CLINICAL PERSPECTIVES ON THE CULTURAL IMPACT OF FAMILY RESILIENCE AMONG PEDIATRIC CANCER FAMILIES

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Abstract:

Background: Pediatric cancer diagnoses differ from that of adults as their incidence defies environmental influence. Studies show that mortality rates among pediatric cancer patients disproportionately mirror the incidence rates when stratified by race. Although factors such as cancer type and treatment plans change outcomes, biological differences fail to fully explain this imbalance. Thus, the purpose of this study was to explore the role social and environmental factors play in the prognosis of pediatric cancer patients that may explain racial disparities between incidence and mortality rates.

Methods: This study used a qualitative research design with in-depth interviews conducted with clinical staff at a pediatric cancer clinic. A total of 12 interviews were conducted averaging at 37.5 minutes using a semi-structured interview outline. Interviews were transcribed and coded for emerging themes.

Results: Results showed four main themes in the role of culture on pediatric cancer resilience: social support, family composition, compliance, and individual coping. Social support is imperative to a family's resilience through treatment. However, the importance is not the presence of support, but a family's willingness to ask and accept it. Family composition affected resilience by the presence of support within the immediate household and demographics of the parents, especially their educational background, language barriers, and socioeconomic status. Compliance variation correlated with access to resources, age of patient, and understanding of the diagnosis. Individual coping, primarily with parents, was also a critical component, as an innate ability to be adaptive and flexible improved the family experience and influenced patient coping skills.

Conclusions: Implications of this study can inform medical practice in assessing the psychosocial risk factors of a family prior to treatment initiation. This assessment can improve resource allocation, hone in on family strengths, and address any emotional or social weaknesses they may possess. Understanding the complexity of each family structure and their most influential factors of resilience can inform physician conversations with parents. Recognizing the importance of individual parent and patient coping as well as willingness to accept the support that is available can be critical in promoting positive outcomes and outlooks during an arduous, straining, and labile treatment process.

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CHAPTER I

INTRODUCTION

For centuries, cancer, a collection of diseases, has consistently proven to be devastating and costly for patients and their families. In simple terms, cancer is the deviation of cellular biology from its normal function in which irregular cells are uncontrollably mass produce and jeopardize the integrity and health of the body at its point of origin and over time, the body in its entirety. Cancer is unique in its many mutations and types as well as the variety of locations in the body from which it can originate (National Cancer Institute, 2015). This unpredictable and incurable affliction burdens both men and women of all backgrounds. In the case of many adult cancers, certain cancer diagnoses may be more predictable than others as lifestyle behaviors and other environmental factors contribute to the presence of cancer. Cancer incidences and prognoses, along with other common diseases, can occur along a socially driven pattern. This pattern insists that disadvantaged populations bear a disproportionate burden of disease and mortality. Disadvantaged populations can include racial and ethnic minorities, individuals living at low socioeconomic statuses, or those who have a limited physical environment (National Cancer Institute, 2015).

Statement of the Problem

In pediatric cancer diagnoses are exceptional in their cancer types, incidence rates, and subsequent outcomes. Unlike adult diseases, pediatric cancers are not partial to disadvantaged populations or environmental influence in their incidences. According to the American Cancer Society (2014), white and Latino children have the highest pediatric cancer incidence among all racial groups. However, mortality rates among pediatric cancer patients disproportionately reflect similar mortality rates between white and black children despite the lower rates of incidence among black children. Although survival and mortality rates are dependent on cancer type and treatment options, the biological differences do not fully explain the disparity between incidence and mortality rates among racial groups of pediatric cancer patients.

Thus, this racial disparity between racial pediatric cancer incidence rates and mortality rates introduces the role of influence beyond biology. This notion is supported by a study comparing patients from national cancer registries with the registry from St. Jude, an institution that will treat patients with specific cancer types despite a family's financial situation. Pui et al. (2012) found that black pediatric cancer patients saw better outcomes when money was not a limitation for treatment at St. Jude compared to the national cancer registries. In addition to socioeconomic risk factors such as financial status, access to treatment, and early detection, patient coping and resilience can also play a role in their health outcome. The pediatric cancer treatment process invokes a considerable role on the patient's parents and family. Family resilience has a multi-level definition that involves resilience at the individual, family, and community level.

Purpose of the Study

The purpose of this study is to explore the role social and environmental factors play in the prognosis of pediatric cancer patients that may explain racial disparities between incidence and mortality rates.

Hypotheses

As an inductive explorative study, no hypotheses will be tested during the course of this thesis study.

Significance

There is limited research in the variations of resilience and psychosocial risk among pediatric cancer families from different cultural backgrounds. There are also gaps in the literature regarding the role social and environmental factors play in the prognosis of pediatric cancer patients that may explain racial disparities between incidence and mortality rates. Pediatric cancer resilience research has focused on family and/or physician perspectives, however, there has never been a study evaluating pediatric cancer family resilience from the perspective of a pediatric oncology clinic staff members.

The significance in collecting clinical perspectives regarding pediatric cancer family resilience can provide a more thorough understanding of the recurring themes and prominent factors that promote or inhibit family resilience. By pinpointing themes in family resilience among these families, clinicians can improve their awareness of psychosocial risk factors and promote resilience factors through their social and psychological services. Understanding what factors improve and stunt family resilience can bring insight to possible patterns among patient populations who experience survivorship disparities. This study can provide a foundation for future research regarding resilience and psychosocial differences among families from different cultural backgrounds for all childhood diseases and overall pediatric health. These potential patterns and differences can inform possible explanations for the discrepancies between incidence and death rates among different racial groups of pediatric cancer patients.

Delimitations

This study will only include participants recruited from medical facilities that provide medical services to pediatric cancer patients. Participant recruitment will focus around a single pediatric oncology clinic in Oklahoma. The results of this study may not generalize well to other locations or populations.

Limitations

This study is not without limitation. First, participants self-reported information on personal demographics, their job descriptions, their personal professional experiences, and their perceptions of cultural variation among pediatric cancer families. Second, the study is limited by the recall and accuracy of participants’ experiences and opinions on family resilience among pediatric cancer families. This would include the accuracy of perceptions of social factors affecting family experiences through pediatric cancer treatment. Finally, as probability sampling was not employed, the extent to which the sample is representative of the overall pediatric oncology clinical staff population is unknown.

CHAPTER II

LITERATURE REVIEW

After car accidents, cancer is the leading cause of death for children from the ages of 5-14 (Murphy, Xu, & Kochanek, 2013). Though childhood cancers make up less than 1% of cancer diagnoses per year, it is predicted that over 10,000 children under the age of 15 will be diagnosed and over 1,200 children will die from cancer in 2017 (American Cancer Society, 2017). Although less common than adult cancer, 1 in 285 children in the United States will receive a cancer diagnosis before the age of 20 (American Cancer Society, 2014). Cancer incidence rates for individuals diagnosed before the age of 20 has seen a gradual increase from about 13.0 cases per 100,000 in 1975 to 17.7 cases per 100,000 in 2012 (Stats, 2012). Children, ages 0-4, have the highest incidence rates of all cancer types compared to other age groups (US Cancer Statistics Working Group, 2015). However, the 5-year survival rate for pediatric cancer patients has increased from 58% to 80% since the 1970s (American Cancer Society, 2017). Though outcomes have improved over the last few decades, brain cancers, the second most common among pediatric cancer patients (18%) has the highest death rates (American Cancer Society, 2014; Institute, 2015). Along with brain cancers, other types of cancer common among pediatric patients is leukemia (26%) and lymphoma (14%) (American Cancer Society, 2014).

Pediatric cancer studies and research classify patient populations within varying age groups. Some branch adolescent cancer patients into their own subgroup because of the differences in psychological development compared to their pre-adolescent counterparts, while some include all patients under the age of 20 as pediatric patients (American Cancer Society, 2017). For the purposes of this study, age classifications will reflect those defined by the American Cancer Society defining “children” as those ages 0-14 and “adolescents” as those ages 15-19 (American Cancer Society, 2014). Among children, incidence rates are higher for boys than girls, while both genders experience similar survival rates (American Cancer Society, 2014). Some cancer types common among children are rare among adults because of the development of these cancers from embryonic cells. Pediatric cancers that are more common among adolescents are more similar to adult cancer types (American Cancer Society, 2014). With adolescents cancer incidence rates are comparable between boys and girls, however girls show lower mortality rates and higher survival rates (American Cancer Society, 2014). These difference are partially explained by the types of cancer that may be gender biased (American Cancer Society, 2014). Among facilities affiliated with the Children’s Cancer Group (CCG) and Pediatric Oncology Group (POG), the 15-19 year old age group is underrepresented. This finding may indicate that adolescent cases may be seen by adult oncologists rather than pediatric oncologists (Ross, Severson, Pollock, & Robison, 1996). However, as the diagnosis of cancer for a child and adolescent require consent and active participation of parents and guardians, ‘pediatric cancer patients’ will collectively describe both child and adolescent cases.

