ABSTRACT

A SUPPORT PROGRAM FOR PARENTS WHO HAVE CHILDREN WITH CANCER: A GRANT PROPOSAL

By

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Diagnosis of cancer found in a child impacts not only the child being diagnosed, but the siblings, parents, and family as a whole. The purpose of this thesis project was to write a grant in order to fund the development and implementation of a support group for parents who have children with cancer. In partnership with Camp Ronald McDonald for Good Times, the program would create a 6 week long support group that would provide parents with skills, resources, and interventions needed to parent a child diagnosed with cancer. The W.K. Kellogg Foundation was selected as a funder because of the foundation's dedication to promote the health, happiness and well-being of children. This grant reviews the challenges parents have as well as the positive impact this program could have on the parents and their children. Submission and funding of this grant were not requirements of successful completion of this project.

A SUPPORT PROGRAM FOR PARENTS WHO HAVE CHILDREN WITH CANCER: A GRANT PROPOSAL

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INTRODUCTION

Problem Statement

Children with cancer today receive a large part of their treatment at home, which means more responsibilities are given to the parents and the family members (Klassen et al., 2007). A diagnosis of childhood cancer can be extremely scary for a parent as well as stressful. Many of the parents focus on giving their full attention to the patient while having to set their own emotions and responsibilities aside. As the parental role changes, they focus on learning more about their child's diagnosis, learning how to monitor the child's health, and meeting the child's needs (Anderzen-Carlsson, Kihlgren, Svantesson, & Sorlie, 2010). This change in parental responsibilities may increase their chances of showing symptoms of anxiety, depression, and posttraumatic stress. Other symptoms may also include guilt, sleep disorders, somatic symptoms, changes in diet, and physical and emotional overload (Gedaly-Duff, Lee, Nail, Nicholson, & Johnson, 2006). Caring for their child can be described as an "unexpected career" which can require the parent to leave their occupation and adapt and restructure new responsibilities over time (Klassen et al., 2007).

It is crucial that attention be given to studies that show that parents who adjust well to their child's cancer received better social, emotional, and psychological support. Schweitzer, Griffiths, and Yates (2012) found that parents commented on the support they received as being the most crucial part of their experience. Not only social support was considered important, but positive coping and communication also helped parents alleviate their child's distress regarding cancer treatment (Schweitzer et al., 2012). Parental support groups can provide much needed support and an opportunity for building parenting skills and coping strategies. These groups also provide resources needed to help parents better adapt to their child's diagnosis as well as find ways to support the child and other family members.

Purpose of the Project

The purpose of this proposed program was to partner with a local host agency, locate a potential funding source and write a grant to obtain funding for a support group for parents who have children with cancer. In partnership with Camp Ronald McDonald for Good Times (CRMfGT), the intention of the project would be to provide funding for a support group to be implemented at the CRMfGt main office. The overall program goal is to help parents with developing the methods needed by increasing their support network as well as increasing resources available. Specifically, the support group would consist of providing parents with the skills, interventions, and resources needed. In addition, they would be provided with a safe environment in which they can express their feelings and concerns while sharing it with others who share similar experiences in order to establish group cohesiveness. Parents' mental health, such as symptoms associated with cancer (i.e., depression, anxiety, PTSD), will also be addressed.

Two part-time social workers will facilitate the support group and will be responsible for teaching skills that will in return help parents learn to adapt and cope with their new living environment. To minimize the parent's effects of caring for a child with cancer and make it easier for parents to access the support group, it is important for the support group to be developed in a community where the parents will have easier access to their services. The CRMfGT is the perfect location considering easier access to the parents and the fact that the parents are already aware of the Los Angeles office.

Definition of Terms

The following terms related to childhood cancer and effects it has on parents will be used in this thesis.

Childhood cancer: The most common cancer that occurs in childhood includes various forms of leukemia and lymphomas, brain and central nervous system tumors, embryonic tumors, sarcomas of bone and soft tissue, and gonadal germ cell tumors (Ward, DeSantis, Robbins, Kohler, & Jemal, 2014).

Mental health: Parents of children with cancer may experience mental health problems. These diagnoses may include, but are not limited to, anxiety, depression, PTSD, and somatic symptoms (Clarke, McCarthy, Downie, Ashley, & Anderson, 2009).

Psychological distress: Distress levels for parents, children and extended family members in this population are extremely high and expected. Parental psychological distress can have a dramatic impact on the child with cancer as well as their siblings. Recognizing and helping to ease distress can help parents cope with their distress which can improve family well-being (Rosenberg et al., 2013).

Social support: Social support may come from family members, co workers, community members, other parents experiencing the same type of event, health care providers, and many others. Most families and parents mention at least one source of social support that was helpful in managing their child's cancer experience (Patterson, 2004).

Multicultural Relevance

According to Ward et al.'s (2014), there are an estimated 15,780 new cases of cancer that will be diagnosed for the year 2014. In addition, there will be 1,960 deaths from cancer among children and adolescents age birth to 19 years. Although all ethnicities are impacted, White and Hispanic children have the highest rates for childhood and adolescent cancers (Ward et al., 2014). American Indian/Alaska Native children have the lowest cancer incidence and mortality of all ethnic groups. Also, pediatric cancer has been found to be higher in industrialized countries than in developing countries (Ward et al., 2014). Childhood cancer rates vary by cancer type. Leukemia (40%) and brain and central nervous system tumors (27%) are the two most common cancer diagnoses in adolescents (American Childhood Cancer Organization, n.d.). Factors that have been mentioned by Ward et al.'s (2014) in regards to why racial and ethnic disparities exist in survival for childhood and adolescent cancers had been noted. Factors include socioeconomic status, parental education, health insurance status, timely diagnosis, and knowledge about the cancer diagnosis.

It is important to incorporate a family's unique ethnic and cultural considerations when discussing terminal illness of a child. Sourkes et al.'s (2005) state the important areas to explore such as how one's ethnic, cultural, or national background impacts one's experience at the hospital or with caregivers. Also, attention should be given to immigrant and minority families, prejudices the family might be encountering, their beliefs and values towards childhood illness and death. In addition, addressing unique roles that the family members play is important, such as certain cultures believing that the father is the decision-maker and finds it offensive when critical information is discussed when father is not present (Sourkes et al., 2005). It is difficult in areas such as California, with its complex mix of ethnicities, to know all backgrounds. However, it is expected for the health care providers to assess for this information to build rapport with these families and provide them with the best care possible.

The proposed program will be housed out of the CRMfGT's office in Los Angeles, California. According to the CRMfGT, by the end of 2007, there were more than 6,000 campers from 10 states and eight countries that had attended Camp Ronald McDonald for Good Times (Camp Ronald McDonald, n.d.). This number shows the high amount of parents that can potentially participate in the support group and the different ethnicities involved. Special care will be taken to outreach to parents of all socioeconomic, racial, and ethnic backgrounds.

Social Work Relevance

Social workers value the importance of human relationships and recognize the importance of promoting, maintaining, and enhancing the well-being of individuals and families (National Association of Social Workers, n.d.). This is extremely important to focus on while helping a family who has a child with cancer. The diagnosis of cancer in childhood can bring about many different challenges for the parents. Social workers play a significant role in reducing the symptoms of the child and the family by alleviating suffering and providing support (Jones, Christ, & Blacker, 2006). In the same study done by Jones et al. (2006), social workers found that families and the patient felt lost when entering the medical setting and needed guidance from social workers at that moment.

Interventions with the children and their families can help decrease parents' burden and increase communication between the family and the child (Jones et al., 2006). Social workers also provide a unique voice to the understanding of the needs of the children and their families and provide the skills needed to take on such a challenging task.

CHAPTER 2

LITERATURE REVIEW

Childhood Cancer

Cancer Statistics

In 2014, there is an estimated 15,780 new cases of cancer that will be diagnosed and 1,960 deaths from cancer that will occur among children and adolescents aged birth to 19 years old (Ward et al., 2014). Approximately 1 in 285 children will be diagnosed with cancer before they are 20 years old. Additionally, approximately 1 in 530 young adults between the ages of 20 and 39 years are survivors of a childhood cancer. Cancer is now the second leading cause of death among children who are between the ages of 5 to 14 years (Ward et al., 2014). Although there have been advances made in the treatment, there has been less progress made in understanding and preventing childhood cancer (Ward et al., 2014). In the United States, there are more than 2,000 children aged 0 to 19 years that die each year of cancer (Jones et al., 2006). Patients who survive 5 years may still be at risk of recurrence and could possibly be at an increased risk of developing subsequent chronic diseases (Ward et al., 2014).

