2011

What children should know about cancer: Parent's perception

Kristyn Gina Sutton

Recommended Citation

Sutton, Kristyn Gina, "What children should know about cancer: Parent's perception" (2011). *Theses Digitization Project*. 3903.
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WHAT CHILDREN SHOULD KNOW ABOUT CANCER:

PARENT'S PERCEPTION

A Project

Presented to the

Faculty of

California State University,

San Bernardino

In Partial Fulfillment

of the Requirements for the Degree

Master of Social Work

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by

Kristyn Gina Sutton

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Approved by:

[redacted] 6/9/11

Dr. Carolyn McAllister, Faculty Supervisor Social Work — Date

[redacted]

Lynnett Wilhardt, L.C.S.W., Kids Konnected

[redacted]

Dr. Rosemary McCaslin, M.S.W. Research Coordinator

ABSTRACT

Little is known about parental relationships with their children while the parents are battling cancer. Parents struggle with their own emotions during their cancer treatment. Children, on the other hand, are rarely given the opportunity to express their feelings, because many times they are not fully informed about their parent's cancer. The present study focuses on how and for what reasons parents inform their children of their cancer. Through multiple focus groups, the present study tries to uncover what parents feel their children should know and why it is important for them to know about their cancer.

ACKNOWLEDGMENTS

I would first like to acknowledge my husband, Ronnie without you by my side I would not have had the strength to get through these past 3 years. You are my rock thank you. I love you with all my heart.

Second, I would like to thank my family. You all have been so supportive and also have allowed me to follow my dreams. Thank you mom and dad for loving me and encouraging me every step of the way. Katie, you are a great teacher and I know that I have learned many things from you. Thank you all for being such a wonderful family.

Third, I would like to thank Dr. McAllister. Thank you so much for your support through this whole process. You were able to keep things in perspective for me and allow me to process through my difficult times.

Lastly, I would like to thank Kids Konnected for allowing me to utilize your knowledge and families for my research. You are an amazing organization with a great mission. I hope to see your love and support for children who have a parent(s) with cancer flourish. It is because of you that children are allowed to have a voice through the chaos of cancer.

DEDICATION

I would like to dedicate this study to all the children who have or had a parent(s) with cancer. It's not easy being a kid and seeing your parent go through something so traumatic. My sister and I struggled with questioning why this happened to our family for many years. But we have come to realize it was that struggle that has made us stronger people. No matter how bad it gets remember you are always loved.

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CHAPTER ONE

INTRODUCTION

This chapter will cover the reasons why a lack of understanding about the needs of children and assurance, both with regards to emotional support and informative discussions from parents while they are battling cancer is detrimental to children, and how the effects of cancer affect everyone in a family system. This chapter will also cover the benefits of support groups for kids and how this need is under researched and underutilized. Social workers will continually be faced with families who are battling cancer, thus, it is important for them to have a better understanding of the necessity to help these children and their families cope with the cancer and its many effects.

Problem Statement

In today's society, cancer has become a common disease that affects many people a year. It is estimated that approximately 1.5 million new cancer cases will be diagnosed in 2009 (American Cancer Society, 2009). This disease not only affects the individual that is diagnosed with cancer but also their friends and family. To assist these individuals, many resources have been created to help them cope with the life changes that occur when someone is diagnosed with cancer. These resources may be financial, emotional, psychological, or physical. Many support groups are also created to support the various types of cancer patients in their struggles through their cancer diagnosis and treatment (American Cancer Society, *2011*; Kids Konnected, 2010a; National Cancer Institute, 2010b).

Support groups have been a beneficial resource for many individuals experiencing stress and chaos in their lives. They allow individuals to feel free from the stresses of being too emotional around others. In these groups they are able to let go of their emotions and indulge in their unspoken feelings of anxiety, fear, shame, self-worth, loneliness, and doubt. Here they are also able to find comfort in knowing they are not alone in their struggles and find camaraderie with others. Through this they find comfort in their feelings and are able to then find acceptable and healthy ways of dealing with and coping with their emotions. Support groups are a great way for individuals to learn better ways of coping and healthier ways to communicate their feelings to their loved ones. On gaining these tools individuals are able to find more happiness in the chaos around them (Barrera, Chung, Greenberg & Fleming, 2002; Barrera, Chung, & Fleming, 2004; Bedway & Hartkopf-Smith, 1996; Houtzager, Grootenhuis, & Last, 2001; Register & Hilliard, 2008; and Werner-Lin & Biank, 2009).

While there is an abundance of support groups for those diagnosed with cancer there are very few, if any, that are created to support the children of those patients (Children's Treehouse Foundation, n.d.b). With so many people being diagnosed with cancer there are twice as many children who are affected. The Children's Treehouse Foundation estimates that nearly 592,000 children are affected by a parent diagnosed with cancer in the United States (Children's Treehouse Foundation, n.d.a). With this many children affected in the United States it is important for this need to be exposed and understood. Proper resources for these children are necessary for them to develop and cope in a healthy manner. Why are children not being provided such a beneficial resource?

As of now there is only private funding available for support groups for children whose parents have/had cancer. Organizations like The Children's Treehouse Foundation and Kids Konnected are few and far between and therefore the funding is very minimal. If there were more awareness of the impact on children's emotional and psychological development when their emotions are not expressed or acknowledged one would hope that more funding would be available. With the proper funding more resource centers and organizations such as Kids Konnected would be able to provide a safe space for children to express and cope with their feelings.

Kids Konnected is a non-profit organization dedicated to serving children whose parents have or had cancer. They provide support, guidance, and education to children about cancer and its effects. It would also allow better training of parents, medical professionals, teachers, and social service providers as to the effects of children's emotional and psychological health during times of stress and chaos, such as cancer (Kids Konnected, 2010b). It is imperative to allow children the opportunity to know about their parent's cancer and be able to express their feelings in a non-threatening and supportive environment.

Purpose of the Study

When dealing with a disease such as cancer that is so volatile, many people have a hard time coping with the various changes that they must go through let alone helping their significant others, children, other family members and friends cope with these as well. Many times children are not afforded the same right to know information because they are "too young" or they "wouldn't understand" (Siegel et al., 1992, p. 327). They are therefore given minimal information and left alone to go about their normal lives. What parents do not realize is that their kids experience the same fear, anxiety, frustration, and anger that they feel. Children, both young and adolescents, are in need of support through this experience because while they do feel the same feelings their interpretation of those feelings and subsequent behaviors may not be representative of their actual feelings. Children's behaviors can manifest in many different ways through this experience. They may be normal, angry, constantly upset, self-centered, or detached from the entire situation (Love Sick, 2008; National Cancer Institute, 2010a) It is how the parents view these behaviors that will most affect the children.

As one child put it, a parent having cancer is "...like hitting a brick wall, it's like falling and hitting bottom, it's like running as fast as you can and tripping over a root that wasn't there a second ago, and it's like not feeling anything at all" (Love Sick, 2008, p. 13).

Children need a chance to understand the chaos in their life. They have the ability to comprehend changes and therefore should be provided information about the changes around them from their parents. They also deserve and need a safe place to be able to reveal themselves fully, to know their feelings are important and significant; this may be with their parents, teachers or a support group.

Therefore, it is important for children to be given the proper attention and resources they need to properly grieve through and cope with the changes in their lives. Cancer does not just change the individual fighting it but everyone around them. This study will allow the true feelings of parents and their choices for their children to be exposed. It will give them a voice that has yet to be heard, as to the truth of how they feel about their children and subsequently their children's feelings during this chaotic time.

By exploring this topic the researcher hopes to bring light to the fact that children understand and can sense the changes around them. They therefore are in need of some information as to why these changes are occurring so that they will not fabricate their own stories that may in turn be more detrimental. Through the use of focus groups and the participation of parents, sick and healthy, this study will bring to light the truth of what parents feel their children should know about their cancer and why they may felt it necessary to tell them about their cancer. The findings of this research will therefore help educate parents about their role in addressing the developmental and psychological needs of their children through this time. It will also give insight to parents' perception of their role in their children's development and how it is affected by cancer. Last, it will provide a basis for further research to better understand why resources are not being utilized to support children during this stressful time.