Adult vs. Pediatric Cancer

All cancer diagnoses bear the stresses of emotional uncertainty, physical decline, and financial burden. However, with many adult cancers, routine screening or genetic testing can predict potential onset or pinpoint cancer in its early stages. Lifestyle and environmental risk factors can also result in adult cancers. For example, smoking cigarettes have a correlation with the onset of lung cancer. Obesity also increases susceptibility to cancers (Coups & Ostroff, 2005). Causes for most pediatric cancers are, on the whole, unknown, making it distinct from many adult cancers that are environmentally influenced or have screening abilities. Few childhood cancers have known associated causes (American Cancer Society, 2014). There is limited evidence regarding the associated between radiation exposure, parental smoking, maternal exposures, and growth rate/birth weight and pediatric cancer diagnoses(American Cancer Society, 2014). Thus, genetic basis for many pediatric cancers, therefore, makes it unpredictable and unpreventable.

Pediatric cancers are also distinct from adult cancers in its effect on child development and the role of the family during treatment. Children continue to develop cognitively, physically, and emotionally throughout their childhood and adolescence. A cancer diagnosis and its subsequent treatment can impede physical growth and substantially impact their emotional well-being and future. The presence of brain cancer and its treatment can also impair cognitive development. With the recent success of higher survival rates among pediatric cancer patients, the growing population of survivors creates a demographic of at-risk individuals requiring enhanced health vigilance through good health behavior practices. These survivors have a high susceptibility to cancer recurrence, cardiopulmonary disease, and obesity in their adult years in part due to toxicities of treatment (American Cancer Society, 2017; Butterfield et al., 2004; Hudson et al., 2002; Tyc, Hudson, Hinds, Elliott, & Kibby, 1997). The support and family structure for adults diagnosed with cancer can vary. Some live and cope with their illness independently, whereas some rely on the support of their children. In pediatric cases, the burden of decision-making and source of support rests heavily on the parents or guardians of the sick child (Brody & Simmons, 2007).

Social Trends in Pediatric Cancer

Within the United States, racial health disparities exist in numerous health conditions such as in hypertension incidence rates, life expectancy, and infant mortality (Lloyd-Jones et al., 2010; Olshansky et al., 2012; Williams & Collins, 1995). Racism, residential segregation, and socioeconomic status can help explain varying incidence rates among racial and ethnic groups for a given health condition (Barr, 2014; Williams & Collins, 2001). Research among adult cancer incidence rates shows a direct association between near poverty status and cancer incidences (Gorey & Vena, 1995).

Incidence rates of pediatric cancers are, however, ignorant to any social or racial constraints on health. For children and adolescents, the highest incidence rates for cancer are among Non-Hispanic white and Hispanic populations. Incidence rates among African American and Asian American/Pacific Islander children are both lower than that of white children. American Indian/Alaska Native populations have the lowest cancer incidence and mortality rates of all the racial/ethnic groups (American Cancer Society, 2014). The reason for such variety of incidence rates across racial and ethnic groups remains unknown. In contrast to adult cancer trends, pediatric cancer incidence rates do not show any association with populations with low socioeconomic status (Pan, Daniels, & Zhu, 2010). Though differing in cancer type, pediatric cancer incidences are lower in developing countries compared to industrialized countries (Bunin, 2004; Stiller & Parkin, 1996).

Unlike incidence rates, survival and mortality rates of pediatric cancers may be more susceptible to social and racial influences. Though incidence rates among African American children are lower than that of white or Hispanic children, death rates are comparable (American Cancer Society, 2014). Many studies evaluating outcomes for specific cancer types show worse prognoses among non-white children. For example, a study by Amirian (2013) found that children of Hispanic ethnicity had a higher risk of death related to their diagnosed Wilm’s tumor than non-Hispanic white cases.

There are a variety of potential explanations for the disconnect between incidence rates and mortality rates by racial category. Results from a study by Henderson et al. (2010) on neuroblastoma pediatric patients suggested a potential genetic basis for higher prevalence of high-risk disease among Native American and black patients that may cause more resistance to chemotherapy. According to Gurney, Severson, Davis, and Robison (1995), biological trends in pediatric cancer do exist. This study evaluated cancer trends by type and subsequently found that certain cancer types have incidence bias according to age group, gender, and race. However, these biases were slight. Thus, distribution of incidence rates, cancer types, and survival rates do have a genetic component, however, the extent of this genetic variation is unknown. Bone marrow and stem cell transplants are common treatment procedures for some cancer types; yet, tissue matches often rely on matching ethnicity between patients and donors. However, bone marrow registries show disproportionately low donor registration among ethnic minority groups such as African Americans, Asians, and Native Americans (Match, 2016). Though biology does contribute to cancer incidence and outcome, social influences, such as low rates of bone marrow donors among racial minority groups, also play a part in the racial disparities among pediatric cancer patients.

A comprehensive review of racial disparities within pediatric cancer performed by Bhatia (2011) indicates that incidence vs. mortality inconsistencies may be explained by the complex interaction among economic, social, and disease biology factors such as health insurance status, stage of diagnosis and external support. Pui et al. (2012) compared national child cancer registries to cases treated at St. Jude Children’s Research Hospital (SJCRH), an institution that treats patients regardless of their ability to pay. This study found that survival disparities between black and white patients persisted on national registries, but were not present among SJCRH patients. These results support that similar access to quality cancer treatment can help narrow the gap in racial disparities in survival rates. Therefore, in accordance with genetic underpinnings, social influence and environmental factors do play a role in pediatric cancer outcome.

Family Resilience & Psychosocial Risk

Although cancer is a medical diagnosis and relies on biological treatments, a patient’s emotional state in relation to their physical diagnosis can play a positive role in health outcome. Scheier and Carver (1985) found that individuals with higher optimism and lower self-consciousness reported being less bothered by their symptoms. Another study evaluating patients with obstetric complications found they had higher levels of anxiety and used less repressive-type defenses (McDonald, 1968).

Resilience, a common theme in cancer treatment for adults and children, is positive coping in the midst of adversity that strengthens internal fortitude and draws on affirming social support (Black & Lobo, 2008). A family's resilience or ability to cope can be evaluated using an ecological model because of its multi-faceted and interworking influences. Three distinct levels together define family resilience. The first relies on the psychosocial strength of each family member independently. Coping methods and psychological progress among mothers, fathers, and children differ. Mothers report greater distress post diagnosis than fathers and fathers are more likely to suppress their emotions (Brody & Simmons, 2007; Pai et al., 2007). Diagnosed children, depending on their age and maturity at diagnosis, can have trouble understanding the significance of their symptoms and may grasp it through metaphors or examples (Brody & Simmons, 2007). Often, siblings of diagnosed patients are overlooked as role players in cancer treatment and resilience. However, siblings also experience stress during the course of cancer treatment and can affect the family's resiliency (Van Schoors et al., 2016).

Another level impacting family resilience is harmony within the family unit. This level includes many factors of a family's dynamic including spousal relationship, family communication, and maintenance of normalcy. Family cohesiveness prior to the cancer diagnosis can predict the resilience level of families post-diagnosis. Resilient families promote an open dialogue of emotional expression and collaborative problem solving (Black & Lobo, 2008). The dynamic of collaboration between children and parents will evolve as the treatment progresses and as the children mature. Family cohesion also relies on consistent family routines and priority in time together (Black & Lobo, 2008).

External support systems and resources comprise the third level of influence on family resilience. Resilient families know when to ask for help and utilize the avenues to receive this help. Social support can come from extended family or support groups from other pediatric cancer families. Family functioning is positively associated with the relationship the family and patient have with their doctors (Shapiro, Perez, & Warden, 1998). The role of educational settings on children diagnosed with cancer is also significant in maintaining normalcy, receiving peer interaction, and coping with social anxiety associated with their diagnosis, including the way others treat them (Kazak & Nachman, 1991).

Family Resilience Among Pediatric Cancer Families

The strength of family cohesiveness as well as parental distress level is linked to child adjustment to the diagnosis (Robinson, Gerhardt, Vannatta, & Noll, 2007). Therefore, the interchanging effects between a child's cancer symptoms and its influence on the family can impact health outcomes. Therefore, a child's adjustment to their diagnosis can mentally and emotionally affect their treatment process. According to Van Schoors et al. (2016), a family's response to pediatric cancer impacts the adjustment of the children within the family (Van Schoors et al., 2016). Cancer outcomes are not exclusively defined as physical results, but also include psychosocial development. A study performed by Wu et al. (2015) concluded that cancer distress symptoms combined with resilience significantly affects quality of life of adolescents with cancer (Wu et al., 2015).

For children diagnosed with cancer, resilience relies heavily on the actions and coping of their parents. The role of the child in family resilience increases the older they become (Wu et al., 2015). Though resilience is complex and relies on many components, two key elements of resilience are family harmony and social support (Black & Lobo, 2008). The importance of family harmony rests in the dynamic between immediate family members and their ability to address the stresses of a cancer diagnosis with a consistent family routine. Often, siblings of diagnosed patients are overlooked as role players in cancer treatment and resilience. However, siblings also experience stress during the course of cancer treatment and can affect the family's resiliency (Van Schoors et al., 2016). For example, enhanced attention drawn to the diagnosed child can incur negative behavioral consequences from the sibling, which then intensifies parental stress. Also, siblings offer a distinct mode of support and influence over the diagnosed child. If the sibling exudes acceptance and adaptability to the cancer diagnosis, the patient may mirror a similar response.

