

Changing the Story: Improving the Quality of Life Experienced by Children with Cancer
Best Practices, Programs & Interventions

A Senior Honors Thesis

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By

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Abstract

It is no secret that children get cancer. While the battle against cancer is no light matter regardless of one's age, the impact of such a diagnosis for a child or adolescent can be incredibly devastating. The necessity for this project lies in the research that illustrates a need for increased action to be directed toward fulfilling the psychosocial needs of children as they navigate cancer treatments. Children are still in the early stages of development; they are meant to be enriching their minds, building social relationships with peers, and playing and exploring their world. Cancer threatens all of those childhood norms, in addition to a child's psychosocial well-being and overall quality of life. This paper examines the current research on these facets of childhood cancer, while assessing the impacts of a kit that facilitates effective coping skills and a mentorship program that provides support-based social interaction. Drawing on the presented evidence, this paper serves a means to analyze and advocate for the necessity of broad implementation of psychosocial programming that improves the quality of life experienced by children battling cancer.

Keywords: quality of life, childhood cancer, psychosocial, programs and interventions, therapeutic recreation, child life

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Section 1

Background and Statement of the Problem

For years the question has been, “how will we cure childhood cancer?” While medical researchers and scientists are working on that answer, I see a need to improve the quality of life (QOL) for children with cancer right now. My relationship and experience with the field of pediatric oncology began with a summer spent at Camp Good Days and Special Times Inc. As a member of the summer staff team, I had the honor of serving some of the strongest, most resilient, and admirable children that I have ever met. Witnessing their smiles of pure joy while playing freely, finding companionship in others, and expressing themselves through recreation sparked a desire to continue serving this population through my chosen fields of study. Witnessing the confession of a camper whom I knew very well fueled the fire that ultimately drove me to explore how the fields of therapeutic recreation (TR) and child life could positively impact the quality of life experienced by this population. My education and experience in the fields have culminated in the development of my own understanding of what it means to experience a high quality of life. In building on each of the letters present in the word *life*, I arrived at the concept of “living in full expression.” When my camper confessed to me that camp is “the only place I feel normal,” I desperately wanted to know how “normal” could be brought to everyday life for her and others like her. I wanted to know how we could foster an environment where she could live in full expression every day; I wanted to know how we could improve the story of childhood cancer.

Children in treatment for cancer endure countless hours of procedures and treatments, resulting in experiences of pain, distress, uncertainty, restriction, and isolation (Cline et al., 2006; Einberg et al., 2016; Gibson et al., 2010). Hinds et al. (2004) concluded that quality of life for

pediatric cancer patients can be defined as “an overall sense of well-being based on being able to participate in usual activities; to interact with others and feel cared about; to cope with uncomfortable physical, emotional, and cognitive reactions; and to find meaning in the illness experience” (p. 767). The incongruence between the current experiences of children with cancer and the more desirable experiences of QOL is striking, and clearly illustrates a deficit that must be addressed.

Given the nature of a disease that is on a mission to take over a child’s body and treatments harsh enough to combat such a disease, it comes as no surprise that the cancer experience naturally poses barriers to a child’s experience of a high QOL. Due to the historical lack of understanding that psychosocial care plays an essential role in one’s overall experienced QOL, acknowledgement that the patient and her health must be viewed holistically has only occurred more recently. As evidenced by Wiener, Viola, et al. (2015), prior to 2015, pediatric oncology lacked “a widely accepted, up-to-date, evidence-based and consensus-based, comprehensive standard to guide provision of essential psychosocial services to all patients with pediatric cancer” (p. 209). Formation of the Psychosocial Standards of Care Project for Childhood Cancer (PSCPCC) was an effort to address this deficit head-on, and proved successful. In December of 2015, the Standards for the Psychosocial Care of Children With Cancer and Their Families (“The Standards”) were published as an outcome of the PSCPCC’s efforts. As crucial as this success has been, and continues to be, to the process of improving and standardizing psychosocial care, there remain additional implementation measures to be taken to reach the goal of fostering high QOL for all children with cancer.

Purpose

The purpose of this paper has evolved significantly throughout the thesis process; yet, the project has remained rooted in aiming to benefit childhood cancer patients in some form.

Originally setting out to gain a better understanding of how TR and child life are providing care in ways that contribute to high QOL, I began by seeking out relevant literature and studies.

Research revealed a revolutionary, multi-phase project with goals to establish official psychosocial standards of care and then implement those standards, ultimately standardizing—and making accessible—psychosocial care for all children with cancer (Mattie Miracle Cancer Foundation, n.d.). In gaining knowledge of these efforts throughout the thesis process, I sought to contribute to the conversation and make an evidence-based argument for specific implementation measures.

