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Special Issue: Family Science Careers Through the Eyes of Theory

This manuscript is part of a special issue of Family Science Review entitled *Family Science Careers Through the Eyes of Theory*, edited by Raeann R. Hamon, Ph.D., CFLE. The authors of these deliberately unconventional manuscripts were asked to select and describe a career that a professional with a family science background might pursue. After outlining the professional role, authors reflected upon the family theories that most influence the way they approach their work and perform their professional duties. Authors briefly review the scholarly literature on selected family theories, provide case studies or work scenarios as illustrations of theory in action, and discuss the strengths and weaknesses of the theories in their unique professional contexts. The Special Issue articles are designed to be used individually or in combination, and feature articles about careers in early intervention, special education, family court, child life, and higher education. The introduction to the special issue is available at https://doi.org/10.26536/GMJK4953. The complete special issue is available at https://doi.org/10.26536/ZLUL3923.

Child Life through the Lens of Family Stress Theory and Family Systems Theory

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ABSTRACT. Certified Child Life Specialists (CCLS) are an integral part of the healthcare team, who address children and families' psychosocial needs and help children and families cope throughout their healthcare experiences. The history of child life, description of the interventions provided by Certified Child Life Specialists, and educational preparation needed for child life certification will be discussed. Certified Child Life Specialists use family science theories in their interventions with patients and families. Two of the family science theories that influence assessments and interventions are family stress theory (Boss, 1988; Hill, 1949; McCubbin & Patterson, 1983) and family systems theory (Smith & Hamon, 2022). Certified Child Life Specialists utilize these theories to provide support to families and create resources for positive coping and adjustment to their hospital experience. These theories will be discussed, and case studies will be examined to illustrate how Certified Child Life Specialists integrate these theories into their practice.

Keywords: child life specialist, family systems theory, family stress theory

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Child Life through the Lens of Family Stress Theory and Family Systems Theory

When a child is hospitalized, the experience challenges the hospitalized child and the family system as a whole. Certified Child Life Specialists (CCLS) professionally "help infants, children, youth, and families cope with the stress and uncertainty of acute and chronic illness, injury, trauma, disability, loss, and bereavement" (Association of Child Life Professionals [ACLP], 2016). CCLS play an integral role in designing, implementing, and providing family life education to patients and families. With an education rooted in family science, CCLS utilize family science theories to guide their practice.

This paper will review the history of child life and describe the work of CCLS. A brief overview of two theories relevant to the field of child life, family stress theory and family systems theory, will be discussed. Additionally, two case studies will illustrate how the theories provide a valuable framework to promote growth within families while navigating the stresses of hospitalization.

The Field of Child Life

Certified Child Life Specialists (CCLS) are integral members of the healthcare team when it comes to addressing the psychosocial needs of children. With education in child development and family science, CCLS offer services to promote positive coping when children and their families face new stressors. Child life services originated in the inpatient hospital environment and have expanded to other settings such as dentist offices, school systems, disaster relief organizations, and hospice facilities (Rosenblatt et al., 2023). While interventions in each setting vary, the goals remain the same: to promote coping and reduce the negative effects a stressful or traumatic event has on a child and their family's ability to cope (Lookabaugh & Ballard, 2018).

History of the Child Life Field

The field of child life has grown tremendously since the early twentieth century when "play leaders" first recognized the need to support hospitalized children. The Association of Child Life Professionals (ACLP, n.d.-a) reported 6,558 CCLS in 28 countries in 2021 and the number continues to grow. CCLS began working in the 1920s to improve the experience of hospitalized children to promote development and coping within the hospital. The role at this time also included advocating for family visits and family participation in the medical care of the child, as this was discouraged by other medical professionals (ACLP, n.d.-b). In 1962, Emma Plank published an important book titled *Working with Children in Hospitals* in which she outlined the work of the Child Life and Education Department at Cleveland Metro Hospital. This text energized the child life movement and initiated a shift to recognize the psychosocial needs of children in the hospital. Plank (1962) asserted that children in the hospital need space to play and benefit from medical preparation, and also emphasized the importance of collaboration among the hospital team for the psychosocial and physical benefit of young patients.

After Plank's introduction of Child Life in 1962 many hospitals joined the movement and began child life programming in their hospitals.. Over the years, programming expanded from focusing on play-based interventions to also focusing on supporting the coping, educational, and emotional needs of patients, parents, and siblings. CCLS have expanded their services to include outpatient and community settings (ACLP, n.d.-b). In the past, CCLS were viewed as the "play ladies" (Rubin, 1992), however, today child life services are recognized as a key element in the provision of evidence-based pediatric medical care (Romito et al., 2021). As summarized by Boles et al. (2020):

> Certified Child Life Specialists, as psychosocial healthcare professionals with focused training in child development, family systems, and evidence-based supportive interventions, are indispensable members of high-caliber healthcare teams. In collaboration with medical and

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> allied health professionals, Certified Child Life Specialists bring a multifocal lens, individualized to the needs of pediatric patients and their families, grounded in developmental theory attuned to the influence of past and present trauma, and aimed at building resilient family systems (p. 2).

