the shortcomings and gaps in the literature, and they are working to address these gaps with their current and ongoing work – a promising trend. The state of the literature on PHHC is limited in scope, and researchers and clinicians must be cautious with its use to inform practice, as multiple authors in this review have noted (Northington et al., 2017; Sterni et al., 2016). It is hoped that with increasing awareness of this important domain of care, and with the ongoing efforts of dedicated researchers, the literature will continue to grow.

Implications for Multidisciplinary Education in Pediatric Home Health Care

By conducting this literature review, I have identified relevant implications for my practicum project. When it comes to multidisciplinary education in PHHC, I will need to consider three areas: the experiences of home care professionals, key education subjects, and educational resources and formats. *The experiences of professionals* were very prominent in the literature. Both research and my professional experience show that home health professionals generally want to increase their competency in PHHC by receiving education from their employer and from acute care pediatric partners. I must understand the learning needs of home health professionals who have an adult-predominant practice in order to plan appropriately for PHHC education. This approach also echoes the literature review finding that there are similarities and differences between adult and pediatric home care that must be considered to inform care. I must also be aware that health professionals' positive or negative experiences with PHHC may impact their educational expectations and needs. To this end, I am planning an extensive consultation process involving home care nurses, care coordinators, managers, and educators to elicit their educational interests and preferences pertaining to PHHC.

Key education subjects in the literature included domains of rare and challenging health situations and pediatric considerations for more routine home care situations. I plan to investigate these two domains during the consultation process to identify topics within each domain that are relevant to the practice of home health professionals in Nova Scotia. The care of medically complex children and their families and the associated use of technology in home care (e.g. tracheostomies and ventilators) encompassed a large proportion of the literature, so I anticipate this may be a subject of interest for PHHC education. In addition, a compelling finding in the literature review was the need to understand, assess, and respond to the profound contextual considerations in PHHC, particularly in terms of knowing and assessing the child within their family context. This will be an important subject area to explore for possible educational implications.

A third area to consider in PHHC education is possible *educational resources and formats*. Acute pediatric care and home care partnerships were essential to providing education to home care professionals, so I will need to investigate resources that I can access through the acute pediatric care portion of my role. I will also be searching out PHHC education formats used by other pediatric hospitals and provincial home care programs in Canada when I conduct an environmental scan. This practice of leveraging existing resources when appropriate for use within PHHC was also identified in the literature review and will help me maximize educational impact. Formats for educational resources noted in the literature included standardized policies, checklists, and guides that were formatted and designed for practical use in the home care setting. Having accessible copies of educational information and guidelines was an important consideration in home care setting, since professionals may not be able to readily access resources. Depending on the educational subjects desired, a combination of in-person teaching using approaches such as the teach-back method, self-directed written resources, online resources, or standardized checklists may be necessary. Flexibility in educational formats will be essential to responding in a meaningful way to health professionals' learning needs.

The final implication for multi-disciplinary PHHC education is the need to ensure *FCC principles* are at the forefront of all educational endeavors. Given the centrality of FCC in pediatric health care and in the PHHC literature, it is essential that PHHC education initiatives are based on information sharing with families, respect and honoring differences, partnership and collaboration, negotiation, and care in the context of family and community (Kuo et al., 2012).

Ways of Knowing in Pediatric Home Health Care

During the course of this literature review, I considered whether Carper's (1978) fundamental ways of knowing were present in each article, the role of each individual way of knowing, and how the ways of knowing can inform my practicum project. In all of the articles identified for the literature review, I was able to identify empiric, personal, ethical, esthetic, and sociopolitical ways of knowing. At least one or two ways of knowing were prominent in each article, while the others were alluded to in a lesser or indirect way – yet they were all present.

Empiric Knowing

Empiric knowing formed the foundation for other ways of knowing, representing the anatomy, physiology, pharmacology, and other scientific principles that underlie patient care. Empiric knowing was prominent in articles such as Shesser's (2014) discussion of safety and best practices in home care. She focused on explaining information in concrete ways such as infection rates in home care, and providing systematic and standardized practices such as hand hygiene in the home. Empiric knowing was present in an indirect sense in Fraser et al.'s (2018) article outlining how case managers make decisions to allocate home care resources. Understanding the acuity and complexity of the patient's health condition was one of many factors influencing decision making, informing other domains such as the context of resources in the patient's social, familial, and community context.

Personal Knowing

Personal knowing was present to a moderate to strong degree throughout the literature, showing clear relevance for PHHC. Personal knowing was a focus of Mendes' (2013) article that elicited expert pediatric home care nurses' perspectives on high quality care for technology-dependent children. Nurses emphasized the importance of knowing and respecting the patient as a person, having respect for the family's personal space and home environment, and caring for the child as part of their family. Importantly, nurses also spoke about taking time to self-reflect on the care of technology-dependent children, which would promote self-knowing as a component of personal knowing. One article that alluded to personal knowing indirectly was Norman and Crill's (2011) article about home parenteral nutrition. When the authors discussed teaching families the information and skills needed to care for their child at home, they noted that clinicians should be aware of family members' confidence as a factor that affects learning. Confidence in learning is a personal consideration in knowing and accepting a family as they are.

Ethical Knowing

Ethical knowing was easy to identify in Fraser et al.'s (2018) article on resource allocation and decision-making in home care. Case managers voiced their struggles to balance what was right for patients' needs within the limitations of the home care system, and their sense of professional responsibility to see patients, yet not having enough hours to do all their assessments in a timely manner. It was interesting to note that ethical knowing was present but less obvious in other articles, such as Nageswaran and Golden's (2017) description of home care agencies not fulfilling their professional obligations to educate staff regarding the care of medically complex children.

Esthetic Knowing

Esthetic knowing was the most prominent type of knowing in the literature. Given the earlier finding that PHHC is contextual and multi-factorial, it makes sense that esthetic knowing is influential. It is essential for professionals to combine creativity, empathy, and perception to know and discover how to meet the needs of pediatric patients and their families. This concept was demonstrated in Mendes' (2013) article on ideal home care for technology-dependent children. Nurses used esthetic knowing when they were empathetic and sensitive to parents' loss of privacy inherent in needing home care for their child, when they were perceptive about parents' need to build confidence with their child's care, and when they were creative in facilitating play between the technology-dependent child and their siblings who also needed to be included. Together, the use of empathetic expression, perceptive teaching, and creative care serve to meet patient and family needs. Health professionals' abilities to discover and uncover meanings and meet needs in complex PHHC situations demonstrates esthetic knowing, from decision making for home care resource allocation (Fraser et al., 2018) to defining high-quality home palliative care to pediatric patients and their families (Thienprayoon et al., 2018).

Sociopolitical Knowing

Sociopolitical knowing is a broad and critical way to view the nursing profession, and as a consequence, it is an important domain for systems-level change. This way of knowing requires consideration of the sociopolitical context of the nursing profession, that is, hearing and critiquing all voices on a given issue as a means to move toward greater equity and understanding (White, 1995). When McCormick et al. (2015) described families' experiences when taking their child home with a tracheostomy, sociopolitical knowing was present. Only 48% of families felt very prepared for discharge and only 40% felt their home nursing needs were mostly or fully met. The authors directly and indirectly allude to a system where health professionals do not always fully appreciate and plan for the stresses and challenges faced by families after discharge, and where there are not adequate resources invested in discharge planning and home care supports for patients and families, and particularly for pediatric patients with complex health needs. From a sociopolitical lens, our health care system remains largely centered on hospital-based care, despite ongoing shifts in ideology toward a more inclusive definition of health and health care that includes home- and community-based health (Butler-Jones, 2009) and a greater focus on the social determinants of health (Government of Canada, 2019). The sociopolitical context of PHHC, as illustrated in McCormick et al.'s (2015) article, is a context where health professionals and health systems must be supported to provide care that incorporates the social determinants of health across care settings. Such care requires more than government documents; it requires adequate health care funding and revamped health professional roles and responsibilities that allow appropriate care in the home setting for a small but vulnerable population of pediatric home care patients.

Implications for Carper's Ways of Knowing

Carper's (1978) ways of knowing are present throughout the literature on PHHC, so they must also be present when teaching health professionals about PHHC. Empiric knowing must be included as a foundation of knowledge that is heavily influenced by personal knowing, both knowing patients and families for who they are and having a self-reflective practice. I must give due consideration to the unique ethical knowing implications of PHHC, but focus extensively on the prominent domain of esthetic knowing. An awareness of the sociopolitical contexts that influence PHHC will help me know where resource gaps exist and the best ways to bridge the gaps by adding educational resources. Helping health professionals develop greater empathy and use their insight to discover the myriad factors influencing PHHC will be essential to meeting patient and family needs in a meaningful way.

Conclusion

Despite the small body of PHHC literature, a significant amount of data have been uncovered to inform multidisciplinary education. The key themes in the literature have helped me identify possible educational subjects, resources, formats, and experiences to consider for my practicum project. When I develop PHHC resources for my practicum, I anticipate that some of the most helpful areas of focus will be the care of children with medically complex conditions, the need for tailored pediatric advice in home care, and the intensely contextual nature of PHHC. The philosophy of FCC, which is integral to all pediatric health care, must be “acknowledged and actively incorporated within all clinical care delivery and practice guidelines” (Kuo et al., 2012, p. 302), including my educational initiatives for PHHC. I will also foster added depth in PHHC by ensuring empiric, personal, ethical, esthetic, and sociopolitical knowing inform the resources I develop.

Although there is considerable room for growth in the PHHC literature, it has proven helpful for confirming, guiding, challenging, and growing my approach to fostering best practice in PHHC, and ultimately, ensuring the best outcomes for pediatric patients and their families.

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Appendix: Quantitative Literature Summary Table

Study Information	Design and Sample	Aim and Methodology	Results	Strengths	Limitations
McCormick et al., 2015. Life after tracheostomy: Patient and family perspectives on teaching, transitions, and multidisciplinary teams.	International cross-sectional survey of tracheostomy patients and their families. No theoretical framework noted, but study was conducted from a safety and quality improvement perspective. n = 220. 90% of respondents cared for a pediatric	Aim: To elicit patient and family experiences and outcomes after a tracheostomy and use this information to inform care. Using input from multiple stakeholders, a 50-item survey was developed and disseminated via known international tracheostomy social networks.	The emotional and mental stress of taking on a tracheostomy can be overwhelming for patients and families. The transition from hospital to home, including home care collaboration and planning, is a critical point in the tracheostomy journey. Standardized tracheostomy teaching for	International survey across multiple social media groups has more potential for generalizability. Focus on patient and family perspectives with predominant pediatric representation. Extensive 50-item survey that provides both demographic and experiential information.	Lack of health provider perspectives to complement patient and family perspectives. The survey was not subject to reliability or validity testing. Limited discussion of implications for home care nurses and care coordinators, despite identified gaps in care.

Study Information	Design and Sample	Aim and Methodology	Results	Strengths	Limitations
	patient with a tracheostomy. Most respondents were in North America.	Survey tool included basic demographic information, and patient and family experiences pertaining to readiness for discharge with a tracheostomy, perceptions of teamwork among the health team, home nursing care required, whether home nursing needs were met, and other factors.	patients and families, and for home care nurses, is essential. Care coordination needs and home nursing needs for tracheostomy patients and their families are not consistently met, despite 86% of patients having home nursing care. Only 40% of patients and families felt their home nursing needs were "absolutely" or "mostly" met. For 32% of respondents, care was fragmented or	Survey questions shed light on important clinical implications for tracheostomy patients and their families. Authors had a detailed discussion of potential biases and limitations within their study, such as response bias and recall bias in surveys.	Limited rigor in descriptive study designs. Overall moderate study quality.

Study Information	Design and Sample	Aim and Methodology	Results	Strengths	Limitations
			teamwork was limited.		
Norman & Crill, 2011. Optimizing the transition to home parenteral nutrition in pediatric patients.	Literature review as the basis for a practice guideline. No theoretical framework noted. n = 30 articles.	Aim: To describe best practices for the collaborative and complex process of discharging a pediatric patient from acute care to home parenteral nutrition. Literature review and best practice guideline; no specific literature review evaluation criteria noted. The ASPEN guide for home parenteral nutrition is an overarching reference.	Institutional and home care roles center on open communication and collaborative care planning and partnership that extends to the post-discharge phase. Education of home care clinicians by acute care professionals on all aspects of the care plan is a cornerstone of this model. Education should include in-person and written resources.	Referenced well-known ASPEN guidelines. Clear outline of roles within the institution and home care setting, including collaborative and multidisciplinary discharge planning and outpatient support. Numerous practical tables, guides, and checklists to be used in discharge	Evaluation of included articles was not present, limiting rigor. Overall moderate study quality.

Study Information	Design and Sample	Aim and Methodology	Results	Strengths	Limitations
			Home health clinicians should conduct a home assessment prior to discharge to highlight practical and safety considerations for in-home care that require planning. Coordination of home care requires appropriate medical oversight and access, and multi-disciplinary support.	planning and home care.	
Northington et al., 2017.	Cross-sectional survey of parents and homecare providers.	Aim: To gather baseline information about children with NG tubes and how	Variability in NG tube practices was noted in the parent and homecare provider groups.	The study addressed a known gap in the literature by describing NG	Possible sampling bias by using parents who were well connected with hospital staff

Study Information	Design and Sample	Aim and Methodology	Results	Strengths	Limitations
Current practices in home management of nasogastric tube placement in pediatric patients: A survey of patients and homecare providers.	No theoretical framework noted. n = 144 parents and 66 homecare providers. Convenience sample of homecare staff whose companies supply NG tubes to patients <18 years old, and parents of children/youth) (<18 years old) who have NG tubes. Parents were contacted via affiliations with hospital staff	their care is managed at home. A team of physicians and nurses developed two survey tools, one for parents and one for providers. Both surveys had 13 items and were based on gaps in the literature and questions from clinical practice. Content validity was established, but reliability was not tested. The surveys were distributed and data were	There is a lack of standards for best practice for NG tube care in the home, so policies and procedures vary between institutions and homecare companies. Most children with NG tubes were between 4 and 7 months of age (28%) and had a size 6F feeding tube (51%) in place for 0 to 6 months (66%). Dislodged tubes were replaced by: primary caregivers	tube practices in the home setting. The authors noted a number of questions raised by their research which need to be addressed in the future. The practice implications and conclusions of the study did not extend beyond the nature and quality of the data.	and/or research projects. Limited data available from Survey Monkey® regarding how many people received an email versus how many completed the surveys. Limited rigor with descriptive study designs. Survey reliability was not tested.

Study Information	Design and Sample	Aim and Methodology	Results	Strengths	Limitations
	and/or research projects and they volunteered to complete the survey.	analyzed using the Survey Monkey® platform.	(71%), homecare agency staff (14%), or hospital staff (12%). Primary tube measurement methods used by parents: NEMU (81%) or previous tube depth (14%). Tube placement verification used by parents: auscultation (44%), gastric pH (25%), inspection of gastric contents (18%), or a combination of these methods.		Overall moderate study quality.

Study Information	Design and Sample	Aim and Methodology	Results	Strengths	Limitations
			25% of parents experienced a complication such as vomiting, high pH results, turning blue, or gagging. Tube placement verification used by homecare staff: auscultation (49%), inspection of gastric contents (25%), or gastric pH testing (28%).		
Sterni et al., 2016. An official American Thoracic Society clinical practice guideline: Pediatric chronic	Literature review and clinical practice guideline. Family centered care and medical home ideology	Aim: To provide an evidence-based approach to hospital discharge and home management of children requiring chronic invasive home ventilation.	The group put forward nine recommendations pertaining to medical management, standardized discharge criteria, training of family	Extensive literature review and expert workgroup panel that followed established methodology to evaluate evidence	Most of the published evidence on this subject is "very low" per GRADE methodology.

Study Information	Design and Sample	Aim and Methodology	Results	Strengths	Limitations
home invasive ventilation.	framed this discussion. n = 86 studies. Interdisciplinary pediatric chronic home ventilation workgroup was convened by the American Thoracic Society.	GRADE methodology was used to assess the quality of published evidence and evaluate the strength of the recommendations. The workgroup convened by the American Thoracic Society decided on the recommendations.	caregivers, family and home health professional education, cardio-respiratory monitoring, maintenance of home ventilators, and necessary home equipment. The quality of evidence was generally "very low" and the strength of recommendations were either "conditional" or "strong".	and outline recommendations. Recommendations and associated data outlined in detail. Proposed standardized discharge criteria were included. Information and ideas on how to operationalize the recommendations were included, such as training approaches for families and home care clinicians (e.g. Teach back	Overall moderate study quality.

Study Information	Design and Sample	Aim and Methodology	Results	Strengths	Limitations
				method) and informational resources (e.g. equipment vendors). Multidisciplinary perspective for acute and home care. Consideration of in-depth patient and family needs and perspectives, such as family coping and the child's school and leisure activities.	
Thienprayoon et al., 2018.	Descriptive survey of OPPEN providers and a	Aim: To establish definition criteria for each quality domain for	The group established consensus definitions for	The authors provided the survey in its entirety for	Limited rigor in descriptive study designs, yet the authors used a

Study Information	Design and Sample	Aim and Methodology	Results	Strengths	Limitations
Defining provider-prioritized domains of quality in pediatric home-based hospice and palliative care: A study of the Ohio Pediatric Palliative Care and End-of-Life Network.	modified Delphi design. No theoretical framework noted. n = 22 providers in the first round, 13 providers in the second round, and 5 providers in the third round. Health professionals from the OPPEN email list were asked to complete the survey. The random, voluntary sample included nurses, physicians, social workers,	pediatric home-based hospice and palliative care. Using a modified Delphi method, a research team identified points of consensus in three rounds of surveys.	nine domains (structure and processes of care; physical aspects of care; psychological and psychiatric aspects of care; social aspects of care; spiritual, religious and existential aspects of care; cultural aspects of care; care of the child at end of life; ethical and legal aspects of care; and coordination of care) and added and defined a tenth domain (bereavement care).	review; this also enhances replicability of the survey in other areas. Use of Likert scales and free-text questions provided quantitative as well as qualitative survey data. Effort to achieve consensus throughout the process. Used an IQR of <2.5 to indicate consensus.	modified Delphi method to enhance their methodology. Significant attrition between survey rounds. Small study in one geographic area has limited generalizability. No mention of reliability and validity of the surveys. Overall moderate study quality.

