

Quality of Life for Pediatric Cancer Patients  
and their Families: The Application of Palliative Care  
Principles into Care by Children's Hospitals

By

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Thesis

Submitted to the Faculty of the  
Graduate School of Vanderbilt University  
in partial fulfillment of the requirements

for the degree of

MASTER OF ARTS

in

MEDICINE, HEALTH, & SOCIETY

May 10<sup>th</sup>, 2019

Nashville, Tennessee

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## Table of Contents

Introduction.....	1
Research Methodology.....	4
Presentation of Literature.....	6
Context of Quality of Life Research.....	6
Context of Quality of Life Risk Factors.....	7
Context of Quality of Life Intervention.....	10
Context of Palliative Care.....	12
Access to Palliative Care.....	16
Review of Quality of Life Services by Children’s Hospitals.....	17
Children’s Hospital of Philadelphia.....	17
St. Jude’s Children’s Research Hospital.....	19
Children’s Hospital Los Angeles.....	23
Discussion.....	28
Review of Observations.....	28
Presentation of Thesis Limitations.....	31
Implications for Future Research and Practice.....	32
References.....	34

## Introduction

Cancer is among the most feared diseases in the United States. Cancer is described as a collection of illnesses whereby cells divide uncontrollably disturbing an organ or organ system's overall functioning (National Cancer Institute, 2015). This illness has a strong effect on American children. According to American Cancer Society data (2018), cancer is the second leading cause of death among children under the age of 15—second only to accidents. The American Cancer Society predicted 1,180 children within this age group would die due to cancer's affects by the end of 2018 (American Cancer Society, 2018). As cancer yields great loss for families, it continues to present more families new hardships. The American Cancer Society expects roughly 10,590 new diagnoses of cancer for children under the age of 15 at the end of 2018 (American Cancer Society, 2018). However, the last half-century shows improvements in pediatric cancer treatment. In the mid-1970s, 58% of cancer patients between the ages 0 to 14 years survived at least 5 years (Siegal, Miller, Jemal, 2018). Between 2008–2014, 83.4% of cancer patients between the ages of 0 and 14 years survived at least 5 years (Noone AM, Howlader N, Krapcho M, et al., 2018). These statistics speak to the power of medical science and research funding and highlight achievement solely in the goal of physical survival.

Quality of life (QOL) factors, such as happiness, ability to cope with distress, and feeling of social inclusion, contribute toward a child's overall experience with cancer and cancer treatment. They also heavily influence cancer's narrative existence. Narrative, as discussed by scholars such as Lenore Manderson, is a method by which society constructs topics such as illness. Narratives exist in both conventional and disruptive forms (Manderson, 2016). Regarding cancer generally—but more prominently adult cancer, the conventional narrative follows the logical trajectory of the biomedical diagnosis. It rationalizes the illness as life-threatening

focusing on the ensuing “fight” and the need to conquer cancer. This aspect of cancer’s social construction leads to public emphasis on fundraising and managing the physical pain cancer and cancer treatment inflict.

Disruptive narratives often reject the cultural anesthesia conventional narratives can place on the public. Cultural anesthesia is described as manufactured public ignorance to the true hardships of specific groups in specific situations due to insufficient media portrayal or a lack of accessible knowledge (MacLeish, 2012). When narrating adult cancer patients, disruptive narratives do not place as much emphasis on the illness’s physical hardships. They often focus on cancer’s negative psychosocial and lifestyle effects such as depression, altered daily schedules, and altered social membership. A disruptive narrative regarding breast cancer, for example, likely does not project pretty pink ribbons, bracelets, and t-shirts. It would focus on the daily gauntlet of pills taken on a daily bases or the missed family vacations or social events due to fatigue. As much as these factors of cancer’s existence are not fun or comforting to think about as unaffected members of society, these unsettling aspects are parts of the haunting reality of being a cancer patient.

Comparatively, when constructing conventional narratives surrounding cancer in children, the public frequently focuses on negative psychological and lifestyle aspects. Pediatric cancer’s social construction views affected persons as innocent victims robbed of childhood’s blissful existence. The public response tends to lean towards providing patients comfort and knowledge of their inspirational power. The plethora of toy donation drives, motivational letter writing, and celebrity children’s hospital appearances exemplify this public tendency. Similar tendencies are seen institutionally. For example, in 2017, fueled by the suggestion of a fan through social media, the University of Iowa football program started a new tradition. At the end

of the first quarter of every home football game, players, coaches, and fans wave to the children watching from the windows of the University of Iowa's Stead Family Children's Hospital which overlooks Kinnick Stadium where the Hawkeyes play (Caron, 2018). These simple hand movements can make children in adverse situations, like cancer, feel acknowledged and cared for. This challenge to social isolation directly and indirectly impacts the quality of life for pediatric cancer patients and their families.

The narrative variance between how society discusses pediatric cancer versus adult cancer plays a foundational role in why this thesis focuses on quality of life interventions for children. It is important to investigate whether society's current narrative structure and the subsequent actions are simply means of making the public feel better about their role in battling pediatric cancer or if they concretely benefit patients and families in need. Seeing as the future of America lies in the success of its up-and-coming generation, it is critically important to provide the best possible care for the nation's youth. This care, idealistically, would serve a greater purpose than merely ensuring survival. It would set survival as the foundational goal of pediatric cancer treatment while taking action to create the highest quality of life for patients and families as they overcome cancer's physical challenges.

This thesis looks into the pediatric cancer services provided by some of the nation's most prestigious children's hospitals. The goal is to assess whether or not the services provided by these pediatric cancer facilities align with palliative care principles known to contribute to the quality of life for patients and their families. I begin this thesis by presenting literature that describes the history of non-biomedical, quality of life factors as a research interest. I continue with research discussing past interventions related to quality of life factors. Furthermore, I present the psychosocial risk factor knowledge that stemmed from that research. I conclude my

literature review by outlining the principles of palliative care and recognize it as a credible framework for approaching holistic treatment—in this case, specifically for pediatric cancer patients. Supported by my analysis of the services provided by 3 major American children’s hospitals (Children’s Hospital of Philadelphia, St. Jude’s Children’s Research Hospital, and Children’s Hospital Los Angeles) and their alignment with palliative care principles, I argue for more comprehensive application of palliative care principles in services provided at Children’s Hospitals for pediatric cancer patients. Ideally, this thesis will become a launching point for future research and discussion into how particular services influence the lives of the people they are servicing and which services are needed to fill gaps in quality of life care.

