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# Child life specialists' perspectives on collaboration with schools

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**CHILD LIFE SPECIALISTS' PERSPECTIVES ON COLLABORATION WITH  
SCHOOLS**

by

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**B.A. Honours, University of Guelph, 2007**

**A Major Research Paper**

**Presented by Ryerson University**

**in partial fulfillment of the requirements for the degree of**

**Master of Arts**

**in the Program of**

**Early Childhood Studies**

**Toronto, Ontario, Canada, 2009**

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# CHILD LIFE SPECIALISTS' PERSPECTIVES ON COLLABORATION WITH SCHOOLS

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Master of Arts Early Childhood Studies

Ryerson University

## ABSTRACT

As paediatric patients transition from the hospital environment, there is a lack of programs and supports to assist in this transitional phase. The child life specialist plays a unique role within the interprofessional team of professionals in the hospital. They provide paediatric patients and their families with psychosocial services such as age and developmentally appropriate coping mechanisms. A mixed-method study was conducted through qualitative semi-structured interviews, and a survey to explore how child life managers and frontline child life specialists perceived their role expanding outside of the hospital. Five themes emerged from questions asked in the interviews and surveys. These themes include: role perceptions, collaboration with health care professionals, collaboration with school professionals, challenges to collaboration and recommendations for the role expansion. From these five themes, thirteen sub-themes emerged spontaneously. The findings of this research study indicate that there is a consensus from both child life managers and specialists on the value of expanding their role beyond the hospital. Although considered an essential service in some hospitals, further steps need to be taken to ensure child life specialists feel that their services are validated in the hospital.

**Key Words:** Child life Specialist; Chronic Illness; Expansion; Ecological Perspective; Interprofessional Collaboration; Teamwork; School

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## **Chapter 1: Introduction**

There is a rise in chronic illness with statistics showing that 4.9% of Canadian children twelve years of age and older have diabetes, and 13% have asthma (Sanmartin & Gilmore, 2008, Garner & Kohen, 2008). Thies and McAllister (2001) reported that childhood chronic health conditions such as asthma, diabetes, cancer and cystic fibrosis are on the rise. Despite the rise in chronic illness, children are being discharged from the hospital much earlier and only those in critical condition maintain their stay at the hospital (National Center for Health Statistics, 1996). To, Guttman and Dick (2001) reported that in Ontario, children are being admitted as inpatients to the hospital less frequently than in the past. In addition, there is a shift from service medical model to family-centred care model, as parents and family members have insisted they be a part of the decisions that are made surrounding their child's health care (Kuttner, 1996).

Community-based stress-point nursing interventions have been introduced at varying stages of the child's hospitalization to improve how parents cope. Ultimately, this had a positive affect on the family as well as the sick child's ability to cope and function (Burke, Handley-Derry, Costello, Kauffmann & Dillon, 1997). This study administered a two-group, pretest-posttest research design to test the usefulness of the intervention. Burke et al. (1997) found that when a nurse made telephone calls, home visits and regular written communication prior to and post hospitalization, the child had better psychological adjustment and the family members were able to practice stronger coping skills.

There is a need to investigate how professionals within the hospital, such as the child life specialists might collaborate with professionals in the community to offer adequate outpatient care and follow-up on a variety of levels. The act of collaboration between hospital and school professionals can assist in ensuring that transition from the hospital to school is successful, while

receiving the best possible medical and psychosocial support. It is necessary to investigate how professionals feel about this collaboration and how it might take place.

## **Purpose of Study**

The purpose of this research is to explore child life specialists' and child life managers' perspectives on greater collaboration with schools in order to determine possibilities for role expansion in the community. This expansion would aid in providing outpatients with the necessary psychosocial support when transitioning back to school.

## **Chapter 2: Literature Review**

The literature review will begin by examining the impact that childhood illness has on different members of the family. The role of the child life specialist will then be explored in detail by discussing the status of their profession in North America, their clinical practice, and the assessment process. The following section will look at how interprofessional collaboration is a significant part of the child life specialist role. The aim of this study is to look at how child life specialists might expand their services beyond the hospital to the school; it is also important to explore the current connections between the two systems. Further exploration will include examining a few cases where child life specialists have collaborated with professionals in the school environment. Finally concluding the literature review, there will be a discussion on the significance of the child life role, the transitional process and current transitional programs.

### **The Impact of Childhood Illness on the Child and Family**

For families who have a child with a chronic illness, daily life consists of additional challenges compared to the average family. Feigin, Barnetz and Davidson-Arad (2008) suggested all areas of the family's life are affected by a child's illness, such as personal, physical, social and cultural components. These four components are the four fields of functionality that determine the quality of life for an individual. When a child is hospitalized with an illness, some of their normal activities of attending school and playing with friends are substituted with trips to the hospital and doctor appointments. The child experiences a loss of daily patterns, which are replaced with feelings of separation and anxiety (Kleinberg, 1982).

During this time, each member of the family can be considered a "patient" with specific needs that have to be met even if they are not the one with an illness (Desai, Ng & Bryant, 2002). Woodgate (2006) explained that maintaining some form of the family's regular way of life helps

children cope with this change. One way of maintaining a family's regular way of life is by accepting the child's diagnosis and finding ways to cope with it rather than attempting to overcome it. Murray (2002) suggested that in order for a family to maintain normalcy, they must regard their child's illness and hospitalizations as a part of their new daily routine. If the family does not learn how to adapt to the new structure and routines, the process of change can be psychologically damaging to the entire family (Houtzager et al, 2004b).

It is evident that a child's illness affects all members of their immediate family, however it often impacts individual family members in a variety of ways. Nicholas (1999) examined a group of mothers caring for their child in the end stage of renal disease and revealed that mothers could be placed into three different categories; trapped, adaptive or embedded caregivers. This study suggested that health care professionals such as doctors, nurses, social workers and child life specialists should be among the resources offered to a family in order to ameliorate these impacts. Another study from Nicholas et al. (2009) reported that fathers experience feelings of devastation, sadness and isolation, while being conflicted with the uncertainty of their role as a father not being able to protect their child from the illness.

During this life changing phase, siblings of patients often experience a multitude of feelings as well. Houtzager, Grootenhuis, Caron and Last (2004a) found that although siblings were at first quite upset and anxious at the time of their sibling's diagnosis, they were also very resilient. They reported that psychosocial adjustment to their sibling's diagnosis is often influenced by their age, gender and family structure. Barrera, Chung and Fleming (2004) utilized the Siblings Coping Together (SCT) program as an intervention mechanism to bring together siblings of cancer patients to share their emotional and behavioural challenges. They described

that following the eight weekly sessions, siblings' level of psychological adjustment greatly improved.

It is evident from the following literature the impact that chronic illness can have on the parents, siblings, the sick child and the family structure. Although, there is research on the variety of different services available to these families, there is a lack of research on how these services work together in collaboration to ensure stronger family-centred care (Barrera et al., 2004, Packman et al., 2004, Melnyk, Feinstein, Moldenhouser & Small, 2001). When the child is discharged from the hospital, the journey is not over, as the family and child often require additional support to help them adjust to the new schedules and demands of caring for a child with a chronic illness. It is important that this transitional phase between the hospital and home is successful, in order to promote adjustment and coping skills for the child and family.

### **The Child Life Specialist's Role**

Throughout the course of medical treatment, paediatric patients receive health care services from a variety of professionals. These include social workers, doctors, nurses, psychologists and child life specialists who attempt to coordinate care in order to help the child and family cope with managing an illness. Harris and Curnick (2000) explained health care professionals must form a partnership with the patient and her or his family in order to provide effective care. A large part of the interprofessional team consists of individuals who treat the physical needs of the patient. It is imperative to recognize that the whole child must be treated while hospitalized to ensure that their physical, emotional, psychological and social needs are met.

Thompson and Stanford (1981) stated that the two main goals of child life programs are: “to help the child cope with the stress and anxiety of the hospital experience and to promote the child’s normal growth and development while in the health care setting and after returning home” (p.7). The role of the child life specialist is to provide psychosocial and emotional support to the sick child and her or his family members (Child Life Council, 2008). Child life specialists recognize the family unit as a significant part of the child’s support system and provide guidance and coping strategies for family members. Nicholas, Globerman, Antle, McNeill and Lach (2006) created a framework to reveal how it is valuable for the child to learn how to accept and live with their illness. This framework also highlighted how participants in the study believed it was important to find value, meaning and quality of life from their experience of living with a chronically ill family member. The child life specialist plays a vital role in helping the child accept her or his diagnosis and at the same time learn to develop coping mechanisms. A coping strategy is an action or behaviour an individual adopts in response to a stressful situation, and if used over a lengthy amount of time it can turn into a coping resource (Meert, Thurston & Thomas, 2001).

According to a literature review conducted by Koller (2007), preparing children for medical procedures helps with coping and adjustment, while allowing decreasing levels of anxiety and fear. Another responsibility of the child life specialist is to advocate for family-centred care, while working closely within an interprofessional team in the hospital (Child Life Council, 2008). Family-centred care can be defined as, “...an innovative approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care patients, families, and providers” (Institute for Family-Centered Care, 2009).

## **Child Life Across North America.**

Since 1965, the child life profession has significantly expanded, and now there are over 400 child life programs in North America (Child Life Council, 2003). In Canada, there are approximately 40 child life programs in Health Science Centers and children's and community hospitals (Humphreys, LeBlanc, Ulliyot & Livingstone, 2007). In part, this growth is due to the American Academy of Pediatrics (1971) as they described the importance of the child life field,

...Almost all of this literature supports the idea that the hospital experience is upsetting and that this upset extends into the post-hospital period. Therefore, it is mandatory that each pediatric service concerns itself with this problem and institutes specific programs to ameliorate or prevent psychological upset in the child. (p.51)

Despite this statement from the American Academy of Pediatrics, Cole, Diener, Wright and Gaynard (2001) found that while other professions in the hospital feel that the child life specialist's role is valuable for a patient's psychosocial health, they have minimal power within the interprofessional team. This study administered questionnaires to members of the health care team, who had regular contact with child life specialists (physicians, social workers, nurses and administration team members) to explore their perceptions of the child life specialist. In addition, fifteen child life specialists were given a questionnaire about their own perceptions of their profession. The results of this study indicated child life specialists' play a large role in supporting families and patients, facilitating coping and decreasing stress within the hospital. Despite acknowledging the value of the role, child life was rated as having little power in the hospital. Cole et al. (2001) suggested that educating professionals on the importance of the child life role is a way to ensure child life specialists do not experience burnout and feelings of inadequacy.



## **Clinical Practice.**

When working with a family, a child life specialist considers *child-focused* variables such as age, developmental level, responses to previous hospital visits, and fears and misconceptions. *Family-focused* variables are also considered, which include parents' education, time for the child, cultural factors, and other stressors such as job, financial and life changes. Lastly, *health-related* variables such as diagnosis, prognosis and treatment are considered to assist in determining the best plan for the child (Desai, Ng & Bryant, 2002). As forms of intervention, child life specialists create a safe environment with emotional support, utilizing therapeutic and recreational play and teach coping mechanisms to the child and their family (Child Life Council, 2008).

An important way to establish a safe environment consists of providing hospitalized children with play. According to a literature review conducted by Koller (2008b), therapeutic play can increase the well-being and personal development of a child who is hospitalized. "Play is the most natural activity that children experience (Thompson, 1989); thus, by incorporating play into hospitalization, child life professionals minimize the disruption in the child's development" (Gaynard et al., 1990 as cited in Cole, Diener, Wright and Gaynard, 2001, p. 11). Child life specialists use medical play, tours and photo books, while assessing children's psychosocial needs and listening to their fears in order to help them feel more comfortable during their hospitalization (Desai, Ng, Bryant, 2002). Teaching children specific coping mechanisms to assist them in accepting their illness is another part of the child life specialist's role.



## **Assessment.**

Turner and Fralic (2009) examined the child life assessment process as constant but flexible to make changes when new information is available. “The process of assessment is described as a prioritization task whereby information is gathered through interaction with the child, family, and allied professionals with each child classified for level of service need based on indicators” (Turner & Fralic, 2009, p. 41). The process of assessment is about building a relationship with the child and the family; it is done slowly and carefully in order to ensure all parties involved feel comfortable. It has also been noted that assessments should include interprofessional collaboration. The Evidence Based Practice statement on Child Life Assessment supports the use of interprofessional collaboration and indicates that the outcome for the child and family are much better when collaboration occurs (Koller, 2008a).