Significance of the Project for Social Work

This research is intended to be used as an educational tool to not only acquire the reasons why parents chose to inform their children of their cancer diagnosis but also as a tool for social workers to use when helping individuals who are diagnosed with cancer. Social workers are many times the first to assist those families diagnosed with a chronic disease and therefore play a very integral role in helping them all work and cope through this new process. This research will be available to social workers to help guide them in assessing clients and their needs. Social workers will be able to educate their clients on the psychological and developmental needs of their children and how they can be and are affected by the cancer diagnosis. Through the interaction between social worker and client a dialogue can be made around the reasons why they may or may not feel it necessary to inform their children. It will also allow deeper issues of their possible fear for their children to be addressed.

These findings will also assist social workers who run group settings to be able to target a more comprehensive audience. This research will allow those social workers to appeal to parents at another level, through education and support, to allow them to be more open-minded to the various troubles their children encounter through their cancer diagnosis and treatment. It will also provide social workers with insight as to the internal stressors that prohibit many parents, both ill and healthy, from discussing or attending to their children's needs.

The primary research question in this study is what do parents feel is necessary for their children to know about their cancer? A secondary question is does information given depend on the age of the child? If so, how old should the child be before vital information is given? A third question is how a parent(s) decide to talk to their children about cancer; how do they tell them?

CHAPTER TWO

LITERATURE REVIEW

Introduction

This chapter will cover the guiding theories behind this research study: systems theory, attachment theory, Piaget's cognitive development theory, and Erikson's developmental theory. Understanding these theories will allow the reader to better grasp how children cope with stress, grief, and loss. This chapter will also provide insight on how children actually view the concept of death, the difference between actual loss and anticipatory loss and how their developmental stage will impact these concepts. Due to the fact that no empirical research could be found on the intended topic of this study, this chapter will also provide a basis for the fact that children are affected by cancer by showing the benefit of support groups for children whose siblings are battling cancer.

Theories Guiding Conceptualization

In all studies it is important to understand the theoretical framework from which it derives itself. This study grounds itself in four guiding theories: systems theory, attachment theory, Piaget's cognitive developmental theory, and Erikson's developmental theory. Each of these brings a different perspective on how children understand, conceptualize, and are affected by the environment around them. However, together these theories explain how children, at any age, are able to be and are affected by stressful situations, such as cancer. Therefore, it is necessary to understand these theories as they will lay the foundation for this study, which asks parents, what they feel children should know about their cancer and why they choose to inform their child or children of their diagnosis?

Systems Theory

Systems theory views the world as composed of individual parts, or systems, that interact with each other to achieve a common goal. These individuals systems can be a person, family, or even a community (Bertalanffy as cited in Lesser & Pope, 2007). Due to the fact that these systems are constantly interacting with one another, if a change occurs in one it will inevitably cause a change in all the systems it interacts with. This theory can therefore be applied to the family.

An individual family member is a system and when a change, such as cancer, occurs and changes them it will certainly affect and change all the other family members, systems, around them. It must then be said that through this theory a parent's view that their children are not affected by their cancer is false and not supported because they are; every relationship is interconnected (National Cancer Institute, 2010b).

Attachment Theory

In discussing attachment we need to first look at the intensity of what it means to bond with a child when they are first born. It is in these early days, weeks and months that attachments occur, whether secure and healthy or not. An infant is reliant on their caregiver to care for their every need. The infant expresses their needs through crying or whining and it is the responsibility of the caregiver to determine what the need is and how to appropriately take care of that need. Through this attentiveness the infant becomes more aware of who is trustworthy and who is not and therefore an attachment can be made (Davies as cited in Lesser & Pope, 2007).

This feeling of security sets the stage as the infant begins to walk and talk, in that they are comfortable knowing that their security base, the one who has fulfilled their needs in infancy, will be there when they start to feel uncomfortable (Lesser & Pope, 2007, pp. 214-215). The child again relies on their secure attachments as they enter school to know what is right and what is wrong. Here when faced with frustration or confusion they are again able to fall back on their caregiver as a resource for guidance (Lesser & Pope, 2007, pp. 242-243). If the caregiver is sick, battling cancer, the child is placed at a disadvantage for appropriately developing a secure attachment. This deficit will change the way the child interacts and reacts to the world around them because they do not have a security base to help guide them.

As the child moves into middle childhood and adolescence a shift from caregiver to peers begins to occur. However the secure attachment to the parents reassures the child of the constant ability to return to the parent. Peer attachments and relationships are pivotal for adolescents. It is during this time that they are forming their own identity and find it necessary to be around those who are like them (Sullivan as cited in Lesser & Pope, 2007). Children who have grown up without secure attachments however may lack a sense of self and therefore may struggle with finding themselves and forming a healthy identity (Lesser & Pope, 2007, p. 259). This is why it is necessary for parents to understand that communication to their children about their cancer is vital for the development of secure and healthy attachments.

Piaget

Piaget's cognitive developmental theory brings awareness to the continuance of a child's cognitive development. In attachment theory one learned how important early attachments are for a child to develop a healthy understanding of their world. With Piaget, we begin to understand the complexities to a child's mind and how they interpret the world around them. Piaget (1952) (as cited in Lesser & Pope, 2007) believed that there were four stages that children moved through in their cognitive development: (1) sensorimotor, (2) pre-operational, (3) concrete, and (4) formal operations.

The first stage of this theory begins in the first two years of a child's life. Here infants are becoming aware of the world around them. They utilize their senses to explore what is pleasurable and not in their environment. Children at this stage are beginning to use trial and error to guide their way through new experiences. Towards the age of two children are capable of moving past representational thinking, thinking that is supported by simple mental images, to a more symbolic thinking which allows children to use symbols to represent objects (Piaget as cited in Lesser & Pope, 2007, p. 226). Toddlers begin to use play and pretend as a way to express their feelings and emotions. During this stage a major accomplishment must be made, object permanence. Object permanence allows the child to understand that even though an object or person may not be seen, heard or touched, they still exist (Cherry, 2011, para. 2). In this stage children who have been affected by an illness in their house, such as cancer, may be seen acting out their emotions and frustrations of the changes through their play. They may be more fussy or tantrum a little more due to the fact that their parent is away a lot and they do not know how to verbally express their fears or worries.

The second stage of Piaget's theory occurs between the ages of two and six years old. Here children continue to use play as a means of expression, however move to a more descriptive way of doing things. They are able to put words, sounds and images to what and how they are experiencing life. During this time egocentrism, the inability to view situations from another perspective, limits the child from objectively understanding reality (Piaget as cited in Lesser & Pope, 2007, p. 227). They have limited ability to understand causality and the difference between thought and action. Toward the end of this stage children are becoming more aware of other's feelings and emotions (Piaget as cited in Lesser & Pope, 2007, p. 227). In this stage children are apt to believe that their thoughts can cause things to occur. Children may believe that their fear of their mom or dad leaving them caused them to die, or that their anger towards them has caused the cancer to occur. It is important to express to children in this stage how cancer develops so that they can be relieved of this worry and guilt.

The third stage, concrete operations, is viewed as the years between seven and 12 years of age. This stage is based on the belief that children have moved forward and are now able to think in a more logical fashion. They have shed most of their egocentric views and are more aware of those around them. Children are able to understand their interactions with other and consequences of those interactions. However, children at this stage are still unable to understand abstract ideas that are not of this world, such as heaven. Children continue to use play as a way to express themselves; however, this play is marked more as a way to organize their thoughts, feelings and environment (Piaget as cited in Lesser & Pope, 2007, p. 253). Children during this stage begin to understand and can comprehend what a disease is and how it can affect a person. They are able to understand that they are not the cause of the occurrence of the disease. Children at this stage should therefore be afforded some information relating to their parent's cancer because they can understand and comprehend what is inevitably going to change their life.

The last stage of Piaget's cognitive development theory is formal operations or formal operational thinking. This stage encompasses adolescents beginning at the age of 11 to the early 20's. In this stage adolescents move toward understanding and conceptualizing abstract thinking processes. They are able to comprehend reality on their own, whereas, before they were reliant on their parents' perception of the world and environment around them. Adolescents in this stage are guided by emotions due to the growth of the amygdala, which controls our emotional responses, and also utilize their peers as their initial support system. Toward the late teens, adolescents become more aware of the value of their family and begin to balance their support systems as equally (Piaget as cited in Lesser & Pope, 2007, pp. 278-279). During this stage adolescents can fully understand the complexities of cancer, death, and dying. They are however guided by emotion and self-centeredness and therefore may react in ways which may be perceived as unloving and showing no empathy towards their loved ones. This should not be mistaken for not caring or not understanding but rather as a sign for the need of deeper understanding, love and support from those loved ones around them.