Development of the Association of Child Life Professionals (ACLP)

Certified Child Life Specialists gain and maintain accreditation through the Association of Child Life Professionals. In 1967, the Association for the Care of Children in Hospitals was established, which was a multidisciplinary organization for a myriad of professionals, parents, and patients to continue their work on the issues confronting hospitalized children (Thompson, 2018). In 1982, this association developed into the Child Life Council to provide standards of practice and support for Certified Child Life Specialists, and in 2016 the organization was renamed Association of Child Life Professionals (ACLP, n.d.-b). The ACLP promotes child life by "establishing and maintaining professional standards, enhancing the professional growth and development of members, and advancing the credibility of the child life profession by fostering research and promoting the standards of child life practice on a national and international level. The Association represents trained professionals with expertise in helping infants, children, youth, and families cope with the stress and uncertainty of illness, injury and treatment" (ACLP, n.d.-b, "About the Association of Child Life Professionals" section).

In 2024, in order to be eligible for certification, individuals must have a bachelor's degree and completion of 10 specific college courses: 1 child life course taught by a CCLS, 2 child development courses, 1 family systems course, 1 play course, 1 loss/bereavement or death/dying course, 1 research course, and 3 additional courses in related areas (ACLP, 2024-a). The child development classes must span birth - 18 years to provide the necessary understanding of the stages of development of the population that child life specialists will be primarily working with. This information will provide knowledge which will be beneficial in assessing patient development, providing developmentally appropriate activities, and understanding the challenges of each developmental stage. The family systems courses provide aspiring CCLS an understanding of family science theories, family dynamics, family relationships, family roles, and adaptations within families. The course focusing on play should address the therapeutic aspects of play and may include further knowledge on observing play, guiding play, or varying play interventions. The loss and bereavement course provides foundational understanding that will prepare the individual to support patients and families during end-of-life situations. A research course should teach basic methods, statistics, and outcomes that apply to clinical practice (ACLP, n.d.-a).

The final step before sitting for the certification exam is to complete a 600-hour comprehensive clinical internship under the supervision of a CCLS. Certified child life specialists maintain certification by completing 60 Professional Development Units (PDUs) or retaking the exam every 5 years. With certification, Certified Child Life Specialists have met standards to "help children and their families cope with stressful experiences in a variety of settings. They provide preparation, education, distraction, play, and coping tools, among many other benefits, to children and their families" (ACLP, n.d.-a, "Why Child Life").

Effects of Hospitalization

Franck et al. (2015) found children and families can experience post-traumatic stress disorder (PTSD) following hospitalization, regardless of whether the hospitalization was chronic, terminal, or acute. Not only may patients and families develop PTSD as a result of hospitalization, but families and children are at increased risk of having recurrent difficulties coping with stress or pain later in life (Shea et al., 2021; Wintgens et al., 1997). Knowing the long-term effects hospitalization and illness may have

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on patients and families, Certified Child Life Specialists aim to provide adequate resources and intervention to promote positive coping and reduce the risks of maladjustment and long-term harmful effects.

Pre-existing family stressors, lack of support systems, and limited access to psychosocial services can negatively impact patients and families coping with hospitalization (Isokaanta et al., 2019; Jackson et al., 2015). The severity of the patient's illness and exposure to traumatic experiences also increase the likelihood of patients and parents experiencing PTSD symptoms (Nelson & Gold, 2012). Knowing this, CCLS develop coping plans based on their assessment which includes a review of the patient's developmental status, coping behaviors, support system, and past experience with hospitalization and illness (Turner & Fralic, 2009). Coping plans incorporate a variety of interventions to diminish the harmful effects of hospitalization. For example, if a child was recently diagnosed with a chronic illness, the CCLS may provide developmentally appropriate education to help the patient understand what is happening. This intervention would aid in greater compliance with the treatment plan as well as overall coping as the patient will have a better understanding of the stressor at hand (Compass et al., 2012; Sporer et al., 2019). Overall, children have been found to report lower levels of anxiety when receiving child life services during their hospitalization (Claridge et al., 2020).

Practice Driven by Theory

Certified Child Life Specialists utilize various developmental and family-oriented theories when providing psychosocial care to children and families in healthcare and other community settings. In particular, family stress theory and family systems theory influence the everyday work of a CCLS. Family stress theory is used to assess the ability of children and families to cope with the stressors they may encounter while hospitalized and provide a framework for adaptation. Family systems theory guides the healthcare team to better understand the dynamics of families and the impact of hospitalization and illness on each family member, as well as the family as a unit. This knowledge influences how CCLS provide educational and emotional support.

Family Stress Theory

Certified Child Life Specialists utilize family stress theory in practice, specifically Hill's ABC-X model (1949) and McCubbin and Patterson's Double ABC-X model (1983), to analyze the situation and guide interventions to help families cope with stressors. These two models provide CCLS a framework to understand patients' and families' ability to cope and create individualized coping plans, which are vital to the services a CCLS provides (Wise & Delahanty, 2017). The identification of factors A (stressor), B (family resources), and C (family perception), which interact to predict a family's vulnerability to experience crisis, X (Hill, 1949), are foundational to shaping interventions.

