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Experiencing Parental Loss during Adolescence and Factors Influencing Hospital Involvement and the Grieving Process

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EXPERIENCING PARENTAL LOSS DURING ADOLESCENCE AND FACTORS

INFLUENCING HOSPITAL INVOLVEMENT

AND THE GRIEVING PROCESS

By

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Abstract

EXPERIENCING PARENTAL LOSS DURING ADOLESCENCE AND FACTORS THAT

INFLUENCE HOSPITAL INVOLVEMENT AND THE GRIEVING PROCESS

By

Vaida Kazlauskaite

Dr. Stephen Fife, Examination Committee Chair
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Experiencing the death of a loved one can be traumatic and painful to anyone. Adolescents in

particular experience death in a unique way, during a time in their lives when they are

developing their own autonomy and independence. Experiencing the deteriorating conditions of

a terminally ill parent may affect an adolescent in many ways. However, there is relatively little

research on adolescent involvement in the medical setting during a parent's terminal illness and

how this may affect the adolescent's bereavement. This qualitative study utilized heuristic

inquiry and procedures of Grounded Theory to investigate factors influencing the involvement in

the hospital setting during parental terminal illness and factors influencing the grieving process.

Four factors were identified to influence the involvement in the hospital setting of an adolescent

during parental illness: family structure, communication, age, and realization of the severity of

the diagnosis. Five factors influencing grief were also identified: hospital environment,

availability of support, knowing the prognosis of the ill parent, loss of the parent before the

actual death, and a need for more education from the medical professionals about the diagnosis.

Implications for mental health practitioners and medical professionals include education on how

to work collaboratively to understand and meet the needs of family members of terminally ill

patients and how to effectively communicate with them.

Acknowledgment

To my family, thank you for all your encouragement throughout this journey. Thank you for pushing me to pursue this opportunity and always being there for me when I thought I would not make it any further. Your support means the world to me.

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And finally to my committee members, thank you for your time, effort, feedback, guidance, and contribution to this project. Thank you for being available to me professionally and personally.

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Introduction

Historically, mental health and physical health have often been regarded as two separate components when it comes to people (Clark, Linville, & Rosen, 2009). Patients are seen by medical doctors who treat them primarily on the basis of physical symptoms, perhaps through surgery, prescribing medication, or some other treatment that will help reduce or eliminate the symptoms. Causes of mental health diagnoses are often disregarded by physicians. The primary focus of physicians is to treat the physical symptoms, which may neglect the impact of patients' mental health on their overall well-being and causes of physical symptoms.

Marriage and family therapists have also generally kept the mind and body separate by focusing mainly on individual and interpersonal processes such as thought and behavior patterns, rather than the physical health of family members. MFTs concern themselves with the client's perceived problem, how the family adds to the problem, as well as how it affects the family dynamics, such as boundaries, rules, and hierarchies. In general, mind and body (i.e., psychology and biology) have been seen as independent, leading many marriage and family therapists to ignore physical illness and its link to family problems (Campbell & Patterson, 1995).

As the field of family therapy was coming of age during the late 1960s and early 1970s (Becvar & Becvar, 2003), this highly volatile era in our social history saw a great growth in awareness of the previously unmet needs of those who were dying (Vachon, 1999). This increasing awareness led researchers and therapists to a heightened focus on the topic of grief. Although grief is often a reason for clients to attend therapy, and grief counseling is often utilized, the Commission on Accreditation for Marriage and Family Therapy Education (COAMFTE) as well as the Council for Accreditation and Related Educational Programs (CACREP) do not require curriculums to include courses or trainings in grief and loss

specifically (Doughty, Wissel, & Glorfield, 2011). Grief therapy may be utilized by people who have been diagnosed with a terminal illness, as well as family members and friends of the ill person. A terminal diagnosis of a parent, such as cancer, can impose on the security the family has established for their future. Modifications to everyday life must occur in order to adapt to the short-term losses, such as changes in family roles. During this time family members must also become acquainted with fear and the threat of death (Finch & Gibson, 2009). Doctors and nurses often lack training on how and when to work with adolescents about these changes and fears; therefore, it has been found that children of cancer diagnosed parents, especially adolescents, are often excluded from parents treatment plan (Faulkner & Davey, 2002).