Erikson

The last theory that is necessary to discuss to understand the development of children is Erikson's developmental theory. In this theory Erikson proposes that there are eight psychosocial stages of life and at each stage there is a conflict that must be overcome in order to develop in a healthy manner, both psychologically and emotionally. For the purpose of this study the first five stages of Erikson's theory will only be discussed: (1) trust vs. mistrust, (2) autonomy vs. shame and doubt, (3) initiative vs. guilt, (4) industry vs. inferiority, and (5) identity vs. role confusion (Erikson, 1963).

According to Erikson (1963) the first stage, during infancy, a person must accomplish and overcome is trust vs. mistrust. In this model if a caregiver, the mother, is able to appropriately and effectively care for the basic needs of the infant the infant will develop trust for that person. However, it is not just the basic needs being met but the affection and quality of the "maternal relationship" that will effectively allow the child to develop a trusting relationship (p. 249). If this pattern of positive caregiving continues the trust will be generalized to others. If however, the mother fails to meet these basic needs the infant will develop mistrust. It is very important through this stage, as was discussed with attachment theory that caregivers, sick or healthy, attend to the needs of their children so that healthy, secure, trusting relationships will be able to develop.

The next stage is autonomy vs. shame and doubt and occurs in early childhood. During this stage it is necessary for the parent or caregiver to allow the child a sense of autonomy. Here the child must explore their surroundings and be confident in themselves to do so. It is the parent's job to make sure that while the child explores the parent is cautiously setting limits in a way to not shame the child (p. 254). Erikson (1963) describes shame as being self-conscious and ashamed (p. 252). If shame is continually bestowed on the child for exploring their world, he believes the child will become very self-conscious and begin to doubt themselves and therefore feel the need to rely on others and become dependent (pp. 253-254). During this stage it is vital for parents, sick and healthy, to encourage and support their children to explore and yet not inhibit them or constrain them.

The third stage is initiative vs. guilt. This stage occurs during preschool years and is marked by a child's ability to take on and plan to accomplish a task. Here the child is motivated to think of new ideas and is open to the help of others. However, if not allowed to complete their desired tasks or if reprimanded about the task they wish to undertake the child may feel guilty. This guilt can cause them to steer away from the desire to take the initiative at another time (Erikson, 1963, pp. 255-258). In this stage a child may feel they have discovered a new way to bring joy and comfort to their sick parent, yet adults may not feel the same way. It is during a situation like this that parents remember the innocence of the gesture and explain to their child why it may not be appropriate to comfort their parent in that way. This explanation will allow the child the ability to continue to feel a sense of accomplishment and continued desire to take the initiative yet not cause them to feel guilty and insecure.

The fourth stage is industry vs. inferiority and occurs in the early school years. In this stage the child is motivated to accomplish tasks which bring about attention and praise by others: parents, teachers, and friends. If the accomplishments are met with discouragement the child may lose a sense of hope and revert back to being isolated and closed off, feeling inferior to those who were able to succeed (Erikson, 1963, pp. 259-260). It is important that through this stage sick parents engage with their children and their accomplishments. It is important for parents to be proud of their children to show their continued involvement in their daily lives. It is also in this stage that parents need to be aware that children may feel the need to pressure themselves to do better to overcompensate for the sickness that is affecting their family. In this situation parents need to be open and honest about their expectations for their children and allow the child to express their feelings surrounding the issue.

The last stage that will be discussed is identity vs. role confusion. This stage occurs during adolescence when the child is looking deeper into themselves and the beliefs and values that they have acquired thus far and matching them with the world, friends, and desires around them (Erikson, 1963, p. 261). They struggle to develop an identity for themselves that will allow them the ability to feel comfortable that later life goals will be able to be accomplished. It is when their inner identity and the identity that others see or want differs that role confusion can occur (p. 262). It is necessary for the adolescent to be motivated and feel support during this stage in order to completely and effectively achieve a healthy identity. Parents are vital participants in this achievement when cancer has affected a family because they are the sources of guidance and resource. It is during this stage that parents need to be open and honest with their feelings and emotions in order to model good coping skills for their children.

The theories discussed in this chapter have all shown how delicate a child's development is and how every change within their life impacts who they become. It is therefore essential for parents to understand how important it is for their children to know and understand why there are changes in their lives. These theories have also shown that children are affected regardless of whether they are explicitly and directly told of their parent's illness or whether they just merely observe these changes. Thus, parents should be honest and supportive during this time of chaos and ensure that their children are receiving the best care possible from both of their parents so that they can develop both emotionally and psychologically healthy senses of self.

What Is Death And Grief To A Child?

Many adults feel that children are incapable of understanding death. Yet, many scholars believe that children as young as two are able to comprehend death in their own way (Buirski & Buirski, 1994; Furman, 1974; Marks, 1992; Osterweis, Solomon, & Green, 1984; Smith, 1991). When a parent has cancer most children anticipate the worst, they immediately go into shock mode and do not know what to do (Love Sick, 2008). No matter what age, a child senses a change in their family and is affected by it. When children are young they may not always have the vocabulary or insight to verbalize exactly what they are feeling; thus, they may act out or go on with their play as if nothing happened (Buirski & Buirski, 1994, para.9; Osterweis, Solomon & Green, 1984, p. 100). This type of reaction does not indicate that the child is incapable of grieving or understanding death; it is just their way of coping with it at the present time.

Smith (1991) (as cited in Dickinson, n.d.) observed preschoolers reenacting their emotional reactions to loss and death through their play (p. 213). She also observed the need for a supportive adult figure to be there for them when they were incapable of communicating their feelings. Children at this age are struggling to understand the concept of permanency and so it may take them a lot longer to comprehend the meaning of death and its finality (Smith, 1991, pp. 214-215). For that reason, parents need to be aware of the struggles their young children go through and be supportive and open with them. They need to be patient and understanding about the complex idea they are asking a child to comprehend and cope with.

As children enter into middle school years and adolescence they become more aware of the finality of death and the more abstract concepts of death, such as heaven (Furman, 1974, p. 13). During this period in their developmental life adolescents are concerned with themselves and their worries; how is my parent's sickness going to affect me? Questions and reactions such as this are often mistaken by parents as selfish and reprimanded however, at this point parents must realize the development of their children and how that has affected their response. Children also hide their feelings from parents as a way to avoid burdening them (Marks, 1992, p. 150); and for this reason many children are left to tend to their feelings and emotions alone.

Discussed thus far is the capability of children to understand death and what it means. But in many cases parents do not die; are there still feelings of loss associated with the cancer experience? Yes, this is called anticipatory grief. Aldrich (1974) (as cited in Rosenheim & Reicher, 1986) describes anticipatory grief as feelings of loss and sadness along with anxiety, agony, uncertainty and possible feelings of guilt. Rosenheim and Reicher (1986) found that in families who were experiencing anticipatory grief parents were more likely to be defensive and in denial of the circumstances at hand and therefore avoided their children's need for support. They also found that during this time parents are very poor judges of their children's feelings and emotional state (p. 118).

Children are capable of understanding death and grieving for their loved one. Children react to and are affected by the changes around them. Thus, parents need to be able to be available for their children to comfort, support and encourage their emotional expression during this chaotic time in the family.

Existing Support Groups For Children

Support groups for children who are currently experiencing the stress and chaos that cancer can create for families have not been widely studied. Nor has the perception of parent's feelings of what children should know about their cancer. It is apparent through this lack of research that there is not very much attention afforded to the support of children dealing with this type of stress. While this research is lacking, minimal research has been done on the effects of support groups on children whose siblings are battling cancer and how these children have indeed been affected by cancer.

Importance of Support

There is a consensus among many researchers that support for children who are affected by cancer is of great concern. Yet, it is during this time that many times they are left in the background. Register and Hilliard (2008) believe that bereavement groups for those children who have actually lost a parent provide a safe place to validate their feelings and emotions. They believe that through these groups children are afforded the opportunity and support needed to help "normalize" their experiences (p. 164). Through these groups children are able to learn proper coping and problem solving skills (p. 165).

O'Callaghan, O'Brian, Magill, and Ballinger (2009) found that with parents who were undergoing cancer treatments, when given the opportunity and guidance to turn their feelings and emotions into songs, were able to better communicate with their children. They also found that this expression from the parents allowed the children to process their emotions and feelings in a healthier way (p. 1154). These song lyrics not only helped the children immediately but also gave them a lasting remembrance of their parent to help them through later life struggles (pp. 1154-1155). This study provides support for the necessary interaction between parents and children during their battle with cancer and how children are inevitably affected by it. It is when the support and love are apparent to the children that they are able to thrive.

