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# Psychosocial needs of children coping with parental terminal cancer in a hospital setting

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Psychosocial Needs of Children Coping with Parental Terminal Cancer in a Hospital  
Setting

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A research project submitted to the Graduate Faculty of

JAMES MADISON UNIVERSITY

In

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## Dedication

This paper is dedicated to my beloved late parents, William P. Reed and Carol M. Reed, and seven siblings, Kristin, Amanda, Lauren, Jessica, Lindsay, Devon, and William (Scott) for inspiring me to research this topic.

## Table of Contents

Dedication.....	ii
Abstract.....	iv
I. Introduction.....	1
II. Literature Review.....	2
Prevalence of Cancer.....	2
Palliative Care and Counseling.....	4
Children of Terminally Ill Cancer Patients.....	6
Adolescents of Terminally Ill Cancer Patients.....	9
Family Communication.....	11
Social Support.....	17
Effective Programs and Interventions.....	19
III. Discussion.....	22
Recommendations for Counselors and Professionals.....	22
IV. Conclusion.....	23
V. References.....	25

## Abstract

Cancer rates in the United States continue to be staggering. It is also heartbreaking to note that many of the adults confronting cancer are also parents of children. Parental terminal cancer poses a threat to the psychological well being of the entire family. Children are at a significantly higher risk for developing psychological disorders if their psychosocial needs are not met during this crucial time. Communication is vital in assisting children with their reactions to the illness and impending loss. Research has shown that communication between family members, especially with children, and also between medical professionals and families can often be lacking or complicated. This paper will provide a literature review of the research that has been conducted on children coping with parental cancer, along with a review of programs and interventions that have been successful in meeting the needs of these children. Implications for counselors, along with limitations of this paper, will be identified.

## Psychosocial Needs of Children Coping with Parental Terminal Cancer in a Hospital Setting

This paper will provide an overview of the prevalence of cancer and a review of research conducted on the ways in which parental terminal cancer affects children and adolescents. Children and adolescents' stress responses, coping mechanisms, and factors related to each will be examined. Research on communication between family members and medical professionals will be explored with an emphasis on social support. Interventions with families that have been successful will be reviewed, followed by recommendations for future programs and implications for counselors.

The purpose of this research is to identify the psychosocial needs of families coping with parental terminal cancer in a hospital setting and to describe effective interventions during the specific period of palliative care. Palliative care is defined by the World Health Organization as “an approach which improves the quality of life of patients and their families facing life-threatening illness through prevention, assessment, and treatment of pain and other physical, psychosocial, and spiritual problems” (Strada & Sourkes, 2009, p.35). Information is limited on this topic, but this paper reviews the current literature and analyzes the information, which identifies the increased mental health risks of these family members. The current research, however, fails to agree on a best standard of practice or best method of intervention. This project aims to offer a program proposal of an effective intervention to be implemented into palliative care treatments in a hospital setting.

## **Literature Review**

### **Prevalence of Cancer**

According to the American Cancer Society, 13.7 million people in the United States in 2013 had a history of cancer. In 2013, approximately 1.6 million new cases of cancer were expected to be diagnosed in Americans with well over a half a million people dying from the illness (American Cancer Society, 2013). In 2006, an estimated 1.3 million people in the United States were diagnosed with cancer and about 5% of those were in their child-rearing years (Gabiak, Bender, & Puskar, 2007). Another source reports that 5% of children in the United States experience the death of one or both parents by the age of 15. Although this percentage is not attributed specifically to cancer, the massive rates of cancer deaths in the United States suggest that some of these parental deaths were due to parental terminal cancer (Christ, Siegel, Freund, Langosh, Henderson, Sperber, & Weinstein, 1993). With such large numbers of cancer diagnoses and deaths, it is critical that clinicians work to understand its impact on children of those diagnosed with terminal cancer.

While the terminal phase of cancer poses significant psychological threats for both the patient and his/her family, it is important to note that all stages of a cancer diagnosis and prognosis come with diverse psychosocial struggles. Each case is complex and unique. Some cancer patients go into remission, some may go into remission several times, and others may reach the terminal phase even if it is only a few months after the initial diagnosis. It is important to understand that the terminal phase is only one stage on an unpredictable continuum of a cancer diagnosis and that psychosocial struggles come with every cancer diagnosis and every stage.

