ATHABASCA UNIVERSITY

CHILDREN WITH CHRONIC ILLNESSES' PERCEPTIONS OF "PLAY IN HOSPITAL": A QUALITATIVE DESCRIPTIVE STUDY

BY

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A THESIS
SUBMITTED TO THE FACULTY OF GRADUATE STUDIES
IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE OF
MASTER OF HEALTH STUDIES

FACULTY OF HEALTH DISCIPLINES

ATHABASCA UNIVERSITY
NOVEMBER 2015

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Approval of Thesis

The undersigned certify that they have read the thesis entitled

"Chronically Ill Hospitalized Children's Perceptions of "Play in Hospital": A Qualitative Descriptive Study"

Submitted by

Chantal LeBlanc

In partial fulfillment of the requirements for the degree of

Master of Health Studies

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Dedication

This thesis is dedicated to Ruth Snider and LeeAnn Derbyshire, two amazing women who challenged, mentored and supported me in my development as a child life specialist and a researcher, even when I didn't believe it was within me. Their individual commitment to infants, children and families, their passion for the work of child life specialists and belief in the impact we can have in helping families cope with the most challenging of health care experiences continues to guide me. Ruth may you and your family know how much your sheer determination as a Canadian child life pioneer influenced so many clinicians from all areas of health care in seeing infants, children, youth and families as being our primary concern. Ruth believed that every child and family had strengths and that with support and guidance, they could find their way in complex and challenging health care situations. Her mentorship and clinical wisdom made me a far better child life specialist. LeeAnn, my dear friend and mentor- my ethical convictions and philosophical framework in child life comes from our discussions and clinical reflection.....for that I am forever thankful. You helped me to come to terms with my love/hate relationship with research, helped me appreciate and trust my skills and now I see research as a basic need within the child life profession, as much as toys, places and people for playing in hospital.

Acknowledgements

A special thank you to the children and families who participated in this study. It was an honour to learn with you and from you. Your willingness to help me gain a better understanding about "play in hospital", through your words and drawings was truly amazing.

Dr. Caroline Park- I so appreciated your calm manner, reminding me to breathe and stop perseverating! Dr. Sharon Moore- thank you for your detailed feedback which created thoughtful pauses and reflection…and a better thesis. Dr. Priti Desai- your child life expertise, reflective and patient manner influenced my oral exam experience and has made this manuscript even more child focused.

A huge thank you to my child life specialist colleagues who helped with recruitment. There was never any question about their belief in the study nor their support of this work. The entire child life team's support and understanding during many stressful and challenging points is a testament to the amazing team they are.

Drs. Christine Chambers and Jennifer Parker, in the Centre for Pediatric Research at the IWK Health Centre, provided mentorship and support above and beyond the call of duty as I develop into a clinician researcher; Karen Archibald provided a detailed review and feedback during the ethics process; I am so appreciative-thank you all!

Lastly, but certainly not least, I want to acknowledge my family and friends who have been patient and understanding in my commitment to this major piece of work, the periods of stress and distress, and who have been accepting of my need to prioritize based on my educational demands- I am forever grateful.

Abstract

It is widely accepted that hospitalization can influence the emotional, social, cognitive, and physical development of infants, children and youth. This is particularly true for children with chronic illnesses. Children report many negatives aspects of hospitalization, yet identify "play" and recreation as the best parts. Descriptions of play outside of hospital illustrate commonalities. However, children's perceptions or description of "play in hospital" has yet to be reported. This manuscript based thesis outlines my conceptual framework for the study, background literature, the study's methodology, a manuscript focused on the three arts-based data gathering activities used with hospitalized school-age children in the study, followed by a manuscript of the actual study and its findings. The thesis concludes with a synopsis of the findings, implications for practice and highlights areas for future research in the areas of arts-based data gathering activities with children and "play in hospital".

Preface

This manuscript based thesis is a reflection of the unique research I have completed during my graduate studies, as partial requirement for the Master of Health Studies Graduate Program. This thesis comprises two manuscripts, a methodology manuscript titled, "The Use of Three Arts-based Data Gathering Strategies to Elicit The Perceptions of Children with Chronic Illnesses Regarding 'Play in Hospital'" and a the second manuscript, "Children with Chronic Illnesses' Perceptions of 'Play in Hospital': A Qualitative Descriptive Study" describing the actual study.

A grant from the Graduate Student Research Fund at Athabasca University helped to support the cost of the research study including transcription of participant interviews. I was also humbled when awarded a 2014 Excellence in Research Scholarship from Athabasca University.

Authorship Determination

I am the first author for both of the manuscripts contained in this thesis; having conducted the research, the analysis and manuscript writing. Dr. Park and Dr. Moore have contributed their expertise during the research development and implementation phases, as well as editorial skills in the finalization of each manuscript. The intent is to submit both manuscripts for publication in peer reviewed journals.

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List of Abbreviations and Defining Terms

List of Abbreviations

CACLL	Canadian Association of Child Life Leaders
CCLS	Certified Child Life Specialist
CLC	Child Life Council
IWK	Isaac Walton Killam
Hem/onc	Haematology/oncology
QD	Qualitative Description
PMU	Pediatric Medical Unit

Defining Important Terms

Arts-based activities- includes many art and visual-based techniques such as drawing or "draw and tell", storytelling, puppetry, mapping, photovoice and photo elicitation, as well as child-led tours to facilitate communication, self-expression, share thoughts and emotions related to the topic being researched (Coad, 2007; Driessnack & Furukawa, 2012; Fargas-Malet et al., 2010).

Certified Child Life Specialist- a child life specialist who has successfully acquired the certification credential (Child Life Council, 2002).

Child life specialist- a trained health care professional who "...strive[s] to reduce the negative impact of stressful or traumatic life events and situations that affect the development, health and well-being of infants, children, youth and families", particularly as it relates to health care experiences (Child Life Council, 2002).

Chronic illness- "Chronic illness is the personal experience of living with the affliction that often accompanies chronic disease" (Martin, 2007).

Chronic disease-"… a long-lasting condition that can be controlled but not cured" (The Center for Managing Chronic Disease, 2011).

Dynamic Model for Play Choice- the model theorizes that "play activities perceived as fun are more likely to be repeated because of positive emotions associated with them. This repetition creates a pattern or preference, and continued engagement in the activity contributes to mastery" (Miller & Kuhaneck, 2008, p. 412).

Participatory research- Participatory research (with children) is research whereby the methods are child-centred (take into consideration the child's cognitive,

physical and emotional abilities), encourage the child's active participation, promote expression of thoughts while being engaging and "fun" (Carter & Ford, 2013; O'Kane, 2008; Mandleco, 2013).

Play- a synthesis of researcher definitions describes "play" as having fun, participating in "make believe"/dramatic play; it is more about the child and child's actions than the objects used in the play; not predetermined or predictable and physical activities have also been described as play (Bolig, 2005)

Psychosocial- "involving both psychological and social aspects; relating to social conditions and mental health" (Merriam-Webster, n.d.).

Qualitative description methodology- a method of qualitative research which seeks to answer "why" and "how" questions; learn answers to questions relevant to practitioners, from individuals involved in the phenomenon, without the goal of transforming/interpreting the information or developing a theory about the phenomenon or processes within it (Sandelowski, 2000).

Therapeutic play- "... specialized activities that are *developmentally supportive* [*sic*] and facilitate the emotional well-being of a pediatric patient" and "...focuses on the process of play as a mechanism for mastering developmental milestones and critical events such as hospitalization" (Koller, 2008, p. 3).

Chapter I: Introduction

Statement of the Problem

It is widely accepted, within pediatric health care, that hospitalization can influence the emotional, social, cognitive, and physical development of infants, children and youth. This comes after decades of research and observational reports on the effects of hospitalization on young children and those with chronic conditions (America Association of Pediatrics [AAP], Committee on Hospital Care & Child Life Council, 2014; Kronenberger, Carter, & Thomas, 1997; Pond Wojtasik & White, 2009; Rollins, Bolig & Mahan, 2005; Small & Melnyk, 2006; Thompson, 1985; Visintainer & Wolfer, 1975). Many aspects of pediatric health care delivery have changed since the early 1900's yet concern for the emotional health of young children in hospital remains (AAP et al., 2014; Livesley & Tong, 2013; Potasz, Vilela De Varela, Coin De Carvalho, Fernandes Do Prado, & Fernandes Do Prado, 2013; Rollins et al., 2005; Small & Melnyk, 2006). This awareness has resulted in the provision of play materials, dedicated play spaces and the integration of new roles specializing in pediatric psychosocial and developmental care (Pond Wojtasik & White, 2009; Thompson, 1989). One such role is that of the Certified Child Life Specialist (CCLS). Although early observational research of play in hospital provided the foundation for the work of child life specialists, there is limited new research on play in healthcare settings and specifically children's perceptions and descriptions of play in hospital.

Coinciding with changes in health care delivery were new societal perspectives that children were not just little adults; were unique in their own right and should be

viewed as rightful members of society. There is recognition they have individual rights, should have their "voices" heard and be respected as individuals with their own perspectives and opinions (Carter & Ford, 2012; Coad, 2007; Driessnack & Furukawa, 2012; United Nations, 1989). Since the early 1990's, there has been a thrust in the social research community to include children in evaluation and research, particularly in areas/services which affect them (Clark, 2005; Coad, Plumridge, & Metcalf, 2009; Fargas-Malet, McSherry, Larkin & Robinson, 2010).

Several researchers explored and described children's perceptions of play/their meaning of play outside of hospital (Brockman, Fox, & Jago, 2011; Glenn, Knight, Holt, and Spence, 2013; Miller & Kuhaneck, 2008; Yan, Yuejuan, & Hongfen, 2005; Wong, Wang & Cheng, 2011), their favourite play spaces/activities (Lehrer & Petrakos, 2011), the differentiation of "play" and "not play" and "play" versus "learning" activities (Howard, 2002; Howard, Jenvey, & Hill, 2006; McInnes, Howard, Miles & Crowley, 2009; McInnes, Howard, Miles & Crowley, 2010), and play in the community or their home environment (Berinstein & Magalhaes, 2009; Anthamatten, Wee & Korris, 2013). Researchers demonstrated that children can be active participants and provide valuable insight into their world. Children could define play, make meaning of play, articulate their favourite places to play, and what they needed for play. Additionally activities perceived as 'playful' supported and improved learning outcomes and impacted well-being (Brockman et al., 2011; Glenn et al., 2013; Howard & McInnes, 2013; Miller & Kuhanek, 2008; McInnes et al., 2009, 2010). Although recent studies examined children's experiences and perceptions of hospitalization, their perceptions related to play

in hospital had, thus far, not been studied.

My clinical training, knowledge and experience made me contemplate how school-age children perceived play in the hospital. Was play in hospital different than play at home, or play at school? Was play in the playroom described the same as play in their hospital room? Was therapeutic play with a child life specialist, either for teaching or for expression of emotions, perceived as play? I believe children can help us to understand how they define and describe play in hospital. This can lead to other areas of learning "from them" and "with them" in regard to their hospital experiences.

Purpose of the Study, Research Question and Objectives

The purpose of this qualitative descriptive study was to understand how hospitalized children with chronic illnesses perceived play in hospital, including their play preferences and play needs. The research question was: "How do hospitalized children with chronic illnesses perceive "play in hospital"?" Given the qualitative descriptive nature of this study, the following objectives were developed as a guide to understand how hospitalized children with chronic illnesses:

- describe play in hospital
- define play in hospital
- perceive play in hospital

Significance of the Study

The description of play in hospital by children with chronic illnesses, admitted to hospital, will provide child life professionals and other health care providers with new knowledge. School-age children's description of play in hospital, what they find

enjoyable, helpful, and contributes to their well-being has yet to be described. The findings of the study provide insight into what constitutes play for them, the play materials, the people and play environments important for play and the impact their health condition or treatment has on their play behaviours; all of which can ultimately influence well-being and overall coping.

The findings will provide pediatric health professionals and administrators with a better understanding of the importance of play to school-age children, what they perceive as play in hospital, how they define play, where they play in hospital, their play needs and preferences, the value of trained staff who facilitate play, the impact of diagnosis and treatment on play in hospital, and their resiliency and insightfulness. It is my hope the findings will also help inform decisions regarding clinical environments and the need for play materials and staff specialized in facilitating play. Additionally, it has the potential to inform further research to evaluate play in hospital, normative play and therapeutic play interventions, and/or to assess play's impact on overall coping and well-being for children with serious or chronic health conditions.

In this next section, I will provide historical context related to pediatric hospitalization and the development of the child life profession. This will help with understanding the context of the study along with a conceptual framework created for the study. A review of the literature pertaining to the concepts important in the conceptual framework are also highlighted.

A Historical Perspective of Pediatric Hospitalization

In the 1940's and 50's,researchers reported that lack of stimulation was associated

with infant death (Spitz, 1945) and that psychological effects had an impact on children during and after hospitalization (Bowlby, 1952; Pond Wojtasik & White, 2009; Prugh, Stauer, Sands, Kirschbaum & Lenihan, 1953). Health professional's reportedly observed children being withdrawn, lethargic and disengaged from others and their environment, hence the term "hospitalizism" was coined (Spitz, 1945).

Changes in societal attitudes at the turn of the century, led to hospital staff spending more time interacting and playing with children (Pond Wojtasik & White, 2009; Thompson, 1989). There was increased awareness that health care provision was more than simply doing tests and providing medication, procedures and surgeries (AAP et al., 2014; Hall, 1987; Small, 2002; Small & Melnyk, 2006). Volunteers were introduced in hospitals to play with children and became known as "play ladies", "play teachers", or "play leaders" (Rubin, 1992; Thompson, 1989). This was the foundation for a new profession now known as the "child life specialist" or "hospital play specialist". The primary focus of this health care role was the developmental and psychosocial needs of hospitalized infants, children and youth (Pond Wojtasik & White, 2009; Thompson, 1989).

Pediatric health care changed dramatically over the last century. Overall, hospital lengths of stay reduced significantly (Small, 2002); hospitals adopted a family-centered care approach (Shelton & Stepanek, 1994); more procedures and tests were available for diagnostic purposes (Boyd & Hunsberger, 1998; Rennick, Johnston, Dougherty, Platt & Ritchie, 2002); medical technology and advancements in treatments increased survival rates for serious and/or chronic condition and there was increased knowledge and

utilization of pain medications and non-pharmacological pain management strategies (Bandstra et al., 2008; Kuttner, 2010; McGrath, Stevens, Walker & Zemsky, 2013). All of these factors meant that hospitalized children in tertiary health centres were often more seriously ill and required multiple interventions and/or repeated hospitalization for treatment or complications from chronic conditions (Ahmann & Rollins, 2005; Boyd & Hunsberger, 1998; Clark, 2003; Melnyk, 2000; Pond Wojtasik & White, 2009).

While advances in pediatric health care were positive, the experience of hospitalization continued to be stressful and potentially traumatic for many children. Researchers reported health care experiences continued to cause fear and anxiety for patients and families, during health care encounters and after discharge (Chappuis et al., 2011; Lindeke, Fulkerson, Chesney, Johnson, & Savik, 2009; Melnyk, 2000; Salmela, Salanterä, & Aronen, 2009; Stevens et al., 2011; Wilson, Megel, Erenbach & Carlson, 2010). This was particularly true for children with chronic illnesses (Clark, 2003; Goodman, 2001).

Although a single definition of chronic disease or illness was elusive, for the purpose of this study, the following definitions were used "*chronic illness* [*sic*] is the personal experience of living with the affliction that often accompanies chronic disease" (Martin, 2007) and "chronic disease is a long-lasting condition that can be controlled but not cured" (The Center for Managing Chronic Disease, 2011).

While there were many factors which influenced longterm coping and adjustment of children with chronic disease, there was also recognition children with chronic diseases were at greater risk for psychological problems than children in the general

population (Goodman, 2001). Children with chronic illnesses benefitted from psychosocial supports to meet their developmental and emotional needs during stressful experiences such as repeated and/or lengthy hospitalization (AAP et al., 2014; Goodman, 2001). The provision of psychosocial support for the child and family became a standard of care for pediatric health care facilities with large pediatric populations in North America (AAP et al., 2014; Bolig, 1990; Fereday & Darbyshire, 2008; Rollins et al., 2005; Royal Australasian College of Physicians, Association for the Wellbeing of Children in Healthcare, and Children's Hospital Australasia, 2009). Health centres serving a significant pediatric population often provided play materials, designated play spaces, while larger centres hired child life specialist and/or child life workers[1] to provide group and individualized interventions for optimum coping and play programming. Psychosocial support services were developed and implemented differently depending on the size of the centre, the number of children receiving services, and availability of financial and human resources (AAP et al., 2014; Child Life Council [CLC], 2014) and this remains true.

The Role of Child Life Specialists

The role of child life specialists, and occasionally child life workers, were noted as a standard in North American health care facilities with larger pediatric populations (AAP et al., 2014). Increasingly, community hospitals and organizations serving children and youth experiencing significant life changing stressful events also hired child life

[1] Child life worker- also called a child life assistant, play/activity worker/coordinator or other similar title in other health centres

specialists. They are specially trained non-medical professionals who "...strive to reduce the negative impact of stressful or traumatic life events and situations that affect the development, health and well-being of infants, children, youth and families" particularly related to health care experiences (Child Life Council, 2002). They have a minimum of an undergraduate degree and internship supervised by a Certified Child Life Specialist (CCLS). They must then pass a credentialing exam to be designated a Certified Child Life Specialist. There are more than 260 CCLS in Canada and more than 4400 worldwide (Canadian Association of Child Life Leaders (CACLL, 2015). A child life specialist uses evidence-based assessment variables (the child's developmental level, child temperament, response to health care experiences, changes in mobility which impact coping, memory of past experiences, social status, and family/social supports to identify risks to development and coping for infants, children, youth and their families (AAP et al., 2014; Hollon & Skinner, 2009; LeBlanc & Chambers, 2013). Interventions are based on the child's or family's articulated concerns/fears and observation of their behavioural responses to health care, and the potential risk to typical development. Observations by parents and health care staff, as well as concerns/needs articulated by the patient or family also inform the child life specialist plan of care (AAP et al., 2014; Hollon & Skinner, 2009; LeBlanc & Chambers, 2013).

Child life specialist interventions include the provision of play opportunities, activities focused on the maintenance and advancement of developmental skills, preparation and support during health care experiences (such as medical procedure, surgery, transitions in care), health care play, therapeutic play and/or therapeutic

dialogue, and family facilitation (Hollon & Skinner, 2009; LeBlanc & Chambers, 2013). Child life specialists use play as a healing modality while teaching, encouraging the expression of thoughts and emotions, and promoting adjustment and coping with stressful aspects of the health care experience (CLC, 2002).

As noted above, the child life specialist focuses on both the child's developmental and emotional well-being. The role of the child life worker focuses on providing normalized play and activities, typically, in designated play spaces in larger health centres. The child life worker's educational background is typically focused on child development and normative play. They acquire additional knowledge about the effects of hospitalization on play behaviour during hospital practicum placements or on-the-job training. Their role facilitates play within the health care setting and often integrates the child life specialists normative play goals for the patient in the play program.

Understanding the history of pediatric health delivery and the role of the child life specialist today will inform the reader's understanding as I explain my conceptual framework which helped guide the study, the implementation and the analysis of the findings. The next section will describe the key concepts in my conceptual framework.

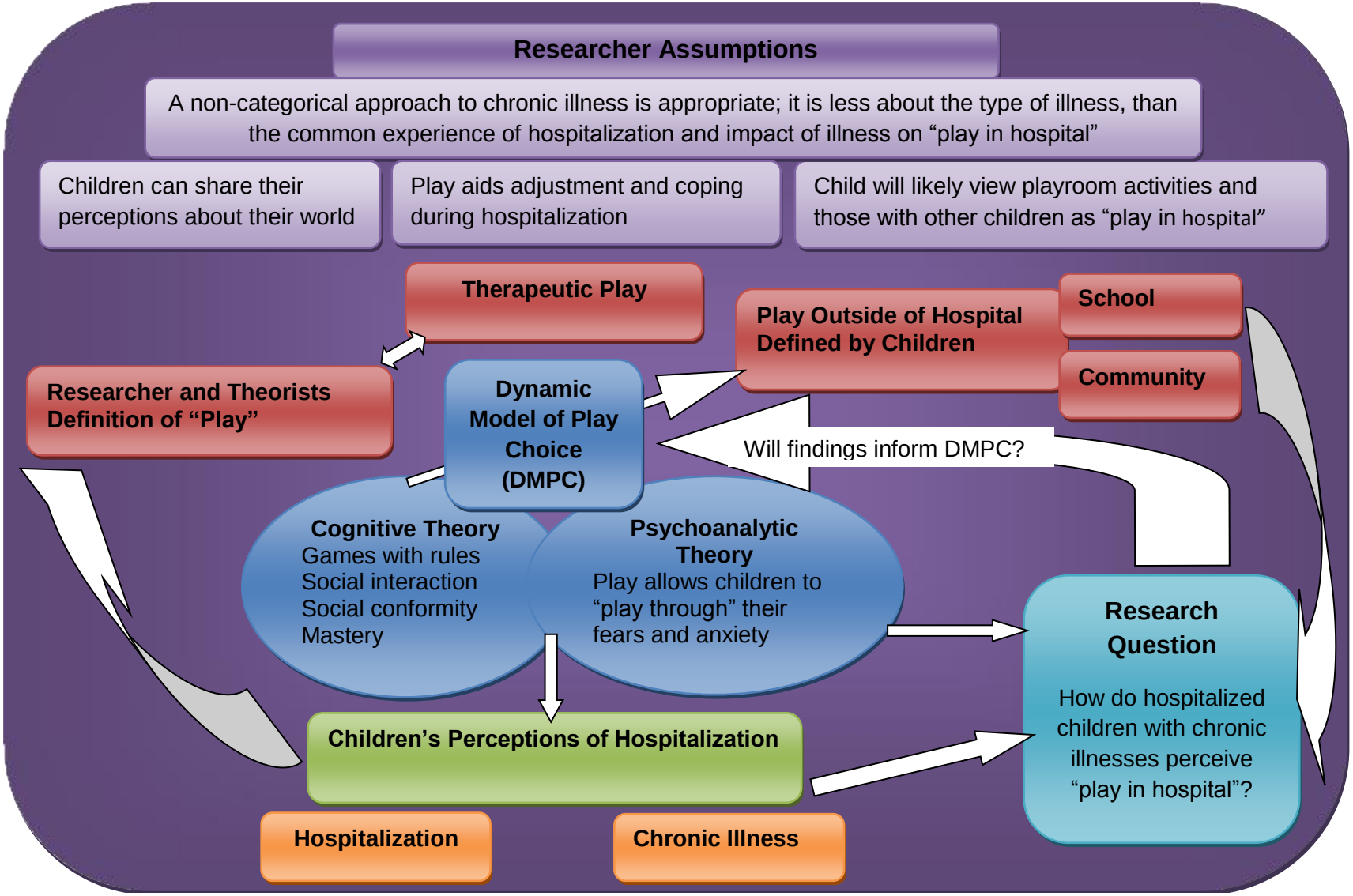
Conceptual Framework

The child life profession was built on many different theoretical frameworks related to child development and play, thus choosing one theoretical play framework from which to anchor this study was challenging. Instead, a conceptual framework was developed to highlight specific concepts that help structure and guide all aspects of the research since there was no single theoretical framework or "comprehensive explanation"

(Weissenmiller in Imenda, 2014, p. 188) forming the foundation for this proposed study. Imenda (2014) supports Liehr and Smith's (in Imenda, 2014) explanation that a research framework (theoretical or conceptual) provides a structure and guides the researcher when formulating the research question, the methodology to be used, and will guide the researcher to make findings relevant to the research question. This allows the researcher to review the data findings using the framework as a lens, to see if the findings reflect the framework used at the outset or whether there are differences.

Figure 1 depicts my conceptual framework. I identified research assumptions prior to the study, two play paradigms which resonate the most in the field of child life: psychoanalytic and cognitive theories as well as the Dynamic Model for Play Choice (Miller & Kuhaneck, 2008), a relatively new theoretical model focused on play choice. The Dynamic Model for Play Choice is highlighted because of its intuitive fit with the beliefs, values and utilization of play in a child life specialist's work. Additionally, other key concepts/findings from the literature which informed the research question are described. Each component of the framework will now be examined more closely beginning with researcher assumptions, a review of the three theoretical frameworks related to play, followed by a review of the literature highlighting each of the concepts which informed the research question "How do hospitalized children with chronic illnesses perceive play in hospital?". Please note a briefer version of this section is repeated in manuscript 2, "Children with Chronic Illnesses' Perceptions of 'Play in Hospital': A Qualitative Descriptive Study" to provide the anticipated journal reader with an overview of my conceptual model.

Figure 1. Conceptual Framework



Researcher Assumptions

It is important to recognize personal and professional beliefs and assumptions in the process of developing a research proposal. My conceptual framework highlights four assumptions of which I was conscious, prior to the study's implementation. First, I believe that children with chronic illness share common experiences regardless of their specific diagnosis. The experience of families with different chronic conditions are more similar than their specific differences. This is supported within childhood disability and chronic illness research where researchers are recruiting participants across conditions for many studies, not just diagnosis specific (Sawyer, Drew, Yeo, & Britto, 2007; Stein & Jessop, 1982). Hence, my assumption was that children with chronic illness would have much in common in their experiences of play in hospital and that participants with various chronic conditions could provide rich and valuable perspectives to the study.

Secondly, working with children of various ages over many years made me confident that school-age children could and would want to share their perspectives about things which affect them, such as hospital play experiences. This philosophy and practice was supported by The United Nation's Convention on the Rights of the Child (1989), social researchers (Driessnack, 2005; Hill, 2006; O'Kane, 2008) and clinical practice experiences.

Thirdly, I assumed that children would likely describe play activities in the hospital's playrooms most frequently, hence I needed to ensure I did not unknowingly influence the conversation to support this assumption. I was interested to learn if children described play in their rooms, play during clinic visits or therapeutic play sessions as play in hospital. Strategies for ensuring rigour and monitoring personal

assumptions are discussed in more detail in the section Ensuring Rigour and in the manuscript titled “Children with Chronic Illnesses Perceptions of ‘Play in Hospital’: A Qualitative Descriptive Study” in Chapter 3.

Educators and researchers emphasize the need to be reflexive and aware of one’s personal experiences, assumptions, philosophical perspectives which may impact each stage of the research study. Although there is recognition that, to some degree, this is the reality of being human and we need to accept that we influence what we do and vice versa, there is also an expectation that a researcher must reflect on how personal knowledge and experiences influence the way the research is conceptualized, designed and implemented. The next section further elucidates my thinking in this regard.

Reflexive stance.

I have become increasingly aware during this learning process that who I am, my knowledge, skills and understanding of children and families’ experiences within health care influenced my decision and passion for doing research with children. I am a Certified Child Life Specialist who has taken on many different clinical, teaching, mentoring and leadership roles, and was recently the principle investigator in a study specific to the work of child life specialists. As such, I am influenced by many different systems and sources of knowledge.

My journey really began when our family experienced a serious motor vehicle collision, nearly 3 decades ago, causing serious injury to one of my younger siblings and the death of a family member. During this experience, my perception as a young adult was that the psychosocial needs of my adolescent sibling seemed to come far after the

medical needs. This, to me, did not make sense. The injuries required admission on an adult unit with little focus on psychosocial or play supports. Our family had to create a youth friendly environment (while respecting the needs of the adults who shared the inpatient room), and manage the play and emotional needs the best we could, without support or guidance. We felt less than ill prepared.

There is no doubt that experience, seeing my sibling in so much physical and emotional pain, influenced my desire to work with children and families in health care and informs my practice today. I believe there is a need to help translate medical jargon into child and family friendly language, that children and families benefit from learning to advocate for themselves, and that they can build resiliency and coping skills when provided with the information and coping supports they need. As a clinician, I have a great deal of respect for children, youth and their families and believe they have strengths and abilities that are often underestimated by the health care team. We do not always ask or listen to children and families about "what" they want or need to help them, or to make their health care experience a more positive one. Learning from hospitalized children with chronic illnesses about their perceptions of play in hospital is a reflection of my desire to help raise the profile of their ability to give voice to what they want and need, in order to improve their experience, and hopefully have an impact on their overall coping.

I anticipated that my knowledge and work with children would guide me and help me feel comfortable and confident engaging with families and interviewing school-age children about their perceptions of play in hospital. Imagine my surprise when I realized I was nervous and unsure of myself, particularly when it came to interviewing the children.

Although I had read that interactions as a clinician and as a researcher were different and required planning and forethought, I was a little disappointed that children were more cautious, needed more time to build rapport before being able to share their perceptions and experiences of play in hospital. I had assumed their familiarity with so many health professionals, particularly staff from child life would make them feel comfortable and at ease to share, and that the activities would simply make things easier and the conversation would flow. I had to acknowledge my personal assumptions, the fact I was a bit over-confident in my engagement and interviewing skills and return to my child development knowledge and re-adjust my expectations. The interviews were harder than anticipated. My expertise as a clinician certainly helped, however I needed to remember these children did not know me; I needed to take the time to build rapport before seeking information from them, and to stay and play with them after the interview ended, if that was an assumption on their part. Although I was clear with children and families about my role as a researcher, there were times when I caught myself slipping in to "child life mode" and exploring comments made about their health care experience and offering information about resources.

Theoretical Foundations

Psychoanalytic theory.

The underpinnings of psychoanalytic theory important for child life specialists include the premise that play allows children to "play through" their fears and anxiety, allows for the cathartic release of emotions, is a way children re-enact their experiences, express fears about what might happen in the future, helps them come to terms with these

emotions, and supports coping (Bolig, Fernie & Klein,., 1986; Doverty, 1992; McCue, 1988; Saracho & Spodek, 1995). Saracho and Spodek (1995) indicated that within the psychoanalytic framework, the child was in control of what was expressed through play, thereby permitting the child to express the emotions at the pace needed; hence the play experience provided an opportunity for mastery and control leading to overall coping. Psychoanalytic theory is a foundation for how child life specialists define "therapeutic play", meaning activities that help facilitate emotional expression, focus on the process of play as a way to master challenging experiences and promote physical and emotional development (Koller, 2008). Therapeutic play is a core intervention used within child life specialist practice.

Cognitive theory.

Piaget's cognitive theory posits that play is related to the cognitive skills of the child, that the child assimilates or solidifies their understanding through play activities and accommodates information during their experiences. According to Piaget (as cited in Turner, 2009) there are four stages of play which are progressive, namely: (a) sensory play (practice, repetitive, functional), (b) symbolic play (representative or pretend play), (c) pre-operational play (independent and associative group play), and (d) games with rules (rule based, social convention).

Although dramatically different in their perspectives on play, the child life specialist uses both cognitive and psychoanalytic theories to provide developmentally appropriate activities for learning, normalization, fun and emotional expression (Bolig, 2005; Jesse & Gaynard, 2009). These theories help guide child life professionals (child

life specialists and workers) and Child Life Programs in the purchase of play materials, the development of play spaces, play interventions and play programming for hospitalized children (Bolig et al., 1986; Turner, 2009; William Li and Lopez, 2008; Sylva, 1993). These theories helped inform decisions related to study design, sampling (the cognitive capacity of school-age children of participants), the data-gathering strategy (arts-based activities chosen for the study are developmentally appropriate and promote expression of thoughts and emotions), as well as strategies for rapport building, the questions asked (the developmentally appropriate wording, open-ended nature of the questions and the general number of questions) and child friendly communication strategy.