Those Who've Lost a Sibling

While much research is absent from this topic there are some studies that have shown the benefits to providing support groups for children whose siblings have cancer (Barrera, Chung, Greenberg & Fleming, 2002; Barrera, Chung, & Fleming, 2004; Bedway & Hartkopf-Smith, 1996; and Houtzager, Grootenhuis, & Last, 2001). Bedway and Hartkopf-Smith (1996) developed a pilot support group, "For Kids Only," as a way to fill the gap they saw with regards to children who were dealing with the effects of cancer in their family. The group was a one-day workshop that was offered eight times with six to 14 participants at each workshop (p. 27). The purpose of the group was to educate, support, and screen the participants who attended (pp. 23-24). Bedway and Hartkopf-Smith (1996) found there were many benefits to their workshop which included providing a safe environment for emotional expression, networking with other children, dispelling myths and rumors about cancer, alleviating anxiety, and teaching coping skills (p. 27). While this was a preliminary program with limitations, it supports the idea that when children are provided the support and knowledge they need to understand the world around them, they are able to find healthy ways of coping.

Houtzager, Grootenhuis, and Last (2001) studied the effects of supportive groups for siblings of pediatric cancer patients. Their group consisted of "five weekly sessions for a maximum of eight siblings aged seven-18 years old" (p. 317). Each participant completed the State Trait Anxiety Inventory for Children (STAIC) pre and post group participation. The results indicate that anxiety levels of participants greatly diminished after participation in the support group. Seventy-five percent of participants prior to group participation had elevated anxiety levels whereas only 46% continued to have elevated anxiety levels after group participation (p. 319).

There were some differences between genders; boys seemed to return to a normal state of anxiety after their participation whereas girls seemed to remain relatively anxious (p. 322). Houtzager, Grootenhuis and Last (2001) also found that the illness of their sibling had an effect on the anxiety levels after their participation. If the sibling's illness was that of a brain tumor they were more likely not to have benefited from the group because there was an added fear of their siblings ultimate death (p. 322). This compounded their ability to find healthy coping mechanisms because for them there was no hope in sight. However, aside from this both children and parent reports showed improvement in the children's anxiety levels and coping skills after their participation.

Barrera, Chung, Greenberg, and Fleming (2002) piloted a group therapy intervention program, Siblings

Coping Together (SCT) which aimed at providing participants the skills needed to help alleviate feelings of depression, anxiety and behavior problems (p. 132). The study conducted three group sessions consisting of eight structured, weekly sessions of two hours each with a participation of six, four, and seven siblings respectively (pp. 132, 134). The participants and parents completed five assessments both pre and post group participation; Children's Depression Inventory (CDI), STAIC, Youth Self-Report (YSR) and the parent completed Child Behavior Checklist (CBCL, Sibling Perception Questionnaire, and Sibling Group Satisfaction Questionnaire (SGS) (p. 135). The results of this study show that the participants, through self-reports, saw a reduction in symptoms relating to depression and anxiety and also in their behaviors (p. 139). However, due to the small sample size the generalizability and reliability of the research is questionable.

Barrera, Chung, and Fleming (2004) expanded the previous study by Barrera, Chung, Greenberg, and Fleming (2002). In this study "...42 siblings...participated in seven consecutive SCT intervention groups. Each group consisted of four to nine children of similar developmental age... to ensure cohesion and developmentally appropriate activities..." (p. 24). The study consisted of two pre and two post-test assessments to control for validity (p. 25). Each participant completed the Children's Depression Inventory (CDI), STAIC, Youth Self-Report (YSR) and Sibling Group Satisfaction Questionnaire (SGS). Parents completed the STAIC, SGS, and Child Behavior Checklist (CBCL) (p. 27). "The SCT program consisted of eight (structured) weekly sessions of two hours each..." (p. 28).The results of the study indicate that there were benefits to participating in a support group while trying to cope with the illness of a sibling with cancer. Both parents and participants reported a decrease in symptoms relating to depression and anxiety (pp. 33-34).

While these studies show a benefit for children participating in group process therapy there is also much to be said about the time taken by the parents to care for and acknowledge these children's feelings and needs. "Siblings enjoy the idea that their parents come to the hospital especially for them" (Houtzager, Grootenhuis, & Last, 2001, p. 322). Barrera, Fleming, and Khan (2004) found that higher social support for siblings of those who had cancer indicated lower symptoms of depression, anxiety, and fewer behavior problems than those with less social support (p. 108). These findings reinforce the idea that support from parents and others is necessary for children who are faced with loved ones battling cancer. The parents especially need to devote time to their needs just as much as they do their own needs or their other children's needs.

Summary

This chapter covered the various guiding theories that lay the foundation for this study. It also covered the reactions of children to death and the grieving process and how the child's developmental stage greatly impacts the perception and understanding of loss, grief and death. It also covered the impact of support groups and their ability to help children of all ages to properly grieve and cope through this stressful time. This chapter brings an understanding of why it is so important to provide resources to children during their parent's cancer diagnosis and treatment; children need to express themselves in a loving, trustworthy, and safe environment. Therefore it is important to understand and gain an insight into a parent's thought process as to why children are not given information concerning their parent's disease; what do parents feel children should know?

CHAPTER THREE

METHODS

Introduction

This chapter will discuss the study design, the instruments used, and the recruitment of the participants. The current study was done to uncover what parents felt their children should know about cancer. This is a qualitative study which relies on the stories of 22 participants' to give their insight into the topic.

Study Design

The present study was designed to explore the reasoning behind why parents inform their children of their cancer. It utilized focus groups to discuss the topic with parents, healthy or ill, of children who have at least one parent diagnosed with cancer. The utilization of focus groups allowed an opportunity to follow up and expand on participant answers. This topic has not been widely studied and therefore, a focus group is an appropriate starting point for future research. It will give a better understanding of what questions to use in a survey and will also give comparative data (Grinnell & Unrau, 2008, pp. 240-243).

The present study employed a focus group from which the responses were categorized into broad and sub-thematic statements. This enabled the researcher to correlate these statements with participant characteristics to determine if there are any associations between them in the study sample (Boeije, 2002; Grinnell & Unrau, 2008).

There are some limitations of the present study. These limitations are similar to those in other qualitative studies. One is that there was a small sample size that will not be generalizable to the greater population (Grinnell & Unrau, 2008, p. 243). Generalizability is also a factor in that the participants used were recruited from support groups and therefore, the study does not take into account all those individuals who do not use support groups during their cancer diagnosis and treatment or who live outside the local Southern California cities in which this study was conducted. Another limitation exists in the loss of anonymity of the participants. The participants may have been embarrassed, shy to answer, or uncomfortable in answering some of the questions and therefore may have lied, not give accurate responses or not have been able to remember specifics to their stories (Grinnell & Unrau, 2008, pp. 242-243). Interview distortions are also a limitation in that the interviewer may not have interpreted the answers correctly. The appearance and other characteristics of the interviewer may also have influenced and elicited information from the participants that would not otherwise be gained from other forms of data collection (Grinnell & Unrau, 2008, p. 244). Lastly, the diversity of ethnic backgrounds and their perception of what children should know about their cancer. This may lend itself to be an important factor that may not be addressed in the present study. Further research will be necessary to determine whether support group attendance and ethnic background are important factors in whether parents discuss their cancer diagnosis and treatment with their children.

While there are limitations to the present study, and qualitative studies as a whole, there are strengths to conducting focus groups. One strength is it will open research of a topic that is not widely discussed or studied. It will offer a platform for further research on parents' perceptions of their children and their cancer. The present study asked parents what they feel is appropriate information for children to know about their cancer and why. This questioning allowed insight to why parents so often disregard their children during a stressful time such as cancer. The naturalness and spontaneity that a focus group allows for participants makes it easier for them to respond as well as give free and honest answers (Grinnell & Unrau, 2008, p. 240). Another strength for conducting focus groups is that the interviewer is able to frame and reframe questions in a way to elicit the most beneficial information for the study as well as ensure that all questions are addressed in a safe environment without the influence of others (Grinnell & Unrau, 2008, pp. 241-242). Lastly, through focus groups there is the ability to access serendipitous information, information that is "stumbled upon" through the participants' spontaneous answers that are useful to the study (Grinnell & Unrau, 2008, p. 241).