The author of this study is interested in the impact of involvement during parental terminal illness on the grieving process of an adolescent. Specifically, looking at adolescents' involvement in the medical setting during a parent's illness, such as visiting the ill parent at the hospital, communicating with doctors, nurses, and other health care providers, and receiving an explanation of what the diagnosis and prognosis of the parent means and what treatment options are available. Being involved in the medical setting also entails being part of the decision making process when it comes to treatments and how much of it was explained directly by medical staff versus the parents.

This qualitative study aims to discover how being involved in the medical setting helps adolescents cope with the death of a parent. The author findings are expected to further help bridge the gap within the biopsychosocial framework, as well as providing guidance to marriage and family therapists on how to help adolescents and their families cope with death of a parent.

<center>**Literature Review**</center>

The Family

Family members may be the most influential or most hindering support a grieving adolescent encounters. Factors such as family dynamics, roles and responsibilities of each member, relationship between members, as well as the emotional expression and communication patterns are all contributing factors to the way family is perceived in times of need (Breen & O'Connor, 2011).

Each family and each member of the family will experience death differently, often creating a story to help them cope. Therapists working with grieving families or individuals often invite clients to share their narratives of loss and grief. These narratives usually include "(a) a basic explanation of how the person died, (b) details about the circumstances of the death, (c) the sequence of events leading up to and following the death, and (d) the experience of each family member at the time or when and how each learned of the death" (Sydney, Gross, & Baker, 1994, p. 288).

After a death occurs in the family, the structure of the family often changes (Jackson, 1968). A new norm that the family creates takes place, which frequently occurs without the individual family members within the family being aware that change has happened. The change may damage or destroy relationships if not communicated thoroughly (Bolby-West, 1983)

Grief counseling can get complicated when the client is an adolescent grieving a parent. Death of a parent may leave an adolescent with several questions and confusion about life. Due to some adolescent's incapability to endure long periods of strong emotions, they may use avoidance, regression, and denial to prevent psychic pain. The support a bereaving adolescent

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receives may influence the outcome of grief and adjustment to the life after the loss of a parent (Payne, 2003).

Adolescence

Adolescence is a transitional stage of physical, social, and psychological development, which is often referred to as the self-discovery period. Death may be the first traumatic event an adolescent experiences (Kuntz, 1991) and if not handled appropriately, a sense of increased vulnerability, inability to trust, and low self-esteem may occur (Taiym, 2011). Various factors such as cultural background, sense of community, and societal norms, influence the way death is perceived by an adolescent. Adolescents in particular tend to either abandon or question their religious or spiritual beliefs, or use it to make meaning out of death and access their spiritual resources to cope with the loss (Muselman & Wiggins, 2012).

Erikson's (1980) psychosocial development theory discusses the different stages a person goes through within a lifetime. Eight stages were identified: trust versus mistrust during the infancy stage, autonomy versus shame during the early childhood stage, initiative versus guilt during the play age stage, industry versus inferiority during the school age stage, ego identity versus role confusion during adolescence stage, intimacy versus isolation during the young adult stage, generativity versus stagnation during adulthood stage, and finally ego integrity versus despair during the maturity stage. Erickson stated that each person goes through these psychological crises, and achievement of each stage marks a strong character and helps the acquirement of positive qualities, such as characteristic strengths which the ego can be used in crisis resolution. Without completion of each stage the ability to continue onto the other stages is decreased and may result in unhealthy character and self-awareness. The uncompleted stages can be attended to and completed at a later time.

