

STRESS AND COPING RELATED TO MEDICAL ILLNESS: IMPLICATIONS FOR  
CHILD DEVELOPMENT

By

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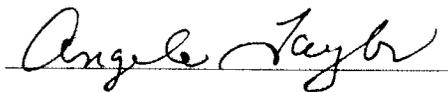
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Approved by:

A handwritten signature in black ink, reading "Angela Taylor", is written over a horizontal line.

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**Abstract**

Child development is a fragile yet intricate process that involves biology, environment, and relationships. When an unexpected illness is included in this process, some degree of stress is inherent. In this project, the implications of stress and the importance of coping during and post medical treatments in children and teens were carefully studied first in a literature review and second in an application. Specifically, the implications of stress due to diagnosis and treatment of cancer in teenagers was evaluated at the time of project application through a panel/support group hosted at University Medical Center in Tucson, Arizona. Last, an analysis and reflection on these two components of my project and a suggestion for further research in the school environment is included.

### **Stress and Coping Related to Medical Illness: Implications for Child Development**

All children encounter experiences that shape them into dynamic, unique adults. No matter what the context, culture or cohort, the common denominator among developing children is the impact that the environment has on the psychological, social, and cognitive traits of the child. The prevalence of serious levels of stress is not considered typical in the literature of child development and alters the course of growth for many children.

Though ecological context and attachment to caregivers are two key factors of development, they merely outline the most common trajectories. The study of development is most frequently centered on what is considered “normal” growth. Exceptions to typical development are sparse in the literature. What about children who experience unusual stressful events? When development is knocked off of its predictable course, the child has experiences that can be difficult to handle simply because parents and professionals are left without examples and tools of how to best help the child.

### **Theoretical Perspectives in Applied Developmental Science**

Applied Developmental Science, a theoretical framework that focuses on relevant, societal issues throughout development, can serve as a basic agenda for studying stress in development. The field of Applied Developmental Science evolved from the need to improve health, general care, education of developing children and the demands to solve practical problems (Lerner, Jacobs & Wertlieb, 2005). The history of this field dates back to the first professor of psychology, G. Stanley Hall, who directed his research from experimental science to the developing child. Hall’s applied principles of society very quickly proved that they were too narrow for the problems that existed in early child development and the growth of Applied Developmental Science began (Lerner et al., 2005).

Today, Applied Developmental Science is applied as a process when looking at prevention and intervention in child development. It is hands-on (applied), takes into account growth and change (developmental), and is based on research so it can be tested (science) (Lerner et al., 2005). These three areas of emphasis characterize Applied Developmental Science as a field that takes experimental and practice-based evidence to design interventions that promote positive development. The interaction between person and environment is valued by researchers in the field and is an important factor in intervention design (Lerner et al., 2005).

Applied Developmental Science has roots in the study of the ecological context of human development by Bronfenbrenner (Lerner et al., 2005). Specifically, Applied Developmental Science recognizes the role of the developing child within multiple levels of organization and includes many different facets as first identified by Bronfenbrenner (as cited in Lerner et al., 2005). Bronfenbrenner emphasizes the interaction between the developing person and the environment as this interaction produces results such as characteristics of the person and perceptions of the environment. The environment in which a child develops has many levels starting with the most intimate setting, which is often the home and sometimes the classroom. For a child with a medical illness, a hospital can be included as an intimate setting in which development takes place. As the hospital is not a typical or anticipated environment for child development to occur, further research and then application of results is important. According to Bronfenbrenner, applied developmental science is essential to understanding the unique needs of each child based on their interaction with their environment (Lerner, et al., 1979).

Family Systems Theory also supports the notion that child development occurs in many systems and subsystems that aim to maintain balance (Bearison, 1998). When a child's medical illness is integrated into the system, the homeostasis is thrown off and the family as a whole must

cope in order to maintain balance (Bearison, 1998). According to Family Systems theory, stress due to medical illness affects relationships within systems such as parental marriage/relationship, siblings, parenting, the family's social support network, and the interactions between various subsystems such as the family and the child's school or hospital (Bearison, 1998). The dynamic of the family system varies by ethnicity, personality types, and other factors, but the key to this theory is the family's necessity to maintain balance, especially in adverse medical illnesses in the child (Bearison, 1998).

Another factor of Applied Developmental Science that is important to keep in mind is that flexibility characterizes maturing children. Applied Developmental Science is valid and useful simply because children are more often easily molded and frequently respond to intervention on the whole (Lerner et al., 2005). Furthermore, these results may suggest that children typically become more flexible and open to intervention as they mature and progress through developmental stages. Therefore, the application of developmental science may be most effective in strategic stages of development and may be more successful as a child grows older (Lerner et al., 2005).

In this paper, I use insights from Applied Developmental Science to first research the implications of stress and coping in child development and second apply it to a case study and analyze the results and feedback directly from the child patients.

### **Stress, Coping, and Medical Illness in Child Development**

#### **Stress, Illness, and Development**

Unusual stressful events can be defined as occasions that are not traditionally outlined in the typical case of development. Some examples include death of a parent, adoption or foster care, and hospitalization. This paper focuses on the unusual, stressful event of hospitalization,

medical treatment, and serious illness of children in certain developmental stages. Childhood stress can alter development, so it is important to understand its functions. In the past, literature on stress focused on the individual. It wasn't until the mid 1980s that researchers recognized that stress in child development involved a much more complex interaction between the child, the family, and the context in light of Family Systems Theory (Haggerty, Sherrod, Garnezy, & Rutter, 2000). Stressors are rarely isolated events and usually part of a more complex environmental influence and vary greatly by child. How the child reacts to the stress brings about a whole other set of trajectories based on factors such as social background, cultural context, developmental age, and current state of mental health (Haggerty et al., 2000).

