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Connecting home and hospital life : cultural influence in child life practice

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CONNECTING HOME AND HOSPITAL LIFE: CULTURAL INFLUENCE IN CHILD LIFE PRACTICE

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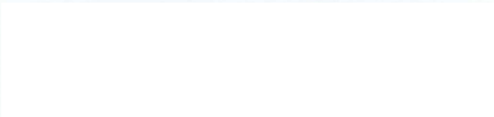In the Program of
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Abstract

The changing demographics of illness necessitate the provision of complex care practices

designed to meet the individual needs of families from diverse backgrounds. Providing

psychosocial care to paediatric patients, child life specialists integrate processes designed to

better understand their patients, thus informing their plans of care. Through the use of

Grounded Theory, this study involves 7 child life specialists from a large city in Ontario and

explores the processes implemented by child life specialists in *getting to know* their patients

and families. Data obtained from semi-structured interviews and a reflective journaling

exercise was examined for evidence of cultural influence and a greater understanding of

child life specialist's perceived comfort and ability was explored. The results of this study

suggest child life specialists engage in culturally responsive practices, however several

barriers and challenges exist. Resource needs are identified and implications for practice are

examined.

Acknowledgement

I would like to thank the child life specialists who participated in this study for sharing with me their time, expertise and their heartfelt desire to provide children and families with meaningful care. Without your willingness to participate and to share, this study would not be possible.

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To Mike, thank you for picking up the pieces; for being my support, for loving me even when I wasn't so lovable and for believing in me, even when I didn't believe in myself. And to Madeline...you are my reason for being. Somehow you always know when I need a hug, a kiss or a nice cold glass of water. You are the reason that all of this makes sense...to find a way to help, to serve and to provide care which matters.

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The changing demographics of illness have resulted in an increase in more medically fragile children with longer periods of hospitalization required. The American Academy of Pediatrics (2006) suggests the need for patient care plans which reflect the individual needs of each patient and family. In order to achieve this goal, complex care plans must be designed and informed through interprofessional collaboration and processes which directly engage the child and family in sharing information that facilitates a greater understanding of their needs.

Child life specialists are contributing members of interprofessional practice teams comprised of healthcare professionals such as physicians, nurses, physiotherapists, social workers and chaplains. Child life specialists provide psychosocial interventions to hospitalized children and families in an effort to minimize the negative effects of illness, trauma and loss while maximizing the potential for typical growth and development. With strong foundations in child development and family systems theories, child life services are considered to be an integral component of healthcare for paediatric patients (Pediatrics, 2006). Provisions of child life services are delivered within the model of family centred care, recognizing the value of collaboration with family members in the creation of programs and services for the hospitalized child.

Although many child life service interventions such as procedural preparation and play can be readily adapted to suit the needs of the individual child, the delivery of normal life experiences including the provision of comforting routines, celebrations, activities and

interests, require a deeper and richer understanding of the whole child. Processes

implemented to understand the hospitalized child must be informed with more than the

medical and developmental information that is readily available in patient charts. According to

Bronfenbrenner (1979) the developing child is an active agent interacting with the changing

dimensions of their immediate settings including family, community, society and culture.

Opportunities for child life professionals to promote the optimal development of the

hospitalized child (Pediatrics, 2006), therefore, must incorporate the multitude of influences on

development. Recognition of the multiple ways to achieve healthy development and the

successful integration and adjustment to hospitalization and illness should be the benchmark

for achievement and the basis from which child life goals are generated. Child life

professionals, must piece together *all* parts of the puzzle to create a clearer vision of the whole

child from which care plans can be designed.

Challenges for the child life professional lie in the provision of care which meets the

diverse needs of the multi-cultural patient population. Providing programs and interventions

that integrate the two worlds of home and hospital life becomes difficult to achieve in

consideration of the child life specialist to patient ratio realities. The American Academy of

Pediatrics Policy Statement on Child Life Services recognizes "successful" ratios of 1 child life

specialist to 15-20 inpatients (Pediatrics, 2006, p. 1757); the reality however, is that numbers

are significantly higher than this. As well, the focus on information sharing is often centred on

medical diagnosis and treatment protocols, devoid of family and cultural context. Contextual

information such as family structures, roles, parenting practices and cultural values and beliefs

often unfolds over time. Culturally relevant and meaningful services for such large caseloads becomes challenging to achieve yet gravely important to attain.

In Thompson (2009), child life best practice and service guidelines include 9 elements of family centred care principles which are linked to performance standards. Element 3 titled "Honor the Racial, Ethnic, Cultural and Socioeconomic Diversity of Families" charges the child life profession with standards of care directly linked to the provision of culturally relevant and meaningful services (Thompson, 2009, p. 104). These standards incorporate the following practices: an awareness of personal values and beliefs, acknowledgement and honouring of family values, customs and experiences, identifying family support systems including culturally specific resources and modelling and reinforcing culturally competent care (Thompson, 2009, p. 104).

This study therefore, seeks to explore the processes implemented by child life specialists in getting to know patients and families from diverse backgrounds. Through the use of Grounded Theory, these processes will be explored for evidence of cultural influence and a greater understanding of child life specialist's perceived comfort and ability.

The Role of Child Life Specialists

Child life specialists are considered to be "experts in child development" (Child Life Council, 2009). Child life specialists promote the effective coping of children facing life threatening and traumatic events, through the use of therapeutic play, procedural preparation, medical education and expressive arts activities (Child Life Council, 2009).

Integral to child life practice is the examination of variables affecting child and family coping including child, family, illness and medical experiences (Koller, 2008). Child life specialists engage in assessments of a child's ability to cope with illness, trauma, loss and hospitalization through careful consideration of the multiple influences on coping and coping behaviours. Assessment practices are essential to the provision of child life programs and constitute the first step in designing a plan of care for the child and family. Through the integration of knowledge and understanding of the potential stressors of illness and hospitalization, collaboration with other healthcare professionals and observations of child and family coping, child life specialists determine an appropriate course of action (Turner and Fralic, 2009).

Along with formal tools of assessment (see Gaynard, 1990), child life specialists employ implicit strategies such as the construction of meaningful relationships with patients and families, providing them with relevant patient and family information (Turner and Fralic, 2009).

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Meaningful connections often illuminate facts and features of family and home life that are integral in understanding the whole child thus providing a sound basis for child life intervention.

Influences on Development

Bronfenbrenner's Theory of Ecological Development

Influenced by Bronfenbrenner's Ecological theory (1979), child life specialists recognize the multiple influences on the development of a child including: family, home, community and the hospital environment. Bronfenbrenner (1979) describes human development as a "...progressive, mutual accommodation between an active growing human being and the changing properties of the immediate settings in which the developing person lives." (p. 21). Within this theory, the ecological environment is comprised of 4 interrelated systems: the Microsystem, Mesosystem, Exosystem and the Macrosystem, all of which contribute to and influence development through reciprocal and dynamic interactions with the individual concerned (Bronfenbrenner 1979).

A child therefore will develop differently within settings such as the school, home and hospital (Microsystem), based on the relationships, roles and activities experienced. Similarly, Bronfenbrenner (1979) proposes that development is influenced by the interrelations between two or more settings in which a child exists such as home and school, home and daycare or home and hospital (Mesosytem). Further still, settings which do not actively involve the developing person such as parental work place and school boards (Exosystem) and the larger

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subculture or culture encompassing belief systems and ideologies (Macrosystem), are all influential on the development of the child (Bronfenbrenner, 1979). These systems are recognized as interconnected where information, knowledge and attitudes from one setting, influence behaviour and development in another (Gardiner and Kosmitzki, 2008).

According to Bronfenbrenner (1986), extra familial processes and contexts influence intra familial functioning. Roles, relationships and experiences in settings such as the home, school and hospital are not independent of one another and jointly influence the reciprocal relationship between the child, environment and family. Bronfenbrenner (1979) also states that the mutual relationship between the child and the environment involves a process of *ecological transition* which occurs when a developing individual's position in the environment is altered in response to a change in setting, roles or both. In the case of hospitalization, a child quickly moves from the home environment where primary roles are designated and influenced by variables such as birth order, and family roles and responsibilities to those roles which are characterized primarily by illness and hospitalization.   Often the change in roles is significantly different between settings, resulting in marked developmental differences and adjustment. Child life specialists and other healthcare practitioners must find ways to ease these transitions to ensure successful developmental progression.

Bronfenbrenner (1979) suggests that "...the developmental potential of settings in a mesosystem is enhanced if role demands and activities are compatible and if dyads in which the developing person engages, encourage the development of mutual trust, positive orientation

and goal consensus between settings..." (p. 212). Bronfenbrenner (1979) continues to state that

the developmental potential of a setting will increase as a direct relation between the existence

of supportive links between settings such as the home and school or home and hospital. Child

life specialists can play an active role in providing the supports necessary to make healthy

connections between home and hospital life. Through careful consideration, understanding

and expertise, child life activities and interventions designed to promote healthy development

can closely reflect roles, relationships, goals and activities which exist already in the child's

world. Clearly, development does not progress along one dimension; rather it is influenced

along the way by a multitude of variables. Child life specialists must consider these influencing

variables and must strive to promote healthy ecological transitions between the home and

hospital environments.

