2010

# Clinicians' understanding and perception of coping behaviors and cultural differences in families dealing with a childhood cancer diagnosis : a project based upon an independent investigation

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Clinicians' Understanding
and Perception of Coping
Behaviors and Cultural
Differences in Families
Dealing with a Childhood
Cancer Diagnosis

ABSTRACT

This research provides insight into social workers' understanding and perceptions of coping behaviors in families faced with a pediatric cancer diagnosis. The three research questions that guided this study were: (1) Do clinicians observe/perceive cultural distinctions in coping behaviors among families dealing with a pediatric cancer diagnosis? (2) How does a clinician's own culture impact his or her assessments of a family's coping abilities? and (3) How can clinicians gain better cultural sensitivity and cultural competence in working with diverse populations? Semi-structured interviews were conducted with 12 social workers who were working in pediatric oncology centers across the United States. Social workers in this study perceived culture to play a significant role in families' coping behaviors; and that coping behaviors such as maintaining independence, activity modification, maintaining a positive attitude, maintaining a sense of humor, spirituality or prayer, denial, time with family and friends, support groups, maintaining routines, gaining information, and nutritional management were observed differences between families. Findings also showed cultural distinctions between Caucasian social workers and social workers of color in their reporting of family coping behaviors. These distinctions were found in use of terminology, presentation of

information, and acceptance of family coping behaviors.  A social worker's own culture and lens of understanding appeared to impact his or her assessment of a family's coping behavior. The outcomes from this study suggest the need for improved cultural sensitivity and cultural competence among social workers who work with culturally diverse population groups. Strategies and tools for developing and becoming more culturally aware were recommended. Some of these recommendations include integrating cultural awareness and cultural activities across teaching curricula, instituting culturally sensitive and culturally competent trainings in the workforce, worker case collaborations as a teaching tool, and open discussions and reflection of self as a service provider in relation to others. The need for more culturally diverse healthcare professionals in human services and communities also were recommended.

CLINICIANS' UNDERSTANDING AND PERCEPTION OF COPING BEHAVIORS

AND CULTURAL DIFFERENCES IN FAMILIES DEALING WITH A CHILDHOOD

CANCER DIAGNOSIS

A project based upon an independent investigation,
submitted in partial fulfillment of the requirements
for the degree of Master of Social Work.

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2010

ACKNOWLEDGEMENTS

This thesis could not have been accomplished without the assistance of many people whose contributions are gratefully acknowledged.

I wish to thank my research advisor, Dr. Narviar C. Barker, for her patient assistance during the year, my agency supervisor, Maura Savage, for her time and interest in assisting the recruitment of participants, and the support of the social work team at Children's Healthcare of Atlanta.  I would also like to thank the Smith College School for Social Work community and my family that has provided ongoing support and guidance through this learning process.

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CHAPTER I

INTRODUCTION

In the United States in 2007, approximately 10,400 children under age 15 were

diagnosed with cancer.  Although this makes cancer the leading cause of death by disease

among United States children 1 to 14 years of age, cancer is still relatively rare in this age

group. On average, 1 to 2 children out of every 10,000 children in the United States

develop the disease each year (National Cancer Society, 2007). Additionally due to

advances in medicine and technology, children with chronic and terminal illnesses are

living longer (Longden & Mayer, 2007). Between 1980 and 2005, treatment of childhood

cancer resulted in a significant increase in long-term survivorship, with an overall

survival rate approximating 79%. Some children with certain diseases approach or exceed

a 90% long-term survivorship (Yi, 2009). Although the survival rate is increasing for

pediatric cancer, usually more progressive cancer diagnoses are fatal.  This means that

the number of families living and coping with chronic illnesses is increasing significantly

(Rolland, 2003).  These families are a growing concern for medical social workers

because a cancer diagnosis causes stress for both the child with the illness and the child's

family members (Mussatto, 2006). Goldbeck (2001) stated that all family members are

actively impacted by a child's illness; and that when this illness is terminal, the stress and

emotional involvement within the family is greater.  Studies show that families living

with the stress of a chronic condition will most likely encounter physical, emotional,

social, and financial challenges (Williams, Williams, Graff, Hanson, Stantin, & Hafeman,

et al., 2002; Mussatto, 2006).  Some research is available on the stress that families with terminal illness endure and the challenges they face in coping with such illnesses, but research on how clinicians can effectively work with these families is limited. The need for research that explores how coping is viewed in different cultural realms and how clinicians can appropriately respond to varying cultural needs is indicated.

This qualitative research explored how clinicians perceive coping behaviors in families specifically with a pediatric cancer diagnosis. This research examined how clinicians view coping behaviors among different cultures and how clinicians respond to these differences. This is important because individuals will cope differently depending on several factors including family relationships, resiliency, additional stressors, and cultural influences. In addition to the three research questions listed below that were used to explore these factors, clinicians in this study were asked to give suggestions on how to better accommodate for culturally different behaviors.  This researcher welcomed the use of participants' case examples, suggestions, and/or explanations of their own understanding and assessing of coping behaviors in a cultural context.

One-on-one interviews were chosen to fully capture the clinicians' understanding and viewpoint on cultural differences in coping behaviors. This focus on cultural differences in coping behaviors was based upon the researcher's assumption that many clinicians' client assessments are grounded in their own coping schemas. Hence, the following three research questions guided this study:

1. Do clinicians observe or perceive cultural distinctions in coping behaviors among families dealing with a pediatric cancer diagnosis?

2. How does a clinician's own culture impact his or her assessments of a family's coping abilities?

3. How can clinicians gain better cultural sensitivity and cultural competence in working with diverse populations?

In an attempt to answer these questions, the researcher created a list of open-ended questions that were made available to participants prior to their participation in the study. Participants had the opportunity to review these questions before the interview and to expand upon them during the interview. These questions were pilot tested by the researcher prior to the study's implementation to establish their validity. A copy of these interview questions is located in the Appendix of this thesis.

Findings from this study provides information that can inform clinicians and healthcare providers on how to respond to, prepare for, and support culturally diverse families with a pediatric cancer diagnosis; and how to deal with the family's increasing stressors and needs. This study also provides valuable information and knowledge to neophyte workers and graduate students interested in working with pediatric cancer patients and their families. Additionally, this study validated the need for more training and practice in cultural competence, as well as the need for culturally relevant assessment tools to allow for cultural differences. Lastly, this study addressed the need for more multi-cultural continuing education in pediatric medical settings, social services, and other human service agencies that work with children and families in today's global culture.

CHAPTER II

LITERATURE REVIEW

This chapter focuses on the family's ability to cope, how these coping behaviors are measured, and how theory and interventions attempt to explain coping behaviors. The researcher discusses cultural influences in coping behaviors and brings attention to the lack of cultural components in current research. This is especially important because today's hospitals serve more and more diverse populations and healthcare providers must be able to work effectively with all population groups.