Family harmony is strengthened through maintaining a positive outlook and maintaining a sense of normalcy within the family unit. This normalcy includes the parent/child relationship of authority and discipline as well as avoidance of parental conflict in front of the children. Resilient families promote an open dialogue of emotional expression and collaborative problem solving (Black & Lobo, 2008). The dynamic of collaboration between children and parents will evolve as they the treatment progresses and as the children mature. Family cohesion also relies on consistent family routines and priority in time together (Black & Lobo, 2008).

Resilient families know when to ask for help and utilize the avenues to receive this help. Social support can come from extended family or support groups from other pediatric cancer families. The amount and type of support also varies among family members, therefore social support should be focused on individuals and the family as a whole (Brody & Simmons, 2007). Social support also includes financial support channels and clinical resources such as clinical trial enrollment or hospital sponsored counseling (Black & Lobo, 2008). Clinicians rely on the mother as the conduit to their family regarding the logistics of care and emotional support (Shapiro et al., 1998).

Conclusion

Pediatric cancer incidence trends among racial and ethnic groups do not reflect the survival and death rates of pediatric cancer patients. Little research has been conducted to investigate the strength of influence of biological and social factors on pediatric cancer prognoses. These interrelated components have yet to be clearly separated, however the presence of both factors and their contributions to a child's potential for survival has been confirmed. Thus, factors such as socioeconomic status and family resilience can contribute to a patient's health outcome. Resiliency and psychosocial risk of a diagnosed child and their family plays an important role in coping and persevering through the treatment process. Family resiliency includes individual, family, and community levels. The psychosocial risk levels and resilience practices at each level can have cultural variation. There is little research exploring the cultural diversity among psychosocial risk and resilience factors in pediatric cancer families from differing socioeconomic status and racial/ethnic backgrounds. Developing a thorough understanding of family resilience among pediatric cancer families and the role that cultural factors play on resilience is essential to understanding the impact social factors have on a child's treatment process and survivorship. A study evaluating pediatric cancer family resilience has never been done from a multi-perspective approach. This research study will be the first case study evaluating resilience trends and cultural influence on pediatric cancer families from the clinical staff and pediatric cancer families.

CHAPTER III

METHODS

Study Design

This study utilized a qualitative research design in which in-depth interviews were conducted on the clinical staff at a small pediatric oncology clinic in Oklahoma. An inductive approach was used to identify key factors to family resilience in pediatric cancer families. This approach also provided insight into potential cultural variations among families and the role these variations may play in predicting psychosocial risk and family resilience. Prior to the initiation of the study, research procedures were approved by the Institutional Review Board (IRB) at Oklahoma State University Center for Health Sciences.

Participants and Recruitment

Participants were recruited solely on a voluntary basis and no incentives were provided for completing an interview. Participants were required to meet the following eligibility criteria: 1) over the age of 18; 2) speak and understand English; 3) spend at least 30% of their workweek with pediatric cancer patients; 4) have contact with both pediatric cancer patients and their parents/guardians; 5) have been working with pediatric patients for at least 24 months 6) are affiliated with the study clinic (St. Francis Children’s Hospital).

Participant recruitment occurred through announcement from a physician who communicated to potential participants the purpose of the study, the time commitment of the interviews, the list of eligibility criteria, and an invitation to participate. Willing participants were invited to meet with the investigator during designated interview periods to ask any additional questions and proceed with the in-person interview.

Procedures

Participants meeting eligibility criteria and expressing interest in participating in the case study were engaged in an in-person interview. The goal of this study was to recruit at least 10 participants from at least 3 differing job descriptions or until saturation was reached. Saturation is reached when no significant codes or themes are emerging from collected data (Corbin & Strauss, 2008). In addition, observation hours at the pediatric oncology department, both outpatient and inpatient settings provided data for this explorative study. These interviews took place in the conference room at the pediatric oncology clinic, staff offices, and charting station at the inpatient pediatric cancer floor, which insured convenience, privacy, and confidentiality. This case study involved in-depth, in-person interviews using a semi-structured interview guide produced by the principal investigator. Interviews were expected to be between 45-60 minutes long. To begin the interview, participants were asked to read over and sign a consent form in order to proceed with the data collection. This document ensured their anonymity and confidentiality in the information they will provide. This consent form also confirmed the participant meets eligibility requirements, framed the interview process, and outlined subsequent use of the data by the investigator.

Following participant consent, participants were asked to complete a brief demographic questionnaire that includes age, family composition, ethnicity, years of pediatric oncology experience, personal education level, personal income, and parental education levels. Upon questionnaire completion, the in-depth interview began. These interviews were structured to elicit narratives from each participant. Structured questions evoked data from participants on their most salient pediatric cancer patient case. Interview questions also prompted participant identification of the most important factors of family resilience among pediatric cancer families. Questions elicited data from participants on detailing their experience with patients and families from varying cultural backgrounds. In-person interviews were audio-recorded, then transcribed in its entirety. Notes were also be taken by the principal investigator to document key points in the narrative and any helpful observations while interviewing participants. These notes were also transcribed and used to supplement transcribed interviews.

Demographic Questionnaire

The principal investigator used a demographic questionnaire instrument prior to initiating the interview to establish the demographic data of each participant. The demographic variables collected include age, family composition, ethnicity, years of pediatric oncology experience, personal education level, personal income, and parental education levels. Additionally, this questionnaire included questions measuring resilience.

Interview Guide

A semi-structured interview outline guided participant narratives to center on family resilience factors. Participant interviews included questions as well as probes to supplement each question. However, the course and fluidity of the interview varied by participant with flexible use and order of questions and probes. The goal of the interviews was to encourage natural, uninterrupted elaboration, with minimal interference from the investigator. The purpose of the probes was to ensure unbiased progression of the narratives. Questions, their associated probes, and the sequence of the semi-structured interview evolved as needed after early interviews were completed to enhance interview value for subsequent interviews.

Data collected through transcripts from participant interviews were analyzed and grouped into common themes among participant responses. Investigator notes were. also included in this grouping.

Data Analysis

Demographic variable analysis. Descriptive statistics were compiled on demographic data. For the demographic variable “age” and “years of pediatric oncology experience,” mean and standard deviation of the sample was calculated. For the demographic variables “family composition,” “ethnicity,” “personal education level,” parental education levels,” and “personal income,” frequency and percentage of the sample were calculated due to the nominal or ordinal level of measurement of these variables.

Interview data analysis. Data collected through transcripts from participant interviews were analyzed and grouped into common themes among participant responses. Investigator notes were also included in this grouping. The interviews were digitally audio-recorded, transcribed verbatim, and double-checked for accuracy against the recordings. Interview data from this study was analyzed using a qualitative approach to inductively identify and interpret concepts and themes that emerge from interview transcript (Corbin & Strauss, 2008). This method involved multiple readings of transcripts and interview notes, and analytic induction via open and axial coding to thematically organize transcripts. Demographic data was used to highlight occurring themes.

CHAPTER IV

RESULTS

Descriptive Statistics of the Sample

In total, 12 interviews were conducted. Criteria was adjusted to involve a total of 24 months working with pediatric populations and 6 months required working with pediatric oncology populations. Proposed 8 hours of clinic observation was also eliminated due to logistical complications, HIPPA, and no added merit to the focus of the study in evaluating clinical perspectives. Table 1 displays the descriptive statistics of the sample. Participants ranged in age from 29-71 (M = 43.80, SD = 13.77) and 92% of participants identified as White/Caucasian with the final 8% identifying as Native American/Alaskan Native. Nearly all participants identified as female (92%) and the majority of participants identified as married (75%). In terms parental status, four participants (33%) reported not having any children, two (17%) reported having one child, two (17%) reported having two children, and four (33%) reported having three children. All participants reported an education background beyond a GED with 17% having some college or technical trade schooling, 60% reporting completion of an undergraduate degree, and 33% completing a graduate degree. Regarding individual income, two (17%) did not wish to disclose their income, four participants (33%) receive an income between \$40,000-\$55,000, four (33%) reported receiving between \$55,001-\$70,000, and two (17%)

reported earning over $70,000 annually. In terms of work experience, 25% have worked for 5 years or less, 50% have 5-15 years of experience, 8% has 15-25 years of experience, and 17% have been working for over 25 years. Regarding their mother's educational background, the responses of high school or GED, some college or technical trade schooling, and completion of undergraduate degree each were reported by four (33%) participants. For father's educational background, 25% reported high school or GED, 33% reported some college or technical trade schooling, 17%. reported completion of an undergraduate degree, and 25% reported completion of a graduate degree.

Cultural Impacts on Resilience in Pediatric Cancer Families

Table 2 presents the emerging codes and sub-codes for the study. Data from interviews with the 12 participants uncovered four primary codes that help explain the cultural influence on family resilience upon a pediatric cancer diagnosis: 1) social support outside of the immediate family has ethnic variation and impacts on coping; 2) differences in family composition can affect the treatment experience; 3) cultural background and personal coping impact levels of compliance; 4) internal drive and personal characteristics influence coping and controls the role cultural background plays in the patient experience. In vivo codes and exemplars from data are presented to feature emergent codes and connections. Pseudonyms were used in lieu of participant names to preserve participant confidentiality. Changes were not made to responses to ensure accurate interpretation in analysis.

