The Future of Child Life in Pediatrics and Its Implications for Health Care Professionals

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Abstract

In the pediatric setting, the child life specialist is a unique member of the health care team, specifically trained in addressing the psychosocial needs of young patients. This is accomplished through a variety of techniques aimed at reducing anxiety and creating a sense of normalcy in the patient's life. Currently, the presence of child life programs varies from hospital to hospital, and the amount of participation by other health care professionals, namely physicians, is limited. This thesis explores the history of child life and the current state of the profession through a case study examining two excellent programs within the United States. The final portion of the project addresses current weaknesses and challenges faced in pediatric medicine, offering novel suggestions aimed at improving collaboration between child life and the physician community. Such a partnership could have an invaluable, lasting effect on pediatric medicine and the future style of care provided to children.

Introduction

It wasn't until the second half of the nineteenth century that the medical community recognized the unique needs of pediatric patients in the hospital setting. Just as the existence of human kind occupies only a small fraction of our planet's history, pediatrics is a relatively recent concept within the overall context of medicine. Throughout most of history, children undergoing procedures or routine medical care were treated as adults, with no regard to the psychological dangers, both short- and long-term, that such treatment may have caused. While adults possess the maturity and intelligence to effectively deal with the unpredictable and often invasive aspects of medical treatment, children instead respond to the clinical environment with apprehension, distress, and at times, even combativeness. With the development of pediatrics as a unique field of medicine came the recognition of the varying psychosocial needs of children.

On a daily basis, pediatric health care professionals today face challenges that are virtually nonexistent in all other areas of medicine. Throughout each developmental stage, children interpret, comprehend, and process the world in drastically different ways[1]. As pediatric medicine began to evolve, it was obvious that while the treatment of physical illness and disease is and always will be a primary role, the medical community must also address the psychological needs of children on an individual and age-appropriate basis. With the realization and understanding of such shortcomings within the medical community, the need for a new team member in pediatrics arose, now called the child life specialist. Today, child life specialists play an indispensible role in providing holistic medical care to children, both in and out of the hospital. Acting as an interpreter between the young patient and the entire health care

[1] In the context of medicine, the term 'children' loosely refers to infants, grade-school children, and adolescents (Child Life Council, 2006b)

environment, the modern child life specialist relies on three guiding tenets to address the psychosocial needs of each pediatric patient: the importance of play as a universal and natural aspect of childhood, the provision of preparation for medical procedures, and an increased emphasis on the family support system to improve the overall wellbeing of young patients (American Academy of Pediatrics [AAP], 2000).

The contributions made by child life specialists have transformed today's top children's hospitals into institutions that provide young patients with a calming and minimally disruptive environment, an idea that was unimaginable up until the later part of the twentieth century. Still, however, the concept of child life has room to mature. While many hospitals throughout the United States have excellent child life programs, a disturbing number have yet to include child life as an essential component of the pediatric care. For those hospitals that do have programs, many are understaffed, underfunded, or underdeveloped. One of the largest challenges faced, however, is the lack of recognition and acceptance of child life by the entire health care team.

We will only be able to realize the full benefits that child life offers once a mutual respect and understanding between all health care professionals exists, leading to a fully integrated and seamless treatment process. A constant effort to promote interdisciplinary collaboration and teamwork is required before our pediatric patients can truly receive the best medical care possible. In order to examine the ways in which we can further improve and incorporate child life, we must explore the past, the present, and the future of the profession and the challenges that accompany it. This thesis hopes to accomplish these tasks by examining early psychological research that lead to the evolution of child life services, the foundation of the child life community, and defining aspects of the profession. Additionally, case studies conducted at two different children's hospitals are investigated in order to gain insight into advancements as well

as challenges within the child life community today. Finally, this thesis looks at ways in which child life specialists and physicians can benefit one another through collaboration, ultimately improving pediatric health care in the future.

Part I: History

The roots of the child life profession date back to the early 1900s, when the study of developmental psychology first began to take hold. With the industrial revolution came an overcrowding of cities, accompanied by disease and sickness as a result of inadequate sanitation in urban America (Wojtasik & White, 2009). As illness quickly began to spread, the number of children hospitalized was staggering. In addition to seeing pediatric patients for procedures such as tonsillectomies and hernia repairs, hospitals were now filled with infants and children experiencing a variety of infections as well as diseases such as tuberculosis, hepatitis, and influenza.

Early Studies

The first suggestion for the need to address the emotional needs of hospitalized children came from psychoanalytic studies done on infants. Throughout the early 1900s, a perplexing but extraordinarily obvious observation was made about hospitalized infants: When babies were hospitalized and treated for infection, they experienced a rapid decline in overall physical health; a condition now deemed “failure to thrive.” Infections that would normally last only a few days would fail to respond to treatment in the hospital and last for months (Bakwin, 1942). Even more mysterious, however, was the fact that once the children left the hospital, the deleterious symptoms seemed to vanish.

In 1941, Harry Bakwin, a pediatrician at New York's Bellevue Hospital, published *Loneliness in Infants*, a paper describing this phenomenon. Bakwin writes, "A striking feature is [infants'] failure to gain properly, despite the ingestion of diets which in the home are entirely adequate for growth. Infants in hospitals sleep less than infants who are at home, and they rarely smile or babble spontaneously" (Bakwin, 1942, p. 31). Observing the phenomenon first hand, Dr. Bakwin describes an account of an infant boy who, at 6 weeks, weighed 8 pounds, 14 ounces. At 8 weeks, the child was admitted to Bellevue Hospital for a nasopharyngeal infection and gastrointestinal symptoms. In the hospital, the boy's digestion problems quickly subsided, but the infection persisted. In spite of a clean, aseptic environment, a supplemented diet, and IV therapy, the infant left the hospital 8 weeks later weighing 6 pounds, less than his weight at birth. The child was also described as pale, emaciated, and severely weak. Incredibly, the young boy "gained promply", and "continued to progress steadily" once being taken home by his parents (Bakwin, 1942, p. 34). After leaving the hospital, the infant became unrecognizably healthier, within only a few short weeks. The transformation was astonishing.

Bakwin concluded that the sharp physical and developmental decline so often observed, termed "hospitalism," was the result of strict infection control policies instituted by hospitals of the era (Wojtasik & White, 2009). To abate the spread of infection and disease within hospitals across the United States, infants were placed in small cubicles where they were handled as little as possible by nurses. Parents, who could pose a risk of introducing additional pathogens, were strictly prohibited from visiting their children. In alignment with a number of other pediatricians at the time, Dr. Bakwin attributed hospitalism to the lack of stimulation and affection normally provided by mothers of infants in the home. As such, the pediatrician instituted a policy at Bellevue Hospital that allowed mothers to visit and bond with their children, in addition to

encouraging hospital staff to affectionately handle and interact with the babies in the infant ward. The results contradicted the commonly held beliefs regarding asepsis at the time: The infant mortality rate markedly dropped upon institution of the new policies, in spite of decreased isolation and sterility (Bakwin, 1942).

Throughout the 1940s, psychoanalyst René Spitz built on the work of Harry Bakwin, observing the responses of infants in institutional settings. Filming his observations, Spitz analyzed the behavior of infants in both a foundling home (orphanage) and a prison nursery. In both institutions, the infants were properly fed, bathed, and changed on a daily basis (Palombo, Koch, & Bendicsen, 2009). While the babies in the prison nursery had frequent contact and care from their incarcerated mothers, those in the foundling home were left alone for hours on end with little stimulation, often inside empty cribs covered by sheets (Palombo et al., 2009). The difference in health and behavior between the institutionalized infants was stark, echoing Bakwin's observations. While the babies in the prison nursery were thriving and responding appropriately, the foundling home infants displayed an extreme form of hospitalism, which Spitz also termed anaclitic depression. The children were listless, unsmiling, emaciated, weak, lethargic, and relatively immobile (Wojtasik & White, 2009). Though the infants were institutionalized for non-medical reasons, approximately one third of the foundling home orphans died at the age of 18 months. The remaining infants struggled to ambulate and speak (Palombo, et al., 2009).

Spitz concluded that once again, the lack of normal stimulation and interaction, rather than asepsis, led to the rapid physical and psychological decline of the children. He recognized that psychosocial factors play an especially critical role in the care and treatment of young patients, possibly determining life or death of a child under conditions as extreme as those seen

in the foundling home. Critics conclude that "[Spitz's] solution was the antithesis of the accepted hospital practice of scrupulous asepsis, and this interface of medical and psychological approaches to health and illness fostered the opening of pediatrics to the idea that social and environmental factors, as well as medical management, influence a child's response to treatment" (Wojtasik & White, 2009, p. 6).