Patterson (1988) defines a stressor as an occurrence that affects the family unit and brings about change either positively or negatively. For families in the hospital, some common stressors may include separation, a new diagnosis, lack of medical understanding, lack of social support, financial disruptions, or changes in routine (Didisen et al., 2020). Also, stressors can be further categorized as normative (temporary and anticipated) or non-normative (unexpected), with non-normative stressors being more likely to result in a crisis (McCubbin & Patterson, 1983). The patient and family's ability to cope with a given stressor then depends on the available resources (B) and their perception of the stressor (C). If they are unable to utilize existing resources or do not currently possess relevant resources, families are likely to struggle. When families do not have a manageable understanding of their stressor or are not able to frame the situation in a manageable way, individuals and families may experience a crisis.

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When families experience crisis as a result of their stressor(s), McCubbin and Patterson's (1983) Double ABC-X model provides a framework to guide practice and considers post-crisis factors (Wang et. al, 2023). The post-crisis factors include stress pileup (aA), new resources (bB), and modified perceptions of the situation (cC). Since families are already likely to encounter a pileup of stressors upon admission to the hospital, the Double ABC-X model is generally the most applicable. Unlike the ABC-X model, which tends to offer a snapshot of the family at a single point in time, the Double ABC-X model recognizes the passage of time as a factor in the family's coping. The following case study will highlight how the ABC-X and Double ABC-X models guided a CCLS practice.

Case Study One: Blake, Teen Hospitalized for Blurry Vision

Blake is a 17-year-old admitted to the hospital after experiencing decreased and blurry vision and headaches for a month. He was accompanied by his mother to the unit to be evaluated for a cause of sudden vision loss and recurrent headaches. Upon admission, the CCLS introduced child life services to Blake and his family to begin developing rapport in anticipation of many upcoming tests and the potential for a difficult diagnosis. Many stressors (A) were evident that could influence the patient's coping: a life-threatening diagnosis, an estranged relationship between his parents, this first hospitalization, and a lack of understanding of the hospital environment/procedures. In addition to the stressors Blake was experiencing, he had limited social support and few pre-existing coping skills (B). Blake also had little experience with the hospital and many misconceptions about the hospital environment which contributed to increased stress levels. With a background in family science and knowledge of family stress theory, the CCLS recognized that this patient had many risk factors that might lead to the patient experiencing a crisis and thus utilized family stress theory to shape interventions.

The patient's body language and nonverbal cues indicated that the influx of people entering the room and ensuing conversations regarding his care were increasing his anxiety. Blake stopped engaging with the CCLS and became withdrawn. Due to the severity of the situation and the eyesight difficulty, the healthcare team immediately ordered many scans and blood tests. The patient began expressing anxiety around the MRI (A) stating, "I can't do it, I am not doing that," whenever the healthcare team discussed it. Recognizing the patient did not have existing coping skills to manage the stressor, the CCLS began providing interventions to promote positive coping and avoid crisis early in the patient's treatment.

Knowing the importance of the patient's understanding of the stressor (C) from family stress theory, the CCLS wanted to reframe Blake's understanding of the stressor. The CCLS utilized developmentally appropriate language and pictures to prepare the patient for and clear up misconceptions surrounding his upcoming MRI (A). Developmentally appropriate preparation is a common intervention provided by CCLS as it reduces anxiety surrounding procedures, giving children a sense of mastery and control over their environment (Diener et al., 2019; Romito et al., 2021). After the patient developed a more appropriate understanding of the MRI, the CCLS advocated for the patient to receive available resources (B) to cope with his upcoming MRI. Like most new patients, Blake and his family were unaware of available resources during this first hospital experience. Thus, the CCLS was sure to make these resources available at this time (Nabors et al., 2013). The CCLS advocated for the patient to receive Ativan (a medication commonly used to calm patients) prior to the procedure and for a parent to accompany them to MRI. Following these interventions, the patient coped well with the MRI and tolerated the procedure without additional needs.

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Once the MRI results came back, the patient faced many new stressors. Blake and his parents were told additional imaging, tests, and surgery were needed. The initial stressor (A) was able to be managed with supportive resources (B) and improved understanding of the stressor (C). However, with the accumulation of stressors and associated pileup (aA), existing resources (B) and current perception of the situation (C) proved insufficient and led Blake and their family to experience a crisis (X). Boss (1988) describes crisis as a state where a family or individual can no longer function utilizing their own resources. With the pileup of stressors, the patient shut down, yelled at staff members, and refused the medications necessary to prepare for surgery. Additionally, the patient's parents became disengaged, avoiding conversations with the care team regarding Blake's care because they were overwhelmed with all the new information. Blake and his parents' response made it difficult for the medical team to provide family-centered care as the family was disengaged in medical conversations and began to develop a distrust of the medical team due to their lack of communication.

With the patient and family already existing in a state of crisis (X), the CCLS utilized the Double ABC-X model to analyze the current situation and reconsider intervention strategies. In addition to understanding the scope and array of stressors the child and family faced (aA), the CCLS tried to identify additional resources necessary (bB) to help the family. The CCLS aimed to help the family reframe their perceptions to make the situation more manageable (cC). The CCLS encouraged them to focus on one stressor at a time, similar to their approach before the pileup of stressors. The parents were receptive to this approach and collaborated with the CCLS to remind the patient to focus on one stressor at a time when faced with increased anxiety. Compas et al. (2012) found that patients experience the most effective coping with stressors when efforts are put forth to adapt to the stressors presented. This approach aided the coping as the patient did not become overwhelmed with the stress pileup.