My project serves to first review current literature regarding psychosocial care for, and quality of life experienced by, children with cancer—notably the published Standards and qualitative research documenting patient-reported needs and experiences. Secondly, this project analyzes two established and unique approaches to fostering the overall psychosocial well-being of young cancer patients: an intervention developed by professionals at Children’s Hospital of Philadelphia (CHOP) and a program created and currently implemented by the Children’s Cancer Association (CCA). In contextualizing the goals and success of both CHOP’s Cellie Cancer Coping Kit and CCA’s Chemo Pal® Mentor Program within the aforementioned Standards and patient-reported needs, I will make a case for standardizing their implementation. Ultimately, the goals of this project are to highlight the evidence that supports implementation of the Cellie Kit and the Chemo Pal Program, illustrate the possible effects of expanded implementation, and change the QOL stories for children battling cancer.

Rationale

While the PSCPCC has made incredible progress toward provision of standardized, accessible psychosocial care for all children with cancer, formal systematic implementation of the Standards themselves has yet to be accomplished. The project is currently in the implementation and evaluation phases, gauging the present status of staffing and care delivery, drawing comparisons between existing and desired practices, and developing the Matrix and Guidelines for use in assessing and improving implementation (Wiener et al., 2019).

The range in areas of specific psychosocial care outlined in The Standards calls for a cooperative, cohesive, and multidisciplinary approach to overall provision of care. This paper serves the necessary role of highlighting the possible benefits of implementing the Cellie Cancer Coping Kit and the Chemo Pal Mentor Program, while demonstrating the need for both child life specialists and therapeutic recreation specialists to lead efforts in implementing programs and interventions that address specific areas of psychosocial care. Both fields value overall health and well-being, placing the patient's personal experience of QOL at the core of their practices. For these reasons, child life and therapeutic recreation must have a voice in the conversation regarding how to improve the QOL experienced by children with cancer, and furthermore, can significantly contribute to standardizing the implementation of select programming and interventions.

Section 2

Review of Literature

Over the course of the last twenty years or so, the realm of pediatric oncology has taken leaps forward in understanding and attending to the unique needs of children diagnosed with cancer. Recognition that a child's needs, experiences, and means of coping vary from an adult's due to differences in developmental stage has been instrumental in the process of effectively providing care to and fostering high quality of life for young cancer patients. Despite evident differences between the experiences of adults and children, it has come to be understood that children can be considered "social actors who play an active role in shaping their environment, and hence have their own experiences and understandings" (James et al., 1998, as cited in Gibson et al., 2010, p. 1398). Thus, as James et al. continued to assert, "even very young children are seen as competent to commentate on their own lives and to be involved in decision-making" (as cited in Gibson et al., 2010, p. 1398).

Research conducted by Hinds et al. sought to build on this notion, as their study focused on articulating the unique perspectives of the young patients themselves. Their results revealed six domains of the participating children's self-reported perspectives on their QOL; these domains were synthesized to create the aforementioned definition for pediatric quality of life (Hinds et al., 2004).¹ Additionally, they concluded that the six domains were not adequately represented in the examined QOL instruments and further recommended measurement of all six throughout treatment to ensure accurate assessment of patient-experienced QOL.

¹ Hinds et al. (2004) derived the following definition for pediatric quality of life: "an overall sense of well-being based on being able to participate in usual activities; to interact with others and feel cared about; to cope with uncomfortable physical, emotional, and cognitive reactions; and to find meaning in the illness experience" (p. 767)

As understanding of the complexities of “the QOL construct in pediatric oncology” (Anthony et al., 2014, p. 779) has been increasingly valued and targeted in research efforts, so has the understanding that appropriate and effective psychosocial care is essential to the QOL experienced by a child with cancer (Wiener, Kazak et al., 2015). This understanding pushed the pediatric oncology community to address the “lacking [of] a widely accepted, up-to-date, evidence-based and consensus-based, comprehensive standard to guide provision of essential psychosocial services to all patients with pediatric cancer” (Wiener, Viola et al., 2015, p. 209).

Eventual publication of the 15 official Standards for the Psychosocial Care of Children with Cancer and Their Families, in December 2015, was the result of years of collaborative efforts from a multitude of disciplines and perspectives within the pediatric oncology field. Four of the Standards cover aspects of psychosocial care that are encompassed by the therapeutic recreation and child life fields; thus, this paper will discuss possible options for their implementation and make recommendations for the fulfillment of these four selected Standards in practice.