Dynamic Model for Play Choice.

The Dynamic Model for Play Choice was developed from a ground breaking study using grounded theory (Miller & Kuhaneck, 2008). The study explored typically developing school-age (7-11years) children's perceptions of play, the meaning they ascribed to play and the rationale for their choice of play. From the one-on-one interviews, data were transcribed and analyzed to provide a theoretical model related to children's play choices (Miller & Kuhaneck, 2008). Simply stated, the model theorizes that "play activities perceived as fun are more likely to be repeated because of positive emotions associated with them. This repetition creates a pattern or preference, and continued engagement in the activity contributes to mastery" (p. 412).

Unfortunately, a search for further research or discussion of the model since its inception proved unsuccessful. The model however, intuitively and clinically fits with

child life specialist knowledge, clinical wisdom, and how play interventions are used. From clinical experience, I have noted that children who enjoyed an activity and who felt a sense of accomplishment often requested the same or similar activities in hospital; those activities perceived as "hard work" or "like school" were not requested for enjoyment (e.g. physiotherapy activities). It was anticipated that findings from this study could add to the credibility and transferability of this Dynamic Model for Play Choice in the hospital setting.

Concepts in the Literature

Children's perceptions of hospitalization.

With the change in focus on childhood and the realization that children had the ability and the "right" to share their views, a new body of literature emerged with a focus on children's perceptions of hospitalization (Horstman & Bradding, 2002; Lindeke et al., 2009; Lindeke, Nakai & Johnson, 2006; Wilson, Megel, Enenback, & Carlson, 2010), their health care experience (Gibson, Aldiss, Hortsman, Kumpunen, & Richardson, 2010), the quality of their hospital stay (Chappuis et al., 2011; Lindeke, et al., 2006), and perceived fears related to hospitalization (Lindeke et al., 2009; Rennick et al., 2002; Salmela et al., 2009; Wilson et al., 2010).

Salmela et al. (2009) reported that 90% of 4-6 year old children expressed being fearful of at least one thing in hospital. Hospitalized children expressed significantly more fears than non-hospitalized children, and identified being fearful of pain, treatments (especially injections) and tests more often than non-hospitalized children. In another study, Chappuis et al. (2010) surveyed hospitalized children, aged 6-12 years old, about

their satisfaction with the quality of their hospital stay. Being fearful was reported by 59% of child participants, 71% indicated their fears were due to "...illness, surgery or the consequences of treatment, pain and specific medical acts" (p.82). Additionally, 63% of the participants identified missing family and pets. These findings are supported by Lindeke et al.'s (2006) survey study where children identified pain and discomfort as the worst aspects of hospitalization.

Qualitative studies by Boyd and Hunsberger (1998), Horstman and Bradding (2002) and Wilson et al. (2010) demonstrated similar findings; that medical procedures, surgeries, isolation from peers, and hospital environment and lack of activities were sources of stress for children 10-13 years of age. Interestingly the only difference noted by researchers when non-hospitalized and hospitalized children were compared in some of the studies was the fact that hospitalized children used more accurate medical terminology, articulated knowledge from their direct experience, and the tasks were more emotionally taxing for them (Horstman & Bradding, 2002; Wilson et al., 2010).

Children were able to give specific and clear information about their needs and desires for hospital environments; the need for spaces with natural light and connection to nature, places to play, spaces that ensured privacy, personal and family spaces as well as the need for reduced noise (Horstman & Bradding, 2002; Lambert, Coad, Hicks, & Glacken, 2014). Repeatedly, play, recreational activities and being in the playroom were reported as the "best thing" about being in hospital (Chappuis et al., 2011; Horstman & Bradding, 2002; Lindeke et al., 2006; Wilson et al., 2010). Children valued play in the hospital environment, yet there is limited knowledge about play in hospital as described

by children. Children who need and use these services and can provide valuable information to inform decisions related to play in hospital.

Defining play: An overview of the literature.

A review of the literature found the study of play was complex and hampered in part by the lack of a clear, consistent and measurable definition of play and/or its various forms e.g. normative, therapeutic, functional, constructive, symbolic, solitary, parallel, associative, and cooperative play to name a few (Bolig, 2005; Bolig, et al., 1986; Turner, 2009; Lifter, Mason, & Barton, 2011; Saracho & Spodek, 1995; Thompson, 1985). Researchers and theorists described what play looked like, what it wasn't, or as in the case of Piaget (as cited in Turner, 2009) described the developmental stages/phases of play rather than defining the construct itself. The definition used by theorists and researchers depended upon the theoretical framework to which they espoused (Lifter et al., 2011).

The study of play in hospitals was further complicated by the many variables noted to influence play behaviours such as length of stay, acuity of illness, hospital environment, opportunities for play, type of play available, and staff who supported play (Jesse & Gaynard, 2009; Lifter et al., 2011). Bolig (2005) synthesized a list of criteria identified by theorists and researchers reflecting the most agreed upon descriptors of play, "play must be: (a) voluntary, (b) internally motivated, (c) pleasurable, relaxed, (d) "as if" or pretense present, (e) organism rather than object dominated, (f) unique, unpredictable, and (g) active, both motorically [*sic*] and cognitively" (p. 84). This meant children were typically observed having fun, participated in "make believe"/dramatic

play; play was more about the child and child's actions than the objects used in the play; play was not predetermined or predictable, and physical activities were also described as play. Bolig acknowledged not all of these needed to be present; however there was no indication how many of these criteria should exist for an activity to be labelled as play.

Conversely, Howard (2002) and colleagues (Glenn et al., 2013; McInnes et al., 2009; McInnes et al., 2010) questioned the value of a single definition of play since they stated play was contextual, based on the child's developmental level and experiences, and changed over time. Howard (2002) and Glenn et al. (2013) suggested researchers should focus on children's perceptions of play, since children were the ones experiencing it and should study the characteristics of the activities or situations that resulted in playfulness. In keeping with this perspective and the purpose of this study, hospitalized children with chronic illnesses' definition of play will be one of the foci of the study.

What is "therapeutic play"?

Koller (2008) described therapeutic play as "... specialized activities that are *developmentally supportive* [*sic*] and facilitate the emotional well-being of a pediatric patient" and "...focuses on the process of play as a mechanism for mastering developmental milestones and critical events such as hospitalization" (p. 3). This definition overlaps with Sylva (1993) who specified that therapeutic play was guided by the adult whose goal was to support the physical and emotional well-being of the child through guided activities. Therapeutic play could be directed or guided by adults when there were specific goals in mind such as desensitizing the child to medical equipment and reviewing information about an upcoming procedure, or, it was non-directed and the

child was in control of the focus of the play experience, although the materials may have been pre-selected to guide the activity (Chambers, 1993; Delpo & Frick, 1988). Child life specialists used directed and non-directed therapeutic play interventions depending on the situation, the child life goals and the frequency of sessions provided.

Child life therapeutic play sessions at this health centre are often offered as choice activities. A directed or guided therapeutic play session is influenced by a child life specialist's goal to build a relationship, explore the child's understanding of upcoming tests/procedures, share developmentally appropriate information, allow for the exploration of questions/concerns related to stressful experiences, assess understanding of procedures, model and practice strategies for coping. All this while trying to make it fun and interactive.

Surgical preparation is an example of a therapeutic play intervention. Preparation using medical play provides an opportunity to rehearse, desensitize and familiarize children with the equipment and procedures, and learn what will happen before, during and after surgery. The child life specialist brings a selection of relevant teaching and distraction materials but the session is guided by the child's developmental and emotional needs. The child life specialist encourages expression and play, uses open ended questions and respects the child's level of participation and interaction with the child life specialist, the environment and the materials. Child life specialists may guide the session with materials and initial focus of the conversation, however the child's verbal and non-verbal cues dictate what and how information is provided, the depth of the conversation and when the session should end.

For the purpose of this study, therapeutic play is defined as an adult guided activity (which can be directed or non-directed) with a focus on supporting emotional well-being, mastering developmental milestones and/or eliciting concerns about health care experience as expressed by smiling, reduced worry/anxiety, increased understanding and/or the expression of happiness. Since the child life specialist's approach fits with many of the positive characteristics described by researchers and children as being equated with play (activity is fun, and the child decides the degree of participation), one must wonder if these therapeutic play interventions, which are adult guided/directed, will be described as play in hospital by a school-age child.

Children's perceptions of play outside of hospital.

"Play" and "learning".

Research of children's perceptions of play began in the fields of early childhood and education. School children categorized photographs of the same activities such as reading a book as "play" or "not play" and "learning" or "not learning", presumably using contextual (in the classroom, on the floor or at a desk) and social cues (smiling, not smiling, teacher directing, teacher presence/nearby or absent) in the photographs. Later studies using similar methodology demonstrated children linked teacher directing activities (e.g. pointing at a book) and teacher presence with learning (Howard et al., 2006; McInnes et al., 2010). Participants' categorization of the activities and justification of their decision supported previous researcher observations and reports that play was an activity of choice, was engaging and pleasurable.

McInnes and colleagues (2010, 2011) found that teachers who recognized and demonstrated a balance in adult-led and child-led activities, who saw themselves as play partners and facilitated learning through play demonstrated more playful interactions, offered more choices and used "play" and "choice" as they described activities. Teachers who supported learning by using "play" but who did not engage in playful activities (unless asked) used words like 'learning', 'busy' and 'doing'. Children seldom engaged these teachers in play requests presumably because they differentiated "play" separately from "learning". Given the nature of therapeutic play interventions in child life practice, I was curious to hear from hospitalized children with chronic illnesses regarding how they describe play and if therapeutic play activities/interventions provided by a child life specialist was perceived as play.

Play outside of school.

Other studies explored the meaning of play for school-age children outside of school (Berinstein & Magalhaes, 2009; Brockman et al., 2011; Glenn et al., 2013). Although the three studies reviewed were from vastly different cultures and countries (Tanzania, UK, and Canada) there were striking similarities in children's perceptions/meaning of play. In all three studies, children reported, took photographs or drew active/outdoor play (playing sports, riding bikes, social games like stick games, tag, and hide and seek) and reported outdoor play as the preferred location for play.

In the UK, US, and Canada more sedentary activities such as computer/video games, watching TV, dramatic play, playing with pets, and music were also reported as play (Berinstein & Magalhaes, 2009; Brockman et al., 2011; Glenn et al., 2013) whereas

these types of activities were not reported in Tanzania, as might be expected (Berinstein & Magalhaes, 2009). Additionally, there were differences noted between children's descriptions of television viewing. British children included television as a play activity (Brockman et al., 2011) whereas other children seldom included television watching as play, and those who did focused on the television as a conduit for interactive video games or as a conduit for engagement in an activity (Glenn et al., 2013). In several studies, children described play as any activity that was 'fun' (Berinstein & Magalhaes, 2009; Glenn et al., 2013; Lehrer & Petrakos, 2011). If an activity was no longer fun and/or was described as "boring" it was not considered play (Glenn et al., 2013).

This raised awareness of the influence of culture on perceptions of play. The physical as well as the emotional environment likely influenced play behaviours. Lehrer and Petrakos's (2011) and Anthamatten et al.'s (2013) studies reported vast differences within their participant populations in regards to the locations in which children played. In both studies, children identified that play locations and parental restrictions were related to perceptions of safety in their neighbourhoods, the presence of children in the neighbourhood and the availability of "safe play parks". However, in Glenn et al.'s (2013) and Brockman et al.'s (2011) studies, children preferred to play outside, in their yard, gardens, on the road and other areas not often considered by adults as places to play, such as alleys. In a separate study in an urban US city (Lehrer & Petrakos, 2011), the children identified their preference as playing at their friends and explained there were few children in the neighbourhood or places to play, such as playgrounds. Interestingly formal playgrounds were rarely identified as favourite places to play in the

Glenn et al. (2013) and Brockman et al. (2011) studies but in Anthamatten et al.'s (2013) study children relied on school playgrounds as a safe location to play and to meet their friends for play. Glenn et al. (2013) concluded children could play almost anywhere, however this may vary depending on where children lived and social circumstances.

Brockman et al.'s (2011) study noted that boys reported playing more with friends, while girls reported playing more with family members. Glenn et al.'s (2013) study reported that, overall, children preferred playing with friends and siblings, and preferred playing with people who liked to play similar things as them. This was similar to the Tanzanian study in which participants photographed peers and siblings in their representation of their "play experiences", and no adults were noted (Berinstein & Magalhaes, 2009). Yet in other studies (Anthamatten et al., 2013; Glenn et al., 2013; Lehrer & Petrakos, 2011), researchers noted children identified parents as play partners and sometimes also as hindrances to play (setting time limitations, safety restrictions related to types of activities etc.).

The studies of play or the meaning associated with play by healthy school-age children demonstrated both similarities and some degree of difference across studies. The differences noted would appear to be attributed to characteristics of participant groups such urban/suburban population, or impoverished community, ethnicity and/or community culture. Interestingly, the studies whose focus was to explore children's meaning/perception of play universally reported school-age children's descriptions of play as "fun" or an activity was play because it made the child "happy", and was voluntary because they reported choosing what they wanted to do (Berinstein &

Magalhaes, 2009; Glenn et al., 2013; Lehrer & Petrakos, 2010). Many of the activities described by typically healthy school-age children were physical activities, activities that were outside and unstructured, activities with friends and siblings, were "fun" and chosen freely. Given that hospitalized children with chronic illnesses are less likely to be able to participate in such activities, with friends and siblings and might not be able to choose their preferred form of play while admitted to hospital, I was eager to hear how they would describe/define play in hospital.

The Status of Play Research in Hospital Today

Prior to the 1990's, play research within hospitals focused on observations of children's behavioural responses during playroom activities, the choice of play materials for hospitalized versus non-hospitalized children, the effect of stress/anxiety on the choice of play materials, as well as memories related to hospitalization (Thompson, 1985). Research was not focused on children's perceptions of play, play interventions, the hospital experience or contextual variables influencing play (Bolig, 2005; Jesse & Gaynard, 2009; Howard, 2002; Howard et al., 2006; Howard & McInnes, 2013; Thompson & Snow, 2009). It is now recognized that simply because one was once a child does not mean one can presume understanding the world from a child's perspective in today's society, or in today's health care facilities. Research with children, to understand their perception of activities, programs, services and environments which affect them, has gained acceptance in the research community and there is much to learn from children about their play in hospital.

Summary

Hospitalization has the potential to influence the emotional, social, cognitive, and physical development of infants, children and youth. This is particularly true for children with chronic illnesses. Some children with chronic illness must be frequently admitted to hospital for treatment or complications related to their condition.

A societal shift in perception of childhood and the awareness that children have the right, the ability and the desire to provide their views about topics which directly affect them, has led to a research movement from doing research "on" children to research "with" children. This includes children's perceptions, descriptions and definition of play in hospital. Recent school and community based studies shed light on play outside of the hospital setting. However to date, hospitalized children with chronic illnesses have not been consulted in regards to their perceptions of play in hospital, how they define play, where they play, the people important for playing, nor what they want and need to play in hospital. This qualitative descriptive study is a description of how children perceive, describe and define play in hospital as well as the impact their health condition and health care experience have on play in hospital. The next chapter contains an overview of the methodology of the study, a brief literature review about arts-based data gathering activities, an overview of the study and contains manuscript 1 which focuses on the use of the three arts-based data gathering activities offered to participants in the study.

Chapter II: Research Design

This chapter will begin by providing the rationale for using qualitative research, specifically a qualitative description research methodology. I then define participatory research and arts-based activities as they relate to research with children. This will be followed by an overview of the research design, namely the sampling process, participants, setting, recruitment, data gathering activities and data analysis. A focus on ethical considerations when doing research with children and on rigour is next. I will then explain how each manuscript relates to the study, after which the first of two manuscripts will be presented.

My first manuscript entitled "The Use of Three Arts-Based Data Gathering Activities to Elicit Perceptions of Children with Chronic Illnesses Regarding 'Play in Hospital'" describes three arts-based data gathering activities, namely photo elicitation interviewing, drawing/play mapping and child-led guided tours offered to enhance a semi-structured interview data collection strategy in a study titled "Children with Chronic Illnesses' Perceptions of 'Play in Hospital": A Qualitative Descriptive Study". Evidence for the use, implementation, as well as the strengths, challenges and/or unexpected outcomes of each data gathering activity are the foci of manuscript 1. Special considerations, including ethical issues when doing research with children will also be highlighted, along with implications for future research using arts-based data gathering activities with school-age children.

Rationale for Using Qualitative Research and Qualitative Description Methodology

It is recognized that qualitative research is best suited when little is known about a topic; a topic is complex and multi-faceted; there is a need for a deep understanding of the phenomenon; to gain insight and meaning of a phenomenon from the participants' perspective; to develop an understanding of a process; to explore perceptions, beliefs, and experiences within the natural context of the phenomenon, or to develop a theoretical model of understanding (Creswell, 2013; Neergaard, Oleson, Andersen & Sondergaard, 2009; Richards & Morse, 2013; Smith et al., 2011; Vaismoradi, Turunen, & Bondas, 2013). Neergaard et al. (2009) and Sandelowski (2000) stated qualitative research was appropriate for answering "why", "how" and "what" questions in relation to perceptions, behaviours, motives, processes and barriers. The researcher's level of involvement with participants can range from being a non-participant observer to being integrally involved in the environment and with the participants, depending on the research paradigm, the research methodology and the study's design (Richards & Morse, 2013). In this study, I participated directly with the children during the arts-based activities and interview.

Qualitative description (QD) was described as one qualitative research methodology with the goal of providing rich description with minimal interpretation of the data (Sandelowski, 2000, 2010). The term "qualitative description" was recently highlighted as a distinct methodological approach within qualitative research (Milne & Oberle, 2005; Neergaard et al., 2009; Sandelowski, 2000, 2010). In 2000, Sandelowski wrote that "...there is no comprehensive description of qualitative description as a distinctive method of equal standing with other qualitative methods, although it is one of the most frequently employed methodologic [*sic*] approaches in the practice disciplines"

(p. 335). A QD study provides "a comprehensive summary of events in the everyday terms of those events" and the findings are reported in a manner described as "close to ... [the] data" (p. 334); with less interpretation than other interpretive methods such as phenomenology and interpretive descriptive methodology (Sandelowski, 2000). While noted to be less interpretive than other methodologies, Sandelowski emphasized that interpretation is required and is an important part of data analysis (Sandelowski, 2000). Qualitative description is helpful in answering questions relevant to practitioners with minimal transformation of the data (Sandelowski, 2000), where the goal is to gain the participant's insight about a particular and narrow topic (Kahlke, 2014).

QD reflects the tenets of naturalistic inquiry (Sandelowski, 2010) which supports the premise that there are multiple realities, not one truth; that the researcher and the participant's worlds influence one another and there is no preconceived "theory", the data/theory comes from the data (Lincoln & Guba cited in Thorne, Kirkham, & O'Flynn-Magee, 2004). A researcher may have a theory/conceptual understanding about the phenomenon to be studied yet remains open/flexible to change as the data is simultaneously being collected and analyzed in an iterative and inductive manner.

QD's purpose, to provide rich description and to report findings close to the data, fit well with my intent of the study and my worldview. QD methodology allowed an in-depth look into children's perceptions of play in hospital and allowed me to report findings in a way that respected children's terminology/everyday language with limited interpretation or transformation of the data. The flexible nature of data gathering within QD allowed arts-based activities with a semi-structured interview. This approach was

respectful of children's typical cognitive development based on Piaget's cognitive theory (in Turner, 2009), and the need for child-centred and child-friendly data gathering and communication strategies.

Participatory Research with Children and Arts-Based Data Gathering Activities

Over the last two decades, there was a dramatic shift in social research of children and youth from research "on" children to research "with" children. Participatory research stemmed from the shift of seeing children as objects to be studied, to "active participants" (O'Kane, 2008); the belief that children could provide valuable information about their experiences/perceptions of the world and those around them. According to the literature, many researchers gave credit to the United Nations' Convention on the Rights of the Child (UN, 1989) as well as significant political and policy change focusing on social and health program reform within the United Kingdom and Australia (Coad et al., 2009; Morgan, Gibbs, Maxwell & Britten, 2002; Whiting, 2009). Since the 1990's the literature described "participatory research" and "arts-based activities" with children and youth when gathering data. These terms were used together and separately in the literature necessitating further clarification for this study.

Upon further reading, the terms arts-based strategies/activities or techniques were typically applied when describing the actual activities utilized with children to facilitate communication, self-expression, share their thoughts and emotions related to the topic being researched. Arts-based data gathering activities included many different art and visual-based techniques such as drawing or "draw and tell", storytelling, puppetry, mapping, photovoice and photo elicitation as well as activities such as tours (Coad, 2007;

Driessnack & Furukawa, 2012; Fargas-Malet et al., 2010). Several researchers agreed that children had varied interests, skills and abilities, hence benefitted from different data gathering activities. As yet, no art-based data gathering activity(ies) has been deemed the best strategy to obtain children's perceptions (Coad, 2007; Hill, 2006; McTavish, Streelasky, & Coles, 2012; Punch, 2002; Whiting, 2009), although there is evidence that "draw and tell" techniques provide more data and greater depth of information than drawing alone or interview alone (Driessnack, 2005).

Thus, in the context of this study, participatory research was conceived as research aimed at actively including children, acknowledging them as experts and using child-centred strategies such as arts-based activities to encourage active *participation* in data making (Darbyshire, MacDougall & Schiller, 2005; Driessnack & Furukawa, 2012; Mathers, Anderson, McDonald & Chesson, 2010). Children were consulted regarding the arts-based activities to be used, in the planning phase of the study. Additionally. I offered each child the choice of three arts-based activities to elicit their perceptions of play in hospital: (a) using photos to elicit their perceptions, (b) drawing a map of play in hospital and describing their map, and/or (c) having the child lead a guided tour of play in hospital. Further details regarding each arts-based activity can be found in Manuscript 1 "The Use of Three Arts-Based Data Gathering Activities to Elicit Perceptions of Children with Chronic Illnesses Regarding 'Play in Hospital'".

Sampling

It was anticipated hospitalized children with chronic illnesses would be more likely to have experienced playing in hospital, were likely to be familiar with the available play

materials/activities, play programming opportunities, and the environments in which play could occur, hence purposive sampling was used.

Participants

A purposive sample of 10 hospitalized, school-age children with chronic illnesses participated in the study. The age of the children ranged from 6-11 years, with a mean age being 8 years (average 8.4 years), 6 girls and 4 boys; 7 of the children were being treated for a diagnosis of cancer, while the other three had either kidney disease, bowel disease or immunological disease; all parents described their ethnicity as White. Four of the children had been admitted 1-3 times in the previous year, four were admitted 4-9 times, one was admitted more than 10 times and one family did not indicate the number of admissions.

Setting

The study took place in a tertiary women and children's health centre that serves a population of nearly 2 million people. The health centre serves as both a primary care facility for the region as well as a tertiary health care facility for children in Eastern Canada. The health centre has three pediatric inpatient units; namely a pediatric medical unit, medical/surgical/neuro unit and a haematology/oncology and nephrology unit (blood/cancer/kidney problems) with nearly 70 beds. This is the health centre in which I work as a child life specialist. Recruitment did not occur on my clinical unit, in order to avoid any conflict of interest or influence on my therapeutic relationships with children and families on my unit.

Recruitment

Parents, whose child had a chronic disease and who was admitted to the pediatric medical unit, the haematology/oncology and nephrology unit, or associated clinics, were approached by a member of the health care team, namely the child life specialist providing services to the family. Parents were offered the opportunity to learn about a research study focusing on school-age hospitalized children with chronic illnesses and their perceptions of play in hospital.

Once the parent(s) agreed to learn more about the study, I provided an overview of the study and obtained consent for their child to participate in the study and separately for the use of quotes and/or drawings. I then reviewed the study information in a developmentally appropriate way with the child and obtained assent to participate in the study and separately for the use of quotes and/or drawings. Every effort was made to ensure children felt informed and offered the opportunity to participate or not participate and this was reviewed at key points during the study process. Parents and children understood the purpose of the study, the data gathering activities, that the interview session would be audio-recorded and transcribed and that quotes and/or drawings would be used for educational and publication purposes. They were also informed of the limitations of withdrawing from the study once data were gathered and the iterative process for data analysis had begun.

Data Gathering Activities

Semi-structured interview questions to learn about the child's perceptions of play in hospital (see Chapter 3, p. 122) were used to guide the interview. The interviews were expected to last between 30-60 minutes. Children chose where to have the interview: in

the child's room, in a small interview space on the inpatient unit, or in the playroom. Additionally, children were offered a choice of three arts-based activities in an effort to be child-centred, be fun, engaging and developmentally appropriate, while appealing to various interests. They were also given the choice to "just talk". As noted above, the three arts-based activity choices included, (a) using photos to elicit perceptions of play in hospital, (b) drawing a map of play in hospital and describing the map, and/or (c) doing a child-led guided tour of play in hospital. Five of the ten children created drawings or play maps, three chose viewing the photographs when discussing play in hospital, one child chose to provide a guided tour, and the other child wanted to just talk. The interview sessions were audio-taped and transcribed verbatim by a transcriptionist.

Data Analysis

The interview data and drawings were reviewed repeatedly and coded. This was an iterative process as each data set was added. Initial codes were defined, clustered into themes and subthemes as analysis continued throughout and after the data were gathered. Of note, the development of codes was both inductive and deductive in nature. Further details regarding data analysis are described in manuscript 2.

Ethical Considerations When Doing Research with Children

There are special considerations when research is (a) undertaken with children, (b) is conducted in a hospital setting, and (c) when it takes place within a clinical researcher's work setting. Given the ethical and procedural challenges these pose, further discussion is warranted and provided below and within manuscript 1.

Research with Children

Consent and assent.

First and foremost, if the child was not interested in participating, their decision will be final, regardless of the parent's willingness to have the child participate. This was in keeping with proper ethical conduct for research (Nairn & Clarke, 2012; Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, & Social Sciences and Humanities Research Council of Canada, 2010). Prior to beginning the interview, the child was reminded it was a choice to participate or not participate, and whatever the decision it was OK. If I sensed the child felt obligated or pressured by family, I did not proceed unless I felt confident the child was making the decision and was comfortable with the decision. Most often, the child was shy but once conversation continued and the activities were explained, s/he was more than eager to help me learn about play in hospital. Assent was revisited periodically particularly when beginning the audio recording and when discussing permission to use drawings or quotes.

In one instance, during the consent and assent process, it was clear the child was not interested in participating but was trying to negotiate a deal with parents for a "treat" and was not able to focus on anything but food. I interjected jokingly that I would get in trouble if my supervisors learned someone was being "paid with treats" to help with the study. He was typically a talkative child who enjoyed play in hospital and parents wanted him to participate. It was agreed I would return another day; parents anticipated the child would be in a different state of mind and truly be interested in the study. Unfortunately, he was discharged prior to being able to revisit participation in the study.

Child participants.

Children are more vulnerable and are at risk of wanting to please others, especially those perceived as being in positions of power. Building rapport was critical and ensuring I was not exploitive in the process of trying to obtain the child's perceptions (Coad, 2007; Fargas-Malet et al., 2010). Given the participants were 6-11 years of age, it was important to be skilled in talking with school-age children to ensure the study information, assent information, and study questions were clear and any potential misunderstandings clarified. I am aware data are reportedly richer when open-ended questions are used because they provide children the opportunity to share more detailed information (Driessnack & Farukawa, 2012; Kortesluoma, Hentinen, & Nikkonen , 2003), however this was balanced with the participant's cognitive ability. Often, questions needed to be reworded or more focused than originally planned. It was important to avoid the use of vague and abstract questions. Parental presence was welcomed to ensure the child felt safe (Salmela et al., 2009).

Most children enjoy being asked their opinions and want to participate in research focused on areas of interest and topics/decisions which affect them (Hill, 2006; Nairn & Clarke, 2012). However, some topics are sensitive and may evoke significant emotional responses or distress for the child, hence the need to ensure the child knows s/he may discontinue participating in the study at any time. Although, this particular study was not focused on sensitive topics, the discussion about play in hospital had the potential to evoke sadness, loneliness and other emotions related to being away from home and/or the child's medical condition. The child life specialists and social workers for the inpatient units involved in the study, were aware that participant families were encouraged to seek

their support if needed; the family and the health care team were aware there was psychosocial staff available during and after the study's completion in the event any debriefing or concerns arose from the interview (Hill, 2006; Nairn & Clarke, 2012).

Resources and researcher skills.

Determining the best data gathering activities, finding good quality supplies, determining the best space and environment, and planning additional time for recruitment is critical for sound ethical research with children (Coad, 2007; Coad et al., 2009; Mathers et al., 2010; Morgan et al., 2002; Whiting, 2009). Researchers must have realistic expectations and an understanding of the best fit between developmental capacity, the research question and the data gathering activities to be used (Clark, 2005); be comfortable with children; have good interview skills; be able to quickly build rapport; maintain focus on the topic, and ensure participants feel comfortable and valued (Coad, 2007; Darbyshire et al., 2005; Gibson, 2007; Morgan et al., 2002; Punch, 2002; Whiting, 2009). Additionally, skills in facilitation and seeking clarification to ensure an accurate understanding of participant's views, redirecting or changing strategies to maintain engagement as well as being sensitive to potentially unexpected responses from children is needed (Clark, 2005; Darbyshire et al., 2005; Gibson, 2007; Whiting, 2009). It was suggested that it would be unethical to proceed in doing research with children without the proper preparation, knowledge and skills.

I acquired Research Ethics Board approval from both Athabasca University as well as the tertiary centre where the study took place, and was constantly aware of the sensitive ethical issues related to doing research with children. Ethical issues related to

power, privacy and confidentiality, as well as the dissemination of findings when doing research with children and families will be described in manuscript 1.

Considerations for the Hospital Setting

Hospital environment.

Hospitalized children are recognized as being a vulnerable population and experience stress due to their medical condition, separation from home, community and many of their family members (Chappuis et al., 2011; Lindeke et al., 2009; Melnyk, 2000; Salmela et al., 2009; Stevens et al., 2011; Wilson et al., 2010). Stress was often significant for parents of children with chronic illness particularly during hospitalization, depending on the situation. Health care stressors, as well as personal and financial stressors are known to impact parent/family coping (Koller, 2008). Being respectful and ensuring families were contacted at an appropriate time and that the study did not impose unnecessary stress to them or their child was important to my success during recruitment.

The interviews were conducted in a private location where the child and parent felt safe and comfortable. The child was offered a choice of locations: their inpatient room, a small interview room on their inpatient unit or a playroom on their unit. These spaces included comfortable seating, were nicely decorated and were located within the areas with which they were most familiar.