Coping begins the moment children are told about the diagnosis. Children in Davey, Tubbs, Kissil & Nino's (2010) study showed concern about how the cancer diagnosis, particularly breast cancer in this study, would affect their futures. Ambivalence about whether or not the cancer would go away, possibly return, or that the parent would die was a common concern. Children's initial reactions that are common to a cancer diagnosis include shock, fear, and loneliness. Throughout the cancer prognosis, children reported feeling sadness, worry, and fear especially during treatments. As a cancer diagnosis worsens, children tend to feel a loss of safety and predictability, which is common due to the tendency for cancer to have a complex course (Davey et al., 2010). The first year after a diagnosis may be filled with emotional and behavioral problems particularly for children, with 20-32% of adolescent children in this study experiencing clinically elevated problems during this time. Even up to five years after a parent's cancer diagnosis, 21-35% of adolescents have been found to suffer from post-traumatic stress symptoms (Visser, Huizinga, Hoekstra, van, Klip, Pras, & Hoekstra-Weebers, 2005).

Parental behavior changes with the diagnosis and prognosis, as well. Parents' behavior tended to change with side effects of treatment and included irritability, impatience, moodiness, and paranoia. The ill parent's behavior altered in terms of energy, physical strength, and emotional strength. Researchers conclude that parental frailty was a significant cause of children feeling guilt and focusing more time on their home life by remaining at home rather than participating in outside activities and taking on more domestic responsibilities. A family's mood, interpersonal conflict, and attitudes change as a result of a cancer diagnosis, prognosis, hospital visits and treatment (Davey et al., 2010). Hospital visits and treatment tend to interrupt daily family routines and cause

stress in the family, leading to increased negative psychological symptoms for the entire family system (Visser et al., 2005).

With each case of cancer being vastly unique and complex, it is difficult to summarize the effects of parental cancer on children at any stage of the diagnosis. This paper attempts to further understand the effects of the terminal phase of parental cancer, although it is important to note that the initial diagnosis along with the following stages, prognosis, and treatment have significant effects on the entire family.

### **Palliative Care and Counseling**

Before the terminal phase of cancer is reached, the patient undergoes either curative or palliative care treatment. Palliative care can be provided in conjunction with curative and life-prolonging treatment in order to minimize side effects. However, it may also become the main focus of care when patients are no longer receiving active treatment and approach the end of life (Strada & Sourkes, 2009). Palliative care focuses on providing relief to terminally ill patients through symptom and pain management. Terminal illness refers to an illness that is no longer able to be cured and therefore will progress until it causes death. The goal of palliative care is not to cure but to provide comfort and quality of life to terminally ill patients. Patients are generally assigned to specific care teams who treat patients until death. In contrast, hospitals operate under a medical approach in which patients are treated primarily by physicians and nurses with a focus on curing the disease. When the goal of treatment is curing the illness, the death of patients is regarded as a treatment failure, as opposed to the natural outcome of a terminal illness (Bachner, O'Rourke, Davidov, & Carmel, 2009). When the two paradigms of palliative care and medical approach are intertwined, doctors and nurses are confronted

with palliative care in a hospital setting, which can create obstacles, because both approaches collide in circumstances where there is no dominating treatment modality.

Traditional psychotherapy and even present day counseling have not given major focus to palliative care and patients/families dealing with advanced illness and ultimately the death of a parent. Little is known about the complicated grief family members experience prior to the loved one's death. As family systems theory suggests, the condition of one person in a system will affect the entire system, which ultimately determines the systemic psychosocial functioning of a family. When a family member has terminal cancer, not only the patient's life is altered, but the entire family system is affected (Faulkner & Davey, 2002). The well parent suffers from expected responses to the diagnosis, possibly along with caregiver responsibilities for both the ill parent and the children. The death of the ill parent poses a threat to the entire family system, and the diagnosis and impending death have significant impacts on both the individuals' and the system's well-being (Mazanec, Daly, Ferrell, & Prince-Paul, 2011). Younger caregivers are at a higher risk for complicated grief pre-loss, suggesting that young families, or families consisting of children under the age of 18, are especially in need of counseling services. There is knowledge that family members and caregivers of terminally ill cancer patients can experience depression, anxiety, sleep problems, fatigue, and increased risk of mortality. Particular attention should be paid to children of parents with advanced cancer, since the research that has been conducted on this population shows that the effects of the illness on children can be catastrophic.