### **Research Methodology**

My research began by sifting through multiple databases for academic literature. Searches were performed through Google Scholar, PubMed, JSTOR, and PsychINFO—due to personal familiarity with these databases—to find peer-reviewed articles and studies. Various phrases were searched on the aforementioned databases to find relevant information. Examples of these phrases include but are not limited to, “Quality of life interventions for pediatric cancer patients”, “Psychosocial interventions for pediatric cancer patients”, “Palliative care for pediatric oncology patients”, “Context of quality of life measurements for pediatric cancer patients”, “Quality of life measurements for pediatric cancer patients”, “Palliative care for children with cancer”, and “Qualitative interventions for pediatric cancer patients”. Analyzing the bibliographies of some sources were used to pinpoint primary source material and expand the range of content reviewed. Relevant content was distinguished by reading abstracts and

methodology sections to ensure literature focused on pediatric cancer (<15 years old) as opposed to adolescent and young adult cancer or adult cancer (>15 years old).

Analyzing institutional treatment services occurred through deep searching of children's hospital websites. The decision to investigate children's hospitals specifically as opposed to major cancer centers was made due to the thesis's focus on the child and services as opposed to the cancer itself. The idea was to isolate an institutional focus on children and their needs and analyze what services are made available to cancer patients with their age in mind. This is in comparison to an institutional focus on cancer whereby there may be a higher probability that services are provided with an emphasis on cancer patients needs generally without the age specific focus. The 3 children's hospitals chosen were picked due to their prestige and location. Prestige was denoted based on rankings by US News and World Report of the best hospitals for pediatric cancer. Their rankings are tabulated based on accumulated data on survival rates, quality and safety of care, as well as patient to staff ratios (Best Hospitals for Pediatric Cancer, n.d.). Knowing that these ranking criteria are subjectively ideal, the hospitals analyzed were not selected from the top to bottom. Selecting the Children's Hospital of Philadelphia, St. Jude's Children's Research Hospital (located in Memphis, Tennessee), and Children's Hospital Los Angeles was done due to their geographical location. These three hospitals primarily serve children in their area of the country—the northeast, south, and west respectively. This decision widened the scope of the thesis so readers for differing locations would be more likely to relate and have interest in the work's findings.

## **Presentation of Literature**

### *Context of Quality of Life Research*

The history of including quality of life related practices into pediatric cancer care stands on the foundational, scholarly research on QOL factors for this patient population. Considering non-biomedical aspects of pediatric cancer care is an enterprise which parallels the advancement of biomedical treatments and the understanding of how children conceptualize life-threatening illness. The psychosocial ramifications of pediatric cancer did not garner much academic interest until the 1960s (Patenaude & Kupst, 2005). The lack of publications can be attributed to the damning nature of the childhood cancer diagnosis at the time and the lack of communication pediatric cancer patients received about their diagnostic details. In the 1960s, the 5-year survival rate of children with cancer was less than 30% (Ries, Harras, Edwards, & Blot, 1996). Henceforth, early consideration of psychosocial implications of children's cancer focused on the family and not the affected person. In the 1960s and early 1970s publications that centered around mourning practices and the larger psychosocial ramifications losing a child at a young age to cancer had on parents were created opening the door for this research interest (Patenaude & Kupst, 2005).

Children were not trusted with specifics of their cancer diagnosis. Adults thought children lacked the emotional maturity to grasp the physical, psychological, and philosophical implications surrounding their illness. This quote from Binger et. al exemplifies this sentiment, "Whereas dying adults can express some of their feelings to their spouses, to mature and respected friends, to the clergy or to doctors, the dying child may have to deal alone with his fears, concerns and apprehensions and also cope with his own inner scheme of fantasies and

‘white lies’ developed by his parents so that meaningful communication between the child and adults is prevented” (1969). When biomedical treatments advanced and more pediatric cancer patients began to survive into adulthood, academics began to directly study and understand the effects of this lack of communication. The latter 1960s and 1970s saw improvement pediatric cancer survival rates which were below 30% in the 1960s. Among the most noteworthy improvements being acute lymphoblastic leukemia, which saw survival rates above 50% in the 1970s (Smith & Ries, 2002). The increase in survivors brought an increase in survivor narratives as well as academics studying current patients through carefully crafted observational studies. For example, a study published in the mid-1970s found that children as young as 6 years old were aware of the gravity of their illness and, furthermore, adult silence and strategic deception led to more internalization of psychosocial suffering (Spinetta, 1974). This newfound research arena continued to produce new knowledge into the 1990s and 2000s.

### *Context of Quality of Life Risk Factors*

Scholars began to pinpoint the disease related, treatment related, personal, and environmental risk factors which affected the psychosocial functioning, and henceforth quality of life, of pediatric cancer patients during and beyond their disease course. In 1998, a study from the University of Cincinnati had the goal to “Evaluate the behavioral reputation and peer acceptance of children diagnosed and treated for brain tumors” (Vannatta, Gartstein, Short, & Noll). Fifteen boys and 13 girls with the average age of 11.2 years who had survived treatment for cancer above the cervical spine were paired with a classmate (COMP) who matched their racial and gender and was as similar as possible in age for comparison. A classroom including the cancer survivors and COMPs were then cast into different behavioral roles in an imaginary play exercise designed to assess social reputation along three dimensions—sociability/leadership,

aggressive/disruptive, and sensitive/isolated (Vannatta et. al, 1998). The children were asked to denote their three best friends in the class and rate all classmates on a 5-point scale (1 meaning “someone you do not like” and 5 meaning “someone you like a lot”). Children and their teachers were also asked to self-report and evaluate respectively sociability/leadership, aggressive/disruptive, and sensitive/isolated (Vannatta et. al, 1998). Results showed that when compared to COMPs, brain tumor survivors received few friendship ratings and were more frequently viewed as sensitive or socially isolated (Vannatta et. al, 1998). This study is an example of work that supported the placement of central nervous system diagnoses as a risk factor for psychosocial difficulties, specifically social acceptance.