## **Support for an Expanded Child Life Role.**

In 2006, the American Academy of Pediatrics created a new policy statement to include the notion of expansion for the child life profession: “Child life expertise has applications beyond conventional hospital care. Child life interventions can help children transition back home, school and community. Child life specialists can actively help with reentry and facilitate a variety of support groups for patients and their siblings” (p. 1760). As the child life field continues to grow in Canada, professionals within the field begin to expand their services beyond the hospital to places such as Family and Children’s Services, Settlement and Immigration Services and the Canadian National Institute for the Blind (Humphreys, LeBlanc, Ulliyot & Livingstone, 2007). There are several other areas that have begun to experience the introduction of the child life field, such as Children’s Bereavement Support Groups, Hospice programs and

working with children who have a parent and grandparent with an illness (McCue & Hicks, 2007).

Although the child life specialist predominately works in paediatric health care, recently the role has begun to expand to include outpatient clinics within hospitals, outpatient healthcare clinics, camps, schools, court systems, funeral homes, hospice care, doctor and dental offices (Child Life Council, 2008). Furthermore, McCue and Hicks (2007) described how child life skills are transferable to a variety of areas beyond the hospital environment. Child life specialists can,

- Assist infants, children, youth, and families in coping with potentially stressful events.
- Provide teaching that is specific to the population served, including psychological preparation for potentially stressful life experiences with infants, children, youth, and families.
- Function as a member of a service team.
- Provide a safe, therapeutic, and healing environment for infants, children, youth and families. (p. 4)

The skills of the child life specialist have the potential to reach beyond the hospital. This further supports the literature and the expansion of the child life role.

### **Child Life Collaboration with Health Care Professionals.**

A large component of the child life profession is working within an interprofessional team to treat the whole child. Although there is minimal research on interprofessional collaboration between institutions such as the school and hospital, there is literature to support that interprofessional collaboration in the hospital can increase the quality of care for patients (Schmidt, 2001). Halm, Ganger, Goering, Smith, and Zaccagnini (2003) stated that interprofessional collaboration encourages individuals from various health care disciplines to work together in order to dissolve barriers and ultimately meet the needs of the patients. "Inter-

professionalism is defined as the development of cohesive practice between professionals from different disciplines. It is the process by which professionals reflect on and develop ways of practicing that provides an integrated and cohesive answer to the needs of the client [and] family” (D’Amour & Oandasan, 2005, p. 9). This form of collaboration is intrinsic to the child life profession.

Reeves and Lewin (2004) suggested that although many hospitals promote interprofessional collaboration among healthcare professionals, there is minimal research exploring how professionals understand this collaboration and the impact on their patients. This study utilized an ethnographic approach through interviews and observations to gain a more in-depth understanding of how professionals collaborate with individuals in the hospital verbally and nonverbally. The findings of this study demonstrate that there is a wide variation in how different professionals in the hospital understand the meaning of interprofessional collaboration, thereby adding to the challenges, which can inhibit effective practice.

San Martin-Rodriguez, Beaulieu, D’Amour and Ferrada-Videla (2005) verified that willingness to collaborate, trust, communicate, and display mutual respect is a key component to successful collaboration among health care teams. A pilot project called the Interprofessional Patient Care Review (IPC) seeks to teach medical students the importance of interprofessional practice (Barker & Oandasan, 2005). This project involved medical resident students to participate in their daily routine of reviewing patients’ charts but under the supervision of various professionals, such as a nurse practitioner, social work, family physician and pharmacist. While the primary goal was for residents to learn about other professionals’ roles, they also experienced personal changes and a better understanding of the health care system and practice. Taken together, the research reflects the notion that interprofessional collaboration within a hospital

setting needs to be learned from the time of entry. To ensure successful collaboration all members of the team must have similar perspectives of its definition.

Papa, Rector and Stone (1998) suggested that being a part of an interprofessional team requires learning new skills for health care professionals, such as coordinating referrals, while understanding the roles of the professionals that make up the team. This type of training requires a large amount of commitment, time and finances; however the results can ensure more cost effective, culturally sensitive, and holistic family-centred care (Papa, Rector & Stone, 1998).

An initiative in Canada has worked on how to increase interprofessional collaboration in hospitals across the country. The Structuring Communication Relationships for Interprofessional Teamwork (SCRIPT) project is one of eleven programs funded by the federal government to investigate interprofessional collaboration and the impact that it has on patient care in Canada. This project examined interprofessional collaboration in three different settings: general internal medicine, primary care, and rehabilitation and complex care. A primary goal of this project was to enhance patient-centred care through collaboration between front-line staff members and administration staff (Reeves et al., 2007). As part of the SCRIPT program, Reeves et al. (2007) discovered that during interprofessional team meetings, the emotional needs of a patient were rarely discussed. Further if the issue was brought to the table, it was not received well by the rest of the team.

Cole, Diener, Wright and Gaynard (2001) discovered in their study that 36% of health care professionals stated having contact with child life specialists many times throughout the day. The results from this study also found that advocacy and educating other professionals about the responsibilities of their job are apart of the child life role. Thompson and Stanford (1981)

explicitly stated that child life specialists must work in collaboration with other health care professionals in order to understand a child's full story. In fact, different health care professionals will acquire different information about the child that could be beneficial to how the child life specialist delivers care to the child.

There is a wealth of literature discussing interprofessional collaboration between nurses and social workers in the hospitals, however there is minimal research in the area of child life. Although there is a basis of literature on interprofessional collaboration within the hospital, there is also minimal research on collaboration with other community institutions like the school. In fact, Papa, Rector and Stone (1998) stated that the health care and educational systems are often faced with similar problems but seldom work in collaboration to address these issues. The HealthyCHILD model, which stands for Healthy Collaborative Health Interventions for Learners with Difference is a five-year program funded by the federal government in Pittsburgh, USA to foster a partnership between health care and educational professionals. This partnership was established in order to create strategies to offer positive behavioural support, interventions and medical consultations to enhance their involvement with children who have chronic or acute illnesses (Bagnato et al., 2004).

### **Teachers in the Hospital.**

In the majority of pediatric departments, a teacher is employed within the hospital to facilitate this partnership between the educational and health care systems. The role of the teacher in the hospital, which is funded by the school board is to assist children with their academic needs in order to ensure the child does not fall behind while absent from the classroom. Harris and Curnick (2000) emphasized the importance of maintaining normalization for the child

while in the hospital, which includes participating in different forms of education. There are often teachers working explicitly within the hospital environment, who have contact with the child's mainstream school in order to help the child keep up with their school assignments.

An example of the connection between schools and hospitals is the Children and Youth Connected with Learning technologies to Education (CYCLE) program. It is a new initiative that allows children who are homebound or hospitalized to connect with classmates and teachers at their community school through computers. Fels, Shrimpton and Robertson (2003) explained that this program is an alternative to having teachers employed within the hospital environment. Some of the preliminary evaluations report that all participants had positive feelings toward the program and most children explained the program motivated them to do their school work.

It is possible that teachers are not adequately trained in properly meeting the needs of chronically ill children and therefore require outside support. Olson, Seidler, Goodman, Gaelic and Nordgren (2004) examined school personnel's perceptions on the impact of childhood chronic illness in the classroom and found that teachers had two primary concerns; extra time commitment and personal or liability risk factors. The findings of this study also reported that there were minimal opportunities for additional information or training for teachers. The study concluded that schools would benefit from having health care professionals educate and clarify misconceptions about chronic illnesses with school personnel (Olson, Seidler, Goodman, Gaelic & Nordgren, 2004). Clark (2003) explained that parents of chronically ill children felt that teachers and schools minimized the severity of the illness and ignored their child's feelings. Although the main purpose of hospital-based teachers is to ensure academic needs are met, Harris and Curnick (2000) advised that the psychosocial needs of patients also needed to be addressed. The child life specialist is the professional in the hospital, who ensures the patient's psychosocial



needs are met and, it is imperative that these psychosocial needs continue to be met after leaving the hospital environment.

### **Health Care Professionals' Collaboration with School Professionals.**

Interprofessional collaboration between institutions such as the school and hospital is not common in Canada. However given the value placed on collaboration and the possible benefits to the patient, interprofessional collaboration between the most significant areas of the child's life (home, school and hospital) could have benefits for all individuals involved, especially in terms of exchanging information about the child. Currently in North America, there are only a few examples of collaboration between hospital and school personnel in helping children transition.

One example of this collaboration is the Pediatric Cancer School Support Program of Southwestern Ontario, which provides school staff with training and information on how to assist the child's reentry into the school (Rynard, Chambers, Klinck and Gray 1998). The program ensures that teachers feel adequately prepared and confident to academically, emotionally and socially support these children, who are returning to the school environment. Among the program support team are professionals from the hospital such as the social worker, nurse, and a program coordinator who has regular contact with members of the oncology team at the hospital. The support teams' resources include the *Why, Charlie Brown, Why* (Schulz, 1990) movie and *Helping Schools Cope with Childhood Cancer* booklet (Chambers, Klinck, & Rynard, 1992) in their program. Rynard, Chambers, Klinck and Gray (1998) found that both teachers and parents believed the outcomes of the program were positive and therefore saw a need to further investigate more individualized intervention strategies for children returning to school after hospitalization.

A second program, which enlists the collaboration of both health care and school personnel, is at a school in Sauquoit Valley, New York. Brown (2008) described a school in the Sauquoit Valley school district, in Sauquoit Valley of Central New York, where a Wellness Centre is attached to the school with a child life specialist and social worker. The program was proposed to the school board and considered valuable as the majority of families lived a far distance from the city and relied on the school to meet the many diverse needs of their children. The social worker and child life specialist collaborated to identify students who would benefit from their services. The child life specialist provided psychosocial support for students who have a family member with an illness or who are returning to school themselves from being hospitalized. The program also provides support and strategies for teachers to use in their classrooms, as well as referrals to community agencies. Currently, the feedback from this program is positive and they are in the process of developing a formal evaluation tool. The individuals, who are a part of this initiative, recommended that child life specialist's services be used on a consultative basis with daily travel to different schools. Brown (2008) justifies the value of having child life in the school by stating,

School is the ideal place to provide child life services, and not merely because children attend school for approximately one-third of their waking hours each day. The school is a place where they feel comfortable and secure, where they learn and grow, and where expression is encouraged. It also should be a place where children receive the help necessary to deal with the stress and trauma of life. (p. 228)

### **Transitional Programs**

The child life field is continually evolving to provide a greater range of children with services as the demographics of patients change. For example, there are younger children with increasingly complicated needs, who are less able to participate in group programs due to stricter



isolation rules, thus individualized programs have been created to meet the needs of the current patients. The Child Life Council (2006) explained that expansion in the child life field is moving toward greater involvement in ambulatory care. In the early 1990s, expansion of the child life field became a point of contention as some child life specialists felt that expansion would hurt their profession, that they did not have the skills to work outside of the hospitals and if they were to expand they might be invading on other professionals' such as psychologist and social workers areas of practice. However in 1996, the Child Life Council created the Vision-to-Action process and altered their mission and vision statement to include non-traditional hospital settings to the child life profession (McCue & Hicks, 2007).

Miller (1996) explained that in order to help a child with an illness, a teacher, who is often a short term but stable role model must work in collaboration with the family to ensure a smooth transitional process from school to hospital. Miller (1996) suggested allowing the child to have a special toy as a transitioning object to take with her/him, while moving from hospital to home to school. A transitioning object that has been a part of the various environments can help the child feel more secure during this time of new surroundings. A previously hospitalized paediatric patient in Bessell's (2001) study described how school is a significant institution in their life. "School [is] the place where I live my life, where my friends are, and where I spend most of my time when I'm not at home" (p. 355).

### **Current Programs Assisting Transition From Hospital to School.**

Sexson and Madan-Swain (1993) stated reintegration of the hospitalized child into the school system must be one that involves all educational, parental and medical personnel. By involving these individuals during the process of the child's reintegration, the expertise of each

person can be utilized to create a comprehensive and successful plan. Botcheva, Hill, Kane, Grites, and Huffman (2004) reported on a program in northern California called the Program for Children with Complex Medical Problems (CCMP), which incorporates a range of professionals. This program provides support for children who are being discharged from the hospital and in the beginning stages of recovery. It helps children reintegrate into the school system with the help of educational specialists, psychologists and occupational therapists (Botcheva et al., 2004). This study provides a good overview of the program however it has a limited examination of how the professionals from different disciplines collaborate.

Although there is some literature surrounding health care professionals collaborating with the school and transitional programs, further research is required to determine best practices. In addition, further research is required to understand how professionals feel about collaborating with others outside of their institution. By researching new ways that the educational and health care system can collaborate together on patient care, new ideas and programs can be created to facilitate normalization for the child.

