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Kids Alive! Support for Children of Parents with Cancer: An Exemplar Program for Children of  
Parents with Cancer

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Parents with Cancer

Cancer in a parent or caregiver is an event that affects the whole family. The roles and responsibilities of the diagnosed parent, as well as those of each family member, are affected at the time of diagnosis and throughout the progression of the illness. According to the American Cancer Society, there will be an estimated 1,665,540 new cancer cases diagnosed and 585,720 cancer deaths in 2014. This staggering statistic means there are a number of cancer diagnoses that will directly affect thousands of parents and their children. Past research suggests this upheaval in the system is particularly stressful on children and can lead to a number of responses including anxiety, depression, distress, and other negative reactions. Despite the large number of parents and caregivers diagnosed with cancer in the United States each year, there are relatively few support groups aimed at supporting children affected by parental cancer.

Support groups provide opportunities to serve this population in a number of advantageous ways by providing safety, support, and a sense of community. Additionally, support groups allow this population of young people to express their fears and worries, connect to others going through similar circumstances, and explore their parent's diagnosis in a context that is helpful and developmentally appropriate. Past research has found that children who do not receive support during this life-changing event can be negatively affected throughout the life span. On the other hand, this event can be a time to build a child's resilience and provide the structure through which they may thrive in adversity. Support groups offer the opportunity to address this difficult event and lead to positive results. Kids Alive! is one such group that has been proactive in support for children of parents diagnosed with cancer since 1995.

Kids Alive!, a support group that runs out of Porter Hospital in Denver Colorado, uses Joseph Campbell's Hero's Journey to structure monthly groups. The Hero's Journey, described in Campbell's *The Hero with a Thousand Faces* (1949), focuses on a set pattern that all heroes must go through during their journey towards an ultimate victory and self-discovery. Kids Alive! incorporates this journey into a curriculum aimed at helping children explore their thoughts and feelings around their parent's cancer and leads to a realization that they are not alone on this journey. Over the course of eight months, children in Kids Alive! receive support and solidarity that leads to life-changing experiences and an understanding of what a diagnosis of cancer in a parent can mean. Kids Alive! consists of professionals and volunteers who take time to recognize and support this underserved population. The program has led to positive outcomes for nearly two decades and consistently increases the numbers of children and families served.

The purpose of this paper is to describe the Kids Alive! program as an exemplar program that addresses these problems by utilizing protective factors research has found in this population. Further, this paper will discuss areas of future research while providing the model of an effective program aimed at serving an important population. Additionally, the model of Kids Alive! will be described through this paper in a way that allows for other oncology settings to consider this relatively simple program that provides consistently positive results.

### **Literature Review**

This section presents a review of the literature pertinent to children of parents diagnosed with cancer, particularly as it relates to demographic information, risk factors, and protective factors associated with this population.

### **Prevalence of Cancer in Parents of Children**

According to the National Health Interview Survey (NHIS) conducted by the National Institute of Health, a substantial proportion of parents with minor children are affected by cancer in this nation. “An estimated 22.4% of cancer cases occur in individuals between 21 and 55 years of age. These are prime child-bearing and parenting years, so a substantial proportion of survivors in this age range may have minor children” (Weaver, Rowland, Alfano, & McNeel, 2010). Further analysis of the Survey indicates that more than a million families in this nation with minor children have a parent with a diagnosis of cancer. This staggering figure has implications for the youth of this nation, their parents, medical settings, clinicians, and the mental health system.

### **Risk Factors of this Population**

Children of parents with cancer face a number of unique challenges and developmental risk factors; however, these factors can often be overlooked in medical settings due to the focus on the parent with cancer. These factors can also be overlooked by the families where the cancer is occurring due to added stress. A number of studies have highlighted risk factors and drawn significant conclusions about this population. For example, past research examined the hypothesis that children who have a parent with cancer experience greater difficulty in terms of psychological adaptation than children with a parent suffering from another chronic pathology. Children in one study completed the Rorschach Inkblot Test which revealed that children who had a parent suffering from cancer exhibited a higher number of signs of anxiety and depressive affects as well as reduced self-esteem than control group children (Flahault & Sultan, 2010). This suggests that this population is at a higher risk of negative outcomes and functioning and in need of added support. It is important to note that adverse effects in this population do not just occur