Family Challenges

Many studies have shown that family members generally encounter a period of transition in functioning and coping when a diagnosis of a terminal illness is given, which also includes learning about the disease and the prognosis (Boling, 2005). This period of transition related to the child's diagnosis and illness can occur any time throughout the development of childhood. Ratliffe, Harrigan, Haley, Tse, & Olson (2002) identified four main themes that often occur in families dealing with medically fragile children: conflict, financial burden, care burden, and independence. Each of these themes produces stress. In another study, Sherman & Simonton (2001) reported that the challenges families face are formed by medical factors such as type of cancer, extent of disease, type of treatment, and phase of illness. The family's reactions to these challenges are influenced by qualities of the family and their environment, such as developmental stage, coping resources, social supports, and coexisting stressors. Additionally, these

factors are influenced by the family's cultural background and their perceptions of the illness trajectory. Family cohesion has been named a positive factor in dealing with illness; family cohesion can take many forms, including showing support to family members, educating each other, and being empathetic towards family members' roles and coping abilities; all of which help ease this transition.

Cancer presents the affected family with major challenges and disruptions. Family therapists offer valuable support that could assist with these challenges, but often this support is underutilized during cancer treatment because of clinicians' diverse cultural ineptness, improper attitudes, and differential behaviors toward culturally different clients (Sherman & Simonton, 2001). Many family therapy approaches may be helpful when appropriately modified to the characteristics of the illness and to the family. Some of these approaches are presented later in this literature review. Unfortunately, family therapy is not a routine aspect of the cancer treatment offered by medical providers. Often times families report being too busy for therapy, are resistant to the idea of therapy, don't understand the importance of family therapy during the medical crisis, or families have other issues that take precedence over family therapy (i.e., finding adequate housing, work, obtaining health benefits, transportation, medical maintenance, etc.). Therefore clinicians in the medical setting often work with families more fluently on these concrete or primary services rather than secondary family therapy services that address emotional trauma, stress, and coping.  Sherman & Simonton (2001) reported that it continues to be important for clinicians to take the family's qualities and cultural background into account while assessing family needs and developing interventions especially during periods of trauma.

Since the 1990s budget cuts have led to a decrease in available resources for healthcare centers. These budget cuts not only are impacting service providers but also those individuals and families in dire need of these services, especially families of differing cultures. Families are becoming more diverse and complex, which makes treating and helping these families more specialized and focused.  Helping these families adapt to a cancer diagnosis that may not have full interpretative meaning for them is even more difficult (Kazak, 2004). This is significant because the needs of families trying to cope with a cancer diagnosis are becoming more multifaceted and severe; yet with the decreasing healthcare resources, families are struggling more with fewer available resources and less access to care. This, too, creates added stress. Due to these changes and demands, more research concerning feasible and multi-cultural approaches to family-oriented interventions within the medical setting is needed.

Coping

Lazarus and Folkman (1984) defined coping as 'efforts to manage demands regardless of the success of those efforts' and 'constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person'. Goldbeck (2001) stated that there is no standard assessment for the effectiveness of coping because the adaptability of coping is determined by the outcome. Families that are well supported and have stable relationships prior to illness may experience a smoother coping process than those families with minimal support or interpersonal relationships.  Families that are low socioeconomic status, disadvantaged, have divorced parents, have single parents, have multiple medically fragile children, or experience other debilitating factors will face

additional stressors, and therefore may struggle to cope with the illness. Most cancer behavior research focuses on physical, emotional, mental, and social and behavioral components of well being and functioning, which can be helpful in providing foundational knowledge on coping patterns. However it is important for social workers, psychologists, doctors, nurses, and other healthcare providers to understand the level of coping in working with families and individuals stricken with cancer.

Sorgen & Manne (2002) stated that the role that coping plays as a protective factor has been well documented and has been shown to play a mediating role between stressful events and adaptation outcomes, such as depression, anxiety, and adjustment to illness among children and adolescents with cancer. Studies examining the relationship between coping efforts and adjustment have consistently found avoidant strategies, such as wishful thinking and self-blame, to be associated with poor outcome or adjustment. In contrast, problem-focused coping strategies, such as problem-solving and information-seeking coping are associated with good outcome or adjustment (Sorgen & Manne, 2002).

Goldbeck's research (2001) indicated that parents' coping and understanding of the cancer during the initial phase of diagnosis and initial phase of disease is supposedly crucial for the long-term coping process of the family. Svavarsdottir and Sigurdardottie (2006) recognized this as problematic as parents with newly diagnosed cancer need to cope with their situations, care for their own well-being, and adapt to their child's health status; which is overwhelming for most parents who aren't expecting a cancer diagnosis. Sherman & Simonton (2001) stated that openness of communication, flexibility of family structure, adaptiveness of personal meanings associated with illness, and response to

existential/mortality issues influence how difficult each specific phase of cancer will be for the individual. Goldbeck (2001) also found that parents of children with a pediatric cancer diagnosis develop more rumination, defense, and information seeking strategies than that of a control group within his study. Additionally, maternal and paternal coping styles differed as mothers report more active coping than fathers, and only slightly overlap in the category of religious support. One study found that fathers relied on support from healthcare professionals, extended family, and the church; all of which helped them to stay positive during their child's illness (Brody & Simmons, 2007). Although it is not a part of this review, much research has been done to examine similarities and differences in coping between mothers and fathers.

<center>Current Measurement Tools</center>

Svavarsdottir and Sigurdardottie (2006) used several scales to measure responses to illness. These scales included the General Well Being Scale (GWB), which is an 18-item scale to assess how individuals feel about their inner personal states; the Family Hardiness Index (FHI) that consists of 20-items that cover commitment to, challenge of, and control over family life; and the Family Adaptation Scale (FAS), which is an 11-item assessment tool that measures satisfaction with internal family fit and family-community fit. The Coping Health Inventory for parents (CHIP), a 45-item checklist that provides self report information about each parent's effectiveness in coping with a child's illness, has also been used. CHIP has been the most visibly used assessment tool among parents in current research; and all research suggests that CHIP has good psychometric properties (Han, Cho, Kim, & Kim, 2009; Goldbeck, 2001). The CHIP requires the respondent to indicate how helpful (from 0= not at all to 3=very helpful) each coping strategy has been

in managing the illness situation. Three scales have been constructed by factor analysis: (I) maintaining family cohesion, co-operation and an optimistic definition of the situation; (II) maintaining social support and psychological stability; and (III) understanding the medical situation by communication with the staff or with other parents (Goldbeck, 2001). In his research, Goldbeck (2001) compared coping strategies used by parents of children with cancer to those used by parents in the control group. When compared to the control group, parents in the oncology group used significantly more withdrawing or backwards-directed coping styles, optimism, and information-seeking, and less social support-seeking. In a study that analyzed coping strategies and psychosocial adjustment in Korean mothers of children with cancer, the authors found the item mean scores on the CHIP subscales to be: coping pattern I (mean 52.07, SD 50.49); coping pattern II (mean 51.12, SD 50.49); and coping pattern III (mean 52.05, SD 50.58). Goldbeck (2001) stated that pairwise comparisons between clusters of coping strategies revealed that the strategies related to coping patterns I and III were rated significantly more helpful than those related to coping pattern II; and there was no difference between coping patterns I and III (Han, Cho, Kim, & Kim, 2009). Similarly, a Hellenic study produced the following results when the CHIP was given to 41 mothers and 30 fathers at a large pediatric hospital. The statistical analysis of the perceived efficacy of specific coping behaviors revealed that the coping strategies related to the coping pattern I were rated significantly more helpful than coping pattern III, and coping pattern II (Patistea, 2005).