There is plenty of research suggesting that specifics surrounding treatment have an effect on the psychosocial outcomes of pediatric cancer patients. For example, a review article written in 2000 by Armstrong and Mulhern supported the claim that radiation treatment to the central nervous system is associated with decreased cognitive functioning and worse academic performance. Chemotherapy also has negative effects as more intense treatment is associated with decreased psychosocial adjustment for pediatric cancer survivors (Zebrack, & Zeltzer, 2002). The duration of the treatment itself and the elapsed time since the completion of the treatment also had psychosocial effects—particularly related to coping as well as personal and familial adjustment. According to a 6-year follow-up study involving 43 families of children with acute leukemia, as time passed, patient and parental coping metrics improved within remission and post death groups (Kupst & Schulman, 1988). According to the work of Koocher & O’Malley (1981), the shorter the duration of the treatment itself, the better the psychosocial adjustment for childhood cancer survivors.

Personal factors, such as perceived stress, have been researched and effects have been seen on long-term psychosocial functioning. A 1994 study measured depressive symptoms, state, trait, and social anxiety, general self-esteem, and perceived social support from classmates, parents, and teachers for 30 newly diagnosed children between the ages of 8 and 13 years. The study showed that better measurements of perceived support from all parties were correlated with less psychological distress and high self-esteem (Varni, Katz, Colegrove, & Dolgin, 1994). Last and Grootenhuis (1998) published a study which assessed the coping strategies of pediatric cancer patients and their parents. Their data showed that children and parents with a lower level of perceived distress had better coping strategies and better psychosocial adjustment outcomes (Last & Grootenhuis, 1998).

Much like treatment specific factors, research suggests that the environment and family unit affect the psychosocial outcomes of pediatric cancer patients. Kupst and Schulman's (1988) 6-year follow-up study addressed the notion that coping improved as time passed for remission groups and groups where the child had died of cancer. The study also showed that open communication between the patient, families, and physicians as well as strong social and familial support was positively correlated with better psychosocial outcomes for both groups (Kupst & Schulman, 1988). Mary Jo Kupst also first authored a study published in 1995 related to familial coping with pediatric leukemia 10 years after treatment (Kupst et. al). Coping and perceived adjustment to their new life was assessed through measures including the Current Adjustment Rating Scale and the Family Coping Scale. The work found that more socioeconomic resources were positively associated with better adjustment outcomes (Kupst et. al, 1995). This further supports the notion that environmental factors affect the psychosocial adjustment of patients and families battling pediatric cancer.

### *Context of Quality of Life Intervention*

With this wealth of knowledge came a shift in practice. For example, open communication between medical staff and pediatric patients as well as between parents and their children became a more frequent occurrence. Studies such as Spinetta's 1974 work *The Dying Child's Awareness of Death* sparked the genesis of what can be looked at as quality of life related interventions. It is around the mid-to-late 1960s and mid-to-late 1970s when patients began to be included in conversations related to informed consent and mental health professionals began to be included more frequently on treatment teams (Patenaude & Kupst, 2005). In the mid-1970s and 1980s, research interests expanded to behavioral studies related to psychosocial responses to diagnosis, treatment, and late effects of cancer in children. Studies, mostly funded by the National Cancer Institute (NCI), continued into the 1990s and 2000s, and often focused on quality of life factors such as cancer's impact on the child's ability to perform academically, bond with family, and feel socially included among peers (Patenaude & Kupst, 2005).

Studies performed in result of the NCI's increase in funding had outcomes which supported the inclusion of quality of life interventions for pediatric cancer patients. In 1988, a study was published which assessed whether a school and social reintegration intervention was beneficial for children with cancer. 49 school-age children (average age being 9.8) with newly diagnosed leukemia, lymphoma, or solid tumor cancer were selected from the Division of Hematology-Oncology at Children's Hospital Los Angeles to be a part of the study (Katz, Rubinstein, Hubert, & Blew, 1988). The children were assessed on a multitude of different psychological measurements before the beginning of the intervention. They were then assessed again at a follow-up which occurred, on average, 8.8 months after the initial screening (Katz et.

al, 1988). The data collected on the group that had the reintegration program was compared to the psychological measurements of a control group made up of 36 children who had been diagnosed within 36 months of the beginning of the intervention. Results showed the group which had the intervention had better outcomes related to school and social adjustment than the control group with no significant group differences in grades or attendance (Katz et. al, 1988). Such results demonstrate that the inclusion of a quality of life intervention had a positive effect on the children.

This study's positive effect was, not only, seen in the data but also felt by the people surrounding the child with cancer. A paper published in 1998 presented self-reported data on how teachers, parents, and the children themselves felt about the benefits of the school reintegration intervention. Some of the specifics of the intervention involved the affected children being given supportive counseling, educational presentations, a liaison between the school and the hospital, as well as periodic follow-ups (Katz et. al, 1988). At the end of the reintegration intervention, teachers, parents, and diagnosed children involved were given questionnaires to rate their overall satisfaction, the importance of particular facets of the intervention, and the perceived classroom impact—among other factors (Katz, Varni, Rubinstein, Blew, & Hubert, 1998). Results showed that all parties involved, on average, felt that the intervention was important and had a positive impact (Katz et. al, 1998). This follow-up publication shows that quality of life interventions can, not only, have positive effects on the patient, but also on the patient's support system and environment.

## *Context of Palliative Care*

The vast amount of knowledge accumulated through research drove the advancement of interventions in the twentieth and twenty-first century. From monitoring and evaluation of innovative intervention came the establishment of frameworks and best practices for addressing the psychosocial challenges and quality of life factors relevant in the lives of pediatric cancer patients and their families. Among the most well-known frameworks in this field is palliative care. According to the World Health Organization (2012), palliative care is designed to actively care for the body, mind, and soul of a child with a life-threatening illness as well as provide support for the family. Beginning when a child is diagnosed and continuing regardless of if the child receives biomedical treatment or not, proper palliative care incorporates a multidisciplinary approach to alleviate physical and psychosocial distress (World Health Organization, 2012). Ideally, palliative care exposes patients and their families to a wide variety of community resources and can be implemented within the hospital setting, in a community health center or other non-hospital health facility, or in the child's home (World Health Organization, 2012).