Research Ethics Boards

Prior to hospital Research Ethics Board (REB) approval, it was important to seek managerial approval and present the proposed study to the inpatient unit's Operations Committees to ensure appropriateness of the study, clarify processes and/or make

adjustments based on team feedback. Hospital policy was such that all human research studies within the health centre must be approved by the hospital's REB and that a student researcher required an in-house supervisor. This was in addition to the Research Ethics Board process at Athabasca University and the Thesis Supervisor role.

Considerations for the Clinician Researcher

Recruitment.

As a clinician and student researcher, I did not recruit participants from the unit where I work in order to avoid: (a) any perceived conflict of interest, (b) undue influence in the recruitment process, and/or (c) any impact to my therapeutic relationship with patients and families on my clinical unit. I needed to maintain a student researcher stance, avoid asking about patients who were not in my clinical care nor seek out additional information about patients who might be eligible but whom I had come to hear about during clinical communications with staff. It was important to stay at arm's length and provide overall reminders to child life team members about eligibility requirements for the study. There was the additional complexity of being the professional practice leader for the child life specialists, staff awareness of my passion and commitment to research, and my graduate studies. It was imperative I keep all my roles clearly defined and avoid staff feeling any undue pressure to "find participants" or to provide more information about the participant and/or family than what would typically be provided to a researcher.

Risk of bias and need for reflexivity.

As a CCLS, I value play, its use for therapeutic interventions, for developmental support and for enjoyment. As such, I spent time writing and reflecting on my personal and professional views and assumptions (see Figure 1). I also spoke with colleagues not involved in the study to help process the experiences and some of the findings, as suggested by Appleton (2011). Continuous reflection was valuable and helped me be aware of my interview style, strategies that might improve data gathering and helped me process my insecurities and worries about being a novice qualitative researcher (Richards & Morse, 2013; Trochim & Donnelly, 2008).

As noted above, there were many ethical considerations when doing research with children in the health centre where I work. Although it was challenging to consider all the details in an effort to ensure success, having children participate in this proposed study was the best way to answer the research question. Every effort was made to be well prepared; be respectful; meet the developmental and emotional needs of participants, and to have fun in the process of gathering rich data.

A Focus on Rigour

There continues to be much debate about rigour in qualitative research (Barusch, Gringeri, & George, 2011; Guest, MacQueen, & Namey, 2012; Morse, Barrett, Mayan, Olson, & Spiers, 2002; Rolfe, 2004; Sandelowski, 1993; Whittemore, Chase, & Mandle, 2001). Some researchers feel strongly that the terms "validity" and "reliability" should be used to ensure consistent use of terminology regardless of the paradigm of research (Guest et al., 2012; Morse et al., 2002; Rolfe, 2004; Whittemore et al., 2001). Others report (Barusch, et al., 2011; Lincoln & Guba as cited in Creswell, 2013, Sandelowski,

1993; Shenton, 2004) that different terminology is needed to represent the characteristics of good qualitative research (e.g. quality, trustworthiness, credibility etc.) and must be reported for the writer and the reader to demonstrate and evaluate respectively the strategies undertaken before, during and after the data were gathered and analyzed. I can appreciate the value in using consistent terms across paradigms, as noted by Morse et al., however the terms trustworthiness/credibility, and transferability speak more readily to me. I believe, as Morse et al. reported, that the researcher is responsible for ensuring methodological congruence; the research question dictates the research methodology and design, and that it is the responsibility of the researcher to stay true to this throughout the research process.

Morse et al. (2002) believed it was the sole responsibility of the researcher to ensure the research study was created and conducted in such a way the research itself was valid and reliable through the use of verification strategies. Conversely, other researchers worried that rigid rules applied automatically to all qualitative research would jeopardize the creativity and natural flow that a researcher should take when analyzing and interpreting the data (Sandelowski, 1993). The literature on rigour began to focus on how to assess quality in qualitative research with the focus on the reader needing and perhaps even owning the responsibility to assess the quality of the research, based on specific strategies (Meyrick, 2006; Rolfe, 2004; Sandelowski, 1993). These two stances are vastly different. I believe researchers have a responsibility from both sides of this philosophical argument- to ensure as researchers that (a) we make decisions, based on knowledge and reflexivity, to enhance methodological congruence, (b) we are transparent in our work,

providing enough detail to allow novice and experienced researchers a clear understanding of the researcher's assumptions, theoretical or conceptual stance, and research design, and (c) we report the steps taken, and provide rationale to guide the reader through our decision making process (the audit trail).

I also value providing and reading strategies other researchers use to enhance rigour in their study and recognize that different strategies may be best suited or appropriate for some methodologies and not others. Readers of qualitative research have a responsibility to be aware of the similarities and differences in the spectrum of research paradigms (qualitative and quantitative spectrum), to have a basic understanding of what to look for when reading a qualitative research report to help them ascertain if the study was conducted in a way that allows them to feel confident about the findings, and to be able to determine for themselves if the information is trustworthy, valuable and potentially transferable to their area of work or study (this would be the same for those reading quantitative studies). I used several strategies in my effort to enhance the rigour of my study. Each is listed in the table below with a brief explanation of how it was implemented in the study and strategies are discussed throughout the manuscripts (see Table 1).

Table 1

Strategies Used to Promote Rigour

Strategy	How the Strategy was Implemented in this Study
Methodological congruence	Ensuring the research question guided the method, which matched with sampling, data gathering strategies and analysis.
Prolonged engagement	Spending sufficient time to develop trust and understanding in the environment and with participants to feel confident in the co-construction of the data.
Member checking	In this study- member checking took place throughout the interview; asking for corroboration, confirmation of my understanding of children's responses.
Audit trail	Recording of the steps and decisions made throughout the research design, implementation and analysis were documented and maintained.
Reflexivity	Reflecting and writing prior to, during and after analysis to (a) promote processing of each step, (b) document decisions along the way, (c) explore participant/researcher interactions, (d) document responses of the participants and researcher to the research demands, (e) articulate the perceived challenges and successes, (g) allow for reflection on researcher bias, duality of research/health professional roles, (h) assess risks of preconceived assumptions, manipulation of the participants, and (i) reflect on sampling and data gathering e.g. interview questions/photos chosen. The journal is one component of the audit trail.
Expert Checking	A content expert, not involved in the research study, reviewed preliminary code definitions for content validity and then reviewed the first two transcripts for consistency in coding practice.
Acknowledging/reporting researcher assumptions	Developing a conceptual framework prior to the study including researcher assumptions; articulating the assumptions, reflexive responses and impact of assumptions in the study report(s).
Verbatim transcriptions	Transcribing each interview verbatim. Punctuation and context notes were inserted by the researcher to provide contextual cues during textual analysis.
Cross checking audio and transcribed interviews	Reviewing each transcript while listening to the audio version of the interview, and correcting transcripts prior to textual analysis. Imported corrected version into the software for analysis.
Triangulation	Data gathering from various sources e.g. interview and drawing(s), interview and guided tour which helped to enhance or deepen understanding of the participant's perspective.
Reporting negative cases	Reviewing a case or cases that do not follow the emerging pattern, to compare and analyse the pattern in greater depth.
Thick description	Providing a detailed description of the context, the participants and the methodological processes used during the study allows readers to be able to ascertain if there is transferability to other people and contexts.
Data saturation	Recruiting until analysis demonstrated no new relevant information, hence no new codes developed.

Note. These are a compilation of various strategies I used and do not represent all strategies noted in the literature (Barusch et al., 2011; Creswell, 2013; Morse et al., 2002; Whittemore et al., 2001).

How Does Each Manuscript Relate to the Study?

This manuscript style thesis includes two manuscripts which I am planning to submit for publication. There will inevitably be overlap of information/sections due to the nature and requirements for an academic manuscript thesis, and the need for each manuscript to be understood independently from the thesis in order to meet publication requirements. It is my hope that I will have achieved a balance and that the reader will understand the need for overlap.

The first manuscript "The Use of Three Arts-Based Data Gathering Activities to Elicit Perceptions of Hospitalized Children with Chronic Illnesses Regarding 'Play in Hospital'" provides an overview of the evidence for three arts-based data gathering activities used in this study, how each was implemented, as well as the strengths, challenges and/or unexpected outcomes of their use during the study. Special considerations when doing research with children, and hospitalized children with chronic illnesses, as well as recommendations for future research are highlighted.

The second manuscript titled, "Perceptions of Hospitalized Children with Chronic Illnesses Regarding 'Play in Hospital': A Qualitative Descriptive Study" describes the actual study, including the background literature, design and methodology of the study, the findings, a discussion about the findings, and future directions in clinical practice and in research with children.

Manuscript 1: The Use of Three Arts-Based Data Gathering Activities to Elicit Perceptions of Children with Chronic Illnesses Regarding "Play in Hospital"

Abstract

There is increasing emphasis on the need to seek young people's perceptions about things which affect them. Researchers have gone from doing research "on" children to research "with" children. In this paper, I will describe three arts-based data gathering activities used with hospitalized school-age children with chronic illnesses to elicit perceptions of "play in hospital". The three arts-based activities were chosen after a critical review of the literature and were selected based on evidence, the "fit" with the research purpose, the developmental level of the participants, and feasibility for use in the health care environment. This paper will provide an overview of the evidence for each arts-based data gathering activity, how each was used in the study, the strengths, challenges and/or unexpected outcomes of their use in practice. Special considerations when doing research with children, and hospitalized children with chronic illnesses, as well as recommendations for future research will be highlighted.

Introduction

It is widely accepted, within pediatric health care, that hospitalization can influence the emotional, social, cognitive, and physical development of infants, children and youth. This comes after decades of research and observational reports on the effect of hospitalization on young children and those with chronic conditions (America Association of Pediatrics [AAP], Committee on Hospital Care & Child Life Council, 2014; Kronenberger, Carter, & Thomas, 1997; Pond Wojtasik & White, 2009; Rollins, Bolig & Mahan, 2005; Small & Melnyk, 2006; Thompson, 1985; Visintainer & Wolfer, 1975). While advances in pediatric health care are positive, the experience of hospitalization continues to be stressful and potentially traumatic for many children. Health care experiences continue to cause fear and anxiety for patients and families during health care encounters and after discharge (Chappuis et al., 2011; Lindeke, Fulkerson, Chesney, Johnson, & Savik, 2009; Melnyk, 2000; Salmela, Salanterä, & Aronen, 2009; Stevens et al., 2011; Wilson, Megel, Erenbach & Carlson, 2010). This is particularly true for children with chronic illnesses (Clark, 2003; Goodman, 2001). Repeatedly, play, recreational activities and being in the playroom were reported as the "best thing" about being in hospital (Chappuis et al., 2011; Horstman & Bradding, 2002; Lindeke et al., 2006; Wilson et al., 2010). Children value play in the hospital environment, yet we have limited knowledge about play in hospital as described by children.

The provision of play materials, dedicated play spaces and the integration of roles specializing in pediatric psychosocial and developmental care, including play, has

evolved over the last half century (Pond Wojtasik & White, 2009; Thompson, 1989). One such role is that of the child life specialist who works to prevent or at the very least, minimize the developmental and/or psychological impact of health care experiences on infants, children, youth and their families. Although early observational research of play in hospital provided the foundation for the work of child life specialists, there is limited new research on play in healthcare settings and specifically children's perceptions and descriptions of play in hospital.

In order to study children's perceptions of play in hospital, it was first essential to determine the best data gatherings strategies to elicit children's perceptions. Multiple databases including CINAHL, ERIC, Medline, PsychArticles, Chochrane Database, EPPI as well as Proquest Dissertation and Thesis, and the Digital Thesis and Project Room of the Athabasca University online library were searched. Many different search term combinations were attempted, and additional support from a professional librarian was sought. The search terms consistently used included: *children* AND *research methods*, NOT *consent*, NOT *recruitment*, NOT *ethics*. From these databases, 725 titles were reviewed, resulting in 11 articles going to full review. Hand-searching and "snowballing" strategies, whereby reference related articles or lists of relevant papers were reviewed for additional papers. A total of 35 articles were reviewed. Of these, 18 met predetermined criteria for the review. The remaining articles did not meet inclusion criteria; 9 lacked focus on young people's perceptions and 8 lacked methodological and/or reporting strength.

After completing a critical review of the literature focusing on the research question "What tools, methods, and/or strategies work best in research to obtain children's perceptions?" It was clear there were many different strategies being used with children, typically labeled as participatory research and/or arts-based activities/techniques. Since neither researchers, nor participants identified a single nor cluster of data gathering strategies that were "best" for eliciting children's perceptions in research, this author chose three arts-based activities based on evidence, the "fit" with the research purpose, the developmental level of the participants, and feasibility for use in the health care environment.

In this paper, I will describe the three arts-based data gathering activities used, in conjunction with a semi-structured interview, in a qualitative descriptive study to elicit perceptions of play in hospital from hospitalized school-age children with chronic illnesses. The next section will provide a review of the literature and an overview of the research study, to offer context for the focus of the paper. A discussion of strengths, challenges and/or unexpected outcomes of each data gathering activity, special considerations when doing research with children, and future considerations for the use of arts-based activities with hospitalized children with chronic illnesses will be highlighted.

Review of the Literature

Over the last two decades, there was a dramatic shift within social research from doing research "on" children to research "with" children. According to the literature, many researchers credited the United Nations' Convention on the Rights of the Child

(UN, 1989) as well as significant political and policy changes that focused on social and health program reform within the United Kingdom and Australia (Coad, Plumridge & Metcalf, 2009; Morgan, Gibbs, Maxwell & Britten, 2002; Whiting, 2009). There was a call to action to include young people in decisions and the evaluation of programs that affected them. This led to an expectation that policy makers and researchers consult and involve young people[2] in program change and evaluation (Clark, 2005; Coad et al., 2009; Fargas-Malet, McSherry, Larkin & Robinson, 2010; Morgan et al, 2002; Whiting, 2009).

This shift in research focus propelled social scientists to think creatively and ponder how children and youth perceived their world. It was recognized that just because an adult was once a child did not mean that the adult could provide a child's perspective in the current social and world context (Chappuis et al.. 2011; Darbyshire et al. 2005; Driessnack & Furukawa, 2012; Lindeke, Fulkerson, Chesney, Johnson, & Savik, 2009; Punch, 2002). Although some researchers adapted adult methods of data gathering in their research with young people, others noted the varying developmental needs of young people and questioned the validity of such strategies (Driessnack & Furukawa, 2012).

Researchers in early childhood education, psychology, social sciences and art therapy emphasized the need for reflexive, multiple arts/visual-based data gathering activities with young people, with consideration for developmental level and personal interest. It was believed child-centred strategies would ensure quality data gathering, child engagement and enjoyment (Clark, 2005; Coad, 2007; Punch, 2002; Whiting, 2009). Many different data gathering strategies were described in the field of research

[2] Young people will be used to mean children and youth

with young people. Since the 1990's, the terms "participatory research" and "arts-based activities" were used in the literature to describe research with young people. These terms were used together and separately. I will describe these terms to help provide clarification for the reader and context for the paper.

Participatory Research with Children

According to O'Kane (2000), participatory approaches/techniques stem from participatory rural action (PRA) in the area of rural development work. This form of research emphasizes the ongoing nature of the relationship in seeking information, dialogue, reflection and action as an ongoing process. Participatory research with children stemmed from the shift of seeing children as objects to be studied, to "active participants" (O'Kane, 2008) or *social actors* who have rights and who are experts in their own world (Fargas-Malet et al., 2010; Punch, 2002) and could provide valuable information about their experiences/perceptions of the world and those around them.

The term "participatory research", pertaining to research with young people, has different meanings in the literature, depending on the author's perspective. Some researchers advocated for young people to be included in as many aspects of the research process as possible, including the development of the research question, choosing/developing the data gathering strategies (art/activities), and even participating in data analysis and dissemination (Coad, 2007; Coad et al., 2009; Darbyshire et al. 2012; Punch, 2002; Whiting, 2009). Other researchers focused solely on the use of arts-based activities as part of the research data gathering process. In this study, school-age children were consulted about the arts-based activities being considered during the development

of the research design and hospitalized school-age children with chronic illnesses actively partook in the arts-based data gathering activities.

Some researchers used the terms participatory research, arts-based techniques or arts-based activities separately or interchangeably (Carter & Ford, 2013; Coade et al., 2009; O'Kane, 2008). Some researchers speak of these as "approaches" or methodologies in their own right while others describe them as data collection or data gathering activities. I postulated that the arts-based activities utilized in the study and described herein were data gathering activities. The actual study methodology was qualitative description. The arts-based activities were chosen for gathering data with the children in the study. The following section will provide an overview of the term "arts-based activities" based on a review of the literature.

Arts-Based Activities

Arts-based activities were utilized as early as 1920 (Coad, 2007), however the emphasis on using art or activities with young people during research data gathering emerged in the 1990's. The term arts-based strategies, activities or techniques was typically applied when describing the actual activities used with children to facilitate communication, self-expression, and to share thoughts and emotions related to the topic being researched. There were many data gathering activities being used with young people including: (a) individual interviews, (b) photography, (c) drawing, (d) focus groups, (e) questionnaires, (f) video, (g) graffiti wall, (h) mapping, (i) observation, (j) diaries/journal, (k) role play, (l) jumping and talking, (m) puppetry, (n) puzzles, (o) tours, (p) stimulus prompts such as sentence/phrase/story/wish completion, (q) charts/diagrams

and (r) ranking exercises (Coad, 2007; Driessnack & Furukawa, 2012; Fargas-Malet et al., 2010; LeBlanc, 2013). Many of these activities were used together, in combination with interviews, to build rapport or as a menu from which young people could choose, particularly the art/visual methods (Coad, 2007; Fargas-Malet et al., 2010).

Researchers reported children had varied interests, skills and abilities, hence benefitted from different data gathering activities. Researchers in early childhood education, psychology, social sciences and art therapy emphasized the need for reflexive, multiple arts/visual-based activities for data gathering with children that considered developmental level and personal interest. This was expected to improve quality in data gathering, child engagement and enjoyment (Clark, 2005; Coad, 2007; Punch, 2002; Whiting, 2009).

Lindeke and colleagues (2009) demonstrated that children's perceptions of healthcare, although significantly correlated with their parents, were unique. One should not expect that a 4 year old would have the same perceptions as a 12 year old or an 18 year old. The use of arts-based activities allowed young people to express their views (Clark, 2005; Coad, 2007; Coad, et al., 2009; Darbyshire et al., 2005; Fargas-Malet et al., 2010; Hill, 2006; McTavish, Streelasky & Coles, 2012; Morgan et al., 2002; Patterson & Hayne, 2011; Punch, 2002; Salmela et al., 2009; Whiting, 2009), even for children as young as 4 years of age (Clark, 2005; Coad, 2007; Darbyshire et al., 2005; Lindeke et al. 2009; Whiting, 2009).

Multiple arts-based activities often elicited different information, thereby providing depth to the data gathered. Using multiple arts-based activities reportedly

enhanced and even increased the amount of data collected without compromising accuracy of the information (Carter & Ford, 2013; Driessnack, 2005; Driessnack & Furukawa, 2012). Researchers emphasized the need to plan such activities in detail with a focus on developmental skills, facilitator/researcher skills, the research question and the need to ensure the best data gathering activities were selected in order to obtain the best data, without compromising the rights of children and being tokenistic (Coad, 2007; Coad Shaw, 2008; Hill, 2006; O'Kane, 2008). Below is a brief overview of the study to help provide context for the use of the arts-based activities for data gathering.

Study Method

This article draws from the experience of conducting a qualitative study titled "Children with Chronic Illnesses' Perceptions of "Play in Hospital": A Qualitative Descriptive Study". It is widely accepted that hospitalization can influence the emotional, social, cognitive, and physical development of infants, children and youth. This is particularly true for children with chronic illnesses. Children report many negatives aspects of hospitalization, yet identify play and recreation as the best parts. Descriptions of play outside of hospital illustrate commonalities. However, children's perceptions or description of play in hospital have yet to be reported.

As a child life specialist and graduate student, I was interested in learning from children with chronic illnesses about their perceptions of play in hospital, in a way that would provide rich data, be fun for the children and minimize the sense of power imbalance between myself, as researcher, and the child. Given that school-age children (those aged 6-11 years) are deemed to be in a similar play/developmental level, are

capable of sharing their thoughts more easily with others about the world around them, and that other studies have been successful in seeking children's perceptions of their health care experiences (Bradding & Hortsman, 1999; Gibson, Aldiss, Horstman, Kumpunen, & Richardson, 2010; Samela et al., 2009), it was felt this age group would be well suited to elicit perceptions of play in hospital. Additionally, hospitalized school-age children with chronic illnesses can be expected to have knowledge and expertise about play in hospital because they are more likely to experience multiple and/or lengthy hospitalizations, hence I saw them as the experts about play in hospital.

The study used a qualitative description (QD) methodology, useful when a researcher wants to answer questions relevant to practitioners, from individuals involved in the phenomenon, without the goal of transforming/interpreting the information or developing a theory about the phenomenon or the processes within it (Sandelowski, 2010). This fit well with the intent of my study and my worldview that children have the right and the ability to share their perceptions and experiences. In order for them to be able to actively participate, we must provide the opportunity, the data gathering activities that best meet their developmental and individual needs, and do this in a way that respects children's terminology/everyday language.

The flexible nature of data gathering within QD allowed for the use of arts-based activities. Three school-age children (7, 10 and 11 years of age) were consulted in the planning of the data gathering activities in an effort to explore the feasibility of photo elicitation interviewing and drawing maps of play in hospital. Changes were made based on feedback. Child-led guided tours was suggested by the first child consultant, as an

active way to share perceptions of play in hospital, especially for children who preferred to move around and were less inclined to draw or talk a lot about something (e.g. photos). The other two child consultants independently agreed this third activity would be a good option for children their age (male 7 years old, female 10 years old).

The study was reviewed and approved by the health centre and university Research Ethic's Boards. Recruitment took place in a tertiary women and children's health centre. Parental consent was obtained for each child's participation in the study, and separately for the use of quotes and/drawings/play maps created by participants. Ten hospitalized, school-age children with chronic illnesses provided assent to participate in the study and be interviewed, and separately for the use of quotes and/or drawing/play maps for educational and publication purposes. Privacy was maintained by ensuring the use of pseudo names (which they chose for themselves) and names were placed on the back of the drawings or removed before data were imported into NVivo10 software and analysed. Semi-structured interview questions helped guide the discussions during the data gathering process. The interviews were audio-taped and transcribed verbatim. The children were offered the choice of three arts-based activities: (a) viewing photos, created by the researcher, of hospital locations where play may occur (photo-elicitation interview), (b) drawing/play mapping, and/or (c) doing a child-led guided tour. The participants were also informed of the option to "just talk" about their perceptions of play in hospital, and one of the ten participants chose this option.

Braun and Clarke's (2006) process of thematic analysis was completed and four themes were identified: play is important in hospital, play is "fun", chronic illness

influences play, and children with chronic illnesses are resilient and insightful. A detailed report of the study and its results are reported elsewhere (see Chapter 3). The next section will review the evidence for each of the data-gathering activities, as well as the strengths, challenges/unexpected outcomes of using each data gathering activity during the study.

Interviewing Children

In the review of the literature, interviewing techniques, adapted from adult research, were most often used with adolescents (Clark, 2005). Researchers sought the perceptions of younger children through focus groups and individual interviews with careful consideration of developmental needs (Chappuis et al., 2011; Darbyshire et al., 2005; Patterson & Hayne, 2011; Salmela et al., 2009). Interviewing occurred in various formats: (a) individual structured or unstructured interviews, (b) child-to-child interviews, (c) child-conferencing, described as an informal structured interview, (d) group interviews, described as group discussions with a research purpose (Clark, 2005), or (e) focus groups, where the goal was to discuss experiences, perceptions and understanding of a topic with a group of peers in a non-threatening environment (Darbyshire et al., 2005; Krueger as cited in Gibson, 2007; Morgan et al., 2002). There were contradicting reports about young people's preference for group versus individual interviews, however many young people reported group/focus group interviews as a positive experience. The literature and clinical wisdom suggests this is likely dependant on the topic of discussion, the participant group and if there are perceived risks of being ostracized because of one's comments (Hill, 2006; Morgan et al., 2002; Punch, 2002).

Many researchers incorporated arts-based, task-based activities or visual prompts during the interview format, to increase comfort level, engagement and ongoing participation (Gibson, 2007; Hill, 2006; Punch, 2002; Salmela et al. 2009). Driessnack's (2005) meta-analysis supported and encouraged practitioners to include drawing during interviews or discussions with young people because drawing increased the information acquired by up to 50%. The results of the meta-analysis strongly indicated drawing facilitated communication; increased data collected and did not compromise the accuracy of the data (Driessnack, 2005). One other study compared young people's preference and the data collected via individual interviews and focus groups. Punch (2002) found young people varied in their preferences and that one type of interview format was not deemed better than the other. Hill (2006) explored children's perceptions of taking part in research. He reported that children and youth recognized each person as unique, that their peers may enjoy different activities for data gathering than they enjoy and that certain strategies worked best with certain populations or in certain contexts.

The children in this study were school-age and were managing a chronic disease. Health conditions, treatment regimens and environmental issues were important factors to consider. Additionally, given the evidence regarding the benefit of offering multiple arts-based activities for gathering data with children, I planned to do individual interview sessions with or without one or more of the three arts-based activities, of the child's choice.

Strengths of Using Interviewing

The use of semi-structured interview questions allowed me to ask questions and explore children's perceptions of play in hospital, play preferences and the people they found important for playing in hospital. Having several open-ended questions and follow-up questions allowed me to gain a greater depth of information than the drawings alone. The reverse would likely also be true. I would not expect to learn as much from the children if I was simply viewing the photographs and asking them to speak to each one, without some focused questions, nor would I have learned as much during the child-led tours. The combination of questions, along with the arts-based activity enhanced the data gathered.

Challenges and/or Unexpected Outcomes of Using Interviewing

Interviewing children is not as easy as one might think, even for a health care professional with nearly 25 years of experience in psychosocial care with children in health care settings. Being mindful of asking open-ended questions that were not too complex, abstract or difficult to answer was challenging. There were times when the child's brief answers led me to start asking more direct questions, or I paraphrased the responses to seek confirmation of my understanding. This could be perceived as placing words in the mouth of the child or as member checking (ensuring the researcher has understood the participants meaning and intent during an interview). I was purposeful in checking with children throughout the interviews (member checking) to ensure I was understanding what they were explaining to me. However, in a couple of instances, upon review of transcripts, I question whether I should have asked more clarifying questions before seeking confirmation of my interpretation.

Not surprising, but a challenge none the less, were those children who take longer to warm-up to new people and/or those who are not really talkers but who answer questions briefly, and take the concrete or literal meaning of each question. I rephrased the content of questions in different ways or sought clarification. Sometimes, I made statements about what other children in the study shared with me and then asked their perspective, exploring if the child felt similarly or differently. If a question was not answered initially or was misunderstood, it was important to be flexible and go back later, if the thread of the conversation lent itself to exploring the original content area again. It was also important to avoid interrupting a story the child wanted to share, to show respect for the child and to listen how it may pertain to the research question. Of course, when a child's conversation was no longer on topic and s/he was no longer interested in the study topic or willing to be redirected, I acknowledged the desire to be all done talking about play in the hospital. I asked if they had any others things they wanted to share about play in hospital, thanked the child for their help and the data gathering process was ended.

Sometimes the closure of the session took a little longer than anticipated because several of the younger children wanted to continue to play. They perceived they had helped me and now expected or assumed I would stay and play. Two of the children asked if I would return to play with them another time, because they understood I worked as a child life specialist on a different unit. In these situations I re-explained that I worked in another part of the hospital; my visiting them was because I was going to school and s/he was helping me with a big research project; there were staff and volunteers available

for playing on their unit, and eased the transition back to parents, other staff, or a volunteer. I reinforced how much I appreciated being able to spend time and learn from them. In both cases, the children seemed to understand and I left feeling comfortable that the session was successfully closed.

Drawing/Play Map

In a meta-analysis comparing interviewing alone with interviewing and drawing, it was reported that drawing facilitated communication; increased data by up to 50% and did not compromise the accuracy of the data (Driessnack, 2005). Many researchers reported children enjoyed drawing. Conversely, there were some reports school-age children felt self-conscious about their drawing skills while led them to hesitate or decline to draw (Coad, 2007; Fargas-Malet et al., 2010; Patterson & Hayne, 2011). For those who enjoyed drawing, it reportedly allowed young people an avenue to establish rapport, relax in a new situation, and feel more in control of sharing their information. Drawing was reported to act as a prompt or to trigger memories, organize thoughts/ideas and was helpful in encouraging discussion (Patterson & Hayne, 2011; Driessnack, 2005; Fargas-Malet et al., 2010). Having child participants draw and then tell researchers about the drawing was reported to be more contextually accurate and preferred over researcher interpretations of the drawing (Clark, 2005; Coad, 2007; Driessnack, 2005; Driessnack & Furukawa, 2012; Fargas-Malet et al., 2010; Patterson & Hayne, 2011).

Drawing a map, or "mapping" was used in several studies with school-age children where children drew and discussed the maps they created illustrating favourite play environments in the child's community (Darbyshire et al., 2005; Morrow, 2001;

Veitch, Salmon, & Ball, 2008). Recently, Vilas (2013) presented the use of "play maps" as an expressive intervention whereby children and adults share play memories by drawing a map of their favourite play places/experiences. In a follow-up article, she described play maps as "...an expressive art activity designed to connect children and adults with pleasurable memories of play" (Vilas, 2014, p. 6). It is a new and innovative approach that is gaining attention as an expressive activity in the child life profession.

I used the term "play map" to describe the combination of the "draw and tell" and "mapping" techniques described in the literature and anticipated it would allow children to express pleasurable memories of play in hospital. In my study, children were asked to draw a map of play in the hospital, using a choice of drawing materials. It was expected drawing a play map would allow the child to draw multiple locations of play in hospital on one page, while the researcher listened to the description of the drawing and solicited additional information using the interview guide. A sample play map was shown (see Appendix B) to demonstrate the concept and illustrate the simplicity of the drawing. If the child chose to draw a play map, s/he was offered a choice of drawing materials (pencil, coloured pencils, and markers) and was encouraged to describe the drawing(s).

Strengths of Using Drawing/Play Map

Fifty percent of the children chose to draw as a way to help me learn about play in hospital. For those who chose to draw, it was clear they typically enjoyed drawing as an activity. As noted in the literature, most of the children who gravitated to drawing, became quickly engaged in the activity and focused on their drawing while talking with this researcher.

Ten year old Isabella[3] who loved to draw, created 6 separate drawings after our initial introduction and discussion about the study, in advance of our session the following morning. She had not seen the sample play map since I anticipated having this conversation the morning of the interview. She drew separate drawings on six pages and stapled them together like a book. The drawings illustrated play in different places at the hospital. The first four drawings were of the outdoor Playgarden (an outdoor enclosed play space and garden for families, staff and volunteers and is open dawn to dusk; scheduled play programming and special events occur during the summer season), two drawings were of the inpatient playroom and one of her hospital room. She was animated in her descriptions of the places, activities and people who were important for play at the hospital. The drawings seemed to organize her thoughts and allowed her to describe the many different activities she enjoyed during her admissions to hospital over the years. Her drawings provided an opportunity to draw cumulative experiences; they portrayed not only detailed spaces and play structures but also showed active play and social play in some of the drawings.