The Foundation of Play Programs

While Harry Bakwin, René Spitz, and others were laying the groundwork for future studies exploring the psychosocial needs of the hospitalized child, the first documented play programs were being initiated. A rudimentary play program was reported to have existed at Mott Children's Hospital in Ann Arbor, Michigan as early as 1922. Between 1932 and 1937, a more detailed play program at Children's Memorial Hospital in Chicago was described in a report by Anne Smith, thought to be the program's founder. The program used "play leaders," analogous to today's child life specialists, to address the needs of children admitted to Children's Memorial Hospital in large groups for tonsillectomies (Wojtasik & White, 2009). The panic and resistance of the pediatric patients often created a chaotic, disorganized environment that made surgery more difficult for both the hospital staff and the children. Using simple games, songs, and stories immediately upon admission, and on an ongoing basis throughout the hospital stay, the play leaders were able to calmly and efficiently facilitate each child's transition through surgery (Wojtasik & White, 2009). In addition to helping the children adjust to the hospital environment and minimize sources of anxiety, the early play program also focused its efforts on group play, school programs, and education of play techniques to nurses, students, and volunteers, not unlike today's child life programs (Wojtasik & White, 2009). The most progressive aspect to this early play program, however, was the emphasis placed on the universality of play as a principle means

of communication, comfort, and stimulation for all children. In line with arguments made by pediatricians and psychoanalysts at the time, the program utilized play to prevent the children from regressing both mentally and physically during hospitalization. Moreover, Smith recognized that in addition to the provision of superior medical care, "[the patient's] day should approach the day of a normal child as nearly as possible," in an effort to prevent such developmental delays as those seen by Bakwin and Spitz (Smith, 1937, p. 1). This early form of child life brought the idea of hospital-based play programming to light, setting a new standard for health care in pediatric settings.

By 1950, ten pediatric play programs had been established in children's wards at hospitals throughout the United States and Canada (Rutkowski, 1986). Additionally, the advent of antibiotics eased the strict aseptic protocols enacted in the earlier part of the century. The medical community as a whole finally began to realize that the well-behaved, subdued patient was likely experiencing depression, rather than feeling settled-in and comfortable, contrary to long-held beliefs. Visitations and rooming-in by parents became more widely accepted in most pediatric wards as a result. Along with such practices, the post-World War II era also brought with it a major boom in the areas of psychiatry and humanized medicine.

In 1953, researchers James and Joan Robertson filmed *A Two-Year-Old Goes to the Hospital*, documenting the entire journey of a hospitalized child undergoing a hernia repair. Following more traditional practices, the hospital only allowed brief visitations by the young girl's parents. Throughout the film the child exhibits signs of separation anxiety and fear of abandonment, reminiscent of the distress seen in the faces of the foundling home infants (Wojtasik & White, 2009). The work of James and Joan Robertson indicated that separation from

parents and lack of stimulation produced universal results not only in infants, but among children of all ages.

The reactions of hospitalized children were further examined in a 1953 study by Prugh et al. The colleagues showed that under traditional hospitalization methods, 92 percent of the children hospitalized showed significant psychological disturbances (Prugh, Staub, Sands, Kirschbaum, & Lenihan, 1953). Alternatively, only 68 percent of patients exhibited such adjustment problems when placed in an experimental program that included parental visitation, a play program, psychological preparation for procedures, and integration of family support – aspects universal to all child life programs today (Prugh et al., 1953). Moreover, the researchers observed a similar trend when exploring the long-term consequences of pediatric hospitalization: a substantially higher percentage of children treated under traditional practices exhibited sustained disturbing reactions 3 months after discharge in contrast to those treated under the experimental program. The researchers consequently argued in support for more thorough psychological preparation of children and an effort to educate health care professionals in the psychosocial needs of the hospitalized child.

The Beginning of Child Life

The term "child life" first appeared in *Working with Children in Hospitals*, an account by Emma Plank of the Child Life and Education Department at Cleveland Metropolitan Hospital (1962). Plank presents a variety of novel points in her description of the program. For example, she stresses the need for child care workers to address each patient on an individual and age-appropriate basis, arguing that each child has unique needs, and that these needs need to be continually reassessed throughout hospitalization. She also advocates for honesty and clear

communication between parents, children, and the health care team: Children undergoing painful or threatening procedures should be properly prepared and counseled rather than mislead and deceived. Plank argues for a structured and well-planned day, matching that of a normal child as closely as possible, as well as opportunities for play that allow children to express and work through traumatic experiences. Finally, Emma Plank insists that pediatric health care is incomplete until collaboration and communication exists among all professionals in the hospital environment (Wojtasik & White, 2009) – a major challenge still faced by the child life community today.

In an effort to standardize, promote, and professionalize child life in the context of pediatric medicine, representatives from play and child life programs throughout the United States and Canada founded the Association for the Care of Children's Health (ACCH) in 1965 (Wojtasik & White, 2009). The organization drew members from all areas of pediatric health care – nurses, child life and play workers, physicians, social workers, and psychologists – all with intention of improving the psychosocial support provided to hospitalized children. Ten years after the program's establishment, in 1975, ACCH membership reached 1,200 and the number of child life programs increased to 170 (Association for the Care of Children in Hospitals [ACCH], 1984).

In the years between 1963 and 1983, more than 300 research studies regarding psychosocial aspects of hospitalized surfaced (Gaynard et al., 1998). For example, a 1966 study by Vernon et al. explored the long-term effects of hospitalization in nearly 400 children. It was determined that following discharge, the children experienced "increased separation anxiety, increased sleep anxiety, and increased aggression toward authority" (Vernon, Schulman, & Foley, 1966, p. 593). Furthermore, Douglas was able to show that childhood hospitalization often

lead to adjustment problems extending well into adulthood, including delinquency, poor reading skills, and difficulty maintaining positions in the workforce (1975). The need for child life professionals to address the psychological dangers imposed on hospitalized children was evident.

In 1980, ACCH membership surpassed 4000 as the child life profession became more widely recognized as an essential component in quality pediatric care (Child Life Council [CLC], 2006b). The Child Life Council (CLC) was established in 1982 as a branch of the ACCH, focusing specifically on the child life profession. Since its founding, the CLC has published numerous documents outlining the objectives, standards, culture, philosophy, and official statements of the organization. The Child Life Council also instituted its certifying commission in the mid 1980s, which established and standardized the certification requirements for all child life specialists, in addition to being the issuing body for the certified child life specialist (CCLS) examination (Thompson, 1989). As of 2011, the organization maintained over 4,500 members – mainly child life specialists, students, and educators – and it continues to rapidly grow today (CLC, 2011).

The ACCH Child Life Research Project

The evolution of psychosocial-based care and play programs in the twentieth century, eventually giving way to the child life profession, was rapid and impressive. By the mid-1980s, hospitals that once housed droves of sick children experiencing an unexplained mental and physical decline were now equipping their pediatric departments with child life specialists, playrooms, and weekly programs intended to normalize the hospital stay as much as possible. Countless studies published by developmental psychologists clearly suggested the need to address the emotional needs of the hospitalized child, illustrating, in a number of examples, how

traditional practices had substantially failed. However, a new question within the pediatric community was raised: What *measurable* benefits can a comprehensive child life program provide in the hospital setting? If the child life community was truly going to advocate for the institution of programs in all clinical areas, quantitative data assessing the effectiveness of programming was necessary.

A study sponsored by the ACCH, beginning in 1983, sought to answer this daunting question. Phoenix Children's Hospital was chosen as the implementation site for a new child life program, developed by a team of child life specialists, consultants, and researchers, that was "designed and implemented on the basis of theory and research" (Gaynard et al., 1998, p. 2). The study was the first of its kind to explore the results of an entire child life program, rather than focusing on specific aspects of psychosocial care, such as surgical preparation, as all previous studies had done. According to authors of the manual outlining the ACCH study, "[r]esearch on the functioning of comprehensive programs is essential, as only such an approach acknowledges the reality and complexity of hospital settings" (Gaynard et al., 1998, p. 13).

Formally, the ACCH Child Life Research Project sought to fulfill four major goals: 1) to review the psychological theories of child development and studies relevant to child life practice, 2) to design a child life program around research and theory that was best-suited for the chosen institution, 3) to implement the program, and 4) to systematically and empirically test the program's effectiveness.

The basis of the researchers' theoretical framework for the research project relied on the understanding that children perceive and respond to the environment differently throughout each developmental stage and thus exhibit varying psychosocial needs throughout development

(Gaynard et al., 1998). In the hospital setting, both the physical and emotional wellbeing of the child are often threatened, and the child's appraisal of the threatening situation depends heavily on his or her developmental age. Generally, younger children tend to be less consciously aware and are more likely to interpret unpredictable events as undifferentiated general distress (Gaynard et al., 1998). Additionally, religious, social, and cultural factors may also play a role in determining how the child perceives and interprets a particular situation, underscoring the importance of addressing emotional needs of pediatric patients on an individual basis. Under the model of information processing and stress appraisal (Figure 1), the more a child exhibits emotional distress and perceives an event as a threat, the more likely he or she is to ineffectively process information. This can be problematic during times when physicians or nurses are attempting to rationally walk a child through a difficult procedure, or when a parent must explain to his or her child what to expect before going into surgery. With an inadequate view of reality, children often experience a perceived lack of control, exacerbating the distress felt with each subsequent stressful event. Additionally, low perceived control can ultimately lead to long-term difficulties such as depression, generalized anxiety, and the syndrome termed "learned helplessness" (Seligman, 1975). As such, a traumatic encounter can set precedent for a pattern of ineffective and failed coping strategies throughout one's lifetime.