during childhood but can continue throughout the lifespan. This was demonstrated in a study that examined the long-term impact of parental cancer during childhood and found that posttraumatic growth experiences were reported by 44% of participants, while 59% reported adverse consequences (Wong, Cavanaugh, MacLeamy, Sojourner-Nelson, & Koopman, 2009). These findings are significant because they show how parental cancer can affect a child long after the diagnosis or course of cancer in a parent. Children may be affected well into adulthood due to such a traumatic event. These findings speak to the adversity this population faces throughout a parental cancer diagnosis and beyond. Without necessary supports in place during a parental cancer diagnosis, children may be affected not only at the time of diagnosis and course of cancer, but well beyond this time too (Wong et. al., 2009).

In addition to the greater difficulty this population experiences in terms of functioning short term and long term, it is also important to note that the family system often does not realize their child is struggling through this experience. Families have their hands full when a parent is diagnosed with cancer, and as a result, children in the family often become less of a focus. Researchers have examined parents' and children's reports of emotional and behavioral problems in children and adolescents from patient families in which a mother or father was recently diagnosed with cancer. Children's symptoms of psychological distress varied considerably according to their age, sex, whether their mother or father had cancer, and whether they or their parents were reporting the symptoms. When children did report elevated levels of psychological symptoms, their parents did not appear to be aware of their distress and rated their children as asymptomatic (Welch, Wadsworth, & Compas, 1996). These findings suggest that the child's experience can be easily overlooked during this stressful family event, particularly when the child is not reporting their own distress to the family. This can lead to children feeling

overlooked, ignored, and alone through this experience. Much of this struggle is due to issues related to communication (Rosenheim, 1986). Explaining what this diagnosis means to a child can be a difficult task for which there is little precedent. Also, between treatments, appointments, and the usual busyness of life, communication patterns may decline and a stressed family system inadvertently fails to address this experience with the children of the family. Past studies have explored ways of informing the child of the parent's illness, how the child perceives the parent's emotional state, how the child copes with the parent's illness, and how this coping relates to the parent's coping and concerns for the child. Communication patterns and parental coping seemed to be highly related to the child's coping repertoire (Thastum, Johansen, Gubba, Olesen, & Romer, 2008). Even though most children have the ability to manage rather well, all children are strongly affected by the illness. Adaption in children is likely directly related to factors within the family system, which has implications for the importance of the family's response. This research suggests that children do best in parental cancer situations when there is open communication and family support. This can be hard to come by during moments of crisis, however, and families often need extra outside sources of support.

Families can feel overwhelmed after a diagnosis of cancer in a parent and certain structures and roles in the family are often affected, as well as families' financial circumstances. Past studies have examined the reorganization of family life after cancer diagnosis with a specific focus on parents' self-reports of how their families developed and experienced new routines and roles. Research has found that this restructuring of family routines can be stressful but can also work to strengthen family connection and cooperativeness depending on how it is addressed (Buchbinder, Longhofer, & McCue, 2009). Cancer also is a financially stressful event as treatments are expensive, the parent with cancer often has to stop working, and work hours are

negatively affected. This can lead to the family experiencing financial hardships that affect the whole family and change the daily routine for children (Torp, Thoresen, Gronningsaeter, Grov, & Gustavsen, 2013). Taking these drastic changes and financial shifts into account when focusing on the effects of parental cancer is essential to measuring the full extent of risk factors for children in this population.

### **Protective Factors of Population**

Despite the aforementioned risk factors associated with this population, researchers have also identified certain protective factors associated with children of parents with cancer. Some examples of these factors include the family's response during this time, the individual child's resilience, the child's age and the support of medical professionals during this event.

Evidence from moderate to high quality studies suggests that better family functioning indicates better adjustment through parental cancer (Krattenmacher, Kuhne, Ernst, Bergelt, Romer, & Moller, 2012). These research findings show that families that already struggle with communication, mood features, and other family related dynamics or factors such as parent's depressive mood will struggle more during a parental diagnosis of cancer. However, families that are more adept at communication, support, and structure will function more successfully during a cancer diagnosis. Additionally, social support, and support from sources outside of the immediate family are essential to the successful functioning of both the parent with cancer and the family as a whole (Applebaum, Stein, Lord-Bessen, Pessin, Rosenfield, & Breitbart, 2014; Thompson, Rodebaugh, Perez, Schootman, & Jeff, 2013). These factors suggest that patients, and as a result families and children, who face a diagnosis and course of cancer, are more likely to have positive outcomes when there are others on whom they can rely or turn to for support outside of the immediate family system.