Looking further into the details of palliative care, its mission and core principles are best implemented when specific factors are taken into account. In a 2013 publication in *Nature*, Elisha Waldman and Joanne Wolfe highlighted a few aspects of palliative care that are critical to effective execution and optimal, positive impact. The first of these ensuring the hospital or health care facility is using a team-based approach. According to Waldman and Wolfe (2013), great palliative care teams include physicians, nurses, psychosocial clinicians, child-life specialists, clergy, and possibly other professionals depending on the context of the patient and family's needs. This context is varied based on factors such as the type of cancer, inpatient versus outpatient status, and socioeconomic background to name a few (Waldman & Wolfe, 2013). For

example, an inpatient child may need the palliative care team to focus on helping the adjustment to life within the hospital and staying connected to friends and family not in the hospital. In contrast, an outpatient child might need more attention placed on adjusting to school as well as the lifestyle and diet changes which accompany a cancer diagnosis.

The fluidity of patient and family needs contributes to the challenges of appropriately executing a team-based approach to palliative care. The goals of a child with cancer are dynamic and can change with the progression of the disease state, differing daily levels of psychosocial factors such as motivation and confidence, and life events surrounding a time of the year such as an upcoming family trip—to only name a few influencers. With such variability comes the need for the palliative care team to adapt their goals and actions to the needs of the patient and family. This task can be challenging for individual clinicians let alone a diverse team of skilled and talented professionals. Proper palliative care teams must be focused on a unified purpose, communicate effectively with their unit as well as with the patient and families, and prepare for inevitable conflict (Waldman & Wolfe, 2013).

The challenge of appropriate communication is one which warrants particular attention. This challenge begins at the first conversation revealing the diagnosis to parents and new patients. Existing evidence states that the majority of parents vividly remember the initial conversation regarding their children's cancer (Parker & Johnston, 2008). In most cases, families have positive experiences with the early discussions of their child's cancer (Parker & Johnston, 2008). With that said, there are still many cases where parents report negative experiences or do not retain necessary information related to their child's diagnosis and the forthcoming treatments—notably in cases where the child's cancer is incurable where close to 50% of parents report not retaining necessary information (Lannen et. al, 2010).

This communication hurdle continues as pediatric cancer runs its course. The natural, parental inclination to protect children from the grave specifics of their disease did not dissipate in the twenty-first century. Despite data stating that many children, especially over the age of 10, are aware of the consequences of their disease and are able to participate in discussion regarding the gravest of possibilities (Hinds et. al, 2005), many parents members do not fully include patients in conversations related to their care and possible death. Many parents regret not discussing the possibility of dying with their children especially in cases where the parents feel an inclination that their child is already aware of the gravity of their situation and the possible consequences of their diagnosis (Kreicbergs, Valdimarsdóttir, Onelöv, Henter, & Steineck, 2004). Diminishing this communication gap between patient and parent would increase the strength of the familial unit as the battle cancer. A stronger connection a child possess with their support system the higher the likelihood for high quality of life through the illness.

The communication obstacle is, not only, present between the patient and parental figures but between the palliative care team and the involved parties. On average physicians are aware of when a child's cancer is incurable three months before the family is notified (Wolfe et. al, 2000). Elimination of that gap would present families with more time to converse with their children about the direst of circumstances. Consistent and transparent communication between medical staff and families is associated with an increase sense of control within the family and a decreased level of parental grief (Surkan et. al, 2006). Communication is best performed in a consistent and transparent manner and, ideally, is performed through the team-based model. This is exemplified by data supporting an association between inclusion of a psychosocial clinician in prognostic and treatment related conversations and increased concordance between physician and parental understanding (Wolfe et. al, 2000).

Such findings also support another core principle of palliative best practices which is establishing the family as central to treatment approaches. Understandably, the effects of pediatric cancer reach past patient and parents to siblings and extended family. Though findings are inconclusive on the exact effects pediatric cancer has on siblings and extended family, they are often important facets of the familial unit at large and, henceforth, should be considered when planning appropriate palliative care approaches (Waldman & Wolfe, 2013). Among the most central focuses of these approaches is symptom and pain management. The pain of treatment and the prevalence of symptoms have engulfed much of the research focus related to management in palliative care—particularly during the end of life transition. Palliative care teams often integrate complementary therapies such as acupuncture, hypnosis, and herbal treatments to remedy certain ailments (Waldman & Wolfe, 2013).

In unison with the physical factors, proper palliative care focuses on quality of life considerations such as the economic and spiritual impact on the family. The financial burden of paying for treatments and lost income due to time away from work can lead to negative psychosocial outcomes for families such as increased stress related to increased debt and constant restructuring of formerly routine family activities (Tsimicalis, Stevens, Ungar, McKeever, & Greenberg, 2011). Many families are unaware of resources offered through healthcare facilities and otherwise to help sooth financial burdens and are not able to recover their expenses (Tsimicalis et. al, 2011). Spirituality is a complex factor to consider in pediatrics due to varying levels of spiritual understanding at differing developmental stages as well as differences between patient and familial perspectives (Waldman & Wolfe, 2013). This complexity calls to mind the importance of having a diverse, family-centered palliative care team. Physicians are not clergy and clergy are not financial exports so, to have the best overall

care and psychosocial outcomes for patients are their families, multidisciplinary palliative care teams must be formulated and made accessible.

### *Access to Palliative Care*

Though palliative care principles are theoretically ideal, the resources and treatments which stem from those principles are not universally accessible. A 2008 study published in the *Journal of Clinical Oncology* (Johnson et. al), surveyed 232 institutions in North America investigating the palliative care and end-of-life resources available to pediatric cancer patients and their families. With an 81% response rate, the study showed that 58% of facilities had a palliative care team. Results also showed that 90% offer pain management services, 60% offer hospice services, 80% had a psychosocial support team, and 59% offer a bereavement program. In conjunction with these programs, complementary and alternative medicines were available in 39% of institutions (Johnson et. al, 2008). The presence of these resources represents the first step to appropriate accessibility.