Social Support

Social support emerged as a strong and encompassing theme among families and their treatment experiences. The presence of social support or lack thereof as well as the sources of support varied among different populations. Beyond just the presence of support was the family or parent's ability to ask for and accept this support in promoting the family's resilience.

Ethnic patterns. Although participants conceded to exceptions within each ethnic group, they broke down three major ethnic groups within their patient population and the patterns of social support seen within each. In the most populous group, Jennifer (Inpatient/Outpatient) described that "Caucasians have more, seems like more support systems." She also explained that "African American culture…have less resources, maybe less intact families." A particularly popular description of the Hispanic population praised their families for their high levels of social support. Grant (Inpatient/Outpatient) explains that social support "with Hispanic[s], it's more just they're just part of their fabric." Emily (Inpatient) further explained this fabric of support:

> I'd say Hispanics are very there. They have a lot of family support. But they also, like a few of the patients I've had, the moms are on top of it. They know what medications they take when they need to take them … I mean, not even just mom, dad knows, grandma knows, aunt knows. Yeah, so I feel like it definitely depends on just family values and beliefs.

The variation in patterns of support among different ethnic groups was a common theme that incited and intertwined with other ethnic patterns within other sub codes such as coping, anxiety, and family composition.

Impacts on family coping. Overall, study participants agree that having social support improved family coping. Social support emerges in different forms depending on the needs of the family as well as the source of the support. In describing the role of emotional support, Tammy (Inpatient/Outpatient) stated, "the ones that reach out to family and friends and have more …support network, yeah, cope a little bit better and have less anxiety than the ones that kind of just, I feel like, hold it in or just work themselves up when they hear certain words." Apart from emotional support, Kasey (Inpatient) explains that logistical support to the burden and demands of cancer treatment is also critical to improved family and parental coping as supporting members "can switch out and take breaks or spend time with their other kids. The parent is less stressed and …they come out better as well." In contrast, she also describes that families without a support system "put it all on their own shoulders, and then they just have a really hard coping." Thus, sources of social support, regardless of regional proximity to the families, impacted their ability to cope and get through the weeds and rigors of an extensive cancer treatment. Whether it is a small act of running an errand or being a sounding board, having people to ease the many emotional and physical adjustments of a cancer diagnosis positively impacts these families.

Role in resilience. As social support is associated to improved family coping, its role in resilience is intertwined within that relationship. In contrast, lack of social support can impede a family's ability to thrive. Caitlin (Outpatient) describes that "if it's a family that has lots of drama and doesn't get along and they don't get along with extended family, that can…impact their resiliency through cancer treatment as well." Regarding resiliency, Jennifer (Inpatient/Outpatient) expects "it out of these families that are intact and have all of these things, good support and all that. The ones that…are most resilient are not those families because they already have resources." Therefore, having social support gives families an advantage and enhances the chances of being resilient. As many participants described, including Caitlin (Outpatient), resilience involves an internal attribute that makes someone "willing and open to talk to people and kind of talk through their struggles and their frustrations and their issues and their happy moments and their milestones." In essence, the role that a support system plays in resiliency is not only the people that are available to you, but a personal quality that allows someone to accept help and form new bonds and relationships. Social support is obsolete if, though available, is unwanted and underutilized.

Family Composition

Though two children may have the same diagnosis or look similar on a medical record, their family composition can vary immensely. These differences in family background and structure can influence the support system, financial tier, available resources, and emotional maturity each family possesses. These factors are significant components to how a family may experience treatment and how equipped they are to handle this difficult journey.

Educational background. A medical degree specific to cancer care requires a minimum of 14 years of high level, full time, studies after the high school level. Thus, it is expected that a cancer diagnosis and its complicated treatment plan requires extensive explanation accompanied by countless follow up questions. However, a family's educational background can complicate and place additional stress on their ability to understand, accept, and buy in to their new reality. In families from a lower educational background, Megan (Outpatient) feels "like they have to try harder. They have to, you know, they don't have the background and education, like college degrees and or even a high school degree… definitely plays a part." For these families, Kelly (Inpatient) responded that "they need a lot more education from the from the staff and the physician. They usually ask a lot of same questions over and over again trying to understand things." In describing families from the other end of the education spectrum, one participant stated:

> The really educated, I think, are used to knowing everything or maybe in jobs or situations of life, they're more in control. And they want to be in control and… there's more of this tendency to question and why are you doing this way? Why aren't you doing that way? …They want everything defined and clear. And that maybe you're just getting to the more obsessive-compulsive personality types. (Grant, Inpatient/Outpatient)

Though understanding the intricacies of a cancer diagnosis and its treatment options is daunting for all families, participants reported that, in general, families with lower health literacy or educational foundation required more explanation and repeated their questions. Families from higher educational tiers tended to view their knowledge and understanding as a surrogate for the control and clarity they may be used to.

Single/Non-traditional parent households. Though having a family in which the mother and father are married and together is considered traditional, the reality of many families going through cancer treatment does not necessarily fit this mold. A non-traditional parent household can include single parents, foster care, and grandparents, etc.. These nontraditional family structures can impact the patient and family experience. Jennifer (Inpatient/Outpatient) described that those in DHS custody are "most difficult because then you know most courts will allow the bio parent to still be involved, but then there's just a lot more dynamics when you have the bio parent, the foster parent, the child, and they're all at the same visit and the child wants the [bio] parent." According to Caitlin (Outpatient), it is "hard for the patient sometimes when they don't have like a solid, consistency of knowing who's bringing them… If mom brings in one day and grandma brings in the next day, and step dad brings another day, how those family members react to their port access or their treatment or things like that." Inconsistency in caregivers coming to appointments can also put a strain on the clinicians as each caregiver will require re-education. In families where parents are separated, Caitlin (Outpatient) also describes it is apparent "how different the family dynamics are in mom's house and dad's house. And it translates here to depending on who [they have] been with. It just, it translates in the behavior sometimes." Instabilities in home life and family make up affect patient temperament, caregiver coping, and clinician resources providing caregiver re-education and maneuvering behavioral compensation from patients.

English as a second language. Although many clinics and hospitals have translation services or utilize an English-speaking family member, this method of communication still falls short of the clarity in single language conversations. Though a valuable resource, both family and physician have "to trust that that interpreter is…interpreting what's being said but not with their own, you know, emphasis" according to Jennifer (Inpatient/Outpatient). There is also uncertainty about whether information is properly communicated and if a family's understanding is fully established. Sophia (Outpatient) describes that "when you have that, that language breakdown, that's a big deal because you may not always pick up on things that may be going on" describing an obstacle for what providers are "trying to convey and the seriousness of situations." The freedom to voice any concerns or ask the many questions families have during these confusing times is also lost. Debbie (Outpatient) describes families where English is a second language as "afraid to talk because they're going to be embarrassed because they can't say it correctly." There is lack of relationship building and rapport beyond medical communication such as small talk, passing the time, and increasing social familiarity with clinical staff. Caitlin (Outpatient) describes that it is “hard to build rapport with a family you don't speak the same language with and our interpreters don't have time just come hang out with a family for two hours.” Clear communication is imperative not only to understand the intricacies of the diagnosis and treatment plans, but also to build a foundation of clinician trust and rapport.

Socioeconomic status (SES). Lack of resources, financially and logistically, can delay treatment and cause additional obstacles and stresses that affect outcome. Kasey (Inpatient) describes the relationship of low SES with a low support system because “everybody works or they don't have a car and they can't get help or the parent has to continue working. So sometimes the patients are here by themselves and then the patient feels like no one's here for them.” Another correlation with low SES that Grant (Inpatient/Outpatient) draws is the presence of alcohol and drug abuse. In describing parental coping, he says these “families come to us with those problems and then may or have a history of drugs, maybe alcohol… I think it definitely becomes a crutch. I think it's easy for them to fall back.” Finally, families with more destitute backgrounds can have difficulties accessing healthcare. Even with the ease of insuring children through Medicaid, Taylor (Outpatient) describes the importance of seeking care in “getting health care soon enough to get started in treatment…so they can catch it soon enough.” Whether the issue is transportation, finding the time to bring the child in, or fear of additional costs, the reluctance to seek care secondary to cost can translate in a late diagnosis, which if caught early could mean a different outcome for their child.