Eco-cultural Theory

To further strengthen child life interventions, child life specialists must gather

information to contribute to their understanding of the child and family's culture and how this

influences and contributes to the child's development. Building on the work of

Bronfenbrenner, Weisner (2002) proposes that through the Eco-Cultural perspective, the study

of ecological and cultural contexts provides a platform for studying "units of cultural analysis"

(p. 276), and is believed to be the "preeminent tool that children learn for adaptation to life" (p.

277). Activities and routines which guide everyday life provide a gateway to understanding that

which is meaningful to both parents and children. Routines such as bed time, dinner time,

household responsibility, homework and family celebrations are comprised of activities guided

by the family culture, providing pathways and expectations for growth and development

(Weisner, 2002). Activities are representative of values, goals, relationships, roles, scripts and

emotions and can provide us with "outcome criteria" (p.279) to inform our interventions

(Weisner, 2002). Involvement in opportunities for children to maintain typical routines and

activities can result in a greater sense of wellbeing (Weisner, 2002). It is therefore imperative

that child life specialists find avenues to learn and gather this information to inform their

practice.

Funds of Knowledge

Creating opportunities for the sharing of information between children, families and

child life practitioners creates the space to honour and respect the diversity of each as

individuals. Moll, Amanti, Neff and Gonzalez (1992), introduce the concept *funds of knowledge*

to describe the totality of the lived experiences of each child within their immediate

environment. Funds of knowledge are "historically accumulated, culturally developed bodies of

knowledge and skills that are essential for household, family and individual well being and

functioning (Moll et. al, 1992, p. 133). Teachers, who come to understand family funds of

knowledge, stress the importance of positioning themselves as learners, opening themselves to

the possibility of knowledge exchange and hence ground their practices in meaningful learning

experiences (Gonzalez, Moll, Rivera, Gonzales and Amanda, 1993). Drawing from parallels in

education, child life specialists who ground their practice in inquiry and who seek to truly

understand each family's funds of knowledge are better able to design culturally responsive

and meaningful interactions and interventions.

Gonzalez et. al (2005) purports that creating opportunities for funds of knowledge to be

shared, addresses power differentials and counters the deficit model approach to 'them' versus

'us'. By legitimizing the experiences of students, or patients in this case, through the provision

of familiar knowledge and experience, we allow for individuality and variability within

populations (Gonzalez et.al 2005). Ada and Campoy (2004), whose work is based largely in

transformative educational strategies, state that providing the space to share one's story, offers

validity to a person's heritage and traditions. By allowing one's voice to be heard, educators

and health care practitioners can learn from other's reality and can ensure that institutions or

systems do not disenfranchise the family (Ada & Campoy, 2004). Similarly, narrative therapy is

noted in psychotherapy practice as positioning the therapist as a "facilitator" searching for

valuable subtext in the stories which are shared by clients (Dyche and Zayas, 1995. p.2) The

therapist benefits from perspectives of "naiveté" and curiosity which both "fuel the act of

knowledge", allowing room for client description and attribution of meaning (Dyche and Zayas,

1995, p. 5). Child life specialists therefore must emphasize the value of the hospital as one part

of the whole child. Through provisions of time and space for the sharing of knowledge, child

life specialists can empower the role of family and culture in the development of the child.

One primary challenge in honouring the role of culture and its influence on development lies in the obscure definition of culture itself. An examination of the literature reveals a multitude of understandings that encompasses everything from higher level learning through immersion in activities such as art, music and theatre (Merriam-Webster, 2009), to the popular definition noted by Tylor (1871) as "that complex whole which includes knowledge, belief, art, morals, laws, customs and any other capabilities and habits acquired by man as a member of society" (as cited in Campinha-Bacote, 2003). As Yan (2008) suggests, there are many taken for granted assumptions regarding the definition and understanding of culture and that an emphasis should be placed on critically examining the language that we use and the assumptions which follow.

In Yan (2008), a grounded theory study on social workers' understanding of culture and cross cultural care, yielded two definitions of culture: as a "complex whole", an all encompassing way of life incorporating beliefs, values, norms, practices, rites and customs and as "fluid and interchangeable" either shared among people who identify with the same or as an entity belonging to one's self based on the reactions and responses to the environment. Yan (2008) suggests that theories must be connected to practice through further examination into the meanings and definitions as well as the taken for granted assumptions so that we may understand how best it can be achieved.

The Need

The desire and mandate to deliver culturally competent care is not new to the arena of healthcare literature. In an effort to recognize the needs of an ever growing population of new immigrants and ethnic minorities, workforces, organizations, service providers and professional entities have channelled physical, academic and monetary resources into research which supports the diverse needs of marginalized populations. Work places are engaging employees in educational and reflective strategies such as 'lunch and learns', conferences and symposiums, compelling practitioners to seek opportunities that increase their cultural knowledge and awareness. Purely recognizing the belief and value systems of a particular culture in relation to its illness and coping patterns however, will not provide the depth and understanding necessary to fully achieve culturally competent care for the individual. The risk lies in homogenizing and over simplifying adaptations and needs of certain populations based on a general understanding of possible beliefs, values and traditions (McCubbin and Katson, 1993).

Organizational Responses

The increased awareness of the diverse needs and the implications for health outcomes has necessitated a shift in organizational structure and thought. Professional organizations such as the American Medical Association, the American Academy of Nursing and the National

Association of Social Workers are adopting cultural care principles, embracing the need to develop standards for practice and guiding principles for the provision of culturally competent care (Engebretson, Mahoney and Carlson, 2008). The Registered Nurses' Association of Ontario (RNAO, 2007), for instance has embarked on a multi-year project informed by an expert panel on the development, implementation and evaluation of Evidence Based Practice statements in culturally competent care. The result is a 91 page document entitled: *Embracing Cultural Diversity in Health Care: Developing Cultural Competence*. This document outlines a set of guidelines useful for practitioners, government and unions on best practices for creating and maintaining culturally competent nursing practices (RNAO, 2007). Documents such as these serve to highlight the efforts and leadership of professional organizations in their accountability to culturally responsive care.

Models of Cultural Competence Theory

The achievements of cultural competence are grounded in several models of culturally competent care and are implemented by organizations in efforts to achieve a standard of care. Roots of culturally competent care can be found in nursing practice and research as far back as the mid 1950's when Madeleine Leininger developed the *Cultural Care Theory* (Leininger, 2002). Recognizing the integral components of holistic care in nursing practices, she embarked on research into the similarities and differences of cultural influences on states of health, illness and well being. Influenced by Leininger's research, Campinha-Bacote developed the model: *The Process of Cultural Competence in the Delivery*

of Healthcare Services (Campinha-Bacote, 2002). This model has been used in the development of responsive healthcare practices and situates cultural competence as an ongoing process between practitioner, patient, family and community. In this model, practitioners are always in a state of learning through engagement in processes of cultural awareness, cultural knowledge and skill acquisition and through the continued desire to be engaged in cultural processes and encounters (Campinha-Bacote, 2002). The constructs of this model are cyclical in nature and provide the opportunity for the continuation of skill building, reflection and awareness. In Wells (2000) the focus shifts from that of cultural competence to "cultural proficiency" as the gold standard to achieve, citing both cognitive and affective practices which need to occur in order to provide cross cultural care. Cognitive practices focus on learning and the acquisition of knowledge while affective strategies centre on attitudinal and behavioural changes and the integration of knowledge in all aspects of practice (Wells, 2000). These models, along with many others guide practitioners, employers and policy makers to engage in practices geared towards the delivery of culturally competent care.

Definitions of Cultural Competence

Similar to the lack of consensus on the definition of culture, is the ambiguity in the definition and achievement of cultural competence. The study of cultural competence has been introduced as a quality improvement initiative aimed at eliminating disparities (Betanacourt, Green, Carillor and Elyse, 2005). Cultural competence has been defined by

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Cross, Bazron, Dennis and Isaacs (1989) as "congruent behaviours, attitudes and policies that come together in a system, agency or amongst professionals and enables that system, agency or those professionals to work *effectively* in cross cultural situations" (as cited in Campinha-Bacote, 2003). Campinha-Bacote (2002, p.181) define cultural competence as "the process in which the *nurse* continuously strives to achieve the ability and availability to effectively work within the context of a client, individual or community" and views cultural competence as a "process of becoming". Dreher and McNaughton (2002, p.185) suggest that cross cultural competence has been repackaged as individualized patient care and equates it with a nurse's ability to be "...equally therapeutic with patients from any social context or background". The lack of agreement on the components of cultural competence therefore renders it challenging to define and creates a dissonance on how best it can be achieved.