Children do not typically recognize that they are stressed because they cognitively do not have a concept of stress (Kaneshiro, 2008). Adults are faced with the challenge of recognizing stress in children because it is often internalized and projected as confusion in children less than 12 years of age. Outward symptoms of stress that are more easily recognizable include but are not limited to decreased appetite, new or recurring bedwetting, nightmares, stuttering, sleep disturbances, upset stomach or stomach pain and other physical symptoms without attribution to illness (Kaneshiro, 2008). Other more subjective signals of stress may include inability to relax, aggressive or stubborn behavior, new or recurring fears, clinging, excessive questioning, inability to control emotions, unwillingness to participate in family or school activities that were once enjoyed and regression to the previous developmental stage (Kaneshiro, 2008). Children are rarely isolated in their stress as much of their anxiety is concurrent with parental stress. In the literature of childhood stress, these symptoms and feelings are most linked to negative changes associated with illness and death in the family system (Kaneshiro, 2008). Additionally, some

children are more susceptible to stress as the result of a negative change due to physiological and psychological differences as well as prevalence of other pre-existing risk factors.

It is very important to note that the effects of medical stress on children vary greatly by child, developmental level, and type/severity of illness and treatment. A valuable consideration is the diathesis-stress model, which states that the outcome of the stress will vary based on some biological as well as environmental factors (Hilsman & Garber, 1995). This model is based on a psychological theory that explains behavior as a result of a combination between biological factors and environmental exposure and can be applied to medical related stress such as diagnosis of illness, treatment, hospitalization, and effects of stress on normal development (Hilsman & Garber, 1995). The diathesis-stress model focuses on the uniqueness of the individual, specifically concentrating on personal stress triggers and which coping strategies, if any, the child will employ. This model suggests that pediatric patients may be predisposed to the stress they experience because of a variety of environmental and biological factors (Hilsman & Garber, 1995). The amount of stress and the necessity for competent coping skills has to do with their vulnerability to adverse events in child development based on the diathesis-stress model (Hilsman & Garber, 1995).

As mentioned earlier, this thesis project focuses primarily on the unusual, stressful events connected to medical procedures and serious illness that may or may not include hospitalization in a study of application. Factors that have been recognized to cause trauma, stress and difficulties in children experiencing medical illness at various developmental stages include but are not limited to: chemotherapy, radiation, IV insertion, all surgeries and some side effects of medications (Carpentier, Mullins, Wagner, Wolfe-Christensen, & Chaney, 2007). Research

shows that these highlighted occurrences happen rarely, yet deeply impact the child and context of their development in this way.

As in any life experience, the level of impact and specific ways in which stressful events change the course of development vary by developmental stage and ecological context. Across many different types of stressors, Kaneshiro (2008) predicts that children in later developmental stages (perhaps after age 12) typically fare better when faced with adverse situations such as a medical illness. This may be because they are more likely to have previous success in coping and thus a cognitive-behavioral map of how to handle it (Kaneshiro, 2008). Timing is also an important factor because a child who is able to reasonably cope with a negative change may have their world turned upside down if they are faced with more than one negative change in a short period of time (Kaneshiro, 2008).

Kaneshiro (2008) also references the “ignorance is bliss” concept with younger children experiencing an unusual, stressful event. Despite their lack of experience and coping skills, younger children may fare better in adverse situations according to Kaneshiro (2008) because they do not comprehend the severity or gravity of the stressful situation they are in. For example, a side effect of radiation, a commonly used treatment for pediatric cancer, can cause a child to be infertile later in life. If a child is older, they can comprehend what this means and picture their life being different than what they may have originally thought, which can cause significant stress. A younger child in the same situation may not understand the side effects of the treatments for years and therefore experience an absence of potential stress in this area.

In a study conducted by Carpentier et al. (2007), researchers examined closely the presence of stress in children and the relationship between illness uncertainty and depression symptoms. The main source of stress for children undergoing medical procedures is the

ambiguity of their illness and array of potential results that doctors may communicate. In response to stress, children may often search for an explanation of their illness, and may result with an attribution that is untrue, causing further additional stress in the healing process (Carpentier et al., 2007). Results of this study pointed in the direction of stress having the largest impact on psychological well being when uncertainty about the illness and illness outcome was high (Carpentier et al., 2007). Ambiguity of medical illness, however vital, is still one of the many factors that interact with stress in the case of a hospitalized child.

Carpentier et al. (2007) also found that the manifestations of stress in children coping with medical illness were spiked according to the rarity of the disease. Children and families who perceived isolation in their diagnosis, treatment, and recovery of a more rare medical illness were much more likely to experience symptoms and feelings of depression and hopelessness than families and children experiencing medical illnesses that are much more common, such as diabetes (Carpenter et al., 2007). Preliminary conclusions of this study suggest that isolation in medical illness allows stress to have more long lasting and potentially damaging results among pediatric patients.

The Carpentier et al. (2007) study also showed that it is very beneficial for researchers to consider case studies as instrumental in learning about the implications of these specific stressors. Helping children cope with unusual life events that cause children to carry a lot of stress and anxiety is of vital importance to their development. The application section of this thesis explores a case study designed to collect insights from patients and their families on coping and stress.