### **Kids Alive!**

Kids Alive! was founded in 1995 after participants in a breast cancer support group voiced concern about a lack of organized support for the children of parents diagnosed with breast cancer. Kids Alive! soon included children of parents with any cancer diagnosis. It has run each year from 1995 through the present, and during this time has served hundreds of families at no financial charge. Instead, Kids Alive! is supported by private donations, grants, and Porter Hospital. The program runs out of Porter Hospital in Denver, Colorado and includes professional staff from the hospital, as well as volunteers from both the hospital and greater Denver community.

The goal of Kids Alive! is to address the trauma of a parent's cancer diagnosis by providing a secure and healthy environment in which children are free to express their feelings. Kids Alive! meets eight months of the year for two hours each month. Additionally, kids are invited to take part in an overnight retreat in the Rocky Mountains of Colorado. Throughout the year, children in Kids Alive! receive exposure to other children experiencing similar circumstances, caring volunteers and professionals, and a curriculum devoted to exploring this difficult journey. A unique feature of Kids Alive! is a policy allowing former child participants in the group to take on the role of “junior volunteers” as they age. This adds to the meaningfulness of the group experience as young adults are able to share their own experiences in a way that benefits younger children. Additionally, Kids Alive! allows participants to return each year regardless of the outcome of their parents’ cancer. This leads to a rich combination of participants and volunteers who have various experiences of the course of their parents’ cancer. This means that there are participants and volunteers in the group that have experienced a

parent's death from cancer, a parent's remission, or even a parent's recurrence of cancer during their time in Kids Alive!

Having access to so many different experiences of parental cancer allows the group to serve children going through a variety of unique circumstances. The end result of such a group creates an environment that is emotionally moving, consistently supportive, and deeply meaningful to most involved. The following section of this paper will explore the curriculum and experience of Kids Alive! through a description of the group, the author's personal involvement in the group, and personal quotations of children and volunteers involved in the group.

### **Participants**

Families involved in Kids Alive! learn about the group in a variety of ways. Many of the families involved receive medical treatment at Porter Hospital in Denver, Colorado. Porter Adventist Hospital, located in southern Denver, is a full-service hospital that has a specialty unit devoted to cancer care. Other participating families hear about Kids Alive! through friends, family members, other cancer treatment facilities, and the volunteers who help run the group. The majority of children involved in Kids Alive! through the years have been between the ages of 6 to 16 years. The group's demographics throughout the history of Kids Alive! have included include both girls and boys, and included Caucasian, Latino, and African-American participants and families. Generally, the group ranges in size from 35-45 participants and children are often added through January as new children often enroll. Children involved in Kids Alive! have parents that are in various stages of various different kinds of cancers. Often, children involved in the group participate in one or more years of the group and are invited to come back each year. Once children reach the age of 13, they sometimes have the chance to become junior volunteers and help run the group.

## **Schedule and Structure**

The Kids Alive! support group meets monthly from October through June for two-hour sessions. Each monthly group focuses on a new topic of discussion. In March, the group attends an overnight trip to Snow Mountain Ranch in the Rocky Mountains of Colorado. In addition, two family potlucks are generally held during the year to provide information to the families about the progress of the group and to give families a chance to ask questions or provide feedback.

## **Hero's Journey**

The structure of Kids Alive! follows a curriculum based on Joseph Campbell's Hero's Journey described in his book *The Hero with a Thousand Faces*. Joseph Campbell, an American mythologist, writer, scholar, and philosopher, lived and worked during the 20<sup>th</sup> century. He created the idea of the "monomyth," or "one myth." The monomyth means that all myths, stories and adventures told throughout time by humans have similarities and follow a certain series of events. As Campbell himself wrote, "Throughout the inhabited world, in all times and under every circumstance, myths of man have flourished; and they have been the living inspiration of whatever else may have appeared out of the activities of the human body and mind. (Campbell, p. 1). Campbell further explained that one of the themes of the monomyth is the journey of the hero. "The standard path of the mythological adventure of the hero is the magnification of the formula represented in the rites of passage: separation-initiation-return." (Campbell, p.23).