The following study explores how child life specialists perceive the expansion of their role to facilitate the transitioning process from hospital to home. The child life specialist is ideal to facilitate this transitioning as they have already formed a bond with the child in the hospital. The significance of this collaboration has already been noted in Brown (2008) as an example of how collaboration between the school and hospital might take place. As Sexson and Madan-Swain (1993) the reintegration process must involve family, educational and medical personnel, so although the teacher in the hospital may have already made connections with the community school the child life specialist can provide the medical knowledge on the child's illness. It is therefore imperative to build on these initiatives and directly access the views of child life

specialists who are ideally situated to foster psychosocial supports by creating greater connections with schools.

### **Research Questions**

This study seeks to answer the following questions:

How do child life specialists and managers perceive their role expanding beyond the hospital to provide outpatients with the necessary psychosocial support to assist in transitioning from hospital to school?

The main research question will be examined through the following areas:

1. According to child life specialists and managers, what areas of outpatient care merit greater child life attention?
2. How do child life specialists and managers perceive their role within an educational setting?
3. Are there differences between the views of child life specialists and managers? How can these differences be explained? Where might these differences come from?

### **Chapter 3: Theoretical Framework**

Greater collaboration between hospital and school is based on an acknowledgement of different systems and therefore, an ecological theory is well suited for the framework of this study. Bronfenbrenner's (1975) ecological model will assist in understanding how different institutions such as the hospital and school within the same system can collaborate to increase family-centred care while strengthening the community (see Figure 1). As the child passes through different stages of development, he/she is exposed to interaction from different systems. The types of interactions that occur between systems influence how the child copes and adjusts to their illness. A child with an illness is at the centre of these complex and inter-related systems as will be described below.

The Microsystem is the closest to the child and consists of institutions and people who have daily interaction and influence on the child. For example, family members and teachers interact daily with the child. The level at which the interaction between different institutions occur in the Microsystem is the Mesosystem. For example, this is the system where interaction between the child's medical physician and parents takes place. The Exosystem is the next system in the model, although the child does not have direct contact with this system either, elements within it can impact the child. For example, their parents' place of employment is a part of the Exosystem. If both parents are unable to take time off of work while their child is in the hospital. The child may experience feelings of loneliness. The Macrosystem consists of cultural values and ideologies, however the child does not have direct contact with this system. For the purpose of this study, the Microsystem and Mesosystem will be the main focus as the people and interactions respectively have the greatest influence of the child.

## **The Microsystem**

Bronfenbrenner (1979) described the Microsystem as the closest system to the child, which consists of people who have the most influence over the child. The roles and relationships between the child, people and places of the Microsystem are reciprocal. For a child with an illness, the Microsystem can consist of her/his family, the hospital and the school. Each of these institutions has a unique impact on the child's development because they can provide a variety of different influences (Bronfenbrenner, 1979). For example, within the hospital there are many professionals who have daily interactions with the child, such as the physician, nurse, and child life specialist. Each member of the medical team has a different role and responsibility, however the primary responsibility is to ensure the physical, psychological, emotional well-being of the child. In the school environment, the teacher's main responsibility is to provide opportunities for learning and socialization with peers. In the home environment, the parental responsibilities are to ensure the basic needs of the child are met and to be a role model to the child.

Bronfenbrenner (1986) explained that the Mesosystem is where connections are made between the different settings in the child's life and that these connections are not independent of each other. For example, a challenging hospitalization with many invasive procedures producing fatigue and stress, which when discharged can elicit difficulties adjusting to the home environment and reintegration to school. In fact, Bronfenbrenner (1986) stated "Given the critical importance that hospital care can play in the life and development of young children, it is surprising that so little attention has been paid to the relationship between the hospital and the home as a moderating influence on the child's recuperation" (p.726).

## **The School and the Family within the Microsystem.**

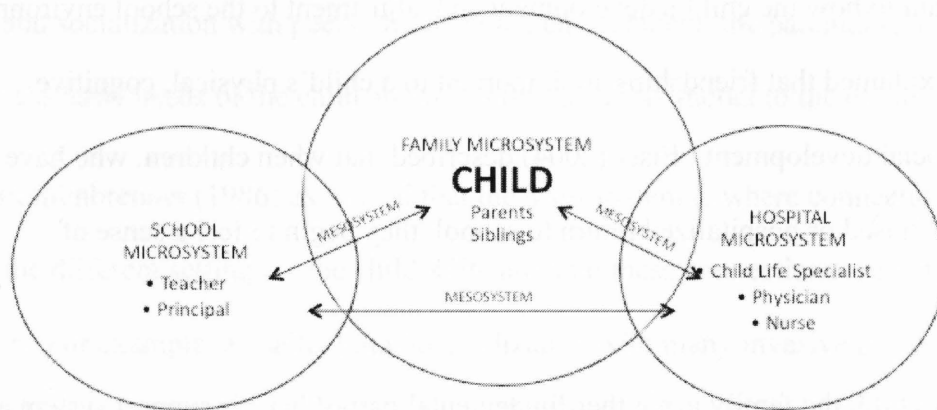
In the lives of most children, the school is a part of her/his world. The school, as a Microsystem, is a place where the child begins to form relationships with members of the school. A child's ability to learn within the classroom is influenced by the relationships that form between the school personnel, family members and themselves (Bronfenbrenner, 1986). Wotherspoon (2004) identified the school as a significant institution in the child's life, as it influences her/his development, personality and life choices on a day-to-day basis. "School is not just about learning the ABCs. School is an opportunity for young people to make friends, learn new things, achieve success, and please their parents...for many children, school is first of all a place to meet and make friends" (Eiser, 2004, p.81). It is valuable to recognize, while a goal of school is to provide children with an academic knowledge, building relationships and making friends is important to how the child's development and adjustment to the school environment. Ramsey (1991) explained that friendships are important to a child's physical, cognitive, emotional, and social development. Eiser (2004) described that when children, who have recently been diagnosed or hospitalized return to school, they begin to feel a sense of normalization.

For a sick child, the family is another fundamental part of her/his support system and during treatments the hospital becomes like a second home for the child. Woodgate (2006) identified that siblings of cancer patients often experience feelings of uncertainty and sadness. Whereas, Harris and Curnick (2000) explained how the impact of a child's diagnosis can affect families in very different ways depending largely on communication between family members. Both members from the school and home environment can influence how the child is adjusting during the transitioning phase.

## The Mesosystem

Bronfenbrenner (1979) stated that transitions from different settings within the Microsystem should be done with the help of a person from a familiar environment in order to create the linkage in the Mesosystem. For example, if a child is transitioning from living at the hospital to living at home, a health care professional, who is a consistent figure within the hospital environment should provide follow-up services and accompany the child back to the home. Bronfenbrenner (1979) explained,

The developmental potential of a setting in a Mesosystem is enhanced if the person's initial transition into that setting is not made alone, that is, if he enters the new setting in the company of one or more persons with whom he has participated in prior settings... (p. 211)



*Figure 1. An Adaptation of Bronfenbrenner's (1979) Ecological Model of Human Development.*

This model represents the relationships between the hospital, school and family.

The family, school and hospital personnel are a part of the child's Microsystem, which can have a direct influence on the child's development. The Mesosystem is the link that connects these institutions together and demonstrates how the people within these institutions interact with each other. By utilizing this model, further research can be conducted to gain a better understanding of how the different institutions within the child's Microsystem and people a part of them impact the child. As well, this framework will assess how relationships in the Microsystem can increase the quality of care for a child in the hospital. This study seeks to explore how school and hospital personnel, might increase their level of collaboration thereby reinforcing their relationship in the Mesosystem. Although both school and hospital personnel play a dominant role in the life of a chronically ill child, currently there is little connection between these two institutions. This study aims to understand how child life specialists and managers perceive the possibility of increasing collaboration between the hospital and the school personnel as children are discharged from the hospital.



## **Chapter 4: Methods**

### **Methodological Approach & Rationale**

This study used a mixed-method design to examine the perspectives of child life specialists and managers across Canada on collaboration with school personnel regarding psychosocial care with outpatients. The rationale for a mixed method design consists of increasing the quality and wealth of the data collected, as it allows a researcher to utilize the strengths of both methods while ensuring a higher level of credibility (Creswell, 2005, Greene, Caracelli & Graham, 1989). Also referred to as triangulation of methods it assists researchers in establishing an extensive and comprehensive study (Neuman, 2006). The process of triangulation is used to examine a research question from different viewpoints and was put to use for this research study.

For the qualitative portion of the study, McCracken's (1988) long interview was used to collect in-depth perspectives and experiences of the child life managers. This form of data collection involves creating an agenda of questions based on a literature review, while anticipating new themes and data to come out of the interviews and being aware of the researcher's own cultural views. McCracken (1988) described qualitative data as a way of understanding the social and cultural context of an environment. The long interview is one of the most useful tools of qualitative research as it allows the researcher to go inside the world of the participant to learn and gain a better understanding of how they perceive the world. McCracken's (1988) four-step method of inquiry involves; reviewing the literature, reviewing the researcher's perspective, constructing and conducting the interviews and identifying themes and categories by analyzing the data. This four-step method of inquiry was utilized as the approach

to exploring and understanding how child life specialists and managers felt about their role expanding to provide greater psychosocial support to outpatients. McCracken's (1988) four-part method of inquiry approach ensured that the researcher went through a process of review, cultural data, discovery process and analytic data.

For the quantitative portion of the study, survey research was used to collect the personal beliefs and opinions about role expansion from child life specialists. Neuman's (2006) six steps of survey research was utilized for this study as it is the most valuable way to collect information from respondents on their beliefs, opinions and attitudes. The first step involves deciding on a survey type, questions and design of the layout of the survey. This process can take time, as the questions often need to be rewritten to be able to more clearly articulate the question that will be asked. The second step of survey research entails the researcher planning on how to record the data and pilot the survey. Next, the researcher determines the sample population, number of participants and selects the sample. In the fourth step of inquiry, the researcher locates participants as well as collects and records data. Following the collection of data, the researcher inputs the data on the computer and performs a statistical analysis. The last step of survey research involves presenting the findings for critique and evaluation. The researcher utilized a web-based survey as they are fast, inexpensive and allow for a flexible design (Neuman, 2006).

## **Participants**

In order to gain a comprehensive understanding of this issue across Canada, there were two samples of individuals invited to participate in the study: child life managers and child life specialists. A cross-sectional sampling technique allowed the researcher to collect data on a particular topic from a large variety of participants (Mertler & Charles, 2008). A child life

specialist is a professional who is trained to work directly with children and families within a healthcare setting. A child life manager oversees the work of child life specialists within a hospital but often does not have daily contact with patients and their families. They are however, still considered part of an interprofessional team. Across Canada there are child life managers, which are also called supervisors, team or clinical leaders. Although the roles and responsibilities are quite similar, it depends on the type of hospital (paediatrics, tertiary or teaching) in which they are working. For example in a tertiary hospital, a nursing supervisor often manages the child life department. In this case, there would be a child life clinical leader. However, for the purposes of this paper, the term 'manager' will be used.

By obtaining the perspective of both specialists and managers the researcher believed a more comprehensive understanding of how individuals within the child life profession feel about expanding outpatient care could be reached. At the same time this research seeks to identify differences and similarities between their perspectives. Child life managers were selected for interviews because of their extensive experience in the field. They were able to provide an in-depth understanding of how interprofessional collaboration works in the hospital and a detailed description on the role of the child life manager and specialist in the hospital. Due to time constraints, the researcher was unable to interview both child life managers and specialists, so instead a survey was created for child life specialists to participate in. The survey provided an opportunity for the child life specialists to discuss their perceptions on role expansion. Taken together, a mixed method approach ensured that the strengths of both the qualitative and quantitative methods could be utilized and increase the probability of collecting the best possible data.

### **Interview Participants.**

The researcher approached nineteen child life managers to participate in interviews (see Table 1). Two child life managers declined to participate due to time constraints in their schedule, three wanted to participate however there was difficulty in coordinating time for an interview, and five did not respond to the invitation to participate. The final sample consisted of nine child life managers from across Canada. Seven of the nine child life managers were female. The participants' experience in the field varied from 12 - 35 years with a collective average of 23.5 years.

### **Survey Participants.**

The second sample of individuals invited to participate were child life specialists presently working in a hospital. They were asked to participate in an on-line survey. The researcher aimed to collect 30 surveys, which would provide a sufficient amount of data to analyze. Nineteen child life managers were approached to share information about this study to their child life specialist staff members, and ten managers complied with the request. Five child life specialists declined to answer the survey as their human resources department had advised them against accessing Survey Monkey. In total, there were 42 participants who completed the on-line survey from across Canada (see Table 1). The participants who completed the survey had a range of experience in the field; 69% (29) of participant had been in the field for 5+ years, 24% (10) for 3-5 years, 5% (2) for 1-3 years and 2% (1) for less than 1 year.