### **Coping with Medical Illness**

Coping characterizes how children process their stress and specifically in this paper, stress due to medical illness and treatment. Coping is defined as the management of demands by changing cognitive and behavioral efforts (Bearison, 1998). Like the diathesis-stress model, coping takes into consideration both biological predispositions and environmental factors (Bearison, 1998). A child's ability to cope is based largely on the child's developmental competency in areas such as self-esteem, motivation, and problem-solving skills (Bearison, 1998).

In an article by Bearison (1998), an in-depth look at the coping mechanisms of pediatric cancer patients reveals a child's ability to cope with a medical illness is based on a few factors and perceptions. Bearison (1998) notes that studies on compliance to orders made by doctors and healthcare workers is connected to developing better coping skills in the pediatric patient. This may be because the patient is more supported, in control, and well-adjusted when they complied with medical orders and thus coped better with the illness overall (Bearison, 1998). Additionally, when the patient perceives more control over their treatment, they are more likely to experience higher self-esteem and are more likely to employ healthy coping skills when thinking about their illness (Santacrocce & Lee, 2006). Compliance and control, among other factors, can encourage the child to cope more efficiently and increase the potential for the patient to experience more normal development.

Further study by Bearison (1998) reveals that personality traits in parents, namely how they react to stress produced by medical illness in the child, can determine the presence of coping skills in the pediatric patient. Personality traits in parents that were considered maladaptive were anxiousness, compulsiveness, and aggressiveness, and these traits especially

predicted noncompliance to medical orders (Bearison, 1998). Parental anxiety can also reverse any previously acquired coping skills by the child because it can disorganize the process of stress management in children (Bearison, 1998). In Bearison's study of 720 pediatric patients, the child fared better in the procedure room when their stressed parents were removed, despite initial separation anxiety. However, 99% of these patients said that it helps to ease their stress when a parent can accompany them to a medical procedure or treatment (Bearison, 1998). The key finding in this portion of Bearison's research is that parents are crucial to reducing stress and anxiety in children undergoing medical treatments, however, only when the parents have lower levels of anxiety and employ as well as model healthy coping skills. In summary, parents should be educated on healthy and helpful coping skills for their anxiety as they are a key component in helping the child utilize coping strategies as well. Often, the parents' anxiety and stress stems from lack of knowledge of how to help their child process stress and cope with changes due to medical illness (Bearison, 1998). This suggests that helping the parents help their pediatric patient can result in positive coping outcomes for both the parent and the child.

When a child's ability to cope is compromised by an unusual medical illness, it is important for healthcare and social workers to aid children in acquiring developmentally appropriate ways of coping in addition to the help of the parents (Bearison, 1998). Without a way to cope, children may insist on noncompliance to medical treatment as well as disrupt the family system by deviating from normal development (Bearison, 1998). Those caring for children experiencing medical illness should be equipped to predict future outcomes in the child undergoing medical treatment so that an appropriate intervention can reduce the risk of adjustment problems (Bearison, 1998).

Unusual, stressful events such as medical illness also put the child at risk for adjustment problems by definition since they are altering the predicted state of development. While it has already been established that unresolved stress changes the course of development, exactly how this stress changes the child varies greatly. The Center for Disease Control has published findings that suggest childhood stress actually disrupts brain development as well as compromises the brain and nervous system, further complicating an existing medical illness (Middlebrooks & Audage, 2008). Serious cases of unresolved stress stemming from medical illness or death in the family put the child at a much higher risk for depression, substance abuse and eating disorders in later adolescence and adulthood (Middlebrooks & Audage, 2008). Furthermore, failure to cope with stress in children increases physiological chances for developing other chronic illness such as heart disease and cancer (Middlebrooks & Audage, 2008). Generally, the most common outcome of a highly stressful medical event or illness in children is depression.

### **Pediatric Cancer and Stress**

Since the audience in which the implications of stress in development through applied developmental science later examined is a group of past and current pediatric cancer patients, this next section will highlight some unique details of stress in pediatric cancer patients. There are various types of cancers seen in pediatric cancers, but on the whole, about 1 or 2 in 10,000 children are diagnosed with a form of cancer annually and about 10% of those diagnosed do not survive within two years (Beder, 2006). These facts illustrate that although the disease is rare, the majority survive, thus there is a great deal of knowledge to be gained by social workers, Child Life Specialists, doctors and nurses, and families in order to prevent the psychological damages that stress from this illness can cause (Beder, 2006).

Because pediatric cancer implies six months to a few years of treatment, the effects of stress in this particular illness have the potential to have longer-lasting effects (Santacroce & Lee, 2006). In order to unveil more of the reasoning behind these common long-lasting effects in pediatric cancer patients, Santacroce and Lee (2006) studied a group of 105 former patients who were diagnosed before age 19 and were at least 3 years post-treatment at the time. The study was based on the previously established Uncertainty in Illness Theory, which states that uncertainty can be interpreted as neutral, threat, or opportunity (Mishel, 1990).

In childhood cancer, uncertainty is a theme in survivorship because there is always risk for relapse as well as the risk for late effects of treatments (Mishel, 1990). Having experienced treatments, risk, and pain for many months or years, uncertainty in pediatric cancer patients is almost always perceived as a threat, even once the child is cancer-free (Mishel, 1990). Most cancer survivors will employ protective factors against this kind of threat, such as focusing on the present and increasing positive thinking. However, uncertainty as a threat is often a precursor for depression in pediatric cancer patients and in some more rare cases, post traumatic stress disorder (PTSD) (Mishel, 1990).