Amelia (10 year old) was rather quiet during the session and many of her responses were short; sometimes shrugging, using single word responses or not answering questions. When asked if she wanted to have me stay quiet while she concentrated and drew, she shrugged her shoulders and her non-verbal facial expression gave the impression it did not matter. Her mom had informed me prior to the session that

[3] All participant names are pseudo names created by the children

Amelia was typically quiet and would hopefully speak more without mom being present. This leads me to believe this was her typical nature with new people.

Interestingly, Amelia made an accurate detailed play map (see Appendix C), on one page as shown in the example. Her drawing showed the spaces where she enjoyed playing, including: (a) her room, (b) the playroom on the inpatient unit, as well as (c) the teen lounge where she went on the weekends for "tween" time or one-on-one time with the child life specialist (when her immune system was compromised due to her medical treatments). She smiled timidly when talking of these places and made several insightful comments related to the difference between the same activity as "play" compared to it being "not play" when done as an activity at school. When asked her perception of what it would be like if there were no places to play or no activities/toys at the hospital, she emphatically and immediately stated "It would suck!" Of course, it is unknown if she would have been this animated if the drawing and discussion were separated in time or if we had simply been talking. However, I believe drawing allowed her to communicate her perceptions and facilitated verbal descriptions of play in hospital which may otherwise have been a very limited.

Challenges or Unexpected Outcomes of Using Drawing/Play Map

One of the first participants, seven year old Rainbow Dash, asked if she could "just draw", to which of course I responded "Absolutely". She drew a detailed image of herself on her bed. During our discussion, she had indicated her bedroom was her favourite place in the hospital to play. She reported she liked her bed because she could play all the things she enjoyed, could play in her bed even if she was not feeling well,

was tired, or when she was isolated because of her medical condition. Her comments about the room and bed being one of the favourite places to play was later repeated by many of the children.

There were several unexpected interpretations of the term play map. Interestingly, two of the boys, Timemine (7 year old) and Sylvester (6 year old) created multi-page maps representing each of the floors of the hospital where there was something of importance to them, from a play perspective, or to help guide the researcher on a journey to play in hospital. They conceptualized the term play map in a very concrete way, even though they had seen the sample play map. Although understandable given their developmental stage, this was not anticipated.

Timemine drew each of the areas in the hospital where he engaged with something like the fish tank, viewed toys in the gift shop, watched and pushed buttons at the large scale model train, as well as creating a visual map from his room to the playroom (which he insisted be accurate). Once he finished his map, he then had an idea to create a game using the map to get to the playroom. He developed an elaborate game with clues, secret doors and rugs, and secret codes so the player needed to get the key to get to the playroom. This creative boy spent more than an hour drawing!

Sylvester also used the concept of the play map differently than anticipated. He decided he wanted to draw a map to the child life office where he often had his favourite person for playing in hospital, the therapeutic clown, be paged. He drew a detailed and accurate map from his room to the elevator bank, the arrow for the directions to go to the lower floor. He even wrote the word “Finish!” at the office, meaning the finish line to

where he would have the therapeutic clown paged and where they would often play together.

As noted previously, Isabella drew individual pictures of the activities and places where she played rather than the single page play map concept. Her drawings may well have been influenced by the fact that she was in the Playgarden at an outside BBQ for families when I met her mother to organize a time for the interview the following morning. Isabella joined the conversation and was visibly interested and eager to participate in the study. I had mentioned there was a choice of activities, looking at photographs, drawing a play map (map of play at the hospital) or the option to be my tour guide. This was a brief conversation. It is not known if her drawing(s) would have been similar or different if I had reviewed and shown the example of the play map concept or if in fact she would have still preferred to make her drawings in this style.

Isabella drew several people in her drawings while Timemine drew a person in the gift shop, where you could buy toys, and in his map to the playroom which was converted into a game. Drawing people is a task that is often more difficult (a skill that is often taught later in middle school art classes) than drawing items. School-age children are often conscious of wanting to make things look accurate and "right" and the level of accuracy and detail in the drawings demonstrated this fact and may in fact have hampered them from drawing people. The children seemed to focus on details relevant to them and the information they were sharing related to play. Most of the children wanted to have a copy of their drawings, hence a photocopy was made and provided to them.

Photo Elicitation Interviewing

A review of the literature found support that photography could be a potential data gathering activity with children; photo elicitation/photo elicitation interviews were reported to be increasingly utilized with child participants (Carter & Ford, 2013; Coad, 2007; Fargas-Malet et al., 2010; Darbyshire et al., 2005; Driessnack, 2005; Epstein et al., 2006; Mandleco, 2013; Mathers et al., 2010; O'Kane, 2008). Terms describing the use of photographs in qualitative research included "photo elicitation" or "photo elicitation interviews" meaning a process whereby photographs were used as a trigger or stimulus for an interview and "photovoice" (Carter & Ford, 2012; Coad, 2007; Epstein et al., 2006). The terms "reflexive photography" or "auto-driven photo elicitation" specified that the participant took the photographs (Epstein, et al., 2006; Samuel as cited in Mandleco, 2013).The term "photovoice" was defined differently based on the researcher, however it was often described as a technique whereby participants were asked to share ideas/thoughts regarding a photograph provided by the researcher and was"…strongly linked to community-based, participatory research and community change" (Carter & Ford, 2012, p. 100).

For the purpose of this study, photo elicitation interview (PEI) was the term used to signify the use of photographs taken by me and used as visual triggers to elicit children's perceptions and descriptions of play in hospital (Epstein, Stevens, McKeever, & Baruchel, 2006). The photographs of spaces where play may occur (playroom, patient room, clinic exam room, and Playgarden- the outdoor play space), including structures and sometimes play materials were taken by the researcher in advance of the study (see Appendix D).

This approach was intended to decrease the power differential between myself, as researcher, and the child by allowing the child to focus on the photographs instead of needing to make regular eye contact and feeling pressured to talk and answer questions (Driessnack & Farukawa, 2012; Epstein et al., 2006). I believed it would be good option for children who did not enjoy drawing. As with all three activities, semi-structured interview questions guided the conversation.

Strengths of Using Photo Elicitation Interviewing

As noted in the literature, the children who chose to view the photographs and talk about play in hospital showed recognition of the spaces and activities, accessing personal memories to share their stories and to respond to the semi-structured interview questions. Some of the children pointed to areas or toys/activities illustrated in the photo to describe some of their preferred activities. Two girls, a 10 and 11 year old, shared empathic stories about other children they interacted with or whom they observed in the playroom; talked of the other children's play behaviours and need for social play; how they liked to play with younger children to help them feel happy; how they enjoyed playing with toys meant for younger children because they didn't get to play with these types of toys at home or school anymore.

Not all the preferred activities/toys described by the children were visible in the photographs, meaning the photos provided a prompt or trigger for such memories. The children who chose this activity spent time viewing the photos, responding to questions, and seemed relaxed and comfortable with this activity. They became more talkative as

the discussion progressed, perhaps because of the ability to divert their attention to the photos, however this is unclear.

An additional benefit of having the photographs and showing them during the explanation of the study and the arts-based activity choices was that I could refer to the photographs at a later point with children who had not chosen the photo elicitation activity as illustrated here:

I[4] So you remember how I showed you the pictures that I have?

P[5] Oh, yeah.

I Yeah. Do you think…I had a picture of the clinic. Are there ever any times where you play at the clinic?

This conversation helped prompt the child to think of that specific area and be able to share their play experience in that space. Jimmy Bob See Joe (11 year old) articulated that using the photographs helped facilitate the interview:

P Yeah, not really knowing like what I am going to be asked and things like, I was like, how am I going to explain play?

I Um, yeah… that makes, and…

P But once it happened it was easy.

I It was easy?

P Yeah.

I Yeah. Good, I'm glad.

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[4] I = Interviewer

[5] P = Participant

P And I like how you showed the pictures cause that made it a lot easier.

I So you knew what to kind of…

P Talk about.

Challenges and/or Unexpected Outcomes of Using Photo Elicited Interviewing

There were no obvious challenges using the photographs taken by the author in this study. In fact, the children who chose this option engaged quickly in conversation by using the photographs to direct their attention and their thoughts. Given the potential challenges of auto-driven photo elicitation interviews in a health care setting, this was the right decision for this study (see Discussion).

Child-Led Guided Tours

This activity was described as a data gathering strategy used in research about children's "special places" (Green, 2012) and in pre-school settings (Clark & Moss, in Clark, 2005). This activity allowed children to be physically active, be in control of the tour (where to go, what to discuss) and end the discussion when they were done sharing their thoughts/experiences. Green (2012) noted that this activity allowed children to share information about places that otherwise could not be well understood out of context.

In this study, one child led me on a walking tour (sometimes a very brisk walking tour) of many different areas on his inpatient unit where he and his family and/or friends played, while discussing the play materials, toys and activities enjoyed.

Strengths of Using Child-Led Guided Tours

Only one 7 year old boy, Stormtrooper, chose to do a guided tour. As noted in the literature and as suggested by one of the child consultants in planning the arts-based activities, this activity is perfect for the active child who does not enjoy lengthy conversations nor is art oriented. Initially in his room, he was easily distracted from answering questions by noises and people, and was fidgety. I needed to be more creative and use humour to engage him. As soon as he was able to leave the room to show me other areas, he was happier, more talkative and more easily focused on the topic. Stormtrooper was able to move around the unit and showed me areas where he enjoyed playing; his "secret" hiding places in very obscure places ("…behind the big brown bin…") and small places on the inpatient unit such as the cabinet in the family room where he played hide-and-seek with his sister and friend, and the different play areas in the playroom. He was animated and energetic as he showed each of the spaces. This activity kept him engaged and able to provide more information and details than an interview alone.

Challenges and/or Unexpected Outcomes of Using Child-Led Guided Tours

Although I had originally planned to do the child-led guided tours during early evenings or the weekend, when there were fewer people/staff who might observe or interrupt, or whose voices might be audio-recorded during the activity, this proved to be unrealistic. As a researcher, I needed to make myself available when the family and child was available and feeling well. In this case, I had missed interviewing Stormtrooper in a previous admission due to fatigue and illness. During this admission, parents identified a good time, which was late morning, often an active time on an inpatient unit.

This was a small unit, with many patients who were isolated at the time of the study, and so fortunately there were not a lot of other children or parents in the hallways who could have been inadvertently audio-taped. Stormtrooper and his parents were comfortable with others knowing he was involved in the study. I informed nursing staff and/or physicians we were recording as we walked about when he interacted with them. I stopped the recorder when these interactions were more than casual hellos and restarted when we moved on to the next area of the tour.

The tour was contained on the inpatient unit. Presumably, since Stormtrooper had not had a real opportunity to play outside in the hospital's Playgarden, he did not entertain bringing me outside. Depending on the number of people, his energy level, and speed of running and likely talking at the same time, going to the outside play area might have posed challenges for audio recording, and privacy for other patients. As it was, it was a challenge for the transcriptionist to hear his voice when he was ahead of me during the tour on the inpatient unit.

Special Considerations when Using Arts-Based Activities with Hospitalized Children with Chronic Illnesses

There are many important aspects to consider when doing research with hospitalized children who have chronic illnesses. The following special considerations when eliciting young people's perceptions will be discussed in further detail: (a) resources and researcher skills, (b) importance of environment, (c) developmental considerations, and (d) ethical considerations.

Resources and Researcher Skills

Researchers reported that extended time was needed to plan, prepare and implement studies to obtain young people's perceptions (Clark, 2005; Coad, 2007; Mathers et al., 2010; Morgan et al., 2002; Whiting, 2009) and specific skills were needed for researchers working with young people (Coad, 2007; Darbyshire et al., 2005; Gibson, 2007; Morgan et al., 2002; Punch, 2002; Whiting, 2009). As noted by others (Coad, 2007; Coad et al., 2009; Mathers et al., 2010; Morgan et al., 2002; Whiting, 2009), not only was it time consuming to determine the best data gathering methods, but finding the proper timing between medical care and recovery required additional time for recruitment, and interviewing was often resource intensive. Additionally, the proper space and environment needed to be well thought-out and was not always readily available.

Realistic expectations and an understanding of the best fit between developmental capacity, the research question and the methodology to be used were important (Clark, 2005; Whiting, 2009). Being comfortable with children, having good interview skills, being able to quickly build rapport, maintaining focus on the topic, and ensuring participants felt comfortable and valued was critical. Moreover, I needed skills in seeking clarification to ensure an accurate understanding of participant's views (which was more challenging than anticipated), and redirecting or changing topics to maintain engagement while being sensitive to potentially unexpected responses from young people. These skills and challenges are also documented by other, well-seasoned researchers (Clark, 2005; Darbyshire et al., 2005; Gibson, 2007; Whiting, 2009).

Importance of Environment

Research can be effected by the environment in which the research is conducted (Coad, 2007; Fargas-Malet et al., 2010; Gibson, 2007; Hill, 2006; Morgan et al., 2002). Researchers have reported being concerned that some participants felt there was no choice but to participate, felt pressured to answer correctly, participated beyond their comfort level and answered what they perceived adults wanted to hear (Coad, 2007; Fargas-Malet et al., 2010; Gibson, 2007; Hill, 2006; Morgan et al., 2002). It was important to me that each child felt safe, was able to share their perceptions freely, able to focus on the activity and be free from distractions. We discussed their rights as participants during recruitment, prior to the interview session starting, and again if I had any sense the child was uncomfortable or no longer interested in the activity/study questions. I tried to ensure each child felt appreciated and was contributing to something valuable; that would improve knowledge and potentially the play services the child or others at our hospital received. Careful consideration was needed when planning for the potential influences, barriers an environment could impose (physical, emotional or for confidentiality) which could impact the child/family and/or risk the quality of the data collected (Coad, 2007; Fargas-Malet et al., 2010; Gibson, 2007; Hill, 2006; Morgan et al., 2002).

Developmental Considerations

As noted in the literature, it was crucial to consider the developmental needs of the young people who would potentially participate in the research study (Coad, 2007; Whiting, 2009). My assumptions as a clinician researcher included the fact that children were not young adults; they were people in their own right; had knowledge and

experience that were important to understand; and that interactions needed to be child-centred and respectful of their developmental and psychosocial needs.

Developmental considerations were critical in planning all aspects of the study including the study methodology, design and arts-based data gathering activities to be used. As others have reported, I believed children have the knowledge and the ability, when provided with the appropriate methodology, to share their perceptions, their views and their meaning of the world around them (Clark, 2005; Whiting, 2009). Age was only one factor to consider. Given the variability in skills and abilities of different children, and potential regressed behaviour as a result of stress and hospitalization, it was better to consider developmental capacity versus chronological age when determining inclusion criteria (Gibson, 2007; Hill, 2006). In a desire to be inclusive, children with cognitive delays were not automatically excluded from the study. If a child was able to communicate (orally, with assistive technology or by drawing/writing) and was able to share thoughts and perceptions, the child was welcome to participate.

Studies which determined the best data collection activities to use with children at various developmental levels were lacking, however the three arts-based activities used in conjunction with a semi-structured interview, in this study, were well described in the literature, particularly drawing/play mapping and photo elicitation interviewing. My clinical experience also helped inform my decisions and interactions before (research proposal and planning), during (rapport building and active engagement) and after the study (translating the findings into a research summary for participants).

Ethical Considerations When Using Arts-Based Activities

As with any form of research, ethical issues were important to consider well before the start of a study with children, even more so when the child participants have a chronic condition and are hospitalized. Some ethical considerations when doing research with children included strategies for recruitment (Coad et al., 2009), consent/assent issues (Coad, 2007; Fargas-Malet et al., 2010), the use of incentives (Coad et al. 2009; Fargas-Malet et al., 2010; Gibson, 2007; Morgan et al., 2002; Punch, 2002; Whiting, 2009), the issue of power (Coad, 2007; Hill, 2006; Morgan et al., 2002; Punch, 2002; Whiting, 2009), privacy/confidentiality (Coad, 2007; Fargas-Malet et al., 2010; Hill, 2006; Punch, 2002), and researcher responsibilities in the dissemination of study findings (Coad, 2007; Hill, 2006; Whiting, 2009). I will now focus on ethical considerations related to the use of the arts-based activities in the context of the study, in some detail below.

Power

As previously mentioned, there is inherent imbalance of power between young people and adult researchers and this was an important consideration for this study (Coad, 2007; Coad et al. 2009; Hill, 2006; Morgan et al., 2002; Punch, 2002; Whiting, 2009). Researchers have noted the risk that young participants feel compelled to answer questions with responses they felt they "should" give or perhaps what they believed the researcher wanted to hear (Fargas-Malet et. al., 2010; Morgan et al., 2002). The power imbalance was reportedly affected not only by age discrepancy but also gender, ethnicity, culture and social background (Coad, 2007; Gibson, 2007; Hill, 2006). The literature suggested the use of multiple arts-based activities to reduce power imbalance. This reportedly allowed children to feel more confidant and comfortable, helped build rapport,

and gain trust of the participants (Coad, 2007; Fargas-Malet et al., 2010; McTavish et al., 2012; Morgan et al. 2002; Punch, 2002; Whiting, 2009).

In this study, children were offered the choice of three arts-based activities; namely viewing photographs, drawing a play map or providing a child-led guided tour. Nearly all the children chose an activity as we discussed play in hospital. The use of these activities during the data gathering process and adopting a *naïve curiosity* (Butler and Williamson, as cited in Coad, 2007; Coad, 2007; Gibson, 2007) to explore and learn from participants allowed children to build rapport more easily, express their views and be creative and flexible.

Privacy/Confidentiality

Children and youth reportedly want to understand where and how the information they share will be utilized (Darbyshire et al., 2005; Hill, 2006; Punch, 2002). It was critical that participants and their parents understood the limits of the privacy and confidentiality of the information they shared during the research process, how the findings would be utilized, and publicly disseminated (Fargas-Malet et al., 2010). Children may have agreed to be quoted and/or their drawings published without understanding the permanency of such decisions, hence the importance of parental consent as well as child assent for this aspect of the study. Additionally, parents were informed that if they were not present during the interview/session, the data gathered with their child would not be shared with them unless the child chose to do so. The limits of confidentiality, in regards to child protection issues, were also discussed with parents and in a developmentally appropriate manner with the child participants.

Other strategies to ensure confidentiality and privacy included the use of pseudo names for quotes and drawings. In this study, the children were asked to choose their own pseudo name, which they enjoyed creating. Those who wished to sign their work, were encouraged to do so on the back of the drawing. Coad (2007) suggested having an adult transcribe participant's statements when transcribing the meaning of drawings. In this study the children's drawings often included words and phrases as a part of the drawing. It would have been disruptive to the creative process to not allow the child to print the words while drawing; the drawings would not have been authentic. As a result, the drawings do have identifiable handwritten words (potentially identifiable to those who know the child). Verbatim quotes were used, with one exception where it was felt the child would be embarrassed by the mispronunciation of a word. In this case, a minor spelling edit was made for publication purposes. The child's intent was retained, hence analysis was not impacted by this adaptation.

As with any study, the transcripts were de-identified and pseudo names added; personal identifying information was kept separate from data gathered. Once data analysis was complete, participants actual names were removed from the master list of participants; data files (paper and electronic) were housed in a locked and secure location and will remain for 5 years post publication.

Dissemination

I have an ethical responsibility, as researcher, to ensure findings are disseminated to stakeholders, including the child participants (Clark, 2005; Coad, 2007; Gibson, 2007; Hill, 2006; Whiting, 2009). Children have the right to know, and thereby the right to

participate or decline participation based on how the drawings and audiotaped transcriptions and field notes will be used and/or displayed.

Parents and children were offered the opportunity to receive a summary of the findings. The parent completed a form to indicate if the child and/or parent(s) wished to receive a summary of the findings ("Yes" or "No"), with a place to write the mailing address. The parent was instructed to place the form in the envelope provided and to seal it. The sealed envelope was kept separate from other data gathered. The envelopes were opened after the study analysis was completed and summary findings were ready for dissemination.

During the initial consent/assent discussion during recruitment, the parents and participants were informed of my plan to present the findings to hospital administrators, professional colleagues and learners (locally, nationally and internationally), that the thesis would be housed online and the plan to submit manuscripts for journal publication (which would also be online). Parents and children were informed they could change their mind about the use of drawings and quotes as well as the limitations in my ability to discontinue their use, depending on when and what they wished to have omitted.

Discussion

The purpose of this paper was to provide an overview of three arts-based data gathering activities, including evidence supporting their use, how they were used in the context of the study, the strengths, challenges and unexpected outcomes for each of the activities used in a qualitative study describing hospitalized children with chronic illnesses' perceptions of play in hospital. Special considerations when doing research

with children as well as ethical implications when using arts-based activities with hospitalized children with chronic illnesses were also discussed. I believe the use of these three arts-based data gathering activities along with the semi-structured interview questions which included questions such as “Tell me about play at the hospital”, “Why is it important for kids to be able to play in hospital?, “What do you think it would be like if there were no toys or places to play in hospital” provided more information and quality data than interview questions alone, for this school-age group of hospitalized children. This will now be further explored.

Drawing /Play Map

Although only one of the children drew a play map as originally conceptualized for this arts-based activity, offering drawing as an activity during an interview with children was deemed to be beneficial. The act of drawing facilitated engagement, encouraged conversation and corroborated content discussed during the interviews. The drawings provided an opportunity to better understand the child’s perceptions and experiences with play in hospital and likely enhanced the quality and quantity of the data gathered. The children who made drawings were accurate in their portrayals of the environments, directionality and details of materials/activities, furniture in the spaces, yet not every detail was drawn.

Photo Elicitation Interview

Carter and Ford (2013) report that photographs can be limiting because a photograph cannot capture the essence of an environment, and there may be varying influences which impact a person’s interpretation of a photograph. In the context of this

study, the images were meant as triggers/reminders for children familiar with the spaces. The spaces with which they were not familiar, were those in which they had not experienced play, thus were not relevant to them and were noted during data gathering. Children were able to discuss other places where play in hospital occurred, such as the Ronald MacDonald Room. Presumably, this meant children were not hampered by the fact that not all photographs correlated with their experiences or perceptions of play in hospital.

All children who chose this activity were asked about other photographs they would take, if they were able to take photographs of play in hospital. One child mentioned the haematology/oncology clinic playroom and the Ronald MacDonald Room and another child mentioned their doctor's outpatient office. A third child suggested a playground filled with outdoor things like at a waterpark. She felt this would be fun to have for children while laughing they may not want to leave the hospital.

It is noteworthy to mention that I chose to use pre-created photographs without people in the images. This was purposeful in an effort to minimize distractors in the images but also to avoid the additional challenges related to consent when taking photographs of people, especially in the context of the health care environment, using these types of photos for research and for dissemination of the findings. I contemplated having children take photographs of play in hospital, however the ethical issues, the need to educate the children and families about privacy, the need to avoid taking photos of people or teaching children/families how to seek consent would have likely hindered the creative process and perhaps impacted participation (Hannes & Parylo, 2014). There was

also the risk that children might regret or not wish to have certain photos viewed by the researcher or included in the analysis (Coad, 2007; Fargas-Malet et al., 2010; Driessnack & Furukawa, 2012). Having children take photos would have required rigourous protocols for REB, additional time to allow the children to take photos, the need for adult accompaniment (either the researcher, which was prohibitive or with a parent which may hinder the creative process and impact the data) and the need for a second meeting with the child. This would have extended the data gathering period significantly and perhaps risked participant recidivism. The strategy of using researcher created photographs in the photo elicitation interview worked well for this research question, the methodology and the environmental context of the hospital.

Child-Led Guided Tour

This activity may be more challenging in a hospital environment from a technical and a privacy perspective, particularly when audio-recording the interview. However, it is believed an active, physical type of data gathering activity, alongside creative art or visual based activities, is an important choice to include when planning studies with children. An activity where the child moves around helps those who prefer physical activities over table, thinking or verbal tasks. Other children with a chronic illness might find this too demanding and potentially exhausting, hence the value of multiple activity choices. The interview with Stormtrooper would have been very short, had little depth and breadth had we not moved out of his room and had he not been engaged in a child friendly way to show what it is like to play in hospital. By contrast, if I chose child-led guided tours as the only data gathering activity, several of the children would not have

been able, and/or been interested in such a physically and cognitively demanding task due to their health condition and/or personality.

Multiple Activities[6]

In this study, each child was offered the choice of three arts-based activities or to "just talk". This allowed the child to be in control and choose an activity they found preferable. It was expected that the arts-based activities would appeal to children with varying personalities and interests. This was beneficial since 5 of the 10 children chose drawing, while 3 chose to view the photographs, one chose the guided tour and one child preferred to "just talk".

I recognized the need for a longer rapport building time early on in the study. I became more purposeful in my conversations, asking questions about current activities, their room or the items within it, pets, and family etc. to help build rapport and comfort with my presence and the topic of the study. Upon reflection, I have wondered if data gathering would have been enhanced by purposefully adding activities to help "break the ice" at the beginning of the interview (a longer rapport building time). Alternatively, I could have spent time initially getting to know the child through play/activities of his/her choice and then setting up a second visit for the actual interview and arts-based activities. This would have required more time on the child and family's part, additional coordination around schedules and medical treatment which may have impacted

[6] The literature often speaks of multiple methods, however I wish to provide clarity that these are multiple (arts-based) data gathering activities versus a new and different methodology.

recruitment. Audio-recording both sessions would have been required and resulted in longer transcripts to analyze.

In my review of the literature, **r**esearchers stated the use of multiple arts-based activities in a study was valuable and increased young people's engagement, active participation and enhanced the depth of the data collected (Coad, 2007; Darbyshire et al., 2005; Hill, 2006; McTavish et al., 2012; Punch, 2002; Whiting, 2009). The researchers also emphasize multiple arts-based activities "…complemented rather than duplicated and enabled the expression of different aspects of the children's experiences" (p. 430). This was indeed my experience.

The children were not expected to do more than one activity, although the option was available if desired. Children in this age group were expected to participate for 30-60 minutes, given their typical attention span for an activity. Interviews ranged from 16 to 65 minutes (see Appendix A), with one session going as long as 90 minutes because one child was very creative and expanded the play map activity into creating a game for other children, while two other children wanted to play after the interview was complete (sessions lasting 45-60 minutes).

Future Directions

Although research with children is reported to be challenging, involving them is worthwhile (Clark, 2005; Coad, 2007; Gibson, 2007, Whiting, 2009). Children have a lot to say about their world and they want to share it. All the children in this study indicated being a part of the study was a positive experience and the activities were enjoyed. Children view things differently than adults, even their parents (Lindeke et al., 2009). I

too noted this when parents prompted children about play with the therapy dogs or with the therapeutic clown. Using multiple data gathering activities such as interviewing, drawing, play maps, photography, and child-led guided tours provides children opportunities to express their thoughts in the best way for them.

The focus on children's rights and the philosophy that young people should be involved in the development and evaluation of programs services, and even policies that impact them is strong in the UK and Australia where legislation and educational reform identified the need for young people to be consulted (Davies, 2010; Royal Australasian College of Physicians et al., 2009; Waterston & Curtis, 2001). Although Canadians advocate for the rights of children and young people to receive the services they need, this is most often adult driven.

There is increasing pressure to have recipients of health care services provide feedback and be a part of quality assurance processes, change and reform; this includes children. Using arts-based data gathering activities in research and presumably quality improvement initiatives with children can expand our knowledge about their perceptions, views and what is important to them as it relates to services which impact them. The need to understand children's perceptions of services/programs which have an effect on them is limitless in scope and most certainly includes health care, health care environments, programs/services and the care they receive. Young people's perceptions have the potential to influence program/services, policy development and evaluation *if* the process for acquiring the data is respected and trusted. In order for this to occur, a true culture of 'listening' to children's voices must be integrated into everyday environments

where they receive health care, education, play and other services and one method of doing so is to use arts-based activities (Coad, 2005; Coad et al., 2009; Darbyshire et al., 2005; McTavish et al., 2012).

There is a need to address gaps in research, perhaps not to determine if there is one "best" data gathering activity or arts-based activity, but to critically analyze the usefulness, strengths and weaknesses of such data gathering activities in obtaining valuable and relevant data. There is a need to determine the arts-based activities that work best for children with cognitive delays or children in minority groups; to compare data gathering activities and determine which work well with various populations and various research methods. The goal is to increase knowledge and evidence about the value of these activities. In order to inform practice, it is important to scrutinize the arts-based data gathering activities used and for editors and publishers to ensure this methodological information is reported in manuscripts (Clark, 2005; Darbyshire et al., 2005; Fargas-Malet et al., 2010; Mathers et al., 2010; Morgan et al., 2002). This paper is an effort to do just that.

Moreover, researchers need to better understand children's experiences of being consultants, participants and co-researchers, not only from a participant level but also the impact on society, education and health care systems, as well as the impact of the change on programs or policies (Clark, 2005; Darbyshire et al., 2005; Fargas-Malet et al., 2010; Morgan et al., 2002; Punch, 2002). Although I did ask most of the children how they perceived their experience in my research study, it was in a casual manner and certainly not in depth. Many studies do not ask their young participants to formally evaluate their

participant experience, their perceptions of being involved in research, or the data gathering activities used during the study. More information is needed in these areas.

Conclusion

There is strong support for the use of arts-based data gathering activities when doing research with young people. Data gathering to obtain children's perceptions is a time consuming, resource intensive and often challenging endeavour. There are many different data gathering activities being utilized. Drawing/play mapping, photo elicitation interviewing and a child-led guided tour offered in a study focusing on hospitalized children with chronic illnesses' perceptions of play in hospital enhanced the quality and quantity of data gathered. There are important aspects to consider when selecting the arts-based activities for data gathering with children. The choice of arts-based activities needs to be informed by the research question, the developmental level of the participants, the research methodology, as well as the procedural and ethical implications. Many researchers report the benefit of incorporating several data gathering activities when doing research with children to allow choice, increase engagement and to enhance the depth of the data collected. Given my initial experience, I would agree. Further research is needed to obtain children's perceptions of their research experiences, to analyze and compare arts-based data gathering activities and the outcomes of young people's involvement.

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Chapter III: Manuscript 2

Hospitalized Children with Chronic Illnesses' Perceptions of 'Play in Hospital': A Qualitative Descriptive Study

Abstract

The goal of this qualitative descriptive study was to better understand and describe hospitalized school-age children with chronic illnesses' perceptions of "play in hospital", including how they defined play in hospital, the activities, the people and places important for play in hospital. Ten children, aged 6-11 years, diagnosed with a chronic disease and admitted at a tertiary health care centre participated in the study. A semi-structured interview, along with the option of three arts-based activities, namely photo-elicitation interviewing, drawing/play mapping and a child-led guided tour, were offered as ways to help the researcher learn about play in hospital. Using an iterative process during thematic analysis, four themes were identified: play is important in hospital, play is "fun", chronic illness influences play, and children with chronic diseases are resilient and insightful. Implications for health care professionals and health care administrators are discussed.