Erikson stressed the importance of the adolescent period, describing it as the underlining phase of development of identity. Adolescence is a main phase in growth where children have to absorb the roles they will take on as adults. During this phase the adolescent's will observe their individuality and attempt to discover who they are. Erikson proposed that sexual as well as occupational characteristics are involved during this phase. Completion of this phase shapes an awareness of self, what the adolescent may want to get involved, such as occupancy, as well as the sex role that suits the individual best (Bee, 1992). Erikson explained that the adolescents may not be secure about their body image until they can familiarize and conform to these changes. Success during the adolescence phase results in the quality of commitment. Such commitment to self and to others, is shown through acceptance of others, even when there are differences in opinions. Throughout exploration of the surrounding realm, adolescents build their unique character. On the other hand, when an adolescent does not explore their realm, it may result in role confusion. Role confusion is identified as uncertainty about self and the purpose of ones being.

Terminal Illness

Although the occurrence of adolescents experiencing the death of a parent is relatively rare, it is a significant topic to research due to the increasing incidence of terminal illness. For example, cancer was the second leading cause of death in 2011 in the United States, with 75,000 deaths and more than 1.5 million diagnoses (U.S. Cancer Statistics Working Group, 2011). Research and literature specifically on children of cancer patients are still low, even though there is a great need for it (Su & Ryan-Wenger, 2007).

Nelson and While's (2002) research on the impact of revealing a parental cancer diagnosis to an adolescent found that adolescents often experience difficulties and concerns

regarding the diagnosis. Such problems had a negative impact on their school lives, family lives, free time, and peer relationships (Finch, 2009). Christ, Siegel, and Sperber (1994) identified five common difficulties and fears of an adolescent's response to the parents declining health conditions: "1) empathy for the parent's suffering, 2) increased involvement with the ill parent, 3) need to help at home, 4) reactions to specific relationships, and 5) guilt" (p.606). The way the child is told about the death, as well as the responses of the living parent, is vital to the way the death will be perceived and understood by the child. Open communication about causes of death and the death itself may increase a child's understanding about the occurrence (MacPherson, 2005).

Finch and Gibson's (2009) study focused on the involvement of the ill person, as well as their family members, with medical providers, and found high reluctance to be involvement in the hospital setting. Reasons included anxiousness around hospital environment and feelings of being just another family in the hospital dealing with a common disease. Reluctance of professionals to engage with the family members is usually inhibited by anxiety and fear about communicating or behaving in a manner that will cause harm and leave permanent emotional damage (Monroe & Kraus, 1996).

A study was conducted to map out specific factors that influence the way parents tell their children that they are dying. MacPherson (2005) found that the conflicting factor of needs was one of the most influential on how parents told their children. Parents are often torn between the needs of the sick parent, the needs of the well parent, and the need of the child. The need of keeping the child safe and away from pain was the most common reason parents were hesitant to reveal the truth. Another element contributing to the decision of how to tell children is the extent to which the sick parent is able to face the actuality and unavoidability of dying themselves.

Grief Counseling

A grieving period of a deceased person is defined as a time spent remembering the loss of a loved one. It is often a time spent in sorrow, frequently accompanied by the five stages of grief: denial, anger, bargaining, depression and acceptance (Kubler-Ross, 1969).

People who lose a loved one to a terminal illness, such as cancer, often endure prolonged grief disorder. Prolonged grief disorder occurs when symptoms persevere for more than six months (American Psychiatric Association, 2013). Grieving survivors may experience doubts about the kind of treatment their loved one received, leaving them with doubts that may lead to anger, and increased grief. Children who are grieving the death of a parent are especially at high risk for prolonged grief disorder, and it is also associated with childhood separation anxiety. Childhood separation anxiety can be a high risk factor for developing healthy relationships as an adult (Tomarken, et al., 2008).

Grief counseling is often sought out by individuals who are experiencing high levels of bereavement, or prolonged grief disorder, and are in need of learning how to continue life without the deceased person, and working toward coming to peace with the death of a loved one. The concept of grief therapy was first labeled by Freud (1917/1957) as "grief work" which is described as a time of feeling strong emotions related to a loss, as well as communicating the experience properly. It was believed that individuals who experience a loss must undergo therapy and work through the thoughts, emotions, and memories related to the loss. More recent studies have found that, while therapy may be beneficial for grieving individuals, it is not an essential approach for everyone (Bonanno, 2004). It has also been found that unlike the original goal of grief counseling, which involves cutting ties with the deceased, it is normal and healthy for bereaved individuals to continue their bonds (Wortman & Silver, 2001). Klass and Walter (2001)

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acknowledged four common customs for individuals to maintain bonds with the departed: feeling like the dead is around them, communicating to the dead, use of the departed as a moral monitor, and speaking about the departed.