In the context of this theoretical framework, the primary role of the child life specialist is to facilitate appropriate and effective information processing. This requires a careful evaluation of each individual patient throughout the changing hospital environment. To the young patient, the child life specialist is an interpreter, charged with addressing stressful situations and working to promote more effective coping strategies. The architects of the ACCH Child Life Research Project designed their experimental program around these principles. Through the foundation of

trusting and supportive relationships with patients and families, the use of therapeutic play, the provision of psychological preparation, and an advocacy for a strong family support system, the experimental program at Phoenix Children's Hospital sought to decrease perceived distress and improve information processing and coping techniques using what they described as an ongoing, interactional approach (Gaynard et al., 1998). The hope was that such a program could not only minimize the stresses of hospitalization, but actually make it a "positive, growth-promoting experience" for children (ACCH, 1983; CLC, 1990).

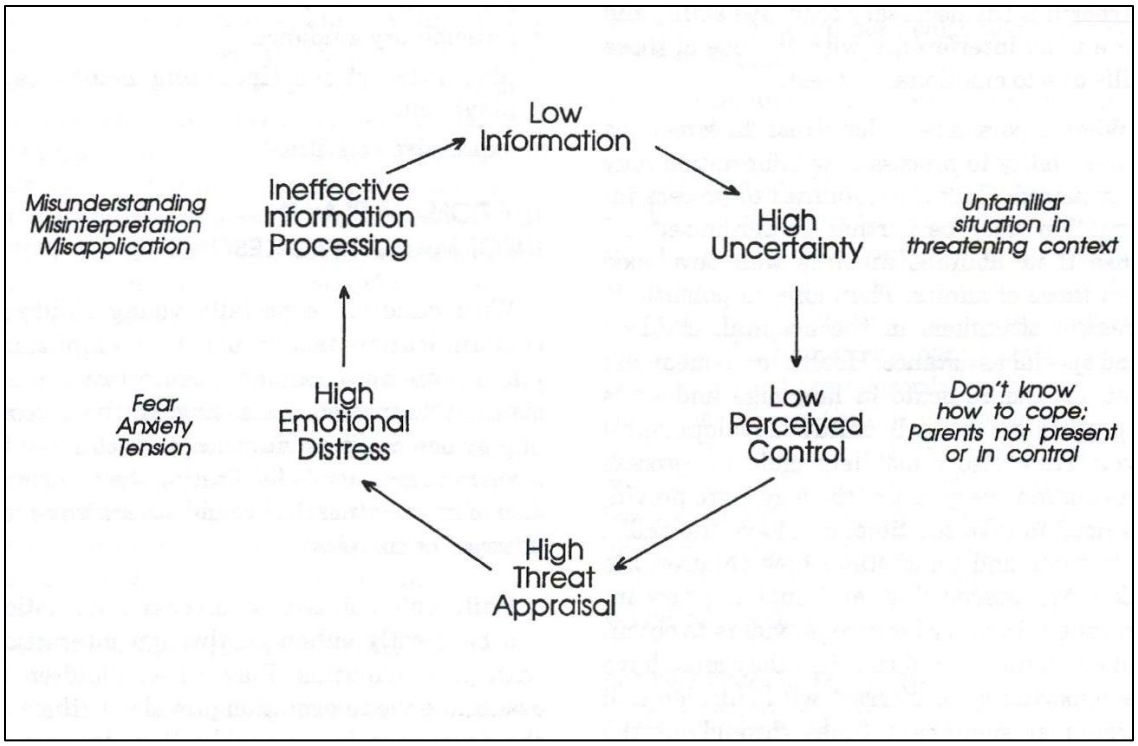

Figure 1. Information Processing and Stress Appraisal Model

(Adapted from Gaynard et al., 1998)

Before the study was to begin, the researchers devoted six months to the implementation of the program at Phoenix Children's Hospital (Wolfer, Gaynard, Goldberger, Laidley, & Thompson, 1988). During this period, hospital staff was educated in the principles of child life

theory. Cooperation was obtained from nursing staff, volunteers, and various other members of the health care team. Children admitted to the hospital were selected for the study if they met the following criteria: 1) they were between the ages of 3 and 13 years old, in order to make the study as comparable as possible to previous research studies, 2) they spoke English, 3) they were hospitalized for acute conditions, or newly diagnosed chronic conditions, 4) they had not been hospitalized within a year prior to admission, 5) hospitalization length was between 3 and 14 days, and 6) they did not experience any invasive procedures prior to admission to the pediatric unit (e.g. in the emergency room) (Wolfer et al., 1988). Patients selected for the study were placed into either the control group (N=160) or the experimental group (N=68), which incorporated the experimental child life program; the only variation between study and non-study subjects was the presence or absence of an independent data collector. On average, each child life specialist was assigned to 12 patients at a given time.

Within a half hour of admission, child life workers met with each new patient and family and gave each child a blank cloth "hospital doll" for medical play purposes. At that point, patients were assessed as low, moderate, or high in vulnerability (Wolfer et al., 1988). Throughout the rest of the admission period, child life continually reevaluated the vulnerability and distress exhibited by the patients on an individual basis, applying research-based techniques to promote coping as much as possible.

Throughout the study, the subjects were scored on 21 different outcome variables. Examples of outcome variables used to measure psychological and emotional elements of the hospitalization included overall coping score, change in heart rate during a procedure, understanding of the hospital environment, adjustment to life after hospitalization, parental anxiety, and parents' perceived participation in care. Examples of outcome variables used to

measure physical wellbeing during surgical recovery included hours to first void, hours to first ambulation, number of analgesics used, days to discharge, and days of initial narcotics used (Wolfer et al., 1988). The results of the study showed that children hospitalized under the experimental program scored significantly higher (better) on 18 of the 21 outcome variables. The ACCH Child Life Research Project, the first study of its kind, proved that a well-organized child life program rooted in psychological theory and research can and will significantly improve the hospital stay experienced by pediatric patients and families. Additionally, it set precedent for the way a child life program should look. While the experimental program at Phoenix Children's Hospital was by no means *the* ideal child life program, its structure and defining elements formed the foundation of nearly all later programs implemented in hospitals throughout the United States and Canada.

Part II: Child Life Today

Today, the presence of child life has grown beyond the confines of the inpatient pediatric ward. While still primarily targeting its services to the hospitalized child, child life specialists now have presence in the emergency room, outpatient clinics, day surgery centers, doctors' offices, and even places such as dental offices, pretrial courtroom areas, and hospice programs (CLC, 2006b). Since the founding of the Child Life Council in the early 1980s and the ACCH research project in 1987, the profession has aligned its philosophy around three clearly defined aspects of psychosocial care: Therapeutic play, psychological preparation, and family support (AAP, 2000). These three underlying principles guide the care provided by today's child life specialists on a daily basis.

Play

According to the authors of the clinical practice manual from the ACCH Child Life Research Project, play is defined as any activity that 1) is pleasurable and enjoyable, 2) involves extrinsic and/or intrinsic objectives, 3) is spontaneous, 4) involves active engagement, and 5) can be looked at as a form of communication (Gaynard et al., 1998). To children, play is universal and essential to human development, and it manages to play an influential role even in cultures where children are expected to be active members in the workforce (Koller, 2008). In the world of the young child, play is the equivalent of work performed by adults (Licht, 2012). Just like the working adult, play provides the child with a sense of motivation, accomplishment, and mastery. Additionally, it is a form of expression that lets children understand, model, and recreate confusing, enjoyable, or stressful aspects of their social surroundings.

In the hospital, play puts pediatric patients at ease, creating a more normal and familiar environment. Offering play opportunities to children communicates a universal respect for childhood by the entire health care team, and similarly, allows children to more readily respect those health care providers (Thompson, 1989). In continuously changing and often threatening surrounds, the concept of play provides pediatric patients with a way to approach stressors and overwhelming information at their own pace (Gaynard et al., 1998). Child life specialists can assess the vulnerability and distress felt by a particular child by observing behaviors during play, and work with the child to address anxieties and confusing topics accordingly. In the context of the stress appraisal and information processing model, child life specialists can use play to assess deficiencies in understanding, improve information processing, and give a child a higher level of perceived control over a threatening situation. Using what is called medical play, child life can focus in more directly on the stress and anxiety elicited by hospitalization. Medical play often

utilizes dolls to vicariously recreate procedures that a patient can work through at his or her own pace. Medical play can also take the form of games and art projects that rely on medical supplies and equipment, allowing patients a chance to become familiar and comfortable with health-related objects in a nonthreatening way (Gaynard et al., 1998) No matter the form, play ultimately decreases the distress and vulnerability often felt during hospitalization, and promotes a more positive form of coping. Often, many children come away from hospitalizations or health care encounters with relatively fond memories when the opportunity for play is readily available (CLC, 2006b).