Among childhood cancers, leukemia has the highest frequency (31.4%), followed by malignant brain and central nervous system neoplasms (17.6%) and lymphoma (12.4%; Miller, Young, & Novakovic, 1995). Hodgkin lymphoma (15%), thyroid carcinoma (11%), brain and central nervous system tumors (10%), and testicular germ cell tumors (8%) are the four most common cancers diagnosed in adolescents (Ward et al., 2014). In children, mortality rates are lower in girls than boys. Among adolescents, rates are similar between boys and girls, while survival is higher for girls.

Cultural Relevance

Although all ethnicities are impacted, White and Hispanic children have the highest rates for childhood and adolescent cancers (Ward et al., 2014). American Indian/Alaska Native children have the lowest cancer incidence and mortality of all ethnic groups. Also, pediatric cancer has been found to be higher in industrialized countries than in developing countries (Ward et al., 2014). Acute Lymphocytic Leukemia (ALL) is more common in industrialized countries than in developing countries. A child's probability of surviving cancer is poor in less-developed countries. Factors that have been mentioned by Ward et al.'s (2014) in regards to why racial and ethnic disparities exist in survival for childhood and adolescent cancers include socioeconomic status, parental education, health insurance status, timely diagnosis, and knowledge about the cancer diagnosis.

It is important to incorporate a family's unique ethnic and cultural considerations when discussing terminal illness of a child. Sourkes et al.'s (2005) state the important areas to explore such as how one's ethnic, cultural, or national background impacts one's experience at the hospital or with caregivers. Also, attention should be given to immigrant and minority families, prejudices the family might be encountering, their beliefs and values towards childhood illness and death. In addition, addressing unique roles that the family members play is important, such as certain cultures believing that the father is the decision-maker and finds it offensive when critical information is discussed when father is not present (Sourkes et al., 2005). It is difficult in areas such as California, with its complex mix of ethnicities, to know all backgrounds. However, it is expected for the health care providers to assess for this information to build rapport with these families and provide them with the best care possible.

Medical Setting

Three fourths of pediatric deaths occur in hospitals each year (Davies et al., 2008). Browning and Solomon (2005) found that the healthcare system has been failing to meet the needs of children and families that are facing a life-threatening condition. The families of these children reported feelings of abandonment as well as feeling overwhelmed with the amount of information they receive. Children and adolescents with cancer should be treated at medical centers that specialize in childhood cancer by multidisciplinary teams in order to help them understand all of the information given. This team includes pediatric oncologists, surgeons, radiation oncologists, and others who have experience such as nurses, psychologists, and social workers (Ward et al., 2014).

Physicians

There are many roles that physicians play. Being a physician implies facing life-threatening conditions, psychosocial issues, and existential frustrations (Stenmarker, Palmerus, & Marky, 2009). The authors found that the most distressing factors physicians experience was informing children about the disease (86.6%) and meeting the parents of children with cancer (81.1%; Stenmarker et al., 2009). In addition, another factor that made it emotionally heavy were economic discussions (15.5%) and having to organize certain aspects of treatment. These physicians are trained to cure and feel as though they have failed when they are forced to deliver bad news (Stenmarker, 2010). While living in a society that fears death, physicians face anxiety and depression due to having to take on a stressful task such as communicating bad news to the family and the child (Stenmarker, 2010).

Primary care providers have often known the family over time and have provided stability and guidance in the medical system. They can be educators such as taking complex information about their child's diagnosis and explaining it in ways that will make it easier to understand. The primary care provider is most aware of the kind of support that is needed for the child and the family (Sourkes et al., 2005). They care for the child during the illness and are called on to make decisions that are best for the child. They also provide pain and symptom management in order to provide the child with comfort and alleviate as much pain as possible. The physician, in this case, would be the one to tell the family about the diagnosis and to build a good relationship with them in order for the family to be able to trust the physician with the care of their child.

Anderzen- Carlsson, Kihlgren, Skeppner, and Sorlie (2007) state that it is important for children to feel as though the physician is not just a medical professional but also a human being with feelings and emotions. The physician has the hands on experience with medical equipment and can help the child make the unknown become known. Anderzen-Carlsson et al.'s (2007) addressed the way in which physicians handle the fear in the child as well as the parents. They are responsible for explaining procedures in a way that can be understood by the entire family. It was also stated that there is a great deal of importance on repeating information to both parents and the child while playing down the negative aspects in order to reduce the fear.

Nurses

Sourkes et al.'s (2005) refer to nurses as being part of the front lines by spending the most time with the child and their families. Families stated that the role of the nurse was extremely important in providing support and taking on educational roles. The primary role of the nurse is to provide hands on care for the child and to advocate for them since they spend the most time with them (Sourkes et al., 2005). They are the ones whom the child and the parents tend to confide their hopes, fears, and concerns with. Although the primary care provider makes the final decisions, the nurses play a vital role in assessing, informing, implementing, and evaluating (Sourkes et al., 2005). Nurses are also the first respondents to help the child with managing their pain (Ljusegren, Johansson, Gimbler Berglund, & Enskär, 2012).

Ljusegren et al.'s (2012) conducted a study on nurses' experiences of caring for children in pain and found that nurses believed it was important for them to have self-confidence and to trust in their own experience when working with children. Having the knowledge about pain and pain management helped the nurses feel confident and they were able to better provide for the child by addressing any questions or fears they had. Also, when working with children who have cancer, not only work experience, but also life experience, was considered important. Children find it important that they have a nurse who is confident in what he or she is doing and also that they provide good communication and observational skills (Ljusegren et al., 2012).

Social Workers

Social workers play a significant role in pediatric oncology in helping to reduce symptoms, alleviate suffering, and by providing support (Jones et al., 2006). The most important role of the social worker is to assess the patient and the family's background, beliefs, cultural/spiritual practice, mental health, behaviors, coping, communication, and needs for resources (Sourkes et al., 2005). They then work as an interdisciplinary team to help staff understand the family and address their needs. Social workers are able to use interventions with the patient and the families in order to ease the parents' burden as well as improve the end of life care for the patient. Social workers are present in the medical setting by helping children and families and providing them supportive counseling and developing interventions with the child. They are also there to help increase communication between the family and the medical system, increase communication between child and family, and supporting the needs of the family as they possibly face loss and grief (Jones et al., 2006). Social workers also allow the children to understand and make decisions about their own treatment.

Jones et al.'s (2006) study showed that physicians, nurses, and other health professionals have reported being ill-prepared to have conversations with children and their families at the end of life. As a result, social workers are called on to provide emotional support to the dying child and their families. While working in an interdisciplinary setting, social workers bring a unique voice due to the values of social work. These values include working with systems, treating the family as a whole, respecting individuality, and fostering clients' self-determination and empowerment (Jones et al., 2006). As part of the interdisciplinary team, social workers are called to provide psychosocial support, advocacy, empowerment, resource management, family therapeutic interventions, and companionships and counseling to the child with cancer

(Jones et al., 2006). Social workers in this field believe that the child should be empowered and should have input over their own life and end-of-life decision-making.

Mental Health

Parents

Due to the fact that parents take on such important roles in caring for a child with cancer, their mental health can be impacted by a range of physiological and psychological symptoms (Granek et al., 2012). The researchers conducted a study in which parents reported disturbances related to sleep, diet and exercise habits, and reported symptoms of anxiety, depression, and feeling down while their child was in treatment. Having a child diagnosed with cancer can increase a parent's risk of having posttraumatic stress disorder (PTSD; Dunn et al., 2012). The behaviors associated with PTSD included difficulty regulating negative affect and cognitions related to the trauma, attempts to avoid emotions and thoughts related to the trauma, and feelings of detachment from others. Parents also experienced increased irritability and anger, and difficulty regulating physiological and emotional arousal in response to trauma-related cues (Dunn et al., 2012).

It has been found that although both parents find it difficult to adjust to their new roles and have mental health problems associated with caring for a child with terminal illness, mothers carry a heavier burden. One study found the parent role to be more central to the identity of the mother than of the father, therefore leaving mothers feeling less in control and carrying a major burden of care and responsibility (Murphy, Flowers, McNamara, & Young-Saleme, 2008). Kaplan, Kaal, Bradley, and Alderfer (2013) found that 27% to 30% of mothers and 12% of fathers of childhood cancer survivors qualified for a diagnosis of PTSD since their child's diagnosis. Among the symptoms found in these parents, there was a great importance in the diagnosis and treatment of depression due to its high morbidity and mortality. Benaroya-Milshtein et al.'s (2014) looked at depressive symptoms in this population and found illness in a child induces depression in a subset of parents that implies the need for psychiatric and psychosocial interventions in parents of children with cancer.