Sue & Sue (2008) recognized the importance of using standard tools for evaluation, but states that appropriate accommodations should be made and results should

be interpreted with care since the tools aren't standardized for all populations. The CHIP appears to be the most versatile assessment tool that has been used in a variety of settings, and has proven reliability and validity (Han, Cho, Kim, & Kim, 2009; Goldbeck, 2001; Patistea, 2005). The differing CHIP results between the various cultures gives evidence to the thought that understanding the families' cultural background is essential to understanding how they cope. Some of these differences between the three-study results from above can be explained through a cultural lens: German culture, Korean culture, and the Hellenic cultures. Patistea (2005) acknowledged that the lower maternal scores in coping pattern II and coping pattern III as compared to other scores can be attributed to differences in the illness related factors examined (e.g., type of cancer, age of the child at diagnosis and length of time since diagnosis). There is support from theory and research for the view that such factors influence parents' responses to childhood cancer and their coping patterns. Patistea (2005) also attributed result difference to cultural factors. For example, Hellenic fathers' higher scores subscale II may indicate their desire to meet society's expectations by transmitting a sense of control and power over their experience and by projecting the image of an effective leader whose family still functions well despite the child's predicament. They may also reflect their effort to counterbalance the damage to their narcissism caused by the diagnosis. Another gender related observation of this study is father participants in this study perceived themselves to cope better with the demands of family life and relationships when the affected child was a male and either the only child of the family or the firstborn. On the other hand, Korean women are traditionally responsible for the care of a sick child; the authors of that study speculate that this is why the scores were significantly lower for pattern II. The

study that took place in Germany didn't specify any culturally-based interpretations of the results, but instead stated the variations within the family system- between fathers and mothers (Goldbeck, 2001).

<div align="center">Theory</div>

According to Bandura (1986), social environments may place constraints on what people do, or can aid them to behave optimally. Whether their endeavors are socially impeded or supported will depend, in part, on how efficacious others perceive them to be (p. 437). Thus, according to self-efficacy theory, persons with cancer assess their own internal resources as well as resources in their environment (family, friends, media, information and responses from medical staff, tumor marker values, etc.) and construct efficacy expectations about their ability to cope. A family systems theory allows for social and cultural variables, such as the stigma attached to cancer, the family's isolation from the community, collectivist versus individualist orientation, and traditional values (Rolland, 2003). People who are more efficacious will cope better with the disease and treatment for side effects than those who are lower in efficacy (Merluzzi and Martinez Sanchez, 1998). If medical staff perceive coping behaviors differently than persons with cancer, those perspectives may affect the way staff communicate with patients, and, in turn, may affect patients' efficacy expectations. Campbell & Patterson (2007) acknowledged that studies tend to emphasize pathological family dynamics associated with poor disease course or treatment compliance, which they state lead to illness-based family systems.

Parents play a crucial role in supporting and developing their children's ability to cope; this includes their capacity for affect regulation through providing comfort,

modeling coping strategies, explaining and clarifying their experience when appropriate. Furthermore, if this parental support isn't provided, children are likely to develop an array of defenses such as dissociation, and tendencies towards being controlling and relying on fantasies of omnipotence (Davies, 2004). It is thought that children who are diagnosed with cancer don't naturally have the ability to cope with the adjustment, and thus must learn from others how to cope in such situations. The child's ability to cope is strongly shaped by how parents respond to their behaviors. The current researcher proposes that these responses can be elicited by other influential people that care for the child on a consistent basis such as doctors, nurses, social workers, and other medical/hospital staff. Vance & Eiser (2004) agreed that parents' behavior is crucial in determining children's' adjustment to treatment, at least in the immediate period after diagnosis, but states that it is unknown how parental behavior after diagnosis affects children in the longer-term.

<div align="center">Interventions</div>

When illness hits a family, a natural response and developmental challenge is for the family to create meaning for the illness. Families' shape their narrative and coping strategies in response to their family's health beliefs (Boling, 2005). Clinicians can assist families in developing plans that address how they will cope with the illness. Families also need reassurance that bad things happen to good people, and that there is a plan to assist in understanding the illness. Rolland (2003) stated a normative, preventative model for psychoeducation, assessment, and intervention with families facing chronic and life threatening illness would be most beneficial because it provides an approach in which families will develop a sense of control and mastery. Svavarsdottir & Siguedardottie

(2005) analyzed a family-level educational and support intervention with newly diagnosed cancer to see whether the parent's well being, coping, family's hardiness, and adaptation would improve short term and long term. The study showed significant differences between before and after the intervention that gives evidence to using a family-level education and support intervention. A family-level education and support interventions tend to originate from a competence-based conceptualization which fosters the competence of families. Concurrently, it identifies those children and families with elevated and/or escalating psychological distress, and provides tailored services to support their adjustment. This approach offers the potential for evidence-based assessment and intervention (applying treatments with scientific evidence), addressing concerns about access to care (serving all families appropriately based on their needs), and attending to cost efficiency (assuring that limited resources are used to help the widest range of families feasible). Although this study appears to offer a feasible solution to a paradigm shift from deficit-based to a competence-based conceptualization of the reactions to childhood cancer, there were limitations to this study such as small sample size and unknown healthcare system. Also children diagnosed with cancer in the study could not have any other physical or mental illness, and all families included two active parents.

Observations and Limitations of Current Literature

The current researcher advocates that research needs to move from descriptive studies to more intervention studies in which the family system is the unit of intervention. It is also important to think about the definition of the family in research. Many families are no longer two-parent households with both mothers and fathers present. Traditional

family definitions are problematic since the traditional family is changing; divorce rates are high, with greater chances for children to have step-parents and step-siblings. Research also should include different family structures representing blended families, gay and lesbian families, and other non-traditional families. These varying family structures, as well as differing socioeconomic status may correlate with different experiences as far as quality of services, access to healthcare, and difficulties in coping. One theme that consistently surfaced in this researcher's review of the literature was less attention on the family unit coping and more attention given to research on the transition of the ill child to adolescence and adulthood. A preponderance of research focuses on how this shift looks through a developmental lens in adolescence between the ill child and parents. Several articles are written in nursing journals and run the risk for a biased view from the healthcare workers' lens. Much of the data on chronic and terminal illness has been collected through facilities that specifically serve this population. This may provide bias results for two reasons; first, participants may feel pressured to respond to an interview and/or survey questions for fear of jeopardizing treatment or services should they choose not to participant. Another reason for potential bias is that not all people with a terminal illness have the same access to the health care system; and these individuals would be omitted from research studies.  Some research utilizes the snowball effect, which can be helpful in finding participants that don't use these services. However, using the snowball effect limits the sample because researchers don't know how many people actually get word about the study and decide not to participate.  Research that explains the ill child's ability to cope when family is not present was not a part of this literature search.

Study Purpose and Questions

The purpose of this study was to explore coping behaviors of diverse families with a child diagnosed with cancer from the perspective of clinicians who treat them. Most research supports the statement that the illness affects the entire family, not just the ill child. Increased mental health problems such as depression and anxiety have been reported for siblings and parents of children with a terminal illness. Thus the overarching research question explored in this study was: what type of coping behaviors do culturally different families with a child diagnosis of pediatric cancer engage in following diagnosis and treatment?  Findings from this study provides data that informs clinicians and healthcare providers on how to respond to, prepare for, and support all families with a terminally-ill child, and how to deal with the family's increasing stressors and needs. Siblings and parents of terminally ill children usually experience stress and hardships from the child's illness. Often the treatment for the ill child is time-sensitive and does not always include family members.  Understanding how families differ in their coping behaviors allows clinicians to respond to each family appropriately. By understanding cultural differences, clinicians can work with the family system to better understand the diagnosis, how to more effectively manage daily maintenance of symptoms, how to attend to medical crisis, and how to discuss or initiate grief/ bereavement therapy, all of which could increase family cohesion and the overall health of the ill child and family.