Campbell noticed that every human culture and society has stories with similar, overarching steps and themes. These themes follow a journey by the human protagonist. Specific steps of the Hero's Journey include The Call to Adventure, The Belly of the Whale, Allies, The Road of Trials, Encountering the Dragon, and Freedom to Live. These trials along

the journey involve different stages of significance for the protagonist and ultimately contribute to the overall meaningfulness of the journey. The steps aforementioned specifically describe the following: The Call to Adventure involves the precipitating event that compels the hero on the adventure, The Belly of the Whale signals the feelings of hopelessness and loneliness the hero experiences when the journey commences and a turn inward, Allies refers to the companions the hero meets and interacts with on this journey, The Road of Trials represents the various struggles the hero must overcome along the journey to progress, Encountering the Dragon is symbolic of the ultimate challenge the hero must overcome on the journey, and the Freedom to Live is the conclusion of the journey when the hero has overcome all obstacles, fears, and challenges in order to return to what is now a changed perspective on life. Over the steps of the Hero's Journey, the hero is altered by experiences, stronger because of the challenges faced, and enlightened by the journey itself. This monomyth is powerful due to its pervasiveness in humanity. Additionally, it follows a storyline that is similar to the development all human's must face in life and therefore immediately relatable.

Kids Alive! incorporates the Hero's Journey throughout the eight month curriculum of each yearly group. The children participating in Kids Alive! are exposed to the Hero's Journey at the first group meeting, and the journey theme is revisited at various times over the course of the program. Utilizing the Hero's Journey allows children to relate their own experience of a parental diagnosis to the story of the hero. They incorporate their own steps of this life changing event into a format that allows them to describe their own reactions, challenges, triumphs, and experiences. Further, the format of the Hero's Journey is developmentally appropriate for children participants due to the clear steps involved, examples from children's culture (i.e., books, movies, and cartoons), and positive message. Additionally, the use of this format allows

for integration of different types of mediums over the course of the year. A few examples of this include art projects, stories, skits, and music therapy. Using these different media while discussing the Hero's Journey and parental cancer allows for a wide range of outlets participants can use to explore and express their own experiences while gaining support and solidarity with others in the group.

### **Kids Alive! Goals and Objectives**

The goals and objectives of Kids Alive! are as follow:

1. To provide a safe, helpful environment for children of cancer patients to express their feelings.
2. To create a place for a child to be a child...to experience fun, support and continuity of life...apart from catastrophic illness.
3. To facilitate a better relationship between cancer patients and their families, reducing guilt and anxiety in children.
4. To help parents interpret their children's behavior as adaptive to the trauma of the family.
5. To develop awareness of resources for both parents and children.

These goals are accomplished through the curriculum and structure of Kids Alive throughout the year and by utilizing the Hero's Journey format discussed above.

The first goal of Kids Alive! is to provide a safe, helpful environment for children of cancer patients to express their feelings. This goal is addressed by providing a safe setting for children where they can feel supported in talking about their own personal experience as well as their parent with cancer. Kids Alive! groups are held once a month for two hours on Saturday mornings. This monthly format allows children consistency without requiring excessive participation in a group that focuses on a very difficult subject. For the majority of meetings,

only children, junior volunteers, and volunteers are welcome to stay while parents are asked to leave their children and not be present for the group. Occasionally, younger children feel overwhelmed being surrounded by strangers, and some parents remain present to calm them, however, parents are generally discouraged from remaining in the group. The reason for this policy is because this group is specifically for the child of a parent with cancer; it provides a place where the child can talk openly about their own experience of a parent's cancer without having to worry about how the parent would react. The structure of Kids Alive! meetings works to address the first goal by providing a comfortable setting in order to increase children's familiarity with the other people in the group. The groups begin by using "icebreakers" that encourage children and volunteers to share information with one another such as their name, favorite foods, activities they enjoy, and other casual information. This is a chance for the children in the group to gain familiarity with others in the group and be put at ease. This is generally followed by more formal introduction in order to increase familiarity and comfort. Additionally, children check in on a scale of one to ten in order to share how they are feeling that day. This introduction format continues throughout the remainder of the year and provides consistency and structure to each group session's beginning. The purpose of having the child share information about themselves is twofold: first, this gives the child permission to participate in this safe setting and begin the process of discussing a challenging topic; and second, this allows children to realize they are not alone in this journey and that other children their age are experiencing a parental cancer diagnosis as well. Children are supported consistently by junior and adult volunteers that remain involved throughout the whole year. This addresses the aforementioned goal by providing consistent help and an opportunity for the participants to gain

comfort working with familiar individuals. The consistent structure and dependable support from volunteers allow children to achieve the first goal of Kids Alive!.