Sampling

The participants were of various ethnic backgrounds, male and female, between the ages of 25 to 65 years old, either diagnosed or not, and battling various types of cancer at various stages. To be able to participate in this study one would have to be diagnosed or had been diagnosed with cancer or have a spouse/partner who is currently or has been diagnosed with cancer, have a child between the ages of two and 18 years old, and be connected with a support group from Kids Konnected. A total sample size of 20 participants was sought. The participants gave first hand insight regarding uncovering parents' perception of what children should know about cancer.

Data Collection and Instruments

The data that was collected in this study was parents' views of what their children should know about their cancer. There were 19 demographic variables that were studied: age, ethnicity, relationship status, income level, type of cancer that the parent is battling, how many children they have, ages of the children, cancer prognosis, cancer treatment, level of education, whether the parent(s) have been affected by cancer before, did the parent(s) experience a death when they were young, the length of time the parent has been battling cancer, who the parent(s) have told about their cancer, changes in their household, how they heard about Kids Konnected, whether they attend support groups themselves, and whether they told their children or not. These variables were used to provide a sociodemographic understanding of the participants in the focus group. Ethnicity, relationship status, type of cancer, cancer treatment, whether the parent(s) have been affected by cancer before, whether the parent(s) have experienced a death, who the parent(s) have told, changes in their household, how they heard about Kids Konnected, whether they attend a support group themselves, and whether they chose to tell their children or not were all measured nominally. Cancer prognosis, level of education, and income level were measured ordinally and age, how many children, ages of the children, and the length of time the parent has been battling cancer were scale measurements.

The participants were initially given a demographic questionnaire which measured the demographic variables (See Appendix A). Once the participants completed the demographic questionnaire they were engaged in a videotaped discussion regarding what parents feel children should know about cancer. The researcher followed an interview guide which was created for this study to help uncover what parents feel children should know about cancer (See Appendix B). Participants were asked about what made them tell their children, how long they waited before telling them, what they felt was appropriate to tell children about cancer and why, how they determined if their children need support, what they have learned about their children since their diagnosis, and what advice could they give to other parents going through a similar situation.

Procedures

Data was collected between June 2010 and February 2011. Participants were recruited from support groups from Kids Konnected where a convenience sample was used. A flyer (Appendix C) was provided to the agency to be passed out or mailed to support group attendees describing the study and the role of participants in that study. Those who wished to participate in the focus group attended the following parent meeting that had been set aside to conduct the focus group. Participants were parents, healthy or ill, of children who have at least one parent who is battling cancer. The focus groups were held at Kids Konnected's affiliated sites so the usual group facilitators were present. The researcher conducted the focus group and informed the participants of their voluntary participation. The focus group lasted no more than two hours during which the participants completed a demographic survey and participated in an open forum focus group.

Protection of Human Subjects

On arriving at the focus group, participants were provided with the informed consent (Appendix D) which informed them of the focus of the present study and what was expected of them and a video/audio consent (Appendix E) which provided the researcher guidance to how the participant would like their responses managed. The participants were asked to identify themselves by their first names only as a way to prevent complete disclosure of their identity. Participants were informed of the importance of confidentiality prior to beginning the focus group. However, due to the nature of group settings, participants were also informed of the inability of the researcher to ensure complete confidentiality due to others talking about the group outside the realm of the focus group.

At the completion of the focus group the participants were debriefed on the possible benefits to them through the knowledge gained in the group and also through the material the researcher presented to them regarding children's ability to understand and comprehend stress. Along with the information provided, the participants gained insight into their own beliefs and value systems. There was an informational handout given to each participant at the end of the focus group highlighting the educational information given to participants (See Appendix F).

The researcher kept the videotape locked in a safe to ensure the confidentiality of the participants after the group was completed. The researcher presented the findings of the present study anonymously.

Data Analysis

Different analytical methods were used for the qualitative and quantitative data collected in the present study. The qualitative data from the two focus groups was transcribed verbatim by the researcher. Once completed the researcher began to code each participants' responses based on themes found throughout the responses during the focus group. The researcher used constant comparative analysis to code and divide the participants' responses into broad and sub-thematic categories (Boeije, 2002; Grinnell & Unrau, 2008).

The researcher began by using a first-level coding method by separating the response from one participant into various sub-thematic categories (Boeije, 2002; Grinnell & Unrau, 2008). Once completed a second-level coding was conducted, where the remaining participants' responses were coded and separated into the existing categories. If responses did not fit into the existing categories, new categories were created. This process was repeated until all participants' responses had been coded. Once thematic statements were made, associations were made between them and the independent variables to see if any are significant underlying reasons why parents told their children about cancer.

The themes helped find commonalities that were a beneficial factor in this study. These themes gave a better understanding of what parents felt children should know and how to better help them with this process in the future. The quantitative data collected was imputed into SPSS and frequencies were calculated.

Summary

This chapter covered the study design, the recruitment of participants and explained the instruments used to uncover what parents felt their children should know about cancer. This chapter also describes the analysis of the data and how results were concluded.

CHAPTER FOUR

RESULTS

Introduction

This chapter will present the findings from this qualitative research study. It provides supplementary demographic data, and presents various responses from the 22 interviewed participants on their perspective of what children should know about cancer. It also provides information on what the interviewed participants felt would be helpful for other families struggling through the same experience.

Presentation of the Findings

Demographic Characteristics

Prior to the taping of each focus group, the participants were given a sociodemographic survey to complete. The following findings come from these surveys. There were two focus groups in which data was collected. The first focus group was conducted on September 20, 2010 and had 18 participants. The second focus group was conducted on February 22, 2011 and had 4 participants. The characteristics of the 22 interviewed participants are summarized in Table 1. The majority of the research participants in this sample were the spouse/partner of a cancer patient, with two grandparents and one friend. Of those 10% were single, 38% were married, 33% were widowed, and 14% were divorced. The mean age was 47 years old, with a range from 32 years old to 65 years old. Most of the participants were Caucasian (57%), followed by Hispanic, Multiethnic, and Other (10%), and 1 participant who was Pacific Islander. The education level of the participants were as follows: high school completion or equivalent (10%), some college (24%), Bachelor's degree (43%), Master's degree (10%), Professional degree (MD, JD, etc.) (5%), and other (5%).

The majority of the cancer patients were deceased (38%) with the remaining having a terminal prognosis (29%). The mean number of years that they were battling cancer was 2 years, with a range from 1 year to 7 years. The treatment received ranged with 76% of cancer patients receiving chemotherapy, 48% receiving radiation, 43% having a surgery, and 19% had another form of treatment.

All participants had children or grandchildren participating in a Kids Konnected support group for children who had/have a parent with cancer. The mean number of children in a household was 2, with a range from 1 child to 4 children. The children's ages range from 6 months to 16 years old. The majority of the children were female.

Table 1. Demographic Characteristics of the Participants

Variables	Frequencies (N)	Percentages (%)
Relationship Status of Participant		
Single	2	10
Married	8	38
Divorced	7	33
Widowed	3	14
Age of participant		
30-40 years old	2	10
41-50 years old	13	64
51-60 years old	2	10
61+ years old	2	10
Ethnicity of participant		
Caucasian	12	57
Hispanic	2	10
Multiethnic	2	10
Pacific Islander	1	1
Other	2	10
Education of participant		
High School Diploma	2	10
Some College	5	24
Bachelor's Degree	9	43
Master's Degree	2	10
Professional Degree	1	5
Other	1	5
Prognosis of Illness		
Deceased	8	38
Terminal	6	29
Years battling		
1 - 3	16	77
4 - 7	3	15
Treatment received		
Chemotherapy	16	76
Radiation	10	48
Surgery	9	43
Other	4	19

Variables	Frequencies (N)	Percentages (%)
Number of children in household		
1 - 2	16	76
3 - 4	4	19
Children's ages		
0 - 3	4	13
4 - 7	4	13
9 - 12	12	38
13 - 16	12	38
Children's Gender		
Male	12	32
Female	25	78

*numbers do not add up to 100 due to missing data in several categories.

Findings Gathered From the Focus Groups

The following sections will describe the data gathered from the two focus groups conducted in this study. The results are categorized into four sections which were determined by the researcher as overall themes based on the research questions asked during each focus group. The four themes are: using age appropriate information to tell your children, children benefit from honest support, parents need support too, and overall advice for other parents.