Age of parent. Parental age can range between teens to retirees. Those on the extreme ends of the spectrum tend to have less control over the child and therefore fall short in their responsibilities in treatment such as not helping with procedures or lapsing in home medications. Mature parents closer to the median of this range can be stricter and have a less anxious temperament. Emily (Inpatient) describes that “the younger the parents are, what I witnessed, they're not as on top of things sometimes, you know, as far as their medications and making sure they're taking them like ‘oh well he wouldn't take it this morning cause he didn’t want to’ or whereas, like the older parents or even some of the teenagers like the parents are more on top of them.” On the other end of the spectrum, a respondent describes:

> A patient that was raised by his grandparents. Both parents are in jail. And he acts up terribly. And, but as he's gotten older, I don't think his home situations change that much. But they they don't discipline. And that's what you see in a lot of grandparents too you know, and so he's a handful. (Shawna, Outpatient)

Kelly (Inpatient) also noticed that “the younger parents will be more likely to get on Google and figure out like if there's other options” as opposed to “older parents may not, they may just go and trust the doctor with what he's saying.” These examples show that age of the parent may impact the trust they have in their treatment team and willingness to actively participate in the treatment plan.

Compliance

In treating any illness, complying to the medical regimen is important to the success of the treatment. Thus, barriers to compliance, whether external or internal, affects overall outcome and can influence resiliency. The difficulties involved in maintaining a rigorous medication and treatment schedule are an added stressor uncovering the important role access to resources as well as health literacy in understanding of the diagnosis and treatment. With a wide age of patients undergoing treatment, patient understanding and the emotional coping of children and caregivers also affects the consistency of treatment adherence.

Access to resources. Not having transportation to come to appointments or money to pay for medications can be legitimate barriers to compliance as well as an excuse for patients to hide behind. The most prominent access issue according to study participants is transportation. Tammy (Inpatient/Outpatient) describes that many families “don’t have cars or don’t drive for certain reasons and that prohibits them from coming to treatment even if they want treatment so it’s a little bit harder for them to comply with the regimens that their children need.” It is important to understand the difference between poor compliance by choice as opposed to lack of resources.

Clinics can support these families by being flexible with scheduling as “they have to find rides and maybe …[can] come on certain days because of that ride” Megan (Outpatient) explains. Noncompliant families can also overutilize clinic resources and time as Grant (Inpatient/Outpatient) describes instances:

> Nurses have to call the pharmacy, make sure the prescriptions were picked up, go over the number of pills with the pharmacist, what was dispensed, and what the family brought in to …try and add up” further describing their “bigger fear was that the mom would run and then the child wouldn't get back into health care for leukemia. Her cure rate was so good.

Therefore, not only can lack of access to resources complicate adherence to treatments and appointments, it can also be the cause of a detrimental prognosis and strain on clinic assets.

Age of patient. Pediatric patient age ranges from 0-18, this wide range involves stark contrasts and transitions physically, emotionally, and mentally. Several subjects describe that school aged children and younger rebound more quickly from treatments such as blood draws or medication dosing. “They get stuck with the needle, they don’t like it, they cry, it’s over ,and they just want to go play” Jennifer (Inpatient/Outpatient) describes. However, at an age when they do not understand it can be difficult to have them buy in and equally difficult to give them medication so frequently. Kelley (Inpatient) recounts an example of a “three-year-old that relapse of leukemia because mom didn't give her medications because the patient refused to take medication.” In contrast, adolescent patients are consistently noncompliant due to several factors including feeling invincible, using refusal of treatment as a means to feel in control, or defiantly because of lack of mature understanding. Caitlin (Outpatient) explains that teenagers “don't want to. They feel like they have to control over it. They fight their parents about it or they tell their parents they took it and they don't.” In describing an example of adolescent coping and compliance, Grant (Inpatient/Outpatient) describes witnessing a patient “pull his IV and storm out to ‘I can't take this anymore’.” The physical, emotional, and mental transformation is challenging enough for the general pediatric population. The added stress of a cancer diagnosis and rigorous treatment regimens can be difficult for younger children to grasp the importance of daily medications and frustrating for adolescence who lose their sense of being in control.

Emotional coping. In addressing the relationship between coping and compliance, Jennifer (Inpatient/Outpatient) explains “compliance is tied to just the coping thing too. Poor coping, they’re just not coping well with it or understanding the severity of it.” Thus, unstable family environment or overwhelming anxiety can cause patients and families to shut down and stop doing their part in treatment. Taylor (Outpatient) describes a particular parent who had “a bit of denial for the diagnosis…. denial that they don't want to believe that their child is really that sick, like if they ignore it than it could go away.” Positive family coping also influenced compliance in the patient as Kelly (Inpatient) explains that “parents kind of pushed them to continue even when they were wanting to stop.” Therefore, having determination and optimism as part of their coping strategies helped drive some families into compliance and trusting in the treatment, while others struggled to invest into the reality of the diagnosis, which translated into poorer medial adherence.

Educational background. In conjunction with the influence of coping on compliance is the relationship between educational background and an adequate health literacy foundation to truly understand the diagnosis and ramifications of compliance. Kasey (Inpatient) reports that “it’s the parents’ understanding of the side effects of poor compliance, like if you don't take your oral chemo the way you're supposed to there's a chance of relapse … they don't realize the long-term effects of what's going to happen.” In supporting this lack of parental understanding of compliance, Sophia (Outpatient) associates poor medical comprehension with being “not as resilient or kind of give up or give in, and things get hard or difficult because it's just easier for them to not be compliant.” Specifically, in the context of achieving remission or a patient appearing clinically improved, Jennifer (Inpatient/Outpatient) states that parents “get to a point where their child is doing better, like a leukemia patient, you know they don’t necessarily see the need for it or they just don’t want to hassle with it.” Families may not understand the significance of complying with medications and treatments and the ramifications of withholding them especially concerning the extreme side effect profile and false sense of security when patients begin responding to treatment.

Individual Coping

Though family resilience does rely on the interplay and mindset of the family unit, each individual member of the family can experience stress and resilience differently. The influence one household member can have on the other can define the experience the family has as a whole. Patients have differing perspectives in undergoing treatment than their caretakers and can differ depending on their age at treatment. How families take on the challenge of a rigorous treatment and the shock of the diagnosis can vary. The change the journey has on the family and its members can ultimately define lasting emotional effects, both resilience and destruction.

Patient anxiety. Participants agreed that overall children take anxiety and stress cues from their parents. Megan (Outpatient) details that patients “mimic their parents…when [parents] have a lot of anxiety, the kids have a lot more anxiety and they act accordingly.” Grant (Inpatient/Outpatient) further supports this coping mirroring by explaining that “it’s very stressful for the kids when the parents can’t get it together.” The cancer treatment process forces children to mature more quickly. Though they can acclimate to the discomfort or emotional stress, they still crave normalcy. This coping method differs depending on patient age and family environment:

> [patients]mature a lot faster than you would another individual that is like the same age, especially our teenagers …kids that are younger even, you just, their sense of normalcy is just completely different than that of a other child their age that would be going to school with them… fitting in with their peers is more of an issue. (Tammy, Inpatient/Outpatient)

For teenagers, many have a difficult time coping as “they obviously have, some of them will have some anxiety and stress about it because they're aware of what's going on in their body and they recognize the seriousness of things" according to Sophia (Outpatient). A patient's anxiety level coincides with their age, innate coping abilities, and influence from parental models. Though some children can adapt well, the need for normalcy and aligning with the milestones of their peers can be an added stressor.

Family dynamic. Families take on new roles within their unit to balance their previous 'normal' with the demands of cancer treatment. Having multiple children at home was more challenging for parents to divide their time. Tammy (Inpatient/Outpatient) describes that parents often divide roles where one is "assigned to the patient so that they can get the patient through it and the other one is managing the family at home" in which the parent with the patient "have more understanding of what's going on and so I feel like knowledge makes them a little bit more resilient. Sometimes the person that's not here just gets anxious more because they don't know what's going on." Coping can vary based on family role and how families overall cope. Emily (Inpatient) describes that families that are "the most fun like you can joke around" create a relaxed atmosphere for the patient and for the clinical staff. She also describes family that are "always positive and have a great outlook on things and took care of their child, like trusted, you know, the treatment plan." Thus, families that trusted, stayed positive, and were able to have fun during this stressful time created a better coping environment for families as a whole, patients themselves, and clinical staff. In contrast, Kelly (Inpatient) describes more needy families who" call you for every little thing like anytime their kid goes to the bathroom anytime they need a drink anything" created a more stressful coping environment. Caitlin (Outpatient) recalls a particular patient who's "family resilience and coping strategies as a whole made this all so much easier for her even though she's had some bumps in the road" supporting the influence of family dynamic on individual coping. Therefore, family dynamic and coping strategies help patient anxiety and resilience.

Adaptive mentality. The process of cancer treatment can be a very transformative process for both patient and family. Kasey (Inpatient) describes the transformation of a "super high maintenance mom, she has managed to now when she comes in, even…if it's like unexpected, she's, you know, happy, upbeat, she's ready for whatever comes. She's not, you know, we're not having a hysterical breakdown." Families who innately have a more adaptive mentality:

> seem so much more resilient because they're so much more flexible and they take things with a grain of salt…they just go with it and cancer treatment hasn't taken a lot out of their life. They've made it a point to not let cancer treatment take a lot out of their family and they still do a lot of the same family things that they used to. This is something they've added to, they found their new normal a lot quicker. And so I feel like those families that are on the more laid back side of the resiliency (Caitlin, Outpatient)

Many family members come out stronger and more able to adapt to new obstacles regardless of treatment outcome. Grant (Inpatient/Outpatient) said "I think they get kinder. I think they've had to. They know life's fragile. I think they become intensely more aware of the plight of other people around. Whether the child lives or dies, the families really are more open and kind might be the better word to use. Yeah, I think I think a lot of our families are better functioning." Further, some families:

> think that they're not strong enough and in the end I think a lot of them are like 'wow I can't believe we did that'… I've heard them say 'we are stronger, I am stronger than I ever thought I could be' because they never had the challenge that they had you know or never been faced with something this devastating and survived it. (Jennifer, Inpatient/Outpatient)

Whether families already possess a flexible outlook or acquire this adaptability over the course of their journey, the challenge of completing cancer therapy can be a positively transformative experience that leave families stronger and kinder.