The second goal of Kids Alive! is to create a place for a child to be a child...to experience fun, support and continuity of life...apart from catastrophic illness. The different experiences children get to have during the year address this goal. Throughout the year, children participate in a variety of activities that allow them to experience the fun and excitement of being a child. Examples of child appropriate activities are readings during most groups from *The Hope Tree* by Laura Numeroff and Wendy S. Harpham, M.D, 2001. This book is a collection of different children's experiences when their mothers were diagnosed with breast cancer. Although the book is specific to breast cancer, it still contains a number of experiences that the children in Kids Alive! can relate to regardless of their parents' type of cancer. This allows children to discuss cancer in a way that is developmentally appropriate. Additionally, the children in Kids Alive! undertake art projects and music therapy activities. These activities provide the children an alternative way to express their feelings rather than constantly being asked to discuss how they are feeling by adults in their lives. Another important component of allowing children in the group to meet the above goal is the spring trip to Snow Mountain Ranch in Granby, Colorado for a full weekend. This trip allows the children in the group a chance to get out of their everyday environment and explore new settings. Although there is some discussion of parental cancer on this trip, the main focus is providing children a chance to have fun and get away for a weekend from the intense event happening in their life. At Snow Mountain Ranch, children have the chance to take part in sledding, roller skating, arts and crafts, rock climbing, games, and other enjoyable activities. Adult volunteers take part in the trip; however, children are given the chance to interact with one another in a free form setting that

encourages a break from the daily routine. In addition to providing the children in the group with an adventure in the Rocky Mountains, the trip also allows the parents of the children a weekend for themselves during this stressful time. The trip is often reported as the most enjoyed part of Kids Alive! by the children year after year. These opportunities throughout the year address the second main goal of Kids Alive!.

The third goal of Kids Alive! is to facilitate a better relationship between cancer patients and their families, reducing guilt and anxiety in children.” This goal is addressed with a focus on the stress and unique experience that only a family going through parental cancer could fully understand. Specifically, different groups during the year focus on encouraging children to explore how their family has changed during a parental diagnosis of cancer. For example, children are tasked with taking part in a family sculpting exercise in which children take turns to show the group their family. This exercise provides a way for children to explore factors such as who they feel closest with in the family, where the cancer is in the family, and different family members’ feelings throughout the diagnosis. This exercise for younger children involves the use of puppets in order to model different interactions and events that have taken place in the family since the diagnosis of cancer. Also throughout the year, children reflect on the following types of questions: How has life changed? How do you know when mom or dad do not feel well? What are your greatest fears? Who are your allies? What do you do to help yourself feel better? These interventions and questions serve as a jumping off point for family discussions after the group itself and allow families in this situation to acknowledge their worries and fears together. These types of group activities and discussion points work to address the third goal of Kids Alive!.

The fourth goal of Kids Alive! is to help parents interpret their children's behavior as adaptive to the trauma in the family. This can be a challenging goal to accomplish during such a hectic experience in a family's life. Kids Alive! addresses this goal throughout the year by providing children an outlet to express anger, frustration, grief, and other difficult and negative emotions in a safe setting. This can be a helpful outlet for children as well as a comforting step for parents who are struggling with a cancer diagnosis and raising young children. Children may experience a number of challenges during their parents' diagnosis of cancer such as academic problems, behavior difficulties, relational conflicts, and anxiety. Kids Alive! groups normalize some of these struggles as part of the child and family journey. This is addressed throughout the year and specifically addressed in the last group during reflection on the year. Families are present during the last group and are allowed to discuss where they are on the Hero's Journey and how they are managing the experience together. This last group also revolves around the idea that the journey is not over despite the fact that the program is completed. This is an important point as many of the families in Kids Alive! will still continue their journeys with parental cancer. Attendance at this group is emotionally moving as families come together both figuratively and literally and discuss the reality of living with cancer in the family. Additionally, at this group families have the opportunity to talk to one another about the group, their experiences, and various other factors associated with the unique circumstances of these families. This open communication and family involvement in the last group of the year address the fourth goal of Kids Alive!.