Challenges in Achieving Cultural Competence

Most theories on cross cultural competence look towards the practitioner to develop skill for cross cultural interactions and interventions; however, measurement is rarely executed at this level (Munoz, 2007). Measurement typically relies on global constructs which may or may not apply to clinical reality and often capture practitioner's exposure to concepts about cultural competence rather than actual cultural knowledge or behaviour (Boyle and Springer, 2001). Cultural competence inventories such as the *Cultural Competence Inventory Revised* (LaFramboise, Coleman and Hernandez, 1991) and the *Multi-*

Cultural Awareness, Knowledge, Skills Inventory (D'andrea, Daniels and Heck, 1991) are often

administered in university settings, creating the challenge of discerning whether these tests

measure practice or the understanding of cultural competence concepts (as cited in Boyle

and Springer, 2001). Engebretson et. al (2008) state that this lack of consensus on the

definition results in a disconnection between organizational provisions for culturally

competent care and the unique needs of clinical practice and application.

Organizations must create standards of practice for "culturally competent" care but

must do so while responsibly planning and strategizing measurement outcomes. Strategies

must be implemented to gather information first hand from healthcare providers on their

understanding of culture and how culture shapes their practices. Studies such as Munoz

(2007) which examined occupational therapists' understanding of culture and perceptions of

"cultural competence" have uncovered the need for alternative strategies to achieving care

which is culturally responsive and meaningful to all. Occupational therapists interviewed,

revealed that is far more beneficial to focus on "cultural responsiveness" as it measures an

openness to and the building of mutual capacity at the practitioner-patient level as opposed

to focusing on the achievement of skill alone.

In a study by Taylor (2005), nurses indicated that despite best intentions, barriers

and challenges to providing culturally competent care were experienced including: lack of

time, resources, educational preparedness and practical experiences along with imposing

one's own belief on others (Taylor, 2005). Yan (2008) in her study on social work practice

highlights cultural tensions and barriers experienced including: conflicting values between organizational and professional cultures, personal values and beliefs and the grounding of culturally appropriate norms in western constructs. Undoubtedly, there is value and much to be learned by defining concepts of culture, cultural competency and gauging outcome measurement through the experience of front line workers who illuminate the inner workings of the reality of practice, interventions and responsive care.

Child Life Practice and Culture-Implications for Research

Culture is present in every aspect of healthcare delivery. From patient and family needs to medical practices, organizational norms and values and the influence of culture on policy and delivery; culture is omnipresent. What then can be learned, from practices implemented daily by healthcare providers who in the face of cultural presence negotiate skills and programs to meet the needs of those who are served? Research in nursing, social work and other healthcare professions, reveals that culture as a concept is variable in both meanings and implications for healthy development and illness. Culturally relevant care, although necessary is often challenging to achieve. A review of the literature reveals the role of cultural influence on child life practice has yet to be examined. This study will provide an opportunity to view perspectives on culture and cultural influence through the lens of the child life profession. Through examination of implicit practices and processes employed by child life specialists, we may gain valuable insight into how best to establish meaningful

connections with patients and families and consequently how to aim for culturally relevant care.

How then do child life specialists seek to inform their practice with culturally relevant and meaningful information? How is this knowledge gathered and how is it integrated into practice? Using grounded theory inquiry, this study seeks to answer the following questions:

1. What processes do child life specialists implement when *getting to know* their patients and families?

2. Is there evidence of cultural influence in practices, interventions and strategies?

3. How comfortable do child life specialists feel in working with patients and families from diverse cultures?

The theoretical lens informing this study includes the ecological, eco-cultural and cultural competence perspectives as well as the experience of the researcher as a practitioner within the child life field.

<u>Research Design</u>

Through the use of semi-structured interviews and a reflective journal writing exercise, child life practice and interventions were examined to uncover processes employed by child life specialists when getting to know and understand their patients and families within a cultural context. A grounded theory approach to inquiry was used to reflect the realities and experiences (Strauss and Corbin, 1998) of child life specialists who work with children and families experiencing hospitalization, illness, trauma and loss.

Influenced by Bronfenbrenner's ecological theory (1979), this research study examines the roles and relationships of child life specialists and their influence on the developing child. As the hospital setting becomes a part of a child's Microsystem, it is imperative that we understand the variables that work towards facilitating successful integration and continued development. The connection between home and hospital becomes central to explore if we are to foster successful ecological transitions (Bronfenbrenner, 1979) and hence the continuation of healthy growth and development. It is therefore necessary to study lived experiences so that we may understand the current processes and learn through the reality of the key players involved.

Participant Recruitment

Recruitment for this study commenced upon approval from Ryerson University Research Ethics Board, in July 2009. The sample for this research study was comprised of 7 Child Life Specialists working in a large city in Ontario, Canada. Participants were recruited

through the child life specialist population at a major paediatric healthcare facility as well as

through a professional child life interest group and were selected based on purposive

sampling strategies (Mertler and Charles, 2008).

Selected participants met the following inclusion criteria: current employment as a

child life specialist, one year minimum full time employment in the child life profession, and

working within a hospital, rehabilitative centre or community setting that services long term

patients. These criteria were selected to ensure that participants have a sufficient amount

of time in the field to adequately reflect upon their experiences, practices and challenges,

and to ensure a significant amount of time was present for specialists to get to know their

patients and families. Exclusion criteria included: those candidates working in short stay

medical units, emergency departments or settings where patient care is provided on a short

term or one time basis. For the purpose of this study, age and gender do not play a

significant role and therefore were not included as either inclusion or exclusion criteria.

Participant recruitment was to include a total of 8 child life specialists; however the

study reached saturation (Strauss and Corbin, 1998) after 7 interviews were completed.

There are approximately 25-35 child life specialists currently employed in the province of

Ontario, 11 of which are employed within settings which do not meet the inclusion criteria,

thus leaving a remainder of 20-25 possible participants. The selection of 8 participants

provides an adequate representative sample of the overall relevant population and is

sufficient for a qualitative study.

Initial contact was made with each participant through email (Appendix A) outlining

the purpose of the research study, the study profile and the voluntary nature of

participation. Participants were invited to make contact with the researcher and interviews

were subsequently scheduled. Prior to the commencement of each interview, consent

forms (Appendix B) were reviewed and signed by each participant. Opportunities for

clarification were provided and each participant was reminded that their participation was

voluntary and could cease at any point during the research process without penalty (Mertler

and Charles, 2008). Participants were provided with light refreshments and were given a

small gift in appreciation for their participation.

Participants

The number of years of employment in the child life profession ranged from 2 to 20

years. All participants engaged in professional development activities including attendance

at conferences, in-services, and the completion of certification in programs such as Infant

Massage, Infant Mental Health and Bereavement. All participants completed undergraduate

degrees in child development or related fields. Three of the participants had completed

post-graduate diplomas and 4 had completed graduate studies.

The patient populations serviced by the participants range from birth to 18 years of

age, however the average age range for this study falls within birth to 12 years. Patients

were from the following programs: haematology, oncology, multi-organ transplant,

rheumatology, cardiology, trauma, neurology, respiratory medicine and general paediatrics.

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Patients were primarily chronic and long term with an average length of stay of 3 weeks and with multiple and frequent admissions.

Grounded theory

This research study implements a grounded theory approach to exploring processes involved in understanding and getting to know hospitalized and ill children, as related through the perspective of a child life specialist. Grounded theory is an interpretive research method (McCallin, 2003) in which the researcher actively collects, analyses, synthesizes and integrates data to uncover emerging theory (Strauss and Corbin, 1998). The researcher does not set out to prove that which already exists, rather the researcher engages in a method of inquiry where theory is derived from the bottom up and grounded in data (Morse and Richards, 2002). This research method allows for the surfacing of concepts and patterns and provides the researcher with the opportunity to build theory from data retrieved through actual experiences. Although the research was conducted by someone who works within the child life field, grounded theory recognizes that experience and knowledge is what "sensitizes" the researcher to the problems and issues which arise (Strauss and Corbin, 1998).

Data Collection

Interviews

Semi-structured interviews were chosen to enable the researcher to gain a deeper understanding of those processes utilized by child life specialists when seeking information to assist them in understanding hospitalized children and families. The use of interview questions (Appendix C) in a semi-structured format offers the opportunity for participants to provide a multi-layered glimpse into the processes, experiences, behaviours and relationships which exist regarding a particular topic or phenomenon (Strauss and Corbin, 1998). As a researcher who possesses a degree of familiarity with the setting and experiences of working with hospitalized children, semi-structured interviews provide the space to guide the questions while still allowing room for emerging themes and concepts to unfold. Data retrieved through questionnaires or surveys would not provide the richness necessary to fully understand those processes involved in *getting to know* the hospitalized child within the context of family and culture. Questionnaires do not provide the opportunity for clarification and further investigation into implied meanings and do not permit the presence of member checking to test categories, interpretations or conclusions which emerge through the progression of interviews (Strauss and Corbin, 1998). In order to explore the complex issues in this study, methods merit qualitative approaches which can provide in depth data rich in experience.