Study Information	Design and Sample	Aim and Methodology	Results	Strengths	Limitations
	and one chaplain, nurse scientist, and pharmacist.			The domains of palliative care were validated in a previous study. The authors noted implications for further study such as consideration of patient and caregiver perspectives.	

Note. ASPEN = American Society for Parenteral and Enteral Nutrition; NG = Nasogastric; NEMU = Nose to Earlobe to the Midpoint between the xiphoid and Umbilicus; GRADE = Grading of Recommendations Assessment, Development, and Evaluation; OPPEN = Ohio Pediatric Palliative Care and End-of-Life Network; IQR = Interquartile Range.

Appendix B: Environmental Scan

Pediatric Education for Home Health Professionals in Canada: An Environmental Scan

Sarah T. King

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Table of Contents

Pediatric Education for Home Health Professionals in Canada: An Environmental Scan

Home care is an integral part of the Canadian health care system, but it is not a sector that is easy to explain or understand. The particular challenges inherent in home care include caring for diverse populations of patients in individual home and health situations, overseeing complex decision-making and resource allocation, and managing and supporting multidisciplinary care providers across different agencies (Fraser, Lisa, Laing, Lai, & Punjani, 2018). An important question for the home health care sector is how to educate health professionals who care for patients of all ages in personal and contextual care settings, and who work in very independent and autonomous roles.

The question of home health professional education has come to the forefront in Nova Scotia, where traditionally adult-focused professionals are providing home care to pediatric patients with a variety of health conditions. The two largest groups of health professionals involved in pediatric home care in Nova Scotia are the home care nurses who provide direct patient care, and care coordinators in the provincial home care program (Continuing Care, 2013). Care coordinators are multidisciplinary health professionals who develop and authorize patients' care plans, and allocate and assess resources. There are any number of health care topics to consider for the pediatric population, yet it is vitally important to develop educational resources that will be useful and helpful within the changing world of home health care (Howell, Prestwich, Laughlin, & Giga, 2004; Pilcher, 2016; Smith, 2011).

An environmental scan involves investigating programs, practices, regulations, roles, structures, and/or any other factors that are currently influencing or being utilized internal to and external to an organization, for purposes including organizational development, resource development, and strategic planning. Data sources may include scholarly literature, but more often involve grey literature, internet searches, and surveys or interviews of stakeholders in an area of interest (Rowel, Moore, Nowrojee, Memiah, & Bronner, 2005; Washington State Department of Health, 2011). Since an environmental scan "can be utilized to collect data to design health programs uniquely tailored to the needs of communities" (Rowel et al., 2005, p. 527), it is an ideal tool to investigate possible subject areas and educational strategies to meet the educational needs of home health professionals caring for pediatric patients and their families in Nova Scotia.

For my environmental scan, I will examine Canadian provincial home care programs, Canadian pediatric health centers, and relevant Canadian national organizations to identify educational initiatives for home health professionals. I anticipate that by identifying current practices and initiatives in this specialty area, I will gain insight to inform my project, which involves the development of pediatric home care resources for home health professionals in Nova Scotia.

Methodology

Before I began my environmental scan, I searched the literature for recent articles that focused on environmental scans in the home and community context, and articles that outlined environmental scan methodologies. The purpose of this search was to determine strategies used for environmental scans specific to the home and community context, and whether these strategies should be used in my environmental scan. The literature was not abundant, and there were no articles focused exclusively on describing methodologies for environmental scans. Rowel et al. (2005) also realized this problem, stating, “the literature revealed that there is no one established methodology to conduct an environmental scan…scans have been designed in various ways and used in a range of sectors” (p. 529). However, I was able to identify environmental scans pertaining to the home and community context, such as public health (Rowel et al., 2005), patient navigation (Luke, Doucet, & Azar, 2018), oncology survivorship care in the community (Wittal, 2018), preventative services in the community (Porterfield et al., 2012), community-based wound care (Abrahamyan et al., 2015), community-based preceptorship (Kassam et al., 2011), and social determinants in public health (Koo, O’Carroll, Harris, & DeSalvo, 2016). The authors of these articles used methods such as internet searches, needs assessments and surveys, speaking individually to leaders and stakeholders, holding focus groups, reviewing reports and grey literature, and reviewing published literature as part of their environmental scans. The authors reported that their methods were an effective way to inform program development, improve services, describe existing resources, bridge gaps in care, and develop educational resources in the community setting. These outcomes related to community-based services, care, resources, and education are perfectly aligned with the purposes for my own environmental scan and practicum project. Therefore, I made plans to use internet searches, speak to leaders and stakeholders, and review reports and grey literature as part of my environmental scan. I have already reviewed the published literature on environmental scans, as noted in this paragraph, and I have conducted a comprehensive literature review on pediatric home care as a separate component of my practicum project. Furthermore, during the consultation phase of my practicum project, I will be conducting focus groups and performing a needs assessment of home health professionals and their managers. Having integrated these methods within my environmental scan and consultation plan, I have enhanced my ability to acquire essential information and develop relevant education and resources for pediatric home care in Nova Scotia.

The specific objectives for my environmental scan are (a) to find examples of education programs for multidisciplinary home health professionals, including educational approaches or theoretical frameworks, educational delivery methods, technological education modalities, and other relevant considerations for community-based practices, and (b) to find specific examples of education programs on pediatric subjects designed for adult-focused home health professionals, such as educational approaches or theoretical frameworks, specific subject areas within pediatrics, and other relevant considerations for building competence in pediatric care.

When I started my environmental scan, I searched the internet to find information on pediatric home health care education in three Canadian provincial home care programs, three Canadian pediatric health centers, and two Canadian national organizations. I read relevant grey literature and reports posted on websites within these domains of home care programs, health centers, and organizations. By searching for pediatric home care information on national organization websites, my goal was to identify whether there was existing national-level awareness of, and strategies to address this important specialty area. Therefore, the information I was seeking from national organizations was of a general rather than a specific nature. On the other hand, I looked for more specific information from provincial home care programs and pediatric health centers. I looked at their websites to identify educational programs and initiatives for home health professionals, and to identify contact people to speak with. I also used my own connections to identify contact people within these programs and health centers. When I communicated with individuals, I used a standard contact letter with set questions to ensure I collected consistent information (see Appendix A). I phrased the questions in a way that was relevant for each person's work within a home care program or health center, and I took detailed notes of verbal conversations to ensure accurate recall of the information discussed.

Once the data were collected, I compiled them into tables to outline descriptive statistics, such as the frequency of pediatric home care subjects across different home care programs and health centers (See Appendix B). I also used content analysis to analyze the data. Content analysis is a qualitative methodology that involves both a careful analysis of narrative content, as well as a critical examination of uncovered themes and concepts to consider relevance for and application to clinical or research situations (Polit & Beck, 2017). According to an established assessment tool, no research ethics board approval was required for this environmental scan (Alberta Innovates, 2017).

Results

During the environmental scan, I collected information on pediatric home care education from three provincial home care programs, three pediatric health centers, and two national organizations in Canada: the Extra-Mural Program (EMP) in New Brunswick (NB), Local Health Integration Networks (LHINs) in Ontario, Continuing Care (CC) in Alberta (AB), The Janeway Children's Health and Rehabilitation Centre (JCHRC) in Newfoundland and Labrador (NL), The Hospital for Sick Children (HSC) in Ontario (ON), British Columbia Children's Hospital (BCCH) in British Colombia (BC), Children's Healthcare Canada (CHC), and The Canadian Home Care Association (CHCA). I was able to identify relevant information pertaining to pediatric home care on the websites for CMC and CHCA, but I needed to contact individuals at the remaining home care programs and health centers as only limited information was available on their websites. I contacted a manager and two nurses within EMP, a manager at one LHIN, a nurse educator, a simulation coordinator, and a manager at CC, three nurse coordinators at JCHRC, a nurse/program educator at HSC, and a nurse/senior practice leader at BCCH. It is important to note that although I used consistent questions for all my conversations, the data obtained are not exhaustive; rather, the information given by each individual reflects their best awareness and recollection at the time of our contact.

The data I collected are summarized in Appendix B. Tables 1, 2, and 3 identify the home care programs, health centers, and national organizations I contacted, as well as their websites. The remaining tables outline the frequency of pediatric home care education subjects (Table 4), frameworks and theories used in home care education (Table 5), and home care education delivery methods (Table 6).

Pediatric Home Care Education Subjects

In total, I identified 17 pediatric home care education subjects provided within provincial home care programs and provided by pediatric health centers for community-based health professionals (see Table 4). I grouped similar subjects together, such as a category of enteral feeding and tubes that includes nasogastric tubes (NGT), gastrostomy tubes (GT), jejunostomy tubes (JT), and related administration of tube feedings in the home. I identified the frequency with which each subject was identified in provincial home care programs and pediatric health centers. A greater number of pediatric home care subjects was covered within home care programs, including basic pediatric information around physical assessment, growth assessment, pain assessment, and family centered care, and more specialized pediatric topics such as seizure care, tracheostomy tubes, diabetes management, and medication management. Fewer subjects on pediatric home care were noted within pediatric health centers, as they seemed to focus on specialty areas such as palliative care, tracheostomy care, and home ventilation. Most subjects were covered to some degree in both domains of home care programs and pediatric health centers, such as tracheostomy care, enteral feeding, and children with medical complexity.

When considering all 17 pediatric home care education subjects, there are five overarching domains: technology and medical devices (e.g. tracheostomy tubes, home ventilation), skills (e.g. urinary catheterization, pediatric assessment), health conditions and domains (e.g. diabetes management, children with medical complexity), care and communication approaches (e.g. family centered care, difficult conversations/conflict), and other subjects (e.g. vicarious trauma).

Theories and Frameworks Used in Home Care Education

A total of 9 theories or frameworks were used within home care programs and health centers (Table 5) to inform education provided to home health professionals. Adult learning principles were utilized across all home care programs and health centers, and simulation-based education, active/experiential learning, and family-centered care were also prominent frameworks. Less consistently used theories or frameworks were strength-based care, Bandura’s social learning theory, the flipped classroom, and constructivism. Overall, the use of theories and frameworks for educating home health professionals was more frequent within pediatric health centers than provincial home care programs.

Home Care Education Delivery Methods

There were 12 delivery methods used by home care programs and pediatric health centers for educating home health professionals (Table 6). Three approaches were used within all the home care programs and health centers, namely, in-person education provided at a hospital, written material in paper format, and e-learning modules. Other frequently used education delivery methods were in-person education at a home care office or in the patient’s home, live webinars or telehealth sessions, recorded webinars or videos, written material available electronically, phone calls with colleagues or pediatric health professionals, and standardized checklists, policies, and procedures. Less common educational delivery approaches included text messaging, cell phone video calls, and continuing education groups.

Canadian National Organizations

CHC is a national organization comprised of pediatric stakeholders from regional pediatric health centers, health authorities, community hospitals, treatment centers, and home and respite care providers. Its purpose is to promote optimal child health thorough system-wide change and integration across the pediatric care continuum using research, data collection, education, advocacy, and other initiatives (Children's Healthcare Canada, n.d.). CHC has a primary focus on pediatric health care, but does it have an awareness of, or initiatives to support pediatric care in the home? I searched the CHC website and read key sections such as "About Us", "What We Do", and the new strategic plan. I noticed that CHC does include the home care sector in their mandate and has recently broadened their strategic plan to have a more inclusive focus on children's health wherever care is delivered, including emphasizing partnerships in the home and community settings. I also searched their website and resource repository and found a large number of subjects that are pertinent to, or directly focused on pediatric home care. Specific examples include home- and community-based care of children with medically complex health conditions, a family-managed model of home care, Jordan's Principle for equitable care of First Nations children in all care settings, the transition from pediatric to adult health care in all care settings, collaborative partnerships between acute and community-based care, home- and facility-based respite for children, and pediatric mental health in the home and community setting. It is also significant that CHC has a very large database of recorded webinars and electronic documents that can be easily accessed by health professionals, stakeholders, and the general public. Overall, CHC has an inclusive focus on pediatric health care that includes and supports pediatric care in the home.

CHCA is a national organization aimed at advancing excellence in home care through partnership with governments, administrations, service providers, researchers, educators, and others (Canadian Home Care Association, 2019). As I examined their website, my goal was to determine if CHCA has awareness of, or initiatives to support pediatric-specific home care. In the website sections that describe the CHCA's purpose and direction, they make no mention of age groups or age limits to their mandate. CHCA has several position statements and strategic position documents on their website. Within some of these documents, home care was described as being for all ages, or specific mention was made of pediatric home care programs for special populations such as children with medically complex health conditions, or First Nations children whose home care needs can be supported by the Jordan's Principle program. CHCA also described pediatric home care needs as varying from routine pediatric nursing care to medically complex home care that includes situations such as home ventilation using a tracheostomy tube, or pediatric palliative and end-of-life care. On the CHCA website is a section for pediatric home care that includes two documents, the most extensive of which is entitled "Home and Community-Based Services and Supports for Children with Complex Care Needs" (CHCA, 2016). In this document, CHCA outlines resources and considerations for home care for children with complex care needs, such as their need for multi-disciplinary home- and community-based supports, the use of technological medical devices in their care, the challenges of pediatric palliative and end-of-life care, the challenges for home care agencies in maintaining competence when pediatric patients are not frequently seen, and the need for specialized training for home care professionals to provide effective pediatric home care. CHCA demonstrates broad awareness of pediatric-specific home care issues across Canada, and they have put forward position statements and information to highlight challenges and changes pediatric home care.

Thematic Analysis of Pediatric Home Care Education

Thematic analysis of conversations with stakeholders in home care programs and pediatric health centers yielded a number of trends and considerations for pediatric home care education. First, the *resources and structures* within home care programs and pediatric health centers influence how pediatric education is provided to home health professionals. Resources include how each provincial home care program is designed, such as the types of services offered in the home setting, whether home care programs have contracts with home health agencies that educate their own staff, and whether home care programs have their own educators and multi-disciplinary teams. Resources in pediatric health centers include whether or not there is a formal home care education program and consistent access to hospital staff who can provide education to home health professionals. Structures include differences in authority, such as programs where home care professionals are mandated to receive pediatric home care education, versus programs where home care professionals must identify their own educational needs and access available resources to meet those needs. Other structural differences in home care programs include whether one area has enough pediatric patients to create a dedicated pediatric home care team, or whether adult-focused home care professionals are taking on pediatric patients on a less frequent basis. Given these differences in resources and structures, it is understandable that the way pediatric home care education is provided across Canada can be quite variable. In one province, a pediatric patient may receive a new GT, and the family is trained by an inpatient registered nurse in the care of their child's GT. If home care is needed, the family would have initial responsibility for teaching home health professionals since they are considered the expert in their child's care. The hospital supports home health professionals by having telephone conversations and providing written resources as necessary. In another province, the stakeholder described how a home care agency may identify the need for GT education when a pediatric patient is assigned to their care. They may attend an in-person education session at a pediatric health center and have ongoing access to online GT resources and be able to communicate with pediatric health professionals to assist with in-home troubleshooting.

The *setting* of each home care program and pediatric health center is closely tied to the resources available for pediatric home care education. A number of stakeholders spoke about differences in rural versus urban areas of their province, which is tied to the frequency with which pediatric patients are seen in home care, and the ease of accessing pediatric resources. Home care professionals who do not have ready access to pediatric health centers may rely on other home care colleagues with pediatric expertise, input from community pediatricians or smaller pediatric units within local hospitals, telephone conversations with more distant pediatric health centers, and online pediatric resources that can be accessed easily. In addition, home health professionals in rural areas have to plan differently as they may not be able to access online resources if there is limited cell phone reception and online access within their area.

The *timing* of education on pediatric home care was largely focused on situations when a new pediatric patient was coming on service, as opposed to general orientation and ongoing or continuing competence within home care programs and agencies. Most stakeholders emphasized that home health professionals want to receive pediatric education when it is relevant to their current practice, namely, when they have a child on their caseload. This timing is particularly relevant for home care programs or agencies that do not see pediatric patients frequently. Home health professionals may be able to access ongoing educational opportunities at pediatric health centers if relevant education is provided several times per year, or they may need to collaborate with colleagues at pediatric health centers to request an education session at the time they need it, referred to as "just in time" education.

Pediatric home care education has a different emphasis for different *health professionals.* In other words, most pediatric home care education was focused on the home care nursing role, as opposed to multi-disciplinary home health professionals, or care coordinators working in provincial home care programs. This is likely related to the need for nurses to provide direct care and gain competency in specific skills, such that safety and best practice create a particular need for nursing-focused education. Also, not all provincial home care programs have the same multi-disciplinary home care teams, and some do not have a care coordinator role, such that there would be a consistent drive for multi-disciplinary home health professional education. In some cases, pediatric education provided to home health professionals included non-nursing health professionals in educator roles, such as respiratory therapists who provided education on tracheostomy tubes and home ventilation. In addition, certain stakeholders said they welcomed the inclusion of care coordinators and other home health professionals in their education sessions, even if they were more tailored to the nursing role.

The need for *customization and flexibility* of educational subjects and means of educational delivery was another prominent theme. Pediatric education subjects must be relevant to the patients on service in home care, the learning needs of the staff must be considered, and education must be accessible and flexible based on the resources of the home care program or agency. Stakeholders described varying experience levels of home care nurses, such as new graduates, nurses with only home care experience, nurses with prior acute care experience who are new to home care, and nurses with or without pediatric experience. Particularly when home care staff have to travel great distances to access in-person education, and agencies have to backfill shifts for staff attending education sessions, this is a significant challenge for the many home care programs and agencies who have limited staffing. Customized and flexible education could be educational sessions on multiple topics that are offered several times per year, "just in time" education on a range of subjects, or diverse e-learning modules or video recordings that are accessible anytime. In addition, it seems that home care programs provide customized education to their own staff on more basic pediatric subjects such as physical assessment and family centered care, which would be more relevant to home care staff who have minimal pediatric experience or need a refresher. In the same token, pediatric health centers focus on more complex and specialized topics when providing education, maximizing the use of their unique expertise and knowledge. Another reason for needing customized education, as one stakeholder stated, is that pediatrics is "very patient and family specific, and there are so many rare conditions. It's not cookie cutter home care".