Santacroce and Lee (2006) found that nearly 70% of former pediatric cancer patients experience a medical late effect such as depression, PTSD, obesity, and cardiovascular and lung disease. Santacroce & Lee (2006) suggest that the event of diagnosis of cancer in later childhood implies rarity, uncertainty, and seriousness enough to cause PTSD because older children are more aware of the serious side effects of treatment such as infertility despite their higher ability to cope. Because of the unpredictability of later relapses, pediatric cancer survivors report uncertainty and risk frequently as threatening to their quality of life. The implications of stress particularly in pediatric cancer survivors play a large part in bridging the gap between uncertain

predictability and the actual reality of their cancer. Most survivors who participated in this study reported feeling a permanent sense of uncertainty and continued to feel the same or at least similar stress manifestations post treatment as they experienced during treatment (Santacroce & Lee, 2006).

Results from Carpentier et al. (2007) suggest that the main trigger of depression among former pediatric patients is a sense of hopelessness after ambiguity and uncertainty has been explored and unresolved. Given that this disease is still extremely rare in childhood, uncertainty and hopelessness are further exacerbated by the isolation of the pediatric oncology patient while in treatment. A child's inability to cope when faced with medical stress and uncertainty can predict maladjustment such as depression and PTSD (Carpentier et al., 2007).

### **Child Life and Hospital Social Work**

Doctors, nurses, social workers and other hospital personnel can contribute greatly to intervention and prevention of stressors through the application of applied developmental theories. Specifically, the up-and-coming position within children's units and hospitals appropriately titled Certified Child Life Specialists (CCLS) as well as Medical Social Workers, serve the specific developmental needs of children and families undergoing medical treatments. Since children have a unique perspective of trauma, death, illness, natural disasters and violence, they are particularly vulnerable to these unusual events. If a child endures these events without the help of a professional who also understands their simultaneous stage of development, the effects on their overall well being can be long-lasting into adulthood (Child Life Council, 2010). Children need the help of trained professionals who can assist them and their families to overcome the adverse effects of events that challenge normal development.

An overwhelming message of new literature on childhood medical illness, stress, and coping is that children generally need a lot of support in order to maintain positive development. In order for a child to fend off harmful risk factors associated with illness, especially depression, they need to be supported by family members as well as guided by professionals in child development such as Certified Child Life Specialists and Social Workers. Children can learn much about coping with stress from parental models as well (Bearison, 1998). This discovery is fairly recent and hospitals did not employ development and coping specialists for children until about twenty to thirty years ago (Beder, 2006).

The field of Child Life has existed since the 1920s, though it wasn't until the mid 1980s that research and literature recognized the benefits of Child Life in the healthcare settings. Preliminary research on hospitalized children in the early 20<sup>th</sup> century revealed that many infant deaths were due to the inability to tolerate pain in the absence of human contact. These studies were a precursor to the study of toddler and children's capabilities of interpreting the hospital environment when familiar comforts such as home, school, and family are absent (Child Life Council, 2010).

When CCLS began working with hospital personnel to teach them the emotional needs of children as well as providing play therapies, their work was not taken seriously. There was much to learn about the culture of the hospital setting for early CCLS, and further observations of pediatric stress, loneliness and boredom were gathered (Child Life Council, 2010). In 1965, a few pioneers in Child Life met in Boston to collaborate on their successes and challenges and brainstormed ways to promote a more child- and family- friendly hospital environment. This group was later called the *Association for the Care of Children's Health* and was the precursor to the current Child Life Council (CLC). During the 1970s, the number of Child Life programs in

hospitals increased substantially and more requirements for professional practice were established. In 1982, the Child Life Council was established and had its own professional conference. Standards of practice, a certification exam, a code of ethics and other tools such as how to start and maintain a Child Life program within a hospital was then established (Child Life Council, 2010). In 1983, the CLC earned a grant to study the efficacy of a hospital program based on Child Life theory and the practice of reducing stress and anxiety in children as a part of the Phoenix Research Project. The 1990s altered the role of the CCLS with the changing function of the hospital in healthcare. There was an increase in services such as outpatient care, hospice programs, and home care (Child Life Council, 2010).

Today, CCLS are still tied to the traditional hospital setting but also employed in private practice, early intervention programs, dental practices and other nontraditional settings (Child Life Council, 2010). The Child Life Council was developed to collaborate resources and best practice feedback to improve the quality and consistency of the field. The purpose of the Child Life Council is to serve CCLS professionals by infusing them with new ideas to advance the field as well as promoting adaptability in each unique medical case (Child Life Council, 2010). The CLC promotes evidence-based practice and recognizes that decision-making and clinical care should be research based.

The mission of a Certified Child Life Specialist as well as Social Workers in the hospital is to empower children and families as they master challenging life events (Child Life Council, 2010). The philosophy of care is to advocate for children's emotional stability and healthy development by promoting family interaction and involvement with care. CCLS accomplish this through various forms of play therapies, preparation for medical treatments and educational programs. All CCLS have at least a Bachelor's degree in child development and family systems

and must complete at least 100 volunteer hours prior to a 480-hour internship preceding board examination and certification (Child Life Council, 2010).