Following a conversation with the surgeons about the upcoming surgery, Blake began verbalizing fears saying, “They are going to cut my face open,” and “My eye will be cut out.” The patient began looking online for information about the surgery and found inaccurate information. The CCLS noted that the patient’s lack of accurate information (B) contributed to the patient's inability to cope effectively with surgery. Similarly, Blake’s perception of the situation (cC) was skewed due to a lack of developmentally appropriate information and understanding about the diagnosis and surgery.

Pediatric patients desire information about their diagnosis and medical treatments, as well as how the condition or procedure will affect their daily lives (Compas et al., 2012). Also, because the patient was in Erikson’s (1998) identity vs. role confusion stage of development, it was appropriate for this teen patient to be concerned about their appearance following surgery. Developmentally appropriate preparation for surgery was provided using photographs of the surgeon’s approach while emphasizing that the eye would not be damaged. The CCLS answered the patient’s questions with developmentally appropriate language, affirmed the patient's fears, and advocated for the patient to talk with surgeons again to review the earlier discussion. With a more accurate perception of the stressor, the patient repeated accurate information about the procedure to their family following the intervention, which helped them cope with the stressor and gain a sense of mastery over their healthcare experiences.

After surgery, the patient again became very withdrawn, refused medicine, slept most of the day, and did not engage with the CCLS, staff, or family. The patient was experiencing fewer acute stressors such as imaging, blood tests, and surgery, but began having difficulty coping with the more common stressors of a long hospitalization separation from peers, and disruption to routines (aA). Recognizing that the patient needed additional resources (bB) and support reframing their situation (cC), the CCLS engaged the patient in syringe painting, an activity where patients write down the hardest things about being in the hospital on a canvas and use syringes to squirt paint at the hard things while discussing

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coping skills. Play is at the center of child life interventions as it is the natural language of children and can be a window through which they can naturally express their experiences (Thompson, 2018). This activity encouraged self-expression in a safe environment and allowed the CCLS to learn more about Blake's coping and areas he needed support. As a result of this activity, the CCLS discovered the patient was having the most difficulty coping with the thought of losing his eyesight and needed additional activities to normalize the hospital environment.

The CCLS encouraged and assisted the patient in finding various resources (bB) to connect them with children in similar situations, as teenagers heavily benefit from peer-to-peer support. After this conversation, the patient found accounts on TikTok of other children who had lost sight or experienced decreased vision. The patient said this was helpful as they saw they could live with decreased vision, knowing "I am not alone." Additionally, the CCLS provided the patient with painting to normalize the hospital environment and promote positive coping with their hospitalization. Blake then asked to paint a ceiling tile to hang in the hospital to encourage other children. The patient expressed seeing other tiles helped because they were "a bright reminder during a dark time." After the ceiling tile was hung, the patient felt a great sense of accomplishment and expressed excitement about helping bring joy to future patients. The patient expressed that painting had become a coping skill (bB) for him and he utilized this coping skill when new stressors arose during the hospitalization.

Eventually, the patient utilized his understanding of the hospital environment as well as his new coping skills to advocate for himself and adjust to new stressors. The CCLS saw this patient about 6 months after he was first hospitalized for another surgery, and when talking with the patient he was able to appropriately verbalize an understanding of the procedure at hand displaying growth in his understanding of his stressors. Throughout the interaction the patient displayed coping skills and resources the CCLS had previously provided such as being able to advocate for medications, making sure his father was well prepared to support him in the post-op room, and utilizing coping skills discussed such as deep breathing and using an eye mask. The patient even asked about his ceiling tile and if it had helped other patients to cope. Over time the patient was able to better adjust to their stressors and find ways to cope in everyday life following the interventions provided by the CCLS.

As evidenced throughout this case study, CCLSs consistently use family stress theory as outlined in the ABC-X and Double ABC-X models to assess and provide interventions to promote optimal adjustment for hospitalized families. While unfortunately, this family experienced a state of crisis, CCLSs strive to be proactive in providing services to prevent this from happening. By identifying potential stressors for families, available resources, and reframing the patient and family's understanding of the stressor in more manageable terms, CCLS can help families experience bonadaptation rather than crisis or maladaptation.

Family Systems Theory

Another widely used family science theory is family systems theory, which views the family as an interconnected unit in which "individual members can be understood only within the context of the whole" (Smith & Hamon, 2022, p. 142). Family systems theory asserts that behaviors, choices, and decisions only make sense in the context of relationships, and each family "possesses its own characteristics, rules, roles, communication patterns and power structure" (Smith & Hamon, 2022, p. 141). These relationships are defined by communication, which encompasses how messages are relayed, as well as the intent of the message. In addition, the family systems theory considers boundaries families establish that serve to separate a family from the surrounding environment. A closed family, for example, may prohibit or limit exposure to certain information, media interaction, and friends. An open

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family is considered a healthy model of family, one bound together by love and respect and encouraging members to make decisions aligning with family rules and goals, interacting with outside entities accordingly. As family circumstances and family life cycle stages of individual family members change, the system's priorities and goals may also change accordingly (Smith & Hamon, 2022).