Psychological Preparation

In adults and children alike, often the most challenging aspect of hospitalization is a fear of the unknown. But unlike the adult, a child's wild imagination and underdeveloped sense of reality can add additional distress to a medical encounter. By way of educating pediatric patients on what to expect throughout a hospitalization, child life specialists rely heavily on preparation techniques to lessen the gap between expectation and reality, and eliminate a significant amount of unnecessary distress. The Child Life Council argues that there are three key elements to effective preparation for medical procedures: 1) the child must be provided with developmentally appropriate information, 2) the patient should be encouraged to express his or her own emotions, and 3) a trusting relation between the child and the health care professional is necessary (Koller, 2007; Vernon et al., 1965; O'Conner-Von, 2000).

As highlighted in the Child Life Council's guidelines for effective psychological preparation, the provision of developmentally appropriate information tailored to each individual patient is paramount to a successful preparation session. For example, while an adolescent

patient may fear mortality or the cosmetic implications imposed by an invasive procedure, a toddler is likely to be most frightened by the thought of separation from his or her parents (Thompson, 1989). On a patient-by-patient basis, the child life specialists of the ACCH research project considered elements such as how to approach the patient, how to explain a procedure in minimally threatening language, the need for repetition and reinforcement, and what materials should be used during preparation (Gaynard et al., 1998). Today, child life specialists must consider these same variables, among others, during the provision of psychological preparation.

Good preparation begins with giving the young patient a clear and accurate description of what he or she is to expect during a procedure. Often, a physician or nurse will consult with the patient and family first. The child life specialist, then, must translate this information to the child in a developmentally-appropriate way. For example, concepts such as anesthesia, blood draws, or the operating room may be ambiguous and unfamiliar to children, and interpreted differently throughout each stage of development (Gaynard et al., 1998). Putting details in the context of a timeframe is also beneficial in easing the anxiety and uneasiness felt by a child prior to a procedure. The use of sensory details is commonly very effective in describing what a child may see or feel, especially when dealing with toddlers. Examples of good sensory details include the smell of an alcohol swab, the pinch felt during an injection or blood draw, or the buzzing sound of a cast cutter (Gaynard et al., 1998). Additionally, child life specialists must remember that not all information is appropriate to share with a young patient, as some details may cause unnecessary confusion or distress. Likewise, the specialist must be mindful of the language used during an interaction with a young patient. For example, describing cancer in the context of "good" vs. "bad" cells may carry a negative connotation, placing unneeded guilt on the child (Greb, 2012).

Child life specialists also utilize a great deal of hand-on preparation techniques. As was the case in the experimental program at Phoenix Children's Hospital, many child life specialists use dolls or puppets to rehearse upcoming procedures at a pace appropriate the particular child. Furthermore, pediatric patients are often encouraged to attend pre-procedural tours and to examine the equipment and tools to be used. Preparation books and kits are also heavily relied upon, which include step-by-step descriptions and images of a variety of procedures likely to be encountered during a hospitalization. Examples of preparation kits include suturing guides, which contain images of the emergency room, sterile dressings, suture, the suture needle, and the needle driver, or pre-surgery guides, which may feature images of the operating table, sterile attire worn by OR staff, the anesthesia machine, the OR lighting, and recovering patients in the playroom (Gaynard, 1998). Commonly, such preparation guides also include nonfunctional demo kits that can be used on patients or dolls during rehearsal.

Finally, successful preparation includes a variety of coping strategies that can be used by patients during procedures as well. When possible, it is best to give children as many choices as possible before and during procedures. Doing so allows the child to play an active role in his or her coping and to feel a sense of control over the threatening situation. Offering choices and autonomy provides a strong foundation for effective coping in future situations (Gaynard, 1998). In addition to offering choices, child life specialists utilize techniques such as guided imagery, progressive relaxation, breathing techniques, distraction, and comfort positioning to lessen distress and create a positive, calming environment.

Family Support

Pediatric medicine is unique in that a child's parents and family members are essentially an extension of her or her identity; in a sense, the entire family unit is treated as the patient. The care provided by child life specialists ends once a pediatric patient leaves the hospital, and it is ultimately the duty of the family unit to continue to address the child's specific emotional needs after discharge. Without such an effort, effective coping strategies are likely to be lost once patients leave the care of medical professionals. Thus, child life specialists are charged with addressing psychosocial needs in the short-term, through their interactions with patients, and in the long-term, by encouraging and developing successful family support systems.

Whereas traditional methods ignored the severity of separation issues, the early work of psychologists such as Spitz and Bakwin underscored the essential role that parental presence plays during a hospitalization. Unfortunately, tension among family members often results from an unexpected hospitalization or illness, disrupting the integrity of the entire family structure (CLC, 2006b) In the same regard, it has been shown that the anxiety felt by parents is often easily transmitted to the child, which can intensify the feelings of distress and the negative effects of a traumatic hospitalization (Heffernan & Azarnoff, 1971; Johnson & Baldwin, 1986, 1969; Wright & Alpern, 1971). Therefore, the child life profession strives to address the concerns of the parents and family members, in addition to those of the patient. Once parental anxiety is addressed, child life specialists work with families to develop strong, long-lasting, and growth-promoting support systems.

During the hospital stay, child life also plays an immensely important role in family centered care by acting as a nonthreatening common mediator. For example, a child life

specialist, having formal training in developmental psychology, may be able to pick up on the anxiety felt by a toddler undergoing chemotherapy that is too subtle for her parents to recognize. Likewise, the professional may also be able to interpret the inconsistent behavior of an adolescent with an eating disorder to a concerned mother. In the same way, parents can be a great resource to staff as well. Parents know their child's demeanor, perceptions, feelings, and responses better than anyone else, and this knowledge is invaluable in precipitating effective communication between patients and health care professionals (Gaynard et al., 1998). By communicating and working with the family, child life ensures that each patient's psychosocial needs are addressed during the hospital stay and beyond.

Part III: Hospital Case Studies

While a careful review of the child life profession, both past and present, is necessary in order to explore ways in which we might further integrate and improve its role in pediatric medicine, an examination of child life in action is also essential. In order to do so, two of the nation's top children's hospitals incorporating child life programming were chosen for site visits in June of 2012: The Children's Hospital of Philadelphia, and Monroe Carell Jr. Children's Hospital at Vanderbilt. Both institutions feature highly innovative and well-established programs, and were selected with the intention that they may share common features suited for a model child life program. Additionally, the institutions were selected because they both offer a diverse range of pediatric subspecialties that incorporate the presence of child life specialists. Finally, and most importantly, the exploration of both hospitals provided beneficial insight into the challenges faced at even the most renowned pediatric institutions in the country, and possible suggestions for improvement. Between the two hospitals, twelve child life specialists were interviewed for this case study project.

Founded in 1855, The Children's Hospital of Philadelphia (CHOP) was the first hospital dedicated solely to pediatrics in the United States, and one of the first in the world. The children's hospital is a freestanding institution located at 34th St. and Civic Center Blvd. in Philadelphia, Pennsylvania and is an affiliate of the University of Pennsylvania. The institution consistently ranks in the top five among various pediatric subspecialties in the United States by *US News and World Report.* CHOP currently has a total of 430 inpatient beds, 15 playrooms, and serves over one million pediatric patients each year (CLC, 2006a; The Children's Hospital of Philadelphia [CHOP], 2013). The Child Life, Education and Creative Arts Therapy program was founded in 1951 and is the largest program of its kind in the nation, with more than 50 staff members. The Child Life, Education and Creative Arts Therapy program includes music therapy, art therapy, a hospital school program, pet therapy, and child life services (CHOP, 2005). Child life services alone includes 40 child life specialists in addition to unit-based activity coordinators who provide care to over 33,000 patients per year (CLC, 2006a). As a result, the child life specialist to patient ratio is approximately 1:17. In addition to providing traditional inpatient care, child life specialists at CHOP are present in units such as outpatient radiation oncology, the intensive care unit, emergency, the cardiac care unit, surgery, and palliative/end-of-life care, to name a few.

Monroe Carell Jr. Children's Hospital at Vanderbilt is a relatively newer institution that, until a decade ago, was housed within Vanderbilt University Medical Center. In 2004, the current freestanding children's hospital was built, taking into account specific design elements to make the space a state-of-the art, child-friendly environment (Monroe Carell Jr. Children's Hospital at Vanderbilt [Vandberbilt], 2013). It is affiliated with Vanderbilt University and is located at 2200 Children's Way in Nashville, Tennessee. Before its recent renovation, Vanderbilt

Children's Hospital had a total of 216 inpatient beds and five inpatient playrooms (CLC, 2006a). The Department of Child Life Services was founded in 1969 and currently employs 23 child life specialists in addition to music therapists, an art therapist, a hospital teacher, and assistants (Vanderbilt, 2013). Cumulatively, the child life team provides care to over 41,000 pediatric patients each year (CLC, 2006a). The child life specialist to patient ratio is approximately 1:24. Unique areas served by Child Life Services include outpatient hematology/oncology and infusion, special events and donations, emergency, diabetes, the burn unit, PICC line service, and a number of surgical areas.