CHAPTER III

METHODOLOGY

This qualitative research study examined clinicians' perceptions of how culturally different families cope with a child's diagnosis of cancer. This research examined differing cultural responses and the importance of incorporating cultural differences when assessing coping behaviors within the family system. This study, exploratory in nature, was purposive in design. Semi-structured interviews were conducted with clinicians who worked in a medical setting with pediatric cancer.  Interviews that included open-ended questions gave the clinicians a chance to explain their use of coping assessment tools, when they chose to use them; and observations of how families cope. At the end of the interview, clinicians had the opportunity to share their observed obstacles associated with family coping behaviors and cultural influences as well as make recommendations and suggestions that may prove valuable to other clinicians who work with families of different cultures.

Lazarus and Folkman's (1984) definition of coping was used for this study.  They define coping as "constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person" (p. 282).  According to Lazarus and Folkman, coping allows individuals to use various skills to manage the difficulties they face in life. This is a process-oriented framework, not trait-oriented, and emphasizes that the approaches individuals use to cope change with time, experience, and the nature of the stressor rather than people being "pre-

programmed" to use the same coping behaviors regardless of the stressful experience. Families coping with diagnosis and treatment of cancer do not remain static; their experiences change during and over the course of treatment; and their stress levels vary. This definition is appropriate for the current study population. Clinicians in this study provided their perceptions of diverse families' coping behaviors. There were cultural differences among the clinicians in this study and families they served.

Institutional Review Board approval was received from both Smith College School for Social Work Human Subjects Review Committee and Children's Healthcare of Atlanta Institution Review Board. The purpose of these board reviews was to ensure ethical review and protection of the rights and welfare of human research subjects; specifically, to ensure the rights and protections of the clinicians who volunteered for this study.

Recruitment of volunteer clinicians in this study occurred from December 2009 through February 2010. Interviews were conducted from February – March 2010; and data analysis was completed April 15, 2010.

Sample

Twelve voluntary clinicians participated in this study. Inclusion requirements consisted of a professional Master's or Doctorate degree (including MSW's, LCSW's, LPC's, Ph.D., PsyD, etc.), current or past experience in working with families with a pediatric cancer diagnosis, at least one year of clinical experience in mental health/therapy/medical social work, speak and understand the English language, and willingness to meet with or have a telephone interview with the researcher for 45 minutes. Convenience sampling and snowball sampling methods were used to recruit

participants. The social workers who participated in the study were 26-54 years old females (M= 41.6; S.D. = 9.1), their experience in pediatric oncology ranged from 1.5 to 15 years (average=7.2), and all held a Master's degree in Social Work. Ten of the 12 participants were licensed in their respective states, and 1 held an advanced clinical oncology license. Participants' self- identified race showed: 9 Caucasians, 2 African Americans, and 1 Hispanic. Participants represented various regions of the United States, ranging from the Mid-West to the Northeast and Southern Region.

Geographical location impacted face-to-face interviews, but was not a limitation for this study. Because the researcher was placed at Children's Healthcare of Atlanta for her internship site and this medical facility provides pediatric oncology treatment, this location became the primary location for recruitment of study participants. Information dissemination about the study occurred via word of mouth, flyers, and email listings. Snowball sampling was the secondary method of recruitment in which participants and professional colleagues provided additional referrals and names of possible recruits. This method allowed the researcher to go outside of Children's Healthcare of Atlanta to elicit participation from other major pediatric cancer facilities across the United States. Sample size and demographics were impacted by location, time frame for study, and access to voluntary participants.

<center>Data Collection Methods and Analysis</center>

The interview questions used for this study were formulated and based upon an extensive literature review and were tested for validity prior to use in this study.

With the assistance of the researcher's Agency Field Supervisor, this researcher contacted clinicians in pediatric oncology center at Children's Healthcare of Atlanta.

Contact was made through e-mail, word-of-mouth and flyers. The recruitment flyer

(Appendix A), consent letter (Appendix B), and survey questions (Appendix C) were

attached to the e-mails. For those contacts made through referrals, the researcher

explained the nature of the study; and for those who agreed to participate in the study, the

researcher mailed this information prior to the scheduled interview.

The survey instrument was divided into two parts. Part I solicited demographic

data about the clinicians including age, race, education/licensure, and number of years in

the field. This data was intended to allow the researcher to observe between group

differences among clinicians. Part II contained interview questions focused on the

clinicians 'observations and perceptions of different coping behaviors in culturally

different families and whether these differences may be attributed to culture or other

factors such as socialization, environment, education, or other characteristics. Participants

also were asked to cite specific case examples that related to differences in coping

behaviors and how prepared they felt to work with cultural differences and coping

behaviors. Interview questions are located in the Appendix of this document.

<div align="center">Data Analysis</div>

Several methods of data analysis were used in this study. A computer-aided

qualitative data analysis software package was used for interview analysis. This package

allowed the storage of documents such as interview transcripts, the coding and indexing

of text-units and provided a tool for establishing and refining categories within the data.

The researcher also maintained a logbook that allowed her to trace both the progress

made in the analysis of the data and the process and changes in the process of the data

analysis itself. This method allowed for the emergence of clinician themes, reduced clinician bias, and noted varied interpretations of the interview.

Descriptive statistics were used to present the demographic data. Throughout the data analysis process, this logbook was used to capture thoughts and ideas about the data. Questions regarding frequencies, magnitudes, structures, causes, and consequences were used to make sense of the data. In addition, a concept map was constructed to see the relationships among the different factors.

## Research Questions

The following three questions guided this study.

1. Do clinicians observe or perceive cultural distinctions in coping behaviors among families dealing with a pediatric cancer diagnosis?

2. How does a clinician's own culture impact his or her assessments of a family's coping abilities?

3. How can clinicians gain better cultural sensitivity and cultural competence in working with diverse populations?

## Limitations of the Study

There are some limitations to this study.  The small population size, the researcher's neophyte status in the research field, and the inability to generalize this study's results to larger population groups are limitations. This study's findings only are generalizable to this study population and cannot be generalized to other clinician groups. However in spite of these limitations, this research is relevant to medical social work practice because children that are diagnosed with cancer, as well as their families, face many challenges that affect each member's ability to cope. Understanding their coping

behaviors and patterns will assist clinicians in their engagement of these families and in

providing culturally-relevant family therapy, support and insight throughout the treatment

process.

CHAPTER IV

FINDINGS

Due to the time limitation of this research project and the researchers' limited access to clinicians that met the study's criteria, the participants do not equally represent a wide range of racial and cultural differences. Two of the twelve participants in this study self-identified as African American, one self-identified as Hispanic, the remaining participants self –identified as Caucasian.  For participants in this study, culture included: race, heritage, nationality, ethnicity, language, gender, religion, lifestyle, sexual orientation, geographic region, socioeconomic status, age, family roles, gender roles, physical/mental abilities/inabilities, and values. Participants, through a closed-ended question, used various descriptors to describe how they defined culture during the initial interview questions, but this researcher noticed that the majority of participants described coping behaviors in terms of race and religion (open-ended questions) throughout the remainder of the interviews.  Participants believed that culture played a significant role in families' coping with a pediatric cancer diagnosis. Coping behaviors such as maintaining independence, activity modification, maintaining a positive attitude, maintaining a sense of humor, spirituality or prayer, denial, time with family and friends, support groups, maintaining routines, gaining information, and nutritional management were examples of measured observed differences between families.