The question stemming from these presence number is whether or not the available resources are being used and if there are trends within statistics on who is using them. The 232 North American institutions surveyed in Johnson et. al's 2008 study were survey for a calendar year. Within that surveying period, the median number of newly diagnosed patients per institution was 45 and the median number of relapsing patients was 7. Among those cases, palliative care services were used by a median of 3 newly diagnoses families and 0 relapsing families (Johnson et. al, 2008). Along with palliative care's underuse, pain management services, hospice care, and bereavement programs were also shown to have been used by a median number of under five patients in the category of newly diagnosed patients and relapsing patients.

A median of 36 patients and their families took advantage of psychosocial services and 22 used home care services (Johnson et. al, 2008). These numbers, when compared to the usage rate of other services, seem impressive but, when compared to the total median of 52 newly diagnoses and relapsing patients within these surveyed institutions, still show that much work needs to be done to improve the usage rates of these helpful services.

### **Review of Quality of Life Services at Children's Hospitals**

Past research supports the benefit of focusing talent and resources toward improving the quality of life, in all its non-biomedical manifestations, of pediatric cancer patients and their families. Based on past numbers, there is room to improve the availability of quality of life treatment resources in healthcare institutions (Johnson et. al, 2008). To assess the availability of these resources and treatments currently, it is important to investigate the institutions most highly touted and trusted with the care of pediatric cancer patients and their families. Large children's hospitals across the country house and treat pediatric cancer patients and their families and are responsible for making wholistic services available. What is and is not available at children's hospitals with the highest esteem in America will indicate gaps in pediatric cancer treatment related to quality of life interventions.

#### *Children's Hospital of Philadelphia (CHOP)*

The first children's hospital analyzed is the Children's Hospital of Philadelphia, known to many as CHOP. According to U.S. News & World Reports, the Children's Hospital of Philadelphia ranks as one of the best hospitals for pediatric cancer in America (Best Hospitals for Pediatric Cancer, n.d.). As a globally recognized and respected children's hospital, it is natural to

assume that CHOP would have a multitude of available resources for cancer patients and their families. That assumption is supported by the services detailed on the CHOP's website. Though there is not an explicitly stated palliative care team, CHOP offers services which align with many of the ideal palliative care principles. For example, CHOP offers robust management services for acute and chronic pain (Pain Management Program, 2014). Their pain management team begins by having a consultation with each child referred to them in order to tailor an individualized pain management plan. The resulting personalized pain management regimen could include a multitude of different approaches from regional anesthesia, medication, pain-focused cognitive behavioral therapy, physical and or occupational therapy, biofeedback, and other complementary therapies such as acupuncture, massages, or yoga (Pain Management Program, 2014).

The Children's Hospital of Philadelphia also provides ample psychosocial support through their Oncology Psychosocial Services Program. Their Oncology Psychosocial Service Program staff exemplifies the team-based tenet of the palliative care concept. Their team is staffed by psychologists, social workers, child-life specialists, creative arts therapists, chaplains and teachers (Oncology Psychosocial Services Program, 2014). This diverse staff provides financial support services, spiritual guidance, avenues for play and creativity, and mental health services (Oncology Psychosocial Services Program, 2014). The teachers and social work staff aid in outcomes related to quality of life factors such as school performance and transition into new developmental stages in life.

The support services at CHOP also exemplify the family-centered focus idealized by the palliative care model. CHOP family support services are headed by a Family Relations Department that help achieve fluid communication between providers and practitioners and families. The Family Relations Department ensures that families are a part of the conversation in

how their child's care is organized, safeguarding privacy, and getting familial perspectives out through "Family News Articles" (Family Relations, 2014). CHOP continues the family-focused theme through their Family Stress and Illness Program (FSIP). FSIP is comprised of psychologists and psychologists-in-training who provide customized counseling for families as they go through the lifestyle changes associated with having a young family member with cancer (Family Relations, 2014).

On top of the team environment and family centeredness, the Children's Hospital in Philadelphia provides some alternative and complimentary services that are beneficial for patients and families. In conjunction with spaces for play and creative expression, CHOP also has 5 gardens where patients and families can interact with nature when the hospital environment gets overbearing (Gardens at Children's Hospital of Philadelphia, 2017). The hospital also has a Clinical Nutrition Department staffed by nutritionists and dietitians which does consultations with patients and families regardless if they were inpatient or outpatient. They provide healthy food options which are beneficial for physical outcomes but can also have psychosocially benefits for children who may miss certain meals from home or are adjusting to dietary changes caused by their illness (Clinical Nutrition, 2014). CHOP even provides home-care options as an alternative to hospitalization which operates as an extension of their outpatient services and is available 24 hours a day and seven days a week (Children's Hospital Home Care, 2014).

#### *St. Jude's Children's Research Hospital*

The next children's hospital analyzed is St. Jude's Children's Research Hospital based in Memphis, Tennessee. St. Jude's Children's Research Hospital and the St. Jude Miracle Network are highly commercialized and publicly known. This notoriety and location make St. Jude one of

the most influential hospitals for pediatric cancer patients in the southern and southeastern United States. Furthermore, their influence calls to mind the importance that they provided robust and accessible services to patients and their families. The majority of the non-biomedical services offered by St. Jude for pediatric patients and their families are coordinated by the hospital's psychosocial staff. The psychosocial services staff oversee a wide array of services including child life support, music therapy, psychological services, a school education program, spiritual care, and social work services (Psychosocial Services, n.d.). This multiplicity of services exemplifies how the St. Jude's Research Hospital operates in accordance with palliative care principles while emphasizing psychosocial treatments options which have the potential for positive outcomes.

One of the most direct examples of a focus on psychosocial determinants of health is St. Jude's Psychology Clinic. Under the umbrella of the Psychosocial Services name, St. Jude's Psychology Clinic is staffed by 12 psychologist and neuropsychologist all of whom are licensed Ph.D's (Psychology Clinic, n.d.). Their services begin with a consultation to assess the individual needs of the patient and family. Staff members of the Psychology Clinic aid in how patients battle concerns such as anxiety, depression, coping skills, mood, and behavioral issues. In conjunction with those issues, they also help with aspects of the patient experience which laypeople may not think of such as sleeping habits, ability to follow medical procedure plans, pill-swallowing issues, and toileting issues (Psychology Clinic, n.d.). The diversity of services the Psychology Clinic as well as the availability of individual consultation and, furthermore, personalized treatment displays a commitment to family-centered intervention.