Common Elements

Upon visiting both children's hospitals, a number of similar components were noted between both institutions' child life departments. These components seem to be universal to today's larger child life programs that are successful, up-to-date, and well integrated, as is the case at both CHOP and Vanderbilt Children's Hospital. While the following list is by no means comprehensive, it may offer some valuable points for hospitals wishing to implement or improve a modern child life program. Some common program components are as follows (Wheaton et al., 2012; Bennett et al., 2012):

- regularly scheduled, daily activities in playrooms
- use of age-appropriate playrooms (e.g. for toddlers, school-age children, adolescents/teens, etc.)
- regularly scheduled movie nights
- use of comfort positioning to minimize movement without restraint during procedures
- integrated art therapy, music therapy, and school programs
- use of MP3 players for individual patient use during therapy sessions
- use of iPads® as preparation books and distraction devices

- CCTV network with interactive games and shows (patients can call in from rooms)
- heavy reliance on dolls during medical play
- child life specialists play a major role in pain management
- the provision of end-of-life care
- a major goal is of avoiding anesthesia use whenever possible; child life plays a role in determining whether anesthesia is needed, and if so, helps with induction preparation
- legacy building by way of making keepsakes, hand molds, "beads of courage," etc.
- presence of children's and family advisory councils within the hospital
- child life specialists carry phones or pagers
- working closely with volunteers who act as an extension of child life services (e.g. help with events, donations, programs, playroom support)
- a focus on sibling support and programming
- child life goes on rounds with other inpatient staff
- child life specialists participate in documentation in patient histories

Innovative Ideas

In addition observing a number of basic components that led to successful child life implementation, both hospitals featured a variety of creative and cutting-edge ideas that made their programs stand out. As with most children's hospitals, the child life teams at CHOP and Vanderbilt Children's are continually looking for new, innovative ideas to improve the hospitalization experience for pediatric patients. The following are examples of novel ideas noted during the site visits (Wheaton et al., 2012; Bennett et al., 2012):

<u>CHOP</u>:

- Pediatric Advanced Care Team – a group of nine rotating physicians, one full-time physician, a social worker, an art therapist, a chaplain, a nurse practitioner, and a child life specialist devoted to palliative care. The team frequently works outside the hospital, making home visits. The child life specialist works with patients in life-limiting circumstances, often following up with a family after the death of a child.

- Special Delivery floor – a mother/baby floor housed in the children's hospital for high risk babies that need immediate, specialized care. The idea was a suggestion based on input from families.
- an annual patient "prom"
- family lounges on units with long-term patients – include a washer and dryer and a quiet space for rest and relaxation
- condition-specific medical play dolls
- physicians strive to present an overview of each patient to child life workers – an excellent example of collaboration and teamwork
- child life specialists have access to all crash cart supplies that may be beneficial during preparation
- child life specialists working in emergency have a designated spot in the trauma room during trauma cases; the family also is allowed into the room
- wireless telemetry monitors for cardiac patients, allowing mobility
- a closed-circuit, interactive radio station known as "The Voice," sponsored by the Ryan Seacrest Foundation, often featuring live groups
- a child life specialist designated to specifically work with siblings

Vanderbilt:

- playrooms open during "normal hours" only, to create structure and normalcy (e.g. they are closed during meal times, late at night, etc.)
- a child-sized theater accessible on the main floor for various performances; theater is run by its own audio technician
- the cafeteria is referred to and designed as a food court to make it less "hospital-like"
- a free movie rental kiosk, similar to Redbox®
- child life specialists rotate on the weekend for on-call bereavement services
- a dedicated A/V team for the closed-circuit TV channel network
- occasional concerts by Nashville celebrities
- a optimal event duration of 30-45 minutes
- limited musical programs, as they are often loud and offer little hands-on interaction; if conducted, instruments are included for patients to use
- an Icee® machine, very popular among children recovering from surgery

- Little Tikes™ cars allowed in pre-op area, and children are allowed to "drive" to the operating room in their cars

Commonly Cited Challenges

While both hospitals had highly-integrated and state-of-the art child life programming, a variety of challenges were cited by the specialists interviewed from both programs. It should be noted that some of the challenges described are generally unit- or institution-specific. However, a considerable amount of the issues faced are fairly universal among the child life profession and should be addressed in the future. Some of the difficulties cited are as follows (Wheaton et al., 2012; Bennett et al., 2012):

- residents are often not receptive to child life services and provide little to no preparation for procedures
- a major difference in child life utilization between old and new nurses is evident
- long-term hospital stays can get stressful and tense with families
- child life specialists must know a great deal of medical information in order to properly prepare and communicate with children and family members; this information must be learned along the way
- surgeons can be tough to work with and unaccepting of child life
- when attending physicians on a unit rotate, it can be very difficult on families
- often health care professionals tend to rush for no reason, forgetting about family and patient care
- child life is not a billable service, and so the specialists often must raise their own funds
- newer child life specialists commonly have boundary issues (e.g. bringing private life into work life); the same can be said about other young professionals as well
- many institutions (Vanderbilt, for example) are understaffed due to financial constraints; such understaffing puts additional strain and burden on child life specialists
- high rate of turnover among child life specialist due to low pay, emotional challenges faced

- the profession as a whole is losing focus on its specific role, as it is not clear cut
- it is easy for child life specialists and other professionals alike to fall into the "out of sight, out of mind" mindset with patients and families
- child life specialists must be very proactive to be recognized and utilized in some departments
- dealing with waiting is difficult for children and families, as it increases anxiety; this is difficult to address when funding, resources, and staff are in short supply
- some families may be resentful with child life and resist care
- at least 50% of patients cannot leave their rooms; this presents a challenge in the context of programming and event planning
- reading patients can be difficult (e.g. some patients who are alone may be happy, while others in same situation may feel isolated)
- funding and staffing depends heavily on child life staff keeping statistics and conducting surveys

Suggestions Provided for Child Life Profession and Physicians

One of the major objectives of conducting the child life case studies was to gain insight into ways to improve the profession and pediatric medicine as a whole. The child life specialists at both hospitals offered their input regarding ways that physicians could support and further the success of child life in the pediatric health care community. Some suggestions are as follows (Wheaton et al., 2012; Bennett et al., 2012):

- it is helpful for anyone working in pediatric medicine to also work outside the hospital in order to gain a frame of reference of normal child development
- all pediatric professionals must keep in mind what is actually important at the end of the day; one should never forget about patient- and family-centered care
- the dynamics of single (private) vs. double rooms are worth exploring – both offer unique advantages and drawbacks
- up-to-date, empirically-based research is needed regarding child life care

- empirical research studying cost is beneficial to the profession (e.g. the cost of sedation vs. the cost of providing child life support without anesthesia)
- Professional boundaries must always be considered before acting by evaluating three questions: 1) Can I provide this service to everyone? 2) Is this something I could tell my coworkers? 3) Whose needs are actually being met?
- doctors should always provide adequate preparation and explanation using sensory details
- physicians need to get on the same level as patients, both figuratively and literally
- always knock first, respect privacy, wash hands in front of the patient, and give the family a place to sit or feel comfortable
- physicians are encouraged to join patients in the playroom and participate in end-of-treatment celebrations
- alter wording based on the family
- be consistent in wording when dealing with a single patient/family
- avoid ambiguous or scary terminology that can be easily misinterpreted by children
- pediatric physicians may incorporate distraction into procedures by using items such as bubbles, toys with light and noise, cause and effect toys, "find it tubes," or electronic books
- maintaining patient focus is key to a successful procedure; it is important to alter the child's focus, however, instead of "sneaking"
- DVD players offer distraction during long procedures
- always give your patients as many options as possible

Part IV: Looking Ahead

The evidence shown in support of child life thus far underscores the need for a unique health care professional trained in recognizing and addressing the psychological needs of children during hospitalization. At a number of health care institutions, child life is heavily respected and relied upon as a central component to quality pediatric care, as demonstrated by the hospital case study. However, within these top institutions and smaller hospitals alike, the profession still faces a wide array of challenges. It is the intention of this thesis to address those

professional challenges and suggest ways in which the pediatric health care team may more effectively work together to improve psychosocial care.

A survey conducted by the Child Life Council in the early 2000s identified 405 child life programs in existence throughout the world, with a majority residing in the United States and Canada (CLC, 2003). Considering that over 4000 hospitals within the United States alone offer pediatric treatment, the percentage of children's health care settings that provide child life services is shockingly low, at under ten percent (CLC, 2006b). Child life can no longer be looked at as an experimental idea, nor can we continue to maintain that such programs are merely a luxury in pediatric medicine. Neglecting the idea of child life would be just as foolish as eliminating physical therapy, for example. These services are both crucial to the health and wellness of our young patients, whether physical or psychological. As stated by the American Academy of Pediatrics, child life programs should be considered an essential requirement for delivering quality pediatric medicine (AAP, 2006).