Since data was collected on social workers working with families, and not on the families themselves, it is important to note that the results of this study are based upon

social workers' perception of coping behaviors among culturally diverse families, and were not confirmed by families that are actually coping with the diagnosis. Based on thematic analysis, this researcher found common themes among different cultural groups, as validated by the clinicians in this study. However participants were hesitate to make generalizations about these coping behaviors because they also observed individual differences between families of like cultures. From the transcribed qualitative data, this researcher found generic categories of coping that were not culturally specific, but rather were basic across all cultures, such as sadness, fear, and uncertainty. Clinicians in this study did however identify three main themes they perceived to consistently influence families' ability to cope with a pediatric cancer diagnosis: knowledge and understanding, language and support system. Clinicians reported observing these themes early on in the treatment process and then used this knowledge to formulate basic interventions and support systems. Some clinicians in the study reported that if families possessed a good understanding of the illness, spoke the dominant language, and had a support system, that staff most likely perceived them to cope better with the illness. Illustrations for these findings are integrated throughout this chapter.

<div align="center">Social Workers Experiences</div>

*Knowledge and Understanding*

Most clinicians in this study spoke to the difficulties of families who did not have a good understanding of the medical treatment and processes. Since many hospitals are required to provide intensive teaching and training with family members of children with a pediatric diagnosis, some clinicians believe that a family's lack of knowledge is contributed to language barriers, poor understanding of the English language, poor

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education, and/or a learning deficit. Several of the clinicians in this study spoke of

families who did not express anxiety about their child's illness because they did not

understand what was going on, and therefore were oblivious to the severity of the

situation as noted in the following excerpts:

> 'one family from an indigenous community didn't understand that when the nurse
> was drawing blood, that the blood would be replaced in the body, so essentially
> they thought we were draining their child of his blood'

> 'A father, who had a very sick child and was in the PICU for a long time, thought
> that every time the child needed a surgery, the doctors were taking the child's
> organs'

> 'We kept a little girl here in the fall for an extra three weeks because we were so
> uncomfortable with the father's level of understanding. Even though the father
> was very loving and caring, seemingly understood, he could not repeat back to us
> the information that we provided him'

*Language*

When asked what challenges came up in working with different cultures, most

clinicians identified language barriers to be a huge source of frustration. Depending on

the geographical location and institutional size and resources, clinicians in this study

spoke of different experiences and addressed the availability of interpreters. It was

acknowledged that it was more difficult to build rapport and to truly have a good

understanding of family fears, needs, and thought process when the family and clinician's

culture differed, or when the language spoken was not the primary language. One

clinician stated another reason why language barriers were difficult:

> 'It's not simply…yes you can work through an interpreter, and yes hugging is
> very universal (if it is appropriate in that culture), the biggest struggle is language
> and it does affect the care the child receives because you do miss a lot of the
> informal face time. I find that to be a struggle and barrier especially when it's not
> our secondary language and have in person interpreters. I think clinically you
> have to think of what is cultural and what is abnormal/pathological. Sometimes
> it's easier to assess your own culture and we don't pick up on pathological

behaviors/signals quickly enough because we attribute it to culture. Sometimes in our over need to accommodate we miss out that their behavior is crazy, not culturally based, or it's not appropriate for this family, but when it is couched in an unfamiliar language we may not see it'

'we had a new immigrant mother who struggled to understand what we were saying, so we explained things to her like 12 times, it turns out that she actually had a cognitive deficit…when it's identified right away with someone in our own culture we can address it. It was 'hidden' for awhile with this mother, we just thought it was because she was new to the country and didn't speak the dominant language. We could have picked it up sooner and taught differently is she spoke the dominant language, her affect and behavior would have been seen as abnormal'

Even when interpreters are located within some facilities, the staff do not always utilize

them, as evidenced in the following excerpt:

'We have a 15 year old patient with a pre-existing condition that gives her a short stature, altered hands, missing digits; she is blind and has cancer. She doesn't sign fluently and does better when dealing concretely. Interpreter will draw pictures for her, but she still doesn't fully understand. I have worked hard to understand what helps her and have tried to put some supports in place, but I am not in the room with the doctors and nurses are with her, and I can only hope they are following the advice.'

The same social worker explained how nurses get frustrated with families, but do not use

the interpreter services that are available to them.

'Some nurses get frustrated when they have to call a non-English speaking family for urgent medical information and they don't feel like they have time for an interpreter or they just don't want to use one, but then they get upset when the mother doesn't understand what is going on, and the child who seeks some English gets on the phone. But he was only 14 and very defiant, so it wasn't a good situation at all. It could have been prevented if the interpreter service was used, but that causes more work for the nurses.'

Another social worker voiced a similar concern:

'It seems easier to find a nurse that 'kind of' speaks Spanish instead of calling for an in-person, or calling the translation line. I don't know if this is because of the cost of the language line, but it definitely isn't used as much as it should be, this is usually the medical staff.'

*Support System*

In addition to assessing a families' level of knowledge/understanding and language, clinicians identified the third point of assessment to be support system. Support system is a broad term that includes family, friends, neighborhoods, religious/spiritual affiliations, community, etc. A few narratives will be explored to demonstrate social workers' experience with assessing support, but many of these factors will also be discussed under observed coping behaviors. These narratives will provide a broad array of atypical support system dilemmas:

> 'In the Ethiopian culture there is a lot of the evil eye philosophy … according to their tradition if a child gets sick, the parents did something wrong and they were being cursed. So they didn't tell anyone is their family [about the illness], and their family is very close knit. They go to an orthodox Christian Ethiopian church, very large, supportive community, couldn't tell anyone in community, or they would be ostracized. Didn't tell their parents, only the mothers' sister. And her husband and that is it, and so they are making end-of-life decisions, and at first they wanted to bring him to our inpatient unit, and they couldn't take him home, and they didn't name him because they have ceremonies about giving names, so they didn't name him and he stayed in our facility until he died.'

> 'Worked with a refugee family that was relocated from Africa, for the first two years they didn't have running water, no plumbing, they lived in tents. There were 3 kids and their father; their mother got left behind due to her HIV status. During treatment, the father worked 3 jobs so the kids took care of themselves, they were young (8, 9, and 11) and alone most of the time. Dominant culture standards state kids can't be alone at that age but that wasn't our issue. Among coming to the states, the patient developed pancreatic cancer, incredibly painful, difficult, she didn't sleep in a bed when she got to the hospital, she slept on the floor. She didn't know what a bed was, and didn't like it. She preferred a pallet. Father couldn't be at the hospital because he was working, he took care of her though. We actually ended up petitioning the state department to get the mother over here. But there again, I had to check with the father to make sure it was appropriate for the mother to come over, and that is what he wanted. It broke my heart to see the child by herself, but I strongly believe you can't blame the family or be mad at them, you can to be mad at the cancer, not the family that is trying to do their best.'