Typically, Medical Social Workers play more of a role in a patient's discharge plan. In children who have been hospitalized for an extended period of time, such as pediatric cancer patients, the social worker plays a vital role in helping the child assimilate into society and aids in the course of their development outside of the hospital (Beder, 2006). Social Workers often play a key role in the interdisciplinary team of doctors, nurses and specialists, and may be the liaison between the medical world and the family. A Medical Social Worker may arrange other services that can help support the developing patient that are both medical and non-medical, such as therapies and support groups to reduce psychological risk factors such as PTSD and depression (Beder, 2006).

The American Academy of Pediatrics (AAP) strongly recommends the inclusion of Medical Social Work and Child Life services across many different contexts. In fact, the AAP suggests that development professionals in the hospital can help reduce length of stay, cost of hospitalization and use of pain medication in addition to reducing harmful, long-lasting psychosocial effects (Wilson, 2006). Development specialists such as CCLS and Medical Social Workers are essential to the interdisciplinary health care team to develop a plan of family-centered care and should be provided by the healthcare facility as well as advocated on the local, state and federal levels (Wilson, 2006).

### **Application: "Circle of Hope" Panel**

#### **Background and Purpose**

During the second semester of my thesis research, I wanted to apply my research and create something meaningful that would benefit the population I am studying. My philosophy in

applying this literature review was to discover more about this subject in a tangible form as well as potentially allow some patients to benefit from my findings on stress and coping during a unique medical journey. On a more personal note, I have spent the latter half of my undergraduate career interested in the field of CCLS and I am planning on pursuing a Master's of Social Work in Fall 2011 and hopefully beginning a career in Medical Social work following graduate studies.

Since I already volunteer at Diamond Children's Center in the Pediatric Oncology department of University Medical Center, I inquired about the existence of some kind of parent support group for the patients of this department. Given the importance of support in the outcome of the stressful treatment of a medical illness, I was curious to see what was being done for the main source of support for pediatric patients in my own backyard. I spoke with a couple of Child Life Specialists and Social Workers in the pediatric oncology department and determined that there was a need for both parent support groups and a teen support group. The idea for a "survival panel" of both parents and teens was instituted based on a similar event that was successful in years past. We changed the language of this event to "Circle of Hope" to reflect a more positive, encouraging, and supportive environment. Eight weeks later, the Circle of Hope panel took place on a Thursday evening, March 10<sup>th</sup>, 2011, at University Medical Center. Throughout the planning process, I worked closely with Laura Hagerty, LCSW, a social worker on the Pediatric Oncology/Hematology floor at Diamond Children's.

The purpose of this event was to connect young cancer survivors and their families to pediatric cancer patients and their families who have recently begun their journey battling cancer. I wanted to employ applied developmental science by using my literature review on

stress and coping to make a more educated attempt at intervention in families affected by stress due to medical illness in their children.

Much of the literature suggested that a child's resiliency to stress and medical illness had to do with the child's support system and nonmedical healing care such as the family, friends, CCLS, and Medical Social Worker's involvement. As Family Systems Theory suggests, the diagnosis of cancer in a child certainly means that the entire family dynamic has been impacted. Bronfenbrenner's idea of the child developing in many contexts would then include the hospital at the time that the cancer was diagnosed. I was interested to see these concepts in action through a qualitative case study where I could hear testimonies on stress and coping and reflections of hospital experience from the patients themselves.

### **Participants**

After I initially approached Laura Hagerty about hosting an event for the families affected by cancer at UMC, she noted that there were currently an uncanny number of new pediatric cancer diagnoses in the past year. I found this very interesting as it seemed obvious to me that the need for parental support was on the rise. I really wanted to create an atmosphere of understanding that can only come from families who have experienced cancer firsthand while still offering the coping expertise of the Medical Social Workers. I furthermore wanted to raise awareness within this group about the effects of stress as a result of medical illness, and specifically pediatric cancer. Based on research about the Uncertainty in Illness Theory, I was aware that this population had a particularly hard time dealing with uncertainty since few patients actually die from the disease and the treatment is long term (Mishel, 1990). I knew I had taken on a particularly vulnerable group to work with but felt lucky to have access to their insights and to potentially raise awareness of the importance of support nonetheless.

The participants of the Circle of Hope panel included two Medical Social Workers as well as a parent and a teenaged sibling of a pediatric cancer patient who passed away at age six, ten years ago. Additionally, there were two male pediatric cancer participants on the panel, one currently aged 17 who was diagnosed at age 14 and is currently in remission and the other facing his second remission and 7<sup>th</sup> year with cancer at age 22. Remission of cancer means that a patient is currently cancer free but still under close watch by healthcare professionals since the nature of cancer can be recurring. There was also a 15-year-old girl on the panel who recently went into remission from her original diagnosis at age 13. These participants were personally recruited by one of the Medical Social Workers, Laura Hagerty, from both the inpatient and outpatient clinics. Other panel members were also identified and invited to participate, but unfortunately were unable to make it that night due to medical complications.

### **Method**

In the weeks leading up to the event, I met with Laura Hagerty weekly so that we were constantly in communication about our efforts to serve the families of pediatric oncology at Diamond Children's at UMC. Initially, I outlined a vision and purpose for this event as well as created a flyer for the event and found volunteers to host a craft for the siblings. Laura distributed the flyers and personally invited the patients that she knew and allowed us access to a budget for dinner and craft supplies for the siblings. We advertised and offered childcare in a separate room for any siblings that wanted to make crafts for an upcoming holiday. I also wrote discussion questions for the panel.