Siblings

Siblings within these families have a unique experience of childhood cancer that can be distressing and traumatic. Studies have found that siblings report symptoms of PTSD and psychological problems (Kaplan et al., 2013; Shea, O'Shea, Robert, & Cavanaugh, 2012). Twice as many girls (29%) than boys (16%) met full criteria for PTSD (Kaplan et al., 2013). In the Kaplan et al. 2013 study, researchers found that one third of the sample met symptom criteria for PTSD. Symptoms that were reported included feelings of intense fear, horror, and helplessness. Three fourths of the sample reported that they thought their brother or sister's life was in danger when hearing the cancer diagnosis. More than half (60%) of the siblings reported experiencing moderate to severe levels of PTSD. This same study showed that the siblings reported symptoms of anxiety and depression as well. The numbers that were reported highlighted the importance of also focusing on the siblings and the development of interventions to address the siblings' distress.

Another study found that 65% of siblings experience some sort of psychological problem following the diagnosis (Shea et al., 2012). They may witness their sibling in pain, looking ill, or losing weight and hair, feel distressed by being separated from the diagnosed child for a long period of time or from lack of knowledge in regards to the disease, or feel fear that the sibling will die or that they may die. Also, they may lose support from their parents as parents shift their attention to the child who is sick and the treatment demands may remove the parents from the home (Kaplan et al., 2013). The siblings of the patient are also at risk for having difficulties adjusting (Kaplan et al., 2013).

Patient

Anxiety is commonly found in children with life-threatening illnesses (Klick & Hauer, 2010). There are many factors that can lead a patient to having anxiety such as separation from family, pain symptoms, loss of control, loss of contacts, and self-image issues. In addition, children have problems coping with the stresses of treatment, surgery, chemotherapy, and radiation (Marcus, 2012). Eilertsen, Rannestad, Indredavik, and Vik's (2011) study found that, out of 20 participants, 16 children had psychological symptoms of anxiety, depression, behavioral problems, eating problems, or suspected attention deficit-hyperactivity disorder. The remaining four children had problems with concentration, fatigue, cognitive and learning disabilities, or were socially isolated.

Eilertsen et al.'s (2011) also found that children surviving cancer had more emotional symptoms, higher total problem scores and poorer academic performance than their peers. Children who survive are at higher risk even after several years following diagnosis and treatment. The type of cancer that is diagnosed plays an important part in determining psychological impact as well. Cancers of the central nervous system are associated with greater levels of psychological distress (Abrams, Hazen, & Penson, 2006). The reason for this is due to the greater burden of cognitive deficits as well as the social difficulties associated with brain tumors. Abrams et al.'s (2006) state that it is important to have early involvement of mental health professionals in addressing potential difficulties in adjustment after diagnosis. This would allow for earlier detection when problems arise and would allow the patient and the worker to build rapport and trust that is needed to help the patient through the stages of their treatment.

Effects on the Family

As a Family

As a family, priorities become rearranged, routines are lost, and emotional stability can vanish. The diagnosis is life altering for not only the patients but also their families. Caring for the child can be described as an "unexpected career" which can require the parent to leave their occupation and adapt and restructure new responsibilities over time (Klassen et al., 2007).

Hallstrom, Wiebe, and Bjork (2005) found two themes in regards to views of one's own family when a child was diagnosed with cancer. The first theme was that of a "broken life world." Family members experienced that their family life had fallen apart. The security and safety they had once felt was now replaced by fear, uncertainty, chaos, and loneliness. They believed their life fell apart. The family, who had been facing everyday life, was now forced to face possible mortality and became vulnerable (Hallstrom et al., 2005).

The second theme was one of "striving to survive." Family members worked together to strive for survival. These families focused on not only the survival of the ill child, but it also included the survival of the entire family. Instead of focusing on the fear and uncertainty, the families would focus on hope and having a positive focus. Although they knew that death could be a result of the diagnosis, the families continued to have hope that their child would get better (Hallstrom et al., 2005). The findings showed that the child's illness affected and controlled the family as a whole. Although each family member responded differently to the experience, the members had their world turned upside down by the diagnosis. Woodgate and Degner (2003) described the family's experience of getting through all the hard times by focusing on keeping the spirit alive. The diagnosis of cancer can also bring about financial, emotional and physical strains on families (Granek et al., 2012).

Sourkes et al.'s (2005) state that a child's illness can either unite or destroy a family depending on the family's resiliency and vulnerability to stress. Family functioning such as specific roles each member plays can be extremely important factors to look at. The way power and control within the family is defined must be understood. No matter what role the family member has, stress is something that affects all members (Sourkes et al., 2005).

As a Parent

The parents need to learn ways in which they can cope with their child's diagnosis in order to be able to better adapt and serve as an example to the rest of the family. The new responsibilities parents have include providing the child with emotional support while regulating their own emotions, dealing with medical visits, operations, possible relapses, paying attention to all medical necessities, all while trying to cope with the diagnosis themselves (Kohlsdorf & Costa, 2012). Parents reported feelings of fear and disbelief when told their child's diagnosis (Hallstrom et al., 2005). Parents also reported difficulty continuing to work and also found that they now behaved differently as family members. Parents also reported now being controlled by the child's diagnosis (Hallstrom et al., 2005). Learning to cope with the diagnosis can be extremely vital in order for the parents to better adapt to their child's illness.

Parents face increased caregiving needs, anticipatory grief, pressure to meet the needs of siblings and other family members, stress from navigating the medical system, anxiety and confusion about the diagnosis, and an increase of emotions (Jones et al., 2006). Parents also reported needing support, understanding, reassurance, education, guidance, and care. Tillery, Long, and Phipps (2014) found that parents of children with cancer tend to overprotect their child, which leaves parents feeling that their child is vulnerable. This type of outlook then impedes the parent from practicing healthy parenting. Parents find it difficult to balance their increased vigilance and protection of their child, while still allowing and promoting age appropriate activities and opportunities. Also, there is a role reversal that should be noted when discussing effects on a parent dealing with a child who has a life-threatening disease. The cycle of life that is expected is that children will one day care for dying parents. When parents instead find themselves caring for a child who is facing the possibility of death, any sense of order is shattered for those parents (Sourkes et al., 2005).

As a Sibling

Hallstrom et al.'s (2005) study found that siblings reported needing different forms of support in order to cope with their sibling's diagnosis. Feelings of missing their own family's usual activities as well as feelings of neglect were reported. If the patient is in the hospital, the sibling receives little to no attention from the parents as they themselves take on the challenge of maintaining equality and normality (Sourkes et al., 2005). Siblings tend to stand outside of the spotlight and receive a lack of attention and care (Sourkes et al., 2005). Siblings, no matter their order in the family, tend to demonstrate a great deal of concern for the patient. Also, siblings take on feelings of guilt that they “escaped” the disease and they are able to continue living their life while their sibling cannot.

Many siblings found that it was important for them to receive information about their sibling’s diagnosis. They wanted to understand what has happened and the reasons for the treatment. It is difficult for siblings to understand whether or not the patient is still the same person, despite the difference in appearance (Sourkes et al., 2005). The siblings wanted to understand the “outings” the parents and the patient went on as well as why the patient did not have to attend school but they did. The study further explains that siblings also suffer academically and show somatic reactions to the illness. Sibling’s academic performance is affected due to lack of guidance at home as well as being impaired due to their preoccupation. Also, physical symptoms and sleep problems may develop due to high levels of stress or as a way of receiving attention from the parents (Sourkes et al., 2005).

As a Patient

The child that has been diagnosed with cancer is now facing many challenges in addition to that of the rest of the family. The patient is dealing with alterations to how they look, feelings, and lifestyle, as well as the loss of support and a need for information on their diagnosis (Hallstrom et al., 2005). Physical appearance and attractiveness are some of the major effects concerning adolescents (Abrams et al., 2006). Researchers have found that the most disturbing changes that occur to an adolescent with cancer was hair loss, the presence of a catheter, weight changes and scars. Hallstrom et al. (2005) found that children between the ages of 0 to 7 and children 13 years and older experience physically distressing events. Children aged 8 to 12 experienced emotionally distressing events. Adolescents experienced the illness as difficult while depending more upon their parents. There was a general theme found of children wanting to know more about their cancer and wanting to feel cared for and special (Hallstrom et al., 2005).