Reflective Practice

The inclusion of a reflective journal writing exercise was chosen as a method to strengthen the qualitative design of the research study. Reflective practice is useful for understanding theories which shape professional actions and strategies, allowing for a critical awareness of professional practice (Osterman and Kottkamp, 1993). Reflective journals provide the opportunity to revisit experiences and to make sense of "fragmented events, feelings and meanings" (Alterio, 2002, p. 321). The study of child life specialist reflections was integrated into the study to help the researcher understand what they know and what they do (Laughran, 2002).

Participants were instructed to capture three days of professional work in a reflective journal exercise (Appendix D) with a specific focus on: processes used to get to know patients, information that is helpful in understanding patients and families, challenges in gathering information and the role of culture in practice. The reflective exercise was designed to include only an additional 10-15 minutes of work so that time would not be a prohibitive factor.

Data Analysis

Grounded theory research is structured to elicit data for analysis resulting in concepts and categories that are the "building blocks" of theory (Strauss and Corbin, 1998, p.101). As each interview was recorded, transcribed and reviewed by the researcher, data

was consistently and repeatedly analyzed for concepts and themes which were deemed to bear significance (Strauss and Corbin, 1998). The process of transcription and analysis for each interview was complete prior to the next interview, allowing the researcher to bring forward emerging concepts and themes to test for authenticity with subsequent participants (Mertler and Charles, 2008). Transcriptions were coded to include such categories as sources of information, types of information, cultural definitions and child life specialist's perceptions of comfort. Categories were further refined to reflect more detail and to answer the question of *what is going on* in the data (Strauss and Corbin, 1998). Grounded theory research offers insight and enhances our understanding. This method of inquiry facilitated the discovery of processes involved in child life practice and contributes to theories of how these processes may contribute to the development of children facing illness, hospitalization, trauma and loss.

The researcher in this study was known to participants through professional affiliation, however all efforts were made by the researcher to limit researcher bias.

Findings from the interviews included in this research study highlight the following: i) child life specialist's definitions of culture, ii) their perceived ability to effectively engage with families of diverse backgrounds, iii) process of information retrieval including sources, method, types and integration into practice, iv) challenges and barriers encountered and iv) resource needs. As participants' response to the reflective journal activity was inconsistent, the decision was made not to include the data as part of the analysis.

Family Defines Culture

When participants were asked to share their definition of culture, data analysis reveals that all participants define culture as characterized primarily by family, including structure, roles, relationships, knowledge and belief systems and values. One participant defines culture as

> "...I think it is important to always recognize that each family has their own individual culture that is different from every other family that you work with...the extended family plays a piece...so whether or not that extended family lives in the household, how are the family roles designated...so the culture of the family certainly being parenting roles, but just roles in general and then extended family and participation and how they view the role of the child within the family. Are there lesser individuals or are they equals? So I find that certainly impacts the way their treatment unfolds and what is expected of them." (Participant 7)

Other participants describes culture as

"...culture, I think it is the families' values and belief system, it may or may not include faith and religion. I think it is what their background is and what they...how they live their life. So, from day to day, how does culture influence how they eat, how they pray, what rules they have in their house for what children, or anyone can and cannot do..." (Participant 6)

and

"...culture can be a couple of different things including religion, culture can be the definition of that family as well, so how is that family made up, what is the culture of their family unit..." (Participant 5)

Although data indicates that participant understanding of culture is primarily characterised by family, many participants attempted to further define culture by highlighting elements which culture may or may not encompass. Participants indicate that culture does not necessarily equate with religion or ethnicity; in fact, many participants state that these characteristics are not integral to the definition. Statements such as the following serve to highlight this perspective:

"...it is everything, I mean when I think about culture, right away religion pops into my head, I mean I guess it is just because there are so many different beliefs, but it is much more than that..." (Participant 2)

"...culture doesn't have to be race driven, everyone always thinks it is, it is automatic

and your second thought is okay, gender or sexual preference and those types of

things..."(Participant 3)

"...culture is whatever the family embraces and whatever is in their world, whatever

they represent and it doesn't have to be race or gender, it can be what their community

involvement is or what they strongly believe in and it doesn't have to be religion,

sometimes it is but it doesn't have to be all these things...sometimes we just focus on

the obvious." (Participant 3)

During participant interviews, many participants were challenged to clearly articulate
their definitions of culture, however, data analysis reveals that for child life specialists,
culture primarily centres upon the characteristics of families and how the roles, relationships
and structures impact the development of the child.

Perceived Comfort in Working with Families of Diverse Backgrounds

Participants in this study were asked two questions pertaining to their perceived ability
and comfort in working with diverse cultures: i) Please tell me about your perceived ability to
effectively engage with children and families of diverse cultures ii) Can you share with me your
comfort in working with children and families whose culture is one that you are not familiar
with. Data revealed that the majority of participants feel *moderately* comfortable and able to

interact with and provide services for diverse children and families. The following statements

effectively demonstrate a moderate comfort level:

"...I am comfortable and certainly open and want to work with everyone..."

(Participant 2)

"...I think I am fairly comfortable, I don't think I have had any issues..." (Participant 4)

"...I think it has been a growth process with that and certainly I don't come from a

community that is very multicultural and I was not exposed to al lot of different

cultures and I remember when I first started working here, I was quite intimidated by

families of different cultures especially when they practiced their faith and culture

very overtly, as they should and there is nothing wrong with that but I was very

aware of my own reaction to that and really wanting to be an observer at first in

order to make good choices about what I was going to recommend or say."

(Participant 6)

Two of the participants indicate a low level of comfort and perceived ability which is

characterized by the following quote

"...well my comfort level isn't always as high because I feel as though I am not as well

educated as I should be in different family dynamics, different types of culture that we

spoke about..." (Participant 3)

Only one participant indicates a high level of comfort and states

"...I actually thrive on it, I embrace every opportunity to work with another culture, I just love it. I see it as a benefit to me and a challenge as well of my professional ability to work with different families and be diverse in my interventions that I provide..." (Participant 7)

Participants, although tentatively confident in their ability, are generally comfortable when providing care to families and children of diverse backgrounds. This comfort and ability is furthered emphasized when examining the processes implemented by child life professionals when getting to know patients and families.

Families, Children and the Healthcare Team as Sources of Information

Analysis of the data demonstrates key elements of process which are implemented by child life professionals when seeking to understand their patients and families including: sources of information, method of gathering, types of information gathered and integration into practice (see Table 1.).

Sources of Information	Method of Gathering	Types of Information Gathered	Integration into Practice
Child	Conversation	Interests/hobbies, likes/dislikes	Provision of activities and opportunities to meet patient needs/likes
	Observation		
		Relationships/friends	Provision of "normal" routines
	Visual cues such as photos, toys, music	Typical routines at home, school and other	
	Expressive Activities including the use of scrapbooks, feelings pizza, narrative and storytelling	What makes you happy? What makes you sad?	Provision of "normal" experiences from home, and community life
		Strengths	
	Creative use of self including: sense of humour, personality, body language and inner skills	School information	
		Present needs such as privacy, socialization	
Family	Conversation	Family structure and dynamics	Sharing information in meaningful and relevant ways including: learning multiple languages, interpreter services, and providing the time for parents to be experts
	Observation		
	Visual scanning	Roles of family members/caregivers/child	
	Questions	Parenting style	
	Information from objects such as photos, toys, artwork	Beliefs, values and traditions	Encouraging connections between home and hospital life including: honouring beliefs/values/practices and encouraging objects/toys/photos to be brought from home
		Language spoken at home	
		Family routines, customs and celebrations	
		Influence of past stressors on development and behaviour	
		How family interprets illness/situation	
Healthcare Team	Multi-disciplinary rounds	Types of illness	Basis for initial assessment/contact
	Charts	Expected length of stay	Understanding coping behaviours/response to illness and hospitalization
	Consultation	Coping behaviours	
		Age/developmental level	
		Family dynamics	

Table1. Information Gathering Process

Study participants noted the value of seeking information in addition to medical facts such as diagnosis, length of admission and impending tests and procedures. The child life specialists interviewed in this study gathered information to facilitate their understanding of patients and families from the following sources: family, children and healthcare practitioners. As one participant stated:

"...okay, so as a child life specialist we always get information from rounds and nurses and from reading charts, but I think that the best way to gain information is from the family and the child themselves, because again, we sometimes misinterpret who the child is and so we put our own biases into it...it's the most accurate and real..." (Participant 3)

Child

Emerging throughout the data is children as a primary source of information. Many participants indicate that the most accurate information is retrieved from the patient himself. As one participant stated

"... sometimes you can ask them lots of questions and sometimes it just evolves by spending time with them and just allowing those interactions, letting it emerge and sitting with a child and they'll tell you, this is what I do at home, this is what I usually do. That is the most accurate way. You can always go in and ask them so what do you do at home or at school, what type of toys if the child is young, or ask the child if the child

isn't too young, depending on the age... but I think the best way if time allows is to just spend time with the patient that is why child life usually knows the most about really who the patient is." (Participant 3)

Others indicate that engaging the child in the sharing of information is necessary and empowering