My role in this endeavor was to facilitate and engage the pediatric cancer patients that were both currently in treatment and had already been through treatment on the panel. It seemed to have worked well to let the experienced cancer survivors provide valuable insight to families

and new diagnoses because of their case examples and firsthand experience. The prompts of the Medical Social Workers and myself helped to organize their thoughts and gave them a platform to begin to share their stories. I really value the perspective of the teenage cancer patients and believe that they add a component that no research paper can offer.

Before the panel began, we shared dinner together and I learned that many of the patients, family, and social workers had already known one another and some shared close relationships. We originally planned on having two separate panels, one for parents of survivors and new diagnoses, and one for teens who were survivors for new diagnoses. However, after we all had dinner together at one large table and due to a lower number of attendees than we had expected, we decided to combine both panels for one group discussion. In the future if there are more attendees, we planned on having the parents and teens separate, though the discussion ended up running smoothly with the entire spectrum at one table. The social workers emphasized that every night in the hospital is different, and the same exact event could have a dramatically different attendance if it were the night before or the night after. There are many factors that contribute to attendance, including how the patients are feeling, their treatment schedules, their immunity and other family factors.

## **Results**

The adolescents were very candid in sharing their stories with those in attendance. I was actually surprised at the amount that they were willing to share in order to benefit others in their same position. I learned a lot from their anecdotal presentations and much of what they said made previous literature I had read make sense and come to life. For instance, I really understood how different each child is and the spectrum of their reactions and response to this particular disease because of their unique family systems and dynamics.

Specifically, the patients shared with me their thoughts and feelings around the time they were diagnosed up until the present, where some are in remission and some are currently battling the disease. A few parents shared specifically on how the disease disrupted their family dynamics and how it changed the way they relate and interact with one another. One mother of a young boy who died of leukemia about ten years ago spoke about how her other children are still having a hard time coping with the loss of their brother. The Smith family (name changed for confidentiality) experienced an imbalance in their family system that was ongoing at the time their young son was diagnosed, experienced treatment, and eventually died of the disease. Though the child no longer lives to experience the aftermath of stress in the absence of adequate coping, some of the family members still experience the effects. One of Mrs. Smith's other sons who is now a teenager, is seeing a counselor for depression and some behavioral problems both at home and in school. The impact that this disease has on the family was very evident in this case and as well as any family affected by cancer in childhood.

Mrs. Smith also told a heartbreaking story of a time when the Make-A-Wish foundation came to her five-year-old son's bedside as he was receiving treatment for cancer and offered him the vacation of his dreams to anywhere he could choose, including Disneyland. When the young boy was asked where he would like to go, he said "in my dad's arms." This is an example of how much a child really relies on the comfort and role of the parents in the midst of uncertainty and stress from medical illness. The child was obviously looking to his father for comfort and this father undoubtedly had the role and responsibility of modeling healthy stress management and coping to his vulnerable son.

I was also pleased to notice the strong bond that some patients had with each other. Two teenage boys in particular, Cody and Jake (names changed for confidentiality), had similar types

of leukemia but at somewhat different times. Cody is four years older than Jake and was diagnosed with Leukemia at age fifteen. After receiving treatment for over a year, he went into remission but still stayed connected to the hospital. Four years later, Jake was diagnosed with cancer, and the Medical Social Workers arranged for the two boys to meet so that Cody could mentor Jake on an unfortunate connection that they shared. Cody asked him “How much do you want to know?” and Jake told him that he wanted to know truths about the disease, even if they were unpleasant or hard to talk about. While Jake was in treatment, Cody continued to spend time around Jake in the hospital and the two became like brothers. They remained friends and eventually, Jake went into remission and was released from the hospital.

Recently, Cody’s cancer has returned, but this time the prognosis is worse and his treatments are much more demanding and intense. Jake, although currently living a normal life cancer-free, spends most of his days in the hospital with Cody. Cody sees his future as rather hopeless and is mad at his friends for not taking the time to be with him while he is confined in the hospital. He blames Tucson tap water for infecting him with cancer and is bitter that he has had it for so long. I noticed a few signs of depression in the short amount of time that I spent with the two young men at the panel, yet Cody continued to speak of how Jake brings him a lot of hope and understanding because he is one of the few people who really knows what he is going through.

The fifteen-year-old girl, Amanda (name changed for confidentiality), spoke of her journey with cancer as an intensely personal and inward suffering. Amanda had a hard time communicating her experience with cancer without being asked direct questions throughout the panel. I assured her that she did not have to share anything or speak about her experiences since she appeared uncomfortable, but she said she wanted her experience to help others. Amanda is a

very unique patient because she was in foster care throughout her treatment and recovery from cancer. Therefore, having a reliable parent to provide not only comfort, but to model stress management and coping was virtually nonexistent and she relied heavily on the Medical Social Workers. She reported remaining painfully embarrassed of her entire cancer experience and tried to keep it a secret at school by wearing a wig and denying anything was wrong if her classmates asked why she was missing school. Though in remission, Amanda still feels uncomfortable talking about cancer in any context, but especially at school and with friends. She feels that despite experiencing cancer firsthand, she lacks knowledge and the ability to explain to others what it is like to have cancer at age thirteen. Furthermore, the uncertainty of current remission is a factor she tries not to think about since she often feels that she has no one to discuss it with outside of the hospital, where she is not currently receiving treatment.