The importance of *partnership* to support pediatric home care education was a particularly prominent theme. Partnership between pediatric health centers and home care programs was the primary partnership stakeholders discussed. Additional partnerships included home health professionals partnering with pediatricians, smaller pediatric centers or units, home care colleagues with pediatric experience, and the families of pediatric patients to acquire necessary education. All stakeholders discussed the importance of partnership not just when initial education and training of home health professionals takes place, but also when home health professionals need to maintain or refresh their competency. There were varying ways that stakeholders approached continuing competence, with some health centers emphasizing the agency's responsibility to maintain staff members' competence, while others relied on the ability to access ongoing education outside the agency to maintain competence. Another important partnership question is the role of the family in providing education to home health professionals. Many stakeholders stated that families needed to receive the same training as home health professionals to foster a consistent approach and trusting relationships in the home setting, and that families should be part of the educational process so home health professionals understood what was unique about their child's situation. However, there were varying opinions regarding whether home health professionals should receive training directly from families as the primary means of education, and whether this would meet standards for professional training of regulated health professionals such as nurses.

The use of *technology* to support initial and ongoing pediatric home care education was unmistakable. When in-person education was provided, participants were expected to do pre-reading of online material or complete preparatory e-learning modules. In-person education often incorporated the use of PowerPoint slides, high- and low-fidelity mannequins for simulation, and the use of post-session online educational materials to support ongoing competence and best practice. When home health professionals were working in their home communities, they relied on heavily on education provided by telehealth or Skype, recorded videos and webinars, and online educational materials or websites. The ability to communicate with colleagues at pediatric health centers to ask questions and clarify care plans also reflected the use of technology. This communication was generally accomplished via telephone or email communication, but some home care programs and health centers also connected via text messaging or cell phone video chat, or had plans to adopt these modalities in the near future.

The use of *theories and frameworks* to support home care education relied heavily on adult learning principles and interactive or simulation-based education. A few stakeholders were less familiar with theories and frameworks that may have been used to provide home care education because they were not involved in the development of the home care education itself. Therefore, it is difficult to understand the full scope of this issue for pediatric home care education.

When discussing pediatric home care with stakeholders, there was a divide in approaches when it came to *subject complexity*. More routine topics that adult-focused home health professionals would see, such as NG tubes or wound care, required minimal support from pediatric health centers or other educational partners/resources, as agencies were largely able to provide their own education. Complex subjects such as administering total parenteral nutrition (TPN) and lipids in the home required detailed instruction from experts at pediatric health centers, as home health professionals may have never provided this type of care even for adult patients. Often these complex subjects were identified as the best or most pressing subjects that home health professionals wanted and needed to learn about to provide effective pediatric care.

An interesting theme in the environmental scan was the discussion of overlap between health care in the *home and school settings*. The need for pediatric patients to receive health care at school is foreseeable, and this need may create overlap between home and school care plans. The way each province or region approaches school-based health care needs is variable. Sometimes educational assistants (EAs) in schools can provide basic medical care to students after they receive education and training, which may be provided by public health nurses, home care nurses, families, or health professionals at pediatric health centers. Sometimes home care nurses go into the school to provide care to pediatric patients, and sometimes schools or regional school boards have a contract with a private home care agency. In a number of situations, stakeholders outlined how they support both home care and school care for pediatric patients, and so there is overlap in the educational needs of their staff when considering both care settings.

A final theme is that pediatric home care education has *implications for multiple sectors*. Within the health care sector, there is emphasis on the close partnership between pediatric acute care health centers and provincial home care programs. In addition, one home care program stakeholder noted that their expanded education program for home health professionals has reduced hospital length of stay and hospital readmission rates for medically complex children, showing the reciprocity between acute care and home care. Pediatric home care education also reaches beyond the health care sector and into the school and education sector, a domain that was not explored in detail, as it was beyond the scope of this environmental scan.

Discussion

The purposes of this environmental scan were to find examples of education programs for multidisciplinary home health professionals and find examples of education programs on pediatric subjects designed for adult-focused health professionals, including educational approaches or theoretical frameworks, educational delivery methods, technological education modalities, relevant considerations for community-based care, key subject areas within pediatrics, and relevant considerations for building competence in pediatric home care. Given the extensive results that have been outlined, I believe these goals were met. However, to be consistent with the process of thematic analysis, a deeper consideration of implications for clinical practice is warranted.

In my thematic analysis, I outlined the following domains that relate to pediatric home care education and how it is provided: resources and structures in home care programs and pediatric health centers, the challenges and opportunities inherent in rural versus urban home care settings, timing considerations for education, the primary nursing focus of current education, the need for customizable and flexible education, the need for initial and ongoing partnerships to support education, the need to leverage technology to provide education, the need to consider relevant theories and frameworks to undergird education, the differing approaches in education based on the complexity of the subject matter, the overlap between education in the home and school settings, and the multi-sectoral impacts of pediatric home care education. What do these themes actually mean for clinicians such as myself who are involved in pediatric home care? It is difficult to make assertions given the limited nature of this environmental scan, and especially given the variability inherent within the few provincial home care programs and pediatric health centers involved in this scan. An important consideration is to interpret the data within this limited context. For example, just because a given subject, theory, or educational delivery method is not used frequently, does not mean it is not worth consideration. It may be an effective but lesser-known or emerging approach within the growing domain of pediatric home care. The data from this environmental scan must be considered in light of my literature review and forthcoming consultation process to gain a more comprehensive picture of how I can use this information to inform pediatric home care education in Nova Scotia. It is also important to be mindful that certain contextual elements of home care programs and pediatric health centers have more in common with the situation in Nova Scotia than others. Nova Scotia has one large urban center, but it will never see the same volume of pediatric patients as urban centers such as Toronto and Calgary. However, all the home care programs and health centers also served small town and rural areas that are characteristic of Nova Scotia, so lessons can still be learned from across Canada. It is also important that I do not limit myself to drawing perspectives only from approaches that are similar to the situation in Nova Scotia, as difference is also a great teacher.

This environmental scan has served to confirm that there is immense diversity in pediatric home care, due to variations in how home care programs and health centers are run, the availability of home care resources, the learning needs of staff who care for pediatric patients, the varied locations of home care, the needs of individual patients and families, and many other factors. I have learned that I can assume nothing and must be prepared to develop personalized, customizable, and flexible educational resources for pediatric home care. I have learned that my forthcoming consultation process will be inherently valuable as I elicit the perspectives of care coordinators, home care nurses, and their managers regarding what challenges they face, what they need to learn, and how they want to learn in their individual contexts. I have incorporated many of the pediatric subject areas, educational delivery methods, technological considerations, and theories and frameworks from this scan within the needs assessments that will be provided to care coordinators and home care nurses; this approach will enable me to narrow my focus to what works for home health professionals who provide pediatric care in Nova Scotia as I move forward in my practicum project.

Conclusion

Across Canada, although there are multifaceted strategies and approaches to providing pediatric home care, this trend reflects widespread awareness of the unique challenges and considerations for this specialty domain of health care. Provincial home care programs, pediatric health centers, and even national organizations are striving to provide the best home care possible for pediatric patients and their families. There is unlikely to be a magic bullet solution for how to provide the best pediatric home care, and the best pediatric home care education. Rather, when planning pediatric home care education, it is essential to consider the key themes identified within this environmental scan – the attributes of and resources available within home care programs, the learning needs of home care staff, the setting of each patient's home care, the timing of home care education, the need for close partnerships between pediatric health centers and home care professionals, the use of technology to support education, the use of relevant theory to bolster educational quality, and consideration of overlap between home care and school-based health care needs. The overarching consideration within these themes is the need for customizable and flexible educational subjects and delivery methods that will have relevance and meaning in the practice of individual home care professionals. The results of this environmental scan highlight that diligent planning and detailed consideration of the individual contexts of patients, families, and home care professionals are essential in order to meet learning needs and foster the best outcomes for pediatric patients receiving care at home.

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Appendix A: Contact Letter

Dear __________,

My name is Sarah King, and I am a registered nurse working in pediatric discharge planning and home care coordination in Nova Scotia as part of the IWK Health Centre and Continuing Care Nova Scotia. I am also a Master of Nursing (MN) student at the Memorial University of Newfoundland under the supervision of Dr. Joy Maddigan.

I am conducting a project for my MN degree to develop pediatric educational resources for multidisciplinary health professionals who work in home care in Nova Scotia, as their practices are traditionally adult-focused. My overall goal for this educational initiative is to enhance the quality of pediatric home care in Nova Scotia. To inform my project, I am conducting an environmental scan to see what other Canadian provinces and territories are doing to build the competence, knowledge, and skill sets of health professionals who care for children at home. I am contacting educators, managers, and leaders in pediatric health centers, government-funded home care programs, and pediatric- or community-focused national organizations to elicit this information.

I hope you will have time to respond to my email, or set up a time to speak via phone or Skype to discuss these questions:

1. Does your [provincial or territorial home care program/health centre/national association] provide education to community health professionals specific to pediatric home care? If so, what pediatric subjects are covered? What educational delivery methods are used? If no pediatric home care education is provided, could you help me understand the reason for this?

2. When your [provincial or territorial home care program/health centre/national association] provides education to community health professionals in any special interest subjects, what are some subject areas you have covered? What educational delivery formats do you use?

3. When providing pediatric or other education to community health professionals, are there any educational approaches, theories, or frameworks that guide your education?

4. When providing pediatric or other education to community health professionals, are there any types of technology that you have found helpful or not helpful to aid education delivery?

5. What successes, challenges, or key considerations have you noted in providing education to health professionals in the community?

6. What pediatric subject areas have been the most or least valuable when it comes to building understanding and competence for adult-focused community health professionals?

I thank you in advance for your time and look forward to hearing from you.

Best Wishes,

Sarah T. King, RN BScN

Discharge/Continuing Care Liaison

IWK Health Centre

Appendix B: Environmental Scan Data

Table 1

Provincial Home Care Programs

Name	Location	Website
Extra Mural Program	NB	http://extramuralnb.ca/
Local Health Integration Networks	ON	www.lhins.on.ca/
Continuing Care	AB	www.albertahealthservices.ca/cc/page15488.aspx

Table 2

Pediatric Health Centres

Name	Location	Website
Janeway Children's Health and Rehabilitation Centre	St. John's, NL	www.easternhealth.ca/AboutEH.aspx?d=3&id=789&p=724
The Hospital for Sick Children	Toronto, ON	www.sickkids.ca
BC Children's Hospital	Vancouver, BC	http://www.bcchildrens.ca/

Table 3

National Organizations

Name	Website
Children's Healthcare Canada	https://www.childrenshealthcarecanada.ca/
Canadian Home Care Association	http://www.cdnhomecare.ca/

Note. NB = New Brunswick; ON = Ontario; AB = Alberta; NL = Newfoundland and Labrador; BC = British Colombia.

Table 4

Pediatric Home Care Education Subjects

Pediatric Education Subjects	Home Care Program	Health Centre
Tracheostomy Tubes	1/3	3/3
Home Ventilation (Invasive/Non-Invasive)	1/3	2/3
Pulmonary Clearance (Suctioning/CA/CPT)	1/3	3/3
Enteral Feeding and Tubes (NGT, GT, JT)	1/3	3/3
Vascular Access Devices (CVAD or PIV)	1/3	3/3
Seizure Care	1/3	1/3
Diabetes Management	1/3	0/3
Peritoneal Dialysis	1/3	1/3
Medication Management	1/3	1/3
TPN and Lipids	1/3	2/3
Urinary Catheterization	0/3	1/3
Pediatric Palliative Care	1/3	2/3
Children with Medical Complexity/Special Needs	2/3	2/3
Family Centered Care/Building Relationships	2/3	0/3
Pediatric Assessment (Physical, Growth, Pain, etc).	3/3	0/3
Difficult Conversations/Conflict	1/3	0/3

Vicarious Trauma	1/3	0/3

Note. CA = Cough Assist; CPT = Chest Physiotherapy; NGT = Nasogastric Tube; GT = Gastrostomy Tube; JT = Jejunostomy Tube; CVAD = Central Venous Access Device; PIV = Peripheral Intravenous; TPN = Total Parenteral Nutrition.

Table 5

Theories and Frameworks Used in Home Care Education

Theory or Framework	Home Care Program	Health Centre
Adult Learning	3/3	3/3
Active/Experiential Learning	1/3	2/3
Flipped Classroom	0/3	2/3
Family Centered Care	1/3	2/3
Simulation Education	1/3	3/3
Strength-Based Care	0/3	1/3
Bandura’s Social Learning Theory	0/3	1/3
Constructivism	0/3	1/3
Accessible Learning (Reading Level, Language, Learning Disabilities)	1/3	0/3

Table 6

Home Care Education Delivery Methods

Delivery Method	Home Care Program	Health Centre

In-Person at Hospital	3/3	3/3
In-Person at Local Site	3/3	2/3
Live Webinar/Telehealth	3/3	2/3
Recorded Webinar/Video	3/3	2/3
Written Material – Paper	3/3	3/3
Written Material – Online	2/3	2/3
Standard Checklists/Procedures/Policies	1/3	3/3
Phone Calls	2/3	2/3
Text Messaging	1/3	2/3
Video Chat	0/3	2/3
Education Groups	1/3	1/3
E-Learning Modules	3/3	3/3

Appendix C: Consultation

Consultation Report: Pediatric Education for Home Health Professionals in Nova Scotia

Sarah T. King

Memorial University of Newfoundland

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Consultation Report: Pediatric Education for Home Health Professionals in Nova Scotia

The increasing acuity and complexity of home care patients in Canada is a considerable challenge facing this fast-growing sector of health care (Canadian Institute for Health Information [CIHI], 2019; Stevenson, McRae, & Mughal, 2008). Home care providers and home care coordinators encounter specialty populations on a regular basis, and they must understand the needs of these populations to make informed decisions and provide effective care. The related educational needs of home care professionals caring for specialty populations must be determined and addressed in a comprehensive and timely manner to support best practice and optimal patient outcomes (Egan et al., 2009; Howell, Prestwich, Laughlin, & Giga, 2004; Stevenson et al., 2008).

Pediatrics is one specialty population that is present and growing within home care. Most commonly defined as patients aged 0 to 19 years, pediatric patients need home care for a variety of conditions – otherwise healthy children may need a short course of intravenous antibiotics for an infection, while other children live for years with multiple chronic health conditions and are fully dependent on respiratory and feeding technology (Mendes, 2013; Smith, 2011). In pediatric home care, situations that may be familiar to a home health professional, such a patient with a nasogastric tube, may lead to a variety of questions and concerns pertaining to differences in practice and concerns about safety and healthy child development (Northington, Lyman, Guenter, Irving, & Duesing, 2017). There is significant clinical diversity inherent within the pediatric home care population, so the learning needs of the home health professionals who care for them are apt to be similarly diverse. There are also many strategies to meet home health professionals’ learning needs – strategies that must account for the particular context of the home environment and home health professionals' autonomous practice (Egan et al., 2009; Pilcher, 2016). Accordingly, what are the possible strategies that can be used to provide relevant education for home health professionals on a variety of possible pediatric subjects? This is a pressing question given the resultant impact of home health professionals' knowledge and competence on the overall health outcomes of pediatric patients and families who use home health care services. This question is also directly relevant to my practicum project, in which I will develop pediatric educational resources for home care professionals, to enhance the overall quality and outcomes of pediatric home care for patients and families in Nova Scotia.

To answer the question of how best to provide relevant education for home health professionals on a variety of possible pediatric subjects, I undertook a comprehensive consultation process in my local context, the province of Nova Scotia. In Nova Scotia, the two largest groups of home health professionals are care coordinators and home care nurses (Continuing Care, 2013). Care coordinators assess patient and family needs and allocate relevant home care resources, collaborating with professionals throughout the system to ensure comprehensive and coordinated home care. Home care nurses provide direct patient care in homes, including medication administration, tube feeding, wound care, respite, and many other types of care. To find out more information about pediatric subjects and learning preferences among these two groups of health professionals, I first conducted two online focus groups, one with the managers of care coordinators, and one with the managers of home care nurses. I also conducted two online needs assessments, one for care coordinators and one for home care nurses. I used thematic analysis (Polit & Beck, 2017) to distill the most important data from these focus groups and needs assessments to ensure I develop pediatric resources that are compatible with, and will be useful for the practice of home health professionals in Nova Scotia. In the following pages, I will outline the methodology and results of the focus groups and needs assessment in detail, and make relevant conclusions.

Background and Methodology

To develop questions for the focus groups and needs assessments, I used a variety of information, including a literature review on pediatric home care, an environmental scan on pediatric home care education in Canada, a limited literature review on learning needs for community and home health care professionals, and my professional experience as a liaison between acute care pediatrics and home care in Nova Scotia.

For my practicum project, I conducted a literature review examining best practices in the domain of pediatric home care as a means to inform educational resource development. The most pertinent findings included the need to elicit professionals' experiences to inform pediatric home care education, the need to consider different educational delivery methods depending on the complexity of pediatric subjects, and the need to use a variety of educational resources to inform pediatric home care education. In addition, the literature review showed an overarching emphasis on the contextual and multi-factorial nature of pediatric home care, a need to balance systemized approaches with openness and flexibility in pediatric home care education, and the need for family-centered care principles to inform all aspects of pediatric home care.

I also conducted an environmental scan for my practicum project, which involved examining information from Canadian national organizations, Canadian pediatric health centers, and Canadian provincial home care programs to determine current practices in pediatric home care education. The most pertinent findings from my environmental scan were the identification of several key subjects used in pediatric home care education, theories and frameworks used to inform home care education, possible home care education delivery methods, and the need to consider customization, flexibility, learners' preferences, and acute care pediatric partnerships for the delivery of pediatric home care education. For example, caring for children with medically complex health conditions and associated technology such as tracheostomy tubes was a common subject in pediatric home care education. Home care education on this subject included e-learning, in-person education, written resources, and ongoing support from acute care pediatric staff.

To ensure my consultation process was well-informed in its overall structure and function, I also conducted a limited literature review on home care education and needs assessments, focusing on the pediatric population and on Canada or the United States where possible. One theme was the need to identify existing education and information resources used by home health professionals as part of a needs assessment (Cooper & Urquhart, 2005; Egan et al., 2009; Frierdich, Goes, & Dadd, 2003). Other considerations were the need to ensure sustainability in home care educational resources (Lange, Mager, Greiner, & Saracino, 2011), the need to elicit the learning preferences of staff (Kassam et al., 2011), and the need to leverage existing resources and adapt learning to the home care environment and professional roles in home care (Howell et al., 2004; Lange et al., 2011).