Sharpe and Rossiter (2002) noted that "family dynamics are an intriguing and often complex set of relationships and even more so when a child in a family is born with or develops a chronic physical illness" (p. 706). When an individual is diagnosed with an illness, all family members are affected and subsequently have varying needs that arise in response to the diagnosis. For example, not only does the child with cancer face difficulties understanding their diagnosis but the healthy siblings and parents do as well. Furthermore, extended family members, such as grandparents, are likely to be affected emotionally and in their daily routines and are generally found to be supportive in providing care (Prendeville & Kinsella, 2019).

Certified Child Life Specialists utilize family systems theory in their assessment of how each family member is affected by the diagnosis and in their provision of programming to advocate for family-centered care, CCLS adopt the viewpoint that the patient and family members are helped when understood within the context of the family relationship (Fraser & Munn, 2020; Jenkins et al., 2023). When the CCLS better understands family cohesion, family rules, and boundaries, they can provide supportive resources to help them cope with their challenging circumstances and function well within the family system as a whole (Leon & Knapp, 2008; Myers et al., 2011). The following case study examines how a Certified Child Life Specialist utilized the family systems theory in assessing and providing interventions to the family of an 8-year-old female oncology patient, Jasmine, throughout her treatment.

Case Study Two: Jasmine, Outpatient Oncology Patient

Upon meeting the family, the Certified Child Life Specialist spoke with the caregivers and the patient to understand their current living situation and support systems. Jasmine's defined family living arrangement included her mother, father, and three sisters. A simple genogram showed she had an extended support network of grandparents, aunts, uncles, and cousins, as well as an extensive local school, faith, and neighborhood community. As a result of the assessment, the family was found to have open and healthy boundaries, through their willingness to gain and share information about the diagnosis, as well as their openness to consider support from their community. This information was important to the CCLS because it signaled that the family would be receptive to therapeutic and educational interventions.

As a result of the diagnosis, the roles of the immediate and extended family members shifted to provide support to Jasmine. The mother was a teacher by profession and chose to take family medical leave to be the primary support person during treatment; she also assumed a new role of providing homeschooling for Jasmine. As treatment progressed, Jasmine spoke of the challenges of having her mom as her "teacher" and the CCLS partnered with Jasmine and her mom to provide various art activities they could enjoy after schoolwork.

The siblings were impacted by the diagnosis in many ways, from having their daily routine interrupted to having the mother at Jasmine's bedside for lengthy treatments. In addition, the siblings had concerns for Jasmine's health and their own health, as the siblings questioned if they, too, could get cancer. In the context of family systems theory, the sibling's sense of self appeared to be influenced by the changing family situation. One of the siblings spoke of jealousy regarding the attention and gifts the patient received from the community and family. These concerns extended to include uncertainties of

how to talk to their friends about the diagnosis and how to answer curious questions they were receiving from well-intended peers. In addition to providing support and education to patients, Certified Child Life Specialists often work within the hospital setting to provide education and emotional support to siblings, and parents can consult these free services for support with language and resources when seeking education for their children (Lookabaugh & Ballard, 2018). The CCLS recognizes that the healthy functioning of the family as a whole is critical in the well-being of the hospitalized child.

Additionally, CCLS often function as a family educator, providing education to parents about how to use developmentally appropriate explanations when communicating with their children (Compas et al., 2012; Sporer et al., 2019; Stewart & Ames, 2014). Deavin et al. (2018) found that "siblings would prefer to have increased levels of information earlier, relating to the disease and its impacts, which may help build their understanding and empathy, helping them to tolerate and accept the situation and their feelings" (p. 8). The parents were provided the option of having the siblings meet with the CCLS through a telemedicine appointment (due to existing COVID visitation restrictions), or to receive education and materials for them to use to initiate and explore the topic further with their children. Due to the COVID-19 pandemic, the family chose to receive materials and education and have those conversations privately in their own home. In advance of the conversation with the siblings, the family talked through anticipated questions and formulated responses with the CCLS. At the next clinic visit, the family was able to discuss the benefit of having those resources and to identify concerns held by the siblings and the steps they were taking to alleviate those concerns. The family, defined by their open communication style, was able to focus on their communication and show flexibility in working to fulfill the needs of the entire unit while being mindful of individual needs as well.

As the treatment became more involved, Jasmine and her mother became more enmeshed from spending so much time together. As a result of the ill sibling's hospitalization and treatments, research has shown that healthy siblings may feel a sense of weakened relationships due to family disruption and physical separation (Neville, 2016). In this case study, Jasmine's younger sibling began to have behavioral outbursts. The Certified Child Life Specialist provided the family with additional resources to help communication and to facilitate greater cohesion. A picture book was created of Jasmine's typical day in the oncology clinic, and the family was able to use this tool to provide the sibling clarity about the medical experience. During their time in the clinic, Jasmine and the mother also started having video calls with the sibling so she could meet some of the staff and be part of the medical appointments. The mother was also encouraged to spend individual time with the sibling, even if only for a few minutes a day. The increased communication and adaptability within the constraints of the COVID-restricted environment allowed the sibling to experience more cohesion within the family.