Making a Case for Child Life Specialists

A question often raised in the discussion of child life services is, "Why child life? Why can't psychosocial needs be addressed by other members of the health care team?" To address this question, it is important to stress that child life specialists are unique in that they never play a threatening role in the hospital. It has been reported that "one potential source of stress for children is the absence of a trusting relationship with at least one care provider who is frequently and regularly available" (Broadhead et al., 1983; Cobb, 1976; Drotar & Bush, 1985; Magrab, 1985; Pearlin et al., 1981; Turner, 1981; Wolfer & Visintainer, 1975; as cited in Gaynard et al., 1998). Whereas all other members of the health care team are responsible for carrying out

functions that may cause patient distress – e.g. administering medication, conducting painful procedures, examining patients in potentially uncomfortable ways, etc. – the child life specialist is never the ”perpetrator” of scary or threatening procedures. Additionally, child life specialists are available on a regular and predictable basis unlike most other health care professionals. For these reasons, the child life specialist can be trusted and relied on as a “safe” caregiver.

Another aspect unique to child life is the diversity of skills that specialists bring to pediatric medicine. According to Dr. James Fahner, a prominent and innovative pediatric oncologist in Western Michigan, child life is truly the “good will ambassador,” bringing everything together within the children’s hospital environment like no one else can (2013). Though child life focuses primarily on patient and family needs, all members of the health care team benefit from their services, as well as the community. Child life has the potential to change hospital policy, reach out to local youth groups and school programs, and work with all members of hospital staff to provide education about psychosocial care. Consequently, child life specialists are uniquely influential, universal, and versatile in children’s health care.

Defining Characteristics

Throughout the development of this project several elements have been presented that may arguably be regarded as the basic requirements for any child life program. These guidelines address the hospital departments served, staffing ratios, the incorporation of technology, and the use of volunteers. It is important to note, however, that the guidelines to follow are intended to be interpreted differently by each pediatric institution in accordance with its specific values, objectives, resources, and challenges. As noted by the architects of the ACCH Child Life

Research Project, it is impossible to classify a specific program as ideal as such a concept varies significantly from hospital to hospital.

Child life programming should address as many departments as possible, in order of priority. The first department that should be served is the inpatient unit, where chronic or acute hospitalization can lead to long-term stays, often accompanied by immobility. Without child life care, such long periods away from the normal aspects of home life and socialization, as previously shown, can have severe and enduring consequences on the wellbeing of a child. The next departments that should be addressed are surgery and the emergency center. Both of these departments include uncomfortable and often unpredictable procedures on a regular basis that can cause a great deal of distress for children. Preparation plays a greater role in the surgical and emergency departments, due to the short-term nature of such care, than in the inpatient unit. Next, oncology units such as infusion or radiation should be considered. These may be inpatient or outpatient areas. Pediatric cancer patients face chronic, life changing conditions and a high susceptibility to depression. Additionally, a lot of the cancer treatments used occur on an ongoing basis and can take many hours. Radiation, even in its most modern form, can be extraordinarily distressing for pediatric patients, requiring long periods of restraint and immobility. The emotional needs of these patients should be addressed by child life specialists, if feasible. Other areas that may then be considered include burn units, transplant units, special events, radiology, rehabilitation, end-of-life care, and other outpatient and inpatient areas.

Child life staffing ratios are another important element to be explored during the implementation process. There are currently around 3500 certified child life specialists in the world, 2800 of which work in the United States (Bennett, 2012). This statistic is encouraging in that it suggests the United States' emphasis on psychosocial care in pediatrics. But keeping in

mind the fact that there are over 4000 hospitals within the United States that treat children, these data stress that 1) once again, a significant number of hospitals do not possess child life programs, and 2) many programs are significantly understaffed. In accordance with the American Academy of Pediatrics policy statement on child life services, a ratio of roughly one child life specialist to 15 or 20 patients seems to be the most successful in addressing patient and family needs (AAP, 1994; CLC, 2006b). Likewise, the ACCH Child Life Research Project maintained a specialist to patient ratio of approximately 1:12, with the occasional need for specialists to care for additional patients. The Children's Hospital of Philadelphia was staffed in a similar manner (1:17), while the patient load was slightly higher at Vanderbilt Children's (1:24), where understaffing was reported as a primary challenge. Again, the suggested ratio of one specialist to 15 or 20 patients is merely a suggested guideline. Hospitals should take into account other variables as well when considering staffing arrangements.

For successful implementation, the services of child life should be extended through the use of technology. Technology has the potential to continuously bring new innovations to patient- and family-centered care. For example, the use of tablets has opened up a brand new world for child life specialists, who can use the devices as preparation books, distraction devices, movie players, music players, and a means of communication. Closed-circuit TV networks and radio stations, as observed during the children's hospital site visits, allow immobile or quarantined patients to participate in regular programming by way of "calling in" to the station. Likewise, the future holds great potential for similar technologies that provide hospitalized children with a means of interaction and participation in normal activities. A prime example of such an innovation is the VGo Robotic Telepresence system by Verizon®. By streaming audio and visual information, the VGo allows a child to "attend" school and communicate with his or

her teacher and peers in real time during a long-term hospitalization. At the same time, however, there are some classical aspects to patient-centered care that will never be replaced. Establishing close relationships with patients and families will never go out of style, and there is extraordinary value in traditional play. Hands-on experience with hospital supplies and equipment, and physical tours through procedure areas will never be completely superseded by the virtual world. Interplay between a variety of traditional techniques and modern innovations is the key to a balanced pediatric program.

Like technology, the use of volunteers can greatly extend the reach of child life care too. As noted, the child life profession as a whole is greatly understaffed, putting strain on existing specialists. Volunteers can greatly relieve a significant amount of this strain, thankfully. For example, in the emergency department at Vanderbilt Children's Hospital there is one child life specialist on staff per shift to cover a total of 60 patient beds. Luckily, through the gracious help of approximately 50 volunteers, the needs of all emergency patients can efficiently be addressed (Gannon, 2012). Volunteers can engage in many aspects of patient- and family-centered care such as handling donations, facilitating events and programs, keeping patients occupied with art projects and games, and providing playroom support. Through such efforts, child life specialists can focus their energy on providing psychosocial care and preparation, evaluating patients and families, educating other members of the health care team, working on relevant research, and integrating child life into other areas of care.

Improvement through Collaboration

Patient-centered psychosocial care will continue to fall short of its potential without full integration into pediatrics. Today's pediatric physicians are arguably the most influential team

members in eliciting this transition to a style of integrated care that relies heavily on child life methods. Physicians are the team leaders in medicine – figureheads of society who have the unique ability to set cultural standards within their organizations. Unfortunately, a majority of today's pediatricians[2] provide little support to the child life community. During the early days of the ACCH, the organization was a multidisciplinary group represented by child life workers, developmental psychologists, and physicians alike. Today's Child Life Council looks much different: The group consists of mainly child life specialists, educators, and students, and draws little attention from other health care professionals. Many current pediatricians know very little about child life's important role. Astonishingly, some have not even heard of the profession. And there are yet others who are familiar with child life, but have little respect or time for the services they provide. If we can change the culture among physicians regarding child life, we can change the culture of pediatric medicine as a whole. And with that culture change come improvements in funding, research, and support for the child life profession, ultimately contributing to a better style of pediatric medicine.

The benefits of collaboration between child life and the rest of the medical community are great; yet they are rarely explored. During the ACCH Child Life Research Project, staff followed five guidelines in order to promote and enhance collaboration: 1) acknowledge the roles and expertise of other professionals, 2) share information with the other team members, 3) be receptive to observations and recommendations by other members, 4) provide in-service education to hospital staff, and 5) recognize the professional limits and boundaries of child life (adapted from ACCH, 1983). As a result of such efforts, it was cited "…that the successful child life program also resulted in a more positive and productive work environment for everyone and

[2] The term 'pediatrician,' as referred to throughout the rest of this thesis, includes all subspecialties of pediatric physicians in addition to general practice pediatricians

that there was a positive public relations value in the program" (CLC, 2006b, p. 2). According to Dr. James Fahner, collaborating with child life is a form of "permissible eavesdropping," where a great deal of important patient data can be collected from patient interactions. Additionally, he describes the child life specialist as an invaluable interpreter between the doctor and child. For this reason, he says, physicians should work closely with child life (Fahner, 2013).

Child life staff, too, benefit significantly from collaborative efforts with physicians. As a result of collaboration during the ACCH project, other professionals within Phoenix Children's Hospital gained awareness and respect for the profession (Gaynard et al., 1998). In addition to a attaining a higher level of respect, child life specialists can more accurately prepare children for procedures by working closely with other team members. For example, a specialist who works with an oncologist would be able to more accurately describe the side effects of radiation to a young boy with leukemia. Similarly, collaboration with a plastic surgeon would help a child life specialist to describe the healing process in greater detail to a teenager injured in a horseback riding accident. With better preparation and less anxiety, children are then less likely to resist during procedures, making the job of the physician much easier. Evidently, cooperation results in a relationship that continually benefits both parties.