Although some of these considerations are directed toward resource development, such ideas can be incorporated into focus groups and needs assessments to maximize the effectiveness of eventual education and learning. Methods used to assess home health professionals’ education and information needs included interviews and focus groups with staff and leadership, written or online staff needs assessments, and feedback from clinical experts (Cunningham & Kelly, 2005; Egan et al., 2009; Frierdich et al., 2003; Howell et al., 2004; Iliffe et al., 2012; Kassam et al., 2011; Lange et al., 2011; Winslow et al., 2016). Several articles outlined ways to frame needs assessments, such as by learning subjects, possible learning gaps, interest in a given subject, past clinical successes and challenges, need for knowledge versus need for skills, or level of experience or comfort in a clinical situation (Cunningham & Kelly, 2005; Hopkins, 2002; Iliffe et al., 2012; Kassam et al., 2011; Pilcher, 2016; Winslow et al., 2016). Suggested formats for needs assessments included using Likert scale or multiple choice responses for most questions with periodic free text responses, and using online reporting to increase accessibility and response rates (Cunningham & Kelly, 2005; Iliffe et al., 2012; Pilcher, 2016; Winslow et al., 2016). These findings confirmed my overall approach of using focus groups and needs assessment to elicit home care professionals’ educational and informational needs, and helped guide the questions I developed.

Using the findings from my literature review and environmental scan, applying my learning regarding home care professionals’ education and information needs, and drawing on my professional experiences, I developed questions for the manager focus groups (Appendix A) and the home care professional needs assessments (Appendix B).

Focus Group Methods and Results

I conducted a one-hour focus group with five care coordinator managers in attendance, and two care coordinators attending in the place of managers who were unavailable. I also conducted a one-hour focus group with five home care nurse managers in attendance. I conducted separate one-hour interviews with two home care nurse managers who were unable to attend the focus group. For both the care coordinator and home care nurse management groups, those who attended represented the entire province of Nova Scotia, both from a geographic perspective and from an urban, suburban, small-town, and rural perspective. For both focus groups and for the two interviews, I used my question guide (Appendix A) to maximize consistency in the data I collected, and I took detailed notes to ensure accurate recall. I used thematic analysis to distill important information from the conversations.

Care Coordinator Management Focus Group

Due to the independent nature of care coordinators' practice, managers do not always hear specifics about staff learning needs. However, they do have understanding of overall trends and experiences of care coordinators when it comes to pediatric home care. Managers reported that the overall learning needs of their staff center on needing clear communication and understanding of all partners involved in pediatric patients' care so they can engage in effective multi-sectoral coordination. Sometimes care coordinators needs specific knowledge about a pediatric patient's health condition and sometimes they need information about the patient's care plan, such as the parents' skills and needs relative to what assistance and support the patient and family need from home care providers. Managers often hear about care coordinators' anxieties and concerns when it comes to caring for pediatric patients, since not all staff have experience with this age group. They noted that concepts seen in both adult and pediatric home care, such as the principles of palliative care, are different between these two populations. Adult palliative care patients usually only live for weeks to months, whereas pediatric palliative care patients may live for months to years and may not be considered near end-of-life. The differences between pediatric and adult home care can make care coordinators feel less confident in their role. Managers reported that staff struggle the most when they do not have a clear understanding of pediatric patient situations, and when there are multiple partners and funding sources involved in home care, such as the education system, the department of community services, and home care.

Managers described that current assessment tools used by care coordinators to perform family assessments are designed for patients aged 18 years and older. Care coordinators are not able to use this tool to engage in direct pediatric family assessments, but they may use headings from this tool to guide conversations. For example, there is a heading entitled "informal supports" that some care coordinators would use with pediatric patients' families to discuss their informal supports. Some care coordinators access a tool used by a pediatric long term care and respite facility to inform their pediatric patients' family assessments. Not all care coordinators know about this tool, and the tool itself is of an informal nature, so its degree of usefulness is unclear.

Children with medically complex health conditions present particular challenges to care coordinators. Managers said that care coordinators do not always know the full circle of care involved with each pediatric patient because patients have so many health professionals across multiple settings. Sometimes it is assumed that care coordinators have information about the care of these patients, but there may be gaps in knowledge and understanding. When care coordinators have not cared for a medically complex pediatric patient, one manager said it can be “sheer panic” to see how complex their care plans are. The care needs of children with medically complex health conditions often meet or exceed the usual limits for hours of home care service, so knowing how to navigate these situations may represent unfamiliar territory even for well-experienced care coordinators. In addition, the care needs of these children are frequently changing, so it can take a great deal of a care coordinator’s time to keep on top of multiple updates.

When care coordinators engage in education or learning on any home care-related subjects, managers report that staff prefer recorded videos or recorded webinars, short presentations at staff meetings, quick reference documents such as question and answer format, website links for online resources, and contact information for experts they can speak with. Learning for care coordinators is ideally quick, accessible, and relevant.

In summary, managers identified a prevailing sense of concern and anxiety for care coordinators when they encounter pediatric patients, and in particular, medically complex pediatric patients. Care coordinators need to understand pediatric patients’ health conditions, the differences between adult and pediatric home care, and very importantly, families’ skills and needs in caring for their child. Care coordinators must have information about the various partners and sectors involved in pediatric patients’ care, so they can have a full and accurate picture of how to coordinate home care.

Home Care Nurse Management Focus Group

Home care nurse managers mentioned a number of specific topics their staff might need to learn about when it comes to pediatric home care, such as diabetes, feeding tubes, the care of infants, intravenous medication administration, and calculating weight-based medication doses. Although nurses often need specific knowledge to provide safe and informed care for pediatric patients, managers state nurses struggle with anxiety and confidence when they are assigned to a pediatric patient. If nurses feel they have a process to follow and support people they can call at any hour they are in the patient’s home, this helps reduce their anxiety. One manager stated that nurses’ anxiety may keep them from thinking clearly and troubleshooting effectively, so that even if they are skilled at problem solving with adult patients, they may not problem solve as well with pediatric patients. Some of nurses’ greatest worries, and hence their greatest learning needs, are related to caring for pediatric patients receiving palliative or end-of-life care, having something go wrong in the home and not knowing who to call, having difficult conversations with the family of a pediatric patient, and feeling the family does not trust them or have confidence in them.

Managers reported that home care nurses use a general admission tool for patients of every age. It does not have a great deal of information on family assessment even for adult patients, as it only asks for contact people and support people other than the patient, and sources of stress for the patient. Nurses try and tailor this assessment as much as they can for pediatric patients, such as by asking the parents about stresses within the family. Managers also believe that home care nurses glean a great deal of information from their interactions and observations while caring for the patient and family, and this helps them build a sense of overall family status.

The care of medically complex children and families is a significant challenge for home care nurses' learning. Not only do they need to learn about patients' rare health conditions, but they may also need training on associated technology such as feeding pumps or tracheostomy tubes. Managers state that nurses need time to review patients' care plans with a "fine-toothed comb" to ensure they have the right information and a full understanding of the patient's situation. Given the limited staffing in most home care nursing offices, it can be a challenge to find the time to review care plans and have time for necessary learning. It is important for nurses to have contacts in acute care pediatrics they can call with questions about these complex patients. One manager emphasized how important it is for home care nurses to learn and practice in a way that is consistent with what parents were taught by acute care pediatric staff; such consistency helps nurses build trust with complex pediatric patients and families. Home care nurses sometimes struggle to help families who experience tremendous emotional burdens with the long-term care of their medically complex child, or they may be uncertain how to interact with medically complex children who have limited communication abilities. The experiences of caring for medically complex children are very diverse, so the learning needs of home care nurses vary as well.

When home care nurse managers were asked how their staff prefer to learn about home care topics, they had several suggestions. Having an online link to watch a video, read a policy, or access a resource is helpful because nurses can view it on their work mobile phone, or even download the resource to their phone. Webinars and interactive webinars are helpful as long as they happen at a “convenient time of day” or are recorded for staff to watch at another time. Home care nurses value being able to call experts to support their learning, especially if a question arises when they are in the home. In certain learning situations, hands-on training is also required.

Overall, home care nurse managers identified their nurses’ motivation to learn and provide effective care for pediatric patients and their families, despite significant anxiety about the care of these patients. Nurses’ anxiety was even identified as a potential barrier to learning and problem solving in the home. Home care nurses need to learn about specific subjects and technology, particularly when caring for medically complex children, but a significant source of learning and support is having pediatric experts they can call for support. Nurse managers report that their staff need to learn about how to manage when things go wrong in the home, how to have difficult conversations with the families of pediatric patients, and how to build their confidence and families’ trust in them. Although home care nurses have limited time for learning, and sometimes limited tools such as for family assessments, they are eager to learn about pediatric home care.

Needs Assessments Results

After developing a series of needs assessment questions (Appendix B), I had two online needs assessments developed, one for care coordinators and one for home care nurses. I sent out a link for each survey to management for each group, who in turn forwarded the link to their staff. I kept the needs assessment open for two weeks and then I received a report with the final results for care coordinators (Appendix C) and home care nurses (Appendix D). I received responses from 39 care coordinators and 75 home care nurses, representing the entire province of Nova Scotia geographically and from an urban, suburban, small-town, and rural perspective.

Care Coordinator Needs Assessment

Care coordinators who responded to this needs assessment had limited experience with pediatric patients, with 77% either never having a pediatric patient, or having a pediatric patient less often than once per year. It is unsurprising that 46% of these care coordinators rate their confidence caring for pediatric patients as very low or low.

The needs assessment focused on several key pediatric home care subject areas. Care coordinators generally wanted to increase their learning about interacting with and assessing pediatric patients and families, with particular interest in doing family assessments from a pediatric perspective (79%), as well as explaining health information in a way a child can understand (38%), building rapport with families (36%), and creating partnerships with families (36%). The emotional challenges of pediatric care that care coordinators wanted to learn about most were caring for a child in a palliative or end-of-life situation (77%) and how to coordinate care when a child is developmentally unable to voice their needs (56%). There were a number of aspects of the care of medically complex children care coordinators wanted to learn about, such as in-home medical devices and technology (51%), rare and/or complex health conditions (56%), how to work in partnership with the families of medically complex children (59%), and how to interact with or interpret communication from a child with limited neurodevelopmental abilities (59%). Care coordinators wanted to learn more about how to ensure the appropriate level of home care for pediatric patients (69%), and about particular pediatric considerations for enteral tubes (41%), central lines (46%), and palliative and end-of-life care (62%).

When given the chance to express some of their experiences and learning needs pertaining to pediatric home care using free text, care coordinators offered a great deal of information. A few issues were raised specific to the home support worker role, an unregulated health care role with a focus on supporting personal care and activities of daily living. Care coordinators felt these workers had limited understanding of and training in pediatrics; if home support workers' pediatric learning needs were addressed, this would enable care coordinators to better meet patients' needs. One care coordinator wanted to learn more about facility-based respite and residential care for children, and what level of care can be provided in this type of facility. Other care coordinators explained obstacles that pediatric patients and their families face within the home care program, such as "extensive invasive processes" for home oxygen in palliative situations, the lack of a caregiver benefit fund for caregivers of children, and a lack of resources and role clarity for in-home equipment needs for children. An additional learning need identified by care coordinators was their uncertainty about what types of home care services pediatric patients are eligible for.

In terms of learning preferences, care coordinators generally wanted to learn about pediatric home care subjects ahead of time to build a knowledge base, and then again as a refresher when they have a pediatric patient on their case load (62%). They prefer to learn by watching videos (79%), doing a self-directed learning activity (33%), exploring a website (33%), or reading an educational guide or pamphlet (38%). In the free text field, two care coordinators noted a preference for learning via interactive webinars, while others wanted to talk with an expert, have a checklist, or meet the patient and family before they left the hospital. When care coordinators need information to access during a home visit, they prefer a quick-reference guide or standardized checklist (87%), a website with multiple resource options (36%), or a policy or guideline (33%). Other thoughts from the care coordinators regarding learning preferences included the challenge of maintaining pediatric competency as pediatric patients are infrequent, and the value of having a liaison between acute care pediatrics and home care.

In summary, care coordinators have identified a range of personal, interprofessional, and systems-level learning needs that require careful consideration to identify associated implications for resource development.

Home Care Nurses Needs Assessment

According to their needs assessment results, home care nurses have limited pediatric patient experience, with 36% never caring for a pediatric patient or caring for a pediatric patient less often than once per year. As well, confidence caring for pediatric patients was very low or low for 39% of nurses.

Next, home care nurses outlined their learning needs pertaining to specific pediatric subject areas. With regards to patient and family interactions and assessments, nurses were most interested in learning about doing family assessments that incorporate a pediatric perspective (61%) and how to explain medical information in a way a child can understand (65%). For the emotional challenges of pediatric care, nurses wanted to learn about caring for a child in a palliative or end-of-life situation (85%) and coordinating care for a child who is developmentally unable to voice their needs (60%). When considering the care of medically complex children, there was a high degree of interest in learning about rare and complex health conditions (79%) and a broad spectrum of interest in learning about in-home medical devices and technology (65%), the stresses and burdens of families of medically complex children (59%), knowing how to interact with and interpret communication from children with limited neurodevelopmental abilities (57%), and feeling ethically conflicted about the child's quality of life when they are living with complex health issues (52%). Nurses' interest in learning about pediatric care plans was equally divided between ensuring appropriate levels of in-home care (61%), how to approach families about a necessary change in their child's care plan (65%), and how to make sure the family's context is considered within the care plan (61%). For more general home care situations that need a pediatric perspective, home care nurses wanted to learn about pediatric palliative and end-of-life care (85%), enteral tubes (67%), and medication management (63%).

In the free text sections pertaining to pediatric home care subject areas, nurses provided extensive feedback. Some nurses requested hands-on learning or workshops for subject areas such as technological equipment and communication. A few specific subject areas were noted, such as diabetes, pediatric cardiopulmonary resuscitation, seizures, and palliative care for infants. Nurses highlighted how individual each pediatric patient situation is, and they value receiving education on individual patient situations. Nurses also shared situations that they found challenging, such as a child with limited pain tolerance, a child who had to be connected to a pump around the clock, or struggles to understand certain requests from parents regarding care for their child. Other learning needs and challenging situations were more emotional, such as a “heart-wrenching” experience when a long-term home care patient died, a sense that “kids are scary”, or feeling that pediatrics is “not an area of care I am comfortable with or enjoy”.

Finally, home care nurses shared information about their learning preferences. Most prefer to learn about pediatrics ahead of time to build their knowledge base, then again when they have a pediatric patient (76%). Nurses prefer to learn by watching a video (80%), doing a self-directed learning activity (49%), or reading an educational guide or pamphlet (43%). When asked to provide additional information about their learning preferences, nurses made mention of webinars, lunch and learn sessions, and simulation case studies. When nurses need to access information or learning during a home visit, most would like a quick-reference guide or standardized checklist (83%), but may also like a policy or guideline (47%) or a website with multiple resource options (36%). Nurses also reach out to co-workers, managers, and educators within their office when they need resources or information, while others value having a pediatric expert they can reach out to. When asked to provide their final thoughts, two home care nurses made impactful statements. One wrote, “Taking care of fragile young patients scares me. They are so vulnerable which makes me feel vulnerable.” Another nurse stated they “want parents to have confidence in my care.”

In summary, home care nurses have been forthcoming and sincere in sharing their learning needs, experiences, and emotions in providing pediatric home care. Nurses want to learn about specific pediatric home care subjects such as feeding tubes and medication management, but also about the care of more challenging populations such as medically complex children and patients receiving palliative and end-of-life care. Broader learning themes identified by nurses include care planning and communication with pediatric patients and families, and an overall need for support from and easy contact with pediatric acute care health professionals.

Discussion

A comprehensive consultation process with the managers of care coordinators and home care nurses, as well as the care coordinators and home care nurses themselves, has yielded an incredible volume and depth of information about pediatric home care learning needs. There is a significant proportion of care coordinators and home care nurses that have minimal to no pediatric experience and/or confidence, making pediatrics an area of profound educational needs for home care professionals in Nova Scotia. Using thematic analysis, I have identified some of the most important themes and the most pressing learning needs and challenges within both groups.

Care coordinators and their managers identified learning needs that reflect the care coordination role itself in themes of system navigation, resource allocation, and multidisciplinary and multi-sectoral collaboration. Learning about specific subjects was secondary to learning about populations, and learning about the different roles and players within the circle of a child's care. Care coordinators need clear communication and a big-picture perspective of pediatric patients' and families' needs and overall home care plans, so it is not surprising that some of their most obvious learning needs centered on family assessment, communication, care planning, and home care resources and services. Care coordinators also had a general interest in learning about pediatric palliative and end-of-life care, and about children with medical complexity. Learning about these special sub-populations in pediatrics would help care coordinators make sense of the often detailed care plans associated with these two groups.

Home care nurses and their managers identified specific pediatric subject areas for learning, such as seizures and diabetes, but also broader subject areas such as palliative and end-of-life care and the care of children with medical complexity. Similar to care coordinators, home care nurses also wanted to learn about family assessments and communication with pediatric patients and their families. A particular theme for home care nurses was their learning needs around troubleshooting when things go wrong or are not straightforward with pediatric patients. Wondering how to assess a crying child, feeling unsure how to communicate with a child who has neurodevelopmental challenges, or worrying about dealing with emergency situations show that nurses want to develop their pediatric problem solving skills across diverse situations. Home care nurses valued having standard processes to follow for pediatric home care, as well as training, advice, and ongoing support from colleagues in pediatric acute care, all of which were seen as a way to support their learning and overall confidence in caring for children.

In both the care coordinator and home care nurse groups, the theme of feeling anxious, afraid, or unconfident when caring for pediatric patients was prominent. This is an understandable yet concerning finding, given one manager’s wise statement that overwhelming anxiety may cloud clinical judgment and problem solving ability. Another theme that was consistent between both professional groups was the need to have clear understanding of the overall patient and family care plan, know the key players in the circle of care, and have contacts in pediatric acute care who can answer questions and support learning. Neither group had access to a pediatric family assessment tool, although each group made efforts to glean as much information as possible by tailoring existing family assessment tools. Given the centrality of family-centered care in pediatrics (Kuo et al., 2012), the lack of a pediatric family assessment tool is a significant gap in home care practice. As previously noted, both groups had a strong desire to learn about pediatric palliative and end-of-life care, and the care of medically complex children and their families, populations that challenge the most experienced pediatric health professionals.