The Standards

Psychosocial Interventions and Therapeutic Support. Review of 173 peer-reviewed articles resulted in a high quality of evidence supporting strong recommendation for establishment of the following Standard: “All youth with cancer and their family members should have access to psychosocial support and interventions throughout the cancer trajectory and access to psychiatry as needed” (Steele et al., 2015, p. S585). Key findings from review of the relevant literature reveal risk for both children and parents experiencing difficulties in coping, as well as the proven benefits of interventions and support (Steele et al., 2015). Furthermore, Steele et al. (2015) summarized the following specific, relative risks for children

with cancer: “experiencing anxiety, inhibited and withdrawn behavior, behavior problems, intense stress, depression, post-traumatic stress disorder (PTSD), academic difficulties, peer relationship difficulties, and worries about the future in relation to career and relationships” (p. 586).

Because responses to cancer and difficulties in adjustment are highly dependent on the individual child, family, and overall cancer situation, psychosocial intervention and support needs will vary. However, given the recommendation offered by Steel et al. (2015) that “support and interventions... should be provided by an individual with training and expertise in child development, emotional adjustment to illness, psychological and psychiatric syndromes, family systems, and/or concrete resources the family may need,” (p. S585) child life specialists and therapeutic recreation specialists could serve as primary providers in implementation of this Standard.

Anticipatory Guidance and Psychoeducation. Review of 21 studies resulted in moderate quality of evidence supporting an overall strong recommendation for establishment of the following Standard:

Youth with cancer and their family members should be provided with psychoeducation, information, and anticipatory guidance related to disease, treatment, acute and long-term effects, hospitalization, procedures, and psychosocial adaptation. Guidance should be tailored to the specific needs and preferences of individual patients and families and be provided throughout the trajectory of cancer care (Thompson & Young-Saleme, 2015, p. S684).

Perhaps most significant of the findings reported by Thompson and Young-Saleme (2015) is the conclusion that “psychoeducation appears to have the most consistent effects on improving

patient/caregiver knowledge about disease and treatment and increasing health locus of control” (p. S686). However, it is noteworthy to mention that the positive effects could be muddled by the unclear role boundaries among psychosocial care providers that can result from inadequate communication methods and systems (Thompson and Young-Saleme, 2015). Development and clear communication of practices emphasizing structure and consistency in delivery of psychoeducation and anticipatory guidance would serve children well, particularly as various disciplines (e.g. child life, social work, nursing) may take slightly different approaches to providing appropriate information and education.

Procedural Preparation and Support. Flowers’ and Birnie’s (2015) review of evidence detailing the effects of both procedural preparation, and procedural support through intervention resulted in strong recommendations for implementation as a Standard. Specifically, the published Standard is detailed as follows: “All youth with cancer should receive developmentally appropriate preparatory information about invasive medical procedures. All youth should receive psychological intervention for invasive medical procedures” (Flowers & Birnie, 2015, p. S694).

Fortunately, historical ideas that children did not need to be told what was happening to them have been replaced with the more intricate understandings of child development—which reveal the well-developed ability for even a young child to comprehend the world around him (Gibson et al., 2010). However, it is essential for the information to be presented to the child in a developmentally-appropriate manner, one which also allows him to explore and process the information in a way that is individually beneficial. Child life specialists are particularly suited to serving in this role, as their practice is rooted in understanding child development and utilizing that understanding to best serve the individual psychosocial needs of each child (Turner, 2018).

Providing Children and Adolescents Opportunities for Social Interaction. Review of 64 peer-reviewed papers revealed moderate evidence supporting strong recommendations for implementation of the following Standard: “Children and adolescents with cancer should be provided opportunities for social interaction during cancer therapy and into survivorship following careful consideration of the patient’s unique characteristics, including developmental level, preferences for social interaction, and health status” (Christiansen et al., 2015, p. S724). In examining the role of social interaction in a child or adolescent’s life, it becomes clear that developmental stage is a key contributor. Erikson’s development theory indicates a strong need for children and adolescents six years of age and older to have distinct opportunities for peer interaction and connections through normal social channels (e.g. school, home life, friendships) (as presented in Turner, 2018). The intense changes in the personal, environmental and social situations surrounding a child who has been diagnosed with cancer only builds on the existing general developmental needs based on psychosocial stage. Thus, it would follow that the focus on individual, needs-based implementation that is central to the fields of child life and therapeutic recreation would be instrumental in ensuring the fulfillment of this Standard.

The Needs

While a multitude of different studies, ranging in type, are often necessary to build a high quality of evidence, there is significant value to be found within qualitative research that values individuals as “‘experts’ on their own experience” (Mant et al., 2019, p. 14). Mant et al. conducted a study utilizing such research methods to gain a better understanding of what children with cancer are actually experiencing. More specifically, interpretive phenomenological analysis (IPA) was used in this study, and as Smith, Flowers and Larkin (2009) detail, “IPA focuses on understanding how a participant makes sense of his or her own unique experiences