'A Hispanic single-mother wasn't comfortable staying at the hospital with her son, but she was scared to leave him alone so she sat in the room, and never came out. She never had visitors, and she didn't have a phone so unless she used the hospital phone she didn't make calls. It was difficult for me to communicate with her because her basic and poor education. Her son was too sick to communicate so she was really isolated in this experience. She said her support was her friends, but they couldn't come because they were all undocumented and had to work unusual and long hours. His was her only child and she was grieving.'

All three narratives explain how families did not have a support system in place to help them cope with their child's illness. These three factors, knowledge and understanding, language, and support system, coupled with outward expressions (such as physical appearance, dress, language, and demeanor) were found to be key ways in which families were judged by staff.

Distinctions in Clinicians' Understanding and Perception of Family Coping Behaviors

Using thematic analysis and inter-rater reliability, this researcher noted several distinctions between clinicians' perceptions of families' coping behaviors during their child's pediatric cancer diagnosis. Inter-rater reliability allowed for consistency and agreement in clinician perceptions, and lent validation to thematic analysis. The raters also varied in race and culture and thereby reflected cultural relevancy and interpretation of the same data. Three distinctions were observed when examining differences between the Caucasian social workers and social workers of color: clinicians' terminology, presentation of information, and acceptance of family coping behaviors.

*Terminology*

Historically as researchers, we know that language influences culture and often one's thought processes. How individuals live their lives, the context of human behavior, and perceptions of environment are mediated by culture and communication. How

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individuals learn to speak and communicate is directly related to one's culture. Although culture through language guides the terminology used from one culture to another, it is important to acknowledge that distinctions in culture and language are not to reflect superiority or value of one race, or culture over another. For the current study, terminology was one category identified as a perceived difference in clinician responses. All survey questions were formulated and written by a researcher whose environment assimilates the dominant culture. The way in which the clinicians in this study reported perceived family coping behaviors therefore can be interpreted to reflect their culture and language.  The terminology used by clinicians in this study varied; and large differences were noted in clinicians of color when compared to Caucasian clinicians. For example, one of the Caucasian participants claimed one of the interview questions was very judgmental. The question was *'How important do you think a family's cultural background is on their ability to cope with challenging situations?  How is this affected by treatment in a Westernized healthcare facility?'* This participant accused the writer of the questions to be assuming that the Westernized healthcare facility wasn't providing what it needed. While the rest of the participants, including clinicians who identify as African American, Hispanic, and Caucasian, appeared to really appreciate this question and discussed topics such as transitioning to a new environment, staff awareness and education, fear of medical system, understanding the illness, what the illness means to the family, making the family comfortable in the setting, understanding death, and how families address communication of the above topics. One African American clinician explained coping not how it is utilized by the family, but how it is viewed by staff:

'a lot of our families' support is wrapped up in their culture, so being pulled into a 'different world' and more than likely a different way of doing things can be traumatic. Coping or not coping can hinge a great deal on how rejected or accepted they feel their culture is by the medical staff. Nothing can break down a potentially strong system of coping better than feeling that you're being judged or even mistreated because of your differences. A family who otherwise would cope just fine could find themselves thrown off balance emotionally if we are not careful how we handle when with regards to their background'

This above narrative, coupled with the examples above, demonstrate how terminology can be interpreted differently by each individuals' cultural lens. Other terminology differences noted among the responses include: dealing with versus working with families, describing families using deficit words versus strengths perspective, allowing versus accepting cultural changes, focusing on how to gain cultural competency through education/conference versus the internal process of not imposing your own opinions.

*Presentation of Information*

The role of social workers is wide and varied throughout hospitals and other human service settings. The ability of social workers and clinicians to negotiate between cultures is important to cultural and contextual understanding, and allows for more effective worker: client interactions and assessments. How clinicians interpret client information, data, and client behaviors are presented through the lens of the worker's understanding, language, culture, training and environment. Summaries and perceptions of families' coping behaviors and family needs by clinicians in the current study ruminated personal theories, shared meanings, and clinician background in relation to attitudes, values, perceptions and socialization patterns. For example, some social workers from the dominant culture presented as "problem solver" and "diagnostician". Several social workers, of all cultural backgrounds, gave shared meanings to family

needs and coping behaviors, especially in areas of behavior misinterpretations and lack of understanding.  This was especially evident in clinician responses that placed corrective meaning to variations in outward behaviors of African American men, or of mothers whose culture dictated that healthcare professionals address the male or fathers first. Social workers of color presented with more cultural sensitivity and awareness and projected as being able to bridge cultural prescriptions and similarities.  This group also presented as less likely to label or diagnose family behaviors as negative in comparison to their Caucasian counterparts and more likely to engage and address the collective needs and behaviors of families dealing with a pediatric cancer diagnosis. From a contextual frame, it may be that minority workers are more likely to view certain behaviors as normative rather than as a mental or conduct disorder due to associations with their own orientation or acculturation. These social workers also spoke of the felt need to translate a family's culture and experience of hospital care, in relation to culture, to the staff members.

*Acceptance*

Those clinicians who self-identified as African American and Hispanic appeared to have more overall acceptance and compassion for their families and their situations. This was evident in descriptions of their families' experiences and their responses to the interview questions. Social workers of color, because of their cross-cultural experiences may be able to relate more comfortably than Caucasian social workers to their families' experiences; and thus show more empathy and acceptance. This researcher is careful to acknowledge that not all people of color have the same experience, but do share a common thread of being excluded from the dominant group or culture. This shared

experience can lead social workers of minority backgrounds to better understand,

interpret, and objectify the full picture of oppression and how subordination affects every

aspect of one's coping ability. This cultural assimilation seemed to inform their work

with families experiencing a pediatric cancer diagnosis and allowed them the comfort of

sitting with difficult situations and with silence, more than the Caucasian social workers

who tended to search for immediate solutions and focus on physical services for families.

Social workers of color seemed to have less expectations of "what a family should do" in

order to exhibit healthy coping behaviors; stating that it is important to 'allow and

acknowledge' when families add dimensions to their already established culture, or if

they transition between stated cultures. Social workers that self-identified as Caucasian

tended to recognize differences between family coping behaviors and define these

behaviors as 'normal', or what was defined as 'normal' through their lens.  The African

American social workers did add that they believed distinctions in coping behaviors

among families lie more in circumstances prior to the diagnosis and not necessarily the

actual cancer diagnosis.  The following narrative is from an African American

participant:

> 'It is absolutely true that you must meet a family where they are. You will not
> success at imposing your own opinions, ideals, beliefs or even values on them.
> The greatest impact can be made by acknowledging who they are, where they
> believe they are emotionally, who others think they are, where others thing they
> are emotionally, and what your thoughts and feeling are about both. Try to find
> yourself somewhere in this equation, work your plan and respect all parties. Find
> a way to get the family what will assist most and help them see what you feel may
> be a hindrance to where they feel they want to be. The ultimate goal is to exit that
> families' life leaving them in a better state (but at least made no worse by your
> intervention) than when you met them'

Cultural Sensitivity and Cultural Competence among Social Workers

In terms of gaining better cultural sensitivity and cultural competence in working with diverse populations, most participants in this study agreed that more time, training and funding needs to go into hospital staff development, cultural sensitivity training, and securing translators.  One way to achieve more cultural competency among staff is to obtain more culturally diverse healthcare professionals. A common theme discussed in the interviews was the natural tendency to interact and communicate with individuals from similar and like cultures. With this in mind, this researcher believes that minorities would feel more comfortable seeking care when there are healthcare professionals from cultures similar to their own. Since pediatric healthcare facilities are limited, it is important to understand the implications of having an over-representation of dominant healthcare workers providing services to families outside their dominant culture. More collaborative work among and between culturally different workers and case conferencing were also suggested as ways to teach and introduce more in-depth cultural competence. Lastly, the offering of continuing education on cultural sensitivity and competency were identified as a necessary step in sustaining the quality of care provided to diverse families within a pediatric facility.