Addressing Funding through Teamwork

Securing funding for child life programs continues to be a major challenge today. As mentioned, child life is not a billable service; the patient and the patient's insurance company are never charged for child life care. As such, the cost is typically absorbed as part of the daily bed cost within the general hospital operating budget (CLC, 2006b). The hospital, then, is required to find ways to recoup the expenses. Often, grants and donations from philanthropists or

organizations such as Children's Miracle Network help to offset costs. When funds are scarce, child life programs are charged with finding new sources of revenue to support daily functions and staff salary. Funding for the Child Life Department at Helen DeVos Children's Hospital in Grand Rapids, Michigan, for example, is supported by the hospital operating budget, funds from the DeVos family endowment, and monies from other community donors (Fahner, 2013). The Child Life, Education, and Creative Arts Therapy Department at CHOP cites similar funding sources, as well as support from fundraising events and product sales (CLC, 2006a). The program at Vanderbilt also lists sources such as the hospital operating budget and endowed funds, as well as funding derived from student tuition (CLC, 2006a).

These sources of support seem to be adequate for programs in place already, but they certainly are not sufficient enough to accommodate any considerable growth. And with the recent push to reduce health care costs in the United States, further pressure has been put on hospitals to reduce excess spending. Once child life becomes respected by the physician community and recognized as a necessary component of pediatric medicine, funding may likely improve. The American Academy of Pediatrics reinforces this idea, suggesting that all members of the medical community should work to advocate for the financing of child life services (AAP, 2006). Increased recognition for the profession would raise awareness among philanthropic support within the community and may play a role in future alterations in hospital billing and budgeting. Child life specialists and physicians must work side-by-side in deciding how to maintain necessary components of health care in the midst of cutting costs.

Collaborative Research Efforts

Another way that the physician community can support the child life profession is through research. A number of sources have expressed the urgent need for current, data-based research in child life methods. A careful review of pertinent literature has revealed a general lack in recent studies in this area. Physicians, especially those at academically-affiliated institutions, commonly take part in scientific or clinical research projects within the hospital. Clinical research in various aspects of child life care could be greatly advanced with the help of the pediatric physician community. Studies exploring the financial benefits of using child life services have the potential to change misconceptions about the unnecessary expense of hiring specialists. Research in the development of time monitoring tools to measure efficiency and productivity could help streamline the profession (CLC, 2006b). Also, a number of practices popular among child life specialists today still lack data-based evidence. Physicians, working closely with child life staff, should explore these techniques in a scientific manner in order to ensure that the profession can continue to utilize evidence-based practices.

Longitudinal studies represent a final area of child life research that has been almost completely neglected. While the early works of researchers such as Douglas, Quinton, and Rutter have linked traumatic hospitalizations with disturbances later in one's life, few studies have explored whether child life interventions significantly decrease the occurrence of such long-term effects. At the time of the ACCH project, no longitudinal studies had been conducted, but the researchers suggested that "[a longitudinal study] should be a part of a program of future research" (Gaynard et al., 1998, p. 18). Nearly three decades later, longitudinal studies of patients treated under child life programs vs. traditional practices are still greatly needed.

Research conducted by child life specialists in conjunction with physicians would not only benefit the child life profession, but it would also be an invaluable experience for pediatricians. Working together would allow pediatricians to observe the effects of child life first hand and incorporate innovative techniques for patient-centered care into his or her daily practice. Working closely with physicians on research would also be an excellent way for child life specialists to learn a considerable amount about various illnesses and procedures, further improving knowledge and skill. Research is a means of significantly lessening the gap between the child life and physician communities, while strengthening and raising awareness for child life and accomplishing necessary scientific research.

Other Ways of Working Together

There are other ways in which child life can work more closely with the rest of the medical team as well. Allowing child life specialists to chart on patients is one method of facilitating greater teamwork. By carefully and professionally documenting observations and outcomes of patient interactions, child life's role is validated and respected as a necessary aspect of pediatric medicine (CLC, 2006b). Having access to the patient medical history also gives child life specialists a more detailed background of each child and more tools to work with during a consultation. Likewise, physicians benefit from the notes and analyses made about their patients by child life staff. The ACCH research project lists documentation as one of the primary daily duties of its child life specialists during the implementation of the experimental program (Gaynard, 1998). Similarly, specialists at both CHOP and Vanderbilt Children's Hospital were encouraged to regularly chart on patients, owing partially to the high level of respect and integration observed at both institutions.

Additionally, participating in in-services and grand rounds can have a profound effect on the advancement of the child life profession. Educating other staff at regular meetings or orientations not only validates the importance of child life, but it also allows for other hospital staff to gain a firm grounding in psychological theory and the needs of hospitalized children. Staff can then provide feedback regarding in-service education, facilitating two-way communication. The same can be said about child life participation in pediatric grand rounds. Presence during rounds would enhance discourse between child life and other departments, further integrating the treatment process. Participation in daily rounds occurred within a few of the departments at CHOP and Vanderbilt, and such participation was said to increase the level of individualized care provided during the ACCH project (Gaynard et al., 1998). Physicians today should welcome and encourage child life staff to participate in daily rounds on the young patients that they jointly serve.

Physicians and child life specialists should also work together to establish consistent vocabulary and terminology with patients (CLC, 2006b). Child life specialists are specifically trained to work with children and families using age-appropriate and minimally-threatening language. Such practices are useless, however, unless the entire health care team adopts similar practices. Physicians, nurses, and child life must work together in developing appropriate language and descriptions in order to maintain consistency. Pediatricians should also be encouraged by child life to take part in positive, personal interactions with patients. Examples of such interactions include presence at end-of-treatment celebrations, during crafting and group activities, and building rapport with children in the playroom (Fahner, 2013; Grobbel, 2013). These suggestions are commonly pointed out by modern child life specialists, but are rarely heard by pediatric physicians.

In working to integrate child life into the rest of the hospital setting, it is important to focus on working with other team members rather than merely advocating for child life. Working with physicians and other professions on a common goal demonstrates the depth of child life care first hand and signifies a sense of mutual respect. As such, physicians and others are likely to want to play a hand in making child life "their own." A prime example of such a collective effort is sharing a research project, as previously highlighted. A pediatrician who works with a child life specialist to determine whether progressive relaxation can shorten the duration of a lumbar puncture is likely to adopt new techniques in his clinical practice, which he can then demonstrate to others. Physicians and child life can also work on other projects, such as developing a new support group for children in need of organ transplant. In such a case, both professionals could learn a great deal from one another about the emotional and physiological challenges of awaiting transplant. To be successful in this way, an effort to cultivate respect and increased cooperation must be made by all members of the health care team.

Reforming Pediatric Medical Education

The final element that must be looked at in an effort to improve the integration of child life within pediatrics is medical education. While many of the humanistic traits that accompany patient- and family-centered care are difficult to teach, a greater emphasis needs to be placed on child developmental theory during pediatric training. Currently, medical education in child development is focused around basic developmental milestones that pediatricians must recognize in order to recognize deficiencies in growth and maturity. Very little time is spent on the stages of psychological development or the perceptions of children at different ages (Fahner, 2013; Turner, 2013). A majority of the skills crucial to being a dynamic, receptive pediatric clinician, shockingly, come from experience outside of education – through mentoring, parenting,

childhood experiences, etc. – or they are picked up along way the through interactions with attending physicians. But aside from these outside experiences, most pediatric residents feel relatively unprepared to deal with the emotional needs of children, varying in age from infancy to adolescence (Fahner, 2013). Most pediatric physicians would agree that little real world tools are provided for addressing children's psychosocial needs, and that a majority of doctors feel "inadequate" and "not deeply skilled" in this regard (Turner, 2013).

A firm grounding in child developmental theory should be the focus of future medical education in pediatrics. Coursework in child development and required readings should form the foundation of this education. An essential text to be included in this study is *Psychosocial Care of Children in Hospitals: A Clinical Practice Manual From the ACCH Child Life Research Project*, the primary handbook used in the training of child life specialists, including a report of the ACCH study at Phoenix Children's Hospital. Pediatric residents in training may also benefit from reading the Child Life Council's evidence-based practice statements, which explain the scientific basis of many commonly used child life techniques. Additionally, developmental psychologically should be an area of study that is more heavily addressed during the education of all pediatric physicians.

The USMLE Step 3 exam, taken at the end of pediatric residency prior to licensing, must reflect these curriculum changes and evaluate skills and knowledge pertaining to child psychology and psychosocial theory. Medical education in child and developmental psychology can be further enhanced by teaching efforts in which medical students and pediatric residents receive hands-on training from child life specialists. The accrediting body for medical residency programs, the ACGME, strongly suggests that pediatric residency programs should include teaching by other clinical staff, including child life services (Accreditation Council for Graduate

Medical Education, 2003) Today's clinicians also affirm that this style of hands-on experience would be invaluable for tomorrow's pediatricians (Turner, 2013).