Table 1

*Participants: Child Life Managers and Specialists Across Canada*

| Province         | Child Life Managers<br>N=9 | Child Life Specialists<br>N= 42 |
|------------------|----------------------------|---------------------------------|
| Alberta          | 1                          | 4                               |
| British Columbia | 2                          | 8                               |
| Quebec           | 2                          | 5                               |
| Manitoba         | 1                          | 5                               |
| New Brunswick    | 1                          | 0                               |
| Nova Scotia      | 1                          | 3                               |
| Ontario          | 1                          | 17                              |

## Recruitment

Following approval from the Research Ethics Board at Ryerson University, the researcher employed a cross-sectional purposive sampling technique. The process of recruitment began with an introductory e-mail to all members of the 2007-2008 Canadian Association of Child Life Leaders (CACLL) affiliated with a hospital. The researcher used the 2007-2008 list, as it was the most current available. The inclusion criteria for managers consisted of being employed as a manager, director, practice or clinical leader within a Canadian hospital. This introductory e-mail briefly stated the purpose of the research study and invited participation (see Appendix A). Approximately two to three days later, the researcher sent a follow up e-mail inviting the child life managers to participate in an interview and seeking their assistance in sharing information about the study with child life specialists at their hospital. The child life manager's only role was

to inform the child life specialists about the research project via an e-mail forwarded by the researcher. This e-mail contained a research study profile and the contact information of the researcher (see Appendix B). All contact during the initial recruitment phase was done through e-mail.

## **Data Collection**

Nine interviews were conducted with child life managers across Canada. This number was deemed sufficient as McCracken (1988) stated that a sample of eight participants is adequate in order to reach data saturation. Indeed, saturation of data was reached by the ninth interview, eight of which were conducted over the telephone due to geographical distance, while the ninth interview was conducted in person.

During the semi-structured interview process, an interview template was used to ensure a similar order of questions were followed however the researcher allowed for flexibility. Babbie and Benaquisto (2002) recommended that the interviewer take on the role of an active listener, while allowing the interview process to flow like a conversation. Therefore the researcher felt it was important to leave room for flexibility, so that probing could occur and new themes could emerge within the data.

In terms of the online survey, the researcher sent an introductory e-mail with a study profile and the researcher's contact information to the child life manager, who forwarded it to each child life specialist. This e-mail contained a link to the on-line survey. The survey and the consent form were completed on-line via Survey Monkey. Following the survey, if the participant had any questions he/she could contact the researcher through e-mail.

## **Qualitative Rigour.**

Prior to administering the survey, the researcher piloted the survey with two child life specialists who acted as key informants on the study. The child life specialists provided feedback on the wording of some questions as there was ambiguity in how the participants and the researcher could perceive the question. Both child life specialists suggested that a clear distinction needed to be made between teachers in and outside of the hospital. As well, both key informants believed that the design of the survey appeared as very “doable” for reasons such as length. The final draft of the survey reflected revisions and comments from the key informants. By piloting the survey, the researcher was able to gain useful feedback about the questions on the survey, which allowed for revisions. To ensure that appropriate questions were being asked, the researcher randomly selected two participants to complete member checking with, in order to ensure the accuracy of the data collected.

## **Procedure**

The interviews were completed over a two-week period, during a time that was convenient for the interviewee. Prior to the interviews, the participants were mailed two copies of the consent form: one for their own records and one to be returned to the researcher (see Appendix C). All of the interviews were recorded using a digital recorder with the use of a special device for phone interviews. Prior to the interview the participant was told he/she can refuse to answer any questions and could withdraw from the study at any time. At the beginning of the interview, the researcher filled out the location, time, date, and participant’s name on the interview protocol form, including assigning the participant a code such as CLM 1-9 (see Appendix D). The researcher informed each of the participants that data would be stored



securely on a computer and separate from consent and interview transcripts. The interview began with demographic questions to gain information on the participant's level of experience in the field and his or her province of employment. Following the interview, the post-interview script was read to the participant informing them that a summary of the findings would be mailed after the study was completed.

For the survey, child life specialists completed their consent on the first page of the survey (see Appendix E). Participants were required to consent in order to continue with the survey. If the participant wished, they were able to print off a copy of the consent form for their own records. Survey Monkey is used as an on-line tool for creating and distributing surveys. The survey was made available on Survey Monkey for three weeks.

### **Data Organization**

A Research Study Checklist was used to organize tasks throughout the data collection process. The Research Study Checklist kept track of interview participants, contact information, responses from the introduction e-mail, and the number of received consent form, completed individual interviews and transcriptions. Following each interview, the researcher wrote field notes about how the interview process went and reflected on ways to alter questions for the next interview. This process of review allowed the researcher to alter the wording and structure of questions and to ensure the questions being asked were accurately addressing the research question. Each interview was transcribed and securely stored on a computer with a password.

### **Data Analysis**

Prior to collecting interview and survey data, the researcher established pre-determined codes based on the literature review and research questions. However, since new themes often



emerge during the data collection process (McCracken, 1988), additional themes were created throughout the analytical process. The researcher followed McCracken's (1988) five steps of the analysis process, which starts with the very detailed transcriptions and proceeds to data being placed into more general observations. The first step looks at the data collected as utterances, and classifies them as observations without making connections to the other data. The second step takes these observations and develops ideas compared to the transcript and the literature review. The third step looks at the connections made as a result of the second step between the literature and the observations. In this phase, the researcher begins to focus on the observations and no longer uses the transcript. The fourth step involves looking at all the observations made in steps one to three and identifying common patterns and themes. The final step involves looking at the themes and patterns that have emerged from the data in a more general context to answer the research question (McCracken, 1988). Once initial coding was conducted, all qualitative data were organized and managed through NVivo, a qualitative software program. This program helped to identify similarities and differences in the data within the various themes.

### **Survey Data.**

The survey contained both qualitative and quantitative data. The qualitative data from the survey was also analyzed using McCracken's (1988) five steps, while the quantitative data was organized using graphs and tables. Qualitative data from the surveys were incorporated into the interview data analysis.

## **Chapter 5: Findings**

A mixed method comprised of qualitative data collected from the interviews with child life managers and both qualitative and quantitative data from the on-line surveys completed by front line child life specialists. Throughout this section, both qualitative and quantitative results are integrated together into themes to demonstrate the differences and similarities that exist between child life managers and specialists perceptions on expansion across Canada. Prior to data collection, preliminary themes were established during the literature review stage.

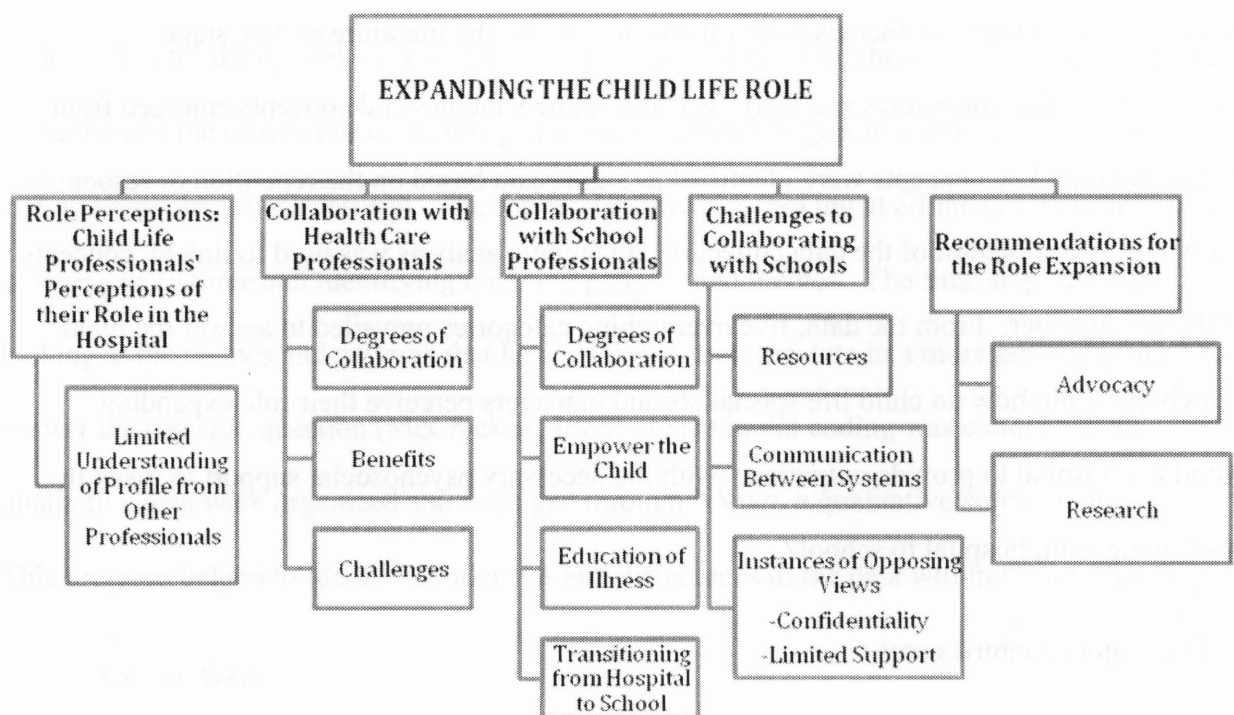
Throughout the nine interviews and forty-two surveys new themes and concepts emerged from the data and later key concepts were identified as significant based on the repetition of responses. Following the completion of the data collection, a thematic analysis was used to link all concepts and themes together. From the data, five overarching categories prevailed to answer the main research question; how do child life specialists and managers perceive their role expanding beyond the hospital to provide outpatients with the necessary psychosocial support to assist in transitioning from hospital to school?

The five major categories are:

1. Role Perceptions: Child Life Professionals' Perceptions of their Role in the Hospital;
2. Collaboration with Health Care Professionals;
3. Collaboration with School Professionals;
4. Challenges to Collaborating with Schools; and
5. Recommendations for the Role Expansion.

The following five categories emerged as themes from the interview and survey data. Within each of the five major categories exist thirteen sub-themes, which help to explain the significance and relevance of the main categories in answering the research question (see Figure 2). Some of

the sub-themes emerged directly from the questions asked, while others emerged spontaneously from the data. This process will be described for each category and definitions will be offered for each code.



*Figure 2.* Themes and Sub-themes on the expanding the child life role. This figure demonstrates the themes that emerged from qualitative and quantitative data.

## **Role Perceptions: Child Life Professionals' Perceptions of their Role in the Hospital**

The first category that was identified as a code was *Role Perceptions*. This code came directly from a question that child life managers answered in the interviews and describes different components of the child life profession in the hospital from the perspective of both specialists and managers. There is one sub-theme to the category, which is *Limited Understanding of Profile from Other Professionals*. The role of the manager is complex in nature as participants explained that there are many components to their job, e.g., clinical practice, administration, staff training, fundraising and volunteer duties, managing child life specialists and research. Three of the nine participants, who identified themselves as child life leaders, explained that the child life department is a part of the paediatric program, which is managed by nursing. All of the child life managers reported that they were responsible for ensuring that the philosophies of the child life profession were followed within the hospital. One child life manager explained,

I am responsible for ensuring that principles and philosophies of the child life field are adhered to by the staff but also to ensure that our program is meeting the principles through the programs that we offer here at the hospital.

Several of the child life managers explained that when hiring a child life specialist they did not necessary look for experience in the hospital, instead tried to identify adaptable skills. Another role perception identified was that child life specialists had transferable skill. One participant described it as follows,

It is the skill set that child life specialists have, it is about helping to prepare children, helping to provide emotional support and psychosocial care. I think those are all skills that are transferable. I really think that our skill set that we teach is extremely transferable outside of the hospital setting.

The majority of the participants explained that being a child life manager involves being a part of an interprofessional team. A participant described their role as,

The child life manager is a part of the multidisciplinary team within an interdisciplinary environment with particular emphasis on psychosocial needs of paediatric patients and their families. I am responsible for the administration, coordination, development and communication of the child life department.

Lastly, the majority of child life managers expressed that they felt their service was not fully valued in and outside of the hospital, perhaps a lack of knowledge on the child life role.

### **Limited Understanding of Profile from Other Professionals.**

A *Limited Understanding of Profile from Other Professionals* spontaneously emerged as a sub-theme to role perceptions. All nine of the managers explained that there was a lack of recognition and understanding of their role outside of the hospital. One participant stated,

I believe we are very important in the hospital environment and starting to become important outside of the hospital. I do not think we have the recognition that we should have. In hospitals, we are not considered essential services, in hospitals the primary idea is to heal and treat the patient physically. I would like child life to become an essential service. You can treat the body, but if you do not treat the mind you will have problems somewhere in the near future. One of my biggest hopes is that there is continued recognition and respect for the child life specialist as a valuable and important part within the system.