The fifth and final goal of Kids Alive! is to develop awareness of resources for both parents and children. This goal is addressed by involving various professionals in groups, a quarterly newsletter, and collaboration with Porter Hospital where the group is held. At various

groups during the year, children take part in activities led by professionals in fields such as art therapy, music therapy, pet assisted therapy, as well as working with volunteers who are professionally involved in medical and mental health field. This provides parents the chance to connect with individuals and organizations that can further support their children outside of group if so desired. Additionally, a quarterly newsletter is sent out to all involved with Kids Alive! that discusses group activities and themes, as well as resources in the community. Lastly, Kids Alive! is held in Porter Hospital in Denver, Colorado. Porter Hospital has a Cancer Care Center and a wide variety of information about additional resources for families experiencing a parental diagnosis of cancer. This wide exposure to different resources addresses the fifth and final goal of Kids Alive!.

### **Author's Previous Grief Experience**

Throughout this author's secondary education and graduate school experience, he has been involved in grief work with children, teens, and families in a number of different ways. Initially, the author became interested in the grief process after graduating from the University of Denver's undergraduate program. At this time, he was connected with a volunteer organization called The Starfish Program that provided grief support to children and teens who experienced the death of a loved one. Following this experience, this author did a graduate school practicum from 2011-2012 at Judi's House, a grief counseling center in Denver, Colorado. In this placement, the author ran grief counseling groups for various age groups that included children ages three through eighteen, as well as groups for their parents. Most of the children participating in the groups had experienced the death of a parent. Additionally, this author has been involved in providing grief therapy to various individuals including both children and adults. Due to these experiences, this author was drawn to Kids Alive! and its focus on

childhood grief from the potential loss of a parent to cancer. This author has been a volunteer in Kids Alive! for the past two years and plans to continue volunteering in the future.

### **Effects of Kids Alive!**

#### **Past Research**

A quantitative study was completed by Laura Meyer, PhD using a Kids Alive! sample in 2011. This quantitative study focused on the effectiveness of the support Kids Alive! provides. During that year's Kids Alive! program, parents and children in the group completed questionnaires at three different times. The first questionnaire was completed prior to the first session of the Kids Alive! Group, another questionnaire was completed after the fourth meeting of the group, and the final questionnaire was completed at the conclusion of the last Kids Alive! meeting. Questionnaire data were collected and statistically analyzed. The results of this study suggest that children benefit from participation in Kids Alive!. The hypotheses about this finding concluded that as family functioning and children's difficulties returned to a more normal level, parents focused on more typical problems.

It is important to note that the results of the quantitative study above suggest some positive changes for participants as well as some limitations of a quantitative study for a group such as Kids Alive!. Due to the number of participants, a lack of control group, and attrition rates over the times follow up studies were conducted, it is important to consider other designs for researching the efficacy of Kids Alive!. Parents that were interviewed for this study reported that they noticed positive changes in communication with their children. However, the data collected during this study did not support this finding. Despite parents' reports that communication with their child was improved, an analysis of covariance (ANCOVA) revealed that scores on one assessment, the McMasters Family Assessment Device (FAD), increased

significantly ( $p < .05$ ) from the first test administration to the third, suggesting an increase in negative communication issues affecting the family over time.

### **Anecdotal Evidence**

In addition to this research, there is plenty of anecdotal evidence to support the positive effects of Kids Alive! for individuals and families. Kids Alive! has been running since 1995 which has led to nearly 20 years' worth of experiences and stories. During that time, hundreds of families have been through the program and have reported the value of having a program like Kids Alive! to help with their journey. Additionally, Kids Alive! has no limit on the amount of time a child can be in the group. This policy allows children the chance to return to Kids Alive! for years and make lasting connections to other children, adult volunteers, and families.