The commitment to family-centered aid is further exemplified within the Psychosocial Services staff by the Social Work team St. Jude offers. All members of the Social Work Team

are licensed and have earned a master's degree in social work (Social Work, n.d.). All social workers are available at the hospital Monday through Friday from 8:00 AM to 4:30 PM. There is also one assigned social worker at the hospital during those same hours during the weekends as well as one assigned social worker on-call at all times (Social Work, n.d.). Their Social Work Team does work which combats possible communication issues that could occur between the patient, family and other parties. Social workers at St. Jude help communicate between patients, families, and medical staff. They also coordinate communication and relationships with community resource groups for important need such as financial support (Social Work, n.d.). Services are also offered related to the impact cancer diagnoses have on a child's development and daily activities such counseling on transitioning to life in the hospital as well as from hospital living back to life outside of the hospital (Social Work, n.d.). Providing individualized services designed to ease the environmental effects of a cancer diagnosis is directly impactful to overall quality of life.

Another heavily researched factor in the quality of life of pediatric cancer patient is school adjustment. St Jude Children's Research Hospital combats possible challenges related to academic pace and performance through the School Program operated within the hospital and a part of the Psychosocial Services Department. The St. Jude School Program is staffed by 6 teachers, 2 English as a Second Language coordinators, and 1 school liaison (School Program, n.d.). The classroom space in the hospital is available throughout the day so students can use it as a study area. Each teacher is available at their own set time periods and each student enrolled completes at least 3 hours of instruction per week (School Program, n.d.). Families can also work with the school liaison at St. Jude (or a social worker or similar type of support) to have assignments and lessons faxed, emailed, or mailed from the child's school to the hospital (School

Program, n.d.). This process provides an avenue for patients to not face unnecessary academic hindrances due to their diagnosis. The School Program also gives patients a connection to the world outside of the hospital as they work on similar assignment as friends and peers who are not at St. Jude.

The St. Jude Children's Research Hospital also provides avenues for self-expression which can be therapeutic for patients and their families. Spiritual expression exemplifies such therapies and aligns with the wholistic care model of palliative care presented by the World Health Organization (World Health Organization, 2012). Spiritual Care Services at St. Jude are a referral only service which provides support for spiritually inclined patients through counsel and education of religious perspectives via prayer or interacting with religious doctrine (Spiritual Care Services, n.d.). Their team consults with patient care teams on ways to best understand the significance a religious perspective has on that patient's individual care. Spiritual Care Services also provides liaison between the family and the family's religious community outside of the hospital (Spiritual Care Services, n.d.). This connection between the family and the care team and religious community has the potential to decrease the feelings of isolation which can come with a child's cancer diagnosis.

Children at St. Jude also have the option of expressing themselves through music or play as guided by the Psychosocial Services Department. The hospital staffs 19 nationally certified, full-time Child Specialists (Child Life, n.d.). They help improve the coping and adjustment skills of patients while also providing age appropriate means of play for patients and family members. These services are available to all clinical areas of the hospital (Child Life, n.d.). St. Jude also offers Music Therapy as a means of treatment via self-expression. The hospital staffs two full-time music therapist who are available by referral (Music Therapy, n.d.). Music therapists at St.

Jude run individualized assessments to tailor therapy plans to the patient's needs. This therapy is designed to reduce anxiety and pain perception as well as support development, familial integration in feeling expression and care, self-expression (Music Therapy, n.d.).

From music to academics, the offerings of the Psychosocial Department of St. Jude Children's Research Hospital complement the other unique services available to pediatric cancer patients and their families. St. Jude offers guidance for appropriate nutrition in the hospital setting through a diverse care team of lactation consultants, registered dietitians, and registered nutritionists many with specialties in oncology (Clinical Nutrition, n.d.). The hospital staffs an Ethics Committee designed to help guide families through major medical decisions by facilitating conversation between families and medical treatment teams. Committee members are available for consultation within 72 hours when responding to a common request and within 24 hours in case of emergency (Ethics Committee, n.d.). Such a unique service exemplifies a commitment to quality communication and diverse team building. Grief and bereavement support are available through counselors staffed by St. Jude in the case of a child passing away (Grief and Bereavement Support, n.d.). Such post-mortem shows that St. Jude is dedicated to positively impacting the lives of families regardless of the circumstances or outcomes of the patient's biomedical battle.

### *Children's Hospital Los Angeles*

The third children's hospital analyzed is the Children's Hospital Los Angeles or CHLA. CHLA is one of the most respected and nationally recognized hospitals in the United States (Best Hospitals for Pediatric Cancer, n.d.). Being located in Los Angeles, California, the hospital has large sphere influence as one of the best medical facilities on the West Coast for children who

have cancer. Children's Hospital Los Angeles is unique, not only, due to its prestige and location but due to the fact that they offer services specifically branded as palliative care. The Comfort and Palliative Care Team at CHLA is comprised of physicians, nurse practitioners, support coordinators, psychologists, nurse care managers and support counselors (Comfort and Palliative Care - Holistic Symptom Management, 2019). Their goals are to provide symptom management, relieve distress, collaborate and communicate with the primary medical team to help families through difficult decisions and provide family tailored support, as well as provide end-of-life services and bereavement care for families and hospital staff (Comfort and Palliative Care - Holistic Symptom Management, 2019). CHLA's Comfort and Palliative Care Team's diverse membership and robust services align well to the outlined palliative care framework created by the World Health Organization.

Children's Hospital Los Angeles's palliative care services are not the only means by which the hospital makes quality of life interventions available to pediatric cancer patients and their families. Another significant factor toward that objective is headed by CHLA's Survivorship and Supportive Care Program. This program provides a wide array of clinical services aimed at improving the quality of life of children with cancer and serious blood disorders (Survivorship and Supportive Care Program, 2018). At large, the program is divided into 4 unique services: the LIFE Cancer Survivorship & Transition Service, the HOPE Behavioral Health, Neuropsychology, and Education Service, the Medical Supportive Care Service, and the Adolescent/Young Adult Cancer Service (Survivorship and Supportive Care Program, 2018). The first two services require specific attention as they are supportive services which target aiding non-biomedical life factors for children.