When considering home care professionals' learning preferences in the context of their autonomous and time-limited practices, it makes sense that they favor quick and easy-to-access resources, such as recorded webinars and videos, self-directed learning, websites to explore, or guides and pamphlets to read. It is encouraging to note that both groups showed a strong desire to learn about pediatric home care, wanting to increase their baseline competency in this specialty area and also learning when a new pediatric patient was assigned to their care.

Conclusion

Engaging in consultation with home care professionals in Nova Scotia has been an incredibly rich and valuable experience to inform my practicum project. Building on my prior pediatric home care literature review and environmental scan, and adding learning from the literature on needs assessments and educational needs in home and community care, I conducted focus groups and needs assessments for these home care professionals.

The generous responses and feedback from care coordinators and home care nurses have helped me identify specific and general learning needs within and between these groups of professionals. I have also narrowed down ideal learning formats for these groups to inform their home care practice in an accessible and relevant manner. Although it is a daunting task to choose only select learning needs to address in my final practicum project, I am confident that the educational resources I develop will support best practice in pediatric home care, and foster evidence-informed home care that will benefit pediatric patients and their families.

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Appendix A: Focus Group Questions

1. What pediatric home care learning needs are you aware of among your staff?
2. Are your staff members' pediatric home care learning needs related to needing additional knowledge, acquiring additional psychomotor and/or interpersonal skills, building confidence, or other factors?
3. What are the pediatric home care situations that result in the most questions or concerns from your staff?
4. What kinds of approaches do staff use to perform family assessments with adult patients? Are these approaches also used for pediatric patients and their families? If so, do they work well or not work well?
5. What would be (or are) the biggest challenges for your staff in caring for a child with a medically complex health condition?
6. When your staff need education or resources in a specialized home care domain such as pediatrics, what learning or resource formats work well when in-person education is not possible?

Appendix B: Needs Assessment Questions

Please answer the following questions to the best of your ability. There will be space at the end to share general thoughts and ideas. There are 3 opening questions, 8 questions about pediatric home care subject areas, and 4 questions about your learning preferences.

Opening Questions:

1. I work within the __________ zone of the Nova Scotia Health Authority.

a. Western.

b. Central.

c. Northern.

d. Eastern.

2. On average, I have a pediatric patient (age 0-18 years) on my caseload:

a. Once a month or more often.

b. At least once every 1 to 6 months.

c. At least once every 6 to 12 months.

d. Less often than once a year.

e. I have never had a pediatric patient.

3. I would rate my overall confidence coordinating care for pediatric patients (age 0-18 years) as:

a. Very low.

b. Low.

c. Moderate.

d. High.

e. Very high.

Pediatric Home Care Subject Areas:

Each question represents a pediatric home care subject area. Choose one or more item(s) in each subject area (letters a, b, c, d, e) that you want to learn about. You may also indicate that you don't need to learn about this subject area.

1. Pediatric and family interactions and assessments – I want to learn more about:

a. Building rapport with pediatric patients.

b. Building rapport with the families of pediatric patients.

c. Doing family assessments that incorporate a pediatric perspective.

d. How to create and maintain partnerships with families of pediatric patients.

e. How to explain medical things in a way a child can understand.

f. I don't need to learn about this subject.

2. Emotional challenges of pediatric care – I want to learn more about:

a. What to do when I feel overwhelmed about coordinating care for a sick child, no matter what their health situation.

b. Caring for a child and family in a palliative or end-of-life situation.

c. How do coordinate home care when children are not developmentally able to voice their needs or contribute to care planning.

d. I don't need to learn about this subject.

3. Medically complex children (i.e. Children who have chronic health conditions that significantly affect their functional/day-to-day abilities, often have a neurological or

developmental disability, often have a medical device or technology to sustain or improve life, and are high users of the health care system) – I want to learn more about:

a. Understanding in-home medical devices and technology. (e.g. Feeding tubes, feeding pumps, tracheostomies, ventilators, oxygen saturation monitors, etc).
b. Rare and/or complex pediatric health conditions.
c. How to work in partnership with a family that is highly experienced and self-directed with the specialized care of their medically complex child.
d. The stresses and burdens that are unique to families of medically complex children.
e. Knowing how to interact with, or interpret communication from, a child who has limited neurodevelopmental abilities.
f. Feeling ethically conflicted about how much home care one medically complex child is receiving relative to other patients.
g. Feeling ethically conflicted about the child's quality of life with complex health issues.
h. I don't need to learn about this subject.

4. Developing and modifying pediatric care plans – I want to learn more about:

a. Ensuring appropriate level of care determinations for pediatric patients (e.g. home support versus licensed practical nurse versus registered nurse).
b. How to approach families about a challenging situation or a necessary change in their child's care plan.
c. How to make sure the family's context and situation are considered when developing or making changes to a child's care plan (e.g. Considering the parents' and siblings' needs,

whether changes to a care plan are feasible with the family's unique challenges, making sure the child's emotional and mental needs are considered, etc).

d. I don't need to learn about this subject.

5. Pediatric considerations for general home care situations – I want to learn more about:

a. Pediatric enteral tubes (i.e. Nasogastric, nasojejunal, gastrostomy, and/or jejunostomy tubes).

b. Pediatric central lines (i.e. Broviac lines, Hickman lines, Port-a-Caths).

c. Pediatric skin and wound care.

d. Pediatric medication management.

e. Pediatric palliative and end-of-life care.

f. Other.

g. Please share exactly what you would like to learn about in the area(s) you chose:

h. I don't need to learn about this subject.

6. Please share a pediatric home care experience that you wish you were better prepared for, or that you found particularly challenging. <u>Be careful not to disclose any identifying patient or family information.</u>

7. In the space provided, share any additional thoughts or suggestions for pediatric subject areas you want to learn about.

Learning Preferences:

1. I prefer to learn about pediatric home care subjects:

a. Ahead of time so that I already have a knowledge base.

b. When I have a pediatric patient on my caseload so I can apply and use the knowledge in real life.

c. Ahead of time and again when I have a pediatric patient.

d. In another way. Please explain.

2. When in-person teaching is not possible, I prefer to learn by:

a. Watching a video.

b. Doing a self-directed learning activity.

c. Exploring a website.

d. Reading an educational guide or pamphlet.

e. Another method. Please explain.

3. When I need resources or information to access during a home visit, I prefer:

a. A policy or guideline.

b. A quick-reference guide or standardized checklist.

c. A troubleshooting algorithm.

d. A scholarly article.

e. A website with multiple resource options.

f. Another option. Please explain.

4. In the space provided, share any additional thoughts or suggestions about your learning preferences for pediatric home care.

Appendix C: Care Coordinator Needs Assessment Results

Opening Questions:

1. I work within the __________ zone of the Nova Scotia Health Authority.

a. Western 46%

b. Central 23%

c. Northern 8%

d. Eastern 23%

2. On average, I have a pediatric patient (age 0-18 years) on my caseload:

a. Once a month or more often. 8%

b. At least once every 1 to 6 months. 3%

c. At least once every 6 to 12 months. 13%

d. Less often than once a year. 41%

e. I have never had a pediatric patient. 36%

3. I would rate my overall confidence coordinating care for pediatric patients (age 0-18 years) as:

a. Very low 13%

b. Low 33%

c. Moderate 49%

d. High 3%

e. Very High 3%

Pediatric Home Care Subject Areas (Respondents may choose more than one answer):

1. Pediatric and family interactions and assessments – I want to learn more about:

a. Building rapport with pediatric patients. 28%

b. Building rapport with the families of pediatric patients. 36%

c. Doing family assessments that incorporate a pediatric perspective. 79%

d. How to create and maintain partnerships with families of pediatric patients. 36%

e. How to explain medical things in a way a child can understand. 38%

f. I don’t need to learn about this subject. 13%

2. Emotional challenges of pediatric care – I want to learn more about:

a. What to do when I feel overwhelmed about coordinating care for a sick child, no matter what their health situation. 33%

b. Caring for a child and family in a palliative or end-of-life situation. 77%

c. How do coordinate home care when children are not developmentally able to voice their needs or contribute to care planning. 56%

d. I don’t need to learn about this subject. 13%

3. Medically complex children (i.e. Children who have chronic health conditions that significantly affect their functional/day-today abilities, often have a neurological or developmental disability, often have a medical device or technology to sustain or improve life, and are high users of the health care system) – I want to learn more about:

a. Understanding in-home medical devices and technology. (e.g. Feeding tubes, feeding pumps, tracheostomies, ventilators, oxygen saturation monitors, etc). 51%

b. Rare and/or complex pediatric health conditions. 56%

c. How to work in partnership with a family that is highly experienced and self-directed with the specialized care of their medically complex child. 59%

d. The stresses and burdens that are unique to families of medically complex children. 59%

e. Knowing how to interact with, or interpret communication from, a child who has limited neurodevelopmental abilities. 59%

f. Feeling ethically conflicted about how much home care one medically complex child is receiving relative to other patients. 26%

g. Feeling ethically conflicted about the child’s quality of life with complex health issues. 36%

h. I don’t need to learn about this subject. 5%

4. Developing and modifying pediatric care plans – I want to learn more about:

a. Ensuring appropriate level of care determinations for pediatric patients (e.g. home support versus licensed practical nurse versus registered nurse). 69%

b. How to approach families about a challenging situation or a necessary change in their child’s care plan. 59%

c. How to make sure the family’s context and situation are considered when developing or making changes to a child’s care plan (e.g. Considering the parents’ and siblings’ needs, whether changes to a care plan are feasible with the family’s unique challenges, making sure the child’s emotional and mental needs are considered, etc). 62%

d. I don’t need to learn about this subject. 10%

5. Pediatric considerations for general home care situations – I want to learn more about:

a. Pediatric enteral tubes (i.e. Nasogastric, nasojejunal, gastrostomy, and/or jejunostomy tubes). 41%

b. Pediatric central lines (i.e. Broviac lines, Hickman lines, Port-a-Caths). 46%

c. Pediatric skin and wound care. 33%

d. Pediatric medication management. 28%

e. Pediatric palliative and end-of-life care. 62%

f. I don’t need to learn about this subject. 23%

Please share exactly what you would like to learn about in the area(s) you chose:

- How to integrate care with other services available to pediatric clients i.e. Dept. of Community Services.
- How to deal with home support agencies and coordinating HSWs. Helping then understand the complex needs of pediatric client's, lessening their anxieties, empowering them to seek out the training they feel they require and empowering supervisors to empower their employees in providing care to pediatric client's. What our home care services can and cannot support within the above areas.
- Having limited experience in Pediatrics and being an RN my interest is in the nursing aspect of the Pediatric client. In addition, End of Life in children differs than that of adults and feel I would benefit from training.
- Only if the care needs are different from adults.
- In my present role as care coordinator, I do not need hands on info at the present time.

6. Please share a pediatric home care experience that you wish you were better prepared for, or that you found particularly challenging. Be careful not to disclose any identifying patient or family information.

- Level of care needed for teen who requires full assistance with transfers and overall care (ie. 2 workers vs. 1 workers, family involvement, etc).
- Lack of home support resources to properly meet the needs of the child (agency cancelling visits, agency only sending 1 worker when 2 are required, etc).
- I worked as an OT in pediatrics, but I have not had a home care client, except very short term VON. I have had clients in their young 20s come into Continuing Care for Caregiver Benefit and have wondered if we could

  have helped the family earlier on. In the past year I had 2 medically complex young adults who were being cared for by their parents die and I can't imagine how difficult that was for the families.
- NA not involved in pediatric care
- I have had a number or pediatric client's on my caseload over the year and the common theme is that home support agencies struggle in their comfort level and skill set with these client's. I believe some it the issue stems that there is very little if any of that covered in their curriculum. Agencies to not provide advanced training for pediatric client's in house. This has been a huge barrier to service provision, to the point in some circumstances that families to not access home care services. Families feel their child is unwanted or they families feel insecure in having unskilled individuals provide care. In essence the care provision is a greater burden they doing it yourself. I do feel there is a much greater comfort level with nursing agencies and fewer issues arise when nursing is providing care.
- I have not had one to this point.

- Challenges in end of life care, more communication in regards to where the family is in caring for their child.
- How to make conversations less uncomfortable.

7. In the space provided, share any additional thoughts or suggestions for pediatric subjects:

- Mostly making sure that I have understanding of all the services available to them and how to work with those services to benefit the families.
- NA not involved in pediatric care.
- Thank you so much for your survey.
- Without appearing disinterested I work in the Halifax Infirmary and do not have pediatric patients. I do however have a pediatric background in Nursing from both the IWK and the BC Children's Hospital so I do know the complexity and the importance of this education. When I need to know more I will certainly come to Sarah!
- Not exactly home care related so it may not apply, but I'd like to learn more about Evergreen Children's unit and the types of care they can provide / what they are equipped for.
- Two adults caring for their palliative care infant. One parent is not able to continue with work - many obstacles prevented this parent from receiving financial support. Need better programs to meet financial needs of parents, expansion of care giver benefit criteria to include children under 19; exceptions to be made for pediatrics. Home o2 should not be required to follow through on extensive invasive processes to determine eligibility.
- Welcome any and all learning in regards to pediatric clients.

- Who's role is it to access for community needs (ie. equipment- IWK or community CBCC)? And any follow up related to same.

Learning Preferences (Respondents may choose more than one answer):

1. I prefer to learn about pediatric home care subjects:

a. Ahead of time so that I already have a knowledge base. 23%

b. When I have a pediatric patient on my caseload so I can apply and use the knowledge in real life. 26%

c. Ahead of time and again when I have a pediatric patient. 62%

d. In another way. Please explain. 3% (No explanations given).

2. When in-person teaching is not possible, I prefer to learn by:

a. Watching a video. 79%

b. Doing a self-directed learning activity. 33%

c. Exploring a website 33%

d. Reading an educational guide or pamphlet. 38%

e. Another method. Please explain. 15%

- Interactive Skype sessions
- Talking with an "expert". Having reference materials on-line is helpful, but not enough.
- Skype sessions and webinars work well.
- Any and all but most importantly I would need to meet the family and go to the hospital to meet with the team.
- Check list are good when not dealing with situation often. These do not always fit every situations.

3. When I need resources or information to access during a home visit, I prefer:

a. A policy or guideline. 33%

b. A quick-reference guide or standardized checklist. 87%

c. A troubleshooting algorithm. 23%

d. A scholarly article. 3%

e. A website with multiple resource options. 36%

f. Another option. Please explain. 5%

- I would like all of these once out of the home situation.

4. In the space provided, share any additional thoughts or suggestions about your learning preferences for pediatric home care.

- I can see this being challenging because we do not have many pediatric clients, and it is difficult to keep up to date and feel confident when you don't do something often. I think having someone who can act as a resource person, such as Sarah King, is a huge asset.
- I had little confidence regarding dealing with pediatric cases before the session with Sarah. Now I feel moderately confident I could go it more or less alone if necessary but very confident that I have the right resources available. I believe there should be ongoing training to keep us abreast of the changes and how to best service these unique clients/families.

Appendix D: Home Care Nurses Needs Assessment Results

Opening Questions:

1. I work within the __________ zone of the Nova Scotia Health Authority.

a. Western 9%

b. Central 44%

c. Northern 11%

d. Eastern 36%

2. On average, I provide direct care to a pediatric patient (age 0-18 years):

a. Once a month or more often. 35%

b. At least once every 1 to 6 months. 19%

c. At least once every 6 to 12 months. 11%

d. Less often than once a year. 24%

e. I have never had a pediatric patient. 12%

3. I would rate my overall confidence caring for pediatric patients (age 0-18 years):

a. Very low 11%

b. Low 28%

c. Moderate 45%

d. High 15%

e. Very High 1%

Pediatric Home Care Subject Areas (Respondents may choose more than one answer):

1. Pediatric and family interactions and assessments – I want to learn more about:

a. Building rapport with pediatric patients. 32%

b. Building rapport with the families of pediatric patients. 35%

c. Doing family assessments that incorporate a pediatric perspective. 61%

d. How to create and maintain partnerships with families of pediatric patients. 25%

e. How to explain medical things in a way a child can understand. 65%

f. I don't need to learn about this subject. 9%

2. Emotional challenges of pediatric care – I want to learn more about:

a. What to do when I feel overwhelmed about coordinating care for a sick child, no matter what their health situation. 47%

b. Caring for a child and family in a palliative or end-of-life situation. 81%

c. How do coordinate home care when children are not developmentally able to voice their needs or contribute to care planning. 60%

d. I don't need to learn about this subject. 5%

3. Medically complex children (i.e. Children who have chronic health conditions that significantly affect their functional/day-today abilities, often have a neurological or developmental disability, often have a medical device or technology to sustain or improve life, and are high users of the health care system) – I want to learn more about:

a. Understanding in-home medical devices and technology. (e.g. Feeding tubes, feeding pumps, tracheostomies, ventilators, oxygen saturation monitors, etc). 65%

b. Rare and/or complex pediatric health conditions. 79%

c. How to work in partnership with a family that is highly experienced and self-directed with the specialized care of their medically complex child. 49%

d. The stresses and burdens that are unique to families of medically complex children. 59%

e. Knowing how to interact with, or interpret communication from, a child who has limited neurodevelopmental abilities. 57%

f. Feeling ethically conflicted about how much home care one medically complex child is receiving relative to other patients. 47%

g. Feeling ethically conflicted about the child's quality of life with complex health issues. 52%

h. I don't need to learn about this subject. 3%

4. Developing and modifying pediatric care plans – I want to learn more about:

a. Ensuring appropriate level of care determinations for pediatric patients (e.g. home support versus licensed practical nurse versus registered nurse). 61%

b. How to approach families about a challenging situation or a necessary change in their child's care plan. 65%

c. How to make sure the family's context and situation are considered when developing or making changes to a child's care plan (e.g. Considering the parents' and siblings' needs, whether changes to a care plan are feasible with the family's unique challenges, making sure the child's emotional and mental needs are considered, etc). 61%

d. I don't need to learn about this subject. 4%

5. Pediatric considerations for general home care situations – I want to learn more about:

a. Pediatric enteral tubes (i.e. Nasogastric, nasojejunal, gastrostomy, and/or jejunostomy tubes). 67%
b. Pediatric central lines (i.e. Broviac lines, Hickman lines, Port-a-Caths). 55%
c. Pediatric skin and wound care. 56%
d. Pediatric medication management. 63%
e. Pediatric palliative and end-of-life care. 85%
f. I don’t need to learn about this subject. 3%
g. Other 3%

- I feel I don’t get a lot of experience with pediatric medical conditions and technology associated so my knowledge is limited. I think hands on learning would be the best way to have such info stick in your head. A communication workshop with opportunities to practice interacting with a simulated family and Ill child would be an ideal way to develop communication skills in this area.
- Children with diabetes.
- I need hands on training in all of these areas to feel confident in providing care.
- No knowledge or experience with pediatric patients. Training needed in all areas to feel confident.
- Seizures - how to recognize with non-verbal patients.
- I believe in all areas there is room for growth and knowledge. As nurses we must always be willing to learn and become more educated.
- An update on pediatric CPR.
- Doing physical assessment on crying children.