"...I try to get as much information as I can about the child so whether it is directly from the child or from those care givers coming in...I try to get as much information as I can. If you can get it from the patient that is great so you are feeding into that need of offering choice and control and giving them the opportunity to plan for their care that way..." (Participant 2)

Sometimes however, it is challenging to retrieve the information due to the degree of illness and potential communication barriers. As one participant states

"...it isn't always possible. With the population I have now, sometimes they are just too sick to even respond, sometimes they are non-verbal and we do try to address that with other forms of communication but it's all about the timing and you know, where they are and I just have to go to other sources, and so I get that." (Participant 2)

For some participants, creative strategies were implemented to elicit information which is otherwise challenging to retrieve. One participant said

"...I would approach the family with a scrapbooking program which would allow her to sort of display who she is and who her family is and we would hopefully get to know her better." (Participant 5)

Another participant engages both children and families in "icebreakers" and "simple activities like name games" and stresses that

"...I mean I always want to know who that child is away from the illness. I often will talk to kids and when we do narrative work, I will say can you take it off and show me what it looks like and put it in a box and tell me what it looks like and some families find it funny so again it all comes back to icebreakers and how do you get the family to step away from the seriousness of the illness in order to give me a bit more information" (Participant 7)

One of the participants explores feelings and emotions as a way of getting to know her patients and states

"...it goes more into emotions but there is a feelings pizza and we talk about how everyone puts something different on their pizza and some days we might feel like a Hawaiian pizza and some days we might feel like the deluxe pizza and so just like you feel for different things in choosing your pizza, you have lots of different feelings inside of you and so if we imagine feelings like toppings, then what would be on your pizza today? It goes more into emotions, but I find I can ask more questions from that, and use it as a

springboard to find out more about the child...before you came to the hospital, what would

your pizza look like?" (Participant 6)

Family

Utilizing family members as sources of information emerged several times

throughout the data. As one participant stated "...I like to have the family involved. I don't

think it is a good intervention unless the family is there...' (Participant 4). Families provide

information which is often not accessible by asking other healthcare team members or the

child himself. One child life specialist acknowledged that if information was challenging to

retrieve from the child

"...if they are younger, I'll ask the parents and just try to build up the relationship...I like

to have the family there and you get a bunch of information...by watching what the

parents are doing, watching mannerisms, watching what the parents are doing while the

rest is going on..." (Participant 4).

Another participant adds

"...most of the time I just talk to the parents because there aren't usually others around.

Sometimes the nurses will find out something, but most of the time patients are just

here with their parents and talking to them and finding out if it is a new patient that I

haven't gotten to know before...so asking who is at home and who can come and

finding out more about their relationships that way." (Participant 5).

[34]

Some participants explained that gathering information from parents can be challenging at times as some parents are overwhelmed and "...don't need another thing to think about...don't need to meet another person...while others are comfortable with that because that is something that they know lots about. So sometimes they are very willing to share that information..." (Participant 6).

Healthcare Team

Other information sources include members of the healthcare team. Although the healthcare team as a source of information did not surface often within the data, it was noted to be a source of valuable information. One participant indicates that "...multi-disciplinary rounds is crucial for information gathering" (Participant 1), while another states "...if I am lucky, social work is already involved and I can ask them about what is going on..." (Participant 4).

For the majority of participants, the child and family are the greatest sources of information for truly understanding and getting to know the child. In most instances, the healthcare team is accessed solely for information pertaining to the child's diagnosis and medical condition. The child and the family are primary sources of rich information which is utilized by child life specialists to inform their interventions and plans of care.

Conversations, Questions and Observations-Useful Methods of Information Gathering

Data revealed that most participants gathered information from children, families and family members. Although some information was gathered through consultation, charts, multi-disciplinary rounds and patient care conferences, the majority of information was gathered through: questioning, conversations, observation and the use of visual scanning and cues.

Conversations and Questions

Several participants spoke of initiating conversations with children, parents and family members as a way of gathering information. One participant begins her conversation with a particular question, posed to all of the families she works with

"...I think for me it is the question of what is it like to be this child's parent, that is a key

question, tell me about being this little one's mom or dad, what is that like. It opens a

flood gate of responses..." (Participant 1)

Others, do not have a predetermined question, but engage in conversations designed to elicit specific information such as interests and activities

"...depending on the age of the child, it is asking them and starting off conversations

with them, like what do you like, what do you do when you are at home and at school,

what are some of your favourite things..." (Participant 4).

[36]

For some participants, questions and conversations with family members are integral, when patients are not able to provide the answers or engage in conversations themselves. Another participant seeking information on a child who is non-verbal turns to her foster mother and begins

> "...talking with her mom because she is developmentally delayed, about how do you
>
> play with her, white kinds of activities do you do or what would be supportive while
>
> she is here...because if you don't have that background information like what is
>
> family life like at home and how do you manage, then you can't make plans, that sort
>
> of support..." (Participant 1)

Observations and Visual Scanning/Cues

In some instances, observation proved to be the most revealing source of information retrieval. For some children and families, verbal communication was challenging, due to illness, language barriers and for some, feeling overwhelmed. In cases such as these, many participants implement observational strategies to gather information. One participant states

> "...I get a lot of kids that don't communicate so I am not going to get anything from
>
> them except different body language so observation is key, watching to see how the
>
> child is reacting to what is being said...taking cues about what is going on in the room,
>
> you can see what is in the room, like you can see if they are fairly religious, the bible is

out all the time, the chaplains are in and out...yeah, sometimes you can look around and

see what is going on." (Participant 4)

Another reveals

"...you know, you see something in the room and you go oh yeah, yeah...and sometimes

they have pictures ...and sometimes it is even something that a child has brought like a

computer or an iPod or sometimes it is clothing...anything that a child has brought from

their environment into the hospital...pictures of their family, their dog....and then you

start a conversation and then you learn more about who they are." (Participant 3)

Some child life specialists implement strategies of observation and visual

scanning of the room as a standard practice

"...and I also look around their rooms to get cues and clues about who this child is...if

they have got artwork posted, who did the artwork, was it a patient, was it a sibling, was

it something they brought in from home. Often there are photos so looking at the

photos, who are in the photos, what does that person mean to them. Some of the kids I

am working with aren't able to give me lots of that information and sometimes they

look and act quite differently then who is in the picture so I find parents of the children

most affected by their illness and surgery are the ones who bring in those pictures to

help staff understand who their child is." (Participant 6)

The data reveals that there are multiple sources of information from which a greater understanding of patients and families can be uncovered. Child life specialists actively engage in practices which foster the transfer of knowledge from patient and family to practitioner, thus informing their plans of care.

Activities, Routines and Family Life: Essential Information to Collect

Child life specialists seek many types of information to inform their interventions and plans of care. Along with a child's age, developmental level, diagnosis and impending tests and procedures, the data reveals that child life specialists seek rich information such as family roles, activities and interests, home language, family structure and community settings. One participant sums this up by saying

"...family has a life outside...and we need to realize, who is the support network for these children, do they have brothers and sisters, do they have best friends, what is their community like cause often we get kids that are from way up north or right downtown and what is their community like, what do they do in their community, really like who they are rather than what is wrong with them. Does that make sense?" (Participant 3)

When asked "what kind of information do you look for..." many participants indicated that information pertaining to family roles and structures is critical to retrieve. One participant states

"...who else is in the family and what role do they play because not every child comes from a family with mothers and fathers, so who are those other caregivers and who will be around. I think that informs a lot of how you approach situations with families or how you start to offer services and support." (Participant 1)

Child life specialists want to know who the family is comprised of, not just the immediate family, but the extended family as well

"...the extended family plays a piece...so whether or not that extended family lives in the household, how are the family roles designated, I mean you and I know that a lot of time the mother takes on the primary care giving role but in some families, the grandparents might take on that role..." (Participant 7)

A central theme which surfaced for type of information gathered are *normal* routines and activities which children participate in outside of the hospital setting. One participant gathers information such as

"...what is normal for that particular patient and that can be different for every patient, so getting to know them first and what we can do to best match what they like to do outside of the hospital when being here, um you know it could be a matter of providing them with an activity or a favourite game that they like to do, you know arts and crafts..."and then actually providing the normalized experience...just being able to access resources that will help them..." (Participant 5)

Another participant describes this type of information as

"...school, friends, hobbies, things that they feel they are really good at, things they fell they are not good at, what sort of drives their emotions, what makes them happy and what makes them sad, what their view of their hospital stay is so far..." (Participant 6)

One participant indicates that seeking information on activities and routines of everyday life is a good "starting point" and suggests that

"...it is great if they can express that to you, I mean usually children will tell you what they do every day, who their best friends are, who their other friends are, what they don't like to do, what is their favourite thing at school..." and she will "...bring as much of that or what they are suggesting into it..." to make it a" typical day" (Participant 2).