### **Children of Terminally Ill Cancer Patients**

The importance of this research can be seen in knowledge previously gained from studies, specifically in that children of terminally ill cancer patients suffer psychological symptoms which in turn affects their coping strategies. Common symptoms in children include changes in mood or self-esteem, academic changes, somatic symptoms, and social and interpersonal changes such as acting out. Children of patients are more likely to experience somatic manifestations of anxiety and emotional distress if their parents are experiencing anxiety as well (Wong, Ratner, Gladstone, Davtyan, & Koopman, 2010). Age, gender of the child, and gender of the parent all function as variables that influence the symptoms experienced by children of an ill parent (Faulkner & Davey, 2002).

Differences in the ages of children also show differences in symptoms. Pre-school aged children may experience separation anxiety, depression, and attachment issues while school-aged children and adolescents may experience feelings of hopelessness, guilt, burden, anger, or emotional isolation in adjusting to parental diagnosis (Wong et al., 2010). Adolescents also reported having problems with the well parent, who at times became emotionally overwhelmed, angry, and depressed about the spouse's impending death (Christ, Siegel, & Sperber, 1994). Symptoms in adolescents are much more externalized, including behavioral problems when both parents had depressed mood; maternal depressed mood was the main source of influence. In one study, family functioning was significantly related to emotional and behavioral problems: lower family cohesion, poor family communication, family affective-responsiveness, family affective involvement, family behavioral control, and family general functioning predicted adolescents' externalizing problems (Gabiak et al., 2007). Differences in symptoms are also seen across gender. While these are broad generalizations, there do seem to be some

patterns. When the mother is ill, daughters tended to change the quality of their involvement resulting in a different type of closeness between them. Daughters of ill mothers are also more likely to be concerned with their own genetic risks concerning cancer, specifically breast cancer. Boys were more likely to isolate themselves from the family (Christ et al., 1994).

Behavioral consequences can be seen in children of terminally ill cancer patients. Children's distress is often manifested in sleep disorders, somatic symptoms, inability to concentrate at school, difficulty completing tasks and assignments, increased conflict with family members, and conflict or withdrawal from both peers and adults. Behavioral reactions were found to be manifested at home with parents and siblings and at school in relation to educational performance, extracurricular activities, and peers. Children's distress was somewhat alleviated when clinicians emphasized the normality of these reactions as well as involvement by the well parent in supporting the child. Parental terminal cancer disturbs child's entire world, so loss of peer relationships and activities can exacerbate the child's symptoms (Christ et al., 1993).

More severe reactions in young children include strong and frequent outbursts of anger, sadness, and anxiety; suicidal thoughts; severe and prolonged decline in academic performance or school behavior; severe and prolonged conflict with parents; intense somatic symptoms. Some of the severely disturbed children in this particular study had pre-existing behavioral or emotional problems. In other cases, the parent had pre-existing psychological problems (Christ et al., 1993). Severe reactions in adolescents include running away from home, stealing, drug abuse, and promiscuity (Christ et al., 1994).

Factors related to a child's symptoms include length of the parent's illness, guilt, and fear for the well parent. When children expected remissions due to previous experiences with the parent's illness the children typically expressed greater disbelief at the terminal stage. Depression and phobic symptoms were also common responses. Other children confronting a shorter period of terminal illness experienced panic and anxiety due to the parent's quick deterioration, physically and in appearance. Younger children often showed preoperational magical thinking. The preoperational stage is a cognitive development stage developed by Jean Piaget that marks a period of cognitive development in children age two to seven. The children's magical thinking focused on personal responsibility for the parent's illness, which produced intense emotional reactions of guilt (example, kids can make their parents ill by misbehaving). The children often felt responsible and guilty for their ill parent's anger, withdrawal, and lack of affection which may in reality be attributed to the rigor of the illness. Children often expressed elevated concern for the well parent, with whom they had come to feel increasingly dependent. Latency-age children's, ages four to whenever the child reaches puberty, most pertinent fear, associated with their psychosocial stage, was that of separation from the parent. Their anxieties were heightened by their observation of the well parent's irritability, sadness, fatigue, depression, and anxiety. Younger children had a significant need of reassurance that these were only temporary reactions from the well parent due to the patient's illness and prognosis (Christ et al., 1993).