Several of the child life specialists had similar feelings about the lack of understanding for their role in the hospital. They explained that they sometimes felt devalued and not needed, even though they knew how valuable their role was to patients. The following section will describe the degree of collaboration that occurs in the hospital, the benefits and challenges to this collaboration.

### **Collaboration with Health Care Professionals**

The second category was identified as *Collaboration with Health Care Professionals*.

Based on the literature review, interprofessional collaboration is an intrinsic part of working in

health care. This code came directly from a question in the interview and survey. *Collaboration with Health Care Professionals* had three sub-themes: *Degrees of Collaboration*, *Benefits* and *Challenges*.

### **Degrees of Collaboration.**

From the data collected on interprofessional collaboration, it is clear that there are different levels of collaboration experienced by child life specialists and managers. When child life specialists were asked how often they discuss a patient's care with other health care professionals in the hospital such as a social worker, psychologist, teacher in hospital and other child life specialists, the majority of the responses 67% (28) responded *Very Frequently*. The remaining participants reported that they *Frequently* 26%(11), *Occasionally* 7%(3), *Rarely* and *Very Rarely* 0%(0) collaborate with other professionals in the hospital. This finding reflects data from the previous code were perceptions regarding the role constituted an interprofessional involvement.

### **Benefits.**

The following section will examine some of the benefits of collaboration in the hospital from the perspective of the child life manager. Two of the nine interview participants reported that being part of an interprofessional team enhanced the ability to have their voice heard and feel like a respected member of the team. Another benefit to collaborating with other professionals in the hospital is being able to treat the whole child with the expertise of a large number of professionals. Child life managers emphasized that collaboration with other professionals is a valuable practice in family-centred care. This was one of the major benefits reported by seven of the nine child life managers and is consistent with the literature. The degree of saturation was

reached quickly in this category with a large amount of data reduction. One child life manager explained this benefit,

Everybody does what their expertise is, and then we can see the big picture and the family as a whole, so we can treat the child in a better way. Collaboration is a way for us to treat all the dimensions of the child, like the physical, cognitive, emotional, so we treat all the parts together.

From these findings, it is evident that the majority of the child life managers support and value interprofessional collaboration in the hospital. This sub-theme reached saturation quickly as the child life managers repeatedly discussed the same benefits.

### **Challenges.**

In addition to discussing the benefits, the child life managers were asked to consider some challenges associated with professional collaboration within the hospital. This sub-theme can be described as a problem or issue, which makes it difficult for child life specialists and managers to collaborate with professionals in the hospital. Similar to the section on benefits, this section reached saturation quickly as respondents repeatedly mentioned the same challenges. Four of the participants explained that a challenge to collaboration occurs when professionals work independently and do not consult with other health care professionals on patient care. One child life manager described her perception of this challenge,

I firmly believe that people should not be working in silos and that everyone has their role delineation and part of the benefits to the families and patients is that we all play a role in the care that is provided.

Another manager explained that depending on the type and size of the hospital, and the size of the paediatric department often determines how well her/his voice is heard and taken seriously within a team of diverse professionals. Six of the child life managers felt a challenge to



collaboration in the hospital was having their voice heard among so many other professionals. A manager explained,

So paediatrics is a very small component of our hospital. So when you are a very small player in a big game like that it is very hard to be heard. Also it is hard to find time when you are doing clinical work and in between meetings, so there are two sides of it that makes it an obstacle.

Finally, child life managers and specialists identified the sub-theme *Lack of Understanding* as a challenge to collaborating with professionals in the hospital. A lack of understanding constituted a major theme in many areas of the data, thereby emerging as a pervasive issue for child life specialists and managers. This challenge was prevalent in many areas of the data including the challenges for expanding the child life role to collaborating with the school as well.

### **Collaboration with the School Professionals**

The third category identified from the data was *Collaboration with the School Professionals*. This category emerged from questions both in the interviews and surveys and includes four sub-themes; *Degrees of Collaboration*, *Empower the Child*, *Education on Illness and Communication Between Systems*. From the data obtained, it is clear that child life specialists seldom collaborate with professionals within the school system, while managers may do so at a minimal level as well.

Although the majority of the data collected indicates that child life specialists have little connection with teachers or any part of the school system. One child life manager described how collaboration with the school system is mandated in hospital. This is significant piece as it is the only mandated form of collaboration with the school system that was evident in the data. The child life manager explained the process as,



The health contract states what the school, the parents and the hospital are all responsible for that is a government, department of health regulations as a part of an educational contract. All of these individual stakeholders are a part of this contract. It is done with all ages of children, even in high school. Generally speaking the education systems that I work with are very receptive to knowledge and any supportive help that we can provide.

This was the only data that indicated child life specialists were mandated to work with the school.

Perhaps a reason for this current mandated health contract is that in this province there is more effective collaboration between systems than in other provinces. As well, each province manages health care individually so there may be more of a push to collaborate with patient's schools and families.

Even though there was only one child life manager who collaborated with schools, there was one participant who offered a virtual classroom program called Child Life Interactive Computers for Kids (CLICK). It is a program that gives paediatric patients a way to keep up with their academic assignments and observe their classrooms as teachers conduct lessons. The child life manager explained that Microsoft and Aliant corporations are the sponsors for the CLICK program. Unlike other hospitals in Canada who employ teachers to work in the hospital to help children keep up with the academic aspect of school, the CLICK program allows children to interact and socialize with their classmates and their teacher. Taken together, these findings show there are minimal instances of collaboration between the child life specialist and the school, and only one example of mandated collaboration. However, these few examples of collaboration reflect possibilities for future expansion of the child life field. The following sections will discuss the four sub-themes of this category with a focus on how expanding the child life specialist's role can assist children in transitioning from the hospital to the school.

### **Degrees of Collaboration.**

The *Degrees of Collaboration* was a sub-theme that emerged from two questions on the survey and a question discussed in the interviews. To determine the degree to which child life specialists felt it was important to expand their role beyond the hospital, the survey addressed the following question utilizing a Likert scale; do you agree or disagree with the following statement? Child life specialists should expand their role to include psychosocial support services for outpatients. The majority of child life specialists surveyed 79% (33) *agreed* with this statement, while 17% (7) answered *somewhat agree* and 4% (2) were *neutral* with the statement. The participants were also asked a question which addressed how valuable child life specialists believed it was to collaborate with community-based teachers to provide psychosocial support to children while transitioning from the hospital to school. The majority of the participants 57% (24) answered *Important*, while 33% (14) indicated *Very Important*, *Moderately Important* 10%(4), *Of Little Importance* (0) and *Unimportant* (0).

The survey also examined how often child life specialists collaborate with specific professionals for e.g., a teacher, principal, resource consultant and/or a social worker from the community school system (Table 2). Note that there is missing data in this table as the rows do not add up to N=42, which shows that some child life specialists chose not to answer this question on the survey.

Table 2

*The frequency of collaboration between child life specialists and professionals in the community school system*

|                               | Very Frequently | Frequently | Occasionally | Rarely  | Very Rarely | Never    | Total |
|-------------------------------|-----------------|------------|--------------|---------|-------------|----------|-------|
| Teacher in Community          | 5% (2)          | 18% (7)    | 7% (3)       | 18% (7) | 20% (8)     | 32% (13) | 40    |
| Principal                     | 0% (0)          | 5% (2)     | 8% (3)       | 8% (3)  | 15% (6)     | 64% (25) | 39    |
| Resource Consultant in School | 0% (0)          | 3% (1)     | 8% (3)       | 13% (5) | 25% (10)    | 51% (20) | 39    |
| Social Worker in Community    | 5% (2)          | 5% (2)     | 12% (5)      | 17% (7) | 20% (8)     | 41% (17) | 41    |

It is evident from these responses that the majority of child life specialists either *Never* or *Rarely* collaborate with any of the professionals within the community school system. However, participants were also given the option to respond with *Other Professionals*. Six of the forty-two participants chose to indicate involvement with school professionals (school psychologist, mental health worker, nursing support in the community, community professionals, and early interventionist). The level of collaboration differs based on who it is with and in what type of hospital. A major part of collaboration outside the hospital is not mandated, so child life specialists go above and beyond their job description when they collaborate with institutions in the community.

Currently, when collaboration takes place between the child life specialist and the school it is not mandated or a part of their role description. A child life specialist gave details about her collaboration with the school system.

I recently helped an 8-year-old child who was scheduled for an open-heart surgery, and had been suspended from school for "acting out"... Fortunately I was able to work both with the support staff in the school and directly with the child, in answering his questions directly and alleviating his fears. The school staff knew he was a refugee, but had no understanding of what he was facing in hospital. They were completely unprepared to help him with that part of the problem, and it was the basis for his fear and acting out behaviour. I gave them the kind of general pre-op information that families need, so that they could understand what he had heard and seen in the hospital, and have some compassion for his fears...

Although child life specialists reported that the majority of them rarely or never collaborate with professionals from the school system, some of the child life managers explained that they have in the past or are currently collaborating with schools. One manager, who previously discussed the mandated health contracts, described the process of collaboration,

So working with the teacher involves sharing information with the teachers and their colleagues regarding school re-entry for a child who may have had to be in the hospital for oncology and to help them understand the child's needs. So that the child would be accepted in the classroom, to help their classmates understand that they need to have a special diet and finger poke and to teach them that diabetes is not contagious.

On a different level of collaboration, some of the child life managers explained that while they may not directly interact with community school personnel, they do work closely with teachers in the hospital who collaborate with community schools. This finding indicated that in some hospitals there already exists a connection between the hospital and schools, which provides an avenue to explore how child life specialists might expand or facilitate this collaboration.

When discussing the benefits of collaborating with schools to provide greater psychosocial support to patients, three major themes emerged from the survey and interview data. Both child life managers and specialists were asked to describe the value of collaboration with schools in order to help children successfully transition from hospital to school. *Empower the Child, Education of Illness and Transitioning from Hospital to School* are the three sub-themes that came out of the data.

## **Empower the Child.**

*Empower the Child* was coded as a sub-theme to describe a way in which child life specialists could assist a child to feel increasingly comfortable and to gain confidence during their transition back to school. Child life specialists identified this as a benefit of collaborating with schools. By being present during this time of transition, the child life specialist lets the child know he/she is not alone and can be a form of “motivation”, which can “increase their self-esteem and confidence”. A manager identified how collaborating with schools could *Empower the Child* during her of his reintegration back to school,

To help children know how to tell their story in a way that they feel ok about it. The child life can really support the teacher in knowing how to help other children be appropriate with the child, who is reintegrating back into the school system. Also with the permission of the child and family, the child life specialist and / or with the child could do a presentation to the classroom about what they experienced while being at the hospital and who they are now and what that means.

Both the child life specialist and manager agreed that by collaborating with schools, they could provide the child with essential tools that would help them gain control of the situation and feel more comfortable about returning to school. Another important part of collaborating with the school is to assist in educating teachers, parents, siblings and classmates about reasons why the child has been away from school.

## **Education of Illness.**

*Education of Illness* emerged as a very strong sub-theme of *Collaborating with School Professionals*. It can be described as a way of teaching classmates, principals, siblings, parents and teachers about the child’s illness. For example it can help classmates understand why the child is wearing a hat or why the child needs to have a snack during the day. A few of the child life managers described it as preparing the classmates and teachers for the child’s return. The sub-

themes of *Empower the Child* and *Education of Illness* are also overlapping benefits according to one child life manager that indicated how she would give presentations to the class upon the child's return to the school with the help of the child. Several of the child life specialists expressed that the whole class would benefit from the experience of a specialist collaborating with the classroom. One participant offered this response to address the notion of collaboration between child life specialists and teachers,

Prevents students staring and being naturally curious, which may not be comfortable for the returning student. It can help reduce bullying when welcoming students have a chance to understand rather than be left not knowing about the returning student's new lifestyle changes. Students are naturally curious about what may have happened to returning student and needs opportunities to get their questions out with an experienced supportive person [child life specialist], who is collaborating with the school and classroom.

While some respondents articulated that they could do a presentation for the class with or without the patient, others explained that a child life specialist being present in the classroom could help the child "integrate his/her 'normal world' and 'hospital world' together". The presence of a child life specialist in the classroom could entail observing classroom dynamics and behaviours while sitting in the classroom or working one-on-one with the child to adapt to the new environment.

### **Transitioning from Hospital to School.**

Another sub-theme identified by both child life specialists and managers is *Transitioning from Hospital to School* as a valuable reason for collaborating with the school. Currently, teachers who work in the hospital make the majority of connections with a child's community school. However child life specialist's training in psychosocial care and their knowledge of medical procedures could be a benefit to empowering the child and educating the classroom. One child life specialist gave details of her experience collaborating with the teacher in the hospital,



In collaboration with schools, children may be more willing to re-enter school activities more quickly if they know that there has been a connection between school and hospital. At [our] hospital, we have a schoolroom that is accessible to patients in hospital. While child life specialists keep in close contact with the teachers and share observations, it is always the school program that keeps in contact with community school teacher, curriculum and reintegration.