Jones et al.'s (2006) study showed that children need someone to discuss their hopes and fears with, someone other than their parents. Children reported wanting to protect their parents from the pain. Also, children reported they need love, reassurance, comfort, and understanding that their parents will be able to cope if they do not survive. They now feel they have a loss of control, identity, and relationships. They are dealing with a great sense of loss of control in regards to their body, over illness and pain, emotions, passage of time, and over their life itself (Sourkes et al., 2005). Patients also seem to be affected by the diagnosis in the sense that their life no longer has structure. School provides the structure and social contact needed but the diagnosis has now disrupted their attendance in school (Abrams et al., 2006). There is higher level of rates for children who do not attend school if they have Central Nervous System tumors, solid tumors, and those undergoing bone marrow transplant.

In addition, patients report feelings of guilt due to the fact that they now require more attention than before (Sourkes et al., 2005). Although, if giving attention to the patient becomes the norm, the child then takes on too much power, marital dynamics could be affected, and siblings lose their visibility within the family. Sourkes et al.'s (2005) focused on what patients wanted most during this time in their life. It was found that they longed for normalcy of daily life, while continuing to live with the illness. While the illness could be looked at as abnormal, they wanted to still be normal in the eyes of their family. School was where the patient reported feeling normal due to the consistency and stable routine. They also expressed fear due to whether or not their peers would understand their change in appearance and looking "different." Patients report that the diagnosis affects their ability to maintain friends. They classify their friendships into two categories: those from the "healthy" world such as their school and neighborhood and those from the "sick" world such as the hospital, clinics, and camps (Sourkes et al., 2005).

Psychosocial Interventions

Importance of Support

Schweitzer et al.'s (2012) found that parents commented on the support they received as being the most crucial part of their experience. Included in the experience of support was family support, a supportive workplace, support from the education system and being accepted by their peers. Not only social support was considered important, but positive coping and communication also helped parents alleviate their child's distress regarding cancer treatment (Schweitzer et al., 2012). Parental support groups can provide much needed support and an opportunity for building parenting skills and coping strategies. These groups also provide resources needed to help parents better adapt to their child's diagnosis as well as find ways to support the child and other family members.

The physical and psychological health of children with cancer has been linked to the health and the quality of care that they received from their parents (Fotiadou, Barlow, Powell, & Langton, 2008). The problem that is being faced is that there is not enough focus on the psychosocial well being of the parents (Rosenburg, Baker, Syrjala, Back, & Wolf, 2013). Due to the fact that the child's health serves as a priority, there is minimal attention given to the parents and the types of resources they receive. Kato and Suzuki (2003) found that psychosocial interventions used on the parents tend to focus on helping the patient cope by increasing communication about their diagnosis as well as providing support via cancer camps and support groups. In the same study it stated that parents are directed to the Internet for information related to their child's diagnosis along with parent support groups provided online. The resources being given to the parents is Internet based, leaving the parents to find resources on their own.

Schweitzer et al.'s (2012) found that parents commented on the support they received being an important part of their experience. This theme was separated into four sub-themes: family support, supportive workplace, experience of the education system and the experience of being accepted. The support was found to be extremely crucial for the family and helped alleviate some of the stress that was associated with the diagnosis. In addition, it has been reported that parents have emphasized the value of support in regards to receiving practical support and assistance with household responsibilities. Instead of the parents having to focus on household duties such as grocery shopping, cleaning, and cooking, they now had more time to focus on the child with the illness. Having this type of support would help families have a better sense of control in regards to their practical aspects of daily life.

Cancer Camps

Children’s cancer camps came about in the 1970s in order to help children and their families escape the severity of treatment (Laing & Moules, 2014). Since the very first camp opened in Florida in 1976, more than 60 summer camps have been created (Martiniuk, 2003). Cancer camps were structured to meet the needs of the whole family and to make the patient feel “normal” again. The camps provide children affected by cancer, siblings and families with normal life experiences that they have missed out on due to treatment. Campers are offered a variety of outdoor and recreational activities such as swimming, fishing, archery, arts and crafts, and completing ropes courses (Wu, Prout, Roberts, Parikshak, & Amylon, 2011). In addition, it provides children with support around issues relating to cancer and it also allows parents to have a break while the children are at camp.

The purpose of attending cancer camps is to give the child a sense of belonging. It is an experience in which families are in a place where everyone is, or has, experienced similar events. These families are able to understand one another and support each other. Social support is emphasized when discussing cancer camps. The expression, “I know what you’re feeling” now has validity. The patients and their siblings are given the opportunity to express their own feelings that improves the psychosocial adjustment through the feeling of having social support (Martiniuk, 2003).

The goals of these camps are to help children make new friends and allow them to catch up on social interaction skills that cancer has denied them. Briery and Rabian (1999) found that after a child spent a week at camp they reported more positive attitudes about their illness at the end. They help children become more independent and confident all while improving their self-image and help children meet others who have shared similar experiences. Also, it is to help the siblings from feeling left out (Martiniuk, 2003). These camps are designed to provide these children a place in which they could share their anger, frustrations, fears, and guilt with others who can help normalize the feelings. Martiniuk (2003) found that children learned new skills while at camp that helped improve their confidence and self-image. These new skills allowed the child to gain back some control over their life. The most important aspect of camp was the opportunity for the patients and siblings to be children again. Volunteers are asked to treat each camper like “regular” kids while acknowledging that there are some children that may have limitations (Rich, 2002). They are allowed to join in all activities given the fact that they are created to accommodate all needs.

Therapy

Psychotherapy, for both child and family, is important in order for any mental health symptoms to be addressed. Many of the children enter therapy due to the high levels of stress they experience due to their illness (Sourkes et al., 2005). Trauma can extinguish a child’s ability to play. Through child therapy, the child is able to restore the imagination and techniques. Through words, drawings, and play, the child is able to convey his or her experience and is able to “re-enter” childhood (Sourkes et al., 2005). For some children, techniques such as relaxation and guided imagery can be effective. Although the child is provided with these techniques by the mental health professional, it is crucial for the parents to also be involved and incorporate these techniques at home. Abrams et al.’s (2006) state there are also more traditional treatments that can be provided to the child that are associated with cancer treatment. These treatments include cognitive behavioral therapy in order to learn coping skills and support resiliency, psychotherapy, medication, support groups for patients, and music and art therapy. Behavioral and cognitive-behavioral techniques are most frequently used to address the problems experienced by the ill child (Kibby, Tyc, & Mulhern, 1998).

Wheeler (2005) stated that the need for parents to have support seems to be underestimated by health professionals. It is crucial for families to be provided with as many resources available in order to help them during this difficult time, and after. Family therapy can be provided in order to help the family sustain, strengthen, and repair family resources and family communication (Sourkes et al., 2005). Family therapy has also shown to improve the understanding and adjustment of siblings (Lobato & Kao, 2005). It allows the family to learn how to be sensitive to the ill child's needs as well as ways in which they can encourage each other using the skills learned in therapy. In addition, learning ways in which to motivate the child can help apply the learned skills in daily life (Scholten et al., 2011).

Parent's role in caring for an ill child can cause marital distress as well. It is important to assess them when they encounter marital and psychological difficulties in order to enhance their ability to parent their ill child (Cloutier, Manion, Walker, & Johnson, 2002). The authors completed a study in which they assessed thirteen couples with ill children in order to determine relationship distress. They used Emotional Focused couple therapy (EFT) in order to secure bonding and also to work on attachment needs and fears. After a 2-year follow up, results showed 2 couples had recovered, 8 couples had improved, 2 couples remained unchanged, and 1 couple deteriorated. Overall, results showed improvements in marital functioning in distressed couples. Due to the fact that EFT provides couples with the techniques to emotionally engage and respond to each other's needs in a way that builds trust and intimacy, results show they are better able to care for their ill child as partners rather than individually (Cloutier et al., 2002).