(as cited in Mant et al., 2019, p. 5). Furthermore, Mant et al. (2019) point out the previous use of IPA in studies that aimed to understand the perspectives of childhood cancer patients. As such, IPA and other types of qualitative accounts can contribute compelling insight in the pursuit of providing quality psychosocial care that will fulfill patient needs and benefit their experienced QOL. The themes and sub-themes synthesized from interviews with cancer patients ages 8-12 and presented by Mant et al. (2019, pp. 8-12) are as follows:

- “Initially I felt shocked and scared”
- “Chemo is an awful thing”
- “Please talk to me – the more I know the better I feel”
- “I accepted treatment and quickly got used to it because I know I will get better”
- “My family is vital”
 - “I need my family to be present”
 - “I need my family to help with my communication”
 - “I worry about my family’s emotions”

A qualitative study conducted by Einberg et al. (2016), also aimed to gain understanding of 8 to 12-year-old cancer patients’ perspectives. The study followed an exploratory qualitative design and asked participants to take photographs of “subjects or situations that according to the children, promote their own health... health-promoting factors were declared to be ‘what makes you feel good’” (p. 78). The photos were then used to help facilitate focus group discussions around what the children felt promoted health. Analysis of the discussions and photographs, conducted by Einberg et al. (2016, pp. 79-84), resulted in the following health-promoting themes and sub-themes:

- “Meaningful relationships”
 - “Togetherness in family”
 - “Affection for pets”
 - “Friendship with peers”
- “Recreational Activities”
 - “Engagement in play & leisure”
 - “Withdrawal for relaxation”
 - “Feeling enjoyment”
- “Trustful environment”
 - “Confidence in significant others”
 - “Feeling safe”

Review of Existing Programs and Interventions

A wide variety of programs and interventions exist to serve different purposes within the broad umbrella of psychosocial care and contribution to the QOL a child with cancer experiences. Among them are the two featured in this paper: the Cellie Cancer Coping Kit, developed by the Children’s Hospital of Philadelphia (CHOP); and the Chemo Pal Mentor Program, created and implemented by the CCA.

Cellie Cancer Coping Kit

The Cellie Cancer Coping Kit was developed out of the need for expanding “evidence-based child-centered supportive care tools tailored to the experience of childhood cancer and its treatment” (Marsac et al., 2012, p. 3316). Designed for use by children ages 6-12, with their parents, it serves as an engaging tool that can be utilized at home, independent of psychosocial

care providers (Marsac et al., 2012). The kit includes a plush toy named Cellie, 30 cancer coping cards, and a caregiver book (see Appendix Fig. 1 for image), allowing a child to explore a variety of coping strategies for a variety of cancer-related stressors (see Appendix Fig. 2 for example of a coping card) (Marsac et al., 2012). Cellie can be viewed as a knowledgeable companion, as the coping cards can be stored in his zippered pocket for easy access, and a child can ‘go to Cellie’ for coping techniques and comfort.

Chemo Pal Mentor Program

The CCA’s Chemo Pal Mentor Program matches children receiving cancer treatments with adult volunteer mentors, many of whom are cancer survivors or know someone who has had cancer. In a personal phone interview with experienced Chemo Pal Specialist, E. Forsythe, she shared details about the program, its effectiveness, and some of the overall goals. Patients and families at local children’s hospitals are often connected with the program through social workers, then interviewed to assess interests and allow the program to best match the child with a mentor (E. Forsythe, personal communication, June 14, 2019). That mentor then builds a relationship with the child; mentors often accompany their pals to every chemo infusion or hospital visit. As conveyed by the CCA, “Chemo Pal mentors play games, listen to music, share hobbies, and simply offer the comfort of companionship, relieving the anxiety, loneliness, and isolation experienced by kids in treatment” (CCA, n.d., Chemo pal mentor program).

Section 3

Discussion & Analysis

For the purposes of this project, the population of children—ages 6-12 years and in treatment for cancer—are considered for implementation of intervention and programming efforts.

A Case for Communication

Communication, in itself, exists as a fundamental structure in human existence, and at its core, serves to enable understanding. As the social beings that humans are, we crave connection; the need to give, to exchange, to receive. Without open and honest communication, how can we expect anyone to develop trust, to understand and accept certain truths? Without open and honest communication, how can we expect a child to develop trust in family and medical providers, to understand and accept the necessity of treatments? How can we expect a child to experience a high QOL—to live in full expression—if we do not provide appropriate opportunities for understanding and acceptance?

Studies reporting the lived experiences of children with cancer have detailed pleas for open communication, for information about the disease and language that meets each child where he is (Gibson et al., 2010; Mant et al., 2019). A young cancer patient, 12-years-old, articulated feelings of anxiety and fear due to the lack of information provided to her; “I was not sure what was going to happen...I was scared about what was going to happen...it was just not knowing things” (Mant et al., 2019, p. 10). This experience does not remain unique to this child alone, as evidenced by the following overall observation revealed by Mant et al. (2019): “the children frequently emphasised the importance of information in increasing their sense of control and their understanding of why their treatment was necessary” (p. 10). Furthermore, these

patient-reported needs and experiences align with evidence that provides strong recommendations for both the anticipatory guidance and psychoeducation standard, as well as the procedural preparation and support standard.