- I don't know anything about them, including the care that is needed for a child that has one.
- Gastrostomy and/ or jejunostomy.
- Everything indicated. I am a good communicator and have decent assessment skills, but my experience caring for infants to 18 with complex needs are nil.

6. Please share a pediatric home care experience that you wish you were better prepared for, or that you found particularly challenging. Be careful not to disclose any identifying patient or family information.

- I have received training from IWK re: pediatric patients. It is ideal to receive training specifically related to the patient we will be seeing as opposed to generalized pediatric training. Every client and their needs are different and while it is helpful to receive the generic training, sometimes that doesn't always apply to the patients you see.
- I wish I could provide better advice for my clients and parents regarding their complex disorder known as hemochromatosis. We assist them with their Desferal infusions that they receive via pump. But I don’t know very much about the disorder and what could go wrong at a pediatric level.
- It is particularly challenging when you hear parents say that "they are going to take all they can get" regarding services offered. This is their child. If they had of been "healthy" it would of been different. I think it needs to be taught that this is their healthy child and their normal. Not take every service you can get so you spend a bare minimum of time with the child providing the care that is required.
- I have not had any pediatric home care experience.

- Providing palliative care to an infant.
- Found it difficult to assist an under 2 year old who was sent home for multi dose of antibiotics who would have been required to be strapped to a pump 24/7.
- Ambulation of a patient in their teens- tall, large and hard to ambulate
- I find it challenging when the main caregiver will request extra duties for the nursing home visits but that they are able to do. i.e. trach changes. Also keeping an eye on expiry dates of meds but then the family won't get them replaced before the expiry date, or running out of med that we are supposed to give.
- Luckily I haven't had any difficult experiences. But what to be prepared in case of emergency.
- Young guy with little pain tolerance. Very time consuming.
- Pediatric PICC care. Prevention of exclusions, appropriate flushing and locking solutions, etc.
- Only twice in 30 years was I involved in pediatric care. The most challenging and stressful was a two year old who had severe developmental delays was non-verbal had a G-tube and a sleeping disorder plus frequent seizures. We were responsible for respite care. During this time meds were given, feeds were ran, etc. He did die while on our caseload but not during our service time. He had a grand mal seizure in the night. It was heart wrenching for all staff we grieved along with the family.
- Accessing a port.

7. In the space provided, share any additional thoughts or suggestions for pediatric subject areas you want to learn about.

- I have no experience so would need to learn a lot.
- Currently we don't often have what would be considered pediatric patients and the only ones I have seen have been older. I have some experience in rural hospital/emerg nursing but in general ... kids are scary!!!
- Each case is different so we are always learning.
- Keeping up to date on emergency situations. I have been with my client for 4 years and all has been good but would like to have emergency scenarios practiced for all the possible issues that could go wrong.
- How to make families understand that home visits are more restrictive than hospital setting and time is limited as well.
- I am new to home care but have peds experience in acute, learning how/having opportunity to transfer my acute experience to the community environment would be helpful.
- Anything and everything. This is not an area of care I am comfortable with or enjoy.

Learning Preferences (Respondents may choose more than one answer):

1. I prefer to learn about pediatric home care subjects:

a. Ahead of time so that I already have a knowledge base. 31%

b. When I have a pediatric patient on my caseload so I can apply and use the knowledge in real life. 9%

c. Ahead of time and again when I have a pediatric patient. 76%

d. In another way. Please explain. 3%

- On the job, in person.

- Be with another nurse who is competent in the procedure and watch a demonstration; then return demo with nurse present.

2. When in-person teaching is not possible, I prefer to learn by:

a. Watching a video. 80%
b. Doing a self-directed learning activity. 49%
c. Exploring a website 25%
d. Reading an educational guide or pamphlet. 43%
e. Another method. Please explain. 9%

- Skype with an educator.
- Nursing in service or lunch and learn, some sort of in person group setting.
- Online webinar/discussions.
- Nurse teaching another nurse.
- Teleconference.
- Classroom text then hands on needed to grasp 100 percent confidence.
- Simulation case studies are very helpful.

3. When I need resources or information to access during a home visit, I prefer:

a. A policy or guideline. 47%
b. A quick-reference guide or standardized checklist. 83%
c. A troubleshooting algorithm. 29%
d. A scholarly article. 12%
e. A website with multiple resource options. 36%

f. Another option. Please explain. 7%

- Also a designated person to reach out to who specializes in this type of care, during all hours of VON operation.
- Call a manager or clinical educator.
- I reach out to coworkers.
- A phone contact expert.
- A team leader or other experienced nurse I can reach out to.

4. In the space provided, share any additional thoughts or suggestions about your learning preferences for pediatric home care.

- Taking care of fragile young patients scares me. They are so vulnerable which makes me feel vulnerable.
- Want parents to have confidence in my care.

Appendix D: Pediatric Resources for Home Health Professionals

Pediatric Resources for Home Health Professionals in Nova Scotia

Developed by: Sarah T. King, BScN RN
Date: October 2019
Update Due: October 2023

Many thanks to the health professionals from the IWK Health Centre, Nova Scotia Health Authority Continuing Care, and VON Canada (Nova Scotia) who reviewed these pediatric home care resources and provided invaluable feedback. Special thanks to my MN supervisor Dr. Joy Maddigan, whose encouragement and wisdom made this project possible.

Disclaimer

The following resources are designed to support current practices for home care in Nova Scotia, and are designed to provide general guidance and information about pediatric and family-centered care in the home. Should there be discrepancies, home care professionals should defer to their professional practice guidelines and organizational policies or procedures, and/or discuss questions with their manager.

This resource was developed with the understanding that home care professionals have received initial and ongoing training in patient and family assessment and communication. This resource is not a substitute for basic education in these domains.

Instructions

Use the table of contents to find the subject area you're interested in.

Each subject area has its own table of resources, including information about specific subjects and time requirements for each resource to help you find what would be most helpful, whether you have a shorter or longer amount of time for education.

Table of Contents

Pediatric Resources for Home Health Professionals in Nova Scotia

Pediatric Communication Basics: Building Rapport and Explaining Health Information

These resources will help you learn developmentally-appropriate communication for getting to know children and youth in a beginning therapeutic relationship. They will also help you learn to communicate in an age-appropriate way when you're talking about health information.

Resource Title	Description	How To Access	Best Uses
Age-Appropriate Communication and Developmental Issues	Comprehension levels, communication strategies, and other tips for communication with children at each developmental stage.	Texas Children's Hospital Website: https://media.bcm.edu/documents/2015/76/palazzi-et-al-tch-guide-to-patient-communication.pdf	In-depth learning, > 30 minutes.
Building Rapport with Children & Youth	Short (2 page) document with quick tips for communicating with pediatric patients.	Available from the IWK Health Centre: http://www.iwk.nshealth.ca/page/pediatric-resources-home-health-professionals	Quick learning, < 5 minutes.
Practicing Building Rapport with Children & Youth	Several scenarios and pictures you can use to practice building rapport with children and youth.	Available from the IWK Health Centre: http://www.iwk.nshealth.ca/page/pediatric-resources-home-health-professionals	Quick or in-depth learning – you choose how many scenarios.
Communicating with Children in Healthcare	A video (2 minutes) outlining basic strategies on how to communicate and build rapport with children and families in health care situations.	Available from AUS Med: https://www.youtube.com/watch?v=tOZDAVj3X5Y	Quick learning, 2 minutes.
Talking to your Pediatric Patients	A short website article with tips from a pediatrician.	Available from UCLA Medical School: https://medschool.ucla.edu/body.cfm?id=1158&action=detail&ref=806	Quick learning, < 5 minutes.

Communicating with Children and Families: From Everyday Interactions to Skill in Conveying Distressing Information	A detailed article on the basics of communicating with pediatric patients and families, as well as information on more complex communication.	Available online from the American Academy of Pediatrics: https://pediatrics.aappublications.org/content/pediatrics/121/5/e1441.full.pdf	In-depth learning, > 30 minutes.
5 Tips on Connecting with Your Pediatric Patients	Short blog with 5 tips useful for any clinicians working with children.	Available online from CHOC Docs Blog: https://docs.chocchildrens.org/5-tips-connecting-pediatric-patients/?__hstc=45511931.a1d2850e30e07de78b44b1421d65dad6.1569105712267.1569105712267.1569105712267.1&__hssc=45511931.4.1571079881497&__hsfp=3570664279&_ga=2.260191693.1319690361.1571079899-963079020.1569105724	Quick reference, 5 minutes.

Pediatric Communication: Patients with Neuro-Developmental Challenges

The following resources provide guidance for communicating and interacting with children and youth who have minimal verbal communication abilities.

Resource Title	Description	How To Access	Best Uses
Communicating with Children and Youth with Neuro-Developmental Delay	A quick reference guide (2 pages) that provides tips for clinicians working with this specialty population.	Available from the IWK Health Centre: http://www.iwk.nshealth.ca/page/pediatric-resources-home-health-professionals	Quick reference, 5-10 minutes.
11 Ways to Communicate with Children with Special Needs	A website with quick and easy-to-understand ideas.	Available from Unity Point at Home: https://www.unitypoint.org/homecare/article.aspx?id=538d6c28-b8c1-488e-bdc9-6ff5900ccfff	Quick reference, 5-10 minutes.

Procedures and Distraction in Pediatrics

This section of resources is designed to support health professionals who need to do procedures with children and youth in the home. Some resources are for specific procedures such as needle-related procedures, some are general tips around any type of procedure, and others are focused on how to effectively distract children and youth during procedures. Several resources will help you know how to guide parents and caregivers and elicit their help during procedures.

Resource Title	Description	How To Access	Best Uses
Tips for Procedures in Children and Youth	Quick reference tips. Includes a care plan template for doing procedures with a particular patient.	Available from the IWK Health Centre: http://www.iwk.nshealth.ca/page/pediatric-resources-home-health-professionals	Quick learning, 5 minutes. Care plan template for procedures.
Needle Pain Prevention in Pediatrics	A webinar (35 minutes) outlining why preventing needle pain in kids is important, and the 4 steps of needle pain prevention.	Available from Children's Healthcare Canada: https://youtu.be/uSdHIvvuEPo	In-depth learning > 30 minutes. Principles are suitable for many painful procedures.
The Power of a Parent's Touch	A video (2.5 minutes) outlining why preventing pain in infants is important, and how to use skin-to-skin care and breastfeeding to minimize pain during procedures.	Available from the IWK Health Centre: https://www.youtube.com/watch?v=3nqN9c3FWn8&feature=youtu.be	Quick learning, < 3 minutes.
It Doesn't Have to Hurt	A video (2 minutes) outlining steps that can be taken to prevent pain during children's procedures.	Available from the IWK Health Centre: https://youtu.be/KgBwVSYqfps	Quick learning, 2 minutes.
Distraction Toolkit	A variety of resources for clinicians to learn about distracting kids during procedures.	Available from Children's Healthcare Canada: https://ken.childrenshealthcarecanada.ca/xwiki/bin/view/Paediatric+Pain/Distraction+Toolkit Quick references include "positions for comfort"	Quick reference and in-depth learning options.

		and a “tip sheet” for clinicians, as well as power point slides, videos, and research articles to learn more about distraction for kids.	
Helping Your Child During Medical Procedures	A video (3 minutes) that a clinician and family could watch together, to give families ideas how to help and distract their child during a procedure.	Available from the University of Illinois Children’s Hospital: https://www.youtube.com/watch?v=D6GSPUVh2k0&feature=youtu.be	Quick learning, 3 minutes.
Reducing Your Child’s Discomfort During Procedures	A websites designed for parents, but also helpful for clinicians, to plan how to help children during procedures. A clinician and family could use this resource together.	Available from the Royal Children’s Hospital Melbourne: https://www.rch.org.au/kidsinfo/fact_sheets/Reduce_childrens_discomfort_during_tests_and_procedures/	Could be used for quick learning, 5-10 minutes, or in-depth learning > 20 minutes if you explore the entire site.
Ways You Can Help Children Cope During Treatments and Procedures	Quick 1-page guide for parents and clinicians.	Available from BC Children’s Hospital: http://www.bcchildrens.ca/Child-Life-site/Documents/Tips%20for%20Caregivers.pdf	Quick reference, < 5 minutes.
Dressing Changes	Although designed for in-hospital dressing changes, this document has some ideas for how clinicians can explain dressing changes in a way younger children can understand.	Available from BC Children’s Hospital: http://www.bcchildrens.ca/Child-Life-site/Documents/Dressing%20Change%20Prep%20Book%202018.pdf	Quick reference, 5 minutes.
Open Pediatrics: Non-Pharmacologic Pain Management Videos	A series of videos about non-pharmacologic pain management, by different age groups.	Video series available at: https://www.openpediatrics.org/assets/video/non-pharmacologic-pain-management-strategies Look for the drop-down menu next to “Chapter 1” to find the videos: Intro (1.5 minutes)	Quick reference learning (videos 0.5-1.5 minutes) Open Pediatrics videos can be downloaded.

		Age-Appropriate Coping Strategies (0.5 minute) Infants (1 minute) Toddlers (1 minute) Preschoolers (1 minute) Schoolchildren (1 minute) Adolescents (0.5 minute)	

Pediatric Palliative Care and End-Of-Life Care

These resources will help you understand the differences between adult and pediatric palliative care as you care for patients receiving longer-term pediatric palliative care. A number of resources also focus on the challenges of pediatric end-of-life care, including self-care for clinicians. There is also information on anticipatory grief and grief support for families.

Resource Title	Description	How To Access	Best Uses
Top Ten Tips Palliative Care Clinicians Should Know About Caring for Children	Short and practical research article (5 pages) with quick tips on the differences for pediatric palliative care.	Look up in an online library or database using DOI 10.1089/ jpm.2018.0482 – or the full citation is in the reference list under first author Jordan.	Allow 10 minutes for a quick read, or in-depth learning of > 30 minutes to take time to reflect.
Early Integration of Pediatric Palliative Care: For Some Children, Palliative Care Starts at Diagnosis	Short and practical research article (4 pages) introducing pediatric palliative care as more than just end-of-life care.	Look up in an online library or database using DOI 10.1097/ 01.mop.0000193266. 86129.47 – or the full citation is in the reference list under first author Mack.	Moderate time of 10-15 minutes to read, or in-depth learning of > 30 minutes to take time to reflect.
Age Appropriate Communication and Developmental Issues - Talking About Death: A Special Situation	A table showing how the ages or developmental stages of children understand death.	Available on the Texas Children's Hospital Website: See pp. 32-33: https://media.bcm.edu/documents/2015/76/palazzi-et-al-tch-guide-to-patient-communication.pdf	Quick reference of 5 minutes, or can be used to guide in-depth learning.
Pediatric Palliative Care Podcasts	A series of podcasts on topics related to	Available from the Canadian Pediatric Society:	In-depth learning, ~15-25 minutes.

	pediatric palliative care.	https://www.pedscases.com/specialty-area/palliative-care Guiding principles of pediatric palliative care (~ 15 minutes). Medical assistance in dying in children (~22 minutes). Pain assessment in verbal and non-verbal children (~ 15 minutes).	
Open Pediatrics: Pediatric Palliative Care Video Series	A series of videos on pediatric palliative and end-of-life care.	Videos available at: https://www.openpediatrics.org/assets/video/palliative-and-end-life-care Look for the drop-down menu next to “Chapter 1” to find the videos: Overview of Palliative Care (8 minutes) Patient Eligibility (5.5 minutes) Understanding Suffering (9.5 minutes) Palliative Care Outcomes (4.5 minutes)	Quick-reference and in-depth learning options (videos of 5-10 minutes each). Open Pediatrics videos can be downloaded.
Orphanet	A searchable website for rare diseases and medications.	https://www.orpha.net/consor/cgi-bin/index.php	Quick or in-depth learning options.
About Kids Health: Preparing for the Death of a Child	A short but detailed article meant for families, but also helpful for health professionals, describing how to prepare for the death of a child.	Available from About Kids Health: https://www.aboutkidshealth.ca/Article?contentid=1689&language=English	Quick learning, 5-10 minutes.
Introduction to Pediatric Palliative Care	A 1-hour webinar about pediatric palliative care, including how it’s different from	Available from the Children’s Hospital of Philadelphia: https://media.chop.edu/data/files/chop-open-presentations/palliative-care/03/index.html	In-depth learning (1 hour).

	adult palliative care.		
Case Study in Pediatric Palliative Care	A 1-hour webinar exploring the journey of Philip and his family over 3 years receiving palliative care.	Available from the Children's Hospital of Philadelphia: https://media.chop.edu/data/files/chop-open-presentations/palliative-care/14/index.html	In-depth learning (1 hour).
Caring for the Dying Child	A 1- hour webinar exploring this challenging topic.	Available from the Children's Hospital of Philadelphia: https://media.chop.edu/data/files/chop-open-presentations/palliative-care/18/index.html This is hospital-focused but still has information that is helpful for the home setting.	In-depth learning (1 hour).
Striving and Thriving in Pediatric Palliative Care	A 1-hour webinar on self-care in pediatric palliative and end-of-life care situations.	Available from the Children's Hospital of Philadelphia: https://media.chop.edu/data/files/chop-open-presentations/palliative-care/22/index.html	In-depth learning (1 hour).
Courageous Parents Network	A website developed by parents of seriously ill children, with oversight from health professionals.	https://courageousparentsnetwork.org/ Helpful content for health professionals on grief, anticipatory grief, supporting parents and siblings as a child approaches end-of-life, and more.	Quick or in-depth learning options such as stories, podcasts, and quick reference documents. Subscribe to the provider portal for access to more resources.
Kids Grief	A website aimed at helping parents and other adults talk to kids and teens about death and dying, supported by health professionals.	https://kidsgrief.ca/ There are brief kids grief articles in the resources section (top right of home page) and a series of short articles in the "Talking about Death and Dying" module (bottom of home page).	Predominantly quick learning options (< 5 minutes) such as articles and module sub-topics. If you read an entire module, it will take longer, such as 30-60 minutes.