Online Support Groups

Online support groups have showed to be a great source of help for individuals (Gilat, Tobin, & Shahar, 2011). There is now over several hundred thousand groups that have been created in order to cover health and illness related topics (Coulson & Greenwood, 2012). With an increase access to internet, there are now new opportunities available to families to seek information, advice and support about childhood cancer (Coulson & Greenwood, 2012). Online support groups have proven to help cancer patients feel as though they are better informed and believe it has also enhanced their social well-being (Seydel, Taal, Laar, Drossaert, & Uden-Kraan, 2009). Patients reported feeling empowered due to the fact that they were partaking in an online support groups. The study suggested 61% of the participants felt they knew what questions to ask their doctor and 53% felt prepared for a doctor's appointment and knew how to clarify their needs to the doctor. There were 55% of the participants that reported feeling more open about their illness by participating in an online support group.

Coulson and Greenwood (2012) found that these families looked for different types of social support: emotional, informational, esteem support and tangible assistance. Emotional support was shown through empathy, encouragement, as well as understanding that was provided by individuals who were surrounded by stressful situations themselves. For example, when one mother asked for advice on how to approach her daughter's reluctance in taking her medication, members were able to relate and provide understanding. Informational support was shown by those who were provided with referrals to other resources and teaching of various issues relevant to childhood cancer. Esteem support was reported as compliments, validation, and relief of blame. Tangible assistance referred to direct tasks that needed to be completed as well as willingness from members to help one another.

Overall, the research found supported the grant writer's conclusion that parents of children with cancer lacked many resources and could benefit from an increase in support groups. It was through the research that the grant writer found that children with cancer today receive a large part of their treatment at home, which brought about a theme throughout the literature of more responsibility being given to the parents and the family members. Also, there was a constant theme of many of the parents focusing on giving their full attention to the patient while having to set their own emotions and responsibilities aside. It was through the research that the grant writer found that parents could benefit from additional resources specifically targeting parent's needs and the type of resources that they continue to lack.

CHAPTER 3

METHODS

Project Purpose

Camp Ronald McDonald for Good Times (CRMfGT) is a 6 day, 5 night summer camp that provides activities of a “normal” camp, adapted to meet the special needs of the campers. The CRMfGT also provides families with a weekend long experience, also known as “Family Camp,” in the Spring and in the Fall. The purpose of family camp is so that parents and their children can play together without having to worry about their daily environment (www.campronaldmcdonald.org). There has yet to be an implementation of support specifically focused on only the parents. The intention of the project would be to provide funding for a support group to be implemented at the CRMfGt Los Angeles office. The support group would consist of providing parents with the skills, interventions, and resources needed. In addition, they would be provided with a safe environment in which they can express their feelings and concerns while sharing it with others whose share similar experiences in order to establish group cohesiveness. Parental mental health, such as symptoms associated with cancer (i.e. depression, anxiety, PTSD) will also be addressed.

Having a support system has been shown to make a difference in parent’s depressive symptoms; parents have more depressive symptoms with a decrease in social support over time (Norberg, Lindblad & Boman, 2005). Parents of children diagnosed with cancer enter this new environment in which they are required to develop methods and skills in order to manage their new circumstances (Schweitzer et al., 2012). The overall program goal is to help these parents with developing those methods by increasing the parental support network as well as increasing resources. Two part-time social workers will facilitate the support group and teach skills that will help parents learn to adapt and cope with their new living environment.

Potential Funding Sources

The grant writer initiated the process of seeking grant funding by using an online database. The funding sources considered for this project were explored through various websites including Fundsnet Services (www.fundsnetservices.com), www.grants.gov, as well as databases available through the Long Beach Non-Profit Partnership Library. Fundsnet Services is a fundraising and grant directory, free of cost, which has been available for use since 1996. The search directory involved topics such as “Children, Youth and Family Grants” and “Public Society Benefit.” After searching different topics, the writer found this cite to be too complex to use due to the fact that it was difficult to find grants related to topic and based on location needed.

The second online source, www.grants.gov, has been providing a location for grant seekers to find and apply for funding for grants since 2002. It was designed to provide a common website for agencies to post different funding opportunities and for those seeking grants to be able to find and apply to them. Keyword terms used for searches included: s*upport group, cancer, and mental health*. Over a thousand results showed and after specifying grant type and category, 212 results were left. The search resulted in finding sources that met the population needs and project criteria to fund it. The writer ruled out these results after finding it difficult to access the grant application.

The Long Beach Non-Profit Partnership Library was visited to conduct additional research into potential funding sources for this project. The grant writer contacted library staff in order to access their listing of over 120,000 grant makers. After participating in an hour long training session, the grant writer was able to navigate through the directory. The grant writer searched, while using The Foundation Directory Online, under key terms under h*uman services*, *mental health*, and *crisis services*. Key terms such as *family services, parent education, counseling,* and *support groups* were also used during the search. Some terms were combined in order to increase potential funding sources. The search did not yield any viable funding sources that met the population needs and project criteria to fund it.

After searching many different databases, the writer felt it was too complex to understand on her own. This writer then sought help from her advisor, whose guidance assisted the writer in finding three prospective funding sources relevant to the grant being proposed: The Weingart Foundation, Annie E. Casey Foundation, and W.K. Kellogg Foundation. After reviewing all three foundations, W.K. Kellogg Foundation was found to fit best with the writer's goal for this project. W.K. Kellogg concentrates on the belief that all children should have an equal opportunity to thrive. The foundation works exclusively on issues with children, their family, and the community.

Description of Funding Source and Submission Process

Founded in 1930 by Will Keith Kellogg, W.K. Kellogg Foundation (WKKF) is among one of the largest foundations in the United States whose focus is to promote the health, happiness and well-being of children. The foundation has continued to evolve throughout the years and is now awarding grants in the United States, Mexico, Haiti, northeastern Brazil and Southern Africa. The foundation's mission is now in support of children, families and communities in order to help strengthen and create conditions that help vulnerable children achieve success. Their vision is to use all of their resources in order to make sure that all children thrive (W.K. Kellogg Foundation, n.d.).

In 1906, Mr. Kellogg accidentally let stand a batch of boiled wheat which then turned to flakes. This then became the basis for Corn Flakes and the Kellogg Company. In 1909 he wrote that if his company thrived, he would make good use of his money. In 1930 that is exactly what he did by establishing, what was then called, the W.K. Kellogg Child Welfare Foundation. He instructed his staff to use the money in any way they wish as long as it promoted health, happiness and well-being of children.

The Kellogg Foundation accepts grants all year long and does not have any submission deadlines. WKKF places the optimal development of children at the center of all they do. Their three strategic goals are educated kids, healthy kids, and securing families. Within and around these goals are the commitment to community and civic engagement and racial equity. They believe that if they partner with diverse communities, they are able to amplify their voices and help create conditions in which their children can thrive (W.K. Kellogg foundation, n.d.).

The submission process for the W.K. Kellogg Foundation is all online. The online application requests that grant seekers provide information such as the overview of the project, program outcomes, total budget and total amount being requested from the Kellogg Foundation. Once the application is submitted, an automated response will be sent in order to acknowledge its receipt. The application is reviewed within 45 days which is when the application is either declined or selected for further development. The application guidelines of the W.K. Kellogg Foundation grant application were followed.

Agency Description

The host agency for this project is Camp Ronald McDonald for Good Times (Camp Ronald McDonald, n.d.). Founded in 1982, Camp Ronald McDonald for Good Times has been providing services for families, siblings and children who have cancer. The mission of CRMfGT is to create a positive long-lasting impact on children with cancer and their families by providing fun-filled, medically supervised, cost-free, year-round camp programs (www.campronaldmcdonald.org). They believe that nothing can compensate for the anguish that childhood cancer inflicts, but they have helped thousands of children and their family members recapture hope, enthusiasm, and love of life in a medically and psychologically safe environment created especially for them.

Camp Ronald McDonald for Good Times is a 6 day, 5 night experience that offers a variety of opportunities for cancer patients and their siblings. They also provide weekend long family camps, in the spring and in the fall, where parents can join in the fun. Activities at the camp site includes swimming, horseback riding, hiking, backpacking and other sports that can be adapted, as needed, to ensure each person is able to participate, regardless of his or her level of ability or challenge (Camp Ronald McDonald, n.d). Campers are able to express their creativity through arts, crafts, pottery, music, dancing, performing arts and radio broadcasting. They are also given the opportunity to challenge themselves at the Adventure Courage Course and 50-foot climbing tower. The CRMfGT main office is located in Los Angeles, California and their campsite is located in Apple Canyon, California.