Integration into Practice

Child life specialists utilize the information gathered to inform the strategies and interventions used with each child and family. Interventions for children are designed to minimize the degree of stress and anxiety experienced in the hospital setting and to reflect those normal life experiences from home and in the community. One participant describes her interventions as

"...creating a routine for a child because everything gets turned upside down when they come to the hospital. We know that kids are stressed when they come, they wear

strange clothes, they maybe don't eat or eat strange food because it comes on those

trays so providing activities like...if one of their favourite things is board games,

providing that activity, like hey this is kind of neat, I have hard things in my day but I

have things that I can look forward to like playing board games or those kinds of things

like creating a routine so that children would have some expectations that they would at

school, you know that they are going to get up and they are going to do self care, they

are going to brush their teeth and they are going to comb their hair, you know those

kinds of things, they are all normal activities..." (Participant 1)

Providing children and families with the opportunity to celebrate normal life

experiences was revealed as important to integrate into practice. One participant actively

seeks out information about birthdays and other family celebrations

"...certainly their birthday is a huge normal life experience so finding out from their

chart if their birthday is coming up and how they want to celebrate it if they are going to

be here and looking at what the families' culture is and if there is a certain celebration

that is coming up in their faith, so how to help them recognize that and if they

celebrate, how to celebrate that." (Participant 6)

The same participant goes onto explain the value of recognizing celebrations for one

particular patient

"...there was a patient here that celebrates Ede and before meeting her I didn't know

a lot about Ede and learned from her and her family about it and we celebrated it here

in the playroom and it was a nice way to celebrate it for her, and she felt very special

and she wasn't having a lot of family interaction at that point and I think that it filled

that need as well. (Participant 6)

When examining the data for valuable practices in working with parents and families,

the opportunity for the sharing of knowledge in relevant and meaningful ways surfaced on

several occasions. One participant enhances her ability to communicate through learning

multiple languages

"...because I don't make assumptions about families, I don't assume that because

there is a Sikh family, that they don't speak English but at the same time, I have learned

to address and speak in a number of different languages and I will say you know, what

language do you speak in the home and if it is something that I know, I will respond to

them in that language and usually the child laughs and the parents smile so it...shows

respect..." (Participant 7)

In several instances, the use of interpreters was implemented to facilitate the sharing

of information including the use of sign language interpreters and "AT & T interpreter

services" (Participant 2).

A common element in the data was the provision of the time and space for families to share thus facilitating the transfer of knowledge. As one participant states

"...I think it evolves through time because I know it is hard because a lot of people don't have time but I think you get to know them because I spent a bit of time with this mom last week and you know okay...so she lives up north and this is what they value and this is what the dynamics are in the family and so you just learn about what you know, how their world is and what their culture is and what you know what they do in their free time, and those types of things...what they value and again, I think to have a true picture of it, which we don't always. You need to spend time with the family."

(Participant 3)

Another participant has made provision for time in her practice and states

"...I do build in time to my sessions, time with the parent and I tell them that their child is a source of information, but they are the experts on their child"

Data also suggests that child life specialists work with parents and families to facilitate the connection between home and hospital life. One participant discusses her strategies in bridging normal life experiences pre and post trauma. She states

"...I know that this particular family have had a hard time with their trauma and that they can't remember everyday life so everything I do with that child and family usually revolves around normalizing the experience and that has included things like, they talk

and they reflect regularly about life on the island of Jamaica so I bring foods from that culture or I take them grocery shopping and they pick out food from that island because it is positive, it helps them break away from the trauma that happened to them and it is something they can do together and he can do something for his mother, which is good for this family because the relationship is strange now since the trauma, so I do whatever I can to foster that relationship, so it doesn't just normalize you know post-trauma...it brings him around to spend normal time with his mom..." (Participant 7)

Another strategy implemented by some participants is to encourage the presence of photographs and comforting objects from home. As one participant states

"...I think this is something that I and many others recommend is to bring in those familiar things because it transforms their sterile hospital room into something that is more their own for the time that they need to be here...I think that there is comfort in it for them. I think that it reminds them that things won't always be this bad, I have got people who love me, I have got things that I love and it will get better." (Participant 6)

Making the connection between home and hospital life is a strategy which inherently honours and respects that which is important to families. As stated by one participant

"...his family is quite different and so you get to know the whole family culture and what is valued there and what they represent and so I think it makes a huge difference

[45]

on how I approach what I do and being respectful of that family and tailoring my interventions to what might be most important to them." (Participant 3).

During hospitalization, illness and trauma, access to information about the child and family is often challenging to retrieve in light of impending medical diagnoses, treatments and procedures. The integration of family and cultural information into child life practice involves strategies designed to foster knowledge transfer and incorporates platforms for learning which move beyond traditional methods of information gathering to include observations, conversations, visual cues and the integration of creative tools.

Challenges and Barriers Encountered

Although not explicitly asked, emerging from the data are common barriers and challenges that are experienced by child life specialists when working with children and families from diverse cultures. (see Table. 2)

Challenges	Characteristics
Cultural Knowledge	Lack of knowledge/education
	Language and communication
Cultural Awareness/Cultural Self	Personal culture
	Personal experience
	Personal beliefs/values
Institutional Barriers	Clinical Environment
	Time
	Limited Access to Resources
	Organizational Culture

Table 2. Challenges and Barriers

Cultural Knowledge

Several participants indicate that the lack of education or information regarding cultural

traditions, values and beliefs, poses a challenge when working with children and families from

different cultures. One participant feels "worried...and nervous" with the lack of knowledge

and information and another participant states

"...I wish I understood what their cultural traditions are so that I mean, this is such a

multi-cultural environment, I wish there was sort of more resources, and maybe there are but I

just don't know. I want to sort of learn what is valued in that culture, is it sort of that fathers

make all the decisions or that parenting is a joint venture and I have questions from volunteers

about the moms who wear head scarves and I don't really know much about them..."

(Participant 1)

Cultural Awareness/Cultural Self

The data revealed that some participants experienced barriers and challenges in working with diverse cultures due to their own cultural beliefs and practices. These barriers however, are influenced and impacted by personal experience. One participant's comments provide a detailed example

"...there was one case and I remember, I had no understanding of this and no appreciation until I had my kids but there is this whole attachment focus now, attachment parenting and I think that is a culture in itself and I remember nurses coming down on this family because the mom had an infant and didn't want a crib, she wanted a bed to be brought in and typically you know, when an infant is coming in, they push the crib in and the parent gets the couch and mom was adamant that you know, that her child slept with her. And I remember us all saying, oh here comes the crazy one, right are you serious, just deal with the crib, but you know, I think because I ended up sleeping with my kids, you know I can understand that now and I can see that is a whole element to that family, that is culture along with everyone else, but now I would find myself advocating on behalf you know, only from my own maturity and education and I think that is the whole thing with culture and advocacy too, is that we do need to grow a bit in yourself and experience different things..." (Participant 4)

Institutional Barriers

The most common barriers experienced and touched upon by every participant were

the institutional barriers present in the work place. These barriers include limited access to

resources, time, the organizational culture and the clinical environment. One participant

states

"...I find that the clinical environment, that the hospital is the worst environment for

a family because it is so artificial, it is scary, they are there for a particular reason, they

are usually overwhelmed and not necessarily happy with what is happening in the

hospital so that just acts as a barrier to getting to know a family and if I can meet with

them in a setting that is a bit more positive and even take them for a walk or just do

something that takes them away from that super clinical environment, I often find that

they are more responsive and opened to talking about who they are and who their child

is separate from their illness." (Participant 7)

Cultural Knowledge and Institutional Provisions-Identified Needs and Resources

Participants were able to articulate resources which would facilitate their work with

diverse children and families. Although some resources stated address the need for cultural

knowledge and information, the majority of the needs include those that would be met

through institutional provisions. (see Table. 3)

[49]

Resource Needs	Description
Cultural Knowledge	Increased understanding of various cultures/customs/religions
	Consistent and ongoing learning opportunities
Institutional Provisions	To move beyond holiday recognition
	Increased Patient care conferences
	Increased hands on experience/in services
	Organizational culture which values/fosters family "ability to be who they are"
	Increased translator resources
	Increased training/development from professional designation
	Increased education at the undergraduate/graduate level

Table. 3 Resource Needs

"...I think as a group, we do talk a lot about diversity and I know it is important but I don't think that we have enough hands on stuff or opportunities for in services or presentations to go and learn... think it would be great for lunch and learns and we have them for wellness and we have them you know but there isn't as much... I just wish there was something more consistent and ongoing and I don't even know who would take charge of that or is it combined you know asking social workers or chaplains for the religious side of things , I wish there was more, I guess too that we can always research on our own and there is always opportunity for that and the danger with doing that too is that you lump different people together and you can't do that either because every family has got their own unique

and I understand there are pitfalls with that I just wish there were a little bit more yeah...
more resources and sometimes I am just not sure like where do I go, who do I go for
information." (Participant 2)

"...I think that there should be a course, in your orientation for the whole day, like
how do you provide the best practice you possibly can in your situations, you know whatever
your profession is, everyone in the whole hospital can provide family-centred care, whether
you are the anaesthesiologist or you are the PSA or what not, it looks different for people
but I don't think people understand how it looks for them and I think that people make it too
big and that there is a way to break it down so that it can be simple." (Participant 5)

Child life specialists demonstrate a need for accessible resources to support their
vision of culturally relevant and meaningful care and seek institutional provisions such as
workshops, courses an environment which fosters respect for individual cultures to be
honoured.