Physicians often work with patients who are terminally ill and therefore engage in a type of grief counseling as well. However, physicians often disregard the patients' family and the impact that the illness has on the whole family dynamic (Hooper, Tomek, & Newman, 2012). Grief therapy is one of the most common therapy types a marriage and family therapist provides. Grief counseling is typically grounded in an individualistic model that marriage and family therapists utilize when clients are coping with the death of a loved one.

A type of therapy that may require both physicians and therapist to work together is grief therapy. Grieving may cause mental and physical health to decline. A grieving person may experience physical symptoms such as fatigue, headaches, and chest pain, while mental symptoms include depression, feelings of guilt, and hostility (Kowalski & Bondmass, 2007).

Grief has been the topic of many studies, and researchers have come a long way in identifying what factors are helpful during the grieving period. Previous research conducted on the adolescent grieving focused on topics such as the different grieving processes between child, adolescent, and adults. Adolescents do not concern themselves with the guilt or responsibility that children often feel after the death of a loved one (Kuntz, 1991). Adolescents, unlike adults, often feel as if they have matured more quickly than their peers who have not experienced death. This phenomenon was labeled *instant maturity* (Berman, Cragg, & Kuenzig, 1988).

Other studies focus on which interventions are most beneficial to the grieving adolescent. Research found that peer group interventions with bereaved individuals are helpful in the process of coping with a death, by normalizing the situation, and creating a space of harmony and

mutuality (Hopmeyer & Werk, 1994). Parrish's (1994) study resulted in the conclusion that group interventions led by children with peers experiencing the same kind of trauma, are most effective when it comes to helping children resolve grief.

Another focus of the grieving process are the stages a mourning adolescent must go through in order to accept the death. The Harvard Child Bereavement Study (HCBS) recognized four tasks in mourning for a child or adolescent: accepting the actuality of the death, allowing self to feel pain or emotional aspects of the death, adapting to an environment without the deceased, and discovering ways to remember the deceased (Worden, 1996). Despite all those research topics and studies, none have been conducted that specifically focuses on an adolescent grieving the death of a parent.

Several research studies suggest that many factors influence the ways bereaved individuals experience and express their grief. Such influential factors include culture, experience, personality, and social and family support (Shapiro, 2001). Therefore, therapists are encouraged to conceptualize cases dealing with grief through a socio-cultural, systemic, and emotional perspective.

One of the most critical factors in the grieving process for adolescents is social support. Social support is often categorized into three types: informational, instrumental, and emotional. Informational support provides guidance and advice, while instrumental support consists of receiving goods such as money and services. Emotional support entails providing empathy and understanding (Taylor, 2007). Social support comes from family members, partners, friends, colleagues, and even acquaintances.

Kubler-Ross Grief Model

In order to help clients conceptualize grief, therapists often utilize the Kubler-Ross model of five stages of grief: denial, anger, bargaining, depression, and acceptance (1969). The five stages are utilized in various situations--at a time of a diagnosis of terminal illness or when receiving news that a loved one has died.

During the first stage, people often experience initial denial or disbelief, used to avoid reality. It is often described "as a temporary state of shock from which people recuperate gradually" (Kubler-Ross, 1969, p.36). When the first stage of denial cannot be maintained, it may be replaced by anger. A question that often accompanies anger is "why me?" and often the anger cannot be explained and has no logical meaning. During the bargaining stage, the realization that anger is not a solution sets in. Bargaining is used to postpone the inevitable by compromising with God, doctors and families.

A fourth phase of the Kubler-Ross model is depression. Depression sinks in when the consequences of the death or illness are fully apparent; such as physical changes due to illness, or loss of a job due to absence. There are two types of depression during this phase: reactive and preparatory. Reactive depression often sets in after a loss of a person or physical features, i.e. mastectomy or hair loss. Preparatory depression occurs when impending losses become apparent.