CHAPTER V

DISCUSSION

Findings from this study suggest that social workers' perceptions of coping behaviors are contextualized by one's own culture and prior life experiences. These experiences influence how social workers assess patient needs and interact with patient families. Social workers also may be limited by the constraints of the medical system in which they work. The current study explored some of these cultural differences and found distinctions in clinicians' understanding and perception of the coping behaviors and cultural differences in their patients and patient families dealing with a childhood cancer diagnosis.

Many participants in this study mentioned the need for all medical staff to be trained in cultural competency rather than the current model where the social worker is a translator between the family and the medical staff. A refocusing of the current model would encourage medical facilities to have more culturally diverse team members, as well as available translators when they are needed. More research that will include medical and support staff feedback is needed to examine effective and proficient ways to achieve cultural awareness in the healthcare professions. This is necessary because the majority of our current healthcare professionals were not exposed to culturally integrated curricula and behaviors during their educational training. Most graduate programs did not begin teaching cultural competence in coursework until the late 1990s; so many

professionals in the field do not have formal education on cultural sensitivity and outreach to patients.

These implications are huge in the social work realm where oftentimes social workers are the only advocates for families. Because culture includes a variety of factors, including how we view the world and how we function in it, as well as personal experiences and style, it is impossible for workers to fully know how another person perceives their illness, and therefore coping. However this researcher does venture to say that obtaining cultural sensitivity and competency is an infinite process that changes through time. In our global and constantly expanding society, the need for cultural awareness is great, especially as we face issues with health outcomes, increased patient services as a result of the passage of the new healthcare bill, and escalating numbers of immigrants needing and seeking services from healthcare professionals whose culture is different from their own. Social workers, as patient advocates and champions of care, must be able to understand and relate to all patients and to communicate in a manner that is respectful, engaging and globally understood.

There were limitations to this study and the most salient of these were the small sample size of clinicians who voluntarily participated in this research. There was a clear imbalance in race and culture among the clinicians with the majority of social workers self-identifying as Caucasian. Only three clinicians self-identified as minority, or persons of color. Therefore in examining clinician understanding and perceptions of coping behaviors among culturally different families, the responses overwhelmingly represented the majority culture. This means that the researcher's interpretations are largely based upon majority social workers with less input from minority social workers. Yet even

within this small sample, distinctions between clinician perceptions were evident as presented in Chapter IV of this thesis.  These differences are substantial and are supported in current research studies.  The more pronounced studies are those that address concepts of belief and value and the impact that these attributes have on worker's behavior and assessment of clients.  Euro-American cultural values and beliefs have dominated our society and tend to be accepted as universal.  However this universality has restricted effective communications and interactions between cultures.

A serendipitous finding to this study occurred between the researcher and the inter-rater reliability rater.  The researcher is a member of the majority race and culture; and the rater is a member of a minority race and culture. In identifying transcript themes and interpreting clinical data, clear demarcations surfaced between researcher and rater in understanding clinician communication styles and patterns, and how they were used to interpret family coping behaviors. The researcher, like many well-trained clinicians, is well versed and proficient in diagnoses and patient behaviors, and articulated this understanding in well-defined concepts and theoretical frameworks. The researcher also has skills and understanding of cultural differences and how these differences impact perception and family coping behaviors. The rater, a member of a minority group, articulated her identification of clinician themes from a cross-cultural perspective and offered a precise framework for viewing and defining diverse factors at work in intercultural communications and assessments. Both researcher and rater were trained in Ivy League Schools of Social Work, are from affluent families, live in mixed communities, and proficient verbal and written communication skills. Yet the view and insight that the rater possessed extended to her culture, life experiences and assimilation

into larger society. This same phenomenon was observed in the minority clinicians who participated in this study. This observation clearly is not to be interpreted as good: bad; competent: incompetent; or even culturally astute verses culturally inept. What it does address however is the cross-cultural patterning and interpretive styles that minority clinicians have that may not be present in clinicians from the dominant population, and thus the need for culturally sensitive training and inclusion in curricula of learning. This observation further stresses the need for more culturally diverse professionals and clinicians within the helping professions, as recommended by the clinicians in this study. Finally as previously mentioned, expanded research with larger population groups, movement towards a more radical view of cultural competence, including cross cultural training and learning opportunities will prove invaluable to diminishing the cultural divide that presently exists within our society.

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APPENDIX A
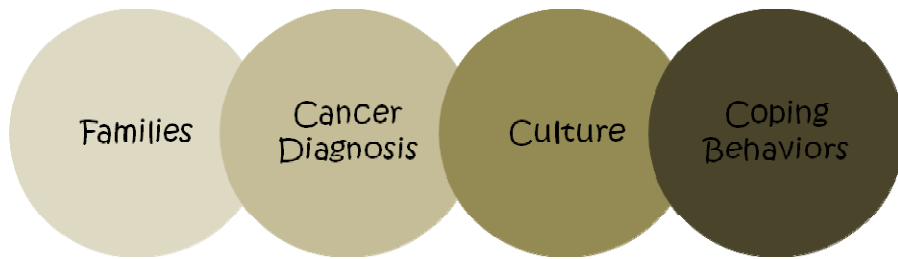


Interested in cultural differences? Work with families from different cultural backgrounds dealing with a pediatric cancer diagnosis?

How do you address cultural differences in your work with patients and families?
I want to hear about your experience!



| Criteria: | If you are interested please contact Kara Rule, MSW candidate |
|---|---|
| • Professional Master's or Doctorate degree<br>• Current or past experience in working with families diagnosed with cancer<br>• At least one year of clinical experience in mental health/therapy/medical social work/direct practice<br>• Speak and understand English<br>• Willing to have an in person or telephone interview with the researcher |  |

Research study for thesis is being conducted as part of the requirements for the Masters of Social Work degree at Smith College School for Social Work and future presentations and publications.

APPENDIX B

Dear Potential Research Participant:

My name is Kara Rule. I am conducting a qualitative study to examine how clinicians perceive coping behavior in families with a pediatric cancer diagnosis among different cultures. I will be conducting one-on-one interviews (either in person or over the phone) to fully capture the clinicians' understanding and viewpoint. This research study for my thesis is being conducted as part of the requirements for the Master of Social Work degree at Smith College School for Social Work and future presentations and publications.

Your participation is requested because you have been identified as a clinician who works with families dealing with a pediatric cancer diagnosis. If you choose to participate, I will ask you to provide demographic information about yourself and your clinical work with families, such as your age, your race, ethnicity, education, how long you have been working with families, etc. I will interview you regarding your past experiences on different coping behaviors you have seen in families and how you believe these behaviors related to cultural influences. I will also ask you to share specific examples in which you feel relate to this topic.