Discussion

Research data gathered from participants reveal child life practices which are guided by the desire to fully understand environmental influences which impact the development of patients facing illness, trauma and loss. Information such as family composition, roles and the everyday routines and activities of home and community life are valuable sources of knowledge which serve to inform child life plans of care.   Despite the challenges and barriers which emerged through the data and indications of participant's moderate comfort and ability, child life professionals engage in processes and practices which demonstrate elements of cultural responsiveness and sensitivity.

This study contextualizes culture within the child life profession and provides a greater understanding of the way that culture is interwoven throughout all aspects of child life practice. This study demonstrates the importance for child life specialists to understand the multiple influences on the development of the child (Bronfenbrenner, 1979) as evidenced in those processes used to *get to know* the child.   Information gathering strategies implemented by child life specialists are centred upon achieving a greater understanding of the child's environment outside of the hospital setting, including relationships, roles and the many settings in which the child exists (Bronfenbrenner, 1979). Participants actively seek information regarding family member roles, friendships and school life and utilize this information to inform their strategies of care.

Child life specialists value continuity between home and hospital life and strive for

connections which support the continuation of development through hospitalization and

illness. Steeped in eco-cultural influences (Weisner, 2002), child life specialists recognize

culture as primarily shaped and determined by family, consisting of family roles, structure

and the routines, practices, celebrations and activities evident in everyday life. Recognizing

the inherent values, goals and relationships which exist for children within the routines of

family and home life (Weisner, 2002), the participants in this study use the information

gathered from patients and families to create hospital experiences reflective of home and

family culture. Information gleaned from parents, family and children inform the structuring

of normal life experiences, opportunities and routines, thus promoting successful ecological

transitions (Bronfenbrenner, 1979) between home and hospital settings. Gaining insight into

the pathways of healthy development in the home, child life specialists translate this

knowledge into meaningful goals of child life care. This notion of culture as defined by

family challenges professionals to relinquish perceptions that culture is characterized

primarily by religion and ethnicity. This valuable perspective provides child life specialists

and all healthcare providers with avenues to access and understand culture at the individual

level and has implications for culturally relevant and competent practice.

Although child life specialists indicate a need for access to increased cultural

knowledge and education, when asked to describe their perceived comfort in working with

children and families of diverse cultures, the majority of participants suggest their comfort

level as moderately to highly comfortable. The data suggests that child life specialists

engage in regular opportunities to learn, reflect and develop skill, and demonstrate

openness to working with children and families from diverse cultures. Child life specialist

therefore, can be characterized as engaging in an ongoing process of cultural competence

(Campinha-Bacote, 2002), leaving space for the continuation of learning through the

engagement in professional growth, development and reciprocal relationships of sharing

with children and families.

Recommendations for Effective Integration into Practice

In order to progress towards the delivery of culturally relevant and meaningful care,

it is necessary for organizations and institutions not only to set forth recommendations for

standards of practice, but to ground these standards in the practical application of those

who engage in the provision of care to diverse populations. As stated in Engebretson et. al

(2008), there exists a disconnect between organizational mandates and front line practice

which is further perpetuated by the lack of exploration and understanding of the taken for

granted assumptions embedded in definitions of culture and cultural care (Yan, 2008). The

voices of participants in this study clearly highlight the desire for organizational support and

resources to aid in their cultural understanding and knowledge, however the achievement of

this can look different for everyone. Individual definitions and understandings of culturally

meaningful care, translate to practice in very distinct ways and as one participant suggests

"...I think that there should be a course, in your orientation for the whole day, like how do

you provide the best practice you possibly can in your situations, you know whatever your

profession is... (P3). It is therefore necessary to deconstruct the attributes of culture including definitions, challenges and needs to gain a comprehensive understanding of how culturally relevant and meaningful care may be achieved for all.

Despite organizational strategies such as the development of guiding principles, standards of cultural competence and the provision of cultural education, efforts must be made to explore the barriers and challenges faced by those who engage in direct practice with children and families. Participants in this study refer to institutional barriers and include the clinical environment, limited resources and the lack of sufficient time as prohibitive factors in their perceived comfort in working with diverse families. Organizations can learn from challenges which are encountered on a daily basis and can shape their opportunities for learning and reflection in response to these needs. Examination of frontline experience can also serve to highlight successful practices and strategies which can then be shared for the benefit of all. For example, data analysis from this research study highlights effective child life strategies of information gathering. Although limited by time, child life specialists foster the transfer of knowledge by providing opportunities for resourceful exchanges of information. Ideally, the child life specialist prefers to engage directly with the child and family, however barriers such as language and communication ability prevents this at times and creates the need to utilize observational strategies and creative tools for eliciting information exchange. Evidenced in every strategy is the desire for child life specialists to position themselves as learners and children, parents and families as the expert (Gonzalez et. al, 1993). This stance of cultural "naiveté" and curiosity (Dyche

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and Zayas, 1995), fosters the collaborative role of practitioner and client and paves the way for knowledge transfer and the space for families to share their story thus validating individual backgrounds, beliefs and traditions (Ada and Campoy, 2004). As evidenced in this study, child life specialists engage in practices which are responsive to the cultural needs of children and families and as Yan (2008) indicates, perhaps this should be the benchmark for the achievement of culturally meaningful care.

Limitations and Recommendations

Limitations

One limitation of this study is the lack of ability to generalize the findings to the

greater Child Life profession. This study was situated in a large city in Ontario, Canada which

is home to a diverse population of individuals and families. The child life specialists included

in this study are immersed within the diverse population and therefore have the potential to

possess a greater cultural awareness. Participants are also affiliated with teaching facilities

that are home to some of the greatest leaders in healthcare and innovative practice. This

factor could lead to this study capturing data from participants who are highly engaged in

cultural learning and therefore may not highlight the prominent challenges or views of those

located in smaller communities or healthcare settings.

The inclusion of a reflective journal writing exercise was both a limiting factor and an

area for future growth and recommendation. Personal reflection proved to be challenging

for many of the participants to complete and resulted in the need to ask ongoing questions

and to seek clarification. The reflective exercise, although considered to be a valuable

practice (Osterman and Kottkamp, 1993) did not yield data replete with rich and relative

information. Healthcare environments create high levels of demand for professionals

working directing with patients and families. The lack of time is often a prohibitive factor for

engaging in additional responsibilities and practices, which may have had a contributing role

in completing the reflective journals. As reflective practice is not always integrated into child

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life practice, participants may have benefited from opportunities to learn about and engage in reflective exercises prior to their involvement in the study.

Recommendations

As this study was part of the degree requirements for a master's thesis and therefore subject to time limitations, additional provisions of time may have allowed for further examination of the data and hence further implications for practice. This study represents a first attempt to study the role of culture and cultural influences on child life practice and is not intended to be representative of all aspects and variables on a global scale. Future research could include a study of the varying needs of children and families from diverse cultures, from the perspective of the children and families themselves. An evaluative study on the implementation of specific tools and strategies such as the use of self authored books (Ada and Campoy, 2004) in facilitating a greater understanding of culture could hold valuable learning for the child life profession as well as for other healthcare members.

Conclusion

In the words of Mary Catherine Bateson (2000) cultural anthropologist, "the encounter with persons, one by one, rather than categories and generalities, is still the best way to cross lines of strangeness" (as cited in Gonzalez et. al, 2005, p. 29). As evidenced through this study, child life specialists embrace this philosophy, integrating it into their approach with children and families through daily practice and intervention strategies.

Processes used to achieve a greater understanding of the child within the context of family and culture, are best guided by an appreciation for the multiple influences on human development. Gathering information to understand home and community life, can provide an opportunity to understand individual developmental goals and how best to foster the continued progression towards healthy developmental outcomes. Child life specialists strive to honour and reflect the unique nature of children and families as individual entities by seeking out information directly from them. Recognizing challenges such as language and communication abilities, child life practice highlights the need to seek multiple sources and methods of information retrieval which can even the power differential which often exists between professional and client. Creating a space where the transfer of knowledge is welcomed and honoured fosters programs and interventions that are delivered in culturally relevant and meaningful ways.

The perception of culture as encompassing more than religion and ethnicity provides a valuable contribution to cultural understanding and challenges professionals to defy

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notions of *achieving* a definitive state of cultural competence. Culture as defined by family

challenges all practitioners to continuously strive for cultural understanding as dictated by

each individual child and the roles, relationships and activities which exist within the

immediate environment that contribute to the continuation of development.

Appendix A

Recruitment Email and Study Profile

Dear Colleagues,

You are being contacted today to let you know about an upcoming research project that I will be leading as part of the degree requirements for my Master in Early Childhood Studies from Ryerson University. This research study is being completed as part of my Master's thesis.