### **Discussion**

Pediatric cancer affects more than just the child; it has an effect on the entire family system. In the case of the Smith family, the diagnosis, treatment, and eventually the death of their young son continues to have a daily affect on the family dynamics and relationships ten years later. It is important for CCLS and Medical Social Workers to realize the impact that childhood cancer has on many levels of relationships because healing involves not only the illness, but of many relationships involved. This panel also highlights how the risk of depression from illness uncertainty and loss of normal life not only has an effect on the child patient, but other family members such as siblings as well.

One of the most predictable risk factors of childhood stress due to illness is the presence of depression. Though current literature on depression cites general hopelessness as a leading factor in depression, Carpentier et al. (2007) cite hopelessness as an effect of being isolated

during treatments, especially of cancer. In my experience with deriving a brief case study from the application of my research, I didn't have to look far to find a testimony of companionship and pediatric cancer such as Jake and Cody. Though Cody does show some signs of depression such as not enjoying the things he used to and general apathy and hopelessness, he was still able to communicate hope through his friendship with Jake and the effort that Jake puts forth to be a quality companion to him throughout his cancer experience in the hospital. This friendship likely acts a buffer against maladjustment such as depression in Cody. Jake also models positive coping despite the most stressful phase of treatment Cody has yet to experience.

Friendships such as Jake and Cody's suggest that there may be benefits to support from other levels of context besides parents and hospital personnel. The opportunity of a peer-to-peer panel or a mentoring program could potentially give patients a chance to decide how they are going to cope based on their peer example in addition to intervention from the social worker or CCLS. Based on findings from Carpentier et al. (2007), children with medical illnesses need a balance of both intervention by development professionals and opportunity for self-exploration and development of unique coping skills in order to fend off negative results of stress such as depression.

In Amanda's case, the uncertainty in her illness and lack of familial support led to an extreme avoidance of her serious and rare illness. The uncertainty in her case threatened her normal functioning and as a result, Amanda's peer relationships shut down due to a feeling that she called "embarrassment." Since this kind of illness uncertainty added to a lack of a secure base translates into a threat for ones overall well being, Amanda is at a very high risk for developing depression and other psychological maladjustments (Mishel, 1990). Though the family subsystem, namely parents, cannot really be replaced by anyone else, Medical Social

Workers may be able to intervene (Bearison, 1998). This heightens the importance of the work of CCLS and Medical Social Workers because of their duty to ensure healing of the entire child, not just of the cancer as in Amanda's case.

Finally, the application of research on stress and coping in hospitalization highlighted the variation among different patients. It is important to remember that the level of stress and stress outcomes vary dramatically by patients. Children may react to the same diagnosis or treatment with a level of stress based on their previous experiences, learned coping skills, perceived social support, age and overall temperament (Kaneshiro, 2008). Social workers and CCLS must be aware of this dynamic in order to be able to provide the best care in reducing stress for the individual patient.

### **Summary and Conclusion**

Overall, I gained a great amount of knowledge about stress and coping in hospitalized children both in literature and hands-on experience. I recognize the importance of applied developmental science in support of existing literature on childhood medical illnesses. I felt it was very beneficial for me to have tangible field examples in order to have a point of comparison for the research I had done and I really feel that my understanding of the stress and coping in hospitalized children was benefitted by this experience. Though I had originally studied literature on the effects of stress and the implications of coping in childhood hospitalization in general, I chose to place emphasis on childhood cancer, as it was the population to which my research was applied with the Circle of Hope panel.

Emphasis should be placed on the difference between each case. The complexities and variations of each pediatric patient and their subsequent family system highlights the necessary flexibility of CCLS and Medical Social Workers when working with the needs of children under

medical stress. I really noticed how the same kind of treatment could elicit a much different reaction because of the many different backgrounds, temperaments, and other risk factors that are unique to each individual.

Throughout my research, a common theme I noticed in applied developmental science literature was the importance of recognizing needs in pediatric patients and their families and taking action against maladjustment in a timely manner. Children and teens experiencing a medical illness such as cancer may also benefit from age appropriate levels of control. A social worker or CCLS who is sensitive to the developmental and psychological capacities of the patient will be able to give the child more room for control, a chance to employ coping skills, and a sense of empowerment of reducing stress on their own (Carpentier et al., 2007).

The most common intervention for stress related to medical illness is giving children a developmentally appropriate amount of information, such as what defines the illness, what it will feel like, and what their life will be like during and after treatment (Bearison, 1998). Unexpected stress is more anxiety provoking and harder to cope with and recover from than stress that is predicted in children and adolescents (Bearison, 1998). Children experiencing medical illness who are given more information about their disease and treatment may be more apt to use healthy coping skills if the stress is expected. Giving children information that they can understand and process cuts down uncertainty and opens the lines of communication between the child and their environment. CCLS and Medical Social Workers are experts on communicating this information with patients and families and are almost essential to the success of a maladjustment intervention (Wilson, 2006).

The connection between knowledge about the illness as well as coping strategies and the actual application of coping skills in a pediatric patient is notable. Bearison (1998) states that

since kids may have knowledge about coping that is based on hypothetical situations, actually applying them can be difficult (1998). While giving pediatric patients knowledge about their illness and offering ways to cope is important, these skills may never be put into action to intervene against maladjustment without further encouragement and support by CCLS, Medical Social Workers, and perhaps most importantly, parents.