Target Population

The target population for this grant proposal is the parents of children who are currently participating with Camp Ronald McDonald for Good Times (CRMfGT). For the purposes of this project, the parents were defined as biological mother and father, stepparents, or legal guardians. This program is designed to provide a weekly support group that will meet once a week for 6 weeks, geared specifically to the parents of the CRMfGT campers. The support group will occur four times a year. According to the CRMfGT, by the end of 2007, there were more than 6,000 campers from 10 states and 8 countries that had attended Camp Ronald McDonald for Good Times (Camp Ronald McDonald, n.d). This number shows the high amount of parents that can potentially participate in the support group. Special care will be taken to outreach to parents of all socio-economic, racial, and ethnic backgrounds. The program's goal will be to provide parents with education (i.e. skills and interventions) and resources needed to raise a child during treatments and procedures for cancer. Parents will also learn how to cope through the education and support provided.

The program will be based out of the CRMfGT's office in Los Angeles, CA. The need for these services was based on the grant writer's personal experience within the host agency. The CRMfGT provides many resources for the child and the sibling, but currently lacks additional support for the parents, aside from the Family Camps that occur seasonally. The implementation of this program would provide the parents the space to find support from other parents as well as assistance from social workers who will be facilitating the groups, providing education and needed resources.

Needs Assessment

The need for these services was based on the grant writer's personal connection to host agency as well as literature that has proven the importance of providing parents with a support group. Children with cancer today receive a large part of their treatment at home, which means more responsibilities are given to the parents and the family members (Klassen et al., 2007). A diagnosis of childhood cancer can be extremely scary for a parent as well as stressful. Many of the parents focus on giving their full attention to the patient while having to set their own emotions and responsibilities aside. As the parental role changes, they focus on learning more about their child's diagnosis, learning how to monitor the child's health, and meeting the child's needs (Anderzen-Carlsson et al., 2010). This change in parental responsibilities may increase their chances of showing symptoms of anxiety, depression, and posttraumatic stress. Other symptoms may also include guilt, sleep disorders, somatic symptoms, changes in diet, and physical and emotional overload (Gedaly et al., 2006). Caring for their child can be described as an "unexpected career" which can require the parent to leave their occupation and adapt and restructure new responsibilities over time (Klassen et al., 2007).

It is crucial that attention be given to studies that show that parents who adjust well to their child's cancer received better social, emotional, and psychological support. Schweitzer et al.'s (2012) found that, parents commented on the support they received as being the most crucial part of their experience. Not only social support was considered important, but positive coping and communication also helped parents alleviate their child's distress regarding cancer treatment (Schweitzer et al., 2012). Parental support groups can provide much needed support and an opportunity for building parenting skills and coping strategies. These groups also provide resources needed to help parents better adapt to their child's diagnosis as well as find ways to support the child and other family members. In addition to the literature, the thesis writer also found, from personal volunteer experiences, that there was a need for parental support in the organization.

Program Goal

There are three main goals for this project: (1) to provide support to the parents of children with cancer by introducing interventions and skills needed for themselves, the child, and the siblings, (2) to provide resources available to the parents, and (3) to provide parents with a social network of those who have experienced, or are currently experiencing, having a child with cancer. Evaluation tools will be created to measure and monitor each of the established goals.

Potential participants for the program will be recruited through the CRMfGT camp roster. By contacting each camper, this grant writer will be able to talk to parents who are interested in participating in support group. The programs contact information and overview will be given to parents.

Project Budget Proposal

The budget for this project was estimated at $101,100. This budget will incorporate two part-time Spanish-speaking MSW personnel, their salary and benefits. Additional resources for the program will include: computers and software, travel expenses, office expenses, promoting expenses.

CHAPTER 4

GRANT PROPOSAL

Purpose of Proposed Program

The purpose of this proposed program was to partner with a local host agency, locate a potential funding source and write a grant to obtain funding for a support group for parents who have children with cancer. In partnership with Camp Ronald McDonald for Good Times, the intention of the project would be to provide funding for a support group to be implemented at the CRMfGt Los Angeles office. The support group would consist of providing parents with the skills, interventions, and resources needed. In addition, they would be provided with a safe environment in which they can express their feelings and concerns while sharing it with others whose share similar experiences in order to establish group cohesiveness. Parent's mental health, such as symptoms associated with cancer (i.e. depression, anxiety, PTSD), will also be addressed. A literature review was conducted to examine the effects cancer can have on not only the patient, but the family structure overall. Literature also proved the importance of providing the parents with the support and resources needed in order to alleviate the stress and burden associated with having a child with cancer.

This actual submission or funding of this grant was not a requirement for the successful completion of the project. For the purpose of this thesis, there are elements of the grant proposal that have been omitted.

Host Agency

The host agency for this project is Camp Ronald McDonald for Good Times (Camp Ronald McDonald, n.d). Founded in 1982, Camp Ronald McDonald for Good Times has been providing services for families, siblings and children who have cancer. The mission of the CRMfGT is to create a positive long-lasting impact on children with cancer and their families by providing fun-filled, medically supervised, cost-free, year-round camp programs (Camp Ronald McDonald, n.d). They believe that nothing can compensate for the anguish that childhood cancer inflicts, but they have helped thousands of children and their family members recapture hope, enthusiasm, and love of life in a medically and psychologically safe environment created especially for them.

Camp Ronald McDonald for Good Times is a 6 day, 5 night experience that offers a variety of opportunities for cancer patients and their siblings. They also provide weekend long family camps, in the spring and in the fall, where parents can join in the fun. Activities at the camp site includes swimming, horseback riding, hiking, backpacking and other sports that can be adapted, as needed, to ensure each person is able to participate, regardless of his or her level of ability or challenge (Camp Ronald McDonald, n.d). Campers are able to express their creativity through arts, crafts, pottery, music, dancing, performing arts and radio broadcasting. They are also given the opportunity to challenge themselves at the Adventure Courage Course and 50-foot climbing tower. The CRMfGT main office is located in Los Angeles, CA and their campsite is located in Apple Canyon, CA.

Assessment of the Problem

The need for these services was based on this grant writer's personal experience with the host agency. The CRMfGT provides many resources for the child and the sibling, but lacks in providing additional support for the parents, aside from the Family Camps that occur seasonally. The implementation of this program would provide the parents the space to find support from other parents as well as assistance from social workers who will be providing education and resources needed.

In addition to this grant writer's personal experience with host agency, literature has proven the importance of providing parents with a support group. Children with cancer today receive a large part of their treatment at home, which means more responsibilities are given to the parents and the family members (Klassen et al., 2007). A diagnosis of childhood cancer can be extremely frightening for a parent as well as stressful. Many of the parents focus on giving their full attention to the patient while having to set their own emotions and responsibilities aside. As the parental role changes, they focus on learning more about their child's diagnosis, learning how to monitor the child's health, and meeting the child's needs (Anderzen-Carlsson et al., 2010). This change in parental responsibilities may increase their chances of showing symptoms of anxiety, depression, and posttraumatic stress. Other symptoms may also include guilt, sleep disorders, somatic symptoms, changes in diet, and physical and emotional overload (Gedaly et al., 2006). Caring for their child can be described as an "unexpected career" which can require the parent to leave their occupation and adapt and restructure new responsibilities over time (Klassen et al., 2007).

It is crucial that attention be given to studies that show that parents who adjust well to their child's cancer received better social, emotional, and psychological support. Schweitzer, Griffiths, and Yates (2012) found that, parents commented on the support they received as being the most crucial part of their experience. Not only social support was considered important, but positive coping and communication also helped parents alleviate their child's distress regarding cancer treatment (Schweitzer et al., 2012). Parental support groups can provide much needed support and an opportunity for building parenting skills and coping strategies. These groups also provide resources needed to help parents better adapt to their child's diagnosis as well as find ways to support the child and other family members.

The CRMfGT is the ideal program to implement a support group for the parents of those patients. A support program is proposed to further enhance the parent's resources, network, and skills in order to help them better address the situation they are currently in. To minimize the parent's effects of caring for a child with cancer, it is important for the support group to be developed in communities where the parents will be able to access their services. The CRMfGT provides a perfect location considering for the parents to access the services as their children are already connected to the camp.