Conclusion

Child life is a fundamental aspect to quality pediatric medicine today. Born from the work of early child psychologists, the profession has evolved into an extraordinary component of patient-centered care that incorporates psychological principles, family support, hospital culture, community outreach, and technical aspects of medicine. Child life specialists are changing the practice of pediatric medicine, turning traumatic, emotionally-scarring encounters into growth-promoting experiences with lasting effects on the health and wellbeing of hospitalized children. Looking at the early work of researchers such as Bakwin, Spitz, Prugh, Vernon, and Douglas, the need for a style of pediatric medicine that addresses both physical and emotional wellbeing was made obvious. By researching the role that child life plays in today's hospitals, we were able to see how unique and indispensible child life specialists are, and how child life presence is a necessity in modern pediatric medicine. The children's hospital case studies revealed a number of aspects of child life care that are universal to programs everywhere, in addition to a variety of novel ideas for improving the pediatric health care environment. Institutions that wish to implement new child life programs or improve a program already in place may find these observations beneficial, and may use some of the aspects noted as a basis for further innovation. Finally, the case studies also revealed a number of challenges commonly faced by child life today, such as underfunding and a lack of current research. By reforming pediatric medical education and cultivating a sense of unity and teamwork between physicians and child life specialists, there are a variety of ways in which we can address these challenges.

With help from physicians and the rest of the clinical community, the child life profession can continue to grow and innovate while being an invaluable asset to others. It is intended that this thesis can be a resource to child life specialists, current clinicians, and aspiring physicians alike, providing a comprehensive overview of the child life profession with an emphasis on a culture of collaboration and teamwork. The suggestions highlighted thus far only begin to scratch the surface of potential collaborative efforts among health care professionals. Hopefully the research that has been presented will continue to inspire further consideration, cooperation, and innovation among the individuals dedicated to caring for tomorrow's pediatric patients.

References

Accreditation Council for Graduate Medical Education. (2003). *Program Requirements for Residency Education in Pediatrics*. Chicago.

American Academic of Pediatrics, Committee on Hospital Care. (1994). Staffing patterns for patient care and support personnel in a general pediatric unit. *Pediatrics, 93*, 850–854.

American Academy of Pediatrics, Committee on Hospital. (2000). Child Life Services. *Pediatrics, 106*(5), 1156–1159.

American Academy of Pediatrics, Committee on Hospital Care. (2006). Policy Statement: Child Life Services. *Pediatrics, 118*(4), 1757–1763.

Association for the Care of Children's Health. (1983). *Child life position paper*. Washington, DC: Author.

Association for the Care of Children's Health. (1984). *Guidelines for the development of child life programs*. Washington, DC: Author.

Association for the Care of Children's Health. (1986). *Child life: An overview*. Washington, DC: Author.

Bakwin, H. (1942). Loneliness in Infants. *Am J Dis Child, 63*(1), 30–40.

Bennett, K. (2012, June 26).

Bennett, K., Gannon, R., Bauers, J., Reynolds, S., Gentry, K., & Licht, B. (2012, June 26). Vanderbilt interviews.

Broadhead, W., Kaplan, B., James, S., Wagner, E., Schoenbeck, V., Grimson, R., … Genlback, S. (1983). The epidemiologic evidence for a relationship between social support and health. *American Journal of Epidemiology, 117*, 521–537.

Child Life Council. (1990). *Standards of clinical practice*. Washington DC: Author.

Child Life Council. (2003). *Directory of Child Life Programs in North America* (13th ed.). Rockville, MD: Author.

Child Life Council. (2006a). *Guidelines for the Development of Child Life Programs in Health Care Settings*. (J. M. Wilson, S. Palm, & L. Skinner, Eds.) (4th ed.). Rockville, MD: Child Life Council.

Child Life Council. (2006b). *Child Life Council Directory of Child Life Programs* (14th ed.). Rockville, MD: Author.

Child Life Council. (2011). About the Child Life Council. Author.

Cobb, S. (1976). Social support as a moderator of life stress. *Psychosomatic Medicine, 3*, 300–314.

Drotar, D., & Bush, M. (1985). Mental health issues and services. In N. Hobbs & J. Perrin (Eds.), *Issues in the care of children with chronic illness* (pp. 514–539). San Francisco, CA: Jossey-Bass.

Fahner, J. (2013, January 24).

Gannon, R. (2012, June 26).

Gaynard, L., Wolfer, J., Goldberger, J., Thompson, R., Redburn, L., & Laidley, L. (1998). *Psychosocial Care of Children in Hospitals: A Clinical Practice Manual from the ACCH Child Life Research Project*. Rockville, MD: Child Life Council.

Greb, A. (2012, June 6).

Grobbel, K. (2013, February 21).

Heffernan, M., & Azarnoff, P. (1971). Factors in reducing children's anxiety about clinic visits. *HSMHA Health Reports*, *86,* 1131–1135.

Johnson, R., & Baldwin, D. (1968). Relationship of maternal anxiety to the behavior of young children undergoing dental extraction. *Journal of Dental Research, 47*, 801–805.

Johnson, R., & Baldwin, D. (1969). Maternal anxiety and child behavior. *Journal of Dentistry for Children*, *36*, 13–18.

Koller, D. (2007). Preparing Children and Adolescents for Medical Procedures. Child Life Council.

Koller, D. (2008). Therapeutic Play in Pediatric Health Care: The Essence of Child Life Practice. Child Life Council.

Licht, B. (2012, June 26).

Magrab, P. (1985). Psychosocial development of chronically ill children. In N. Hobbs & J. Perrin (Eds.), *Issues in the care of children with chronic illness*. San Francisco, CA: Jossey-Bass.

Monroe Carell Jr. Children's Hospital at Vanderbilt. (2013). Retrieved from http://www.childrenshospital.vanderbilt.org/index.php

O'Conner-Von, S. (2000). Preparing children for surgery:An integrative research review. *AORN Journal*, *71*(2), 334–343.

Palombo, J., Koch, B. J., & Bendicsen, H. K. (2009). Rene Spitz (1887-1974). In *Guide to Psychoanalytic Developmental Theories* (pp. 81–94). New York, NY: Springer.

Pearlin, L., Lieberman, M., Menaghan, E., & Mullin, J. (1981). The stress process. *Journal of Health and Social Behavior*, *22*, 337–356.

Plank, E. (1962). *Working with children in hospitals*. Cleveland, OH: Western Reserve Press.

Prugh, D. G., Staub, E. M., Sands, H. H., Kirschbaum, R. M., & Lenihan, E. A. (1953). *A Study of the Emotional Reactions of Children and Families to Hospitalization and Illness*. s.n.

Rutkowski, J. (1986). A survey of child life programs. In *Child life: An overview*. Washington, DC: ACCH.

Seligman, M. (1975). *Helplessness*. San Francisco, CA: Freeman and Co.

Smith, A. (1937). *They play with you here, The Modern Hospital, Report on the development of play at the Children's Memorial Hospital, Chicago, IL*. Unpublished paper.

The Children's Hospital of Philadelphia. (2005). Child Life, Education and Creative Arts Therapy.

The Children's Hospital of Philadelphia. (2013). Retrieved from chop.edu

Thompson, R. H. (1989). Child life programs in pediatric settings. *Inf Young Children*, *2*(1).

Turner, J. (1981). Social support as a contingency in psychological well-being. *Journal of Health and Social Behavior*, *22*(December), 357–367.

Turner, L. (2013, February 23).

Vernon, D.T.A., Foley, J. M., Sipowicz, R. R., & Schulman, J. L. (1965). *The psychological responses of children to hospitalization and illness*. Springfield, IL: Charles C. Thomas.

Vernon, David T.A., Schulman, J. L., & Foley, J. M. (1966). Changes in Children's Behavior After Hospitalization. *Amer J Dis Child*, *111*.

Wheaton, J., Greb, A., Sharp, E., DePhillips, E., Polise, S., & Phillips, H. (2012, June 6). CHOP interviews.

Wojtasik, S. P., & White, C. (2009). The Story of Child Life. In *The Handbook of Child Life: A Guide for Pediatric Psychosocial Care* (pp. 3–22). Springfield, IL: Charles C. Thomas.

Wolfer, J., Gaynard, L., Goldberger, J., Laidley, L., & Thompson, R. (1988). An experimental evaluation of a model child life program. *Children's Health Care*, *16*(4), 244–254.

Wolfer, J., & Visintainer, M. (1975). Pediatric surgical patients and parents' stress responses and adjustment. *Nursing Research, 24*, 244–255.

Wright, G., & Alpern, G. (1971). Variables influencing children's cooperative behavior at the first dental visit. *Journal of Dentistry for Children*, *38*, 60–64.