In addition to managing Jasmine's medical treatments, the family needed to be adaptable in managing the household and the changed financial situation from the mother's leave from work. Certified Child Life Specialists and social workers often partner to help families identify formal and informal support networks following the diagnosis of a child. Adaptation to a serious diagnosis can be enhanced by support from the health care team, extended family, and community support (Bates et al., 2023; McCubbin et al., 2002). Financial, emotional, or physical support with daily tasks and childcare help can also be helpful. Transportation needs, respite care, assistance with siblings, and emotional support may be able to be met by extended family members (McCubbin et al., 2002). Jasmine's family was hesitant at first to accept help from the community, but they were able to adapt their thinking and consider that in light of the changing demands of the medical situation, they would benefit from using additional resources and supports. The family's open boundaries allowed the family to accept the help and information offered from the outside.

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Jasmine's family was fortunate to have grandparents living nearby who were able to assist with babysitting, and household upkeep, and provide additional support at hospital appointments. The family was able to shift their roles and allow for greater interdependence in this new situation. The grandparents shared with the Certified Child Life Specialist the ways their lives had been impacted by the diagnosis, and while grateful they could be supportive of their family, they also acknowledged the impact of the diagnosis on their personal lives. Grandparents' stresses are similar to parental stresses and may include balancing work, emotional relationships, and concerns about their children and grandchildren's coping (Wilson, 2024). Prendeville and Kinsella (2019) found that extended family members who are providing support would also benefit from supportive intervention from the medical team, as they are greatly impacted as part of the family system. Support groups and educational resources can be offered and hospital staff can help families identify existing supports within the family unit as ways of providing additional interventions (Wilson, 2024). In this situation, the Certified Child Life Specialist was able to provide space for the grandparents to share and encourage them to seek emotional support from their existing friends and supportive relationships, with the knowledge that they could seek professional counseling if needed.

This case study is just one example of how the diagnosis of a critical illness can impact not only the pediatric patient, but parents, siblings, and extended family. In this situation, the CCLS was able to provide assessments and interventions over the course of several years. The family's values and strong foundational relationships, adaptability, and continued strengthening of communication allowed members to find a balanced level of cohesion and flexibility during a time of changing needs and roles.

Discussion

As discussed throughout this paper, family stress and family systems theories provide useful lenses through which CCLS assess and provide services to patients and families. Due to the fast-paced nature of the hospital environment, CCLS can apply many theories in their work, based on the circumstances involved and the most acute needs of their patients and families. Incorporating family stress theory and family systems theory in the curricular preparation of CCLS will continue to benefit hospitalized children and their families.

Family stress theory provides an invaluable framework for CCLSs to support families when faced with the stressors associated with being in the hospital. McCubbin and Patterson's (1983) addition of time to the double ABC-X model provides CCLSs an additional framework to understand children and families coping, specifically when a child is diagnosed with a chronic illness. Children with chronic illnesses have needs that are ever-changing in light of flare-ups, medication changes, hospitalizations, and times of remission. The element of time accounts for the families adjusting to the illness as they begin to cope with the stressors which come along with their chronic illness, integrating it into their daily life.

Using family systems theory, CCLS consider the patient in relation to their family as a whole since what happens to one individual impacts all of the family, providing a valuable framework essential to providing family-centered care. When applying this theory, CCLS should be mindful of the diverse backgrounds and cultural beliefs of their patients and families as they may impact how family science theories are utilized in practice. It is important to keep in mind the specific strengths of the family and how cultural gaps may influence individual family members and the family as a whole (Bámaca et al., 2019).

When family science theories such as family stress theory and family systems theory are used in conjunction with one another, they strengthen a Certified Child Life Specialist's practice. Where one

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theory is lacking, another may offer valuable insight to enhance interventions. When these theories are used together it allows CCLS to provide more effective interventions and a more holistic approach to care.

Family stress theory and family systems theory add value to child life practice as they emphasize two main goals of Certified Child Life Specialists; to reduce children's stress following hospitalization or a traumatic event and to promote family-centered care. Utilizing these two well-known theories, Certified Child Life Specialists are better able to implement evidence-based practice and explain proposed interventions to the healthcare team. CCLS should remain up to date with family science theories that can be utilized in practice and educators should continue to include and emphasize theories such as these to further progress the field and gain credibility.

References

Association of Child Life Professionals. (n.d.-a). *Become certified.* Retrieved July 2, 2024, from https://www.childlife.org/certification/become-certified/academic-requirements

Association of Child Life Professionals. (n.d.-b). *The Beryl Institute White Paper*. Retrieved July 2, 2024, from https://www.childlife.org/about-aclp-legacy/support-aclp/partnership-opportunities/the-beryl-institute-white-paper.