The symptoms experienced by children also negatively affect their coping skills. Latency-age children tend to identify with the ill parent and become frightened by the parent's physical pain and appearance (i.e. loss of weight and hair). Latency-age children

also sometimes experience somatic symptoms themselves. Adolescents, on the other hand, are able to empathize with their ill parent's pain have a heightened desire to lessen this pain. This empathy can become overwhelming to the adolescent and cause the adolescent to avoid contact with the ill parent. Preadolescents sometimes deal with their empathic sense of the parent's distress by becoming angry with hospital staff and believing that the medical professionals are causing the pain or not properly treating the illness (Christ et al., 1994).

### **Adolescents of Terminally Ill Cancer Patients**

Adolescents developmentally have increased empathic skills and intellectual abilities. Coping abilities in adolescents are related to three areas of functioning associated with their increase skills: the use of intellectual defenses, the search for meaning and deeper understanding, and the ability to seek help. The formal operational stage of cognitive development, also part of Piaget's cognitive development stages, allows adolescents to use intellectual defenses to gain a greater sense of control over the impending parental death; control in this sense is related to intellectual understanding of the terminal course of the illness. In a specific study, adolescents were aggressive and assertive in seeking information, possibly due to their intellectual defenses. Even when the information sought was correct, adolescents tended to distort the information as a result of cognitive regression. This regression occurred because the adolescent felt emotionally overwhelmed or his/her lack of life experiences created an obstacle to fully understanding the information. Adolescents can conceptualize the meaning of parental loss in more abstract terms than latency-age children, who tend to worry about concrete needs, i.e. "who will teach me baseball if dad dies?" Adolescents tend to worry about abstract

aspects of their relationship with the ill parent, like the loss of the parent's personality qualities like his/her sense of humor, changes in family roles, and the effect of the death on the family's financial situation (Christ et al., 1994). As compared to pre-pubertal children, adolescents' more advanced cognitive abilities lead them to deal with their intense psychological responses with emotional detachment. To control their emotions, reactions to the illness are sometimes kept separate from their normal daily experiences ("strategic withdrawal" – which, in follow-up studies, was found to be used by adolescents who had best adapted). Adolescents are also in a psychosocial stage where identity and independence from parents is being explored, therefore resuming normal developmental activities can be a helpful distraction for adolescents during the parent's terminal stage (Christ et al., 1994).

Common problems characterize adolescents' reactions to a parent's worsening condition as the terminal illness progresses including empathy for the parent's suffering, increased involvement with the ill parent, increased responsibilities at home, and feelings of guilt. Adolescents experienced increased household responsibilities, including caring for the patient and more household chores; however this tended to affect females more than males due to traditional gender roles, while males tended to seek outside jobs to support the family (Christ et al., 1994). Emotion-focused coping is related to greater avoidance and to higher symptoms of anxiety/depression in the adolescent (Grabiak et al., 2007). Many children used distraction as the most common form of coping and preferred engaging in routine or normal activities to distract themselves from ruminating on their parent's illness (Kennedy & Williams, 2009a). Adolescents in this study reported that people from the community were helpful in supporting the family, like neighbors

bringing meals, but did not offer them personal or emotional support (Gabiak et al., 2007). Many children reported needing to talk to someone outside of the family about the illness but felt like this support was not available. Children also reported not wanting to worry their parents with their own needs, hence highlighting the importance of open communication during this time (Kennedy & Williams, 2009a).

### **Family Communication**

One of the most important reasons families need open communication during a time of parental advanced cancer is the reality that many of the emotional reactions of many family members, specifically pre-pubertal children, are tied to misconceptions of the disease and its treatment. It is not unusual for latency-age children to have misconceptions about the parent's illness and treatment, especially due to their cognitive developmental stage. Children's misconceptions are sometimes more extreme or dire than the actual reality of the situation. These distortions often shape emotional reactions, which further interfere with their understanding of the terminal illness. It is necessary to understand how their developmental cognitive abilities both limit and influence perceptions of the illness. Most latency-age children cannot understand the complexities of constantly changing medical information, which is common with a cancer diagnosis. As is usual with preoperational thinking patterns, younger children may find it difficult to describe situations related to the parent's illness and organizing sequences of events. As mentioned earlier, many children tend to make inaccurate causal connections related to the illness, usually due to magical thinking. Cognitively and emotionally, children need explicit, concrete, and definitive information, which is difficult when the course of a cancer diagnosis can be so fluctuating. Ambiguous statements made by both parent