Using Age Appropriate Information to Tell Your Children

The responses related to telling children about their parent's cancer diagnosis were very interesting. The majority, 18 of the 22 participants interviewed, felt that it was necessary to tell the children. Participant 1 said:

"I told my kids because I was diagnosed with a terminal cancer and they deserve the right to know no matter what age" (Personal Interview, September 20, 2010).

There was an overwhelming sense that children were perceptive and saw the changes that were going on in their house anyway, and therefore should be given the opportunity to learn the facts about what was happening to their parent. Participant 15 stated:

"Be honest with your kids. They need to know what is going on and be in reality. Don't try to deny what's happening" (Personal Interview, September 20, 2010).

Although many had the same feelings that parents should be honest with their children, 14 of the 22 participants interviewed felt honesty and truth came with proving age appropriate information to each child. Participant 19 chose to separate her children and tell them individually to ensure that they were given as much information that they could understand given their age and developmental levels. Participant 5 stated:

> We from the very beginning we let them know what was going on they were a little bit older because we knew that there wasn't much time. We started slow, we didn't come home the first day and let them know, it took a few months to ease into it but for the last 6 months they knew what was going on as she did hospice at home...They were old enough...there's nothing you can hide from them...we felt that we had to let them know (Personal Interview, September 20, 2010).

There were some participants (4 of the 22 interviewed participants), however who felt that it was not necessary to tell their children either of their cancer in general or of the severity of the cancer. Participant 4 stated:

"I don't want to tell my 4 year old that I'm going to die...But we, my wife and I, wanted him to learn about what cancer is as a start" (Personal Interview, September 20, 2010).

Several of those who chose not to tell stated that they were respecting the wishes of their spouse/partner who was the individual diagnosed with the cancer. Participant 6 stated:

"They knew she was sick, just didn't know she had cancer. That was my wife's choice and I respected that" (Personal Interview, September 20, 2010).

Several times (5 of the 22 interviewed participants) the children were just told that their parent was sick, and it was not until after their death or during their last days that the children were actually informed as to what the source of their parent's sickness really was. This may be due to the fact that many of the parents themselves were in denial of the severity of their illness. Participant 3 stated:

"My wife never, she said I'm not going to pass, I can't pass I have young children" (Personal Interview, September 20, 2010).

Children Benefit From Honest Support

Throughout the focus groups, 7 of the 22 interviewed participants were adamant that children needed honest support during their parent's cancer diagnosis, while 11 of the 22 interviewed participants simply agreed that children needed this type of support. These children were sometimes exposed to the deterioration of their loved one and needed to be able to know what was happening.

"He saw my pick line, I mean I was a monster, I had lines coming out, tubes coming out, they hardly saw me I was in the hospital" (Participant 1. Personal Interview, September 20, 2010).

"My daughter saw her go from looking like she did, like a model, to looking like she was 105 year old and couldn't even walk up one step" (Participant 2. Personal Interview, September 20, 2010).

However, this was also a topic in which brought some disagreement. Others felt that being exposed and talked to honestly from the beginning was not always helpful to the children in the long run. Participant 8, for example, shared that her daughter was exposed at the age of 7 to her father's first bout with cancer; however, when he was diagnosed for a second time, she did not have an "ohh cancer outlook" and was very nonchalant with the news (Personal Interview, September 20, 2010).

Participant 10 shared that her children were told of their father's cancer and that he was going to die. Yet, he survived and now her children live in constant turmoil about it.

While there was some disagreement on this issue, everyone did agree that there were inevitable changes to their children's lives and therefore these changes needed to be addressed in some way.

"We've all been hit in the pocket book with paying for treatments and all that, that's what my kids don't understand, why they don't have money like other families. And that's the thing that I have to drill in them...because mom's sick" (Participant 1. Personal Interview, September 20, 2010).

They also overwhelmingly (15 of the 22 interviewed participants) felt that by bringing their children to a support group environment, like the one Kids Konnected provides, is a great way for their children to be able to express themselves, their fears, frustrations, and emotions in a place that is safe and comfortable. They are given the opportunity through Kids Konnected to know they are not alone and there are others who are dealing with the same things they are.

> When a child has a parent with cancer where they're dealing with chemo, they are dealing with all the stresses and strains of that in the house...they can come here and see other kids just like they are experiencing it and so it's just wonderful in that they can be kids and see that there are other kids

and not feel that they are just alone out there in this world because it is a very horrible situation to be in and have that diagnosis (Participant 3. Personal Interview, September 20, 2010)

(My children) each have a couple of close friends they can talk to. But this is a group of kids that (are) in various stages, either 6 months ahead of them or 6 months behind them and they can share. They have a whole group of kids that are going through the same exact thing (Participant 5. Personal Interview, September 20, 2010).

The one reason why my daughter really truly loved coming here...there was nobody at school that had anything like this, and no one understood. But her being able to come to this has made her that much of a better person as well. (Participant 2. Personal Interview, September 20, 2010)

My 14 year old refused to come to a meeting the first time, but tonight I got home from work and both (my children) had their homework done (and said), "We got to go, we got to go, we have our session tonight." So I was really surprised...(they)

> don't talk to me about it. (Participant 7. Personal Interview, September 20, 2010)

Each of these parents realized that their children needed more support than they were able to provide. By giving them the opportunity to find support with other children going through similar experiences the parents are showing their children they care.

Parents Need Support Too

Along with providing a healthy, supportive environment for the children during this time, those interviewed also felt it was necessary to have their own support system both during the treatment process and after a loved one had passed away. Without this support they felt it could cause more stress and anxiety about having to parent a child alone.

> I was supposed to get a lot of help from my sister in-laws to help tell my daughter, but a week before we were talking to hospice and no one said anything to her. So I (had to) take her aside at the last minute and tell her. Coming here helps to hear everybody else... you always have some people to talk to or I can just listen, I don't even have to say anything and I still know that they know exactly

> what I'm thinking. (Participant 2. Personal Interview, September 20, 2010)

"(Support) is good for me too, to talk with other people that have the same scenario, or similar scenarios, been through the same scenario" (Participant 4. Personal Interview, September 20, 2010).

Participant 17 was the mother of participant 16 and shared that she tries to be the best support for her daughter and her family.

Overall Advice For Other Parents

The consensus from all 22 participants was that children are affected by a cancer diagnosis. The majority of participants felt that being honest and giving age appropriate information to children was very helpful. Each participant acknowledged the difficulty of finding the "right" way to tell their children but in the end felt it was the best. For those participants who did not share their entirety of the situation with their children there were mixed feelings. Some felt that if they could, they would have informed their children earlier to avoid the mistrust and shock that came along with the passing of their parent. However, others still felt that it was necessary to respect the wishes of their loved ones and not tell.

In both focus groups the participants all felt that support groups like Kids Konnected were necessary for children to feel some kind of normalcy during the chaos and stresses that come along with a cancer diagnosis. They felt that through Kids Konnected, their children were given an opportunity to grown and express themselves that many times they refused to do at home. Each participant was very involved with the organization and utilized the many resources they offered.

Summary

This chapter presented the findings from this qualitative study. Demographic data was provided along with qualitative narratives from participants about how their families have dealt with informing their children of their diagnosis. Parents answered questions of what they felt was age appropriate, how honest support is beneficial for children during this time, how parents themselves also need support and finally they gave advice for other families struggling through the same dramatic changes in their homes.

CHAPTER FIVE

DISCUSSION

Introduction

This chapter discusses the significance of the results found in this study. It also discusses those findings that were not anticipated and provides possible explanations. The strengths and limitations of the present study as well as the implications for social work research and recommendations for the future are also discussed.

Discussion

Using Age Appropriate Information to Tell Your Children

In this study overall, parents felt that children should be given age appropriate information regarding their parent's cancer diagnosis and treatment plan. They felt that while details were not necessary for some age groups, they needed to know enough to provide them honest support throughout the cancer journey. Not surprisingly, given prior research, for those parents who did not tell their children of their parent's cancer diagnosis until after they passed away, the participants stated that those children experienced more emotional conflict because they did not know.

> We never used the "C" word at all until the very day after when I had to announce the news. So they were really surprised when I told them what the ultimate cause was as opposed to mommy's sick or mommy has a disease, we didn't label it. (Participant 6. Personal Interview, September 20, 2010)
>
> They knew that she had cancer but didn't know that it was terminal. After my wife passed my son kept coming (to Kids Konnected) and my daughter refused. And she said 'ok I don't need it you're the one and my brother's the one that got the problem.' (Participant 3. Personal Interview, September 20, 2010)

Children are affected by the changes around them. Therefore, for those who chose not to inform their children completely, they still saw the effects of cancer being played out in their children's lives. This fact is consistent with prior research on this topic. Siegel et al. (1992) found that regardless if the child was told of their parent's condition, the changes in the household, familial roles, physical changes were all observed and noted by the children as indicators to the severity of their parent's illness (p. 328).