Association of Child Life Professionals. (n.d.-c). *History of the ACLP*. Retrieved July 2, 2024, from https://www.childlife.org/about-aclp/history-of-aclp

Association of Child Life Professionals. (n.d.-d). *Why Child Life*. Retrieved July 2, 2024, from https://www.childlife.org/practice/why-child-life

Association of Child Life Professionals. (2016). *Association of child life professionals message handbook.* https://www.childlife.org/docs/default-source/about-aclp/aclp-message-handbook.pdf

Association of Child Life Professionals (2021). 2021 ACLP Annual Report. https://www.childlife.org/docs/default-source/about-aclp/2021-annual-report_aclp.pdf?sfvrsn=78f804d_2

Bámaca, C. M. Y., Henry, C. S., Perez, B. N., Gayles, J. G., & Martinez, G. (2019). Cultural orientation gaps within a family systems perspective. *Journal of Family Theory & Review, 11*(4), 524–543. https://doi-org./10.1111/jftr.12353

Bates, C. R., Pallotto, I. K., Moore, R. M., Covitz, L. M., & Dreyer Gillette, M. L. (2023). Barriers and facilitators of family rules and routines during pediatric cancer treatment. *Journal of Pediatric Nursing*, *72*, e33–e39. https://doi.org/10.1016/j.pedn.2023.06.002

Boss, P. (1988). *Family stress management*. Sage.

Buchbinder, D., Casillas, J., & Zeltzer, L. (2011). Meeting the psychosocial needs of sibling survivors: a family systems approach. *Journal of Pediatric Oncology Nursing: Official Journal of the Association of Pediatric Oncology Nurses*, *28*(3), 123–136. https://doi.org/10.1177/1043454210384601

Bugel, M. J. (2014). Experiences of school-age siblings of children with a traumatic injury: Changes, constants, and needs. *Pediatric Nursing*, *40*(4), 179–186.

Claridge, A., Hajec, L., Montgomery, L., & Knapp, B. (2020). Child and parent psychosocial experiences of hospitalization: An examination of the role of Child Life Specialists. T*he Journal of Child Life: Psychosocial Theory and Practice, 1*(1), 2-14. https://doi.org/10.55591/001c.22218

Compas, B. E., Jaser, S. S., Dunn, M. J., & Rodriguez, E. M. (2012). Coping with chronic illness in childhood and adolescence. *Annual Review of Clinical Psychology, 8*, 455–480. https://doi.org/10.1146/annurev-clinpsy-032511-143108

Deavin, A., Greasley, P., & Dixon, C. (2018). Children's perspectives on living with a sibling with a chronic illness. *Pediatrics, 142*(2). https://doi.org/10.1542/peds.2017-4151

Didişen, N. A., Karakul, A., Ertürk, S., & Dökümcü, Z. (2020). Anxiety levels and needs of fathers of children hospitalized in pediatric surgery intensive care units. *Journal of Pediatric Research, 7*(1), 38–45. https://doi.org/10.4274/jpr.galenos.2019.83435

Diener, M. L., Lofgren, A. O., Isabella, R. A., Magana, S., Choi, C., & Gourley, C. (2019). Children's distress during intravenous placement: The role of child life specialists. *Children's Health Care, 48*(1), 103–119. https://doi.org/10.1080/02739615.2018.1492410

Erikson, Erik H. (1998). *The life cycle completed*. Extended version. Norton.

Franck, L. S., Wray, J., Gay, C., Dearmun, A. K., Lee, K., & Cooper, B. A. (2015). Predictors of parent post-traumatic stress symptoms after child hospitalization on general pediatric wards: A prospective cohort study. *International Journal of Nursing Studies, 52*(1), 10–21. https://doi.org/10.1016/j.ijnurstu.2014.06.011

Fraser, C., CCLS, C., & Munn, E. K. (2020). *The value of Certified Child Life Specialists: Direct and downstream optimization of pediatric patient and family outcomes*. Association of Child Life Professionals. https://www.childlife.org/docs/default-source/aclp-official-documents/value-of-a-certified-child-life-specialist_full-report.pdf

Hill, R. (1949). *Families under stress: Adjustment to the crisis of war separation and reunion*. Harper.

Isokääntä, S., Koivula, K., Honkalampi, K., & Kokki, H. (2019). Resilience in children and their parents enduring pediatric medical traumatic stress. *Paediatric Anaesthesia*, *29*(3), 218–225. https://doi.org/10.1111/pan.13573

Jackson, A. C., Frydenberg, E., Liang, R. P., Higgins, R. O., & Murphy, B. M. (2015). Familial impact and coping with child heart disease: a systematic review. *Pediatric Cardiology*, *36*(4), 695–712. https://doi.org/10.1007/s00246-015-1121-9

Jenkins, C., Geisthardt, C., & Day, J. K. (2023). Supporting children and families in medical settings: Insights from child life specialists during the COVID-19 pandemic. *Journal of Child and Family Studies*, *32*(6), 1599-1616. https://doi.org/10.1007/s10826-023-02537-9

Krieger, T., Salm, S., Dresen, A., & Cecon, N. (2023). Cancer patients' experiences and preferences when receiving bad news: A qualitative study. *Journal of Cancer Research and Clinical Oncology*, *149*(7), 3859-3870. https://doi.org/10.1007/s00432-022-04311-8

Leon, A. M., & Knapp, S. (2008). Involving family systems in critical care nursing: Challenges and opportunities. *Dimensions of Critical Care Nursing, 27*(6), 255–262. https://doi.org/10.1097/01.DCC.0000338866.47164.6d