Erik Erikson’s psychosocial theory of development describes how children experience the world at different developmental stages, in addition to articulating the needs most pertinent to each stage. Even children as young as four and five years of age experience a limited sense of control and independence, as well as misunderstanding and fear (as cited in Turner, 2018). Application of Erikson’s theory to child life practice suggests that assessing a child’s understanding, providing age-appropriate explanations and overall increasing opportunities for control will all benefit a child of this age (as cited in Turner, 2018, 2nd ed., p. 44). If a child as young as four or five years of age requires appropriate explanations, and opportunities for experiencing more control over their own situations, it would follow that older children would also require these, particularly as autonomy and complexity of understanding tend to increase with age.

CHOP’s Cellie Cancer Coping Kit serves as an answer to the pleas, delivering developmentally appropriate information outside of the medical setting, and opening conversation with psychosocial care providers within the clinical setting. Proving to be beneficial, engaging and comforting in the acceptability and feasibility pilot studies conducted by Marsac et al. (2012), I will make the case that Cellie can appropriately serve as an intervention to address patient-reported needs and experiences, as well as an implementation of two of the aforementioned Standards of Psychosocial Care.

In the studies conducted by Marsac et al. (2012), it was reported that “families used the Cellie Kit for psychoeducation and/or to learn new ideas for coping, to normalize

experiences, to gather information, to initiate conversations, for fun, to promote emotional expression, and for general comfort” (p. 3321). Cellie offers comfort, while the coping cards encourage and facilitate communication. More specifically, the strong patient-reported needs for honest communication directed at them, connection with family, and family’s aid in the communication process (Einberg et al., 2016; Mant et al., 2019) can be met with the help of the Cellie Kit. In the pilot intervention feedback presented by Marsac et al. (2012), a parent provides evidence of this, stating that ““(the Cellie Kit) helped him [the child] formulate questions so (that I could) understand exactly what he was looking for”” (p. 3322). This positive experience in communication indicates that Cellie and the coping cards gave the child a voice in the cancer conversation.

Although each family’s needs are entirely unique, particularly in the context of a cancer diagnosis, there is potential for this resource to ease some of the stress and strain that can be associated with family conversations regarding the disease. Another parent reported that the kit ““made us more comfortable talking about (cancer) with him. (Before receiving the Cellie Kit), there were a lot of things we probably wouldn’t talk about”” (Marsac et al., 20 p. 3322). Reflection on this statement reveals the opportunities for other families to also experience positive shifts in communication, if given access to a Cellie Kit.

Mant et al. (2019) report one 8-year-old child’s unfortunate experiences with understanding his cancer and accepting the treatment process:

He described being afraid to ask questions and felt he would get in trouble for finding out more about his disease. “(I would be) doomed if I ask anymore...I wouldn’t be allowed to know...no idea why they won’t let me know” (p. 11).

In addition to the child's experiences of fear and the absence of communication, Mant et al. (2019) report descriptions of "treatment being forced upon him," and the child's belief that because it is his body, information should be better communicated to him (p. 11). Drawing on Thompson and Young-Saleme's (2015) findings that "psychoeducation appears to have the most consistent effects on improving patient/caregiver knowledge about disease and treatment and increasing health locus of control," (p. S686) it can be argued that the Cellie Cancer Coping Kit has the potential to educate and empower him. Cellie and the coping cards would not only provide developmentally-appropriate information intended for him, but also offer a comforting, tangible resource to facilitate conversations and questions with family, as well as medical staff.

Looking beyond psychoeducation and anticipatory guidance, preparation for and support during specific procedural situations can further bolster positive experiences for young patients. Flowers and Birnie (2015) present the evidence-based consensus that "providing children information about procedures and implementing psychological intervention can ameliorate many of the deleterious effects from invasive medical procedures, increase child coping and cooperation, and prevent increased pain and distress with subsequent procedures" (p. S694).

One of the essential roles of a child life specialist is to prepare children for procedures and support them through the procedure itself. It is well understood that the universal language of children is play; they explore themselves, their feelings, and their world through it. Consequently, medical play is often central to procedural preparation, as it allows children to become familiar with the procedure's steps and equipment in the language that is most natural and comforting to them. Furthermore, facilitation of preparation is often enhanced with the use of dolls, puppets and medical equipment (Goldberger et al., 2018). The child life specialist guides a child through the steps of the procedure, (e.g. placement of a peripheral IV line)

allowing the patient to become the doll's doctor or nurse and ultimately fostering the child's experience of control, autonomy, and competence (Koukourikos et al., 2015). If deemed developmentally appropriate, the child life specialist will facilitate the medical play intervention with the actual equipment that will be used in the procedure itself. This choice enhances the authenticity of the preparation, thus limiting the opportunities for unwelcome surprises during the actual procedure.