Kids Alive! also has a junior volunteer program that encourages participants in the group to become volunteers when they enter their teenage years. This adds a meaningful level to the program as it allows children who have experienced a variety of outcomes during their parents' diagnosis and course of cancer to share their experience with others and assist in running the group as they develop. Further, junior volunteers serve as positive role models to the younger children in the group. The younger children see teenagers who have been on a similar journey to them and still have the ability to help others, talk about their experience, and assist in running groups.

Adult volunteers are also an essential part of the Kids Alive! experience. Many of the adult volunteers in the group have either had cancer, had a parent with cancer, or have personal experience working in a medical setting involving cancer. This leads to invested volunteers that meet the children in the group where they are at with their journey. Adult volunteers often return for several years to help run the group as well which speaks to the meaningful experience of a

program like Kids Alive!. Lastly, Kids Alive! is run by three caring, experienced, and passionate founders. Jeanne Curry, RN, MN, CNS, Madelyn Case, PhD, and Lorraine Hart, PhD, are all Denver area professionals who have been involved with Kids Alive! since its inception. These three individuals bring decades of experience working with children and families to the Kids Alive! experience. They are constantly making new connections in the community to support Kids Alive!, while also facilitating the minute to minute structure of Kids Alive! groups. The leadership of these passionate professionals allows Kids Alive! to not only survive year after year, but also to thrive as time continues.

Throughout its existence, Kids Alive! has consistently sought feedback from participants in both informal ways and in structured meetings. This has led to a number of meaningful quotes and stories that have captured the essence of the Kids Alive! experience anecdotally. The following are some of the quotes gathered from individuals connected with Kids Alive!. Names have not been attached to these quotes in order to protect confidentiality:

“Kids Alive! is a program that places the experience of the child at the forefront and encourages each individual to be the hero/heroine of his or her own journey.”

“My daughter is so well adjusted I cannot believe a 7-year old could be so strong. Thank you to the Kids Alive! Program and all the Saturdays they had spent with my daughter.”

“We were comforted knowing he had a place to share his feelings.”

“Kids Alive! – both the professionals and the volunteers – really gives our kids the tools they need to be fully present to the moment by helping them to deal with the fear and the anger and the sadness – and not to deny it but to deal with it in a place that is manageable for them.”

“I realized this may be the only place where people understand what my family is going through.”

“Kids Alive! taught me how to recognize children’s sensitivities and how to help them overcome problems out of their control.”

This is a small sample of the different ways Kids Alive! positively changes lives as families go through this experience. A program that has existed for nearly 20 years and is continually funded by grants and donations speaks for its own success.

### **Future Research Needs**

In order to measure and more accurately explain the experience of children and parents involved with Kids Alive!, it would be beneficial to run a qualitative study because of the limited size of the group and the interview format. Specifically, a phenomenological study might capture the essence of the actual lived experience through the use of interviews. These interviews could capture the meaning and essence of the participants’ and parents’ experiences as they reflected upon their journey during a parental cancer diagnosis and involvement in Kids Alive!. A narrative analysis could be used to identify common themes among the words and phrases of the study participants. This type of analysis could better capture the participants’ improvements and growth during their participation in the Kids Alive! program. Further, Kids Alive! participants have a variety of different backgrounds and situations related to parental cancer. This type of design could allow for a more diverse sampling of the participants and parents in Kids Alive!.

To set up this sort of study design, a questionnaire and a semi-structured interview protocol could be utilized. The questionnaire would be designed to collect demographic information about the program’s child participants. Following administration of this questionnaire, a semi-structured interview could be used in order to capture the experience of the participants and their parents. The interview questions would include follow-up questions to increase the clarity and depth of responses. Ideally, the interview questions and format would

allow the researcher to explore specific themes and factors associated with children of parents with cancer. For example, the researchers could write interview questions designed to explore changes in anxiety associated with Kids Alive! program participation. Use of this qualitative design would enable a researcher to capture relevant information about Kids Alive! and to possibly make recommendations that could further enhance the program curriculum.

### **Discussion**

Kids Alive! is an exemplar program that is meeting the needs of an underserved population. Considering its nearly two decades of existence and consistently high attendance, Kids Alive! provides a unique, valuable service to an underserved population. Specifically, the Kids Alive! program supports families experiencing a parental cancer diagnosis, an outlet for children to communicate their experiences of a terrifying reality, and a developmentally appropriate setting and curriculum that provides comfort and encouragement to children.