and/or clinicians confuse children and may lead to misinterpretation. Concrete, operational children age seven to about eleven, as described by Piaget's cognitive development theory, gain a better understanding of mental operations and have increased logic skills. These children are more cognitively inclined to take information and infer a "yes" or "no," for example that yes the chemotherapy will cure the cancer. Parents' communications can sometimes be too general and not developmentally appropriate for the child (Christ et al., 1994).

Children sometimes interpret the side effects of cancer treatment as evidence that it was working. In situations like palliative care where a patient's pain and symptoms may be alleviated but not cured, children may infer that it is evidence that the patient is getting better. In some studies when parents were able to be informed and therefore comprehend that these misconceptions were due to the child's developmental stages, they could help to better understand the child's perception and attempt to clarify the reality of the situation in developmentally appropriate manners (Christ et al., 1993).

The majority of discussions about a patient's condition occur between adults and medical professionals. Children have a minimal role in communication about the illness, especially from the medical staff who use complicated terminology and tend to direct the information to the patient and spouse. While some children have reported no desire in the decision making of treatment others wished to be involved. Involving children in the decision making process varies by the child's wishes and should therefore be taken into consideration in each unique circumstance, although communication about the illness should always be included (Coyne & Gallagher, 2011). Being outspoken and asking children what aspects of the illness and treatment they wish to be informed of along with

guidance from professionals about developmentally appropriate information can help to determine an appropriate level of detail to include in the discussion with the child (Wong et al., 2010). A child should never be completely restricted from receiving information about his/her parent's condition before death but should be respected in his/her desires to be involved in the decision making processes. The involvement of children, however, seems to be vital when providing effective family-based interventions and therefore requires further research.

Communication during parental terminal illness lessens anxiety. Despite parents' intention of protecting children from further worry, avoidance of any discussion of the illness or treatment often contributes to children's anxiety. While these conversations can be difficult for both parents and children, it does not mean that they are not perceived as supportive (Wong et al., 2010). Good family functioning is correlated with open communication between family members and less distress among adolescents (Lindqvist, Schmitt, Santalahti, Romer, & Piha, 2007). Therefore even without an illness, open communication is an important component for healthy family functioning and is even more vital during a parent's terminal illness. Studies have related quality of communication and whether children have been informed about the illness to children's levels of anxiety. Even with the acknowledgment of these correlations, studies have shown that many children are not told when a parent's illness has turned terminal. Reasons for this lack of communication include parents (both well and the patient) being unaware of the fact that their children are experiencing distress, fears of emotionally breaking down in front of children, guilt about not being able to fulfill their parenting role, grief over lost opportunity to see their child grow up (specific to the ill parent) and

not wanting to further anguish their child. Cohen et al. (1977) found that 50% of children under the age of 8 only found out that their parents were going to die in the terminal phase, meaning communication in those situations failed to include children until the illness was nearing death (Kennedy & Lloyd-Williams, 2009b). It is vital for both parents and clinicians to be aware that willingness to communicate about the illness openly increases children's resilience and sense of well-being and should therefore be incorporated early on in the parent's illness. (Wong, Ratner, Gladstone, 2010).

Research indicates that adolescents are usually informed about a parent's impending death soon before the death approaches (Sheehan & Draucker, 2011). The terminal phase of an illness refers to three to six months prior to death of the patient, yet it is recommended that information about the parent's prognosis be provided soon after the diagnosis rather than closer to the patient's death (Christ et al., 1993). In some studies, adolescents came to know the ill parent was going to die through overhearing conversations with medical professionals and other family members rather than direct conversations. Children could also see the physical deterioration of the parent as a sign that the prognosis may be turning terminal. Withholding medical information, even if the objective is protecting a child from distress, correlates with lower family cohesion and poorer parental wellness (Wong et al., 2010). All children interviewed in this particular study wanted to be included in communication about the illness in order to be prepared for the future and feel included in the family's situation. All children wanted information about their parent's condition therefore communication is vital for this information to be exchanged. The initial stages after the parent's diagnosis was identified as the time in which children needed the most information, particularly with regards to the disease itself

and what treatments the parent would be undergoing. At later stages there was more need for information regarding how to help their parents, both the ill and well parent (Sheehan & Draucker, 2011). Once the terminal phase is reached, preventative interventions for the family should be implemented which will be discussed later in this paper.