The last stage is acceptance, in which the affected person comes to terms with reality. This is followed by a composed, reflective view for the individual, and an established mindset. During the depression stage in particular, families often need more help, understanding, and support from one another.

Although widely used, critics of The Kubler-Ross model have suggested that conceptualizing grief in stages overemphasizes the outcome rather than the process. However,

today the reverse is often emphasized: process rather than outcome (Rando, 1993). In addition, the five stages were generalized to the larger population and did not explain how they manifest within the various life stages and unique circumstances that individuals may face.

Since then Kubler-Ross has published a follow-up book which looked at the five stages through a grief process lens and offered more insight beyond the five stages (Ross & Kessler, 2005). This update goes further than the grieving stages by examining the way people cope with loss. They also emphasize that the five stages may not be experienced by all individuals, nor are they necessarily experienced sequentially. In addition, Kubler-Ross provided awareness on important topics such as anniversaries, birthdays, and holidays that people who have lost a loved one often dread. Further, Kubler-Ross went beyond a generalized model of grief and discussed some unique dimensions of coping with death related to experiences of tragic death, suicide, or the way young child perceive death and grief. "Kubler-Ross contributed immensely to the public's understanding of how we die, how we prepare ourselves for death but, ultimately, how we live" (Butts, 2006, p. 980).

Death and Fear

People frequently avoid the topic of death, due to reasons of fear. Such fears are often about the dying process, what will happen after death, and the loss of one's only life (Becvar, 2003). As Hanh (2002) summarized:

> Our greatest fear is that when we die we will become nothing. Many of us believe that
> our entire existence is only a life span beginning the moment we are born or conceived
> and ending the moment we die. We believe that we are born from nothing and so we are
> filled with fear of annihilation (p.4).

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The death apprehension theory states that being scared of dying, in principal, is inevitable because death is often associated with "pain and death brings an end to the pleasures of life including all of those derived from social, sexual, and family relationships" (Elis & Wehab, 2013, p.152). Further, the theory explains that when a person's pain and illness escalate and the desires of life lessen, the fear of death also diminishes.

Theoretical Framework

Currently there is not one leading theoretical model for helping individuals who are suffering from grief and loss; conceptualization of grief is as unique as the clients themselves. Today, therapists and counselors are utilizing a diversity of models to theorize their clients' concerns (Center for the Advancement of Health, 2004). The MFT systems approach emphasizes healthy family functioning as a way to manage terminal illness as well as the death of a loved one (Kissane, Block, McKenzie, McDowall, & Nitzan, 1998).

Attachment Theory

Originally developed to understand a child's separation from caregivers, attachment theory is often utilized to understand and facilitate bereavement grief. The origins of attachment theory were developed by John Bowlby, concerning the children who have lost a parent (Bowlby, 1980). Bowlby suggests children retain a relationship with the deceased parent. Four main attachment styles were then later added to conceptualize those effects: secure, anxious, avoidant, and disorganized (Ainsworth, Blehar, Waters, & Wall, 1978). The anxious/ambivalent style can cause extended, long-lasting or complex grief. Absent grief, or grief that is not being expressed, is seen by the avoidant attachment style. Finally, disorganized style can be depicted in learned helplessness behaviors when coping with the loss of a loved one (Doughty, Wissel, & Glorfield, 2011).

Secure attachment is defined as a person that is high functioning and has psychosocial skills and coping strategies to respond to stressors, illness, and adverse events in a flexible and adaptive manner (Hooper, Tomek, Newman, 2012). Secure attachments are identified by characteristics of positive self-view and higher self-esteem, which are used to evoke positive

memories during grieving periods. Secure attachment and grief are similar in that a secure person may react with non-defensive coping strategies (Pistole, 1996).