Introduction

Many aspects of pediatric health care delivery have improved since the early 1900's, yet hospitalization continues to be stressful and potentially traumatic for many children (Chappuis et al., 2011; Chesney, Johnson, & Savik, 2009; Lindeke, Fulkner, Salmela, Salanterä, & Aronen, 2009; Melnyk, 2000; Stevens et al., 20011: Wilson, Megel, Erenbach, & Carlson, 2010). Children and youth identify being affected by and fearful of health care related experiences (Chappuis et al., 2011; Lindeke, Fulkerson, Chesney, Johnson, & Savik, 2009; Melnyk, 2000; Salmela et al., 2009; Stevens et al., 2011; Wilson, Megel, Erenbach & Carlson, 2010). Hence, the concern for the emotional health of young children in hospital remains. This has resulted in the provision of play materials, dedicated play spaces and the integration of new roles specializing in pediatric psychosocial and developmental care, such as that of the child life specialist (Pond Wojtasik & White, 2009; Thompson, 1989).

Coinciding with changes in health care delivery over the last century were new societal perspectives about childhood; that children were not just little adults; they were unique in their own right and should be viewed as rightful members of society. The UN Convention on the Rights of the Child, along with political and policy changes in the UK and Australia helped to highlight the rights of children and the need to seek their perspectives on programs and services which affect them (Coad et al., 2009; Davies, 2010; Morgan, Gibbs, Maxwell, & Britten, 2002; Royal Australasian College of Physicians, Association for the Wellbeing of Children in Healthcare, & Children's Hospital Australasia, 2009; Whiting, 2009). There was recognition children should have

their "voices" heard and be respected as individuals with their own perspectives and opinions (Carter & Ford, 2012; Coad, 2007; Driessnack & Furukawa, 2012). Since then, there has been a thrust in the social research community to include children in evaluation and research, a shift from doing research "on" to doing research "with" children (Clark, 2005; Coad, Plumridge, & Metcalf, 2009; Fargas-Malet, McSherry, Larkin & Robinson, 2010).

My clinical training, knowledge and experience made me contemplate how children perceived play in the hospital. As a child life specialist I believe play is important for children to explore, gain developmental skills and to express emotions. I have seen and heard from parents that hospitalization, the effects of treatment and/or illness effects play behaviours. However, the literature, as yet, does not describe children's perceptions of "play in hospital". I wondered whether play in hospital was different than play at home, or play at school? Was play in the playroom described the same as play in their hospital room? Was therapeutic play with a child life specialist, play that is facilitated or guided by a child life specialist, perceived as play? Children could help health professionals to understand how they define and describe play and this could lead to other areas of learning "from them" and "with them" in regard to their hospital experiences. Although early observational research of play in hospital provided the foundation for the work of child life specialists, there is limited new research on play in healthcare settings and specifically children's perceptions and descriptions of play in hospital.

Child life specialists are specially trained non-medical professionals who "...strive to reduce the negative impact of stressful or traumatic life events and situations that affect the development, health and well-being of infants, children, youth and families" particularly related to health care experiences (Child Life Council, 2002). They use evidence-based assessment variables (the child's developmental level, child temperament, response to health care experiences, changes in mobility, memory of past experiences, social status, and family/social supports) to identify risks to development and coping for infants, children, youth and their families (AAP et al., 2014; Hollon & Skinner, 2009; LeBlanc & Chambers, 2013). Child life specialists use play as a healing modality while teaching, encouraging the expression of thoughts and emotions, and promoting adjustment and coping with stressful aspects of health care (CLC, 2002; Hollon & Skinner, 2009; LeBlanc & Chambers, 2013).

This study took place at the health centre where I work; a tertiary centre for women and children. At the health centre, there are also child life workers (sometimes called child life assistants or play coordinators at other centres) whose role is to provide normalized play and activities in the Activity Areas (playrooms)[7] and in the Playgarden, an outdoor play space on health centre property. They supervise volunteers who provide support to the play program, facilitate room visits, and the provision of developmentally appropriate toys/activities for patients. The child life worker's educational background is typically a bachelor's degree with a focus on child development and normative play.

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[7] Activity area - term used at our health centre to describe playrooms. For ease of understanding, the term playroom will be used henceforth.

Child life workers acquire additional knowledge about the effects of hospitalization on play behaviour during hospital play practicum placements or on-the-job training. Their role facilitates play within the inpatient units and often integrates the child life specialist's normative play goals for the patient during play programming.

Conceptual Framework for the Study

Prior to beginning the study, I created a conceptual framework that informed the research question and guided the research design (Imenda, 2014). It highlighted: (a) my research assumptions, (b) the theoretical frameworks which guide child life specialist practice and which informed the study, (c) literature on play, children's perceptions of hospitalization, as well as their perceptions and definition of play outside of hospital. All of these concepts helped to inform the research methodology, the design of the study and the analysis of the data and will now be described in the section below.

Researcher Assumptions

My assumptions were that: (a) children with various chronic diseases share common experiences regardless of their specific diagnosis (Sawyer, Drew, Yeo, & Britto, 2007; Stein & Jessop, 1982); they would have much in common in their experiences of play in hospital; and could provide rich and valuable perspectives to the study, (b) school-age children could and would want to share their perceptions about things which affect them, such as play in hospital (Driessnack, 2005; Hill, 2006; O'Kane, 2008; UN, 1989), (c) play helps promote adjustment and coping in hospital (Rollins, Bolig, & Mahan, 2005; Thompson, 2009), and (d) children would likely describe play activities in the hospital's playrooms most frequently, hence I needed to ensure I did not unknowingly

influence the conversation to support this assumption. I was interested to learn if children described play in their rooms, play during clinic visits, or therapeutic play sessions as play in hospital.

Additionally, it was important to acknowledge that I was a child life specialist with many years of clinical experience and I would be doing research within the hospital where I work, although not on my clinical unit. I have past personal experiences with health care that influenced my career choice and influenced my belief that children have internal strengths. It was my belief that most children have the ability to cope well in the face of adversity when provided with developmentally appropriate and child-centred supports.

Theoretical Frameworks

Although there are several theoretical frameworks which inform child life specialist practice, cognitive theory and psychoanalytic theory are key to informing this study design. Although dramatically different in their perspectives on play, child life specialists use both cognitive and psychoanalytic theories to provide developmentally appropriate activities for learning, normalization, fun and emotional expression (Bolig, 2005; Jesse & Gaynard, 2009). Piaget's cognitive theory posits that play is related to the cognitive skills of the child, that children assimilate or solidify their understanding through play activities and accommodate information during their experiences. According to Piaget (as cited in Turner, 2009) there are four stages of play which are progressive, namely: (a) sensory play (practice, repetitive, functional), (b) symbolic play

(representative or pretend play), (c) pre-operational play (independent and associative group play), and (d) games with rules (rule based, social convention).

The underpinnings of psychoanalytic theory important for child life specialists include the premise that play allows children to "play through" their fears and anxiety, allows for the cathartic release of emotions, is a way children re-enact their experiences, express fears about what might happen in the future, helps them come to terms with these emotions, and supports coping (Bolig et al., 1986; Doverty, 1992; McCue, 1988; Saracho & Spodek, 1995). These theories informed decisions related to study design, sampling (the cognitive age of participants), the data-gathering strategy (arts-based activities chosen for the study), as well as strategies for rapport building, the formulation of the questions and child-friendly communication strategies.

The Dynamic Model for Play Choice was a new model developed in a study using grounded theory (Miller & Kuhaneck, 2008). Simply stated, the model theorizes that "play activities perceived as fun are more likely to be repeated because of positive emotions associated with them. This repetition creates a pattern or preference, and continued engagement in the activity contributes to mastery" (p. 412). It was anticipated this study had the potential to add credence to this theory and support its relevance for hospitalized children with a chronic condition.

Important Concepts from the Literature

Children's perceptions of hospitalization.

In the literature, children repeatedly identified fear of needles, pain and being separated from family, friends and pets as the most challenging aspects of hospitalization

(Chappuis et al., 2011; Boyd & Hunsberger, 1998; Horstman & Bradding, 2002; Lindeke et al., 2006; Wilson et al., 2010). Interestingly, the only difference noted by researchers when non-hospitalized and hospitalized children were compared was that hospitalized children used more accurate medical terminology, articulated knowledge from their direct experience, and the data gathering activities were more emotionally taxing for them (Horstman & Bradding, 2002; Wilson et al., 2010).

Researchers also asked about the best and worst aspects of the hospital. Repeatedly, play, recreational activities and being in the playroom were reported as the "best thing" about being in hospital (Chappuis et al., 2011; Horstman & Bradding, 2002; Lindeke et al., 2006; Wilson et al., 2010). Children valued play in the hospital environment, yet there is limited knowledge about play in hospital as described by children. It is important to understand what constitutes play for them, the play materials, the people and play environments important for play and the impact their health condition or treatment has on their play behaviours; all of which can ultimately influence well-being and overall coping.

Defining play.

A review of the literature found the study of play was complex and hampered in part by the lack of a clear, consistent and measurable definition of play and/or its various forms e.g. normative, therapeutic, functional, constructive, symbolic, solitary, parallel, associative, and cooperative play to name a few (Bolig, 2005; Bolig, Fernie & Klein, 1986; Turner, 2009; Lifter, Mason, & Barton, 2011; Saracho & Spodek, 1995; Thompson, 1985). The definition used by theorists and researchers depended upon the

theoretical framework to which they espoused (Lifter et al., 2011). Bolig (2005) synthesized a list of criteria identified by theorists and researchers reflecting the most agreed upon descriptors of play, "Play must be: (a) voluntary, (b) internally motivated, (c) pleasurable, relaxed, (d) "as if" or pretense present, (e) organism rather than object dominated, (f) unique, unpredictable, and (g) active, both motorically [*sic*] and cognitively" (p. 84). This meant children were typically observed having fun, participated in "make believe"/dramatic play, play was more about the child and child's actions than the objects used in the play; play was not predetermined or predictable and physical activities were also described as play. Bolig acknowledged not all of these needed to be present; however there was no indication how many of these criteria should exist for an activity to be labelled as play.

Recent studies seeking children's perception of play outside of hospital demonstrated both similarities and some degree of difference across studies. The differences noted appear to be attributed to characteristics of participant groups such urban/suburban population, or impoverished community, ethnicity and/or community culture. Interestingly, the studies whose focus was to explore children's meaning/perception of play, universally reported school-age children's descriptions of play as "fun" or it made the child "happy", and that it was the child's choice (Berinstein & Magalhaes, 2009; Glenn et al., 2013; Lehrer & Petrakos, 2010; Miller & Kuhaneck, 2008).

Howard (2002) and colleagues (Glenn et al., 2013; McInnes et al., 2009; McInnes, Howard, Miles & Crowly, 2010) questioned the value of a single definition of

play since they stated play was contextual, based on the child's developmental level and experiences, and changed over time. Howard (2002) and Glenn et al. (2013) suggested researchers should focus on children's perceptions of play, since children were the ones experiencing it and should study the characteristics of the activities or situations that resulted in playfulness. In keeping with this perspective and the purpose of this study, hospitalized children with chronic illnesses' definition of play will be one of the foci of the study along with understanding their perceptions of play in hospital.

The terms "play" and "therapeutic play" are sometimes used interchangeably, however in the field of child life (and other health/mental health professionals), they are differentiated. The term therapeutic play will now be defined.

What is "therapeutic play"?

Koller (2008) described therapeutic play as "... specialized activities that are *developmentally supportive* [*sic*] and facilitate the emotional well-being of a pediatric patient" and "...focuses on the process of play as a mechanism for mastering developmental milestones and critical events such as hospitalization" (p. 3). This definition overlaps with Sylva (1993) who specified that therapeutic play was guided by an adult whose goal was to support the physical and emotional well-being of the child, through guided activities. Therapeutic play was directed or guided by adults when there were specific goals in mind such as desensitizing the child to medical equipment and reviewing information about an upcoming procedure, or, it was non-directed and the child was in control of the focus of the play experience, although the materials may have been pre-selected to guide the activity (Chambers, 1993; Delpo & Frick, 1988). Child

life specialists used directed and non-directed therapeutic play interventions depending on the situation, the child life goals and the frequency of sessions provided. I was curious if children would speak of therapeutic play interventions as play in hospital.

Perceptions of play outside of hospital.

Research of children's perceptions of play began in the fields of early childhood and education. School children categorized photographs of the same activity, such as reading a book, as "play" or "not play" and "learning" or " not learning", presumably using contextual (in the classroom, on the floor or at a desk) and social cues (smiling, not smiling, teacher directing, teacher presence/nearby or absent) in the photographs. For example, children classified the photograph of a child reading as "play" and "not learning" when the teacher was not in the photo and the child was on the floor. In contrast, children categorized the same photo as "not play" and "learning" when the child in the picture was reading at a desk and/or when the teacher was present or nearby. The explanations for their categorization, supported that children perceived play as an activity of choice, was engaging and pleasurable.

Studies focusing on the meaning of play for school-age children from three different cultures and countries (Tanzania, UK, and Canada) revealed that typically healthy school-age children described play most frequently in terms of physical activities, activities that were outside and unstructured, activities with friends and siblings, were "fun" and were chosen freely (Berinstein & Magalhaes, 2009; Brockman et al., 2011; Glenn et al., 2013; Miller & Kuhaneck, 2008). In the UK, US, and Canada more sedentary activities such as computer/video games, watching TV, dramatic play, playing

with pets, and music were also reported as play (Berinstein & Magalhaes, 2009; Brockman et al., 2011; Glenn et al., 2013). However, there were differences noted between children's descriptions of television viewing. British children included television as a play activity (Brockman et al., 2011) whereas others seldom included television as play; those who did focused on the television as a conduit for interactive video games or as a conduit for engagement in an activity (Glenn et al., 2013).

Lehrer and Petrakos's (2011) and Anthamatten et al.'s (2013) studies reported vast differences in regards to the locations in which children played. In both studies, children identified that play locations and parental restrictions were related to perceptions of safety in their neighbourhoods, the presence of children in the neighbourhood and the availability of "safe play parks". However, in Glenn et al.'s (2013) and Brockman et al.'s (2011) studies, children preferred to play outside, in their yard, gardens, on the road and other areas not often considered by adults as places to play, such as alleys. Glenn et al. concluded children could play almost anywhere, however this may vary depending on where children lived and social circumstances. Interestingly, Brockman et al.'s (2011) study noted that boys reported playing more with friends, while girls reported playing more with family members. Glenn et al.'s (2013) study reported that, overall, children preferred playing with friends and siblings, and preferred playing with people who liked to play similar things as them.

As noted above, children described play as any activity that was 'fun' (Berinstein & Magalhaes, 2009; Glenn et al., 2013; Lehrer & Petrakos, 2011; Miller & Kuhaneck, 2008). If an activity was no longer fun and/or was described as "boring" it was not

considered play (Glenn et al., 2013). Given that hospitalized children with chronic illnesses, were less likely to be able to participate in such activities, with friends and siblings and might not be able to choose their preferred form of play while admitted to hospital, I was eager to hear how they would describe/define play in hospital.

Research Question

A societal shift in perception of childhood and the awareness that children have the right, the ability and the desire to provide their views about topics which directly affect them, has led to a research movement from doing research "on" children to research "with" children. This includes children's perceptions, descriptions and definition of play in hospital. Recent school and community based studies shed light on play outside of the hospital setting. However to date, hospitalized children with chronic illnesses have not been consulted regarding their perceptions of play in hospital, how they define play, what constitutes play, nor what they value about play in hospital. Furthermore, what they want and need in regards to play materials/supplies, people and places important for playing in hospital need to be understood. Hence, the purpose of this study was to better understand hospitalized children with chronic illnesses' perceptions of play in hospital including their play preferences and play needs and to define play in hospital from their perspective. The overriding research question was "How do hospitalized children with chronic illnesses perceive play in hospital?

Research Method

Study Design

Qualitative research is well suited when little is known about a topic; a

topic is complex and multi-faceted; there is a need for a deep understanding of the phenomenon, and/or when there is a need to gain insight and meaning about a phenomenon from the participants' perspective, to explore perceptions, beliefs, and experiences within the natural context of the phenomenon (Creswell, 2013; Neergaard, Oleson, Andersen & Sondergaard, 2009; Richards & Morse, 2013; Smith et al., 2011; Vaismoradi, et al., 2013). Qualitative research is appropriate for answering "why", "how" and "what" questions in relation to perceptions, behaviours, motives, processes and barriers (Neergaard et al., 2009; Sandelowski, 2000).

Qualitative description (QD) is one qualitative research methodology with the goal to provide rich description with minimal interpretation of the data (Sandelowski, 2000, 2010). The intent was to provide a rich description of the data, as reported by children, as well as make sense of themes generated from the data. In keeping with QD, the analysis was guided by the data, not the researcher. QD methodology does not prescribe data gathering strategies. As such, I was able to incorporate multiple data gathering activities that were reported in the literature to work well for school-age children.

Setting

The study took place in a tertiary women and children's health centre that serves a population of nearly 2 million people. The health centre serves as both a primary care facility for the region as well as a tertiary health care facility for children in Eastern Canada. The health centre has three pediatric inpatient units; namely a pediatric medical unit, medical/surgical/neuro unit and a haematology/oncology and nephrology unit

(blood/cancer/kidney problems) with nearly 70 beds, an inpatient mental health unit with 14 beds, a neonatal intensive care unit with approximately 40 beds and a Pediatric Intensive Care Unit with 8 beds.

At this health centre, Child Life Services includes child life specialists, child life workers, a music therapist and therapeutic clown as well as other programs such as Therapy Dog visits. The child life workers provided play programming in two inpatient pediatric playrooms during specified play programming times, 7 days a week. Additionally, children, aged 9-11 years could participate in "Tween"[8] programming in the Teen Lounge on the weekend. The play spaces provided a place for inpatients, healthy siblings and family and/or friends to play (Ivany, LeBlanc, Grisdale, Maxwell & Langley, 2015). The spaces had developmentally appropriate activities to support the developmental and expressive needs of children of varying developmental levels and abilities. The rooms contained toys, art/craft supplies, dramatic play centres (e.g. to play house, restaurant, hospital play centre), puppets, board games, computer, table top activities (air hockey, miniature pool table, foosball), portable and adjustable basketball net, construction/Lego toys, musical instruments, infant play area, special needs toys, books etc. The two rooms, although one was larger than the other and not all items were identical in each play space, contained the same general content to ensure children had opportunity for constructive play, creative/expressive play, dramatic play, games and individual activities on these two inpatient units.

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[8] Tween – term used to mean children 9-11 years; in between school age and adolescence

Given the nature of each of the inpatient areas connected to the two playrooms, their hours of supervision and play programming with a child life worker were different. The larger playroom, which supported the play needs of children on the medical/surgical/neuro unit and the pediatric medical unit (about 52 beds) was open for designated times for play programming with a child life worker. There were small inpatient unit play spaces which were not supervised and housed limited play materials, typically for very young children which were accessible to families.

The playroom on the haematology/oncology and nephrology unit also had designated play programming provided by a child life worker, most days of the week. However, due to the nature of the small and relatively consistent patient population, and the parents' diligence regarding infection prevention practices and safety, parents could bring their child to the playroom any time, providing supervision and ensuring the room was tidied after play.

Additionally, there is an outdoor play space, called the Playgarden, that families can access dawn to dusk and where play programming happens with the child life workers during the spring and summer months. The Playgarden is accessible for wheelchair and beds, with accessible play structures e.g., a glider swing, sand box, garden boxes and a play cottage, a basketball area, a paved walkway for bikes and tricycles, as well as flower gardens and trees, and zones for sitting and picnic areas (Turner & Fralic, 2009).

Sampling

It was anticipated hospitalized children with chronic illnesses would be more

likely to have experienced playing in hospital, therapeutic play, were likely to be familiar with the available play materials/activities, play programming opportunities, and the environments in which play could occur at this tertiary health centre. They were the ones most likely to have knowledge and expertise that was paramount to understanding children's perceptions of play in hospital and thus a purposive sampling strategy was used.

In an effort to gather varying perspectives and enhance the transferability of the findings, I wanted to have children with a variety of experiences with play in hospital. As a result, children with varying experiences (able to access play spaces as well as those children who were confined to their room were welcome to participate). Hence, hospitalized school-age children (6-11 years of age) with chronic illnesses were recruited from two inpatient pediatric units, namely the pediatric medical unit and the haematology/oncology and nephrology unit, as well as the associated clinics where children received follow-up care and treatment. In an effort to minimize perceived or real conflict of interest, I did not recruit children on the unit where I provided clinical care. The focus of the study was clear and distinct, hence it was expected a small sample would provide valuable data with recurring themes (Guest, Bunce & Johnson, 2006; Morse, 2000).

Inclusion and Exclusion Criteria

Children with chronic medical illnesses, aged 6-11 years, admitted on the pediatric medical unit or the haematology/oncology/nephrology unit, and who experienced repeated and/or lengthy (minimum 7 days) hospitalizations within the

previous 6 months were the target population for this study. Exclusion criteria included: (a) non English speaking children/families, (b) children with cognitive delays impacting their ability to communicate their perceptions, (c) children with chronic mental health illness, due to the significant differences in their access to play materials, play programming and the cognitive, behavioural and emotional challenges often associated with mental health diagnoses, (d) children with chronic medical illness admitted to my clinical unit, (e) children whose admission was shorter than 7 days, and (f) children who were not interested in participating. Additionally, if health care staff (particularly the family's child life specialist, social worker, or team leader) indicated the parent/child was either too ill or too distressed, or that a request to participate in the study would potentially cause unnecessary stress, the parent(s) were not approached until it was deemed appropriate by the family's child life specialist.

Participants

Ten, of 13, families approached consented to the study. Only one 11 year old child, who was present when parents were told of the study by the child life specialist, declined to participate. The two other families met with me and showed interest in participating. However, timing was not appropriate and they were discharged prior to being able to complete the recruitment process. Hence, of the families approached 77% (10 of 13) participated. Nine of the children were hospitalized on either the Pediatric Medical Unit or the Haematology/Oncology and Nephrology Unit, with only one child interviewed in the oncology clinic.

The age of the children ranged from 6-11 years, with a mean age being 8 years

(average 8.4 years), 6 girls and 4 boys; 7 of the children were being treated for a diagnosis of cancer, while the other three had either kidney disease, bowel disease or immunological disease; all parents described their ethnicity as White. Four of the children had been admitted 1-3 times in the previous year, four were admitted 4-9 times, one was admitted more than 10 times and one family did not indicate the number of admissions. Five of the parents were married, two lived in common-law relationships, two identified being single, and one parent indicated being divorced. Five of the parents identified working full time (one family noted both parents were on leave from work), two parents were homemakers, one mom was on maternity leave, one person was a seasonal worker and another was on a pension. The combined family income ranged from <15K (1), 15-29.9K (1), 30-44.9K (3), 45-59.9K (2), 75-90K (2), to > 90K (1).

Recruitment

Once Research Ethics Board approval was achieved at both the hospital and the university (see Appendix E & F), recruitment began. Recruitment took place in the two pediatric inpatient units previously noted, and in related outpatient clinics when the child life specialist was providing services and met an eligible family. Information posters directed to families and information posters for staff were placed in strategic areas (family kitchen, information board, and staff work stations and washrooms).

At this health centre, patients needed to be asked about participating in research by a known member of the health care team. As a result, the child life specialist on each of the noted units reviewed their patient lists each day and identified children/families who met the inclusion criteria. The child life specialist known to the family approached the

parent(s) to offer the opportunity to learn about the research study from me, the principal investigator, and provided the parent with an information brochure (see Appendix G) for review. The brochure contained information required by both the university and the health centre's Research Ethics Boards to ensure parents were fully informed about the study and their research rights. The parent was informed s/he could contact the researcher directly (contact information was highlighted on the brochure and on recruitment posters), or with parent verbal consent, the child life specialist forwarded the family's name and location to me. Recruitment continued until the interview data were saturated (data saturation), meaning I was hearing consistent information in the interviews and no new codes were being created.

I met with the parent(s) to discuss the study and often times the child was present for the discussion. The child was typically already aware of the study and interested in hearing the information. I reviewed the study information, the consent and assent forms and obtained consent to have the child participate, with separate consent to use direct quotes and/or drawings created in the interview session (See Parent Consent and Signature Form, Appendix H).

When discussing the study with the child, I described the study in a child-friendly and developmentally appropriate manner to ensure clarity and to hopefully avoid a sense of obligation due to the power imbalance and the risk of wanting to please an adult researcher. This allowed me to explore the level of interest and willingness to participate in the study. A simplified child brochure was also provided to the child/family (Appendix I). Assent was sought for the child's participation in the study, and separately for the use

of and potential publication of any quotes as well as drawing(s) from the interview (Appendix J). If the child was not interested and/or unwilling to participate, their decision superseded parental consent.

A separate form was provided to the parent(s) asking if s/he, or their child were interested in receiving a summary of the findings ("Yes" or "No"), as well as a place for their name and mailing address. The parent was asked to complete the form, place it in the sealable envelope and return it to me. These envelopes remained sealed until after the study was complete, manuscripts were written and participant data were de-identified.

Incentives

Each family was provided a $5 gift card to a coffee/snack shop (accessible within the hospital and in Maritime communities) after meeting to discuss the study, regardless of their decision about participating in the study. The gift card was given after the study was reviewed and the decision about participation was made, to ensure it did not provide undue influence (Fargas-Malet et al., 2010; Nairn & Clarke, 2012). Additionally, once a child completed the study s/he received a certificate of participation and a small surprise gift worth less than $5 as a token of appreciation. The certificate and gift were provided after the session ended, in an effort to minimize any sense of obligation.

Procedures

Each child was asked their preference of location for the interview, unless s/he was isolated for medical reasons and was required to stay in their patient room. The interviews took place either in the child's room, a nearby quiet/interview room or in the unit's playroom. Some parents remained during the interview and activities, while other

parents chose to leave (because they felt their child would be more focused and communicative without their presence). Parents were informed they were welcome to stay and watch and listen while their child participated. There were a couple of instances when I forgot to mention the "watch and listen" hints and parents made comments in an effort to prompt or encourage their child's discussion of their experiences. In most cases, this provided positive prompts whereby the child enthusiastically provided additional information, particularly during discussion about who was important for play in the hospital. Five of the ten children created drawings or play maps, three chose viewing the photographs when discussing play in hospital, one child chose to take me on a guided tour and the other child wanted to just talk.

Data Generation

As principal investigator, I conducted the study, gathered all the data and completed the analysis. In an effort to have methodological congruence, be child friendly, and be sensitive to the developmental needs of the school-age child being interviewed, it was important as a child life specialist clinician and student researcher to implement data gathering strategies or activities that would work best to elicit children's perceptions. After conducting a thorough review of the literature, I felt confident that offering arts-based activities along with conducting a semi-structured interview, as well as maintaining an attitude of naïve curiosity would provide greater likelihood of rich and valuable data. The data gathering strategies are described below.

Interviewing

There were many aspects to consider when using interviews or focus groups

with children because of their developmental needs and abilities (Gibson, 2007; Kortesluoma, Hentinen & Nikkonen, 2003; Morgan, Gibbs, Maxwell & Britten, 2002; Punch, 2002). Data are richer when open-ended questions are used because they provide children the opportunity to share more detailed information (Driessnack & Farukawa, 2012; Kortesluoma et al., 2003). However, this was balanced with the child's cognitive ability and need for more concrete questions. I tried to avoid being vague and asking abstract questions, especially for younger children. Sometimes questions were asked in different ways if the child did not understand, or the question was deferred until later in the interview. Table 2 lists the semi-structured interview questions which formed the basis of the interview. The wording and sequence of the questions was fluid depending on the child's temperament and communication style and the data gathering activity (Aldiss, Horstman, O'Leary, Richardson, & Gibson, 2009; Fargas-Malet et al., 2010; Glenn et al., 2013). The interview session was audio-recorded to allow for transcription and data analysis.

Table 2

Semi-Structured Interview Guide

1. Can you tell me about "play in the hospital"?
    a) What's it like to "play in the hospital?
    b) Do you have favourite places you like play at the hospital?
2. * Why is it important for kids to be able to play in hospital?
3. * What do you think it would be like if there were no toys or places to play in hospital?
4. Can you tell me about your favorite kind of play at the hospital?
    a) What are your favourite things to play?
5. Are there things about "play in the hospital" that you don't like?
    a) Can you tell me about it?
6. Tell me about people who are important when you play in hospital?
7. Are there play activities you like but can't do at the hospital?
    a) Can you tell me about it (them)?
8. If you had a camera and could take pictures of play at the hospital, what pictures would you take?
9. Are there more things you want me to know about "play/playing at the hospital"?
10. What would you tell your friends or other kids in the hospital about doing this today?

Arts-Based Activities

Three arts-based activities were selected for data gathering, based on evidence in

the literature, consultation with school-age children, as well as the feasibility of their use in a health care setting (LeBlanc, 2015, see Chapter 2). In an effort to explore the feasibility of my initial two choices, photo elicitation interviewing and drawing play maps (map of play in hospital), I spoke with three school-age children (an 11 year old girl, 10 year old girl, and 7 year old boy) who would not be involved in the study. The first child consultant suggested child-led guided tours as an active way to share perceptions of play in hospital, especially for children who preferred to move around and were less inclined to draw or talk a lot (e.g. photos). The other two child consultants agreed this third activity would be a good option for children their age.

The arts-based activities included: (a) photo elicitation interview (PEI), (b) drawing/play mapping, or (c) child-led guided tours focused on play in the hospital. Children were also offered the opportunity to "just talk" if they preferred not to do any of the arts-based activities. Semi-structured interview questions helped guide the discussions during the data gathering process. Each of the arts-based activities will now be further described.

Photo elicitation interviews.

The use of photo elicitation/photo elicitation interviewing, as a data gathering strategy is increasingly utilized with child participants (Carter & Ford, 2013; Coad, 2007; Epstein et al., 2006; Mandleco, 2013; O'Kane, 2008). The terms photo elicitation or photo elicitation interviews (PEI) describes a process whereby photographs are used as a trigger or stimulus for an interview (Carter & Ford, 2012; Coad, 2007; Epstein et al., 2006). The photos provide an opportunity to help trigger memories, ideas, or thoughts.

The use of photos during interviews to elicit perceptions reportedly helps decrease the power differential between participant and researcher by allowing the child to focus on the photographs instead of feeling pressured to discuss his/her self and personal experiences (Driessnack & Farukawa, 2012; Epstein et al., 2006). In this study, the photographs were taken by me in advance of the study, with a focus on spaces where play may occur during hospital admissions or outpatient clinic visits (playroom, patient room, clinic waiting area, clinic exam room, see Appendix C for sample photographs), including structures and sometime play materials.

Drawing/play map.

The act of drawing can prompt or trigger memories, organize thoughts/ideas and is reported by Patterson & Hayne (2011), Driessnack (2005), and Fargas-Malet et al., (2010) as helpful in encouraging discussion with child participants. This arts-based activity combined the data gathering techniques described in the literature as "draw and tell" (Driessnack, 2005) and "mapping" (Darbyshire, MacDougall, & Schiller, 2005; Morrow, 2001; Veitch, Salmon, & Ball, 2008). The "play map" concept was meant to allow the child to draw multiple locations and types of play in hospital while the researcher listened and solicited additional information using the interview guide. Having children draw and then tell researchers about drawing is reported to be more contextually accurate and is recommended instead of researcher interpretation of the drawing (Clark, 2005; Coad, 2007; Driessnack & Furukawa, 2012; Fargas-Malet et al., 2010; Patterson & Hayne, 2011).