Another perspective from a child life manager explained the importance of the connection with the child's world outside of the hospital,

We want to normalize, we want have a continuity of care. We want the child to have a liaison with the school and not to get far behind. Normalization even means taking the cards, letters and pictures from the classmates, and helping the child to decorate their room with them. So I think it's really important to keep a child connected to the world that they are returning to and to let them know they have not really left. To let them know that they are still part of it, in these kinds of ways.

In summary, the sub-theme *Transitioning from Hospital to School* demonstrated that child life specialists are ideal to facilitate the transition between hospital and school because they play a significant role in the hospital helping children to normalize their experience. The child life specialists experienced collaborating with teachers in the hospital as an asset to making a connection with teachers in the community. The data presented has indicated that child life specialists and managers believed it would be valuable to collaborate with schools and that there were four sub-themes (*Degrees of Collaboration, Empower the Child, Education of Illness and Transitioning from Hospital to School*) which describe this collaboration with a particular emphasis on acknowledging the benefits.

### **Challenges to Collaborating with Schools**

In addition to several benefits to collaboration, child life specialists and child life managers identified several barriers to collaborations with schools. *Challenges to Collaborating with Schools* were noted in both the survey and interview data. This category had three sub-themes: *Resources, Communication Between Systems and Instances of Opposing Views*. The

sub-themes *Resources* and *Communication Between Systems* came directly from a question asked in the interviews and surveys, while the sub-theme *Instances of Opposing Views* emerged spontaneously. However, unlike the sub-theme *Resources*, *Communication Between Systems* was an unexpected finding.

To begin with child life specialists were asked to indicate the challenges to collaborating with a patient's community school (see Figure 3). It is important to note that *Privacy Laws* was a choice on the survey; however no one selected this option.

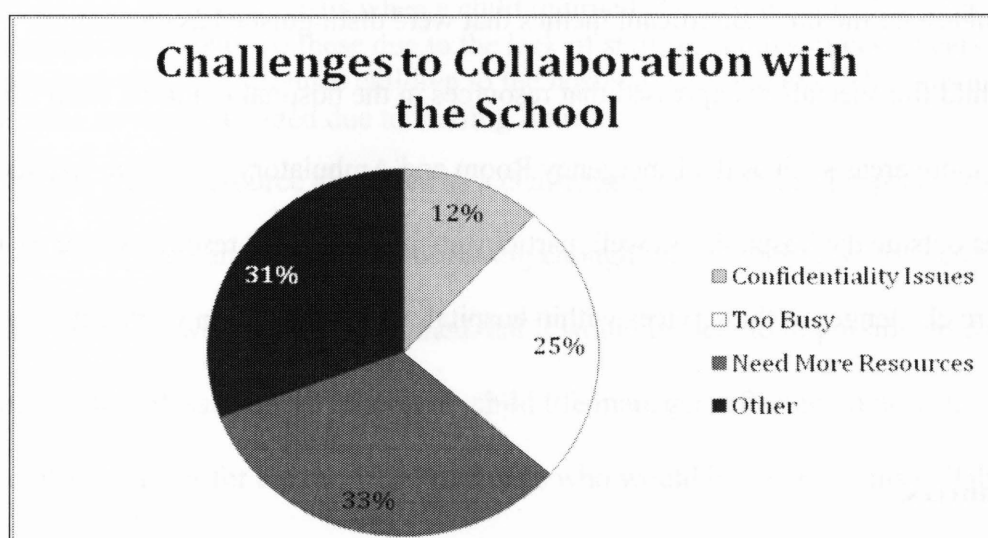


Figure 3. Challenges to collaboration with the school. This figure demonstrates the perspectives of the child life specialists and the challenges to collaborating with the school system.

The survey provided an option for participants to identify *Other* challenges to collaboration outside of the hospital. Sixteen of the forty-two participants chose to identify with the *Other* option. The *Other* challenges included: better recognized as a profession, education for staff, community, family about child life specialist role, only mandated to work with inpatients, time/too busy (seeing all patients is a big issue), discipline boundaries (stepping on toes),



“resistance from family members and direct caregivers as they believe that they are more informed and best prepared to do this”, resistance and politics from school board, resistance & lack of support from hospital managers/directors because lack of understanding of educational issues, benefits of child life involvement.

Both child life specialists and managers identified key challenges associated with greater school collaboration. Some of the challenges that the participants identified are also challenges that they are facing in their practice within the hospital. *Resources and Communications Between Systems* are the most significant themes that were distinguished as challenges. Currently, child life specialists expressed that resources in the hospital require a child life specialist in more areas such as the Emergency Room and Ambulatory Care prior to expanding their services outside the hospital. As well, participants indicated that resources such as funding and time were challenges in the services within hospital, which they often work with on a daily basis.

### **Resources.**

Resources can encompass a variety of different challenges for the child life field. These can include funding, lack of child life specialists and time constraints. Both managers and specialists indicated *Resources* as a challenge to expanding their services beyond the hospital. Financial uncertainties and budgetary limitations were among the most cited challenges reported by child life managers. Some of the participants stated that with the current difficult economic times, it would be impossible to even think about expanding their services. Many of the child life managers explained how their services are first to be cut because they are not considered essential to the patient.

The need to have more child life specialists in the hospital was reiterated several times by both specialists and managers and is directly related to funding. The majority of the participants made it clear that their staff/patient ratios were inadequate to meet the demands of the hospital and therefore it is difficult to spend an adequate amount of time with each patient. One child life specialist responded by saying, "If budget permits, hire more child life specialists however, due to the hard economic times, we cannot". Another child life specialist describes her previous experience working in a school and explains the reason for why this partnership ended.

[We used to do] school visits when a child returned after a traumatic, life altering illness or injury. We cannot do these due to the lack of staffing and resources. Years ago, we did school visits to introduce children to the hospital environment. This was a very valuable service but ended due to staffing issues.

Time constraints were a resource identified as a challenge by both child life specialists and managers. Some participants described not having enough time in their days to even meet the needs of their patients, while others explained that it would be near to impossible to coordinate a time to work with professionals in schools. A child life manager reflected on how the challenge of *time* was also a barrier for the other professionals who would be a part of this collaboration.

Probably mostly it would be their time. It is not easy the basic teacher day, you know trying to find the time, and it may just be one of your thirty children that you are dealing with at the time. We tend to do a lot of stuff during business hours, so you would have to be a little flexible in terms of being available at different times.

It is apparent from the data that a lack of *Resources* is a significant challenge to expanding the child life role beyond the hospital.

## **Communication Between Systems.**

In addition to challenges associated with resources, a high number of responses from both specialists and managers reflected the lack of knowledge and understanding regarding their role, which resulted from limited *Communication Between Systems*. Many participants felt that if people were made more aware of their services, then more institutions and professionals in the community would be interested in including a child life specialist among their team. One child life specialist explained this barrier by stating,

I think the biggest obstacle is lack of communication and that would be because the health system and school system are two separate bodies. When the health system is already huge, and we lack communication and coordination from the hospital to the community, it is difficult to cross boundaries. It is hard to leave the health system and enter the school system to set things up or to communicate because it's two systems dealing with the same children but it's never been made a priority to make the two things coordinate together.

Child life managers also recognized this sub-theme as a challenge to collaborating with schools.

However similar to the data collected from child life specialists, managers believed there was nothing mandating them to make this connection with the schools. It was difficult to initiate this collaboration when they had so many other responsibilities in the hospitals. One child life manager described her perspective,

Yes, I think it is very valuable to collaborate with patients' schools. I do think that there are opportunities there that we don't take because there is actually no mechanism for collaboration in place. So anything that we do is very informal and initiated by either the child life or the teacher. So it's not a very good system, and there is no guarantee that we are going to interact with the teacher. There are no health care protocols in place to ensure that to happen. For example, if you broke your leg the physiotherapist would be guaranteed to come down and see you but that does not happen like that here in child life.

## **Instances of Opposing Views.**

Contrary to the majority of child life specialists' and managers' responses, there were a few individuals who felt that collaborating with the school was not an ideal opportunity for the

child life specialist. There were a few different views, which showed resistance to change and felt that *Confidentiality Issues* and *Limited Support* were reasons to why collaboration would not be attainable. An instance of a negative case analysis emerged in the data as a child life manager described her belief that teachers in the hospital, were already making enough of a connection to the schools and that if a child life specialists were to take on this role it would be crossing a professional boundary. The child life manager explained,

We have schoolteachers that work here in the hospital. So if there were that link to a home school than that would be done by the teachers at the hospital not the child life. It wouldn't be appropriate for me to do that; it would be crossing a professional boundary. If it were identified that the school teacher needed to be involved, those teachers would do it.

Another instance of negative case analysis emerged when a child life specialist believed *Confidentiality Issues* would be a problem with collaboration between the school and the hospital. One child life specialist describes her disagreement with collaboration,

In general, I am not confident in school teachers' abilities or commitment around maintaining confidentiality, (e.g., freely using students names, asking personal health care questions at cocktail parties). When I see evidence that they understand and respect boundaries, I might be more inclined to share information.

In summary it is clear from the interview and survey data that there resources and communication issues between the two systems inhibit role expansion. Although there were many similarities, there were also some differences in perspectives especially from the child life specialists. Six of the forty-two survey respondents explained that they felt *Confidentiality Issues* were an obstacle to collaboration. While a few of the specialists explained that they felt there was a *Limited Support* for this form of collaboration from their own managers and directors within the hospital. In order for collaboration to occur between the hospital and the school, further consideration needs to be made on how to foster increased confidentiality and communication between these systems along with greater allocation of resources.

## **Recommendations for the Role Expansion**

Participants in both the interviews and surveys acknowledged recommendations for how to initiate role expansion. One child life manager stated that, "Growth and Research are the most significant areas for the future of the child life profession". While other participants felt that international and advocacy work were pertinent to the future of the child life field, in order to expand the awareness of the field. A strong theme indicated by both managers and specialists was that they did not often feel valued or considered as an essential service in their current positions within the hospital. The majority of respondents identified the expansion of the child life field as inevitable. In order to address these feelings and make growth possible there needs to be more *Research* and *Advocacy*.

### **Advocacy.**

A large number of child life specialists and managers explained that their services and roles in the hospital need to be valued and considered essential before expansion outside of the hospital environment can occur. A manager described the consequences of not being considered a necessary service within the hospital,

The hope that funding stays in place because sometimes when you are a softer discipline like we are it is sometimes hard to prove that there is value. Except I know that anyone who has ever worked with a child life specialist in the program has not doubted that. I wish there could be some sort of mechanism to prove our usefulness; you know to somehow show that it is cost effective to have a child life specialist.

This is a key implication for expanding the child life role. It demonstrates how the child life manager knows the importance of the field, yet experiences difficulty in proving the usefulness of their service. In order to prove the usefulness of child life service, have the profession considered an essential service in all hospitals, acquire more money and staff; the majority of child life specialists and managers identified advocacy as the key way to overcome these

challenges. One manager explained the value of the Child Life Institute in advocating for role expansion.

I think through the Child Life Institute, we are going to be able to have some more credibility. The thing is, I myself would like to see children who are having any healthcare experience to have child life intervention, whether it is blood work, an emergency, or x-rays. Any child and every child deserve child life.

The majority of the participants reported that a large part of their role as manager was to advocate and maintain the child life role in the hospital and to continue to work towards expanding the role.

### **Research.**

Another way to demonstrate to the public and the hospital personnel on the importance of the child life field is to continue to conduct evidence-based practice research. Several of the child life managers expressed that advocacy for child life services could only make so much of a difference. They explained that when proposals are being created at the hospital, they require evidence-based research to justify these changes. A child life manager explained this perspective,

I think we really need to build up the research side of things, we really need to get some more evidence for our practice to be based on and that will help these other pieces fall into line in terms of advocacy and funding.

In summary, the main themes from the data consisted of *Role Perceptions, Collaboration with Health Care Professionals, Collaboration with School Professionals, Challenges to Collaboration with Schools* and *Recommendations for the Role Expansion*. Within these five categories were thirteen sub-themes, which emerged both spontaneously and from the questions asked in the surveys and interviews. Taken together, these five key findings assisted in answering the main research question, which will further be addressed in the discussion.



## **Chapter 6: Discussion**

The purpose of this research study was to understand how child life specialists and managers perceive an expansion of their role to include greater collaboration with the school after children are discharged from hospital. Bronfenbrenner's (1979) ecological model was utilized as a framework to examine how health care and school professionals from the child's Microsystem can collaborate to support successful transition back to school.