> ...(S)ometimes I'm a little worried about some things because he'll be playing with himself or talking to himself and I notice that a lot of his creatures are dying you know; robots and things like that, the word death in his scenario. I'm wondering where he's getting it from, I'm not mentioning it. And in fact it's something that I'm very aware of not to say. I don't know who knows maybe that's just modern day TV. (Participant 4. Personal Interview, September 20, 2010)

This finding is consistent with Smith (1991) who observed preschoolers acting out the concepts of death and dying during their play. Children at this age are unable to conceptualize the idea of death and therefore utilize their play, something with which they are more familiarized with, to cope with the emotions felt during and throughout the changes in their lives.

Children Benefit From Honest Support

An unexpected finding, for this researcher, was found that parents' ability to tell their children was dependent upon their own acceptance of their diagnosis and prognosis. This was not anticipated to be true; however, after conducting this research this researcher has found how impactful a parent's coping style is on their children's own development and how that inherently affects their own coping style. Prior research suggests that the parent's style of coping with their illness influences the child's coping style, both positively and negatively. Korneluk & Lee (1998) found that "(p)arents who attempt to shield their children from awareness of their illness may inadvertently deprive the child of opportunities to model either problem-solving or emotion-focused coping" (p. 187). This is why it is so important for parents to understand that regardless of age, children are affected and deserve some explanation of what is happening to their loved one.

Kliewer, Fearnow, and Miller (1996) found that the coping styles of both children's parents shape the children's coping mechanisms. This is consistent with the findings from this study in that 9 of the 22 interviewed participants had a different coping style than their loved one and stated their children were surprised or confused once informed fully of their parent's true diagnosis and prognosis. Whether done consciously or not, children sense the discrepancy between each of their parent's coping styles. This discrepancy can lead to confusion and misunderstanding for the child, and therefore lead to an acquisition of unhealthy coping skills. Having consistency between parent's views and coping styles also helps build and reinforce healthy and secure attachments which allows children to feel comfortable with the chaos around them (Davies as cited in Lesser & Pope, 2007; Kliewer, Fearnow & Miller, 1996; Lesser & Pope, 2007; Sullivan as cited in Lesser & Pope, 2007).

Kotchick, Forehand, Armistead, Klein, and Wierson (1996) and Steele, Forehand, & Armistead (1997) found that avoidant coping mechanisms used by either parent significantly contributed to increased internalization and externalizing problems in their children. This supports the findings of this study in that parent's who denied or hid their true prognosis had children who were more shocked and unstable with their emotional responses.

Consistent with current research, honest support for children who have a parent with a cancer diagnosis was found to be very helpful for the emotional development of all the children (Hilliard, 2008; O'Callaghan, O'Brian, Magill, and Ballinger, 2009). Involving children in support groups such as Kids Konnected gave them a chance to be supported by those who have similar experiences. They were able to see that they are not alone and that many other children are trying to cope with the same issues. It also gave them an opportunity to express feelings and emotions that may not have been felt or expressed within their family unit (Barrera, Chung, Greenberg & Fleming, 2002; Barrera, Chung, & Fleming, 2004; Bedway & Hartkopf-Smith, 1996; Houtzager, Grootenhuis, & Last, 2001).

Parents Need Support Too

As discussed so far coping styles of the parents have a great affect of their own acceptance of their diagnosis or of their spouse's/partner's diagnosis (Kliewer, Fearnow, & Miller, 1996; Korneluk & Lee, 1998; Kotchick, Forehand, Armistead, Klein, & Wierson, 1996; Steele, Forehand, & Armistead, 1997). This finding also brings awareness to the necessity of support for both parents during this time as well. As has been found in this study, many parents feel that support groups for themselves has truly been life changing. This is consistent with research and common knowledge across the field and that is why so many cancer support groups and caregiver support groups are offered; support is necessary and within a group setting many people are able to find comfort and relief (American Cancer Society, *2011*; Kids Konnected, 2010a; National Cancer Institute, 2010b).

Strengths and Limitations

The current research provides strengths in that it brings awareness to the issues surrounding parent's with a cancer diagnosis informing their children. Regardless of the age of the child, it is hard to tell them of this diagnosis. This research suggests that regardless of how difficult or uncomfortable it may be for the parents, it is necessary. This research allows parents the opportunity to voice their opinions, tell their stories, and also provide helpful hints to other families dealing with the same thing.

Some overall benefits of using qualitative research are that it allows for more in depth questioning and information to be gathered. The researcher can utilize follow up questions to gain further access to information participants might not otherwise find useful. It also allows for a more relaxed and flexible environment which invites participants to become comfortable and allow for more spontaneous responses. Along with the flexibility of qualitative research it allows the participants the opportunity to take needed time to think and answer questions (Grinnell & Unrau, 2008).

While the current research is helpful, due to the qualitative nature of the study there are some limitations. Due to the fact that the research used a convenience sample, and the small sample size, the findings cannot be generalized to the greater population of cancer patients with children between the ages of two and 18 years old. Another limitation related to the generalizability of the current study is that all interviewed participants were associated with Kids Konnected in middle to upper-class communities. While there were some differences in ethnicity, the majority (57%) of participants were Caucasian. Further research should attempt to gather information on those patients who have a lower socioeconomic status and are from a variety of ethnic backgrounds.

Another limitation to the current study is that a majority of the participants had a spouse/partner who was currently deceased. This particular finding can provide a different perspective on why children should be informed of cancer. Further research should attempt to gather information from cancer patients' who are still surviving cancer. This will allow for a more comprehensive view the struggles parents go through when trying to decide whether to inform their children as well as give a clearer understanding of why some parents choose not to tell. Future research should also address issues surrounding how parents who are currently undergoing cancer treatment process their diagnosis and treatment and how that affects and/or influences the process of their children.

Recommendations for Social Work Practice, Policy and Research

As we have seen, children are affected by cancer in many different ways. However, one commonality between all children is that they are affected and their lives are altered. For social workers, it is important to remember when working with families that each individual plays an important role in the family unit. It is therefore important to include the children when discussing and dealing with cancer in the home. Social workers have the opportunity to educate and inform parents about systems and how each entity is affected and help parents cope with telling their children.

Social workers also have the responsibility to support the children during their time of need and give them a safe space to reveal their emotions and feelings. Not only can they provide this support for the children but for the family as a whole too.

While working with families on an individual level it is also important to bring a more global awareness to the need of attending to children's needs during chaotic times like these. Education in schools, churches, and communities about the affects of cancer on children will help provide more services and support. It is important for agencies to be ready to provide services to all family members. This type of systematic approach to ensuring a continuity of care for all members will bring an awareness to local and federal government agencies to the need of financial support to provide and support programs, like Kids Konnected, who are attempting to establish safe places for children to cope with their parent(s)' cancer.

Conclusions

Battling cancer is a stressful hardship within itself, but when children are also involved the overwhelming responsibility of being a parent becomes enormous. While battling cancer is a priority, allowing your children to be involved and understand what is happening to their parent should also be a priority. Children are affected whether they are told of their parent's cancer or not. Therefore, providing age appropriate, healthy support to them through these chaotic times is essential to establishing a family unit that works and copes together rather than individually. This will not only allow children to witness responsible role models coping through difficult times but it will also establish meaningful and lasting bonds with their parents.