Communication involves more than the giving of information. Communication includes support as well. Adolescents identified parents, support groups, physicians, school and media as their main sources of information with parents being the main identified source of information. Adolescents did report a fear that parents were withholding information to protect them from further distress. Adolescents wished to receive concrete and specific information as the illness progressed. Although most children felt that they could ask questions about the illness to their parents, they were concerned that they might upset them which therefore created a barrier in communication. Children become skilled in hiding the information they know from parents, who often assume that the lack of questions or discussion on the child's part indicates unawareness. The simple sharing of information may be more important to a child than the content of the information being communicated. When children felt that information was being withheld they described a need for receiving it or seeking it elsewhere, such as through media sources. While the Media has a copious amount of information, whether correct or not, children perceived medical professionals to be the most valuable sources of information regarding the disease. Obstacles children faced when attempting to gain information from medical professionals included lack of access as well as developmentally inappropriate ways of explaining the disease and treatments to children, again highlighting the importance of developmentally appropriate

communication not only by parents but also by medical professionals. Adolescents in this particular study felt that their need for information was unmet. When seeking information or support from people outside of the family, adolescents also faced obstacles. Children experienced other people's awkwardness about the topic and insensitivity in hearing about the illness. Although many children wished to confide in someone outside of the family other than neighbors, friends, etc. (healthcare professionals, clinicians), this opportunity was rarely presented. (Kenney & Lloyd-Williams, 2009a). The information from these studies strongly supports the need for children of terminally ill parents to receive specific, detailed information and also have people around to support them after this information is exchanged.

In their study with family members of cancer patients, Krant and Johnston (1977) reported that 92% thought about their relative's impending death but only 22% discussed this with the patient. Vess, Moreland, Schwebel and Knaut (1988) suggest that family members and patients commonly engage in "mutual protective buffering" or avoidance of discussion of fears and concerns in order to protect one another, although research reviewed earlier in this paper has shown that communication of the illness lessens anxiety and future pathology. Of course a family's pre-existing communication patterns and psychosocial functioning affect the quality of communication during the patient's illness (Bachner et. al, 2009). While considering pre-existing communication patterns and functionality, open communication still appears to predict higher levels of empathy and intimacy between patients and their spouses, higher levels perceived support by the patients, and reduced feelings of caregiver burden from family members. Bachner and Carmel (2007) report an inverse association between open communication and negative

affect (emotional exhaustion and depressive symptoms) among family members but specifically caregivers of the patient. This research supports the notion that open discussion of family member's thoughts and feelings regarding the patient's illness and eventual death may facilitate meaningful interpretation of the experience and emotional acceptance of the loved one's impending death (Bachner et. al, 2009).

### **Social Support**

Social support is necessary during the impending loss of a parent. Social support refers to the quality and function of social relationships. Aside from family members, social support can be given by medical professionals, nurses, hospital staff, community members and family friends. Social support includes specific communication about the disease itself, treatments, and also the progression of the disease, which is reported to lessen feelings of confusion, helplessness, and seclusion. Again, exchanging information in a developmentally appropriate manner cannot be emphasized enough. A family's level of connectedness, abilities to express emotions and feelings, and flexibility impact the effectiveness of the social support it receives. Adolescents who perceived receiving strong social support also experienced less depressive symptoms after the loss of their parent (Wong et al., 2010).

There are four different domains of social support: information and advice, tangible assistance, encouragement and reassurance, and listening and understanding. Problems occur when a child seeks support from medical professionals but the skill of the professional is not meeting those needs. Based on previous research reviewed earlier in the paper, many medical professionals fail to adequately communicate with children and children who seek valuable information from medical professionals. This creates a

mismatch in which children are seeking important information from professionals who tend to not include children in the treatment plan of the patient. It is also vital for those giving social support to understand the difference between healthy responses to the parent's illness versus pathological responses. The child may perceive misunderstanding of his/her emotional experiences as insincere and therefore an ineffective form of support (Wong et al., 2010).