Destructive change. In contrast to the positive experiences some families have upon completing treatment, others can come out of this process in a worse position. Tammy (Inpatient/Outpatient) describes some families feeling "more vigilant and like hypersensitive to like getting a cold or anything like that they just um hone in on they're afraid, they're fearful of it coming back or something triggering it." In other situations, family coping may be so poor that they turn to drugs and alcohol "which we see occasionally. Of course, that is not good coping, but

I think sometimes that's just what they have to do" according to Debbie (Outpatient). Finally, for many families, the stress of an ill child can drive a division within the family unit and put a strain on relationships and marriages. Kasey (Inpatient) explains "just the stress of being in hospital going through everything just kind of causes a rift that they're constantly at each other's throat and they cannot manage it. They can't kind of pick the pieces back up at the end." Grant (Inpatient/Outpatient) further explains that in cases in which the child does not survive, some parents "deal very differently with the child's death and they just can't reconcile it or maybe they're just the co-memory is too painful and they just have to go off on their own and deal with it." As with any stressor, poor coping can bring destructive change upon those experiencing it. On some occasions, individuals can turn to drugs and alcohol, while others can isolate themselves from others in dealing with difficult circumstances.

CHAPTER V

DISCUSSION

The study found several associations with resilience among pediatric cancer families. These associations comprised of external factors, family dynamics, and individual coping of each member. Many of these associations were confirmed or supported by multiple participants in the study. Collecting testimonials and stories about patient experiences through the years revealed both consistencies and contradictions among themes supporting that every family and every patient experience is unique with overlapping characteristics in their journeys. The main goal of this research was to better understand the outcome discrepancy among pediatric cancer families that were medically similar and socially distinct. In this sample of clinical staff working with pediatric cancer patients and families, it was found that resilience is most affected by social support, family makeup, compliance, and individual coping.

Supporting the definition of resilience taken from Black & Lobo (2008), the data emphasized resilience as positive coping in the midst of adversity that strengthens internal fortitude and draws on affirming social support (Black & Lobo, 2008). It illustrated the complex interplay of internal qualities, willingness to adapt, and acceptance of provided support. The components of this resiliency formula did vary primarily based on age of the patient, perceived social support, and family functionality prior to cancer diagnosis. It was originally assumed that more racial and cultural patterns would emerge, however, the data collected showed more cultural trends in external factors than innate characteristics.

Positive coping

The data suggests that positive coping needs to be evaluated at the patient, parent, and family levels. It was suggested that parental ages on extreme ends of the spectrum do not cope as well as mature parents closer to the median. A study evaluating parents of intensive care children supports that older, more self-directed parents, with less anxiety used coping strategies focused on problem solving rather than on their emotional response. This further explains that problem-focused strategies resulted in more involved care for the child (LaMontagne, Hepworth, Pawlak, & Chiafery, 1992). Age of patient also affect coping skills in that school aged children handled the treatment process better than adolescent patients due to their maturity and understanding levels. The understanding level at grade school age grasps realities of their diagnosis and treatment as metaphors with associating their treatment with the pleasant experiences such as time on a tablet or sticker rewards (Brody & Simmons, 2007). The relationship between parent and child also affected how children coped. Data suggests that children mirror the coping and emotional processing of their parents. Thus, higher anxiety parents translated to more behaviorally challenged patients. This is an established relationship of family environment serving as a significant source of stress for children (Flinn & England, 1995).

It was originally thought that most examples of poorly compliant families were a result of limited access to external resources such as financial status or transportation. In many instances, study participants suggested that poor compliance reflected poor coping among parents. Whether it was due to denial, limited understanding, or hesitancy; studies support that amplification of negative emotion was associated with poorer treatment compliance (Cipher, Fernandez, & Clifford, 2002). Poor coping, for some families, also resulted in overall destructive change such as divorce or drug and alcohol dependence. A study evaluating anxiety levels of parents of pediatric cancer patients even five years after treatment completion, though decreasing with time, still had higher levels of clinical distress compared to parents who did not have pediatric cancer treatment experiences (Wijnberg ‐ Williams, Kamps, Klip, & Hoekstra ‐ Weebers, 2006). Research therefore suggests that poor coping undermines compliance in families and can affect parents and families negatively not just during treatment but years after treatment has concluded.

Strengthening internal fortitude

The influence of positive coping to strengthen internal fortitude describes a resolute mentality that approaches situations with confidence and purpose. Instilling confidence in families to overcome obstacles in treatment heavily emphasizes the importance in establishing trust in clinicians and the process. The foundational relationship between clinician and family was found to be stunted in families with lower educational backgrounds. Another population that research participants described that showed strained or limited relationships with clinicians were families in which English was a second language. Establishing rapport and trust between families and clinicians positively affects family functioning (Shapiro et al., 1998). The significance in building this relationship as well as the factors that can impede its growth has cultural associations as English as a second language and lower educational status has specific racial trends (Bhatia, 2011). With increased difficulty in reinforcing a physician-family relationship, strengthening confidence and knowledge in parental decision making and responses to complications is harder to achieve.

In strengthening internal fortitude for the patient, age stratifications need to be considered. Among all patients, establishing a sense of normalcy was important to establishing self-confidence and overall happiness. An important factor in establishing normalcy was mirroring their peers as well as possible in terms of age-appropriate milestones, values, and interests. This was particularly important in the way they were treated by others in that this treatment was similar to a peer without a cancer diagnosis (Kazak & Nachman, 1991). Specifically for adolescent patients, these patients often felt a loss of control and frustration associated with a cancer diagnosis and treatment, which negatively affected their compliance level (Wicks & Mitchell, 2010). A child's ability to adjust to a diagnosis was also found to link to parental distress level and strength of family cohesiveness (Robinson et al., 2007). Therefore, both the patient and parent's distress levels influenced one another.

The most important source of fortifying internal fortitude was through an innate adaptive mentality. Schieier & Carver (1985) explained that higher optimism and lower self-consciousness in patients paralleled with reports of being less bothered by symptoms (Scheier & Carver, 1985). This adaptive mentality did not necessarily need to be a personality trait within parents prior to treatment, as for some, it was a transformative process. This new mindset can be related to the altered perspective of life's frailty and awareness of suffering of others. It can also be associated with the strength found in overcoming obstacles that were seemingly impossible. There is a sense of pride and empowerment that comes with success in something that was once felt to be too overwhelming. A study performed by Ashcraft et al (2019) describes that consequences of this empowerment include increased parental involvement, symptom improvement, increased child advocacy, and engagement of empowering others. In addition to the overall cancer treatment experience in shaping this empowered mentality, Ashcraft et al (2019) also designate parent-physician relationship, informational support, and experience with community resources as antecedents contributing to this frame of mind (Ashcraft et al., 2019). Thus, the uplifting adaptiveness family hone or acquire during treatment leaves families feeling kinder and stronger.

Affirming social support

In discussing the importance of social support to families and their resilience, nearly all interviews agreed that social support was a key aspect of resilience. In addressing racial patterns of social support, many interviews detailed that generally, white families had an abundance of external support, including social support. Black families overall were more likely to be single parent households with little external support, while Hispanic families were very well supported in their families and communities. The Hispanic population and their robust support system was described as being part of their cultural fabric. This description of social support in the Hispanic population was confirmed by Kaniasty & Norris (2000) in their comfort in seeking help in both emergent and nonemergent situations, which contrasted to the white and black populations in the study (Kaniasty & Norris, 2000). A common example of racial differences in external support for pediatric cancer families from literature review was the vast difference in minority participation in bone marrow registries, which the data from this study did not discuss (Match, 2016). Another facet of social support among different ethnic groups that was also not evident in the data was the sources of social support different groups value or perceive. Though the data discussed the increased likelihood of black families having non-two parent households or less social support, research suggests that the perceived support and value placed in familial support in this population is stronger than when compared to other cultural groups (Sheffler & Sachs-Ericsson, 2016). Thus, though families may have a smaller quantity of individuals in their support system, it does not necessarily translate to less perceived support.

For most families, their relationship with clinicians and staff is an important source of social support. This relationship can be strained when families have more difficulty understanding the diagnosis or when communication is complicated by need for an interpreter. Studies support that families in which English is a second language are less likely to feel physician empathy, receive adequate information , and feel encouraged to participate in medical decision making (Ferguson & Candib, 2002). In addition to providing families with resources to alleviate some of the burdens of treatment, a provider's willingness to assist a family can also affect their level of perceived support and enhance compliance. A study by Ohana & Mash (2015) details that when a patient perceives their provider to be culturally competent, it increases the patient's level of compliance. Therefore, the more understanding and supportive providers seem to patients, the more confident patients will be in trusting the treatment plans.