The HOPE Behavioral Health, Neuropsychology and Education Service at CHLA is a subset of the Survivorship and Support Care Program which, within itself, has multiple services geared toward psychosocial and educational support. Mirroring the Survivorship and Support Care Program at larger, HOPE services are staffed by a diverse team of nurses, physicians, and other psychosocial support staff (HOPE Behavioral Health, Neuropsychology and Education Service, 2018). They offer behavioral health support which provides consultation, evaluation, and treatment related to patient psychological health. On a similar vein, neuropsychological health education is also offered through HOPE which helps patients and families understand the neurobiological consequences of their specific cancer diagnosis including consultation on how quality social, emotional, and educational development can be achieved (HOPE Behavioral Health, Neuropsychology and Education Service, 2018).

The education component of the HOPE Program mission is further exemplified by the Health Education and School Support services provided. HOPE's Health Education Service provides classes, support groups, and various educational resources, such as a book library and online resources located in the HOPE Resource Center in the Hematology and Oncology Clinic (HOPE Behavioral Health, Neuropsychology and Education Service, 2018). These health education resources and services directly impact the knowledge of the patient and families which indirectly affects the capacity for appropriate communication and understanding with physicians, nurses, and other biomedical treatment staff. HOPE's School Transition and Re-entry (known as STAR) offers information, consultation, and materials to support patient success in school and advocacy for school-based needs. The STAR team also serves as liaisons between the patient and family and biomedical treatment staff, school professionals, and community resources (HOPE Behavioral Health, Neuropsychology and Education Service, 2018). These vast educational

services can help patients not feel excluded or variant from the lives of their peers aiding in likelihood of quality social integration.

The other sector of the Survivorship and Support Care Program to give particular attention is the LIFE Survivorship and Transition Program. An acronym for Long-term Information, Follow-Up, and Evaluation, CHLA's LIFE Program was started in 1992 and is designed to provide direct clinical care and continuous support to pediatric cancer survivors (LIFE Cancer Survivorship & Transition Service, 2019). Pediatric cancer survivors obtain these services by visiting the LIFE clinic overseen by the hospital. The clinic is staffed physicians, nurse practitioners, medical social workers, and other treatment and research staff all of which have expertise in best practices for supporting cancer survivorship (LIFE Cancer Survivorship & Transition Service, 2019). The program teaches patients and families best ways to monitor their health through checklists and symptomology knowledge. It also discusses signs associated with many adult cancers so patients and families can be aware and prepare if cancer was to return later in life (LIFE Cancer Survivorship & Transition Service, 2019). This unique program demonstrates a drive to provide a consistently high quality of life for pediatric cancer patients and their families who interact with the Children's Hospital Los Angeles.

During inpatient life, CHLA provides many other avenues to achieve better quality of life. A way of moving towards such as goal is by providing spaces for children with cancer to express themselves as the see fit. Children's Hospital Los Angeles provides these spaces through their Art and Music Therapy Program as well as their Child Life Department. The Art and Music Therapy Program, more specifically called the Mark Taper and Johnny Mercer Artists Program, strives to alleviate anxiety and provide psychosocial support through visual art, music, dance, and drama (Mark Taper and Johnny Mercer Artists Program, 2019). CHLA's artistic services

uniquely incorporate local artists, performers, teachers, and registered and certified expressive arts therapists bolstering the experience for patients (Mark Taper and Johnny Mercer Artists Program, 2019). The Child Life Department at CHLA offers spaces for patients and families to play board games and with toys, do crafts, and express themselves in a fun environment staffed by diverse professionals similar to what is offered at other Children's Hospitals (Child Life, 2018).

Artistic and physical expression is viewed as therapeutic by many hospitals alleviating distress much like the pain management services offered. CHLA offers robust pain management services staffed by physicians with pain related specialties, nurse practitioners, counselors, and other specialists such as nutritionists, acupuncturists, and masseuses (Pain Management, 2018). This staff manages pain through various means such as intravenous opioids, region therapies, such as epidurals, spinals, and peripheral nerve blocks, animal assisted therapies, and acupuncture. These services are individualized through two evaluation including a 60-90-minute initial consultation and 20-30-minute follow-up consultations to ensure that interventions are working (Pain Management, 2018). Pain management services are also offered to outpatient children and education is available to patients and their families on pain management strategies which can be applied outside of the hospital (Pain Management, 2018).

Within the palliative care framework, pain management is frequently discussed but CHLA provides more services which some may assume as complimentary but could be argued as critical. Children's Hospital Los Angeles provides Spiritual Care which gives counsel, performs religious rituals, and communicates with the patient's religious community outside of the hospital. Patients and families can also interact with The Thomas and Dorothy Leavey Foundation Interfaith Center which is available around the clock in the hospital as well as holds

various religious services (Spiritual Care and Clinical Pastoral Education, 2018). CHLA provides as Sleep Center which conducts studies and gives consultation and recommendations on ways patients can improve their sleep (Sleep Center, 2018). The hospital even provides Occupational Therapy for patients whose illness drastically affects their ability to perform activities of daily living. Occupational therapists and occupational therapist assistance can help patients adjust to environments which can be difficult to traverse due to their cancer's consequences and stay on typical developmental and social paths (Occupational Therapy, 2018). This wide range of individualized services run by diverse staffing shows that Children's Hospital Los Angeles is providing robust quality of life interventions for their pediatric cancer patients and families through the illness course.

## **Discussion**

### *Review of Observations*

Upon review of services offered by the Children's Hospital of Philadelphia, St. Jude's Children's Research Hospital, and Children's Hospital Los Angeles, it can be said that these major children's hospitals are providing adequate services to improve the quality of life for their patients and their families. Their services are run by educated, qualified professionals and span a wide range of factors which contribute to the overall life experience of childhood cancer patients. These hospitals do a good job of aligning their services and creating their support teams in congruence with palliative care principles. Many of the treatment teams providing the services to patients and families are staffed by physicians, nurses, and specialized support staff which creates a diverse, team-based environment akin to what is preferred by palliative care principles.