For this study, I showed the children an example of a play map to help illustrate the concept and to demonstrate the simplicity of the type of images or wording that could be used in the play map (see Appendix B). If the child chose to draw a play map, s/he was offered a choice of drawing materials (pencil, coloured pencils, and markers) and was encouraged to describe the drawing(s).

Child-led guided tour.

This approach allows children to be physically active, be in control of the tour (where to go, what to discuss) and end the discussion when done (Green, 2012). In this study, a guided-tour involved the child leading me on a tour in the hospital focusing on play in hospital, including the places and materials the child enjoyed while being audio-recorded, and the interview questions.

Data Analysis

I was interested in understanding the patterns of information (themes) shared by the children about play in hospital rather than the frequency of the words or types of words being used, which are more relevant for content analysis. Braun and Clarke (2006) explained "thematic analysis is a method for identifying, analysing and reporting patterns (themes) within data", and "...minimally organizes and describes your data set in (rich) detail" (p. 79). I followed their process of (a) becoming intimately familiar with the data, (b) generating initial codes, (c) collating codes into themes/sub-themes, (d) reviewing the themes as they related to codes and as well to the entire data set, (e) creating a thematic map, and finally (f) naming and defining the themes (Braun & Clarke, 2006) in an effort to help make sense of the data (see Appendix K & L).

I documented field notes which included a description of the participant and contextual reminders, and maintained a reflexive journal. Each of the interviews was audio-recorded and transcribed verbatim by a transcriptionist. Once transcribed, I listened to the audio-recording while reading the transcript, made transcription corrections, changed punctuation to be reflective of the emotion expressed and experienced during the interview. I added contextual notes and relevant non-verbal communication within the transcripts to ensure each transcript was as reflective of the interview experience as possible. Once transcripts were ready for coding, they were imported into NVivo10, a data management tool.

Reviewing transcribed interviews, shortly after transcription, and adding contextual information helped me be aware of superficial data, and data gathering strategies needing improvement (Milne & Oberle, 2005). As a result, I added two additional questions (Table 2, the * notes the additional questions) to improve clarification and increase the depth of information acquired. I tried to be mindful of the need to pause and wait for responses, rather than assuming the need for a more specific or closed question. This was challenging at times.

Member checking, asking for corroboration or confirming of my understanding of the child's response, was conducted throughout the interviews to ensure I was understanding what they were explaining to me. This was accomplished by repeating or summarizing the child's responses and/or asking for clarification (Shenton, 2004, for example:

I[9] So it sounds like playing is things that you get to choose and you get to decide about. (child nods) Yeah? So if we were telling other big people what's play at the hospital, is there anything else that we should tell them?

P[10] No.

I No, that's, that's play. It's fun, you get to choose.

P Yes.

This was felt to be a more accurate and immediate way to ensure the content and meaning was understood, as well as being more developmentally appropriate. For example, children would not be able to review lengthy transcripts or be able to understand the synthesis of a final report in order to acknowledge their thoughts and perceptions were captured. This strategy also helped avoid other challenges and pitfalls reported in the literature related to member checking (Barusch, Gringeri, & George, 2011; Morse, Barrett, Maryan, Olson, & Spiers, 2002; Sandeloswki, 1993).

Interview Data

Following Braun and Clarke's (2006) phases of thematic analysis, the transcripts were read in their entirety, allowing me to be familiar with the interview data. I then developed initial codes (with definitions, when to use and when not to use) for each of the transcribed interviews and began collating codes into subthemes/clusters of codes. This was an ongoing and iterative process with the addition of each participant's data set. Of note, the development of codes was both inductive and deductive in nature. For

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[9] I = Interviewer

[10] P = Participant

example the code “health impacts” came from children speaking of the impacts their health condition or equipment had on their ability or desire to play, while the code “a hospital without toys or play activities” was created in order to capture children’s responses to the a specific question within the interview. I then reviewed the data extracts within these initial subthemes, to ensure relevance and connection to the code and the subtheme, and changes were made accordingly. I then reread the data extracts, identified potential over-arching themes, and then collated relevant codes to the themes and subthemes. The data extracts for each theme and sub-theme were reviewed to ensure there was a coherent pattern for the proposed theme. Once I felt confident the data extracts were collated with the appropriate theme, that the themes were distinct and yet related to one another, I then reviewed the themes and subthemes again to analyse their connection to the data set, the research question and objectives. A thematic map was created and adapted during this review process and final themes were named and defined.

Data from Drawings/Play Maps

Drawings/play maps created during the data gathering process were photocopied and the photocopies were provided to the children/families. Each child was asked about their drawing during the interview. Each individual drawing was scanned and imported into NVivo10, data management software. The drawings were reviewed and codes were created based solely on the content of the drawing. This allowed me to review the findings from interviews, the discussion about the drawing(s) and then the drawings themselves, allowing for triangulation of the data.

Findings

There were four themes which I concluded from my analysis of the data: (a) play is important in hospital, (b) play is "fun", (c) chronic illness influences play, and (d) children with chronic conditions are resilient and insightful. The four themes will now be further explored (see Appendix K & L).

Theme 1: Play is Important in Hospital.

Within this theme, I categorized several subthemes including: (a) perceptions of a hospital without play, (b) people (and sometimes therapy dogs) are important for play in hospital, (c) places for playing, (d) play activities children enjoy in hospital, and (e) what's missing for play in hospital? Each of these will be highlighted below.

Perceptions of a hospital without play.

During my second interview, I began asking an additional question "What would it be like if there were no toys/activities or play places at the hospital?" This came to be a very important question. Children immediately reacted with emphasis and with passion "That would suck" (from a typically quiet 10 year old girl) and 6 year old Sylvester[11] who eloquently stated,

P It would be like floating in outer space.

I Like floating in outer space and…. what would that be like?

P It would be like…nothing. (Field note- I took this to mean that it would be similar to outer space, there would be absolutely nothing, like a blackness, black hole, void of anything)

[11] All names are pseudo names, most were provided by the children.

While several others emphasized it would be “boring” and Stormtrooper said “It would be scary….I wouldn’t like it”. The children seemed surprised and had a look of disbelief that such a thing could or would even be considered.

People (and sometimes therapy dogs) are important for play in hospital.

The children in this study were asked if there were people who were important for playing. Children identified family (mom, dad, siblings), child life staff (child life specialists, child life workers, and the therapeutic clown), friends, other patients, and even the therapy dogs as important for play in hospital. Additionally, three of the children mentioned they enjoyed playing on their own, and for one child, this was his preference. Only one child mentioned other health professionals.

***Family*.**

The children spoke most often of their moms who played with them, giving a strong feeling of how much was enjoyed and special,

I So it sounds like games and drawings are some of your favorite things.

P Yeah

I Yeah. What makes them so fun?

P Doing it with my mom.

Dad and siblings were also highlighted as active play partners in games and in playroom activities respectively. Several of the children mentioned how much their siblings enjoyed playing with the play materials in the playroom and spoke of playing together and independently from one another.

***Child life staff*.**

The child life staff were described as important for playing and mentioned enjoying playing with the child life specialist on their unit as well as the child life workers who worked in the playrooms, particularly the fact that they "play with" the child. Here is one example,

I That was one of the things I was curious about too… was… who are the people that are important for playing when you are here? You mentioned other kids, anybody else?

P People who work in the playroom.

I People who work in the playroom. Yeah. They're important for helping being able to play? Nod. Yeah?

Can you tell me a little bit about that? Silence as she draws.

What do they do that helps play? Helps you to be able to play? Silence…

Is it just because they get the stuff for you or because they play with you or…

P They play with me.

Although prompted by parents during interviews, once prompted, the children spoke enthusiastically about their play interactions with Child Life Services' therapeutic clown. Sylvester's enthusiasm about play with the therapeutic clown was instant and spontaneous. He immediately began drawing a map from his patient room to the child life office where he has had the therapeutic clown paged during his outpatient visits. Crazy Cool also described her play interaction with a smile,

P …I like (the therapeutic clown).

I Is he a playing person?

P Yes.

I Yeah.

P I met him down in the playroom once and we played doctor and he just kept getting mixed up with the tape like this (smiling and laughing at the memory she is describing).

Friends.

Some of the children spoke of friends who come from their community to visit as well as children they meet in hospital as important for playing. None of the children mentioned strong, lasting friendships formed through their play in hospital. However, they spoke more casually about making friends and playing with other children in the playroom, or playing with the younger children admitted to the unit in a supportive manner. It is important to note many participants lived a great distance from the hospital, so many of their friends and siblings were likely unable to come and visit and/or able to play with them in hospital.

Therapy dogs.

Three of the children mentioned they enjoyed playing with the two therapy dogs that visit weekly as part of child life programming. The dogs and handlers spent time in the playroom or did individual visits in the room, when children were too fatigued or weak to go to the playroom. The children all smiled as they spoke of the therapy dogs. Interestingly, Isabella differentiated the interactions with the dogs, one was play because the dog did tricks and played fetch while the other dog was “relaxing” because it was quiet, laid down and enjoyed being petted. For one quiet child, going to play with the

most active of the two therapy dogs was a motivator to get out of his room and a reason to go to the playroom,

I What kinds of things do you play in the play room?

P Ah, once we went there because um… usually the dog always goes there.

I Right.

P So that's why I went.

Places for playing.

The two most frequently mentioned places for playing were the playroom and the child's inpatient bedroom. Interestingly for several children, their bedroom was their favourite place to play because they could play any time, even when they did not feel well or were tired, while most described the playroom as their favourite place to play. Children also mentioned the Playgarden, the Teen Lounge, the haematology/oncology clinic playroom, and the Ronald MacDonald Room. The Playgarden was mentioned by several of the children who described not only the structures that promoted play but also the "physical" kind of play activities that come with being outside. Eight year old Isabella spoke with enjoyment as she talked about her 4 drawings of play in the Playgarden. Her drawings showed active play, social play with other children, and special events for families such as the family BBQ. Of note, more than half of the children in the study had not yet experienced the Playgarden and its seasonal play programming because recruitment started during winter and continued through the spring. However, for those who spoke of play in the Playgarden, they spoke of it with excitement and animation, it

was a highlight for them. One child noted, when she was feeling well and able to be out of her room, the Playgarden was her favourite place to go.

None of the children mentioned play in relation to the outpatient clinic rooms. Even when viewing the photographs, children indicated they did not play in clinic rooms. Jimmie Bob See Joe spoke of lengthy clinic visits and that, as a patient, she was bored, during these visits when parents and medical staff spoke at length and there was nothing for playing.

Eight year old Timemine mentioned other places such as the large-scale model train, the gift shop where he enjoyed looking at the toys/activities as well as the Subway restaurant where you could get a toy to play with your meal. The model train was a place where children could push buttons to make the trains stop or start, engage lights, vehicles etc. during designated hours and facilitated by volunteer model train enthusiasts. His description of play was broad, likely influencing his perception of places where he engaged with playful things and where play can happen in hospital.

Play activities children enjoy in hospital.

The children described many activities they enjoyed playing in hospital. They spoke of the many art/craft materials and being able to paint, draw and make things for themselves and others, imaginative/dramatic play (e.g. playing restaurant, using puppets, playing doctor, Barbies), constructing Lego, board games, playing table top games such as the miniature pool and foosball games, and air hockey game. Only a few children mentioned using the computer in the playroom, or their personal tablets and/or playing

video games in their bedroom. The children who had opportunity to play in the Teen Lounge spoke of crafts and baking as fun activities.

Many of the same activities were mentioned in the context of their room, the playroom, and in the Playgarden, namely arts/crafts, board games, imaginative play, and the therapy dog visits (their room and playroom). Other activities were based on the specific play space such as the table top activities, air hockey table (medical and surgical floor playroom), baking (Teen Lounge), water play and basketball (Playgarden), and movies (Ronald MacDonald Room). As would be expected, physical activities such as basketball, riding a bike, water play were outside activities, yet some of the more active children played hide-and-seek in the inpatient units and their rooms.

Participants, whose siblings came to visit, mentioned how much their siblings enjoyed playing with the toys and materials available to them, either in the playroom or in the participant's room. For both the participants and siblings, there was something about the novelty of having different toys/activities and/or the volume of choices that made them feel as though the hospital had a lot for children to play, as Jimmy Bob See Joe notes,

P My sister was there and she was just kind of obsessed with all of the…

I All the …

P All the stuff, the toys and stuff because since she's older she doesn't really get to play with lots of kiddy toys and stuff so…. (Jimmy Bob See Joe, 11 years old)

Isabella sounded in awe or appreciation of all the choices:

I Now…are there things that you would like for playing that we don't have or that we don't do at the hospital?

P I don't know, you guys have so much (underlined because of emphasis in her voice).

What's missing for play in hospital?

When asked if there were toys/materials or activities they felt were missing, were needed or wanted for playing, most children stated there was nothing they lacked or wanted because the hospital had so many things available to them. They often noted they (or someone on their behalf) simply needed to go and borrow things from the playroom, or the child life staff or volunteers would make sure they had the things they wanted, so they would "not be bored". A few of the children did make suggestions. Drew (10 year old), who spent a lot of time in his room recommended a hover ball (used like a soccer ball), a different video game system for those who did not enjoy the current one in the rooms, nerf guns and wall mounted basketball hoops that could be played from bed or a wheelchair. Stormtrooper reported missing his trampoline from home. In contrast, Jimmy Bob See Joe appreciated everything available on the inpatient unit, however articulated the need for play materials in the actual outpatient clinic rooms, "I wish like they had toys there for like kids and then they, then once the parents are done talking then they explain it to me and then the parents can be bored for once."

She goes on to suggest,

P Just have like something small set up, like you could have like um, like a little train track or something.

I Yeah.

P Even like um, just pencil and paper.

I True, just for drawing.

P Just for like drawing.

Children played where they could, with accessible games, art/craft supplies and activities. Although there were a few suggestions for different activities/equipment, they enjoyed typical activities of children in this age range and enjoyed having many activity choices and places to play such as the playroom and Playgarden.

Theme 2: Play is "FUN".

Defining play in hospital.

Play was defined by all the children as being "fun" and an activity of their choosing, as described clearly by Amelia, "Play – it's when you play with toys and play you can choose to do what you want to do." Most of the children described activities or playing with people as play, like 10 year old Isabella,

P And the playroom is fun for um crafts, um, if you want to paint some pictures or play a game on the computer, it's fun.

I Um hum.

P Even Legos and play the violin and a little kitchen and then Barbies and dinosaurs and a piano.

I Oh my goodness.

P And it's fun to play with all that stuff.

I So when you say that it's fun, can you tell me what makes… what makes it fun?

P Well, playing with some people.

I Um hum.

P And making some friends.

I Yup.

P And also try new things when you do.

For some children play included physical activities such as running, playing outside (e.g. water balloon fights, sprinkler) and playing hide and seek, while others mentioned sedentary activities such as arts and crafts, board games, and building Lego . As mentioned earlier, for most of the children there was an interactive component of some kind- you had to be "doing something" such as making something, pushing buttons, exploring something or engaging with someone or with the therapy dogs. Only a couple of the children spoke of video games, online games, or using a tablet/phone for activities as play. When it came to movies, there were differing perceptions; 11 year old Jimmy Bob See Joe stated she believed watching movies was play because it was enjoyable while 7 year old Crazy Cool stated:

P "Watching a movie is like… just sitting down, kicking up your feet and just watching what's ahead of you.

I Right.

P Playing is what you can do when you're really energetic and running around and having fun.

This differing perception was also noted when children spoke of looking at play items in the hospitals gift shop. For 8 year old Timemine "It's kind of like playing

because you are going around and seeing new things" while for the girls who mentioned the gift shop, they differentiated that this was not playing but rather shopping for things with which to play.

"Play" and "learning".

When asked about the difference between an activity being "playing" or "not "playing", 10 year Paddington summed it up "Um, you have fun when you're playing and you, it's boring when you're not playing". Many others also spoke of boredom when they do not have activities or people with whom to play. Additionally**,** children spoke of the difference between "play" and "learning"; Crazy Cool's response reflected the common perception:

I If you can do the same thing for school and the same thing for playing, how come it's playing and that's school?

P Well… it actually isn't playing, it's learning.

I Ahh, okay.

P 'Cause you have to learn at school and if they want you to draw a picture you have to. But if you really want to draw anything you want then that's drawing a picture that you want and play. That's (emphasized this with her voice and pronunciation) what playing is.

All the children identified that an activity at school was for learning, a requirement from the teacher, and that it was not play because it was not an activity of choice as noted by Jimmy Bob See Joe "Like it's nice to have an idea that somebody gives you but sometimes it's not fun to be told you have to do it". Even Isabella who initially stated that

drawing for her was play, regardless of it being at home or at school, as she talked it through, she identified that although the activity was the same, the aspect of true choice was removed when it was an activity at school

I …are they both playing? Or are they different?

P They're both playing.

I They're both playing. So for you, if you were doing art at school, you would think that that was playing?

P Um hum.

I And if you did art at home it would be playing for you?

P Hmmm.

I Yup? You kind of have a face that says hmmm, I'm not sure. Maybe it depends, does it depend?

P Um hum, well you have to do what the teacher says at art in school and then at home you can just make whatever you want.

Normative play and therapeutic play.

Of note was the fact that all but one child (Isabella) spoke of play in the context of normative or normalization play activities, meaning play activities one would typically expect a child to appreciate and enjoy given their developmental level. Isabella not only spoke and drew many types of normative play activities and social play interactions she enjoyed in hospital, she also spoke of activities described within child life practice as "therapeutic play/dialogue". These are activities where the goal of the child life specialist

to enhance emotional wellness, support positive coping, elicit concerns and mastering developmental milestones (Koller, 2008). Isabella describes,

P Mmmm reading is calmness...I think

M Calmness

P [To] Calm yourself,

Later when her mom prompted her about her play interactions with her child life specialist, Isabella responded,

> P Well it's fun and it's crafts and it's, we just get along and we talk and stuff.
>
> I Yeah.
>
> P About…
>
> M Get your mind off of things
>
> P Yeah, it gets my mind off of things and I um, we talk about like how would I feel if I got like a surgery or something.

Children equated play with fun and choice, that play was in contrast to being bored, and, as was highlighted earlier, they perceived that people (and sometimes therapy dogs) were important for play in hospital.

Theme 3: Chronic illness affects play in hospital.

Throughout the interviews, there were comments highlighting the effect each child's chronic disease and treatment had on their play choices, the location of play in hospital and also the child's level of physical endurance, amount of play s/he did and sense of grief and loss.

Disease and treatment effects.

Fatigue and low energy level.

The most commonly mentioned health impact on play in hospital was that of fatigue or energy level, while a couple children mentioned being on protective isolation due to treatment regimes. Many of the children spoke of sleeping a lot, not being as physically active, like Jimmy Bob See Joe, "Well, my play, when I was at the hospital, I usually stayed in my room a lot. Cause it was hard, cause I was tired and I couldn't move around a lot", and Drew, "Hmm, well, well sometimes if you're in bed and you're hooked up to something you can't do a lot of stuff" and when asked about other activities "I don't really want to bother with it…. Just tired a lot of the time."

Impact of medical equipment.

Children also spoke of the medical equipment, such as their crutches, IV pole and port-a-catheter (a small device under the skin, when accessed with a special needle allows intravenous medication, fluid, blood products etc. to be given ,or from which blood can be drawn) which influenced their choice of play activity, as articulated by Drew,

P I would want to play basketball but I can't.

I Um, and is it…can you tell me a little bit more about that?

P Well, I have my crutches.

I Yup.

P But I also have to move the basketball but I can't so I have to use my crutches so I can't play basketball.

Crazy Cool stated,

P I think play basketball… because sometimes I'm scared…

I Um hum, sometimes you're scared?

P Like just in case like it bounces back at me and then hits my port and then it [the needle] goes in too far. Shortly after she says

P Well I wish I could like run around and play.

I Umm.

P But I can't because of the pole.

I Right. That does kind of get in the way doesn't it?

P But I never really wanna run around, I just want to sit down and get better.

She seemed to differentiate between what she wished she could do and what she needed or knew she should do to get well. This was the beginning of further insightful comments this young girl had about her illness and the importance of treatment in order to get well, even though she did not like it (see Theme 4).

Immune system compromise.

Interestingly several of the children spoke of the impact of being isolated, meaning they were not able to leave their inpatient room due to having a communicable illness or because their immune system was suppressed, requiring protection from germs, bacteria etc. These children (all on the haematology/oncology/nephrology unit) spoke of isolation as a matter of fact, indicating others could bring them play or could play with them, if they followed the special guidelines for protective equipment. In contrast, 6 year old Sylvester, indicated he is always isolated when he is admitted to hospital and spoke

longingly of going to the playroom "I never get to go to the playroom. I wish I could go there…To play!"

Jimmy Bob See Joe spoke of the special precautions she took when she went the playroom, demonstrating how health issues come first and affects life, even play,

P I just had to be really sanitary, that was the only thing.

I Right, so you had to be really careful of others, you know, washing things down or making sure things were really clean,

P And I can't put my hands by my face after I played.

I Right.

P I would have to put hand sanitizer on or wash my hands.

Emotional and social effects of chronic illness on play.

Grief and loss.

One of the most striking findings was the grief and loss children expressed when discussing how chronic illness changed their play, as so eloquently described by Jimmy Bob See Joe (11 years old) in the following two quotes,

P I was really tired and I was trying to do everything.

I Um hum.

P Cause I was really athletic and I really liked to play and stuff and then I couldn't and it was really weird.

I I bet that was really hard.

P And I cried.

and,

P I tried to like throw the basketball and my sister was running around like crazy.

I Trying to catch the ball?

P Well yeah.

I Or just playing?

P And like, my platelets were also low, like my Mom and my Dad wanted me to go outside and get fresh air.

I Um hum.

P But it really, it really just made me sad.

I Cause you couldn't do the things you really loved to do?

P Yeah.

I Yeah. And… so…

P I had a bad experience with outside.

Drew's quiet and reserved responses gave me the sense that the experience of chronic illness, was difficult for him, influenced all aspects of his activities, playfulness and social interactions. His father reported, separately, about how the side effects of his medication influenced his level of social engagement with others he did not know well. Timemine's voice was longing when he responded to his mother in regards to being connected to a feeding pump,

M We have 4 hours of freedom, we could use some now and probably we should save some for the drive home.

P Well I don't have any freedom. Look – (pointing to his feeding tube connected to the IV pole)

M Ah, but you will. Just wait.

Social effects.

Sylvester spoke longingly of wanting to go to the playroom because he was routinely isolated from other children and unable to go to the playroom. Other children's voices changed when talking of their friends. Nearly all the children discussed the impact of their chronic illness on their ability and/or frequency of being able to see friends, particularly when hospitalized and how they missed their friends and their play together. Sylvester, Drew and Crazy Cool shared that their friends at school seldom asked about their medical condition, what it's like to be in hospital, or about access to play. They stated most times, their friends did not come to hospital to visit or play (some were unable due to distance) as seen in this quote from Drew,

I What do you tell your friends at school?

P About the hospital?

I Yeah.

P Nothing.

I You don't tell them anything?

P They don't ask.

I They don't ask.

P So I don't.

I So you don't tell them, that's fair.

P Kind of… I guess.

Crazy Cool spoke of how she worries about telling friends about her experiences with her medical condition, how hard procedures have been, and how much she misses them,

P Like all of my friends at school, I don't want to tell them about how I feel and how it makes me really sad.

I Um…

P About how I can't see them… because then they will just make fun of me and I don't want that to happen.

She was empathic and knew how it felt to be lonely or left out, and spoke of reaching out to other children at different points in the interview. Here is one example,

I would help them and actually make them feel like they are not alone.

I That's nice. (serious, change in mood and tone of the interaction)

P Cause sometimes I do that when some…when I find someone crying and I sit down beside them and say 'what's wrong?'

I Um hum.

P I do that same thing with everybody at school.

I Do you?

P Because sometimes if they say 'you can't play' and then I go and… help out.

And shortly thereafter,

P I would even be sad but if anybody else was sad then I would go over to them and say… 'you can play with me'.

Theme 4: Children with Chronic Diseases are Resilient and Insightful

Resiliency.

The inner strength, determination and acceptance of their situation, as matter of fact,

was evident in the many insightful and reflective statements the children made. Although there was sadness, loneliness, and a hint of fear about procedures expressed by many of the children, there was also resiliency. Most of the children, all perhaps except one or two, spoke from a positive view, focused on what they could do, what they did for and with others, and how other children were impacted by illness or hospitalization. Crazy Cool spoke with emotion and with insight beyond her 7 years:

P Well I wish I could like run around and play.

I Umm.

P But I can't because of the pole.

I Right. That does kind of get in the way doesn't it?

P But I never really wanna run around, I just want to sit down and get better.

I Oh, okay. Okay. You know what? That's a really cool thing to tell me because I think that…

P 'Cause I want to kick leukemia's butt.

I You want to kick leukemia's butt and you want to get better, you want to let that medicine work and your body needs to rest with it.

P Sometimes I don't really want to have the stuff but I have to.

I Um hum.

P And then I settle down.

I Right, right. So…

P It makes me feel better about myself…sometimes.

Yes, I'm doing what I need to do.

She later goes on to say "I feel like I have to…. And I really want to."

Jimmy Bob See Joe spoke about the value of play for children on the unit and shared this insight which also highlights the resiliency of some of children, "And some of the younger kids don't even want to leave cause they don't know what this place is and all they see is toys and they don't know what's getting pumped into them…All they know is there's toys and then there's play." She also took it upon herself to fundraise and buy toys for the playroom knowing that some items, like the trains might disappear "… and some of them actually take them home because they won't let go. And how can you tell a kid who's going through… who's probably… who's having the worst time of their lives, probably getting chemotherapy maybe, and stuck in the hospital and say 'no, you can't take the train'?"

Insights about play behaviours.

She and Crazy Cool also spoke of how their play differs depending on whether they are alone or with others. They both enjoyed imaginative play and articulated being more cautious in their play when others were nearby. Jimmy Bob See Joe shares, "Like, if you are alone then you kind of go… I sometimes go full out play, like if I'm alone and nobody else is near, I talk out loud and I do whatever I want but usually some other people are there you do it a bit quieter and you do it in your head….And you just aren't, you don't want, you know what it is like how to be embarrassed, or what words mean, and when you're a little kid and somebody says 'that's weird' you are like 'I don't care, I'm going to do it anyway'.

Discussion and Implications for Practice

The purpose of this study was to better understand school-age hospitalized children with chronic illnesses' perceptions of play in hospital. A qualitative description methodology was used and children were offered a choice of three arts-based data gathering activities to elicit their perceptions of play in hospital. Four main themes were described in this paper: (a) play is important in hospital, (b) play is "fun", (c) chronic illness influences play in hospital, and (d) children with chronic illnesses are resilient and insightful.

Play is Important in Hospital

As a certified child life specialist, I philosophically believe play is vital to healthy overall development (physical, emotional, cognitive and social). As a profession we feel strongly that children need play in health care settings to support coping (CLC 2002), and use play is a healing modality. Health care administrators often struggle with the financial and health human resources to ensure play spaces, play activities and people to facilitate and support play experiences. This study shows that participants value and expect play in hospital. The children could not imagine a hospital without play, they were surprised when asked to consider it, stating 'It would suck!", "I would be scared" and "It would be like floating in outer space…It would be like…nothing." These are powerful statements. Other studies, seeking children's perceptions of hospitalization and being an inpatient, repeatedly report children identify play materials/activities, playrooms and playing with a hospital play specialist as the best part of hospitalization (Chappuis et al., 2011; Gibson et al., 2010; Horstman & Bradding, 2002; Lindeke et al., 2006; Wilson et al., 2010).

This health centre has a strong play program in the Children's Health Program. Many children and families with chronic conditions have come to depend on the availability of various play materials/activities and quality play programming provided by our child life staff for all hospitalized children and healthy siblings. It would seem they believe it is their right to have play and materials, and places for playing within the health centre. The United Nations' Convention on the Rights of the Child (1989) supports this right to play, even in health care settings. Some countries, such as the UK and Australia, have been explicit in mandating through public policy that children receive developmentally appropriate health care services, including the right to information, appropriately trained health providers, child friendly health care environments, including play environments (Davies, 2010; Royal Australasian College of Physicians et al., 2009; Waterston & Curtis, 2001).

Family-centred care is a philosophy espoused by most pediatric health settings in Canada (CAPHC, n.d.). Family-centred care is an approach whereby the patient and family are at the centre of the care, are partners in the delivery of health care (Shelton & Stepanek, 1994; Bell, Johnson, Desai, & MacLeod, 2009). Although there is progress in partnering with parents/caregivers in the care of their child, seeking family caregiver feedback about policy and health care delivery, seeking adolescents' perspectives through youth advisory councils, there remains much to be accomplished. Children's perceptions are not often sought about programs or services which affect them, a significant gap if we are to be truly family-centred in our service delivery.

Children are able to express their thoughts and perceptions, share their experiences, and their wants and needs. They identified key people for play in hospital including family, child life staff (their child life specialist, the play program child life workers, the therapeutic clown and even the therapy dogs), and friends. Children enjoy being able to play with their parent, likely something they cannot always do when at home with busy schedules and routines. This may also relate to previous findings that hospitalized children describe their mothers as their primary comfort person in hospital; knowing what they need emotionally and physically and how to provide comfort (Angstrom-Brannstrom, Norberg, & Jansson, 2008) and that they help promote coping during hospitalization (Boyd & Hunstberger, 1998). Friends and siblings were positive play partners when they were able to visit but this was not often possible. Children in Aldiss et al.'s study (2009) also reported having parents, particularly mothers close by, was important during hospitalization. In this study, as well as Angstrom-Brannstrom et al.'s study, fathers were mentioned as visitors and sometimes play partners. There is also the practical aspect that most often father's continue to work and help to manage the daily routine of other children at home.

Children's comments regarding the child life staff demonstrates the value placed on these relationships and interactions, and the importance of engaging with the children through play. Participants stated that child life specialists and workers "bring play" and "play with me". Most children spoke of the many choices they had for play activities and had only a few ideas for additional activities/equipment, some which are possible to purchase while others may not be feasible for the current health care space.

As child life professionals and for administrators, there is often a struggle about where to focus limited time and resources- play programs or individual/group therapeutic interventions. The challenge is that this is not a choice we should be forced to make. I believe children need both. Children benefit from normative/free play to help them adapt to the hospital and/or process their health care experiences (Fereday & Darbyshire, 2008; Potasz et al., 2013). In addition to normative play opportunities, many children need individualized child life specialist interventions to help teach, prepare, express concerns and worries, to support overall coping, or focus specifically on developmental needs (Humphreys & LeBlanc, in press; Rollins et al., 2005; Thompson, 2009). This is dependent upon psychosocial risk factors for coping with health care experiences such as their developmental level, temperament/coping style, perceptions of previous health care experiences, available family/social support, and maternal and child trait anxiety level (Gaynard, Goldberger, Thompson, Redburn, & Laidley, 1990; LeBlanc & Chambers, 2013; Staab, Klayman, & Lin, 2013; Sylva, 1993).