The discussion section will first examine how the data collected addressed the research question. Relevant literature will be reviewed where possible, and the theoretical framework will assist in offering greater collaboration between child life specialists and school personnel. Implications for the future of the child life profession will include areas of further research such as the perspectives of teachers and families on the role of the child life specialists. Based on data and the adopted theory a proposed model of how child life specialists might collaborate with schools will be provided. Finally, the strengths and limitations of this research study will also be highlighted.

The findings of this research enhance our understanding of the child life specialists' and managers' role in the hospital environment. As described by both child life specialists and managers' being a part of an interprofessional team within the hospital is a significant part of their job description. All child life managers were able to cite examples of benefits and challenges associated with collaboration in the hospital. The degree to which collaboration occurs with professionals in the health care and school environment was also highlighted. It was clear from the findings that while a large amount of collaboration occurs within the hospital, there are only minimal examples of collaboration with professionals in the school. Therefore,

despite an acknowledgement that such collaboration is important little has been done to put this into practice. The data from this study explored how participants felt about expanding the child life role to provide more psychosocial support to children transitioning to the school environment and discussed some of the possible benefits to this expansion. Participants discussed in detail the numerous challenges that hinder the expansion of child life services. Finally, both specialists and managers identified the need for additional advocacy and research as prerequisites for expanding the role.

The findings from this research provided data from both child life managers and specialists to answer the main research question; how do child life specialists and managers envision role expansion beyond the hospital to provide ongoing psychosocial support to children in collaboration with school? The following section will examine the findings on specialists' and managers' perceptions of their role in the hospital.

### **Role Perceptions**

“Child life professional preparation is grounded on an accumulation of theory, knowledge and skills focused on identifying and addressing the needs of children and families within the health care setting” (Turner & Fralic, 2009, p 41.). Despite the fact that the child life profession is grounded on theory, and evidence-based practice (Koller, 2007) many participants described that they believed their role in the hospital was not taken seriously.

Although the findings indicate that child life specialists and managers believe that their services are essential, they perceive that professionals both in and outside of the hospital are unaware of their role and the services they provide. This was a major theme in many areas of the data, thereby emerging as a pervasive issue for child life specialists and managers. It is necessary



to recognize how this overarching theme makes a difference in how they view their roles and how confident people in the profession feel about expansion. This challenge was prevalent in many areas of the data including expanding the child life role to collaborating with the school as well. From the findings of this study, it is evident that we cannot begin to consider the expansion of child life services until we have educated more professionals in and outside of the hospital on the importance of psychosocial services and their role. The findings demonstrate that advocacy and research are two strategies for child life role expansion. Therefore it is necessary to continue to engage in evidence-based practice and to conduct research in the field of child life. The following section will examine the findings on current levels of collaboration with schools and how an example in Sauquoit Valley, New York could serve as a model for expansion in Canada.

### **Current Levels of Collaboration with Schools**

It is evident from the findings that the majority of child life specialists never collaborate with school personnel outside hospital environment. We learned from the data that most of the collaboration with the community school is done by teachers working in the hospital. However, these teachers mostly focus on the academic needs of the child while in the hospital, leaving the child with little guidance on how to address their psychosocial needs while transitioning from the hospital to the school. Bessell (2001) found that homebound educational instruction programs were inadequate compared to real school and left the child feeling increasingly isolated, similar to their feelings while in the hospital. The study also suggested that there was no consistency in curriculum, assignments and information provided by the teacher in the classroom.

Collaboration with schools often occurred at the initiation of the child life specialist. Since there was only one province, which mandated such collaboration it, is difficult for child life

specialists to expand their services beyond the hospital without such policies and guidelines.

This collaboration was reported by a child life manager, who indicated that when a child returns back to school a Health Contract is created in order to outline the roles and responsibilities of all members involved and to ensure the transition is successful.

Although child life specialists in Canada have limited contact with schools, there are a few examples in the U.S. practicing this form of collaboration. As discussed in the literature review, Brown (2008) described a school in Sauquoit Valley, New York that has a Wellness Centre attached with services from both a child life specialist and a social worker. The program was initiated because the majority of children live in rural areas with minimal access to health care centres, and the families depend on the school to take care of the needs of the children. The process of implementation began with a proposal to the school board, following this a brochure was designed for the children to take home, while the social worker presented this new service to the school personnel. Referrals to meet with the child life specialist or social worker can be given by a parent or any school personnel (Brown, 2008). Brown (2008) provides an excellent example of how professionals from different institutions can collaborate together to devise a plan to help meet the needs of the children. This example provides testimony that if this program can operate in the U.S., there is the possibility to work through the challenges that child life managers and specialists discussed in this study to create a similar program in Canada. The following section will discuss the importance of validating the child life profession.

### **Theoretical Implications**

Bronfenbrenner's ecological model (1979) places the child at the centre of many complex systems, some of which have a direct impact on the development of the child. This study utilized

Bronfenbrenner's (1979) ecological model to examine how members from two of the institutions (hospital and school), which are a part of the child's Microsystem, could collaborate together to assist the child in transitioning back to school. The findings suggest that although the school and hospital are a part of the child's Microsystem, the professionals within these systems seldom interact or communicate with each other. Harris and Curnick (2000) explain that in order to provide effective care, professionals need to work together to meet the needs of the child.

The Mesosystem is where interaction takes place between the different people within the child's Microsystem. The goal of this study was to explore how child life managers and specialists felt about collaborating with another group of individuals from the child's Microsystem. The findings demonstrate that although there are some challenges to collaboration, both child life specialists and managers believe expanding the role to collaborate with school professional holds many benefits for the child. Bronfenbrenner's (1979) ecological model will serve as a framework for the proposed model of child life expansion, which will incorporate the many roles and relationships within the Microsystems of the professionals from the school, hospital and home to transition back to school.

### **Strengths & Limitations of the Study**

One of the strengths of this study is that the researcher piloted the survey with key informants within the child life profession. Another strength of this study is that researcher is not a child life specialist or a member of the health care team. This allowed the researcher to take an outsiders position on the topic of the child life specialist expanding beyond the hospital and perhaps a more objective stance. On the other hand, the researcher's own bias can impact the data collection, analysis and interpretation of the data, particularly, since in this case, the

researcher believes that the child life specialist should be the professional to facilitate the transitional process from hospital to school.

Although this research study has made a contribution to the literature on the child life profession and interprofessional collaboration, there are some limitations evident in this project. The sample size is relatively small and does not represent the entire child life profession. Even though it was a cross-sectional sample, there are provinces and territories where no sample was available due to time of the study, a limited availability of staff in the summer, no response or knowledge of child life specialist or manager employed in the area. In addition, recruitment of participants was done through the CACLL 2007-2008 members list this limited the sample population to members. Finally, many of the interviews had to be conducted over the phone. Perhaps, if the researcher was able to conduct more of the interviews in person, more in-depth data could have been obtained through face-to-face contact.

## **Recommendations**

As indicated in the literature, interprofessional collaboration between members of the healthcare team breaks down barriers in order to meet the needs of the patient (Halm et al., 2003). The purpose of this research was to investigate how professionals from the hospital and the school could collaborate to meet the needs of the child while transitioning back to school. The findings from this study found that both child life specialists and managers believe collaboration with the school would be valuable and there is a need to investigate how the schools' perceive collaboration with the hospital.

### **Further Research.**

The findings from this study indicated while *Resources* is a challenge for child life specialists, it is also an obstacle for professionals outside of the hospital. In order to find the best possible way to facilitate the child's transition with ease, it is important to consider the obstacles impacting all professionals. There is a need to further explore important areas of this research. For example, future research should determine how teachers perceive the prospect of greater collaboration with child life specialists. Some areas for exploration could include asking teachers, do they feel prepared to work with chronically ill children? How would they help a child transition back to the school after being hospitalized? How do they feel about collaborating with a child life specialist? Do they understand the role of the child life specialist? A second area of inquiry consists of ascertaining the perspectives of the child and family. Further research should consider the perspectives of parents and what they believe is best to help their child reintegrate into the school system. Additional research could explore how children feel about transitioning back to school and what would help them feel more comfortable during this time. It is important to consider the perspectives of the child and ensure he/she feels they are playing an active role in decision-making.

### **Implications for Practice.**

Despite reported challenges, there are feasible opportunities for child life specialists to engage in collaboration with schools. Based on a review of the findings within an ecological framework, a proposed model for expanding the child life role is depicted in Figure 4. This model envisions the role of the child life specialist working primarily in the hospital as well as assisting children as they transition back to school. The model consists of six phases:

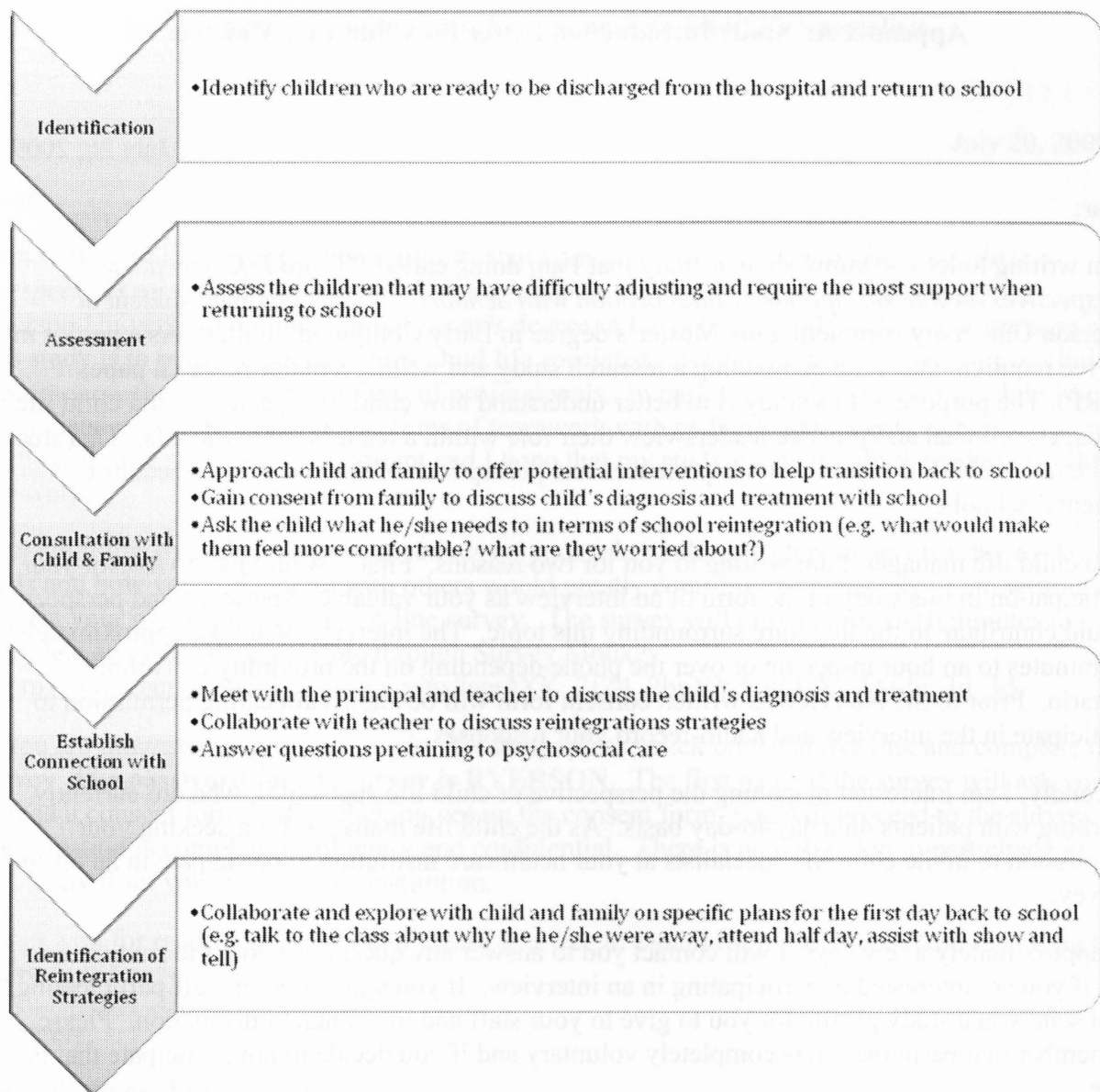
Identification, Assessment, Consultation with Child and Family, Establishing a Connection with School and Identification of Reintegration Strategies. The Identification phase consists of the child life specialist making weekly checks to determine the status of patients who will soon be discharged from the hospital. The Assessment phase would involve a more in-depth analysis, where the child life specialist might determine the patients, who may experience a greater difficulty transitioning back to school. The Consultation with Child and Family phase includes approaching the family to offer possible services and to discuss potential interventions in helping the child transition back to school. This phase also involves seeking parental permission to share information about the child's diagnosis and treatment. In addition, the child life specialist would explore the child's feeling about going back to school. In this phase, it is important to negotiate the requests of the parents and the child in order to create the best possible plan for reintegration.