Attachment theory may provide a blueprint for attachment-based practice in the context of medical settings. The blueprint can aid physicians to have an enhanced understanding of their patient's symptomology and how to effectively intervene, in a manner in which the patients form relationships and interact with other significant people, including health care providers such as nurses (Hooper, Tomek, & Newman, 2012). Attachment theory can also be a predictor of the manner in which a patient forms relationships and interacts with the medical staff, such as doctors and nurses. In addition, the style of attachment of family members may influence the way they interact with medical professionals, when necessary. A link has also been found between attachment style and health presentation, communications and relations with caregivers, and illness behavior and functioning (Ciechanowski, 2010). Furthermore, the link may predict the health outcome, patient satisfaction, treatment adherence, and the relationship between the patient and physician (Arbuthnott & Sharpe, 2009).

Attachment theory is often used by therapists as preventative care in sessions with clients confronted with the loss of a loved one. For the patients, the palliative situation means an unavoidable abandonment to family and friends in a situation of loss. During palliative care the role of the medical provider changes from trying to cure the disease, to becoming a companion to the ill patient (Loetz et al., 2013).

Dual Process Model

The dual process focuses on loss-oriented stressors and restoration-oriented stressors linked to bereavement, identified by Stroebe and Schut (2010). Loss-oriented stressors are related to the death and the emotions that are accompanied by the death, such as focusing on how

life was before the death occurred. Restoration-oriented stressors are the losses secondary to the death, such as taking on new roles and creating a new life without the deceased (Doughty, Wissel, & Glorfield, 2011). Research has found that bereaved individuals often alternate between the two identified stressors, as well as periods where grief is not the focus at all. This is considered a healthy adaption and process of healing.

Constructivism

Constructivism is a theoretical framework that posits the idea that people's reality is composed of how they make sense of their experiences, perceptions, and narratives. Constructivism highlights numerous realities that individuals structure (Servaty-Seib, 2004).

Realities created by individuals are often questioned after death is experienced within the family. Their ideas about the meaning and purpose of life are often confronted and challenged, which may result in an emotional or existential crisis. Neimeyer (2000) has created a list to broadly define the reconstruction of meanings that follow death:

1. The attempt to find or create new meaning in the life of the survivor, as well as making meaning of the death of the loved one.

2. The integration of meaning, as well as its construction.

3. The construction of meaning as an interpersonal, as well as personal process.

4. The anchoring of meaning making in cultural, as well as intimate discursive contexts.

5. Tacit and preverbal, as well as explicit and articulate meanings.

6. The processes of meaning reconstruction, as well as its products. (p. 552-554).

Adolescents who have not yet formed their own identity independent of their parents may struggle after the death of a parent. They are adapting to a new life without their parent, and are trying to develop an identity and narrative that works for them in order to live a healthy life.

Narrative Therapy

Narrative therapy originated from Michael White, who used the aphorism: "The person is not the problem, the problem is the problem." (White & Epston, 1990). Narrative therapy is aware of the constant process of change in a person – "who we are is always being constructed in the context of relationships, and that these relationships are formed against the cultural backdrops of stories" (Hedtke, 2014, p. 2).

Hedtke (2014) explored grief and loss through a narrative lens, explaining that it is the meaning employed to an experience that could hinder or benefit a person caught in a grief and loss situation. Narrative treatment plans specifically tailored to families and individuals dealing with grief and loss employ interventions such as: naming the problems – identifying the problem as well as separating the problem from the client; externalizing – linguistically separating the problem from the person in addition to personifying the problem by giving the problem its own identity and name (Gehart & Tuttle, 2003); exploring the effects through relative influence questions– finding out how the problem has influenced the client and vice versa (White, 1988/9); and identifying "unique outcomes," – exploring when the problem was not a problem. Therapists working with a grieving adolescent may help them create a narrative that allows them to work out emotions that often accompany grief: guilt, sadness, denial, anger, and depression; all of which could hinder the adolescent from processing the grief successfully.