Children and Youth with Medical Complexity

A child or youth with medical complexity (CYMC) has one or more health conditions that affect multiple body systems; has functional limitations that often include technological dependence; has high service use across health and other sectors; and their family has high self-identified needs. This section of resources will help you learn about the unique day-to-day challenges faced by these patients and families as they live in their homes and communities, and how to provide care that will address their multiple, complex needs. There is also information about technological devices (e.g. feeding tubes, tracheostomies, ventilators) and searchable websites that include information on rare health conditions, medications, and more.

Resource Title	Description	How To Access	Best Uses
Nurse-Parent Dialogue: Illuminating the Evolving Pattern of Families with Children who are Medically Fragile	Moderate length research article (8 pages) that describes the experience of families with children who are medically fragile – the themes are how families are "living in uncertainty" and "experiencing order in chaos".	Look up in an online library or database using DOI 10.1177/ 0894318403253130 – or the full citation is in the reference list under author Tommet.	In-depth learning and reflection, > 30 minutes.
Home Care of Children and Youth with Complex Health Care Needs and Technology Dependencies	Detailed research article (8 pages) that outlines the care of this specialty population, including a section on home care (pp. 1000-1001) and family needs (pp. 1002-1003).	Look up in an online library or database using DOI 10.1542/peds.2012-0606 – or the full citation is in the reference list under first author Elias.	In-depth learning and reflection, > 30 minutes.
Bright Futures: Promoting Health for Children and Youth with Special Health Care Needs	Quick reference on the care of this specialty population by age group, including assessment, developmental stages, family needs, and more.	Available online from the American Academy of Pediatrics: https://brightfutures.aap.org/Bright%20Futures%20Documents/BF4_CYSHCNHealth.pdf Birth to 11 months, pp. 70-72. 1 to 4 years, pp. 72-73. 5 to 10 years, pp. 73-74. 11 to 21 years, pp. 74-75.	Quick reference of 5 minutes for each age group.
Guideline for the Management of Medically	Canadian national guideline on the care of children and youth with medical	Available online from Children's Healthcare Canada: https://ken.childrenshealthcarecanada.ca/xwiki/bin/download	Quick reference for individual sections, in-depth learning

Complex Children and Youth Through the Continuum of Care	complexity. Can be used as a comprehensive guide, or use individual sections as a quick reference.	/Management+of+Medically+Complex+Children+and+Youth+Across+the+Continuum+of+Care/WebHome/CAPHC%20National%20Complex%20Care%20Guideline%202018_final.pdf See p. 17: How to identify a child or youth with medical complexity. See p. 26: What to include in a care plan for a child or youth with medical complexity.	> 30 minutes for the entire guideline.
The Chronic Pain Assessment Toolbox for Children with Disabilities	Webinar (25 minutes) explaining how experts developed a tool to assess chronic pain in children with disabilities – includes links to a clinical toolbox.	Available from Children's Healthcare Canada: https://www.youtube.com/watch?v=HDGXmsDn25k&feature=youtu.be Toolbox for pain assessment: http://www.hollandbloorview.ca/research-education/knowledge-translation-products/chronic-pain-assessment-toolbox-children	In-depth learning ~ 30 minutes.
Fact Sheet: Medically Complex Children	A 1-page sheet describing and defining children and youth with medical complexity.	Available from Children's Healthcare Canada: https://images.squarespace-cdn.com/content/v1/5bd8a55e4eddecb150a2acdb/1544463180836-VT72S3T72SC2CNRCVLMH/ke17ZwdGBToddI8pDm48kJZW6zhob9awPz640NRRJcR7gQa3H78H3Y0txjaiv_0fDoOvxcdMmMKkDsyUqMSsMWxHk725yiiHCCLfrh8O1z4YTzHvnKhyp6Da-NYroOW3ZGjoBKy3azqku80C789l0pa5utEcoDWpn0hH27EPHs6YpqR16Q5b3RWnth7I4iloUNq0q9F7nstxtmKTcbqtlw/MedicallyComplexChildrenPHactSheet.png	Quick learning, 5 minutes.

Global Developmental Delay and Intellectual Disability	This webinar (18 minutes) is designed for pediatricians but contains basic information for any clinicians. It's about caring for children and youth with medical complexity who also have global developmental delay or intellectual disability.	Available from the Canadian Pediatric Society: http://pedscases.com/global-developmental-delay-intellectual-disability-cps-podcast Note that not all children and youth with medical complexity have global developmental delay or intellectual disability.	In-depth learning, ~ 20 minutes.
If You Only Knew… The Voices of Families of Children with Complex Care Needs	Series of 8 videos exploring the experiences and perspectives of families of this special population (videos are 5 to 8 minutes each).	Available from Children's Healthcare Canada and In-Gauge: https://www.youtube.com/watch?v=ghsKm1Zm6ro&list=PLdQfM1_yW0PtI3s0sy0ZGBvuUyXUZ1bHG	Quick reference or in-depth learning options.
Complex Care at Home for Children	Developed by pediatric experts in Quebec, this website has information specifically about home care for children and youth with medical complexity. It's aimed at families but is also suitable for health professionals.	Available at: https://complexcareathomeforchildren.com/ Topic highlights: Preparing the child for home care, families preparing themselves for home care, preparing the home itself, tracheostomies, ventilators, cough assist machines, ostomy care, catheterization, and more.	Quick reference and in-depth learning options.
Open Pediatrics Resource Videos	From Boston Children's Hospital, there are a variety of information videos and webinars on topics that support the care of all children, with many topics specifically for those with medical complexity.	All videos are listed at: https://www.openpediatrics.org/resources/all?title=&flagged=All&field_asset_type_tid%5B%5D=511&sort_bef_combine=created+DESC&items_per_page=20&og_group_ref_tar	Quick reference and in-depth learning topics. Open Pediatrics videos can be downloaded.
Open Pediatrics: G-Tube Videos	Basic information on Gastrostomy or G-tubes and their care.	G-Tube Basics (1.5 minutes): https://www.openpediatrics.org/assets/video/gastrostomy-tube-basics	Quick learning, < 2 minutes for each video.

		G-Tube Balloon Assessment in the Home (2 minutes): https://www.openpediatrics.org/assets/video/assessment-gastrostomy-tube-balloon-home-setting Connecting and Disconnecting a G-Tube Extension Set (1 minute): https://www.openpediatrics.org/assets/video/connecting-and-disconnecting-g-tube-extension-set	Open Pediatrics videos can be downloaded.
Open Pediatrics: Tracheostomy Videos	Short videos on tracheostomies and their care.	Look for the drop-down menu next to "Chapter 1", "Part 1", or "Case #1" to find the videos: Basic tracheostomy information – 5 videos (2.5, 1, 1.5, 1.5, and 2 minutes): https://www.openpediatrics.org/assets/video/tracheostomy-primer Tracheostomy care at home – 3 videos (3, 7, and 2.5 minutes): https://www.openpediatrics.org/assets/video/nicu-nursery-–-tracheostomy-care-home-setting Tracheostomy troubleshooting – 4 videos (5, 3.5, 3.5, and 5.5 minutes): https://www.openpediatrics.org/assets/video/tracheostomy-troubleshooting?chapter=1	Quick learning, 2-7 minutes for each video. Could also be used as part of in-depth learning. Open Pediatrics videos can be downloaded.
Open Pediatrics: Respiratory Assessment Video	A short (4.5 minute) video describing how to recognize respiratory distress and failure in children.	Video available at: https://www.openpediatrics.org/assets/video/recognizing-respiratory-distress-and-failure	Quick reference, < 5 minutes. Open Pediatrics videos can be downloaded.
Open Pediatrics: Ventilation Videos	A series of videos about ventilation and home ventilation.	Look for the drop-down menu next to "Chapter 1" to find the videos:	Quick and in-depth learning options (videos of 2-10 minutes in length).

	Some ventilator videos are at a hospital level of detail but contain some information that would be useful to home health professionals.	Non-Invasive Positive Pressure Ventilation at Home (5.5 minutes – first video only): https://www.openpediatrics.org/assets/video/managing-nippv-home-and-indications-return-hospital CPAP and BiPAP at Home (9.5 minutes): https://www.openpediatrics.org/assets/video/how-navigate-cpap-and-bipap-home Ventilator Safety (1.5, 4, 2.5, 2, 1, and 7.5 minute videos): https://www.openpediatrics.org/assets/video/ventilator-safety-assessment	Open Pediatrics videos can be downloaded.
Open Pediatrics Videos: Home Visit for a Child with Medical Complexity	A series of videos about Jack, a child with medical complexity, and his family, and how they live at home and in their community every day.	Video series: https://www.openpediatrics.org/collection/virtual-home-visit-child-medical-complexity Key Topics: Meet Jack (3 minutes) Home Accessibility and Safety (8.5 minutes) Medication Safety (6 minutes) Travel Outside the Home (5 minutes) Family and Community Participation (5.5 minutes) Provider-Family Partnerships (7 minutes)	Quick or in-depth learning options (3-9 minutes per video). Open Pediatrics videos can be downloaded.
Orphanet	A searchable website for rare diseases and medications.	https://www.orpha.net/consor/cgi-bin/index.php	Quick or in-depth learning options.
About Kids Health	Created by experts at Sick Kids Hospital in Toronto, this is a searchable site with information and videos on pediatric health information.	https://www.aboutkidshealth.ca/ Topics to search for may include health conditions, medications, technology such as CPAP, G-tubes, and more.	Mostly quick learning, but in-depth options are available as well.

Connected Care	A special learning hub within About Kids Health focused on complex care topics. Includes written information, pictures, and diagrams.	https://www.aboutkidshealth.ca/connectedcare Helpful topics include G- and J-tubes, NG tubes, vascular access devices, tracheostomy care, and injections.	Quick learning and in-depth options are available.
Courageous Parents Network	A website developed by parents of seriously ill children, with oversight from health professionals.	http://courageousparentsnetwork.org Helpful content for health professionals on rare diseases, challenging symptoms such as neuropathic pain, supporting the entire family, patient and family stories, and more.	Quick or in-depth learning options such as stories, podcasts, and quick reference documents.

Pediatric Family Assessment Resources

These two resources will help you incorporate the pediatric family-centered perspective into your initial and ongoing in-home assessments by providing conversational guides and important questions and subjects to consider.

Resource Title	Description	How To Access	Best Uses
Family Assessment for Pediatric Clients Receiving Home Care	A basic family assessment tool for clinicians to use in the home, specific to pediatric patients and their families. Presented in two versions: Either a list of questions to guide conversations, or a table of questions home health professionals can chart on directly.	Available from the IWK Health Centre: http://www.iwk.nshealth.ca/page/pediatric-resources-home-health-professionals There are sections for concerns about family functioning, for patients with chronic illness or medical complexity, and for children receiving palliative or end-of-life care.	Routine use for initial in-home assessments, and ongoing in-home reassessment for patients with basic and/or complex health needs.
Sibling Support	A website from Seattle Children's Hospital with information and resources on how to support siblings who have a brother or sister	https://www.siblingsupport.org/ The resources section has documents such as "What siblings would like parents and service	Quick and in-depth learning options available.

	with special health care needs.	providers to know" and "How to let young siblings know you care".	

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Tips for Building Rapport with Children & Youth

⇒ Take your time. Building rapport isn't always a fast process. If you move too quickly with a child or youth who is not ready to engage, you could actually push them away and make interaction more difficult.

⇒ Introduce yourself by name and explain your role. "I'm here to talk to you and your parents about having help to take care of you" or "I'm here to help with your medicine".

⇒ Always be genuine in your interactions. Don't fake it - kids can tell. Try to be relaxed, friendly, and even curious.

⇒ Show an interest in the child or youth as a person. Ask about things the child or youth cares about – a toy they're holding, the music they're listening to, their hobbies, what they're learning in school, etc.

⇒ Bring something with you to help engage the child – some stickers, a book, a picture, a toy, etc.

⇒ Use developmentally-appropriate language. Avoid medical jargon, or any words that can be misunderstood especially by younger children.

⇒ Be truthful in what you say, even to the youngest children.

⇒ Be sensitive to the child or youth's reactions. If they seem reluctant to talk to you or approach you, give them some space and time to warm up to you. Try talking to the parents for a few minutes before re-approaching the child.

⇒ Acknowledge the emotions and concerns of children and youth. Rather than saying "don't be scared" or "everything is okay", say, "it's okay to be scared, but your Mom and I are going to help you" or "I see that you're crying - can you tell me what you're feeling?"

⇒ Ask the parent/guardian for tips on how to engage with their child and build trust.

⇒ Involve children and youth in discussions and planning for their care. Incorporate the child's or youth's preferences into the care plan whenever possible. This will help build a partnership. Another way to build a partnership is to assign the child a role in care, such as "Your job is to keep your arm as still as a statue" or for a teen "Let me know if you're having any pain or discomfort". This also helps the child or youth have some degree of control.

⇒ Allow the child or youth to ask questions about your role and work.

⇒ Be sensitive to the family context. You may need to take extra time to build trust with the parents and even siblings to gain the trust of the child or youth. Be aware of the parents' anxieties and questions as a way to guide how you build trust and rapport.

⇒ Acknowledge the child's efforts. "Thank you for helping answer my questions about your health", or "I know it was hard to sit still when we changed the tape on your PICC line, but you did very well."

⇒ Show respect for the child's emotions, questions, and concerns.

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Practicing Building Rapport with Children and Youth

Use the following pictures and scenarios to consider how you might build rapport with the child, youth, and/or their family. Scenarios are oriented toward being either a home care nurse or a care coordinator. No matter what your role, try to think what you might say in all scenarios. The child or youth may be the patient/client, or the family member of a patient/client.

Baby Ben is receiving IV antibiotics through a PICC line for osteomyelitis. You are seeing Ben for his first home visit after leaving hospital. The care plan from the IWK says Ben's Mom was anxious about leaving the hospital, but looked forward to being at home again.

You're visiting 3 year old Kristopher, who gets dressing changes every 2 days for a wound on his arm. When you arrive, he's reading a book on his big sister's lap. He tells you he wants to read a book and not have his arm fixed tonight.

You're doing an annual assessment on 28 year old Lisa, who is on home oxygen due to Cystic Fibrosis. Her little son, Jin, arrives home from pre-primary and charges into the room where you're having a conversation. He looks at you curiously, since you've never met before, and seems unsure what to do.

In this family are parents Aaron and Naomi, son Marcus, age 5, and baby Michelle, age 10 months. Michelle has a trach and feeding tube, and gets overnight respite. Mom Naomi asked you to do a home visit to discuss their hours of support as she is struggling with Michelle's care. When you arrive, Naomi is having a conversation with Marcus, trying to help him understand why you're coming for a visit. Marcus says to you, "What's your job with my sister? Why do you come to my house?"

You arrive to see 10 year old Hannah, who was recently diagnosed with type 1 diabetes. Hannah's sugars have proven difficult to control, so she is receiving some nursing visits as the entire family learns to manage diabetes. Hannah and her 12 year old brother Michael greet you as you arrive. Michael says, "The nurse who was here yesterday was mean, so I'm staying with Hannah for today's visit."

You arrive at the home of 16 year old Nick, who has been having dressing changes for several weeks since his surgical wound on his back from scoliosis surgery got infected. He's been discouraged about missed time from school and missed time with his friends. When you get to his house, his Mom hollers "Hello!" from the kitchen, but Nick doesn't even look up from his phone to greet you.

Dominique is 16 years old, and she has paraplegia from a car crash when she was a child. She is learning to do more of her own care as she gets older, but she still needs occasional help with self-catheterization and showers. She isn't comfortable having her parents help with this personal care anymore, so she has home care services. Dominique is not new to home care, but you were recently assigned to be her care coordinator due to her prior coordinator's retirement. You're meeting her for the first time to do her annual reassessment. When you arrive at Dominique's house, she's in her wheelchair out front, saying goodbye to a friend who's just leaving.

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Tips for Procedures & Distraction in Pediatrics

1. Prepare yourself: In the same way you prepare mentally for the steps of the procedure and gather your supplies, think about you're the nature of pediatric procedures. What are you unsure about? What concerns do you have? Make sure your questions are addressed. And even if you feel nervous, be confident and professional.

2. Prepare the patient: Planning is essential with pediatric procedures! Ensure you have built rapport with your patient, and if you haven't, take 5 minutes and get to know them. Part of planning is finding out how past procedures have gone, including what works well and or doesn't work well for each unique child, youth, and family. Be sensitive about whether or not to have this conversation in front of the patient.

3. Prepare the family: The parents may have different needs compared to the child when it comes to the procedure. They may be too "hands off" and need specific instructions to partner with you in helping the child. They may be more nervous than the child and need specific encouragement from you. Some parents may be so nervous that their presence isn't helpful during the procedure!

4. Consider the child/youth's developmental level regarding how they are most likely to be comforted and distracted. Have a variety of distractions ready!

- Infants are most often comforted by being held by a parent or loved one. Swaddling with only the procedure area exposed, offering a soother, having soft music playing, or having a familiar toy or blanket next to them can help add comfort.
- Toddlers are often comforted by being held by a parent or loved one, and by being distracted, such as with toys, books, and videos.
- Schoolchildren might want to use distractions such as videos, video games, books, toys, listening to music, deep breathing, or visualizations. They may or may not feel the need to have their parents close by, so talk to them and their family about this option.
- Teenagers will likely be able to tell you what they want to do during a procedure. They may or may not want their parent present, as their need for privacy may the most important part.

5. Explain what you're going to do and what the patient might feel: With your explanations, use age-appropriate terms and give the explanation before you start. For a dressing change: "I'm going to take off the old bandages, clean your leg, and put on nice, clean bandages. You will feel me pulling off the old bandages, and the cleaning might feel cold." For an IV medication: "I'm going to give you some medicine to help you feel better. It goes in this small tube, which is similar to a straw, in your arm. It might feel cool when it goes in." Very young children such as toddlers may not need any explanation, but just to be distracted before you begin. Older children such as teenagers may not need an explanation if they've had the procedure before; ask if they have questions before you start.