The School Connection phase would involve the child life specialist making contact with the school personnel (teacher, principal, social worker). This meeting would involve explaining the child's diagnosis, treatment and answering any questions. The team of professionals would brainstorm together the best way to reintegrate the child into the classroom, so that the child and all professionals involved feel comfortable and adequately prepared to follow through with the plan. The last phase is the Reintegration phase, this is where the child life specialist would take ideas from the meeting with the school personnel and propose them to the child and family. Then the child life specialist, the child and the family would design a plan for the first day of school. For example the plan might specify that the child would only go to school for half day for the first week, or that the child life specialist or parent might accompany the child to school.

In summary, this model proposes the building of a partnership between hospital and school. This model will allow child life specialists to assess and work more closely with children

who are in need during the process of transitioning to school. The purpose of this study was to explore how child life specialists and managers felt about expanding their role and services beyond the hospital to collaborate with the school. This study has demonstrated there is a need to facilitate collaboration between different professionals in order to treat the whole child. The World Health Organization states, "Health is a state of complete physical, mental and social-well-being and not merely the absence of disease or infirmity" (WHO, 1946). The data from this study cite the willingness of child life specialists and managers to engage in greater collaboration with schools. However, challenges around a limited understanding of their profile from other professionals and lack of resources still remain. Despite these challenges, it is incumbent upon professions in the child life field to overcome obstacles so the health and welfare of the child is at the forefront of their practice. Therefore, child life specialists must continue to strive to find ways to expand their services to meet the needs of the children transitioning back to school.





*Figure 4.* A model for child life collaboration with schools. This figure demonstrates a set of proposed phases for collaboration between child life specialists and schools.



## Appendix A: Study Introduction Letter for Child Life Manager

July 20, 2009

Dear:

I am writing to let you know about a study that I am doing called, "*Child Life Specialists Perspectives on Interdisciplinary Collaboration with Schools*". I am a graduate student at Ryerson University completing my Master's degree in Early Childhood Studies. As a part of my degree requirements, I am completing a research study and writing a major research paper (MRP). The purpose of this study is to better understand how child life specialists and child life managers, clinical and practice leaders view their role within a team of professionals. This study will explore child life specialists' experiences and perceptions of teamwork with pediatric patients' schools.

As a child life manager, I am writing to you for two reasons. First, I would like to ask for your participation in this study in the form of an interview as your valuable experience and perspective would contribute to the literature surrounding this topic. The interview will take approximately 30 minutes to an hour in-person or over the phone depending on the proximity to Toronto, Ontario. Prior to the interview, a written consent form will be signed allocating permission to participate in the interview and audio-record your responses.

Secondly, I am interested in gaining the perspective of child life specialists, who are currently working with patients on a day-to-day basis. As the child life manager, I am seeking your permission to invite child life specialists at your healthcare institution to participate in an on-line survey.

In approximately a few days, I will contact you to answer any questions about the study and to see if you are interested in participating in an interview. If you agree to your staff participating, I will send you a study profile for you to give to your staff and my contact information. Please remember that participation is completely voluntary and if you decide to not participate that is fine.

Thank you for reading this letter and please feel free to e-mail for more information regarding the study.

Sincerely,

Sarah Pershick , MAECS (c).  
[sarah.pershick@ryerson.ca](mailto:sarah.pershick@ryerson.ca)

Donna Koller, PhD.  
Associate Professor, ECE  
[dkoller@ryerson.ca](mailto:dkoller@ryerson.ca)

## Appendix B: Study Profile Letter for Child Life Specialists

July 20, 2009

Dear:

I am writing to let you know about a study that I am doing called, "*Child Life Specialists Perspectives on Interdisciplinary Collaboration with Schools*". I am a graduate student at Ryerson University completing my Master's degree in Early Childhood Studies. The purpose of this study is to better understand how child life specialists and child managers, practice or clinical leaders view their role within a team of professionals. In part, this study will explore child life specialists' experiences and perceptions of teamwork with pediatric outpatients' schools. The role of the child life specialist is important and I hope that my study can highlight the value of child life work.

As a child life specialist, your perspectives on your role working with patients on a day-to-day basis and how you collaborate with others would greatly contribute to this study. I am writing to request your participation in an on-line survey. The survey will only require 5-10 minutes to complete and is easily accessible through Survey Monkey  
[at http://www.surveymonkey.com/s.aspx?sm=XK\\_2fZ4\\_2bnYYdQR4sXsal44dg\\_3d\\_3d](http://www.surveymonkey.com/s.aspx?sm=XK_2fZ4_2bnYYdQR4sXsal44dg_3d_3d).

If you are interested in participating in this study, please click on the above link and complete the survey. **The password for the survey is RYERSON.** The first page of the survey will ask you to read a consent form. After clicking yes on the consent form, you will proceed to the survey. Participation is completely voluntary and confidential. There is no obligation to participate in this study from your manager or institution.

Thank you for reading this letter and please feel free to e-mail for more information regarding the study.

Sincerely,

Sarah Pershick, MAECS (c).  
[sarah.pershick@ryerson.ca](mailto:sarah.pershick@ryerson.ca)

Donna Koller, PhD.  
Associate Professor, ECE  
[dkoller@ryerson.ca](mailto:dkoller@ryerson.ca)

## Appendix C. Child Life Manager Interview Consent Form

### Dear Participant:

You are being asked to participate in a research study exploring child life specialists and managers' perspectives on collaboration with schools to provide psychosocial support for pediatric patients and siblings. It is important to read the following information before you give consent.

**Title of Research Project:** *Child Life Specialists' Perspectives on Interprofessional Collaboration with Schools*

### **Investigator:**

Sarah Pershick, B.A.

[sarah.pershick@ryerson.ca](mailto:sarah.pershick@ryerson.ca)

### **Purpose of the Research:**

The purpose of this study is to better understand how child life specialists and managers perceive their role within an interdisciplinary team of professionals. This study will explore child life specialists' experiences and perspectives of collaboration with pediatric patients' schools.

**Description of Research Study:** The interviews will be conducted with child life managers who are currently working in a Canadian healthcare institution. The research process will consist of a standardized open-ended interview, which will take approximately 30-60 minutes. Each interview will be audio-tape recorded and notes from the discussion will be written. The findings of this study will be used to complete a Master of Arts in Early Childhood Studies at Ryerson University. There is a possibility that this information will be published in a graduate thesis paper.

**Potential Risks:** The inconvenience associated with participating in this study includes the time commitment for the interview. This inconvenience will be minimized by the investigator traveling to interviewee's choice of location and time for interview.

**Potential Benefits:** The findings from this study will benefit child life specialists practice by helping them better understand ways to provide children support during and after their stay in the hospital.

**Voluntary Participation:** Your participation in this study is completely voluntary. Throughout the interview, you may choose not to answer any of the questions and if you choose you may withdraw from study at anytime without prejudice or penalty.

**Privacy and Confidentiality:** Your privacy is respected. All information collected in this interview will be kept confidential with the use of a pseudonym in place of the interviewee's name. When presenting the findings, individual responses will be presented utilizing pseudonym names. The data collected in this study will be stored in locked files accessible only to the researcher for the length of two years. All consent forms and interview protocol forms will be stored separately from the data to ensure confidentiality. After the completion of the study, participants may request a copy of the thesis paper.

## Audiotape Recording Consent

Your signature below indicates that you are aware that this interview will be audiotape recorded and verbatim transcriptions will be later made from the audiotapes.

\_\_\_\_\_  
Signature of Participant

\_\_\_\_\_  
Date

### **Consent:**

By signing this form, I agree that:

1. You have read the information on this consent form.
2. You would like to participate in this study.
3. You are aware that the following information maybe published in a thesis paper.
4. You are aware that you can withdraw from this study at any time with no penalty by contacting the investigator.
5. You have been given a copy of this consent form.

\_\_\_\_\_  
Name of Participant (please print)

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature of Participant

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature of Investigator

\_\_\_\_\_  
Date

☐ **Yes, I would like a summary of the findings.**

If you have any questions about this study or require further information, please contact Sarah Pershick (primary investigator) at [sarah.pershick@ryerson.ca](mailto:sarah.pershick@ryerson.ca).

If you have any concerns about this research or your rights as a participant, please call faculty supervisor, Donna Koller at [dkoller@ryerson.ca](mailto:dkoller@ryerson.ca)

## Appendix D. Pre and Post Interview Protocols Form

**Title of Project:** Child Life Specialists' Perspectives on Interdisciplinary Collaboration with Schools

**Research Purpose:** The purpose of this study is to better understand how child life specialists and managers perceive their role within an interdisciplinary team of professionals. This study will explore child life specialists' experiences and perspectives of collaboration with paediatric patients' schools.

**Location of Interview:** \_\_\_\_\_

**Time of Interview:** \_\_\_\_\_

**Date of Interview:** \_\_\_\_\_

**Interviewer:** \_\_\_\_\_

**(Pseudonym):** \_\_\_\_\_

**Pre-Interview Procedure:** Hi! I am Sarah Pershick and I am a graduate student in the Master of Arts Early Childhood Studies at Ryerson University. Thank you once again for volunteering to participate in this study.

The purpose of this interview is to gather information for my thesis paper, which is a requirement for my Master of Arts degree. The intent of this study is to gather personal perspectives from child life specialists and managers on their role within an interdisciplinary team of professionals. In particular, to reiterate the value of the child life specialists and ultimately exploring how their role can expand to provide psychosocial support outside of the hospital. The purpose of this study is to better understand child life specialists' experiences and perspectives of collaboration with paediatrics patients' schools.

In order to comply with ethical guidelines, your interview will be transcribed using a pseudonym name in order to ensure confidentiality. The interview will be recorded with an audio-tape device and transcribed following the interview. At any time during the interview, you may choose not to answer any of the questions and you can withdraw from study at any time. Thank you for participating in the study. Do you have any questions before we begin?

**Post-Interview Procedure:** Thank you again for participating in this study. Next, I will transcribe your responses from the audio-tape to my computer. If you decide at anytime that you would like to withdraw from the study, all information including transcription, recorded interview, consent form and interview protocol form will be destroyed. At the end of August 2009 following the completion of my study, I will send you a summary of the findings.

## Appendix E. Child Life Specialist Survey Consent Form

### Dear Participant:

You are being asked to participate in a research study exploring child life specialists and managers' perspectives on collaboration with schools to provide psychosocial support for pediatric patients and siblings. It is important to read the following information before you give consent.

**Title of Research Project:** *Child Life Specialists' Perspectives on Interdisciplinary Collaboration with Schools*

### **Investigator:**

Sarah Pershick, B.A.

[sarah.pershick@ryerson.ca](mailto:sarah.pershick@ryerson.ca)

### **Purpose of the Research:**

The purpose of this study is to better understand how child life specialists and managers perceive their role within an interdisciplinary team of professionals. This study will explore child life specialists' experiences and perspectives of collaboration with pediatric patients' schools.

**Description of Research Study:** The surveys will be sent to child life specialists who are currently working in a Canadian healthcare institution. The research process will consist of an on-line survey via Survey Monkey, which will take approximately 5-10 minutes to complete. The findings of this study will be used to complete a Master of Arts in Early Childhood Studies at Ryerson University. There is a possibility that this information will be published in a graduate thesis paper.

**Potential Risks:** The inconvenience associated with participating in this study includes the time commitment for the survey. The investigator will make the survey accessible on-line for approximately three weeks, so the participant might complete the survey at a convenient time and location, which will minimize this inconvenience.

**Potential Benefits:** The findings from this study will benefit child life specialists practice by helping them better understand ways to provide children support during and after their stay in the hospital.

**Voluntary Participation:** Your participation in this study is completely voluntary. Throughout the interview, you may choose not to answer any of the questions and if you choose you may withdraw from study at anytime without prejudice or penalty.

**Privacy and Confidentiality:** Your privacy is respected. All information collected in this survey will be kept confidential. The information gathered from this survey is stored on the Survey Monkey's data storage site, which is located in the USA and therefore all information submitted to Survey Monkey is potentially subject to the PATRIOT act. After the completion of the surveys, the data collected in this study will be stored in locked files accessible only to the researcher for the length of two years. All consent forms will be stored separately from the data to ensure confidentiality. After the completion of the study, participants may request a copy of the thesis paper.



**Do you agree to the consent information listed on this form?**

**Yes, I agree to the above consent form.**

**No, I don't agree to the above consent form.**



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