When a caregiver or parent is diagnosed with cancer, a number of things change immediately in a family system. Financial stress, time constraints, role shifts, and communication restrictions are often direct consequences of the diagnosis and children in the system feel less control than ever. Parents with cancer can feel exhausted and challenged to meet everyday obligations, which in turn impacts their children. The healthy caregiver in this situation also feels more stress as they now take on additional responsibilities and the emotional strain of the situation. This leaves children feeling unsupported, lonely, and even resentful. Kids Alive! serves as an alternative source of support in this situation. Children in Kids Alive! are provided additional help and energy from volunteers and other children. Kids Alive! provides a monthly setting for families to gain extra support for their children and themselves. Further, the retreat Kids Alive! holds in March allows for children to get away from their stressful situation for a

weekend. The therapeutic value of this sort of break from the intensity of life cannot be overemphasized.

In addition to the extra support families and children receive from Kids Alive!, children are encouraged to talk about what has changed in their life and environment with others who are experiencing similar situations. This allows children to see that they are not alone. Furthermore, it gives these children a sense of normalcy in an otherwise far from normal circumstance. Hearing peers their age discuss what has changed in their own lives shows the participants that, although it is far from ideal, their situation is survivable. Starting a dialogue in the group furthers discussion within the family system as well. Children are primed to express themselves and their personal experience. When they leave group, they now have a more organized template from which they can discuss their journey with the family. Communication, as discussed earlier, is an essential strength factor when a family goes through a parental diagnosis of cancer. Giving children and families permission to talk about cancer is often a simple but effective step. Families can feel overwhelmed by such a situation and just knowing that it is okay to express this with one another can be relieving and empowering.

Kids Alive! also provides a context and structure that meets children wherever they are in their process of dealing with parental cancer, and then encourages the child to grow. Children in these circumstances must face the harsh reality every day that their parent is seriously ill. This is overwhelming for any individual, let alone an individual that is experiencing the additional challenges of childhood and development. Children often feel that few things are in their control because adults make most of the decisions directly affecting their lives. A parental diagnosis of cancer contributes even more to this feeling of no control. Additionally, children are often experiencing some of the most drastic mental and emotional changes a human can experience.

These developmental factors combined with a stressful family event can lead a child to feel like they are growing up way too rapidly and losing all innocence at once. Kids Alive! recognizes the unique period of life that participants are experiencing and provides a developmentally appropriate program to match. In Kids Alive!, children are not expected to sit in a circle and talk for two hours straight about their parent's cancer diagnosis. At the same time, children are not shielded from the realities that occur because of this event. Kids Alive! manages to blend a nurturing environment with a curriculum that addresses cancer directly. This combination creates a setting that recognizes this stressful life event while providing a comfortable context in which to discuss it.

### **Future Implementation of Program**

Kids Alive! is a program that has run successfully for nearly 20 years. It is consistently well attended and constantly attracts new volunteers and families. It affects families' lives positively during a time when they are struggling with a stressful and overwhelming event. Part of the utility of a program like Kids Alive! is the relative ease with which it could be implemented in other health care settings. Kids Alive! has used the same curriculum with only minor changes since 1995.

The program is mainly underwritten by Porter Hospital but also relies on donations and grants in order to cover costs involved in running such a program. The program runs in a medical setting with an oncology unit. This setting ensures that Kids Alive! is supporting a relevant population in a convenient location. Further, the hospital setting provides a conference room throughout the year which ensures consistency and familiarity of setting for participants. Relying on volunteers and available professionals willing to share their time minimizes the overall costs of Kids Alive!. In addition, the monthly two hour meetings provide a structure that limits the

time intensive nature of volunteering or taking part in the group. For the aforementioned reasons, Kids Alive! could be a viable program for use in many other locations and settings. The Kids Alive! curriculum could be particularly useful in other hospitals and medical settings that focus on cancer treatment. This curriculum centers on parental cancer in a way that is supportive and useful for children, as well as accessible and helpful for families.

Overall, Kids Alive! is an example of an exemplar program filling a specific niche in the medical world. It addresses a difficult subject with a population that is significantly affected by their experience. Kids Alive! has an impressive track record, passionate volunteers and leaders, and access to a relevant population. These factors add up to a meaningful and frequently life-changing experience for everyone involved with Kids Alive!.

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