Lookabaugh, S., & Ballard, S. (2018). The scope and future direction of child life. *Journal of Child and Family Studies, 27*(6), 1721-1731. https://doi.org/10.1007/s10826-018-10316

McCubbin, M., Balling, K., Possin, P., Frierdich, S., & Bryne, B. (2002). Family resiliency in childhood cancer. *Family Relations, 51*(2), 103–111. https://doi.org/10.1111/j.1741-3729.2002.00103.x

McCubbin, H.I., & Patterson, J.M. (1983). The family stress process: The double ABCX model of adjustment and adaptation. *Marriage & Family Review, 6*(1-2), 7-37. https://doi.org/10.1300/J002v06n01_02

Myers, W.J. A., Ballard, S. M., Darling, C. A., & Myers, B. K. S. (2011). Reconceptualizing the domain and boundaries of family life education. *Family Relations, 60*(4), 357-372. https://doi.org/10.1111/j.1741-3729.2011.00659.x

Nelson, L., & Gold, J. (2012). Posttraumatic stress disorder in children and their parents following admission to the pediatric intensive care unit: A review. *Pediatric Critical Care Medicine, 12*(3), 338-347. https://doi.org/10.1097/PCC0b013e3182196a8f

Neville, A., Simard, M., Hancock, K., Rokeach, A., Saleh, A., & Barrera, M. (2016). The emotional experience and perceived changes in siblings of children with cancer reported during a group intervention. Oncology Nursing Forum, *43*(5), E188-E194. https://doi.org/10.1188/16.onf.e188-e194

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

Prendeville, P., & Kinsella, W. (2019). The role of grandparents in supporting families of children with autism spectrum disorders: A family systems approach. *Journal of Autism and Developmental Disorders, 49*(2), 738–749. https://doi.org/10.1007/s10803-018-3753-0

Romito, B., Jewell, J., Jackson, M., Ernst, K., Hill, V., Hsu, B., Lam, V., Mauro-Small, M., & Vinocur, C. (2021). Child life services. *Pediatrics, 147*(1). https://doi.org/10.1542/peds.2020-040261

Rosenblatt, A., Pederson, R., Davis-Sandfoss, T., Irwin, L., Mitsos, R., & Manworren, R. (2024). Child life specialist services, practice, and utilization across health care: a scoping review. *JBI Evidence Synthesis*, *22*(7), 1303–1328. https://doi.org/10.11124/JBIES-23-00025

Rubin, S. (1992). What's in a name? Child life and the play lady legacy. *Children's Health Care, 21*(1), 4. https://doi.org/10.1207/s15326888chc2101_1

Sharpe, D., & Rossiter, L. (2002). Siblings of children with a chronic illness: A meta-analysis. *Journal of Pediatric Psychology, 28*(8), 699-710. https://doi.org/10.1093/jpepsy/27.8.699

Shea, T., Athanasakos, E., Cleeve, S., Croft, N., Gibbs, D. (2021). Pediatric medical traumatic stress. *The Journal of Child Life: Psychosocial Theory and Practice, 2*(1), 42-54. https://doi.org/10.55591/001c.22525

Smith, S. R., & Hamon R. R (2022). *Exploring family theories* (5th ed.). Oxford University Press.

Sporer, K., Speropolous, L., & Monahan, K. E. (2019). Finding the "golden moments": Strategies of perseverance among parents and siblings of persons with severe mental illness and violent tendencies. *Journal of Family Issues, 40*(17), 2658–2683. https://doi.org/10.1177/0192513X19860170

Stewart, P. E., & Ames, G. P. (2014). Using culturally affirming, thematically appropriate bibliotherapy to cope with trauma. *Journal of Child & Adolescent Trauma,* 7(4), 227-236. https://doi.org/10.1007/s40653-014-0028-6

Thompson, R. H. (2018). *The handbook of child life: A guide for pediatric psychosocial care* (2nd ed.). Charles C. Thomas.

Turner, J. & Fralic, J. (2009). Making explicit the implicit: Child life specialists talk about their assessment process. *Child & Youth Care Forum, 38*(1), 39–54. https://doi.org.10.1007/s10566-009-9066-x

Wang, J. Y., Luo, G. Y., Lv, X. Q., Liang, C. M., Wang, D. N., Li, G. J., Hong, J. F., & Cao, Y. X. (2023). Resilience of infertile families undergoing in vitro fertilization: An application of the double ABC-X model. *Applied Nursing Research*, *69*, 151656. https://doi.org/10.1016/j.apnr.2022.151656

Wilson, J. L. (2024). An integrative review of grandparents' experiences in childhood cancer. *Journal of Pediatric Hematology/Oncology Nursing*, *41*(1), 67-77. https://doi.org/10.1177/27527530231194569

Wintgens, A., Boileau, B., & Robaey, P. (1997). Posttraumatic stress symptoms and medical procedures in children. *Canadian Journal of Psychiatry. Revue Canadienne de Psychiatrie, 42*(6), 611–616. https://doi.org/10.1177/070674379704200607

Wise, A. E., & Delahanty, D. L. (2017). Parental factors associated with child post-traumatic stress following injury: A consideration of intervention targets. *Frontiers in Psychology, 8*, 1412. https://doi.org/10.3389/fpsyg.2017.01412