Additionally, due to the fact that children often view Cellie as a companion, they may benefit more from a medical play intervention if it centers around helping Cellie through a procedure. The possible benefit is further supported with remarks from a child who formed a significant bond with Cellie during the pilot intervention study; "I sleep with Cellie. I keep her with me when I'm getting the needle in. Cellie's the bomb... it helps me a lot" (Marsac et al., 2012, p. 3321). If Cellie's presence and companionship served this child so positively, it would logically follow that if given the opportunity to engage in medical play as procedural preparation, Cellie would be the one whom she would want to provide care for.

In examining the results of surveys conducted a few years after publication of The Standards, it becomes evident that a lacking of psychosocial staff, funding for psychosocial staff positions, and time to provide psychosocial care present the most notable challenges to provision of sufficient psychosocial care (Scialla et al., 2017). Although permanent and sustainable solutions will most likely require considerable systematic modifications, standardizing the implementation of the Cellie Kit could reduce the negative impacts of these challenges—both for hospitals and staff, as well as patients and families—while positively contributing to fulfillment of both presented standards. The Cellie Kit was designed for use by the child and family, independent of psychosocial care providers (Marsac et al., 2012). This aspect alone creates an

opportunity for families to receive beneficial psychoeducation regarding the cancer and treatment experience, as well as potential coping strategies, at home and at their convenience. Marsac et al. (2012) further concluded that Cellie could serve as “a viable mechanism by which medical teams can supplement their care without requiring additional time commitments from providers;” (p. 3322) but what if it could do more than that? In allowing children to explore their illness experiences with an engaging friend (i.e. Cellie) and family, the kit could lead to time better spent with psychosocial providers in the hospital itself.

If a family was presented with a kit upon diagnosis, they could come to the hospital with not only foundational information: an idea of what to expect with hospitalization and procedures, and coping strategy options, but also more specific, targeted questions for psychosocial providers such as child life specialists. As a result, the child life specialist may be able to spend less time with each family, but overall increase the value and outcomes of each interaction. In turn, this would allow the psychosocial providers to use theirs and their patient’s time more effectively, benefiting each family, even if the aforementioned challenges limit the frequency and duration of interactions. Ultimately, implementation of the kit would serve to not only supplement care provided by psychosocial staff, but perhaps more importantly, to offer a relatable resource that both encourages and facilitates conversation, coping, and acceptance.

A Case for Companionship

For a child, perhaps one of the most devastating aspects of a cancer diagnosis is the loss of what is considered to be intrinsic to childhood. Innocence, freedom to play, and social interaction are among some of the most valued elements of child’s QOL. The loss or disruption of these three elements arguably hinders a child’s ability to live in full expression. Gibson et al. (2010) present supporting evidence for this argument with findings concluded from patient-

reported experiences. “Being in hospital and being attached to a drip took away their freedom and limited their activities...for the young people, not being able to go out and do things made them feel less ‘normal’” (p. 1401). As unfortunate as these experiences are, they do not come as much surprise, considering the psychosocial development of children and given the traditional nature of hospital environments and treatments.

As cited in Turner (2018), Erikson’s psychosocial theory places children between the ages of 6 and 12 in a developmental stage where feelings of competence, as well as peer and family approval of success, are highly formative. As further outlined by Erikson, the illness and hospital experience can significantly affect these feelings, most likely creating “separation from normal activities associated with home, school and peers...” (as cited in Turner, 2018, 2nd ed., p. 44). Cancer and the side effects of treatments often threaten strengths and abilities that a child may have previously had, and due to the concrete, literal thought that accompanies this stage, it is easy for a child to experience misunderstanding and reduced self-esteem (Erikson, as cited in Turner, 2018, 2nd ed., p. 44). Erikson indicates that children in this stage can benefit from social interaction, structure, support, and engagement in activities that create opportunities for the child to demonstrate competence and experience success (as cited in Turner, 2018, 2nd ed., p. 44). Consequently, when cancer steals a child’s ability to attend school, isolates her from friends, and saps her energy meant for playing, responsibility to provide quality psychosocial care that will benefit a child’s QOL becomes paramount.

CCA’s Chemo Pal Mentor Program is one of their JoyRx® programs and fulfills their “We Prescribe Joy” mission through the meaningful pairing of children with adult mentors. As the CCA articulates, this program “empowers children and teens to positively shift their emotional states during the stressful and painful experiences related to fighting life-threatening

illnesses and extended hospitalizations” (CCA, n.d., About us). I will support this statement with evidence that the Chemo Pal Program additionally meets the patient needs reported in relevant literature, while simultaneously fulfilling both the psychosocial intervention and therapeutic support standard and the opportunities for social interaction standard. Application of evidence will demonstrate the necessity for expanding implementation of the program to more hospitals.