- Some children may also want you to say what you're doing using step-by-step instructions during the procedure, but this is individual. If your explanations are adding to anxiety, then stop explaining and encourage the child to focus on a distraction instead.

6. Use pain control measures: If the patient's procedure may be painful, plan with the family to have them give their child acetaminophen or ibuprofen beforehand, if it's safe for them to do so. If the child is having a procedure such as a port-a-cath access or venipuncture, always plan for using topical anesthetic cream. Breastfeeding is also known to reduce pain for infants and young children.

7. Give control whenever possible: Allow the child to choose where to sit, which toy to hold, or which parent to sit with. If it's appropriate for the child to help, they may remove old bandages, or hold supplies, for example. Be careful not to allow too much control, such as allowing the child to choose when to begin the procedure, or to only start when they feel ready – they may never feel ready!

8. Allow the child or youth to see the equipment or supplies, as long as it's not something that might scare them or hurt them. This helps overcome the fear of the unknown. If they have a doll or a teddy bear, it may be helpful to demonstrate what you're doing using the toy. You might also demonstrate on a parent or willing sibling who wishes to help.

9. Make a game out of it. Draw a smiley face on your mask or decorate it with stickers. Make a glove balloon. Let the child play with some gauze and fold it or decorate it in an animal shape. This helps medical supplies seem less foreign.

10. Role play if needed. For particularly nervous patients, they might want to practice the procedure before actually doing it. You could put on your mask and gloves, open a couple supplies, pretend to take off an old dressing, clean the site, and put on a new dressing, while encouraging and coaching the child and family.

11. If the procedure is not going well, consider taking a break: Acknowledge that what you planned together isn't working well. Give the child a break and allow them to play or have quiet time with their parent. Talk about different strategies to use, and try again once everyone is calmed down.

12. Always be honest, especially if they ask whether it might hurt: You could say, "Some parts of what we're doing might feel uncomfortable, but your parents and I are going to help you focus on your toys and videos if that happens."

13. Things not to say during a procedure: Don't apologize for doing a procedure. Instead draw focus to their distractions or what they're doing well. Don't say "Almost done" because it's hard to predict when you will be done, and "almost" may mean something very different to the child than to you. Don't tell the patient not to cry – it's probably very

appropriate for them to cry, whether they feel nervous, or whether something feels uncomfortable. Instead, you could say, "It's okay to cry. Let's focus on taking deep breaths with your Dad now."

14. Always debrief with the patient and family, particularly if something didn't go as smoothly as planned. Talk about what went well and what didn't go well, and what might work better next time. Add this to the care plan so your colleagues also know what works best.

15. Praise the child or youth for what they did well. "You did a wonderful job holding still!" or "I saw you take some deep breaths when you started to get anxious – that was a great idea."

Procedure Plan

Patient ____

Procedure ____

1. What works well to prepare the patient? ________________________________
____
____

2. What works well to prepare the family? _________________________________
____
____

3. Best comforts and distractions: _____________________________________
____
____

4. Is it helpful to explain the procedure? If yes, what explanation is best? __________
____
____

5. Pain control measures: ____
____
____

6. Helpful things to say or do: ____
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7. Things NOT to say or do: ____
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8. Other helpful information: ____
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Communicating with Children & Youth with Neuro-Developmental Delay

These communication guidelines are meant for children and youth who have limited verbal and other communication abilities.

⇒ **Acknowledge them:** Say hello, touch their arm, notice their clothing or toys. "Hello Ken. I see you have suspenders on today – you look very handsome!" Even if they are asleep, ask how they are doing or acknowledge that they are there, such as saying, "I see Janie is sleeping right now – she looks like she's having a good nap."

⇒ **Get down on their level:** If they are playing on the floor, get down next to them to say hello. If they are in bed, get close to the bedside. If they are in a wheelchair, bend down to greet them at eye level.

⇒ **Make it personal:** Use their name, notice things about them, or remark on things in their environment. "I noticed that Marcus has a lot of Pokemon stuffed toys. Is that something he likes?" If you can, incorporate this knowledge into the care plan. "I'll make a note in the care plan that Marcus loves having his Pikachu with him during respite visits."

⇒ **Ask the parent or caregiver how to communicate with them:** They can help you understand what gestures, movements, facial expressions, sounds, or words may mean. Some children may be able to blink or make movements for "yes" or "no". If it's difficult to describe how they communicate, consider asking the family if you can make a video to help your colleagues understand. You can also work with the family to create an "All About Me" booklet to help other caregivers get to know the child or youth.

⇒ **Be patient and willing to take time:** When any children or youth have communication challenges, the visit will likely take longer, so be mentally prepared for this scenario. You may need to request or plan for more time in these situations. The worst thing you can do is rush, and not take the time to learn to communicate with them.

⇒ **Be aware of visual and hearing differences:** Ask the parent or caregiver if there is a place you should stand or sit so the child can see and be included in the conversation.

○ You may need to speak louder or speak closer to one ear if they have hearing loss. For children and youth with limited vision and/or hearing, touch can be a powerful way to communicate. Ask the family if holding their hand, stroking their arm, or touching their hair to say hello may help put them at ease – touch is often helpful, but some children and youth may prefer not to be touched.

⇒ **Ask about communication aids:** Ask the parent or caregiver if their child has any communication aids or tools that should be used to include them in conversation. Digital speaking tools, a writing board, a picture board, or a noise-making toy are examples of some communication aids.

⇒ **Include them in conversation:** Even for children who are non-verbal or have limited verbal skills, ask the parent or caregiver what their child enjoys, what makes them happy, and what is important to remember in their care. You may even direct some comments to the child, such as, "Dad says you like being around people, so I hope you enjoy visiting with me too" or "I notice you have a lot of pink in your room – I love pink too!" If the child is able to communicate in any way, such as yes/no questions, then direct some simple questions to them.

⇒ **If you're not sure, ask:** If the child's facial expression changes, they make a sound, or they seem to be communicating something and you're not sure if it's meaningful, ask the parent or caregiver about it. "I noticed Timmy made a sound when I mentioned doing a tube feeding. Is he trying to tell me something?"

⇒ **Observe and learn:** Notice how the family interacts with the child or youth. They may communicate in certain ways or do things subconsciously that they didn't think to suggest to you - maybe the family hums a tune to soothe them if they are distressed. You can incorporate these tips into your care as well.

⇒ **Build a relationship:** Based on all the tips above, try and remember some of the ways that were meaningful to communicate with this particular child or youth so you can use them in future visits. They will likely be more at ease in your presence, and the family will appreciate your efforts to include and communicate with their child.

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Family Assessment for Pediatric Clients Receiving Home Care

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Many thanks to the health professionals from the IWK Health Centre, Nova Scotia Health Authority Continuing Care, and VON Canada (Nova Scotia) who reviewed these pediatric home care resources and provided invaluable feedback. Special thanks to my MN supervisor Dr. Joy Maddigan, whose encouragement and wisdom made this project possible.

Disclaimers

This family assessment resource is designed to support current practices for home care in Nova Scotia.
Should there be discrepancies, home care professionals should defer to their professional practice guidelines and organizational policies or procedures, and/or discuss questions with their manager.

This resource was developed with the understanding that home care professionals have already received initial and ongoing education in client and family assessment in the home setting; this resource is therefore not a substitute for initial education in client and family assessment.

Instructions

The answers to these questions can be recorded on approved charting forms, either paper or electronic. Not every single question may be suitable for every client and family situation; use your professional judgement regarding what to ask and in what order.

For all pediatric clients (age 0 to 18 years), home care professionals should complete sections A and B.

Section C is strongly recommended for all clients and families to assess family functioning.

Sections D and E are optional, because they are dependent on individual client and family situations.

Pediatric Family Assessment Tips

- Every family is different, and the family is who the family says they are.
- The family is the pediatric client's context - to understand client needs you have to understand the family.

- Even though most pediatric clients are not old enough to sign an official consent, most are able to give their assent. This means the client can give developmentally-appropriate agreement and participation.
- Ensuring participation of pediatric clients is an important part of pediatric care, as long as their developmental level permits, and as long as they are not harmed by participating (this would be rare).
- Don't default to asking the parent/guardian all the questions.
- Ask the client questions directly, according to their developmental level. e.g. Ask a young child which toys they like, ask a school-age child what it was like when they were in the hospital, ask a teenager about their chronic illness, etc.
- It's okay to allow the client and family to lead the conversation to where their concerns are, even if it doesn't fit in the general assessment categories.
- Show empathy and understanding for the family's situation wherever you can, and validate the family's emotions and struggles. This will help build trust and a professional relationship.
- Show respect and humility in domains where families have expert knowledge.
- Acknowledge and highlight areas of family resilience and strength.
- Be genuine and non-judgmental as you build understanding of the family's situation.

Table of Contents

Family Assessment for Pediatric Clients

Part A: General Information

- Who is the source of information for the assessment? The client, parent/guardian, or someone else?
- What language(s) are being used? Is interpretation required?
- Who is/are the substitute decision maker(s)?
- What is the client's level of involvement in health discussions?
- What is the client's current understanding of their health issues?
- Who are the family members living in the home?
- Are there siblings? What are their ages? Do any siblings have health issues?
- Is there any immediate family living outside the home?
- What are the parents' means of employment?
- Does the client have health insurance coverage?
- Does client live between multiple households? Are there any special custody arrangements?
- Does the client have caregivers other than their immediate family?
- Does the client and family have support from extended family or the community?
- Who are the client's main friends/social supports?
- Who are the family's main friends/social supports?
- Who are the client's and family's health care support? The family physician or nurse practitioner, community pediatrician, specialty teams, or others?
- Does the client and family have cultural, religious, or spiritual supports?
- Does the client attend daycare, preschool, or school? Does the client require any special educational supports? What is the daycare or school schedule?
- What are the client's play preferences, interests, and/or hobbies?
- Does the client have any employment? (For older pediatric clients).

Part B: Client Health and Illness – Impact on the Family

- What are the parent's concerns about the client's health?
- What are the client's concerns about their own health?
- What are the parent's concerns/goals for home care?
- What are the client's concerns/goals for home care?
- What is the client's reaction to medical procedures? Are there ways to distract/help with procedures?
- What is the impact of the illness on the client – emotions, usual routines, school, etc.
- What is the impact of the illness on the family – emotional state, family routines, etc.

Part C: Family Functioning

➔ This section is used to assess general family functioning, particularly when stressors are present.

- What is the client's and/or parent's sense of the family's well-being in the midst of the client's illness?
- What are the current family stressors in addition to the client's illness – Financial? Employment? Cultural? Religious/Spiritual? Physical health? Mental/Emotional health? Needing additional supports?
- Family strengths: Members generally get along, members help out, open communication, joint problem solving, accepting of others, etc.
- Family limitations: Members don't get along, some members bear most of burdens/responsibilities, hard to communicate in certain situations, challenges with problem solving, not accepting of certain family, etc.

*If red flags are present, the family as well as the client are at risk for poor family functioning. Consider supports available within your role, and refer to part E for additional family resources.

Part D: Family Considerations for Special Populations

Clients with Chronic Illness

➔ This section pertains to pediatric clients who have simpler chronic illnesses, (i.e. diabetes, cystic fibrosis, Crohn's disease) as opposed to children and youth with medical complexity, noted in the next section.

- How does the chronic illness affect the client – positively and/or negatively?
- How does the chronic illness affect the family – positively and/or negatively?
- Who has caregiving roles related to the chronic illness? How do the caregivers take breaks?
- How does the family cope with the demands of the chronic illness?
- Who/what is a support for the family in living with chronic illness – Help with caregiving? Financial support? Personal or emotional support?

*Coping patterns that are atypical may actually be functional in families with a child who has a chronic illness. i.e. A strict or inflexible schedule may be a functional way to manage chronic illness in a family. If a coping technique or pattern works well for the client and family even though it's not typical, it may be acceptable.

Clients with Medical Complexity

➔ A child or youth with medical complexity (CYMC) has one or more health conditions that affect multiple body systems; has functional limitations that often include technological dependence; has high service use across health and other sectors; and their family has high self-identified needs. When in doubt, it's better to consider a client as medically complex.

- Does the client have an IWK complex care plan? Is a copy on file?

- Does the client have any advance directives or DNR instructions aside from the complex care plan? Are the directives on file?
- Does the client have an EHS special patient protocol? What is the patient protocol number?
- How does having complex care needs affect the client – positively and/or negatively?
- How does having a child or youth with complex care needs affect the family – positively and/or negatively?
- Who has caregiving roles for the client? How do the caregivers take breaks?
- What are the family's coping mechanisms related to the client's care?
- Who/what is a support for the family as they care for the client – Help with caregiving? Financial support? Personal or emotional support? Disability support program from DCS? Support from certain health professionals or health teams?
- Ask the primary caregiver to rank their stress level on a scale of 0 to 10 – 0 is no stress, and 10 is the most stress they can handle. Is this their typical stress level? Has it increased/decreased lately?

*Families of CYMC are at higher risk for caregiver fatigue and caregiver burnout. These caregiving risks are linked to chronic anxiety or worry about the child's health, grieving the loss of a "normal" life for the child, living with long-term uncertainty, living with high vigilance, chronic sleep deprivation, and other factors.

Clients Receiving Palliative Care

➔ In pediatrics, clients receiving palliative care may or may not be at end-of-life. In most cases, a child who has a life-threatening or life-limiting illness will be followed by palliative care, whether they are expected to live a short time (weeks to months) or a long time (years to decades). When palliative care is involved, the focus is on optimizing the client's and family's quality of life no matter what the stage of the client's illness.

- Does the client have an IWK complex care plan? Is a copy on file?
- Does the client have any advance directives or DNR instructions aside from the complex care plan? Are the directives on file?
- Does the client have an EHS special patient protocol? What is the patient protocol number?
- What are the client's most important priorities for quality of life?
- What are the family's most important priorities for quality of life?
- Are there particular symptom management challenges for the patient? If so, what are the best ways to manage these symptoms?
- Are there certain health professionals the family contacts to help with symptom management? If yes, note their contact information.

Clients at End-Of-Life

⇒ This section is for clients who are actively dying, whether death is expected in months, weeks, or days. Wishes and plans for end-of-life may change as time goes on, so this assessment may be performed multiple times if needed.

- What are the client's hopes, fears, and preferences for end of life?
- What are the family's hopes, fears, and preferences for end of life?
- Where does the family hope death will occur? Home, hospice, hospital, other?
- What supports may be needed for siblings, other close family members, or friends?
- Are there any plans for symptom management and rapid escalation of care needs at end of life? If yes, note relevant information.
- Are there certain health professionals to contact for help with symptom management and rapid escalation of care needs? If yes, note their contact information, including the hours these professionals are available, if they are not available 24/7.
- Are there certain family members or friends who should be called if death is imminent? If yes, note their contact information.
- Does the family have any special considerations or preferences for the time just after death? e.g. Being alone with the client, having only particular people with the client, memory making, cultural, religious, or spiritual rituals, etc.
- What are the family's preferences for bereavement follow-up and support from home care professionals? Would the family be open to receiving a card or a phone call after the client's death, for example?

*The IWK's Pediatric Advanced Care Team (PACT), which provides palliative care services, as well as palliative care teams in local communities, are excellent resources for home care professionals. These teams can provide advice on how to support clients and families, and they can suggest resources for siblings and friends during the end-of-life and bereavement phases. If helpful, these teams are available for self-care and debriefing sessions.

*It is very important for care providers who were involved with the client and family to engage in meaningful follow-up during the bereavement period. Even a phone call or card can help families feel that they and the client were not forgotten after the client's death, and that the client is remembered by care providers.

Part E: Family Support Resources

1. Families can visit their primary care provider (family doctor or nurse practitioner) to ask for guidance. If they need to find a primary care provider, they should visit the Family Practice Registry website (https://needafamilypractice.nshealth.ca/) or call 811.

2. Families could access an Employee Assistance Program (EAP). EAPs are free services are available to many parents and families from the parent's employer. EAPs include counseling and support services available in person, online, or by phone. Parents can check with their employer to see if they have an EAP.

3. Families with private insurance may be eligible for counseling services. Families should check and see what counseling coverage they have. For social worker counseling, visit the Nova Scotia College of Social Work private practice listing (https://onlineservice.nscsw.org/webs/nscsw/) to find a social worker. For psychologist counseling, visit the Psychology Association of Nova Scotia website (https://apns.ca/) to find a psychologist.

4. The Department of Community Services (https://www.novascotia.ca/coms/) provides a variety of community-based supports for individuals and families, such as the Disability Support Program for children and adults, Income and Employment Assistance, and Child, Youth, and Family supports. One resource made in partnership with Public Health is the "Loving Care" series of free guides on parenting (https://novascotia.ca/dhw/lovingcare).

5. Public Health is focused on promoting good health and preventing disease in the home and community setting. Their healthy development resources (https://novascotia.ca/dhw/healthy-development/) include support during pregnancy, breastfeeding, early childhood, and more. Their healthy community resources (https://novascotia.ca/dhw/healthy-communities/) include support for healthy eating, injury prevention, and more. Families may visit a public health office (http://www.nshealth.ca/public-health-offices), public health's family resource centers (https://www.cdha.nshealth.ca/public-health/family-resource-centres), or the Public Health main website (https://novascotia.ca/dhw/publichealth/) for more information.

6. Caregivers Nova Scotia (https://www.caregiversns.org/) is an organization that helps anyone who is a caregiver for someone with special health needs. Their website has a variety of resources such as self-care ideas for caregivers, a respite services directory, and more.

7. The Nova Scotia Respite Guide (https://novascotia.ca/coms/disabilities/documents/Nova-Scotia-Respite-Guide-for-Caregivers-of-Children-and-Adults-with-Disabilities.pdf) is designed to help Nova Scotia caregivers understand what respite is, how to find respite, and how to plan for respite in their day to day life.

8. Call/text 211 or visit the website (http://ns.211.ca/) to find community programs across Nova Scotia.

9. Community Health Teams (http://nshealth.ca/service-details/Community%20Health%20Teams) offer free health and wellness programs in the Halifax region. These programs are led by health professionals from the NS Health Authority and the IWK Health Centre on topics such as making the most of your food budget, how to increase your activity level, dealing with stress, parenting a toddler, and more.

10. Call 811 for non-emergency health advice from a registered nurse in Nova Scotia.

11. Families experiencing a mental health crisis can call 902-429-8167 for support. For mental health emergencies, call 911 or go to your nearest Emergency Department.

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