Such diversity increases the likelihood that someone on the treatment staff is going to relate to the family and be able to aid in communication between biomedical support staff and the patient and family. All the hospitals had liaison services, whether that be between familial unit and medical staff or with the community outside of the hospital, which is a great sign for bettering communication as palliative care emphasizes. Ideal palliative care is also family-centered which is exemplified by the high number of services which begin by consultation. Having these initial meetings and follow-up sessions allow for treatment individualization from the beginning as well as consistent adjustment to keep treatment focused on the specific needs of the family.

Within all of the services offered, themes can be seen which suggest areas of improvement for quality of life intervention moving forward. When reviewing the totality of services offered by CHOP, St. Jude's, and CHLA, certain services are available more than others. The presence of a Child Life Department and creative arts programs at large, social work services, nutrition, and psychological and or psychosocial services were seen in all 3 hospitals. Being important and helpful services for patients and families, the emphasis on these services is justified. With that being said, services such as grief and bereavement, sleep services, home care, animal therapies, occupational therapies, hospital gardens, and ethical support were only seen in on 1 out of the 3 hospitals. All these services each hold their own important impact and facilities should consider expanding services to include them. Not having uniform offering of services such as grief and bereavement, support for ethical considerations, and therapeutic gardens demonstrates a gap in aiding psychological and spiritual health implications patients and families may face. Psychological and spiritual health are pivotal considerations when creating treatment options fully in alignment with palliative care principles. These services need to be expanded if

Children's Hospitals are going to parallel palliative care best practices are provide optimal care for pediatric cancer patients are families.

One relevant quality of life factor which was not directly considered by any of the hospital was the financial impact of cancer diagnoses. This could be indirectly address through the involvement of social work staff whom are present in all of the analyzed hospitals. Despite that, there should be direct support from the hospital itself to help support economically disadvantaged families navigate the financial burden of their child's cancer. Being a directly stated consideration of ideal palliative care programs, the lack economic support represents the most obvious break between palliative care best practices documented by the World Health Organization and how care is currently provided by prestigious Children's Hospitals. This would be difficult to implement and the institutional logistics of creating something akin to a scholarship program are unknown. With that being said, the presence of an office or clinic dedicated exclusively to financial advice on how to overcome the cancer's economic hurdle could potentially be beneficial. It could be staffed by economists and financial analysts as well as physicians, nurses, and other support staff like social workers. A service such as this has the potential to not only help diminish the financial stress which accompanies the biomedical treatment bill but also would help sooth qualms surrounding the philosophical implications of not being able to afford to provide life-saving treatment to a child. Financial support also diminishes the access issues surrounding biomedical treatment by increasing economic inclusivity. Ensuring treatment, in its multiplicity, creates as minimal a financial stressor as possible would bring care closer to ideal palliative care standards and improve the quality of life for all involved persons.

### *Presentation of Thesis Limitations*

This thesis was limited by a couple noteworthy factors. The first of which being the amount of time available for research. Being a one-year program, the schedule within which topics need to be decided, research needs to be done, proposals need to be submitted, and finalized writing needs to be performed—all on top of classwork—is condensed. Due to such, only 3 children's hospitals were fully analyzed for their services. Having a small number of hospitals to draw conclusions from limits the scope of the comparison and discussion that can occur. With more time, interviews would have been performed which could have augmented the influence and visceral nature of the thesis. Interviews would have provided honest narratives about how services at certain hospitals affect the quality of life for pediatric cancer patients and their families.

The other noteworthy limitation of this work lays in the fact that analysis could only occur through the children's hospital websites. Information was only received through the lens of what the website designers for the hospital were instructed to present. Furthermore, trust needed to be placed in the hospital that they were fully representing the totality of the services they offer on their website. Though most common people would assume that hospitals as prestigious as the Children's Hospital of Philadelphia, St. Jude's Children's Research Hospital, and Children's Hospital Los Angeles would present their services in their entirety, such cannot be 100% confirmed. This is another avenue whereby interviewing patients, family members, and/or medical staff would have been beneficial to this thesis. Their stories could have illuminated services which are not presented or given more detail to the implementation or impact of services not accurately represented on the hospital website.

### *Implications for Future Research and Practice*

The future implications of this thesis are yet to be seen but still warrant their own section of the discussion. If this thesis or its still were to be continue or be performed on the dissertation level, it would be beneficial to see the analysis expand to more than 3 hospitals. The more children's hospitals investigated and assessed the more services can be learned about. More knowledge accumulated on services, their staffed, and their implementation yields more points of comparison and, furthermore, more insight on gaps in care and areas for improvement. Specifically, it would be insightful to analyze the offerings of small children's hospitals to see where gaps in services lie between larger and smaller facilities. Resulting knowledge could be used in fundraising efforts by smaller hospitals as they could see what services are offered by major hospitals and attempt to gather funding to provide those services on a smaller scale. A wider range of hospitals could also yield perspective on possible geographical differences between large children's hospitals in different part of the country. This analysis could give rise to knowledge on the uniqueness and specificity of cancer patient needs specifically when patients stem from different geographic areas. Accumulating a wider data set is a goal which most research ventures could strive for.

Another reason supporting a wider data set comes from the wide array of practical applications a robust sample can provide. Knowing as much as possible about the services offered to improved the quality of life for pediatric cancer patients and their families would lead to better monitoring and evaluation efforts. Improved monitoring and evaluation efforts could increase the likelihood of locating services which are being implemented effectively and ineffectively. Furthermore, understanding which services are note being performed adequately would lead to lobbying for advocacy for improved services through conversations with hospital

administrators and or appeals for funding from outside sources. Ideally, such advocacy would be patient and family driven increasing their agency and impact on their own services through honest, open, and compassionate conversation.

The long-term goal of this thesis, as it currently stands and as it could eventually stand, is for it to have a positive and practical impact. Ideally, this would manifest through expansion and standardization of quality of life care for pediatric cancer patients and their families. The best-case scenario would be a future where every child stricken with this illness, regardless of their socioeconomic or environmental context, would have access to, not only, a 100% chance of physical survival but the best possible quality of life during the illness course and after the illness. As more is known about what services are helpful as well as where those services are missing, society takes a step close to that best-case scenario. Though this thesis is limited in scope, it is a strong starting point for eventual investigation and future implementation. It is a step in a forward direction toward a reality where our narrative conceptualization of cancer exists devoid of despair and hopefulness.

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