Project Description

The target population for this grant proposal is the parents of children who are currently participating with Camp Ronald McDonald for Good Times (CRMfGT). The parents were defined as biological mother and father, stepparents, or legal guardians. This program is designed to provide a weekly support group that will meet once a week for 6 weeks, geared specifically to the parents of the CRMfGT campers. The support group will repeat four times throughout the year. The program will be based out of the CRMfGT's office in Los Angeles, CA. According to the CRMfGT, by the end of 2007, there were more than 6,000 campers from 10 states and 8 countries that had attended Camp Ronald McDonald for Good Times (Camp Ronald McDonald, n.d). This number shows the high amount of parents that can potentially participate in the support group. Special care will be taken to outreach to parents of all socio-economic, racial, and ethnic backgrounds.

Potential participants for the program will be recruited through the CRMfGT camp roster. By contacting each camper's family, the project coordinator will be able to talk to parents who are interested in participating in support group. The programs contact information and overview will be given to parents. Flyers will also be mailed out and posted as part of the recruitment process.

Program Activities

This program consists of a closed group (new members cannot join after the first session) six session support group for parents of children who have participated with the CRMfGT. The support group will be provided four times a year. The support group will be led by two part-time social workers who will have assistance of two CRMfGT volunteers. Sessions will take place once a week, lasting two hours each. Sessions will take place from 6:00 p.m. to 8:00 p.m. in order to allow working parents to participate as well. A requirement will be that their child has participated with the CRMfGT within the last year. Special consideration will be taken in order to recruit parents whose child has recently been diagnosed. During each of the support group sessions, different topics will be discussed to address the needs of the parents of children diagnosed with cancer, such as education, resources, skills and interventions needed. At the first session, parents will complete measures in order to assess parents' mental health (stress and coping) at beginning and end of sessions in addition to pre and post surveys which will measure parent's knowledge and ability to cope.

During the first session focus will be on participants sharing their story in order to build group cohesiveness and will be provided with an outline as to what to expect for the six sessions. Parents will be able to discuss challenges and successes among each other. The following four sessions will be structured different. The first hour will be spent on the social workers teaching skills, interventions, and providing different resources that will help them better adapt as well as better provide for the child and the entire family. The second hour will be an open forum for parents to discuss specific challenges and successes relevant to the topic covered. This portion of the group will be monitored by the two social workers.

Detailed session information mentioned below.

Project Goals, Objectives, and Outcomes

The goals of this project are: (1) to provide support to the parents of children with cancer by introducing interventions and skills needed for themselves, the child, and the siblings; (2) to increase resources available to the parents; and (3) to provide parents with a social network of those who have experienced, or are currently experiencing, having a child with cancer.

In order to meet the goals listed above, the following objectives, activities, and outcomes have been developed:

Objective 1:

Provide detailed information on the process of childhood cancer and its different stages. Different affects on each family member. What to expect, how to manage, how to advocate for the child's best interest.

Activity 1:

Session 2 and 3 will focus on explaining childhood cancer and its different stages. Social workers will lead discussion by providing information on cancer as well as different ways it can affect each family member. Parents will have the opportunity for the second half of the session to discuss the challenges and accomplishments their family has experienced. Time will be given for questions to be asked.

Outcome 1:

Fifty percent (50%) of parents will obtain helpful information in regards to their child's diagnosis. They will also receive useful information as to how to understand the effects on not only the child, but as well as each family member.

Objective 2:

Enhance parent participant's understanding of their own mental health.

Activity 2:

Session 4 will focus on social workers providing parents an overview of mental health diagnosis associated with childhood cancer. Interventions will be taught. Development of a resource guide will be provided. Parents will have the opportunity to address their own mental health in addition to their child's.

Outcome 2:

Fifty percent (50%) of parents will be able to better understand how to cope with how they are feeling and manage his or her own mental well-being. Parents will obtain tools to effectively address their own mental health as well as their children. The resource guide will help parents navigate with their mental health as well as within the community.

Objective 3:

Increase parents network of support.

Activity 3:

Session 5 will allow for parents to have an open forum to explore types of support needed. As parents brainstorm topics, social workers will be responsible for creating a resource guide which will then be provided to all participants at the very last session.

Outcome 3:

Fifty percent (50%) of parents will discuss challenges and needs in regards to the support they receive. The discussion will then result in a guide of resources that will provide parents the support they continue to be in need of.

Program Timeline

It is estimated that it will take 12 months to complete the program. Each support group will consist of 3 weeks of planning/recruiting and 6 weeks of the support group. Actual planning will begin in the month of September due to the CRMfGT staff being overwhelmed during summer sessions.

Months 1-3:

Hire two part-time Bilingual MSW Social Workers as Program Facilitators.

Purchase equipment and supplies needed to conduct program.

Topics will be scheduled and planned. Activities will be outlined.

Information packets will be prepared.

Create flyers including group dates and times as well as topics covered.

Recruit two volunteers to help throughout the 4 sessions.

Purchase program and office supplies.

Month 4:

Recruit participants for Support Group 1.

Prepare pre and post surveys to monitor progress.

Print all necessary materials and obtain all materials needed.

Develop guidelines and policies.

Conduct reminder calls for participants of Session 1.

Month 5:

Support Group 1 begins.

Groups will meet weekly for 6 weeks.

Administer pre survey and measures.

Month 6:

Prepare for termination.

Administer post survey and measures.

Evaluate outcomes.

Brainstorming session to improve for Support Group 2.

Month 7:

Recruit participants for Support Group 2.

Prepare for implementation of Support Group 2.

Contact participants to remind them about first session.

Support Group 2 begins.

Administer pre survey and measures.

Month 8:

Prepare for termination.

Administer post survey and measures.

Evaluate outcomes.

Month 9:

Recruit participants for Support Group 3.

Prepare for implementation of Support Group 3.

Contact participants to remind them about first session.

Support Group 3 begins.

Administer pre survey and measures.

Month 10:

Prepare for termination.

Administer post survey and measures.

Evaluate outcomes.

Month 11:

Recruit participants for Support Group 4.

Prepare for implementation of Support Group 4.

Contact participants to remind them about first session.

Support Group 4 begins.

Administer pre survey and measures.

Month 12:

Prepare for termination.

Administer post survey and measures.

Evaluate outcomes from all four Support Groups.

Program Evaluation

The proposed program will be evaluated to determine the mental health symptoms of parents, progress, effect, and satisfaction. At the first session, parents will complete Patient Health Questionnaire 9-item (PHQ-9) and Generalized Anxiety Disorder 7-item (GAD7) measures in order to assess parent's mental health symptoms, specifically targeting anxiety and depression. These measures will be given at beginning of session and termination. In addition, parents will be completing pre and post questionnaires which will measure parent's knowledge, ability to cope, and satisfaction with the group. At termination, MSW's will evaluate outcomes. These results will assist in continuing and changing services in order to cater to the needs of the parents.

Budget Narrative

The total projected budget for this project is $111,210. This amount will be needed to effectively implement the project for a full year. The parents support group will provide many resources, including two facilitators, two volunteers, and material that will assist in meeting the program's goal of providing support and resources for families. A line-item budget is included in the appendix section of this document.

Personnel Costs

Two MSWs will be hired as Program Facilitators. They will report to the CRMfGT's Program Director. This position will be responsible for all program decisions, development, and activities. This position will be responsible of initial outreach, brainstorming specific activities per session, program evaluation, and program outline. This is a part- time position, 24 hours per week, with each social worker dedicating three full working days. Each social worker will be compensated with a salary of $35,000 plus $7350 for benefits at 21%. The annual total cost for 2 social workers is $84,700.

Two volunteers will be recruited from past CRMfGT's camp volunteers. Volunteers will receive a $4,000 annual stipend in appreciation for their dedication and support to the program. Volunteers will report to MSW facilitators. This position will be responsible for making copies, ensuring that each session has all the supplies and printing necessary, assisting MSW's during group sessions and conducting reminder calls weekly. Volunteers will also assist MSW's in recruiting activities. The annual total cost for 2 volunteers is $8000. Total personnel costs is $92,700.

Direct Program Costs:

Program supplies: An average of $200 a month will be used to provide pens, paper, visual aids, arts and crafts materials, white boards, poster boards and markers to assist in educational piece of the program and exercises completed by the parents. Total amount for program supplies for the entire year is $2,400.

Office Supplies: An average of $150 a month will be used for office and desk supplies. Office supplies with include supplies needed specifically by the MSW's and volunteers. This will include pens, markers, notebooks, planners, folders, staples, tape, whiteboards, and other essential office equipment that will assist personnel. Total amount for office supplies for the entire year is $1,800.

Printing: An average of $250 will be used a month. It is estimated that more will be used during the first couple of months of the program. Printing will include the majority of the recruiting, promoting, pamphlets, resource guides, activities, surveys, measures, and handouts needed per session. Total amount for printing for the entire year is $3,000.