Two models that conceptualize the impact of social support are the main-effect model and stress-buffering model. The main-effect model views social support as the everyday support we receive from our social circles, or the support we seek when we are having a bad day. The stress-buffering model of social support views support as needed or desired only when individuals are under stress. This model views the support as specific to a certain stressor or event, such as a parent being diagnosed with terminal cancer. An example of stress-buffering social support is neighbors bringing over dinners while a sick parent is in the hospital. Both forms of social support are present when children are dealing with the terminal illness of a parent and both are necessary from members outside of the family to help the family maintain functioning (Wong et al., 2010).

The importance of communication between family members but also between the family and nurses/physicians is crucial in supporting a family that is experiencing terminal illness. Communication by healthcare providers regarding the illness, prognosis, and treatment options are often inadequate (Yennurajalingam, Dev, Lockey, Pace, Zhang, Palmer, & Bruera, 2008). Barriers to the end of life discussion by medical staff include nurses' and physicians' inexperience in dealing with death and dying, lack of

cultural awareness, unrealistic expectations by the patients and/or family members (i.e. it is the doctor's fault that the patient is dying; there is more the professionals could have done), difficulty of predicting the timing of death, levels of stress experienced by patients and family members during the terminal phase, lack of communication in the family, and a perceived lack of social support by the family and patient. Honest and timely communication by the medical professionals is crucial in helping the family to understand that palliative care in a hospital setting is not giving up on treating the disease but instead realizing that curative measures are no longer working and therefore the goal is to make the end of life process as comfortable as possible for the patient (Clabots, 2012).

### **Effective Programs and Interventions**

Information that has been collected through the reviewed research suggests that families are in need of psychosocial support and there is no concise agreement on the best method of intervention to meet these needs. Although many programs have succeeded in showing effectiveness, there is a lack of concrete procedures to be used in everyday practices.

There are few hospitals where palliative care includes counselors as most instead rely on social workers, chaplains or advanced practiced nurses. The Medical Center of Central Georgia developed the Transitions and Palliative Care Therapy Model, which uses a family systems approach and has the counselor at the heart of the palliative care team. This model is now an accepted standard of practice at the center and has proven to be a successful intervention that has shown positive results in this specific hospital. The question remains whether we can generalize some of the program's most effective

methods into a nationwide or global best method of intervention (Babcock & Robinson, 2011).

Many intervention programs implemented in Europe are part of Children of Somatically Ill Parents (COSIP). Interventions that are included in COSIP focus on the challenges children face when a parent is ill and works to alleviate the children's distress. The interventions promote active coping skills, improve children's understanding of the illness, work to create a sense of hope, normalize responses to the illness and reduce feelings of guilt, identify and advocate for using available resources, and facilitate the overall process of grief. Interventions of this nature have shown positive results, reporting significant decreases in children's depression. The interventions also reported positive changes in children's cancer related worries (Niemala, Hakko, & Rasanen, 2010).

*Kids Can Cope* and The Enhancing Communication Program are two intervention programs aimed at school-age children and adolescents. *Kids Can Cope* is based in Arizona's Banner Thunderbird Medical Center and focuses on teaching children about cancer as a disease, along with the several different ways it can be treated. Social workers help to provide children with the opportunity to meet with peers and share their questions and concerns about cancer in a safe environment while also increasing coping skills. The program uses creative art activities and interactive games to create a fun and supportive environment for children to relate to one another, learn about the disease, and feel comfortable asking questions (Taylor-Brown, Acheson, & Farber, 1993). The Enhancing Connections Program located in Washington aims more toward children's responses to parental cancer, focusing on reducing cancer-related worries (Lewis, Casey, Brandt, Shands, & Zuhlis, 2006). Feedback from the adolescents who participated in this program

suggested that the groups include both male and females invited within four months of the parent's cancer diagnosis, promoting a shared sense of experience and therefore connectedness. Adolescents also suggested that the program teach coping skills specific to each gender and tailored to ethnic and racial backgrounds. Family therapy sessions to promote open communication in the family were also requested by the adolescents. This program revealed significant improvements in children's negative symptoms including decreased behavioral problems, decreased cancer-related distress, and decreased anxiety and depression (Grabiak et al., 2007).