Examination of the Chemo Pal Mentor Program reveals the opportunity for children with cancer to form consistent, supportive, and loving relationships with trusted individuals who may have also had an intimate experience with cancer (E. Forsythe, personal communication, June 14, 2019). Interestingly, Christiansen et al. present evidence from their literature review on social interaction that indicates patient-reported preference for interaction with other cancer patients or survivors (2015). “They [youth with cancer] rate meeting other survivors as even more important than family or friend connections” (Christiansen et al., 2015, p. S725). Contextualizing this social interaction preference within the scope of the Chemo Pal Program suggests positive psychosocial outcomes for participants in the program—particularly in the form of feeling understood, accepted and cared about.

Communication with Chemo Pal Specialist, E. Forsythe, revealed an equally noteworthy experience that seemed to be common among participants in the program. Prior to engagement in the mentor program and being matched with a Chemo Pal, children often fought going to the hospital for treatments; yet, after beginning relationships with their Chemo Pals, they began demonstrating visible excitement and anticipation for hospital and treatment visits due to their desire to spend time with their mentors (E. Forsythe, personal communication, June 14, 2019).

Time spent with a Chemo Pal mentor enables a child to live in full expression—from active engagement to restorative moments of quiet and stillness. Cancer treatment and its side

effects often limit a child's access to essential social interactions and play. As an 8-year-old cancer patient states, “It stops me. It is always slowing me down. I can't go to the park... There are so many things I'm not allowed... There is so much I can't do” (Mant et al., 2010 p. 9). In contrast, treatments may sometimes result in both decreased energy levels and interest in participating in normal activities, as supported by a 4-year-old patient's expression that “sometimes I don't feel like playing anything” (Gibson et al., 2010, p. 1401). While these accounts describe seemingly opposing feelings, both are commonly experienced throughout the treatment process. Due to a Chemo Pal mentor's role as a companion and an enabler, he is able to provide a child permission to be whoever she needs to be in that moment. Moreover, mentors play a significant role in ameliorating the patient-reported experience that “chemo is an awful thing,” (Mant et al., 2019, p. 8) while facilitating a child's choice to play, engage in recreation and leisure activities that are personally meaningful, or spend time together in quiet relaxation—all of which have been identified as health-promoting factors by young cancer patients (Einberg et al., 2016).

In moving beyond social interaction as a standard of care and examining the evidence backing psychosocial interventions and therapeutic support as a standard, it becomes clear that children and parents are at risk for adjustment and coping difficulties, and that these risks must be addressed with some form of therapeutic support (Steele et al., 2015). The father of a child who experienced a distinctive transformation in coping abilities, as a result of a Chemo Pal's support, describes the change as follows:

Phoenix literally turned his back to everyone. He was not talking, and he was just exhausted. Everyone was depleted, and there was nothing we could say that would help him... The first time his Chemo Pal Brenton entered our room with a bag of toys had an

immediate impact. Pretty soon they were fist-bumping! Phoenix carried a lot of trauma and to see his smile – it was everything (CCA, 2019).

While it is not clear if Phoenix also received other psychosocial support or interventions (e.g. cognitive behavioral therapy), there is evidence of the Chemo Pal Program initiating a change in his ability to cope. The extent of the impact is further described by Phoenix’s mother, “‘He’s come so far from being shut down and angry to really advocating for himself...he tells the nurses his preferences, and he’s really good at accessing his port! Things have eased up, and he’s much more responsive to treatment’” (CCA, 2019). The positive shifts in emotional state detailed by Phoenix’s mother suggest that the presence of Chemo Pal Brenton led corresponding shifts in experienced QOL. With Brenton’s support, Phoenix began advocating for himself, actively participating in his own care, and overall responding better to treatment—all of which indicate his increased ability “to cope with uncomfortable physical, emotional, and cognitive reactions; and to find meaning in the illness experience” (Hinds et al., 2004, p. 767).

Although there are no therapeutic recreation specialists on the Children’s Cancer Association’s staff, comparison of general therapeutic recreation goals with the outcomes of the Chemo Pal Mentor Program suggests a case for partnership. As defined by the American Therapeutic Recreation Association (n.d.), TR “embraces a definition of ‘health’ which includes not only the absence of ‘illness,’ but extends to enhancement of physical, cognitive, emotional, social and leisure development so individuals may participate fully and independently in chosen life pursuits” (How Are Recreational Therapies Different section). Acting on this concept of health—and furthermore, quality of life—therapeutic recreation departments in children’s hospitals could partner with the CCA to facilitate the expanded implementation of the Chemo Pal Mentor Program and build on the existing therapeutic benefits of the program.