Recognizing the parents as holding an important yet irreplaceable role in healing and the return to normalcy in the child experiencing medical illness and stress is key. Bearison (1998) suggests teaching the parents stress management and coping skills in the face of adverse medical trajectories as crucial to helping kids be resilient to medical illness. Since the parents are assumed to be heavily involved in the child's life before diagnosis, during treatment, and after remission, children may be looking to them to model healthy coping skills over an extended period of time. The repercussions of parental distress and lack of coping skills could not only leave the child without a model, but also set back the child in terms of working towards a positive goal of healing both body and mind (Bearison, 1998). Additionally, the existence of support groups and panels such as the "Circle of Hope" panel are a valuable tool for children and families to reduce feelings of isolation as these feelings put the entire family system at a higher risk for general maladjustment and depression (Carpentier et al., 2007).

Nevertheless, the study of psychology in pediatrics is still an emergent field of study (Bearison, 1998). This area of study has evolved since the 1980s when intervention efforts first began to take place in pediatrics. The amount of knowledge in pediatric psychology that has been discovered and applied since then signifies the vast potential for future study of medical illness in child development and evolution of applied developmental science as it relates to the subject (Bearison, 1998). This could be largely attributed to the fact that researchers have made a fairly

recent discovery that children approach stress and employ coping in different ways than adults (Bearison, 1998).

### **Reflection and Suggestions for Further Research**

My goal in writing this thesis was to make a contribution to the field of Child Life in hospitals as well as Medical Social Work and to enlighten healthcare personnel. Especially, I wanted to inform parents on the implications of stress in medical illness for children and the coping strategies and interventions that promote healthy development. I feel that I have accomplished a deep understanding of both the impact of medical stress in child development as well as the fields in which I hope to build a career following my graduation from the Family Studies and Human Development program at the University of Arizona. Throughout this project, I have been able to gain a deeper understanding of theoretical framework such as Family Systems Theory outlined by my undergraduate courses. Through this thesis project, I have also been granted the opportunity to explore more in-depth facets of development than my brief time as an undergraduate provided. I hope I have enlightened those involved in the healing process of a child with a medical illness, specifically in pediatric cancer. I plan on continuing to make connections in the field of Applied Developmental Science between knowledge and real-life scenarios involving unique and complex need in graduate school.

Throughout my research, I have gained an understanding of positions such as Medical Social Workers and Certified Child Life Specialists as necessary to facilitate conversations and connections that buffer against medical stress. Panels and support groups such as the Circle of Hope can be effective tools to promote a healthy understanding of childhood illness and in turn, reduce stress by offering coping strategies during and after treatment and hospitalization. One of the purposes of a resource such as a panel is to reduce ambiguity and uncertainty by hearing

from someone else who has experienced the disease firsthand and survived. These kinds of conversations and companionships could potentially reduce stress dramatically in hospitalized children as Carpentier et al. (2007) note that ambiguity is a main trigger of depression and further psychological problems as the result of the medical illness.

The teens with whom I came into contact with were very thankful that we were able to host the “Circle of Hope” and said that they wished they had more human interaction throughout the day with visitors, social workers and each other. Many of them have even shown interest in helping others through knowledge they learned from their experiences, mainly through mentoring other young patients. All of the teens in the Circle of Hope panel gave great feedback and suggestions to the Medical Social Workers as to how their cancer journey can be improved. Some of the suggestions they gave involved the type of care they received from nurses, so that the social workers could be the liaison between the medical team and the patient.

Other important suggestions that the teens gave involved interactions within schools about cancer when a student is diagnosed. The teens expressed to us that children and teens in school settings could be knowingly and unknowingly cruel towards them because of their obvious medical illness. The social workers were surprised to hear this and said they would do a bit more research on this. The teens on the panel suggested ways that could make school a better environment for them and ways that the social workers should get in the school to promote awareness about the implications of cancer. Specifically, the teens said that a presence of Medical Social Workers in their schools and classrooms could clear up confusion and rumors about the impact of cancer on the life of a teen. Much of the grief that these pediatric cancer patients faced in school were rumors surrounding their illness that were not true. Cody shared with us a rumor that went around that his cancer was caused by something he did and could be

contagious. He said he felt extremely lonely throughout the process because he felt his friends and peers were scared to visit him or even talk to him throughout his treatment as a result of false knowledge they had. Members of the panel all agreed that they would rather have a professional such as a social worker answer the questions of their peers regarding cancer then constantly having to address it themselves while in school. Ultimately, these kids crave normalcy and expect school to be a place where they can experience the once-in-a-lifetime occurrence of being a kid or a teenager.

The impact of a childhood medical illness, specifically cancer, on the school and peer environments would prove to be a great further area of study because friends and peers can play a role in coping by social support as well as affect the process negatively. Overall, the importance of structuring the school environment for positive healing from adverse medical situations in childhood is my main suggestion for further research stemming from this thesis project. Each pediatric cancer survivor and family involved in this project had a vastly different experience with cancer, yet all agree that school is further stress provoking because of their illness. The insights the teens provided in this panel for this thesis project are an invaluable insight into the unique impact of medical illness on the whole spectrum of human development.

In the case of this thesis, applying the science, or applying the knowledge of importance of community to buffer stress, produced a result of highlighting another area of research to be studied and applied as well. These areas of applied science are stepping-stones to helping children better cope with the stressors associated with illness and hospitalization.

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