It is not surprising that children spoke frequently of play in their patient room and the playroom, however it was a bit of a surprise that so many spoke of their room as a favourite place for playing. This seemed directly related to their level of fatigue and mobility, although for a couple it may have also been related to changes in physical appearance. These statements were from children undergoing treatment for cancer or blood disorders, those with lengthy and intense side effects from treatment.

The activities of which participants spoke most frequently were typical for this developmental level- games, building things such as Lego, arts/crafts, imaginative play,

as well as physical/outdoor play (although to a lesser degree, see health effects on play) and play with the therapy dogs. This is in-line with other researcher findings (Berinstein, & Magalhaes, 2009; Brockman, Fox, & Jago, 2011; Glenn, Knight, Holt, & Spence, 2013; Lehrer & Petrakos, 2011; Miller & Kuhaneck, 2008; Wee & Anthamatten, 2014). However for the most part, children spoke more about sedentary activities when discussing play in hospital which is in contrast with studies of healthy children (Brockman, et al., 2011; Lehrer et al., 2011; Alexander, Frohlich, & Fusco, 2014). Many spoke of missing being physically active and frustrated with being tired or unable to play basketball etc. because of fatigue, medical equipment or restrictions. This has implications for health care professionals which will be discussed a little later.

Interestingly, as other researchers have noted (Brockman et al., 2011; Glenn et al., 2013), there are variations in children's perceptions about movies as play or not play. None of the children mentioned watching TV as play. Some children spoke of technology based interactive activities such video games and/or using their tablets for watching movies or gaming and perceived this as play, but not as many as I would have anticipated given the proliferation of these devices and the frequency of their use. Once they no longer enjoyed the technology based activity, it was boring and no longer fun. The children appreciated the many choices and options for activities found at this health centre to help so they would not "be bored" and when parents or child life staff |'play with" them. Accessibility to a variety of play materials and appropriate play spaces with trained personnel are important for hospitalized children with chronic illnesses to support coping and decreased stress response (Aldiss et al., 2009; Potasz et al., 2013). Health

professionals, administrators and researchers must not underestimate the role of such play opportunities in the overall coping and well-being of children and youth, particularly those who are repeatedly hospitalized or whose diagnosis effects access to play materials, frequency of play opportunities and engagement in individual, parallel and social play. To do so would minimize the importance of such experiences in a child's overall development (Bolig, 2005; Chambers, 1993; Haait, Bar-Mor, Shochat, 2003; Thompson, 1989, 2009).

Play is "Fun"

It would seem that children, regardless of setting and culture, define "play as fun" and that play is an activity chosen freely (Berinstein & Magalhaes, 2009; Glenn et al., 2013; Lehrer & Petrakos, 2010; Wong et al., 2011); without the need for purpose or a specific goal other than being fun. Although this has been a component of definitions created by researchers and theorists for several decades, the simplicity of children's definition may provide an understanding of why their play changes over time, as they grow and develop, and as technology and social context changes, so too may be their perception of what is "fun" and enjoyable.

The findings from this study seem to preliminarily support The Dynamic Model of Play Choice's theory that "play activities perceived as fun are more likely to be repeated because of positive emotions associated with them. This repetition creates a pattern or preference, and continued engagement in the activity contributes to mastery" (Miller & Kuhaneck, 2008, p. 412). This theory notes that children define play as "fun", and of their choice; that activity characteristics, relational characteristics, child

characteristics/preferences, and contextual characteristics form the foundation of the model along with the right balance of the child's ability and the challenge of the activity. Although there are differences between participant groups related to the experience of chronic illness, there were many similarities in the children's perceptions of play. They spoke of their play activities with a smile and verbalized their enjoyment. They spoke of places for playing, and the context for play; enjoying playing with others (family, staff and friends, and therapy dogs), which seemed to relate back to play being fun. According the Miller and Kuhaneck, this interconnection and repeated behaviours provides a positive emotional response and meaning to their play. This repeated choice of activities creates a patterns for play choice which contributes to mastery. Further exploration of this model, as it relates to play in hospital, may be warranted.

Individualized child life specialist therapeutic interventions for school-age children are often play based, sometimes in conjunction with focused therapeutic conversations. Children in this study primarily discussed normative play when discussing play in hospital. However, one child spoke of therapeutic play and discussion with her child life specialist. Although I did anticipate this might be the case, further research is needed to explore children's perceptions of therapeutic play, what it's like to participate in therapeutic play, if it is helpful in promoting coping responses etc. It would be valuable to understand how children perceive therapeutic play; is it perceived as play or "not play", or perhaps it is perceived as "teaching" or "learning", like other contextually based activities in the school setting (Howard, 2002; Howard et al., 2006; Wong et al., 2011); we need to know more.

Chronic Illness Affects Play in Hospital

The children in this study made some very profound and insightful comments about how their illness has an impact on their play in hospital (and in their lives in general), on their play choices, the location of play in hospital and also the level of physical endurance, amount of play s/he did and sense of grief and loss. These findings are similar to the experiences of children and young people being treated for cancer in a UK study (Gibson, Aldiss, Hortsman, Kumpunen, & Richardson, 2010).

Although one might logically assume this would be the case, hearing the children speak of it consistently made an impression and heightened my awareness of the importance of these findings for clinicians. It is important to be aware of the sense of loss regarding typical play activities, the potential benefit of developing new play interests, and/or adapting ways to do favourite activities. It is an important consideration for all children who experience these types of health effects for significant lengths of time, not only those children with cancer.

Children with Chronic Illnesses are Resilient and Insightful

There are varying perspectives and definitions of resilience. Child life specialists inherently believe in the inner strength and abilities of children and families, while recognizing the many influences and interactions within and among various individual (e.g., developmental level, temperament, coping style) and social constructs, such as the people in their lives (e.g., family, friends, teachers, health professionals etc.), their health status (e.g., diagnosis, treatment demands, and effects etc.) and social worlds (e.g., home, school, hospital, community etc.). When children are provided with child-centred and

developmentally appropriate supports, they can often overcome challenging or adverse events or situations (Humphreys & LeBlanc, in press).

For those who work with children, it is not surprising that they have amazing things to share with us, if we engage and we listen. The children in this study shared their insights and their observations, demonstrated empathy for others in hospital and at their school, likely stemming from their own awareness and experience with challenging and traumatic experiences.

For the most part, the children with whom I spoke emitted inner strength, optimism, determination and hope as they shared their perceptions. I had the sense that they felt supported in their health care journey. Two of the children were quieter and more reserved, yet emitted a sense of resigned determination and spoke fondly of their family (parents and siblings) and their friends as key people for play. These children may have needed more time to trust and engage, or were perhaps feeling more vulnerable and challenged by their experiences. These are important aspects to acknowledge as health care providers as we seek to build/promote resiliency for children and their families. One way to do this is to ensure the provision of play materials/activities, play spaces and play programs provided by trained professionals who can support or facilitate play (Bolig & Weddle, 1988; Gaynard et al., 1990; Humphreys & LeBlanc, in press).

Interestingly several of the children spoke of playing with toys that they perceived as being for younger children and spoke openly of enjoying this type of play, while monitoring their play behaviour based on who was nearby and might be listening or watching them. This is in keeping with this developmental stage. What is not clear, is if

as a result of their health condition and emotional needs they enjoy playing with such activities longer than healthy children. The girls spoke openly about enjoying imaginative/creative play with their stuffed animals, Lego and other toys, which seems to be meeting their developmental needs. Surprisingly none of the older children stated they found the playroom to be "too young" for them. Again it is unclear if this is related to regression in play behaviours due to their experience of chronic illness, or if for this age group, when provided the opportunity for such play, that children gravitate to it when permitted to do so. This may be in part due to the ability to go the Teen Lounge during tween time or as a one-on-one intervention with the child life specialist.

Strategies Used to Foster Rigour

Methodological

Several strategies were undertaken to support methodological congruence and rigour. The study methodology fit with the research question and multiple arts-based data gathering activities allowed for triangulation of the data (interviews, drawings). Data were gathered and analyzed as the study progressed. There was a one month period in which there were no eligible participants. I took that opportunity to have a child life specialist content expert, not involved in the study, review the code definitions for clarity and relevance, and review the first two coded transcripts. Additionally, since I had not coded any new interviews during that time, I recoded the same first two interviews to assess my consistency in coding, as recommended by Guest, MacQueen & Namey (2012). The content expert suggested clarification between two codes (special events and Playgarden programming) and helped me to provide clarity in these two code definitions.

Otherwise, definitions and coding were deemed to be relevant to the study. My thesis supervisor reviewed the first interview transcript and provided comments and suggestions. Additionally, I maintained a reflexive journal which also incorporated methodological questions and decisions as I went along.

Data Gathering

The arts-based activities selected for the proposed study were intended to appeal to children with varying developmental/cognitive skills and varying personal preferences; to allow choice and control of how to participate. The arts-based activities were respectful of children's varying communication skills, cognitive and overall developmental level, based on Piaget's cognitive theory (in Turner, 2009).

Child consultants were asked suggestions related to the arts-based data gathering activities. This enhanced my confidence in the activities offered in the study. Given that each arts-based activity was chosen by at least one participant supports recommendations for multiple activities for gathering data with children.

Participants reported enjoying the activities and that doing the study was "Ok the way you did it". I believe offering the choice of multiple arts-based approaches did enhance the quality and quantity of data provided by child participants as has been reported by others (Coad, 2007; Darbyshire, MacDougall, & Schiller, 2005; Fargas-Malet et al., 2010) and provided more quality data than interviews alone, or interviews with one art-based activity. Although a detailed discussion of the data gathering activities used in this study is beyond the purview of this paper, each activity had strengths, potential challenges or unexpected outcomes which have been reported elsewhere (see Chapter 2).

I tried to ensure that questions were asked in a way that reflected the child's developmental level and personal characteristics and were rephrased if needed. Sometimes the question was dropped until later in the interview when the topic resurfaced. Typically the child was better able to respond. The drawings were accurate in their portrayals of the environments, directionality and details of materials/activities, and furniture in the spaces. Although not every detail of the spaces or people for playing were drawn, the drawings were representative of the interview, corroborating aspects of the semi-structured interview. The photographs, created by the researcher before the study, were effective is triggering children's memories and facilitated responses to the interview questions. The child-led tour was a great option for the child who needed to move about and be able to talk and walk. Although the recording was difficult to hear in a few spots, the overall success of this activity for this particular participant superseded any technical issue.

In retrospect, having several hand manipulatives, or engaging toys/activities to engage the participants at the beginning might have helped build rapport and comfort level more quickly, for some. Additionally, I learned that younger children in the study needed longer to disengage from the encounter. Several wanted to continue to draw or play after the actual data gathering activities were complete. I would suggest planning for this more readily.

Transferability

The study took place in a tertiary maternal and child health centre in Eastern Canada. It serves a large geographical area. The play spaces and play programming

available through Child Life Services at this health centre may be different from other community health centres in the region. We have dedicated child life workers who provide play programming in our playrooms and in the Playgarden, as well as certified child life specialists who provide developmental as well as therapeutic play, often one-on-one with children who require individualized child life specialist interventions. This is most likely similar to larger health centres with child life programs and staffed play spaces. Further research is needed to determine if children's perceptions of play in hospital is different in health centres without a child life program, or centres without dedicated play programming staff, play spaces, and/or those with limited or no play materials.

Study Limitations

Although many of the sentiments and themes reverberated across diagnoses, supporting in a non-categorical approach to research, the degree to which the play behaviours of children with cancer seemed to be affected by their condition seemed greater or at the very least, mentioned more frequently. All but three of the children had some form of cancer or pre-cancer diagnosis. There may be value in exploring, in more detail the effect chronic diseases and their treatments have on children's play access, play choice, and play opportunity. It would be valuable to explore this in the context of hospital, home and school environments.

Conclusion

Children's description of play in hospital, what they find enjoyable, helpful, and contributes to their well-being, to my knowledge, has yet to be described. This study

provides child life professionals, health care providers and health administrators with new knowledge. The findings provide pediatric health professionals and administrators with a better understanding of the importance of play in hospital, what children perceive as play in hospital and how they define it, their play needs and preferences, the importance of trained staff who facilitate play, the impact of health care experiences on play, and the resiliency and insightfulness of school-age children with chronic illnesses. All of which can ultimately influence resiliency, emotional well-being and overall coping with health care experiences. This study also reinforces that children are interested and capable of sharing their perspectives about services which affect them when provided with developmentally appropriate ways in which to do so.

It is my hope the findings will also help inform decisions regarding play environments and the need for play materials and staff specialized in facilitating play in pediatric health settings. Moreover, this study can inform further research on play in hospital including normative play and therapeutic play interventions, children's perceptions of therapeutic play provided by child life specialists, and play's impact on overall coping and well-being for children with serious or chronic health conditions and for those with mental health conditions. There is much to be studied.

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Chapter 4: Discussion

Introduction

This chapter will provide an overview of the findings from both the methodology and the research study manuscripts, discuss implications for practice (for health professionals and health care administrators) and implication for research with children with chronic illnesses. I will also highlight the many areas for future research and close with concluding remarks.

Overview of Purpose and Objectives of the Study

My thesis research journey began with a goal to understand children's perceptions of play in hospital, to understand how children with chronic illnesses described play in hospital, what they enjoyed playing with, where they played, and the people (and, as I learned, animals) important for playing. The research question was: "How do hospitalized children with chronic illnesses perceive play in hospital?" The following objectives were developed as a guide; to understand how hospitalized children with chronic illnesses:

- described play in hospital
- defined play in hospital
- perceived play in hospital

Summary of Findings

Both of the manuscripts contribute new knowledge to the field of child life, paediatric health care, child development and the field of research with children in the social sciences. The methodology manuscript provides a rationale and a review of the

literature related to participatory and arts-based activities used in my research study. This first manuscript provides a description of the evidence and an analysis of the three arts-based activities offered, in conjunction with a semi-structured interview, during data gathering. The manuscript describes the strengths and challenges of each arts-based activity as well as unanticipated outcomes experienced during the study. It contributes new evidence to the value, feasibility and outcomes of using these specific activities for gathering data with school-age children. It was emphasized that the arts-based activities were data gathering activities used within a qualitative description methodology with children, not a methodology in and of itself, as is sometimes described in the literature (Carter & Ford, 2012; Clark, 2005; Fargas-Malet et al., 2010). All three activities helped children to express themselves in a way that fit with their developmental ability, temperament and communication style. Using the activities enhanced the quality and likely the quantity of the data, although this was not formally evaluated. The fact that all three activities, photo elicitation, drawing/mapping and child-led guided tour were selected by the children supports the value in having multiple data gathering activities from which children can choose.

The second manuscript describes the actual research study and the findings. It also provides a lengthy discussion of the findings as it related to my conceptual framework and current evidence (see pp. 128-158). Four main themes were described: (a) play is important in hospital, (b) play is “fun”, (c) chronic illness influences play in hospital, and (d) children with chronic illnesses are resilient and insightful. Although these themes may seem obvious to many who work with children, this study provides

evidence to support previous observational studies as well as our clinical assumptions. It also brings to light the impact of chronic illness and treatment on school-age children's play behaviours.

The study provides evidence that children expect, want and value play in hospital. As the researcher who spoke with the children, there was a feeling that they took "play in hospital" for granted, that "of course" there are toys/activities, and people with whom to play. They seemed surprised or shocked when asked what it would be like not to have toys or places to play in hospital. Their words are only one piece of the data, their voices, and non-verbal responses added so much to their responses that it would be "scary", "boring", "it would suck!" and "it would feel like nothing…like floating in space" if there were no toys or places to play. Children seemed to expect play in hospital to exist, in essence that it was a "right" to play in hospital. Perhaps as noted earlier, this is due to the fact they have experienced our play program, the access to a variety of play materials and activities, the dedicated and specialized staff who focus on play and children's developmental and psychosocial needs, the dedicated play spaces and therapeutic clown and therapy dogs. It is not clear if children from other, smaller health centres or children without chronic illnesses would have the same perceptions and expectations for play in hospital. However, it is clear these participants (and their parents) value, want and benefit from play and people for playing in hospital.

Child life specialists and other health professionals who have had the privilege of seeing the impact of play for hospitalized children would agree with the UN Convention on the Rights of the Child that children have the right to play, even in hospital. This

however, is not always available (e.g. clinics, waiting spaces, community hospitals, doctors offices), likely for many reasons such as infection prevention and control expectations/rules, and the human resources needed (as well as knowledge and skill) for selecting, purchasing, maintaining and cleaning the many items needed to meet various developmental needs. This is an important consideration for health care settings where pediatric patients receive service.

The children in this study define play as "fun" and an activity that is chosen freely. Play included many activities, both physical and sedentary, including creative (art and construction activities), expressive, and outdoor play etc. The study provides evidence, from children, confirming some aspects of theorists/researchers' definitions of play from decades old observational studies, namely play is voluntary (a choice activity), is pleasurable, has no planned purpose other than the fun of the activity itself, includes pretend ("as if") play and active play (physically and cognitively, Bolig, 2005, p. 84). Other aspects of Bolig's synthesized definition, namely that play must be internally motivated, be unique and unpredictable lacked confirmation from children in this study. Children were clear in differentiating between activities that were play and those they perceived were school/learning. These findings coincide with other studies outside of hospital with children (Howard, 2000; Wong et al., 2011; Yan et al., 2005).

An unexpected finding was the extent to which the children discussed the effect their illness and treatment had on their play behaviours. Many were saddened and expressed a sense of loss at not being able to do or perform their favourite physical or social activities. This logically makes sense, given the types of chronic disease and the

treatment plans for most of the participants. However, the frequency and emotion relayed during the interviews was profound and an important consideration for clinicians.

The findings also highlight the resiliency of most of the children in this study, their insights about themselves and their situation, their determination and genuine empathy for others. Several children reflected on how their diagnosis has had an impact on them, their compassion for others, and a sense of mastery when they overcome difficult experiences such as needles. Children spoke of their desire to help and play with others in similar situations or those who were alone or sad, as well as playing with and helping younger patients. One might assume this gave them a sense of being in control, mastery, helping and giving back. As clinicians, being able to support these strengths and active coping strategies during challenging health care experiences is an important aspect of our work.

Limitations the Study

Although many of the sentiments and themes reverberated across diagnoses, supporting a non-categorical approach to research, the degree to which the play behaviours of children with cancer seemed to be affected by their condition seemed greater or at the very least, mentioned more frequently. All but three of the children had some form of cancer or pre-cancer diagnosis. There may be value in exploring, in more detail, the effect chronic diseases and their treatments have on children's play access, play choice, and play opportunity. It would be valuable to explore this in the context of hospital, home and school environments.

Additionally, the study was confined to one setting and to school-age children. Broadening the participant group to different health care settings, such as general/regional or community hospitals may provide additional or new data; doing research with younger children, and/or youth, and children receiving services in mental health programs may provide differing perceptions of play in hospital, what is valued, needed and potentially impacts play behaviours.

Implications for Practice

Implications for Health Professionals and Administrators

Children can and do want to share their ideas and perceptions about things they know or experience in their world. When health professionals/administrators engage with children in a developmentally appropriate way, are sincere and listen to what they say or what they share in visual/creative ways, there is an opportunity to gain true insight into children's experiences, from their perspective. Health professionals cannot assume to know how they feel or how they perceive any given phenomenon, even as seasoned professionals. Health professionals have their own lens from which they observe and experience life. An individual's view/observation of a child's experience of a phenomenon is only one piece of the story. Being able to listen and feel the emotion when children share their stories/experiences provides additional insights. It is important to be respectful and capture children's perceptions in the best way possible, checking with them to ensure their meaning was understood. In practice, this engagement, respect for children's perceptions and views of their world is critical in rapport building, gaining

trust and being able to offer interventions that may be helpful to them, that are informed by research and/or clinical work.

The children and families in this study valued the play program, play spaces (including the playrooms and outdoor Playgarden) and the services and staff which support play. There was little they wanted changed. This does not stop the child life service at this health centre from continually wanting to improve the play program, interventions and services to children and families. There continue to be comment boxes at each of the playrooms and the teen lounge. Different children and families may have differing needs and perspectives. The child life team remains open to other perspectives while taking some comfort and pride in knowing the play program is meeting the play needs of many.

Children often identified their mother as an important person for play in hospital. This is an important finding and one which can be purposely incorporated into play programming or child life specialist's plan of care. Finding activities that both mother and child can enjoy together, helps enhance the play experience for the child (and likely mother as well), supports attachment and allows them to experience something special together. Vilas (2013, 2014) explains that play maps can be used as a way for mother and child to share their favourite play memories with one another, strengthen their understanding of one another, and their individual and mutual play preferences. This activity could be valuable when trying to engage parent and child together in play, or to enhance their play experience with one another.

Child life specialists and others working with children with chronic illnesses whose physical mobility and/or treatment has an impact on their play will hopefully now be more mindful and purposeful in their conversations about play preferences and changes in social play. Children wanted and missed being physically active. When they felt able to play in a more physical way, they enjoyed the environment and play structures in the Playgarden and the outdoor play programming provided by the child life workers. Given these findings, there seems an opportunity for clinicians to potentially prepare children and families for the possible changes in play behaviour, explore changes children are currently experiencing, and discuss strategies to adapt their favourite play activities or explore new activities to expand their repertoire of play. Being purposeful and adding play goals in the plan of care can help emphasize the importance of play, including outdoor play, for children with chronic illnesses and aid their overall coping.

The findings help support and inform other health professionals of the importance of play in hospital as perceived by hospitalized school-age children with chronic illnesses. Evidence, directly from children allows child life specialists, other health professionals, hospital administrators and donors to advocate for improved play access and services for children. For others, it may allow them to feel confident in decisions and the continuing need to support/advocate for play in hospital, the materials and people who can best support it, such as child life professionals.

Implications for Research with Children with Chronic Illnesses

As noted previously, children in this study were excited to participate and share their perceptions using the arts-based activities, to help this author learn about play in

hospital. Nine of the ten children chose one of the three arts-based activities offered. Using the arts-based data gathering activities helped to engage the children in the topic, facilitated the discussion and enhanced the data quality and quantity by prompting memories through the use of photographs created by the researcher, allowing children to draw and illustrate their experiences, and by allowing physical movement and visual memory triggers during the child-led tour.

It is important to keep in mind that when doing research with children or seeking their input about services as a quality assurance initiative that we, clinicians and administrators, are prepared to listen and act upon their feedback. In the case of this study, I will report the findings to our clinicians, administrators and colleagues, identifying the key learnings from the study. I will look to incorporate the feasible activities/equipment to our repertoire for the children (adapted basketball nets that could hang in patient rooms, an alternate video gaming system, and other toys mentioned etc.).

As Hill (2006) reported children want to know the results of what was learned and what will happen with the information researchers learn from them. The children and families in this study all wanted to receive a summary of the findings, hence I will be sending a child and family friendly research summary. The findings will be shared within the health centre and far beyond; through anticipated publication in peer reviewed journals; through our professional council; conferences and teaching opportunities; in the course of clinical work by supporting and advocating for play (activities, toys, places for play, people for play), and adapting physical equipment for play; and exploring new activities for play when old favourite activities are limited or no longer do-able.

Other considerations when doing research with children that were highlighted during this study include:

1. the need to plan for additional time when coordinating research consent/assent, coordinating the actual interview time because of treatment, health care delivery, and the need to feel well enough to participate.
2. the value of planning for a warm up time/activity to allow the child to become comfortable with the interviewer, being prepared for the child to want you to stay and play something of their choice, and being able to close the session effectively.
3. the fact that children are not often aware or concerned about others knowing they are involved in a research study; it is our responsibility to ensure we protect their privacy, to the extent possible.
4. balancing the need to revisit assent throughout the research process with the risk of having the child feel there is a reason why they should not agree to continue, to use their quotes or to use their drawings.
5. the need to consider if a child might be embarrassed by what they said or how they articulated the words and having a plan of how to address this (e.g. changing the spelling of a mispronounced word, or paraphrasing, or keeping the exact words/pronunciation).
6. balancing the reported benefit of having open-ended questions for school-age children and a child's developmental ability; being prepared to ask clarifying questions, rewording the questions or revisiting the question at a different

point in the interview. It may also be necessary to reword the question to be more concrete; it is important to be flexible while not leading the answers. This is more challenging than one would anticipate.

7. being prepared for parent participation; setting the stage in advance of the session if you wish or do not wish parents to participate in the discussion. Practise, in advance, how to address parent involvement if deemed distracting or contrary to your agreement with the parent.
8. being prepared, as a clinician, about how you will engage with the child/family after the interview if you see them throughout the health care setting.
9. recognizing that staff may provide additional child/family or diagnosis specific details to you as a clinician researcher compared to an external researcher because they see you as staff, not as a researcher. It is important to be prepared to remind staff of your role as a researcher with limited need or right to information for which the family has not consented to share.

Summary

Both manuscripts highlight that children want and can participate in research and discussions related to topics of interest and services which affect them. The first manuscript, focusing on the three arts-based data gathering activities used in the research study, highlights the importance of matching the data gathering strategies with the research question, the developmental level and abilities of the participants and with the methodology being used in the study. This methodological paper adds new information

about research with children, the use of three arts-based data gathering activities with school-age children with chronic illnesses, namely the use of photo elicitation interviews using author created photos, drawing/play mapping, and child-led guided tours with school-age children in the context of a health care setting.

The findings in the second manuscript provide pediatric health professionals and administrators with a better understanding of the importance of play in hospital as perceived by hospitalized children with chronic illnesses, their play needs and preferences, places where they play in hospital and don't play in hospital, the value of trained staff who facilitate play, how they define play in hospital, the impact of chronic illness and treatment on play in hospital, and the resiliency and insightfulness of these young patients. It is my hope these findings will inform decisions regarding play environments in health care settings, the importance of play materials and spaces that support children to play, and the value of trained staff specialized in facilitating play. This study can also inform many potential areas of research related to data gathering with children in general, those with acute or chronic illness, as well as research related to play in hospital and child life interventions, particularly therapeutic play. The following section identifies potential areas of future research.

Future Research

These findings provide new and significant evidence about the use of three arts-based data gathering activities with hospitalized school-age children with chronic illnesses as well as providing a better understanding of their perceptions of play in hospital. The findings have the potential to inform further methodological research with

children, research on arts-based data gathering activities as well as research related to play in hospital, normative play and therapeutic play interventions, and/or to assess play's impact on overall coping and well-being for children with serious or chronic health conditions.

As was noted in manuscript 1, there is a need to report how and when arts-based activities are valuable in obtaining data with children, at various developmental levels and within different research paradigms. There is a need to determine what arts-based activities could be used with young people with cognitive delays or children in minority groups. I agree with researchers who call for transparency and clarity when reporting study findings. It would be helpful to describe the successes and challenges of using arts-based activities for data gathering, how they enhanced participant involvement, and the impact on data gathering (Clark, 2005; Darbyshire et al., 2005; Fargas-Malet et al., 2010; Mathers et al., 2010; Morgan et al., 2002). The goal is to increase knowledge and evidence about the value of these data gathering activities. In order to inform practice, it is important to scrutinize the arts-based data gathering activities used and for editors and publishers to ensure this information is reported in manuscripts. My first manuscript is an effort to do just that.

Furthermore, we need to better understand children's experiences of being consultants, participants and co-researchers, not only from a participant level but also the impact on society, education and health care systems, as well as the impact of the change on programs or policies (Clark, 2005; Darbyshire et al., 2005; Fargas-Malet et al., 2010; Morgan et al., 2002; Punch, 2002). Although I did ask most of the children how they

perceived their experience in my research study, it was in a casual manner and certainly not in depth. Many studies do not ask their young participants to formally evaluate their participant experience, their perceptions of being involved in research or the data gathering activities used during the study. More information is needed in these areas.

It would be valuable to understand if severity of illness influences children's participation in normative play in hospital playrooms; if children perceive play in hospital playrooms as different than play in child care centres or school settings; if the context of the play space, the people available for playing in various health care settings influences hospitalized children's play behaviour or perception of play in hospital. Moreover, children with mental health illnesses often do not have the same access to play materials or play spaces as children in general pediatric settings. What is their perception of play in hospital? What do they perceive needing and wanting and how might their play and developmental needs be met in the context of their illness and care environment? These are all important questions.

There remain many questions related to how children perceive therapeutic play; is it perceived as play or "not play", as "teaching" or "learning" like other contextually based activities in the school setting (Howard,2002; Howard et al., 2006; Wong et al., 2011)? Furthermore, we need to better understand children's perceptions of child life specialist's use of therapeutic play; what it's like to participate in therapeutic play; whether children perceive directed play, such as in teaching or preparation sessions, differently than non-directed play sessions where the child is fully in control of the play session. Further evidence is needed to better understand if and how therapeutic play

activities promote coping responses during health care experiences. It would be valuable to know if there is scaffolding or generalization of these coping skills beyond the health care setting into other contexts and environments such as the dentist office, the doctor's office when receiving vaccines, having bloodwork in the community or in other stressful situations.

This study provided an opportunity to learn directly from children about their perceptions of play in hospital. To my knowledge, this had yet to be done. Children in the study valued the opportunity to share their perceptions, and the three arts-based activities seemed to make it easier for them to share their views. The findings in this study will provide child life clinicians, other health professionals and administrators with valuable new information. The children's perceptions and insights about play in hospital, the people important for play, and the impact of their health condition on their play is truly inspirational to me, as a child life specialist and as a researcher. I continue to be amazed by the wisdom, insight and determination of young children. The learning has only just begun.