Black & Lobo's definition of resilience did not merely require the presence of social support, but an individual's active role in affirming it (Black & Lobo, 2008). This important interpretation of the resilience definition was supported in the data collected as interviewees described that though many families possessed a large support system, this did not always translate into accepting the benefits of the support or having a resilient treatment experience. This concept of presence of social support versus utilization of this support system is described by Langford et al.(1997) as an antecedent of social support (Langford, Bowsher, Maloney, & Lillis, 1997). In this paper, what follows these antecedents were termed as social support consequences described by behaviors, perceptions, feelings of stability, self-worth, and psychological well-being.

Overall, the data described social support in relation to support of parents and the family as a whole. Brody and Simmons (2007) emphasizes that support amount and type varies among family members and should be focused on individuals and families as a whole (Brody & Simmons, 2007). The support individual parents or patients specifically needed were not addressed in the data. Additionally, the role that well siblings play in the dynamic of the family's experience and overall stress and coping among each of its members were also not discussed in the interviews apart from siblings being an additional layer of parental stress.

Conclusion

With the dissimilarity between pediatric cancer incidence and mortality trends, there is evidence to suggest that this variation is a consequence of not only biological bias, but the presence of external factors. The interplay of genetic predisposition and social factors contribute to a child's diagnosis, treatment, and overall prognosis. The level of resilience a family experiences through this process relies on a combination of positive coping strategies, internal empowerment, and utilization of social support. Data collected from this project supports this multilayered definition of resilience with prominent themes of social support, family make up, compliance, and individual coping emerging from the interviews. The data also highlighted experience differences among patients in different age groups within the pediatric population, primarily the exceptional journey of adolescent patients. The importance of establishing a sense of normalcy in everyday routine to parallel experiences to that of their healthy peers was significant for all children, especially those among the adolescent age group. The individualized coping strategies, sources of support, and relationship with providers that each individual family member requires to achieve resilience varies depending on the role they play. There was significant racial variation found in ways the physician-family relationships were fostered and ways different cultural groups received and utilized support.

Implications

Implications of this study can inform medical practice in assessing the psychosocial risk factors of a family prior to treatment initiation. Through this thorough evaluation, any family's needs or weaknesses can be addressed prior to complications arising rather than as a response to a problem that could have been prevented. This can improve the role clinicians and support staff can play in providing families with appropriate resources. Understanding the complexity of each family structure can inform physician conversations with parents. A family's background and communication style can make difficult care conversations more fruitful if family and physician goals are recognized prior to treatment. It can also hone in on strengths of the family to optimize their treatment experience. With data and literature to support what is known about resilience and achieving empowerment in a complex medical illness, clinicians can educate families about what individual and familial factors have been shown to enhance this difficult experience and better prepare them for the obstacles involved in this process. Recognizing the wide range and importance of coping among each individual family member as well as their willingness to accept the support that is available can be critical in promoting positive outcomes and outlooks during an arduous, straining, and labile treatment process. These foundational themes of resilience among pediatric cancer families can also be applied to other chronic childhood illnesses in fields outside of oncology, especially palliative care, as these families undergo similar stressors and needs. Often, secondary medical issues associated with cancer treatment can result in chronic debilitation for these children, therefore these resilience principles can persist even after completion of treatment.

Limitations

This study was limited in its small structure at one clinic that may not be representative of all clinic dynamics. The location of this clinic as well as the demographics making up its patient population may not be representative of the general pediatric population. This clinic was also affiliated with a larger cancer treatment network allowing the clinic to send patients to larger facilities for more intensive treatments. The hospital system in which the clinic resides also lacked several collaborating sub specialties and the resources to conduct bone marrow transplants as well as necessary complex surgeries. Thus, not all local pediatric cancer families received treatment at this facility. The items discussed through a qualitative interview approach may have been skewed by social desirability and reflect the subject's wishful perspective rather than unbiased realities. The social desirability played an important role with the sensitive topics discussed including poor patient outcome and evaluation of prejudices or racial patterns. As the data was secondary by gathering participants' perceptions of family dynamics rather than directly observed, retrospective revisions or altered recounting may have occurred. With individual interviews occurring during the workday, increased prompt responses or limited elaboration may have affected the thoroughness of responses.

Recommendations for Future Research

In continuing the investigation of social influence on family resilience, more research is needed to better understand and address the disparity between childhood cancer diagnoses and mortality trends. Some avenues that can better inform medical practice to help bridge the racial gaps in medical outcome include expanding research of social and racial patterns of care into patient and family testimonials. Gathering multiple perspectives and higher numbers of study participants can help collect data that can be more applicable to the general pediatric oncology population. Another path to continue research should be focused on individualized experiences of each family member, primarily among mothers, fathers, patients, and siblings. More specific inquiries should be focused on the adolescent population as their journey and perspective is unique and often more emotionally complex than school aged children. In addressing the psychosocial risk factors of families as well as providing additional support to families, it could be of benefit to evaluate the effectiveness of a dedicated child or family psychologist as part of the multi-disciplinary team to support the emotional burden of this process. Better understanding resilience at its component levels: coping, fortitude, and social support can broaden interpretations of the concept as a whole. Increasing the focus of these understandings to a cultural and racial level is imperative to directing critical change to an imperfect system as made evident with the discrepancy between racial statistics of pediatric cancer incidence and death rates.

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APPENDICES

APPENDIX A

DEMOGRAPHIC QUESTIONNAIRE

This is a study about resiliency factors and cultural variations among pediatric cancer families. In this questionnaire you will be asked personal questions; however, all your answers will remain confidential. To ensure anonymity, please do not write your name anywhere on this questionnaire. Please answer honestly and accurately. Your participation in this study is very important to my research and is greatly appreciated.
Directions: For each question, please circle only one response per question or write in the appropriate answer

1. **What is your current age in years?**

   __________________ years old

2. **How would you identify your race or ethnicity?**

   1 Asian
   2 Black/African American
   3 Latino(a)/Hispanic
   4 Native American/Alaskan Native
   5 Native Hawaiian/Pacific Islander
   6 White/Caucasian
   7 Mixed Race
   8 Other __________________________

3. What is your current marital status?

1 Single

2 Married

3 Domestic Partnership

4 Separated

5 Divorced

6 Widowed

4. Do you have any children?

1 Yes *How many?* _______

2 No

5. What is your highest level of completed education?

1 Less than High School Diploma/GED

2 High School Diploma/GED

3 Some College or Technical Trade Schooling

4 Completion of Undergraduate Degree

5 Graduate Degree (e.g., MA, MS, PhD, MD, DO)

6. Can you give an estimate of your personal annual income (before taxes)?

$___________________________________

7. How many years have you been working with pediatric oncology patients?

__________________ years

8. What is the highest level of completed education of each parent?

Mother

1 Less than High School Diploma/GED

2 High School Diploma/GED

3 Some College or Technical Trade Schooling

4 Completion of Undergraduate Degree

5 Graduate Degree (e.g., MA, MS, PhD, MD, DO)

Father

1 Less than High School Diploma/GED
2 High School Diploma/GED
3 Some College or Technical Trade Schooling
4 Completion of Undergraduate Degree
5 Graduate Degree (e.g., MA, MS, PhD, MD, DO)

End of Questionnaire. Thank you for your time!