Section 4

Conclusions

Beyond valuing a child's quality of life in an academic way, pediatric cancer care must include the necessary actions that ensure a child is able to experience a meaningful quality of life. With the prior establishment and publication of The Standards, the next action must center around standardizing implementation of evidence-based practices. Commendably, some care teams have already implemented practices, programs, and interventions that effectively address QOL; however, widespread implementation of best practices has not yet taken place. Our colleagues, researchers, and most importantly, our patients, all make the case that it remains imperative for practitioners and administrators become the change-makers and devote the utmost effort and dedication to making quality of life improvements to the childhood cancer story.

The foundational acts of the Psychosocial Standards of Care Project for Childhood Cancer and the countless individuals who have contributed to progress toward the overarching project goal to guarantee “universal access to psychosocial support and intervention for patients and family members... for all 21st century families who face childhood cancer and its sequelae” (Wiener, Kazak, et al., 2015, p. S424) should be applauded. Their success in publishing the Standards for the Psychosocial Care of Children With Cancer and Their Families has laid the groundwork necessary for improving the quality of care provided and the quality of life experienced. Furthermore, evidence supports their continued efforts in development of the Matrix and Guidelines for aiding institutions in assessing and improving implementation of the Standards (Wiener et al., 2019)

This paper does not aim to diminish, contradict or supersede any of the project's efforts; instead, it aims to address just a few of the Standards and patient-reported needs, overall presenting evidence and recommendations for the child life and therapeutic recreation fields to standardize and lead specific implementation of the Cellie Cancer Coping Kit and Chemo Pal Mentor Program. As detailed throughout this paper, evidence links the respective benefits and outcomes of the presented intervention and program to fulfillment of the patient-reported needs and health-promoting factors. Additionally, those needs and factors have been further contextualized alongside four of the published Standards for the Psychosocial Care of Children With Cancer and Their Families. Discussion and analysis reveal the ability of the Cellie Cancer Coping Kit to serve as effective implementation of both the anticipatory guidance and psychoeducation standard, and the procedural preparation and support standard, with the Chemo Pal Mentor Program serving as effective implementation for the remaining two standards: psychosocial interventions and therapeutic support; and opportunities for social interaction.

Overall, the Cellie Kit and the Chemo Pal Program have proven effective in positively impacting the quality of life—the ability to live in full expression—experienced by participating children. Evidence of this impact has been analyzed in the context of the presented Standards and needs, showcasing the likelihood that widespread implementation of the intervention and the program would successfully benefit the psychosocial well-being and QOL of pediatric cancer patients. However, more research is necessary to establish an accurate understanding of the significance of outcomes and financial feasibility of such an undertaking. As a result, this paper serves as a call to further the research, to further examine the implications of widespread implementation of these approaches. This paper serves as a call to expand the evidence-base to support the case for standardized implementation of the Cellie Cancer Coping Kit and the Chemo

Pal Mentor Program. If every children's hospital could support the voice of each child battling cancer with the help of Cellie, and provide the companionship of a Chemo Pal, then we could transform the story of childhood cancer.

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Appendix

Figure 1

The Cellie Cancer Coping Kit



Figure 1. The Cellie Cancer Coping Kit: plush toy (Cellie), coping cards and caregiver book. Reprinted from *Buy Cellie Coping Kit*, by Children’s Hospital of Philadelphia, n.d. Retrieved from <https://www.chop.edu/buy-cellie-coping-kit>. Copyright n.d. by Children’s Hospital of Philadelphia.

Figure 2

Example coping card

<p style="text-align: center;">I don’t like needle sticks</p> <ul style="list-style-type: none"> • Make a plan with your parents and your nurse. Your plan could include: <ul style="list-style-type: none"> ○ Squeezing a stress ball before you get poked for a blood draw ○ Using a hot pack in the spot where you are going to get poked before your poke ○ Listening to music (make a playlist only for pokes) or play video games ○ Squeezing Cellie tight and looking at Cellie until it is over ○ Telling your nurse or parent a story <p>(FRONT OF CARD) © 2012 The Children’s Hospital of Philadelphia</p>	 <p>(BACK OF CARD)</p>
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Figure 2. Example coping card. Reprinted from “Acceptability and feasibility of family use of The Cellie Cancer Coping Kit” by M. L. Marsac, A. K. Hildenbrand, K. Clawson, L. Jackson, K. Kohser, L. Barakat, N. Kassam- Adams, R. Aplenc, A. Vinsel, & M. A. Alderfer, 2012, *Supportive Care in Cancer*, 20(12), p. 3317. Copyright 2012 by Springer-Verlag.