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Appendix A

Participant and Interview Information

Pseudoname	Age	Gender	Arts-based Activity	Length of Interview
Amelia	10 years	Female	Drawing/Play Map	25 min 28sec
Rainbow Dash	7	Female	Drawing/Play Map	19 min 51 sec
Jimmy Bob See Joe	11	Female	Photo Elicitation Interview	24 min 07 sec
Isabella	10	Female	Drawing/Play Map	26 min 55sec
Drew	10	Male	"Just Talk"	15 min 61 sec
Crazy Cool	7	Female	Drawing/Play Map	23min 08sec
Sylvester	6	Male	Drawing/Play Map	46 min 19 sec
Timemine	8	Male	Drawing/Play Map	65 min 37sec
Paddington	8	Female	Photo Elicitation Interview	16min 59 sec
Stormtrooper	7	Male	Child-led Guided Tour	33 min 05sec

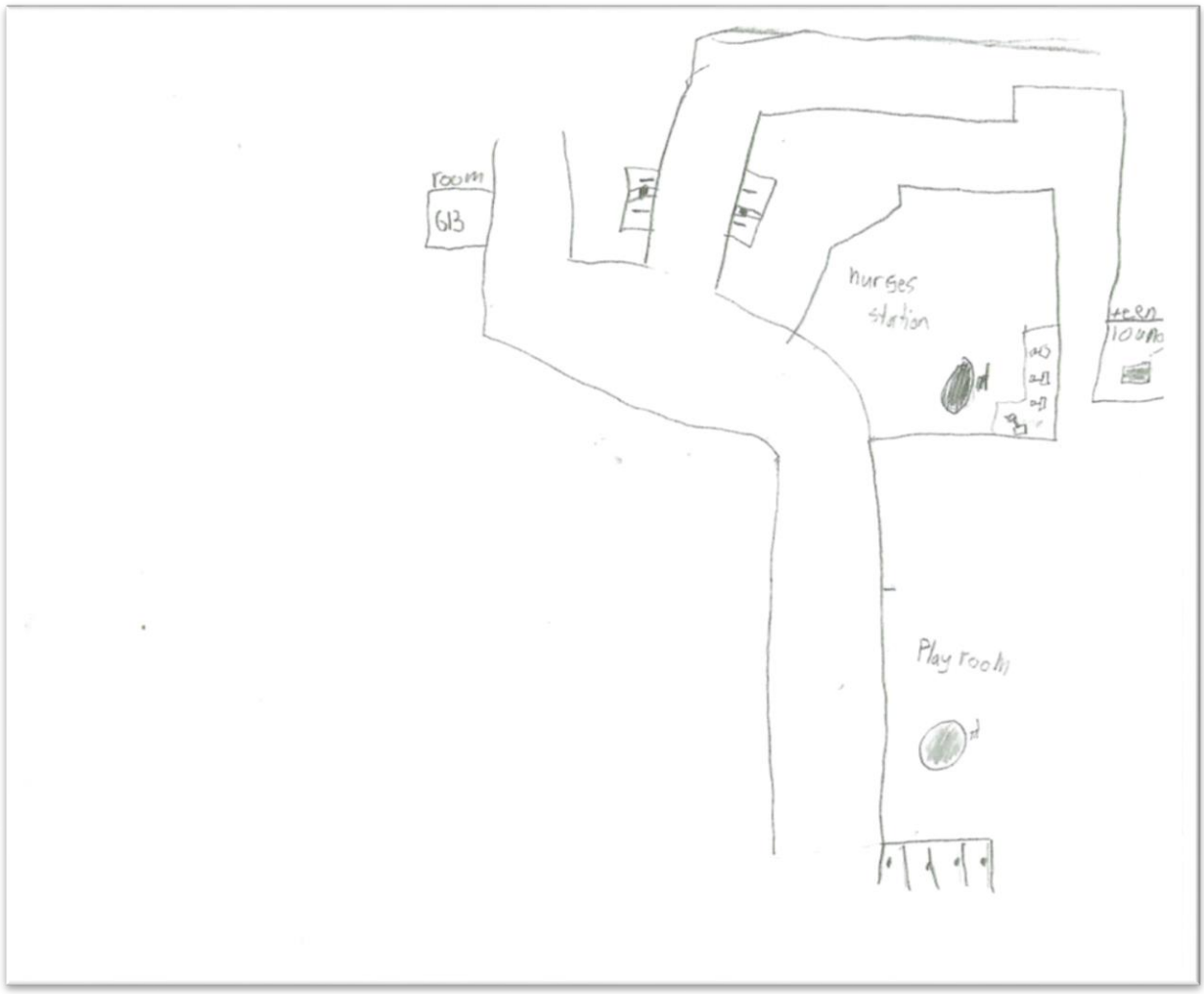
Appendix B

Sample Play Map Shown to Participants

Sample play map McLaughlin, G.B. (2010, December 10). Play memories [Web blog post]. Retrieved from http://www.empoweredbyplay.org/2010/12/play-memories/

Appendix C

Amelia's Play Map



Appendix D

Sample Photo used for Photo Elicitation Interview

Photograph taken by the researcher of the playroom on the medical and surgical floor.

Sample 2 Photo used for Photo Elicitation Interview

Photograph taken by the researcher of a typical patient room.

Sample 3 Photo used for Photo Elicitation Interview

Photograph taken by the researcher of a typical clinic room.

Sample 4 Photo used for Photo Elicitation Interview

Photograph taken by the researcher of the Playgarden

Appendix E

Athabasca University
RESEARCH CENTRE

November 20, 2014

Ms. Chantal LeBlanc
Faculty of Health Disciplines
Athabasca University

File No: 21629

Expiry Date: November 19, 2015

Dear Ms. Chantal LeBlanc,

The Faculty of Health Disciplines (CNHS) Departmental Ethics Review Committee, acting under authority of the Athabasca University Research Ethics Board to provide an expedited process of review for minimal risk student researcher projects, has reviewed you project, 'Chronically Ill Hospitalized Children's Perceptions of "Play in Hospital": A Qualitative Description Study'.

Your application has been **Approved on ethical grounds** and this memorandum constitutes a ***Certification of Ethics Approval***. You may begin the proposed research.

One change is requested to your materials before your begin: please change the word 'candidate' to 'student' on all materials.

AUREB approval, dated November 20, 2014, is valid for one year less a day.

As you progress with the research, all requests for changes or modifications, ethics approval renewals and serious adverse event reports must be reported to the Athabasca University Research Ethics Board via the Research Portal.

To continue your proposed research beyond November 19, 2015, you must submit an Ethics Renewal Request form before October 15, 2015.

When your research is concluded, you must submit a Project Completion (Final) Report to close out REB approval monitoring efforts.

At any time, you can login to the Research Portal to monitor the workflow status of your application.

If you encounter any issues when working in the Research Portal, please contact the system administrator at research_portal@athabascau.ca.

If you have any questions about the REB review & approval process, please contact the AUREB Office at (780) 675-6718 or rebsec@athabascau.ca.

Sincerely,

Sherri Melrose
Chair, Faculty of Health Disciplines (CNHS) Departmental Ethics Review Committee

Appendix F

IWK Health Centre
Research

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

Approval – Delegated Review
January 15, 2015

Principal Investigator: Ms Chantal LeBlanc
Supervisor: Dr Christine Chambers
Title: Chronically Ill Hospitalized Children's Perceptions of "Play in Hospital": A Qualitative Description Study
Project #:1018447

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

Best wishes for a successful study.

Yours truly,

Linda Hamilton
Co-Chair, Research Ethics Board

This approval includes the following study documents:

Document Name	Version Date
EAS Form	2015/01/07
Protocol	2015/01/04
Script - Semi-Structured Interview Guide	2014/07/01 ver V1 July 25
Brochure - Study Information, Parent	2015/01/03
Brochure - Study Information, Child	2015/01/02
Form - Parent Consent and Signature Form	2015/01/02
Data Collection Form - Inclusion Criteria	2014/12/02
Form - Child Assent Signature Page	2014/11/18
Poster - Family	2014/11/20
Poster - Staff	2014/11/20
Questionnaire - Demographic and Descriptive Information	2014/11/23

Confidentiality Agreement - Transcriber Pledge of Privacy	2014/11/09
Certificate of Participation	2014/11/15

The Board's approval for this study will expire one year from the date of this letter (January 15, 2016). To ensure continuing approval, submit a Request for Continuing Review to the Board 2 - 4 weeks prior to the renewal date. If approval is not renewed prior to the anniversary date, the Board will close your file and you must cease all study activities immediately. To reactivate a study, you must submit a new Initial Submission (together with the usual fee, if applicable) to the IWK-REB and await notice of re-approval.

Please be sure to notify the Board of any of the following:
§ Proposed changes to the initial submission (i.e. new or amended study documents)
§ Additional information to be provided to study participants
§ Material designed for advertisement or publication with a view to attracting participants
§ Serious adverse events experience by local participants
§ Unanticipated problems involving risks to participants or others
§ Sponsor-provided safety information
§ Additional Compensation available to participants
§ Upcoming audits/inspections by a sponsor or regulatory authority
§ Closure of the study (within 90 days of the event)
Approved studies may be subject to internal audit. Should your research be selected for audit, the Board will advise you and indicate any other requests at that time.

Important Instructions and Reminders

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

Be sure to reference the Board's assigned file number, 1018447 on all communications.

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

Research Ethics Board Committee Members		
Robert	Bortolussi	Pediatrics (Clinical Researcher)
Kelly	Cameron	Lay Representative
Jill	Chorney	Psychology (Clinical Researcher)
Eleanor	Fitzpatrick	Nursing (Clinical Researcher)
Margo	Fulmer	Lay Representative
Ron	George	Anaesthesia (Clinical Researcher)
Jane	Gillis	Medical Genetics (Clinical Researcher)
Linda	Hamilton	Obstetrics and Gynecology, Co-Chair

Adam	Huber	Rheumatology (Clinical Researcher), Co-Chair
Aileen	McGinty	Legal Representative
James	Morrison	Anaesthesia, Executive Chair
Victoria	Price	Hematology/Oncology (Clinical Researcher)
Krista	Ritchie	Consulting Scientist
Valerie	Shaffner	Privacy
Erna	Snelgrove-Clarke	Nursing (Clinical Researcher)
Marilyn	Tiller	Pharmacy

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

This statement is in lieu of Health Canada's Research Ethics Board Attestation: The Research Ethics Board for the IWK Health Centre operates in accordance with:
- Food and Drug Regulations, Division 5 "Drugs for Clinical Trials involving Human Subjects"
- The Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans - TCPS(2)
- International Conference on Harmonization - Good Clinical Practice Guidelines - ICH-GCP

CHILDREN'S PERCEPTIONS OF "PLAY IN HOSPITAL"

Study Information

Researcher
Chantal K. LeBlanc, BPs, CCLS
Master Health Studies Student,
Athabasca University
Principal Investigator, IWK Health Centre

Supervisors
Dr. Christine Chambers, PhD, RPsych
Centre for Pediatric Pain Research,
IWK Health Centre
Department of Pediatrics and Psychology &
Neuroscience, Dalhousie University

Dr. Caroline Park, RN, PhD
Professor & Academic Supervisor,
Athabasca University

Funding
Athabasca University Graduate Student
Disciplinary Research Fund

Introduction

Child life specialists are trained professionals whose job is to help children and youth cope with being in the hospital and with other stressful events. They *use play or talking to teach what will happen, explain treatment, tests and procedures in a way that makes sense to them.

*practice ways to cope with what is happening and help children/youth to express their feelings.

*ensure that a child will continue to develop, through play and activities, even while in hospital.

Children are the experts about their world. Researchers and health professionals believe children are able to share their ideas and perspectives about the things that are important to them. They can teach us about their lives and about how they see the world around them.

There is little known about how children describe or perceive "play in hospital". Children with chronic illnesses are often admitted to the hospital repeatedly and/or for long periods of time. Because of their experiences in hospital, they are the best ones to help us learn about "play in hospital". This can help us better understand their play experiences, their play needs and how we might improve children's play in hospital or the ways child life specialists use to play to help children cope better.

The Purpose of the Study

The child life team, here at the IWK, wants to learn how children, who have a chronic illness and who are in hospital, describe and perceive "play in hospital".

How will the researcher do the study?

The researcher will meet with you to explain the study and answer any questions. If you agree your child can take part in the study, the researcher will explain the study to your child in a way that makes sense to him/her. If your child wants to be a part of the study, the researcher will plan to meet while you are in hospital. Arts-based activities will be used along with child friendly questions to learn how your child perceives "play in hospital".

What will I be asked to do?

You and your child will be asked to fill out a few questions about your family on a paper questionnaire and return it in the envelope provided. The questionnaire will take less than 5 minutes.

What will my child be asked to do?

You are welcome to stay during the session to watch, if your child would like you to be there. Your child will have a choice of three arts-based activities:
*drawing a "play map", places and play activities your child enjoys doing at the hospital

*looking at photographs of play areas and activities and talking about "play in hospital"

*giving the researcher a guided tour of "play in the hospital".

The discussion will be audio-taped and later typed word-for-word, to allow the researcher to analyse patterns or themes about "play in the hospital" with all the children in the study.

Potential harms and burdens

There are no expected harms. However, a research project can be an "extra", can be an emotional demand and may be an inconvenience at an already stressful time. The researcher will attempt to work around what is convenient for you and your family. If you have any questions, concerns or you/your child would like to speak to your child life specialist or social worker, please ask your nurse to contact the appropriate person on your child's team.

What are the benefits of doing this study?

There are no personal benefits from being a part of the study.
The researcher expects to learn valuable information from children about how they perceive "play in hospital". This information may help other child life professionals, Child Life Programs and hospital leaders better understand children's play preferences, and to help us improve our work in Child Life.

Can we withdraw from the study?

You can choose to have your child be a part of the study or not be a part of the study. The care and services you and your child receive will not change. You and/or your child can withdraw from the study at any time before the interview is combined with other interviews. Once combined with the other interviews, your child's information cannot be identified or separated from the other interviews. Your child can choose not to answer certain questions and/or stop the discussion at any time.
You and your child will be asked permission to use drawings and/or quotes from the interview. You can change your mind about the drawing or quotes being used at any time. However, if they are published and you change your mind, it will only be possible to stop using them in future.

Cost and reimbursements

There will be no cost to you. A $5.00 Tim Horton's gift card is yours to keep, as a thank you for meeting with the researcher to learn about the study. Children who take part in the study will receive a certificate of participation as recognition for being involved.

Will anyone profit from the study results?

This study will not make any money, nor will the researchers be paid for the study. There are no conflicts of interest.

How will my privacy be protected?

All information will be held confidential, except when legislation or a professional code of conduct requires that it be reported. A code will be used to link the questionnaire and the audio-tape; your child's name will be removed from all data and replaced with a pseudo (fake) name (including quotes and drawings).
The study documents and electronic files will be protected and stored in the researcher's locked office during the study and for five years after publication. After which, all data will be destroyed. Electronic files will be encrypted; password protected. Work on these files will only take place where confidentiality can be maintained.

What are my research rights?

Signing the consent form means that you agree to have your child take part in the study. In no way does this waive your legal rights nor release the investigators, or the institution from their legal responsibilities. If you have any questions about research in general, at anytime during or after the study, you may contact the research office at the IWK Health Centre at (902) 470-8520, Monday- Friday 8:00am-4:00pm.

What if I have questions about the study or have a problem?

For questions about the study, please contact the researcher, Chantal LeBlanc at 902-483-7631. If you have any comments or concerns about the study, please feel free to contact the supervisor of the project Dr. Caroline Park toll free 1-866-500-2928, or the Athabasca University Office of Research Ethics at 1-800-788-9041, ext. 6718 or by email to rebsec@athabascau.ca, or IWK Research Services at (902) 470-8520.
This study has been approved by Athabasca University Research Ethics Board as well as the IWK Health Centre Research Ethics Board.

THANK YOU FOR YOUR INTEREST!

IWK Health Centre

Parent Consent and Signature Form

IWK Health Centre

Study Title: Chronically Ill Hospitalized Children's Perceptions of "Play in Hospital"

Participant ID: _____

Participant INITIALS: _____

Consent for My Child to Participate in the Study

I have read or had read to me the information and consent form and had a chance to ask questions which have been answered to my satisfaction before signing my name. I understand the nature of the study and the possible risks. I understand that I have the right to withdraw at any time during the data collection period. Withdrawing from or changing participation in the study will not affect my child's care in any way. I have received a copy of the information brochure and this consent form for future reference. I understand the research study will be listed in an abstract posted online at the Athabasca University Library's Digital Thesis and Study Room, the final research paper will be publicly available and that the research results may be used in teaching, presentations and likely published in a journal and/or online.

I am aware that if I have any comments or concerns about the study, I can contact the academic supervisor of the study Dr. Caroline Park toll free 1-866-500-2928, the Athabasca University Office of Research Ethics at 1-800-788-9041, ext. 6718 or by email to rebsec@athabascau.ca, or Research Services at the IWK Health Centre (902) 470-8520 between 8:00- 4:00.

I understand and I agree to have my child participate in the study, on the understanding that me or my child may refuse to answer certain questions, and may withdraw at any time before the data is analyzed.

Name of Parent: _____

Parent Signature: _____

Date: _____ Time: _____

Statement by Researcher Providing Information and Obtaining Consent

I have explained the nature and demands of the research study and believe the parent named above understands the nature and demands of the study as well as the fact that participation is voluntary and that they or their child may withdraw at any time before the end of data collection, and change permission to use quotes and drawings at any time.

Name (Print): _____
Signature: _____

Date: _____ Time: _____

Study Title: Chronically Ill Hospitalized Children's Perceptions of "Play in Hospital"

Participant ID: _____
Participant INITIALS: _____

Consent for the Use of Quotes
I understand quotes from my child's interview may be used in the final thesis research paper, research articles or manuscripts for publication, presentations/teaching or other dissemination activities (sharing of the research results). I understand my child's name will be replaced with a pseudo-name to protect his or her privacy and my child's age may be used to help the audience understand the developmental level of the child saying the quote.

I understand and I agree to quotes from my child being used, on understanding that my child can withdraw permission to use the quote(s) at any time. However, I also understand that if the quote has already been used, the change in permission will be effective the date notification is received. The quote(s) will no longer be used after permission is withdrawn.

Name of Parent: _____

Parent Signature: _____

Date: _____ Time: _____

Consent for the use of Drawings (if it applies)
I understand my child may create a drawing(s) during the interview and that it (they) may be used in the final thesis research paper, research articles or manuscripts for publication, presentations/teaching or other dissemination activities (sharing of the research results). I understand my child's name will be replaced with a pseudo-name to protect his or her privacy and my child's age may be used to help the audience understand the developmental level of the child drawing the image(s).

I understand and I agree to drawing(s) from my child being used, on the understanding that my child can withdraw permission to use the drawing(s) at any time. However, I also understand that if the drawing has already been used or published, the change in permission will be effective the date notification is received. The drawing(s) will no longer be used after permission is withdrawn.

Name of Parent (Print): _____

Parent Signature: _____

Date: _____ Time: _____

What will happen with the information I share? Or the drawings I make?

The things we talk about will be recorded, so I can remember what we said. Our words will be typed like a story. Then, I read all the stories and put the information together into a research report about how all the boys and girls feel about "play in the hospital".

My report will help my teachers know what I did. The things I learn might be used to teach other people about how children feel about "play in hospital" in a report or presentation here at the hospital, in books or journals, on the internet or at conferences.

Sometimes it helps to show the drawings boys and girls create or to use quotes (words that boys and girls say) to help people better understand and explain something. You will be asked if it is OK to use your drawing (if you make one) or to use the words you say to help with the story. You can say "yes" or "no" and that is OK.

If you want to get a report about what I learned from children who did this research study, I can send you a report in the mail, just fill in the last page.

What if I have questions?

If you or a person in your family has questions about the research, you can email me at chantal.leblanc@iwk.nshealth.ca or call me at 902-483-7631.

If you or your family need to talk to my supervisor, her name is Dr. Caroline Park, RN, PhD, Professor & Academic Supervisor, and you can call her 1-866-500-2928 or you can call Research Services at the IWK Health Centre at (902) 470-8520, Monday- Friday 8:00am-4:00pm.

THANK YOU!

IWK Health Centre

How do Children Feel about Play in the Hospital?

Researcher
Chantal K LeBlanc, BPs, CCLS
Master Health Studies Student, Athabasca University
IWK Health Centre, Principal Investigator

Supervisors
Dr. Christine Chambers, PhD, RPsych
The Centre for Pediatric Pain, IWK Health Centre
Department of Pediatrics and Psychology & Neuroscience,
Dalhousie University

Dr. Caroline Park, RN, PhD
Professor & Academic Supervisor
Athabasca University

Funding made available by
Athabasca University
Graduate Student Disciplinary Research Fund

Who I am and why are we doing the study?

My name is Chantal LeBlanc and I am hoping to learn about "play in hospital" from boys and girls, like you, who need to see doctors or come to the hospital a lot.

I usually work in a different part of the hospital, as a child life specialist, like your friend (name of the child's child life specialist).

The reason I want to learn about "play in the hospital" is because I am doing a big project for university.

What will happen during the study?

I have a few questions about you and your family that you and your parent can answer. This will only take a couple of minutes.

I thought of a few different activities you might like that will help me learn about "play in hospital":

1. I have some photos/pictures of places and play things at the hospital that might help you to think about "play in the hospital" and what it's like for you.

2. I also brought drawing things like pencils, markers and coloured pencils to make a "play map" of the places where you like to play and the kinds of play you do at the hospital.

3. The other choice is to be my tour guide and bring me to places or show me different things that teach me what "play in hospital" is like for you.

We can do whichever activity you like or we can just talk about "play in hospital"; whatever works best for you. Your mom or dad can be with us, if you like.

Are there any good or bad things about the study?

There are no bad things about the study but sometimes talking about the hospital can make people have lots of different feelings. If you have feelings that make you upset, please talk to your family or your child life specialist so they can help you.

The good thing about the study is it will help us learn about "play in the hospital" from children. This could help us know more, teach others about what children enjoy and find helpful when they "play in hospital". It might even help make play in the hospital better in the future, for other boys and girls.

Do I have to be in the study?

Being in the study is something you can decide to do, or decide not to do, or I can come back another time. Whatever you decide is OK. It will not change any part of being at the hospital (like the people who come to see you or the chance to play and do things).

It will probably take us about 30-60 minutes. We can stop anytime you want and finish another time, or stop the whole thing.

Who will know about what I did in the study?

You can tell anyone you want about the activities we do or the things we talk about. I will keep what you say between us, unless I learn something that makes me worried that you are not safe.

We will use a special code and a pretend name so people do not know who you are.

Child Assent Form

IWK Health Centre

Study Title: How Children Feel about "Play in Hospital"

Participant ID: _____

Participant INITIALS: _____

Being in the Study

I read or someone read the information about the study and I had a chance to ask questions. My questions were answered before I signed my name. I know what the study is about and what I am being asked to do. I know that I can stop being in the study at any time before the researcher starts putting my information together with other boys' and girls' stories. If I decide to stop being in the study, I know nothing will change about the care I get and the things I do at the hospital. I have a copy of the information brochure and this form if I want to look at it later. I know the study will be shared with other people, will be used to teach people about what was learned and might be on the internet. I know my name will not be used. This is to protect my privacy.

I understand and I agree to be in the study and I know I can change my mind or not answer questions and that's OK.

Name of Child: _____

Signature/mark to represent signature: _____

Date: _____ Time: _____

Study Title: How Children Feel about "Play in Hospital"

Participant ID: _____

Participant INITIALS: _____

Being able to Use of Quotes
I know some of the things I say (quotes) in our talking time, may be used in the research paper, and when talking or writing about the research study. This can help people better understand the things children want to share. I understand my name will be replaced with a "fake name" to protect my privacy but my age may be used.

I know and I agree that my quotes (words) can be used because I know I can change my mind and the researcher will stop using them as soon as she knows to stop.

Name of Child: _____

Signature/mark to represent signature: _____

Date: _____ Time: _____

Being Able to use Drawings
If I draw any pictures during the study, the drawing or drawings may be used in the research paper, or when doing a presentation or writing about the research study. This can help people better understand the things children want to share. I understand my name will be replaced with a "fake name" to protect my privacy but my age may be used.
I know and I agree that my drawing(s) can be used because I know I can change my mind and the researcher will stop using the drawing(s) as soon as she knows to stop.

Name of Child (Print): _____

Signature/mark to represent signature: _____

Date: _____ Time: _____

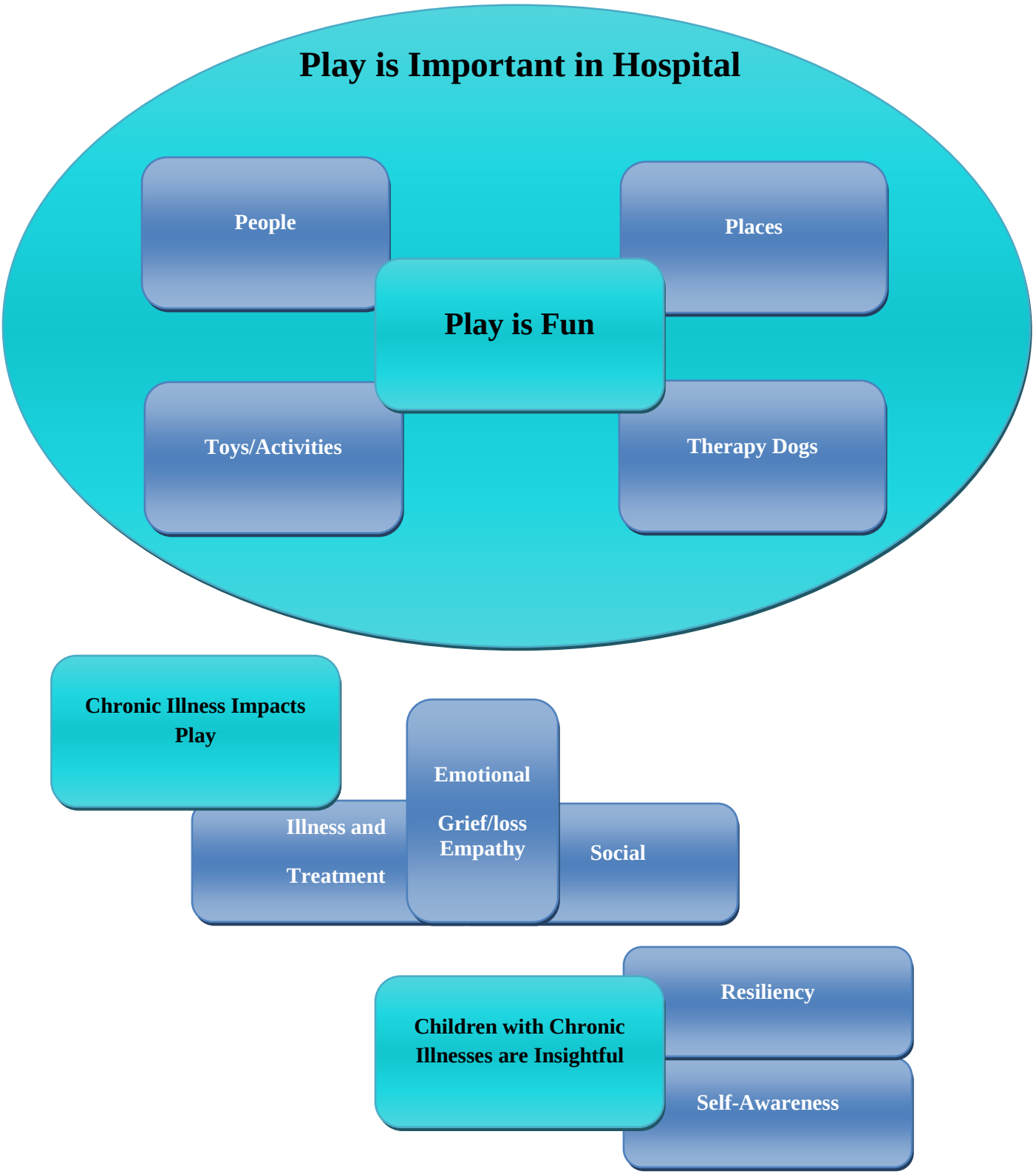
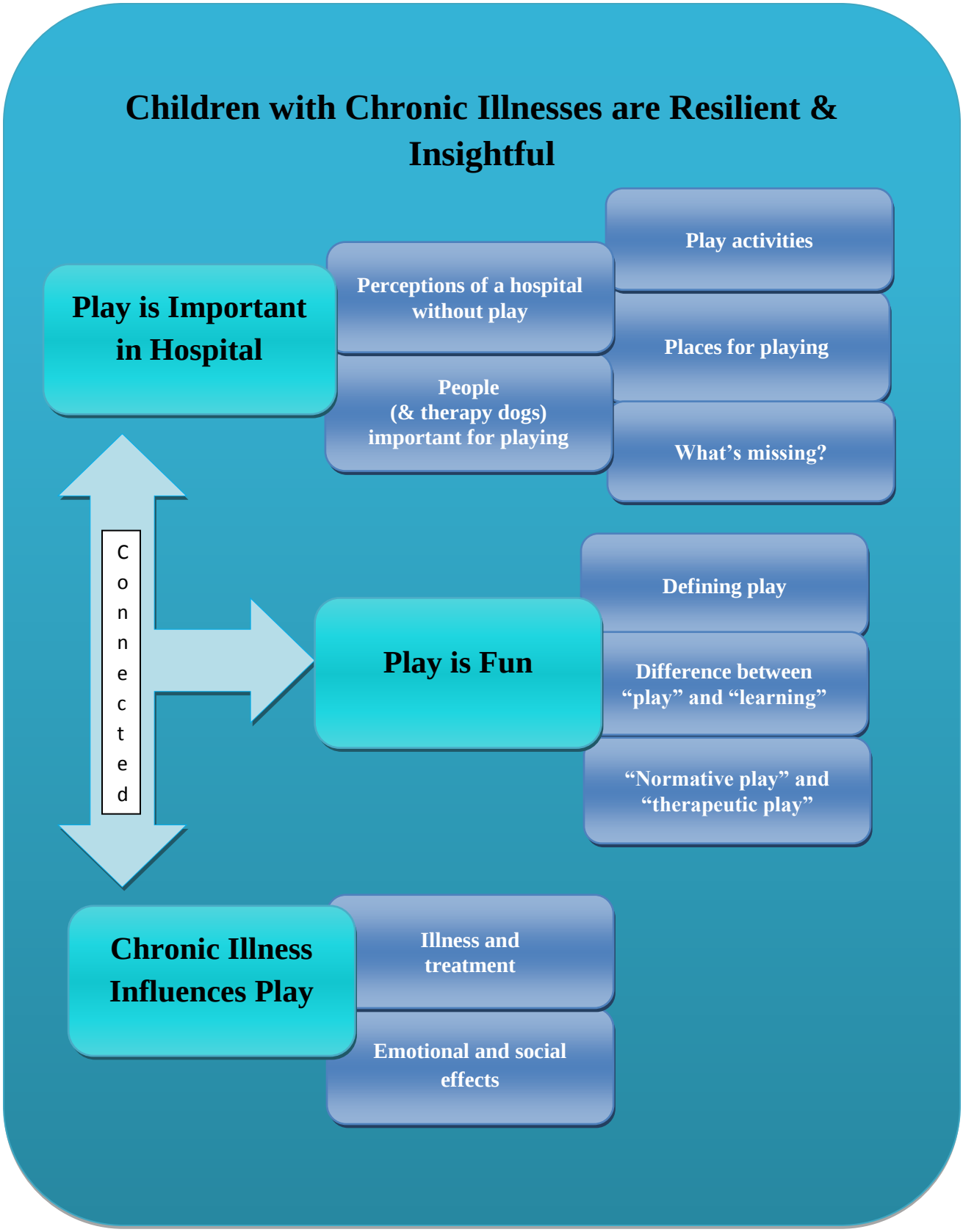
Statement by Researcher Providing Information and Obtaining Consent

I have explained the nature and demands of the research study and believe the child named above understands the nature and demands of the study as well as the fact that participation is voluntary. I believe the child understands s/he may withdraw at any time before the end of data collection, and change permission to use quotes and drawings at any time.

Name (Print): _____ Date: _____ Time: _____

Signature: _____

Initial Thematic Map Illustrating Participants' Perceptions Regarding Play in Hospital, Including Themes and Subthemes



Final Thematic Map Illustrating Participants' Perceptions Regarding Play in Hospital, Including Themes and Subthemes