APPENDIX B

INTERVIEW GUIDE

Pediatric Clinic Resilience Study

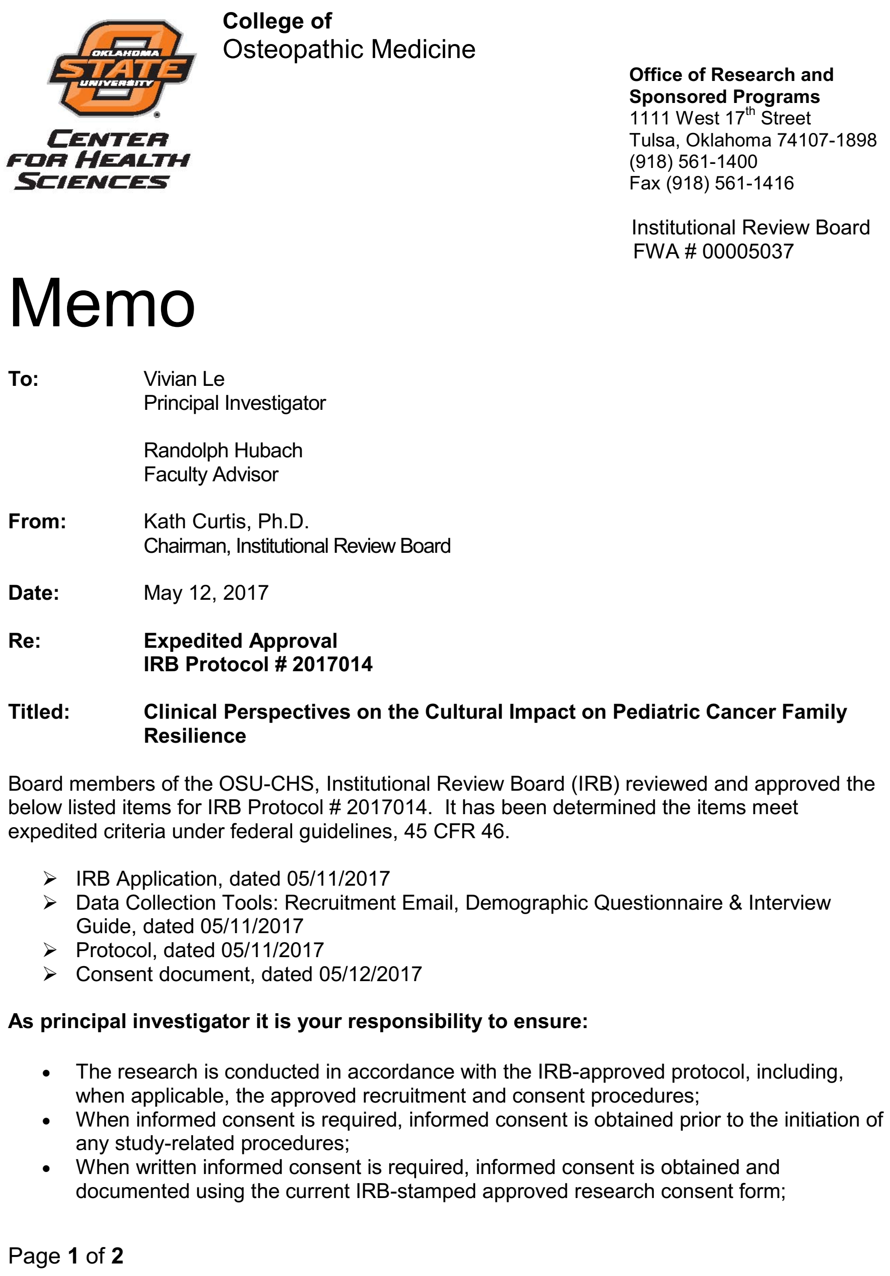
1. What is your job title and job description?
    a. *Probe:* Describe a typical work day
    b. *Probe:* What are your primary responsibilities?
2. From the beginning to the completion of treatment, what is the biggest change you witness in families?
    a. *Probe:* What does the journey and experience of the parent or guardian look like to you?
    b. *Probe:* What does the journey and experience of the patient look like to you?
    c. *Probe:* Describe a case that elicited the most negative change in a family
    d. *Probe:* Describe a case that involved the biggest positive change in a family
3. Please describe, in detail, your most salient experience with a pediatric cancer case
    a. *Probe:* Why is this particular experience significant?
    b. *Probe:* Has this case affected outlook on subsequent pediatric cancer cases?
    c. *Probe:* Has this case influenced the way you view or perform your job?
4. In your opinion, what does a resilient family look like?
    a. *Probe*: Describe the most important resilience factors for the family as a unit
    b. *Probe:* Describe the most important resilience factors for parents/guardians/caretakers
    c. *Probe:* Describe most important resilience factors for patients
    d. *Probe:* Describe the most common resilience factors among families from your clinic
5. In your opinion, what does a family with high psychosocial risk look like?
    a. *Probe*: Which psychosocial risk factors affect overall family resilience most severely?
    b. *Probe:* What psychosocial risk factors most severely affect parent/guardian/caretaker resilience?
    c. *Probe:* What psychosocial risk factors most severely affect patient resilience
    d. *Probe:* Which psychosocial risk factors are most common?
6. Within your job capacity, describe the role you play in promoting family resilience
    a. *Probe:* Describe the role you play in addressing psychosocial risk factors

7. What cultural factors most positively affect family resilience?
    a. *Probe:* Which negatively affect family resilience?
8. What social/environmental factors most positively promote family resilience?
    a. *Probe*: What social/environmental factors negatively restrict family resilience?
9. Describe any trends impacting family resilience and patient care among different racial groups
    a. *Probe:* Describe any biological variability in patient diagnosis and outcome
    b. *Probe:* Describe any emotional variability among patients and families from different racial backgrounds
10. Research studies have shown that racial minority children have worse treatment outcomes compared to their white counterpart. In your opinion, describe possible explanations for this disparity.

End of Interview

APPENDIX C

IRB APPROVAL



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Institutional Review Board
FWA # 00005037

Memo

To: Vivian Le
Principal Investigator

Randolph Hubach
Faculty Advisor

From: Kath Curtis, Ph.D.
Chairman, Institutional Review Board

Date: May 12, 2017

Re: **Expedited Approval**
IRB Protocol # 2017014

Titled: **Clinical Perspectives on the Cultural Impact on Pediatric Cancer Family Resilience**

Board members of the OSU-CHS, Institutional Review Board (IRB) reviewed and approved the below listed items for IRB Protocol # 2017014. It has been determined the items meet expedited criteria under federal guidelines, 45 CFR 46.

- IRB Application, dated 05/11/2017
- Data Collection Tools: Recruitment Email, Demographic Questionnaire & Interview Guide, dated 05/11/2017
- Protocol, dated 05/11/2017
- Consent document, dated 05/12/2017

As principal investigator it is your responsibility to ensure:

- The research is conducted in accordance with the IRB-approved protocol, including, when applicable, the approved recruitment and consent procedures;
- When informed consent is required, informed consent is obtained prior to the initiation of any study-related procedures;
- When written informed consent is required, informed consent is obtained and documented using the current IRB-stamped approved research consent form;

- Changes to the IRB-approved protocol and/or the research consent form are not initiated without prospective IRB approval unless necessary to eliminate apparent immediate hazards to the subject;
- Unanticipated problems involving risks to subjects or others (including adverse events) are reported promptly to the IRB in accordance with IRB policy. When reporting use the **"Reportable New Information Form"** found at www.healthsciences.okstate.edu/research/irb/forms.php.
- Adequate and accurate research records are kept and retained for three (3) years after termination of the study. When applicable, requirements set by the sponsor or FDA should be follow.

A continuing review must be conducted prior to expiration of IRB approval. When the research has been completed or is being closed out prior to completion, a final continuing review report is submitted to the IRB. When reporting use the **"Continuing Review or Study Completion"** form found at www.healthsciences.okstate.edu/research/irb/forms.php.

This study is approved for 12 months. You are free to begin the study once all persons involved with your study have completed CITI training and documentation of that training is received. **An annual review for this Protocol will be due before May 11, 2018.**

If you have questions please contact Amber Hood, IRB Administrator at 918-561-1413 or amber.hood@okstate.edu.

APPENDIX D

TABLES

Table 1

Sociodemographic Characteristics of the Sample (N = 12)

		n	%	M	SD
Age				43.8	13.77
Gender					
	Male	1	8%		
	Female	11	92%		
Race/ethnicity					
	White/Caucasian	11	92%		
	Native American/Alaskan Native	1	8%		
Marital Status					
	Single	3	25%		
	Married	9	75%		
# of Children					
	0	4	33%		
	1	2	17%		
	2	2	17%		
	3	4	33%		
Education					
	Some college or Technical Trade Schooling	2	17%		
	Undergraduate Degree	6	50%		
	Graduate Degree	4	33%		
Income					
	Unreported	2	17%		
	\$40,000-\$55,000	4	33%		
	\$55,001-\$70,000	4	33%		
	more than \$70,000	2	17%		
Years of Experience					
	5 or less years	3	25%		
	5 -15 years	6	50%		
	15-25 years	1	8%		
	25 or more years	2	17%		
Mother's Education					
	High school or GED	4	33%		
	Some College or Technical Trade Schooling	4	33%		
	Undergraduate Degree	4	33%		
Father's Education					

High school or GED	3	25%
Some college or Technical Trade Schooling	4	33%
Undergraduate Degree	2	17%
Graduate Degree	3	25%

Table 2

Emergent Codes and Sub-codes for the Study

Code	Sub-Code
Social Support	Ethnic patterns
	Impacts on family coping
	Role in resilience
Family Composition	Educational background
	Non-two parent households
	English as a second language
	Socioeconomic status
	Age of parent
Compliance	Access to resources
	Age of patient
	Emotional coping
	English as a second language
Individual coping	Patient anxiety
	Family dynamic
	Adaptive mentality
	Destructive change

VITA

Vivian Tran Le

Candidate for the Degree of

Master of Public Health

Thesis: CLINICAL PERSPECTIVES ON THE CULTURAL IMPACT OF FAMILY RESILIENCE AMONG PEDIATRIC CANCER FAMILIES

Major Field: Rural and Underserved Populations

Biographical:

Education:

To complete the requirements for the Doctor of Osteopathic Medicine at Oklahoma State University Center for Health Sciences in May, 2021

Completed the requirements for the Master of Public Health in Rural and Underserved Populations at Oklahoma State University, Stillwater, Oklahoma in May, 2021.

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American Osteopathic Association
Oklahoma Osteopathic Association
American Medical Association
American College of Osteopathic Pediatricians
American Medical Women’s Association
Student Osteopathic Internal Medicine Association