If you decide to participate, please know that your involvement is voluntary and that no payment or reward will be given. If you choose to participate, you may stop at anytime without penalty. If you do not wish to participate, please know that any current or future relationships with the researcher or with Ryerson University will not be harmed.

Please read the study profile below. If you are interested in participating in this study, please contact me at jennifer.butterly@ryerson.ca or at (416) 698-8814. Once you have contacted me, an interview may be scheduled. Interviews will be scheduled between the weeks of July 6th and 13th. After reading the study profile, if you know of another child life specialist who may be interested in participating, please forward them to me at the contact information above.

Study Profile

Child life specialists in paediatric healthcare settings become acquainted with the child and family at the onset of illness. This process of understanding and inquiry often entails detailed questions pertaining to the child's illness and often, information regarding the child's culture, including family life, values, beliefs and traditions, unfold over time. Home and community life are an integral part of a patient's life, contributing to and influencing the development and behaviour of the child prior to and throughout hospitalization. Information regarding family and cultural contexts is a valuable source of knowledge providing insight and opportunities from which practitioners can learn about their patients, thus informing their practice and care delivery.

This study seeks to examine those processes that are used by child life specialists to understand their patients within the context of family and culture. Through the use of interview and reflective practices, the researcher will address the following questions:

- What information do child life specialists find valuable in understanding the hospitalized child?
- What processes or practices do child life specialists engage in to gain a greater understanding of the child within the context of family and culture?

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- Is this information used to inform child life practice? How is this information used?
- What are the challenges encountered? What are the successes?

This study will involve a 35-45 minute interview and a 10-15 minute reflective practice.

Appendix B

Research Consent Form

Connecting Home and Hospital Life: Cultural Influence and Child Life Practice

You are being asked to participate in a research study which is being carried out as part of a Master's degree thesis. Before you give your consent to be a volunteer, it is important that you read the following information and ask as many questions as necessary to be sure you understand what you will be asked to do.

Investigators: Jennifer Butterly, BA, MA (c), Master of Early Childhood Studies, Ryerson University, Patricia Corson, Phd., Ryerson University, Research Supervisor.

Purpose of Study: The purpose of this study is to explore practices used by child life specialists in identifying and understanding the needs of hospitalized children within the context of their culture, including family life, values, beliefs and traditions. This study will include one interview and a personal journal writing reflection. Participants will include up to 8 child life specialists who have more than 1 year of experience working as a child life specialist within a hospital or community setting with long term or chronic patients. Findings will be used within the major research paper as part of the Master's degree requirements. Findings may also be shared in workshops, in services, conferences and publications.

Description of Study: Interviews will be conducted at a location mutually agreeable to both participant and researcher. Interview responses will be tape recorded and analyzed. Interviews will be 35- 45 minutes in length and will include questions such as:

1. Providing "normalized" life experiences for children requires a certain degree of understanding who the patient is and what they are all about. Can you tell me please, your process for understanding and learning about your patients?
2. What strategies or tools do you use to help you get to know your patients?
3. Can you tell me about a time when you have encountered a child or family that was challenging to "get to know"?

Personal journal reflections will be completed by participants and analyzed by the researcher. Journal entries are expected to take no longer than 10-15 minutes to record and will include reflections on topics such as:

1. What are the steps I used to get to know my patients and families?
2. Challenges and successes in getting to know patients and families.
3. Strategies implemented in understanding and getting to know patients and families

What is Experimental in this Study: None of the procedures used in this study are experimental in nature. The only experimental aspect of this study is the gathering of information for the purpose of analysis.

Risks or Discomfort: The researcher expects that as a participant you will engage in personal and professional reflection in both the interview and journal writing exercise. Should you feel discomfort at any time, you may discontinue your participation in the study, either temporarily or permanently without penalty. The researcher will not link participant information to interview responses or journal entries and confidentiality will be maintained at all times.

Benefits: The researcher expects that participants will benefit by gaining a deeper understanding of their current practices in working with children and families from diverse backgrounds. The researcher cannot guarantee however, that you will receive any benefits from participating in this study. Benefits to society are expected to include an increased contribution to the knowledge regarding the processes implemented by child life specialists when seeking to understand patients within the context of family and culture.

Cost and Incentives for Participation: There is no cost to participate in this study and incentives will not be provided, however light refreshments will be available during the interview.

Confidentiality and Rights: Personal information will not be published or shared in any manner. Recordings, transcripts of interviews and journal entries will be coded with pseudonyms to protect your privacy and all study data will be kept in a locked and secure location. Research data will be stored for a maximum of 5 years as stated in the Research Ethics guidelines.

Voluntary Nature of Participation: Your participation in this study is strictly voluntary. Your choice of whether or not to participate will not influence your future relations with Ryerson University. Should you wish to withdraw from this study or decline to answer questions, you may do so at any time and with no penalty.

Questions about the Study: If you have questions about this study now, please ask. Should you have questions at a later date, please contact the research investigator at:
(416) 698-8814 or at jennifer.butterly@ryerson.ca

If you have questions regarding your rights as a human subject and participant in this study, you may contact the Ryerson University Research Ethics Board for information at:
Research Ethics Board
c/o Office of the Vice President, Research and Innovation

Ryerson University
350 Victoria Street
Toronto, ON M5B 2K3
416-979-5042

Agreement: By signing below, you are agreeing to participate in this study and acknowledging your right to withdraw from participation at anytime, without penalty. You agree that provisions have been made for you to ask questions now and that you are able to contact the researcher should further questions arise.

_____
Name of Participant (please print)

_____   _____
Signature of Participant   Date

_____   _____
 Signature of Investigator   Date

Interview Protocol

Title: Connecting home and Hospital Life: Cultural Influence and Child Life Practice

Research Purpose: The purpose of this study is to explore practices used by child life specialists in identifying and understanding the needs of hospitalized children within the context of their family and culture.

Location: _____

Start Time: _____ **End Time:** _____

Interviewer: _____

Interviewee: _____

Interview Questions

A) **Demographics**

   1.   Please tell me about what lead you to become a child life specialist?

   2.   How long have you been practicing as a child life specialist?

   3.   Have you participated in any professional development courses?

- In services?

- Conferences?

- Additional Certification/Qualification courses?

   4.   What populations of patients have you worked with in the past?

- By illness i.e., cardiology, oncology, transplant

- Chronic, traumatic, acute, rehabilitative

5. Tell me about the patients that you work with currently?

- Illness specific?

- Ages

- Average length of stay?

- Frequency of admissions

B) **Understanding and getting to know patients**

6. Outside of medical care, please share with me your thoughts on the types of care you feel are most important in helping a child through the illness and hospitalization experience.

- Psychological, social, spiritual?

7. As a child life specialist, one of your roles is to provide psychosocial care for the hospitalized child. Can you tell me please what "psychosocial care" means to you as a child life specialist?

8. What information do you look for to inform your plan of psychosocial care?

- Developmental stage

- Coping

- Interests/needs

9. One part of psychosocial care for hospitalized children is to provide "normalized" experiences. Can you please tell me what "normalized" experiences mean to you?

10. Providing "normalized" life experiences for children requires a certain degree of understanding who the patient is and what they are all about. Can you tell me please, your process for understanding and learning about your patients?

- Do you ask questions? If so, what type of questions do you ask

- What information do you seek?

- Is there information that you find most valuable in understanding or knowing your patients?

11. What role, if any, do family members play in getting to know your patients?

12. What strategies or tools do you use to help you get to know your patients?

- Can you describe them for me

- Do you find that they are helpful? For all children and families?

13. Can you tell me about a time when you have encountered a child or family that was challenging to "get to know"?

- Can you explain what might have been challenging for you?

- How did you try to overcome this challenge?

- If you were successful, how did you know and can you explain strategies that you implemented that did or did not work?

C) **How does culture play a role?**

14. Can you tell me please if "culture" plays a role in understanding your patients and families?

- If yes, how so?

- If not, can you explain why?

15. Can you share with me your comfort in working with children and families whose culture is one that you are not familiar with?

    - Perhaps ethnic, religious or family structure?

    - Do you seek out the same type of information?

    - Do you implement the same type of strategies? Please explain, why or why not.

16. Please tell me about your perceived ability to effectively engage with children and families of diverse cultures.

    - How prepared do you feel?

    - Are there learning opportunities which you feel you could benefit from?

17. If you could describe one tool or strategy that you find beneficial in helping you to understand and "know" your patients, what would this be?

Reflective Journal Entries

Thank you for your participation in this reflective journal writing exercise. You are being asked to reflect and record your thoughts around the topics listed below. Please complete this exercise over a period of three days. You should expect to spend no more than 10-15 minutes on this journal entry. Your journal entry may be completed at the end of the three day period, or may be completed after each day has finished. Please use the space provided below. Should you need additional space, please use the back or attach another page.

Please consider the following topics during your reflections over the next three days:

- Process used to get to know my patients and families
- Information that helps me understand my patients and families
- Challenges in getting to know patients and families
- The role of culture in my practice

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