APPENDIX A

QUESTIONNAIRE

Demographics

1. Do you have cancer? ___ Yes ___No
   a. If Yes to Question 1 what type? ______________________
   b. If No to Question 1, who does and what type? ______________

2. What is the treatment plan for yourself or your loved one?
   ____ Chemotherapy ____ Hormonal Therapy ____ Radiation
   ____ Wait and See ____ Surgery ____ Other

3. How many children do you have? ________
   a. What is/are their age(s)? ______________________
   b. What is the gender of the children? ______________________

4. What is relationship status?
   ____ Single ____ Domestic Partner ____ Divorced
   ____ Married ____ Widowed ____ Other

5. What is the highest level of education you and your spouse/partner have completed? (Check the one that applies)

	You		Your Spouse/Partner (If applies)
	Grammar School		Grammar School
	High School or equivalent		High School or equivalent
	Vocational/Technical School (2 yrs.)		Vocational/Technical School (2 yrs.)
	Some College		Some College
	Bachelor's Degree		Bachelor's Degree
	Master's Degree		Master's Degree
	Doctoral Degree		Doctoral Degree
	Professional Degree (MD, JD, etc.)		Professional Degree (MD, JD, etc.)
	Other		Other

6. What is your ethnicity? (Check all that apply)
   ____ African American
   ____ Caucasian (Non-Hispanic)
   ____ Hispanic
   ____ Would Rather Not Say
   ____ Pacific Islander
   ____ Middle Eastern
   ____ Asian
   ____ Other Specify __________

7. What is your current household income? (Check the one that applies)
    ____ under $10,000
    ____ $10,001 - $20,000
    ____ $20,001 - $30,000
    ____ $30,001 - $40,000
    ____ $40,001 - $50,000
    ____ $50,001 - $60,000
    ____ would rather not say
    ____ $60,001 - $70,000
    ____ $70,001 - $80,000
    ____ $80,001 - $90,000
    ____ $90,001 - $100,000
    ____ $100,001 - $150,000
    ____ above $150,000

8. What is your age? ____________

9. What is the age of your spouse/partner (if applies)? ____________

10. What is the prognosis of you/your spouse's/partner's diagnosis?

    ____

    ____

11. How long have you/your spouse/partner been battling this cancer?

    ____

12. Is there a history of cancer in either of your families?
    ____ Yes ____ No
    a. If Yes, who and what type? ____________________

    ____

13. Did you experience death or an illness of a family member or someone close to you when you were young?
    ____ Yes ____ No
    a. If yes, who and what type? ____________________

    ____

14. Who was the first person you told about your cancer? ____________

15. Who have you told about your cancer? ____________________

    ____

    ____

16. Have there been any changes in your house since the cancer diagnosis?

____

____

17. How did you hear about Kids Konnected? ____________________

____

____

18. Do you attend any support groups yourself? ___________________

____

____

Developed by Kristyn Gina Sutton

APPENDIX B

INTERVIEW GUIDELINE

Interview Guide

1. What made you decide to tell your children?
2. How long did you wait to tell your children?
3. What do you feel is appropriate for children to know about your cancer?
4. Do you feel your children needed support?
5. How did you know if your child needed support or needed to talk?
6. What is something you've learned about your children since your diagnosis?
7. If you could give advice to other parents who are going through this, what would it be and why?

Developed by Kristyn Gina Sutton

APPENDIX C

RECRUITING FLYER

You're Invited

Come participate in a study directed at discussing

What Children Should Know About Cancer: Parent's Perceptions

This is an important study that will help social service and medical providers assist others in better educating themselves on the effects of cancer on themselves and their children.

If you are interested in participating in this study or have any questions please contact

Kristyn Sutton at (909) 227-1542.

APPENDIX D

INFORMED CONSENT

Consent Form

I am a student at California State University, San Bernardino in the Masters of Social Work program. This study has been approved by the School of Social Work Subcommittee of the Institutional Review Board of California State University, San Bernardino. I am interested in the lack of resources available to children, especially support groups for children, while their parents are battling cancer. As a result, I have decided to investigate what parents feel children should know about cancer. You are invited to participate in my study "What Children Should Know About Cancer: Parent's Perceptions." Specifically, I am asking parents questions about their cancer, the changes in their lives, their children and how they have responded and especially what makes parents decide what to tell their children about their cancer.

If you agree to participate in this study you will be asked to complete an 18 question survey and participate in a video-taped focus group in which a conversation will be had with the researcher and others to discuss what parents think children should know about cancer. All participants must be recorded so that they can be heard; however, one could choose not to be videotaped. The survey will require about 5-10 minutes and the focus group will be no more than 2 hours. The videotape will be used for the purpose of this study. The content of the focus group and the surveys will be locked in a safe to ensure the confidentiality of the participants after the group is completed. The researcher will share the findings of the present study anonymously.

There are no known risks of any harm associated with this research, and your participation is strictly voluntary. It is your right to choose to discontinue your participation, for any reason, at any time during this research. There will be no penalty for discontinuing your participation, or choosing not to participate at all. You are free to ask questions at any time, before, during or after this research, I will be happy to answer them for you.

There are no significant direct benefits to you from your participation in this research, although you may learn something about your own beliefs about children's ability to understand stress such as cancer and how that impacts your interactions with them. There are no other agreements, written or verbal, beyond that expressed in this consent form.

If you have any questions about this research, or concerns about the manner in which this research is conducted, please contact my faculty supervisor:

Principal Investigator	**Faculty Supervisor**
Kristyn Sutton	Carolyn McAllister, Ph D, MSW
E-mail: Suttonk@csusb.edu	School of Social Work
	California State University, San Bernardino
	5500 University Parkway
	San Bernardino, CA 92407-2393
	Phone: 909-537-5559

By placing an X on the line below I understand the above explanations and on that basis I give consent to my voluntary participation in this research.

_____I **do** consent to be videotaped in the present study.

_____I **do not** consent to be videotaped in the present study but would still like to participate and have my voice recorded.

______________________________ ______________
Mark an X above Date

______________________________ ______________
Signature of Investigator . Date

APPENDIX E

VIDEO/AUDIO CONSENT

VIDEO/AUDIO USE
INFORMED CONSENT FORM
FOR NON-MEDICAL HUMAN SUBJECTS

As part of this research project, we will be making a videotape/audiotape recording of you during your participation in the experiment. Please indicate what uses of this videotape/audiotape you are willing to consent to by initialing below. You are free to initial any number of spaces from zero to all of the spaces, and your response will in no way affect your participation. We will only use the videotape/audiotape in ways that you agree to. In any use of this videotape/audiotape, you will only be identified on a first name basis. If you do not initial any of the spaces below, the videotape/audiotape will be destroyed.

Please indicate the type of informed consent

☐ Videotape ☐Audiotape

(AS APPLICABLE)

- The videotape/audiotape can be studied by the research team for use in the research project.

  Please initial: _____

- The videotape/audiotape can be shown/played to subjects in other experiments.

  Please initial: _____

- The videotape/audiotape can be used for scientific publications.

  Please initial: _____

- The videotape/audiotape can be shown/played at meetings of scientists.

  Please initial: _____

- The videotape/audiotape can be shown/played in classrooms to students.

  Please initial: _____

- The videotape/audiotape can be shown/played in public presentations to nonscientific groups.

  Please initial: _____

- The photograph/videotape/audiotape can be used on television and radio.

  Please initial: _____

I have read the above description and give my consent for the use of the videotape/audiotape as indicated above. Please mark and X in lieu of your signature.

The extra copy of this consent form is for your records.

Mark ________ DATE ________________

APPENDIX F

DEBRIEFING STATEMENT

What Parents Can Do to Help Their Children

Facts about Children's Capacity to Understand Stress:

- Children as young as 2 years old can understand death and stress
- Preschoolers show their emotions and grief through play. They may not verbalize their feelings but it can be seen in other ways.
- Middle school age children rely on play but also begin to turn to peers for support.
- Adolescents rely on peers for support but also rely on the values, beliefs, and coping skills they learned from their early childhood.
- Children are affected by stressful situations, such as cancer, even if not directly told.
- Children express their feelings in different ways (play, journaling, over achieving, anger, sadness, internalizing everything, etc.)
- Children tend to hide their feelings because they do not want to burden or upset their parents.
- Children struggle with understanding their own feelings and need guidance from their parents and others.
- Children need to be supported in a loving, open, and honest environment.

How to Help:

- Talk to your kids
- Be honest with them about your treatment and your feelings.
- Know they are affected and may be holding their emotions in because they do not know how to express them.
- Let them see your feelings.
- Be open to their questions and concerns.
- Seek support for both of you when necessary.
- Face your fears together, not alone.
- Do not wait for negative behaviors to appear to be open and intervene.

Thank you all for participating in this study. This focus group was done in order to gain a better understanding of what parent's feel their children should know about their cancer diagnosis.

With your input I will hopefully be able to help gain some understanding of the struggle that many parents go through and how it impacts the entire family.

Thank you again and if you wish to know more about the final project or have any further questions or concerns please contact me.

Kristyn Sutton
University of California, San Bernardino
MSW Graduate Student
suttonk@csusb.edu

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