The interview will last for approximately 45 minutes; the interview will be recorded and transcribed. Your identifying information will not be on the transcription. My research advisor will not have access to any materials until identifying information has been removed. Once my thesis is complete, all recordings and transcripts will be securely stored for three years per federal guidelines. After three years, documents will be destroyed.

There are no serious risks to this study. However you may experience some discomfort during the interview related to your perceptions of how families cope with trauma, your personal recall of specific families that may have touched you emotionally, and or the need to protect vulnerable families. There are however benefits from your participation in this study. You will add to that body of knowledge that addresses how clinicians work with culturally diverse families. Your feedback also will provide insight into how other clinicians can benefit from your work experience. Finally your participation will provide valuable information and knowledge to neophyte workers and students interested in working with pediatric cancer patients and their families.

You will receive no compensation for your participation in this study.

Participation in this project is entirely voluntary and you may refuse to answer any question I ask at any point during participation in the interview. You may also withdraw from the study for any reason at any point up to March 15, 2010, at which time the data will be prepared for submission to Smith College School for Social Work. Should you

choose to withdraw from this study, please notify me in writing.  My contact information is below.  If you have any concerns about your rights or about any aspect of this study, please call me or the Chair of the Smith College School for Social Work Human Subjects Review Committee at (413) 585-7974.

Please keep a copy of this consent letter for your records.

YOUR SIGNATURE INDICATES THAT YOU HAVE READ AND UNDERSTAND THE ABOVE INFORMATION AND THAT YOU HAVE HAD THE OPPORTUNITY TO ASK QUESTIONS ABOUT THE STUDY, YOUR PARTICIPATION, AND YOUR RIGHTS AND THAT YOU AGREE TO PARTICIPATE IN THE STUDY.

_____
PRINTED NAME OF PARTICIPANT

_____                      _____
SIGNATURE OF PARTICIPANT                              DATE

_____
PRINTED NAME OF RESEARCHER

_____                      _____
SIGNATURE OF RESEARCHER                              DATE

APPENDIX C

1.  What is your highest level of education and or certification?

2. What is your gender?

3.  How many years have you worked with families of childhood cancer?

4.  What is your race?

5.  How old are you?

INTERVIEW QUESTIONS
1. What factors do you consider when referring to culture?

2. Please describe your caseload in terms of race and culture differences.

3. Can you describe observed differences in responses and coping behaviors among different

races and cultures of families?  For example do you notice differences between Caucasians and

African Americans, Hispanics, etc.?

4. Do members of the hospital staff make judgments on families' ability to cope based on their

culture?

5. What coping behaviors are deemed acceptable at your medical facility? What behaviors are

deemed unacceptable?

6. What challenges have you personal faced when working with families from a different culture?

7. How does your own coping impact your assessment of families' coping behaviors?

8. How has your agency/institution supported or hindered your ability to complete culturally

competent assessments of families of varying cultures and races?

9. How important do you think a family's cultural background is on their ability to cope with

challenging situations?  How is this affected by treatment in a Westernized healthcare facility?

10. What advice do you have for other clinicians in the field?

# APPENDIX D

SMITH COLLEGE
School for
Social Work

January 13, 2010

Kara Rule

Dear Kara,

Your second set of revisions is fine. We see that you are using two different Consents in terms of the last bit about concerns. That's probably a good idea. I am also glad that you are giving stamped return envelopes. It just makes things easier for your potential participants.

We are glad to give final approval to your study and hope your recruitment is successful. The support from the hospital certainly helps!

*Please note the following requirements.*

**Consent Maintaining Data:** You must retain all data and other documents for at least three (3) years past completion of the research activity.

*In addition, these requirements may also be applicable:*

**Amendments:** If you wish to change any aspect of the study (such as design, procedures, consent forms or subject population), please submit these changes to the Committee.

**Renewal:** You are required to apply for renewal of approval every year for as long as the study is active.

**Completion:** You are required to notify the Chair of the Human Subjects Review Committee when your study is completed (data collection finished). This requirement is met by completion of the thesis project during the Third Summer.
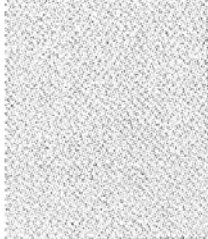
Good luck with your project.

Sincerely,

Ann Hartman, D.S.W.
Chair, Human Subjects Review Committee

CC: Narviar Calloway, Research Advisor

**Date: 01/07/2010**

**NOTIFICATION OF APPROVAL**
Children's Healthcare of Atlanta Institutional Review Board

**Study Title:** Clinician's Understanding and Perception of Coping Behaviors and Cultural Differences in Families Dealing with Pediatric Cancer
**Principal Investigator:** Kara Rule, BA
**CHOA IRB#:** 10-002
**Date IRB Approval Issued:** 01/05/2010
**Date IRB Approval Expires:** 01/04/2011
**IRB Review Type:** ☐ Full Committee ☒ Expedited
**Sites Associated with this IRB Approval:** ☒ Children's at Egleston
☒ Children's at Scottish Rite
☒ Hughes Spalding

**Children's**
*Healthcare of Atlanta*

1920 Briarcliff Road NE
Atlanta, Georgia 30329
404-785-7555
404-785-9470 fax
www.choa.org

You are approved to enroll 12-15 subjects between 01/05/2010 and 01/04/2011. You **MUST** have IRB approval for data collected outside of the approved date range or over the approved number of subjects **PRIOR** to data collection. Failure to obtain prior approval may result in inability to use data.

Children's Healthcare of Atlanta Institutional Review Board approved the above referenced study
☐ The stamped approved informed consent document for use in this study is attached. Only this original shall be used to make copies for study enrollment. You may not use any informed consent document that does not have this Institutional Review Board's current stamp of approval.
☒ The requirement for written informed consent is waived for this study.
☒ The requirement for authorization for the release of protected health information for research purposes is waived for this study.
☐ This study is open for data analysis only.

While conducting this research, please ensure that the following occur:
- As applicable, informed consent is sought and appropriately documented from each prospective subject or the subject's legally authorized representative before the subject participates in the research.
- IRB approval for continuation of the study is obtained prior to the above referenced expiration date. Failure to obtain approval for continuation prior to the expiration date results in immediate termination of the research at the above referenced study sites.
- Any modification to the study procedures or documents approved by the IRB are submitted to and approved by the IRB prior to implementing the change.
- Serious adverse events reports are reported to the IRB within five (5) days of knowledge of them.
- Appropriate study records are maintained as mandated by this institution, the sponsoring agency, and the U.S. Food and Drug Administration.
- Hospital staff involved with this study are fully informed and trained regarding their involvement with this research or its subjects.

The IRB office may provide a request for continuing renewal at 60 and 30 days prior to the expiration date indicated above. However, it is the Principal Investigator's responsibility to ensure that the continuing renewal materials are submitted in adequate time to allow IRB review and approval prior to the expiration date. Failure to obtain IRB approval for continuation results in immediate termination of the research. In this case, the study may not be re-opened under this CHOA IRB# unless the continuing renewal materials are received within 90 days of the expiration date and approved by the IRB. Otherwise, the study must be submitted as a new protocol and a new CHOA IRB# will be assigned.

Sincerely,

Angela Carrico
IRB Manager

Documents Approved:
☒ Protocol - Version date: 01/05/2010
☒ Informed Consent - Version date: 01/05/2010
☒ HIPAA

☐ Decedent's Information
☐ Lay Summary
☐ Wavier of Authorization

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