The Transitions and Palliative Care Therapy (TPCT) Model takes a multi-disciplinary approach with a team comprised of a medical staff leader, nursing leader, medical social worker, pain management specialist, pastoral care representative and an administrator. By having a strong counseling base rather than an emphasis on advanced care, TPCT model integrates family systems therapy into medical practice. The intervention uses transitions counselors to provide family therapy in the medical setting. Transitions counselors are counselors who have earned a master's degree from schools of family therapy and counseling, and therefore have knowledge of counseling and the counseling process. In order to be educated on the disease, counselors attend weekly interdisciplinary palliative care rounds and intensive care unit's surgical unit rounds where they receive knowledge of treatments, medical issues, and specific disease processes. Physicians and nurses tend to not have the time to contribute to patients' and families' emotional and psychosocial experiences. By having knowledge of the disease and its possible trajectory counselors can provide families with accurate information from a collaborative team of physicians, increasing the efficiency of communication between

medical professionals and families. This model is cost effective as it uses counselors at the heart of the intervention, who are hired at a much lower cost than medical staff (Babcock & Robinson, 2011).

A six-month study in which Medical Family Therapists (MedFTs) were integrated into an outpatient oncology unit showed significant positive results in negative symptom reduction for both patients and family members. MedFTs utilize a biopsychosocial and spiritual model to address the whole family's needs during a cancer illness. MedFTs focus on improving communication within families, accommodating structural changes occurring in the family due to the illness, facilitate a sense of meaning, and address impending loss of the patient. In this study, 90% of patients experienced a decrease in emotional suffering and 91% of patients and family members reported that the MedFT was helpful in connecting them with personal and community resources (Hodgson, McCammon, & Anderson, 2011).

## **Discussion**

### **Recommendations for Counselors and Professionals**

As research has shown, including clinical social workers or counselors in the team of professionals who work with patients and families of terminal cancer provides increases in effective communication, improved family functioning, and negative symptom reduction in family members both before and after a patient's death. Counselors should initiate interventions three to six months into the terminal phase of the illness, depending on the expected length of life. Studies support that this time period is when children experience significantly higher levels of depression and anxiety and lower social competence, therefore children's distress is increased and social support is lacking.

Parents also experience increased distress during this time and decreased confidence in parenting skills. This time period is a significant time for increasing support to all family members (Christ et al., 1993).

Counselors working in medical settings must be able to adopt a flexible framework due to the constant modifications of treatment and illness prognosis evident in cancer diagnoses. Case conceptualizations will change frequently (Strada & Sourkes, 2009). Simply listening is not sufficient in providing effective interventions. Counselors should be skilled in empathic listening, provide encouragement and reassurance, be comfortable with exploring grief reactions, and be able to communicate with the patient and family about the illness and its treatment (Wong et al., 2010). Statements that help to normalize the experiences of children should be included in communication with children and adolescents of the patient (Christ et al., 2010). A range of interventions should be tailored to a family's specific situation, including psycho-education, individual and family counseling, and grief counseling to both patients and family members. Long-term as well as short-term approaches should be considered, ranging from existential and insight-oriented approaches to cognitive behavioral focuses. Including the whole family in interventions helps to support the patient, support the family member's anticipatory grief, and can help the family to process the experience and feelings of ambivalence that come with a terminal diagnosis (Strada & Sourkes, 2009).

### **Conclusion**

With the staggering rates of cancer and the percentage of those diagnosed who have children, the psychological well being of cancer patients' families, and specifically their children, is a significant issue that has long gone unexamined. Research has shown

that children of terminally ill cancer patients experience significant psychological distress that, if left untreated, can manifest into psychological disorders rather than situational congruent responses. A lack of communication between family members, as well as between medical professionals and children, creates a gap in which misconceptions of the illness and psychological distress tend to fill. Counselors should be included in hospital based palliative care teams as a way to bridge the gap in communication between medical professionals and families and to provide psychosocial support during a crucial time of need. In providing these services, negative psychological impacts on the family, and especially children, will be reduced. Counselors are a cost efficient addition to the multi-disciplinary team in terminal care and will also provide preventative services by effectively intervening with families at the appropriate time.

Limitations in most studies and in this literature review include a lack of focus on the gender of the diagnosed parent, race, ethnicity and age of diagnosed parent, socioeconomic status of families, specific cancer diagnoses, and pre-existing family psychosocial functioning. Further research is needed to include these factors into our knowledge base.

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