Phone bill and Postage: An average of $100 a month will be used to pay for postage and the monthly telephone bill. This will included mailing flyers home to parents and recruiting. Total amount for phone bill and postage for the entire year is $1,200.

Total direct program costs is $8,400.

<u>In-Kind Contributions</u>

Four computers: An average of $650 will be spent per computer. There will be four computers used which brings the total to $2,600 for the entire year.

Four Office phones: An average of $50 will be spent on each phone. There will be four phones used which brings the total to $200 for the entire year.

Office space (rent and utilities): An average of $1,200 will be spent on rent and utilities per month. The total amount for Office space for the year is $14,400.

Total in-kind donations is $17,200.

<u>Indirect Costs:</u>

Administrative Overhead: Ten percent or $10,110 of total budget will be allocated for administrative overhead to manage the grant.

CHAPTER 5

LESSONS LEARNED

Discussion

The grant writer went into this project already having an idea as to what project would be implemented, but needed research that supported the reasons as to why it would be important. In order to find this support, the grant writer engaged in an extensive review of the literature. The research found supported the grant writer's conclusion that parents of children with cancer lacked many resources and could benefit from an increase in support groups. It was through the research that the grant writer found that children with cancer today receive a large part of their treatment at home, which means more responsibilities are given to the parents and the family members (Klassen et al., 2007). Many of the parents focused on giving their full attention to the patient while having to set their own emotions and responsibilities aside.

It was through the research that the grant writer found that parents could benefit from additional resources specifically targeting parent's needs and the type of resources that they continue to lack. It was found that parents needed to find ways in which they can cope with their child's diagnosis in order to be able to better adapt and serve as an example to the rest of the family. The new responsibilities parents had difficulty with were providing the child with emotional support while regulating their own emotions, dealing with medical visits, operations, possible relapses, paying attention to all medical necessities, all while trying to cope with the diagnosis themselves (Kohlsdorf & Costa, 2012). Parents reported feelings of fear and disbelief when told their child's diagnosis (Hallstrom et al., 2005). Learning to cope with the diagnosis was found to be extremely vital in order for the parents to better adapt to their child's illness. Overall, although the grant writer already had the idea in mind, she was able to learn a lot through the literature review and found this section to be the most vital due to all of the information found.

The Grant Writing Process

The grant writer had never written a grant proposal before and therefore learned a lot about grant applications and what it takes to apply through this process. The grant writer began utilizing different search engines in order to find funding sources. The grant writer found this part to be the most difficult due to all of the information that was found and had a difficult time minimizing the results based on the project in mind. After using different key terms, there were a couple of foundations that emerged that seem to be most fitting. After researching a bit more, the grant writer was unable to access the grant application for these foundations. It was found that it was easier to access private foundations due to the fact that the grant application was listed on the foundations website.

After searching many different databases, the grant writer felt it was still too complex to understand on her own. The grant writer then sought help from advisor, whose guidance provided the writer in finding three prospective funding sources relevant to the grant being proposed: The Weingart Foundation, Annie E. Casey Foundation, and W.K. Kellogg Foundation. After reviewing all three foundations, W.K. Kellogg Foundation was found to fit best with writer's goal for this project. W.K. Kellogg concentrates on the belief that all children should have an equal opportunity to thrive.

The foundation works exclusively on issues with children, their family, and the community.

After finding the funding source, the grant writer felt more comfortable with the grant application. The grant writer learned that the submission process for the W.K. Kellogg Foundation is all online. The online application requests that grant seekers provide information such as the overview of the project, program outcomes, total budget and total amount being requested from the Kellogg Foundation. Once the application is submitted, an automated response will be sent in order to acknowledge its receipt. The application is reviewed within 45 days which is when the application is either declined or selected for further development. The application guidelines of the W.K. Kellogg Foundation grant were followed.

Education About Grant Writing

In order for the grant writer to educate herself about the grant writing process, the Long Beach Non Profit Partnership Library was visited. The grant writer attended an hour long training session to better navigate through the search directory. Key terms were provided that would increase likelihood of finding higher results. The grant writer not only learned about the importance of finding specific key terms to use, but also learned how to combine key terms to decrease the results found. In addition, many different search engines were used, and the grant writer also sought additional help from advisor in order to increase education.

Planning and Collaboration

The grant writer had previously volunteered for five years with host agency and already had the information needed in order to contact the program director directly. The grant writer emailed program director at the very beginning of the grant writing process. Due to their summer camp sessions occurring, the grant writer did not hear back from program director until the end of summer. Once the grant writer was able to discuss the project with the program director, the grant writer received permission to use Camp Ronald McDonald for Good Times as the host agency.

Developing the specific objectives and activities for the program included being artistic and creative with the process. The grant writer knew what the goals of the program would be, but found it difficult to think about specific activities that provide the outcome listed. After conducting research on past support groups, activities included, and ways in which parents could be empowered, the grant writer found the activities. The grant writer decided to have a closed group in order to maintain the same participants and build group cohesiveness.

Although the grant writer wanted the focus to be on providing resources, interventions and skills, it was decided to split each session into two. The first half would be led by the social workers and the second half would allow the parents to lead conversation. The grant writer found this to be extremely important due to the fact that the parents would be the most knowledgeable on the subject due to the fact that they have lived it. Once that was determined, the goals aimed to 1) provide support to the parents of children with cancer by introducing interventions and skills needed for themselves, the child, and the siblings, 2) to increase resources available to the parents, and 3) to provide parents with a social network of those who have experienced, or are currently experiencing, having a child with cancer. Once the goals were set, everything else fell into place; the objectives, the activities, and the outcomes.

Implications for Social Work Policy and Practice

Through the writing of this grant thesis, the researcher came to understand the importance of having social workers work in pediatric oncology. Social workers play a significant role in pediatric oncology in helping to reduce symptoms, alleviate suffering, and by providing support (Jones et al., 2006). The most important role of the social worker is to assess the patient and the family's background, beliefs, cultural/spiritual practice, mental health, behaviors, coping, communication, and needs for resources (Sourkes et al., 2005). Social workers are able to provide skills, which other fields cannot, with the patient and the families in order to ease the parents' burden as well as improve the end of life care for the patient. Social workers are present in the medical setting by helping children and families by providing them supportive counseling and developing interventions with the child. They are also there to help increase communication between the family and the medical system, increase communication between child and family, and supporting the needs of the family as they possibly face loss and grief (Jones et al., 2006).

Finally, through this process, the grant writer was able to understand how important it is for social workers to have knowledge about grant-writing and to build the skills necessary. By extending their knowledge, social workers can truly stand up for change and promote and enhance the well-being of individuals and families. Instead of relying on others to implement a program based on the needs of a specific population, social workers are able to propose their own program, and write a grant in order to provide funding. The grant writer feels that the grant writing process helps empower social workers to take a stand in the front line of the problem and help those programs that are lacking the resources.

APPENDIX: PROPOSED PROGRAM LINE ITEM COSTS

Expenses for 1 Year of Proposed Program

Salaries	
Two Part-Time Program Facilitators, MSW (@ $35,000 each)	$70,000
Benefits for Program Facilitators (@ $7,350 each)	$14,700
Stipend for two part-time volunteers (@ $4000 each)	$8,000
TOTAL PERSONNEL COST	$92,700
Direct Program Cost	
Program Supplies @ $200 per month x 12 months	$2,400
Office Supplies @ $150 per month x 12 months	$1,800
Printing @ $250 per month x 12 months	$3,000
Phone Bill and Postage @ $100 per month x 12 months	$1,200
TOTAL DIRECT PROGRAM COST	$8,400
Indirect Program Cost	
Administrative Overhead (10% of total budget)	$10,110
TOTAL INDIRECT PROGRAM COST	$10,110
In-Kind	
Four computers (@$650)	$2,600
Four office phones ($50)	$200
Office space (rent and utilities) @ $1,200 x 12 months	$14,400
TOTAL IN-KIND CONTRIBUTIONS	$17,200
TOTAL PERSONNEL COST	$92,700
TOTAL DIRECT PROGRAM COST	$8,400
TOTAL INDIRECT PROGRAM COST	$10,110
TOTAL IN-KIND CONTRIBUTIONS	$17,200
TOTAL PROGRAM COSTS	$128,410
TOTAL AMOUNT REQUESTED	$111,210

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