Cognitive-Behavioral Therapy

Cognitive-Behavioral Therapy (CBT) is often utilized when prolonged grief disorder occurs, with the goal of enabling clients to learn how to live and find meaning in the midst of their loss (Greer, 2010). Patients may not be able to find meaning in why their loved one passed, but find meaning in the life they shared with their family member. This can be done by evoking

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memories, pictures, letters, etc. Before starting CBT, therapists are encouraged to get familiar with the deceased's illness and treatment. During treatment, clients are asked to describe a narrative of the time leading up to the death, and the effect the loss has had on them. Therapists should challenge cognitive distortions that may exist such as unwarranted guilt, self-deprecation, and "should have" statements. CBT may alleviate these symptoms by challenging the unconscious destructive thoughts and helping the individual create new sensible thoughts. Behavioral techniques include setting realistic goals with the client, and encouraging emotional expression of grief (Greer, 2010).

Medical Family Therapy

Medical family therapy is an integrative discipline which family medical problems are viewed through a comprehensive treatment approach. The MedFT field views problems through a biopsychosocial perspective. As McDaniel, Hepworth, and Doherty (1992) explained, "All human problems are biopsychosocial systems problems: there are no psychosocial problems without biological features and no biomedical problems without psychosocial features" (p. 26). One application of medical family therapy is integrative primary care (IPC), which entails a treatment team with primary care and behavioral health clinicians. The clinicians work together with clients and families utilizing a systematic approach to deliver patient-centered care (Peek & National Integration Academy Council, 2013, *in* Martin, White, Hodgson, Lamson, & Irons, 2014). IPC has found to be effective in reducing symptoms, especially in disease-specific management, such as depression and anxiety.

Behavioral health clinicians, or medical family therapists, often aid patients and their families in making decisions about medical care and communicating their needs to medical professionals. Informing and involving patients and families in their care choices is known as

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shared decision making. Even though families might know what they want when it comes to medical care for their loved ones, inexperience of negotiating with medical professionals may leave the families unwilling to voice their ideas. Further, medical family therapists help chronically ill patients and their families adjust to the many changes that accompany the diagnosis. The goal is to have the patient and their family tolerate the ambiguity and uncertainty of the prognosis in order to empower effective caregiving (McDaniel, Doherty, & Hepworth, 2014).

When working with families who are seeking treatment for terminal illness, there are two main clinical principles: viewing the family from a non-pathological perspective, and focusing on meeting the immediate needs of the family. Viewing the family in a non-pathological perspective can aid the therapist in helping members of the family conceptualize the illness and think of ways they can work together and share the responsibility of taking care of the ill family member. Focusing on meeting the immediate needs will limit discomfort when the death occurs. The medical family therapist "facilitates discussion of mourning, describes the kind of unacceptable feelings that may exist, and discusses the consequences of not acknowledging sadness" (McDaniel, Doherty, & Hepworth, 2014, p. 268). Often a family will go through intense stress and may need assistance on how to cope with everyday life after the diagnosis.

Aim of the Study

The aim of this study was to understand what factors influence an adolescents' involvement in the hospital during a parents' terminal illness and the impact involvement in the medical setting has on a grief. Thus far research on adolescents' grieving process after a parental death is very limited. Studies to conceptualize grief have been conducted and paired with various theoretical approaches, but none have been specifically done for adolescents.

Only one study has been conducted on the grieving period of an adolescent after the death of a parent. In this qualitative study, Kuntz (1991) examined how adolescent grieving differs from that of a child and adult. The results were drawn from breaking down the data into common themes from the interviews. Kuntz also used Bowlby's (1980) phases of grieving: 1) Shock and Numbness, 2) Yearning and Searching, 3) Despair and Disorganization, and 4) Reorganization and Recovery, as a framework for organizing the accounts of adolescent's experiences of grieving the loss of their parent. Kuntz (1991) found that withdrawal was the common theme in the first phase of shock and numbness, while wishful thinking occurred during the yearning and searching phase. During the despair and disorganization phase, adolescents seemed to hide their emotions, and during the final phase of reorganization and recovery, adolescents tended to be more honest with their thoughts and emotions than adults.

Few studies have been conducted to look at the correlation between involvement in the hospital setting and the process of grief. Finch and Gibson (2009) reviewed the concept of involvement in the medical spectrum; however, the focus of their study was on telling children about their parents' cancer diagnosis. Studies such as Parish (1994) have examined interventions most beneficial to bereaved children, but not specifically with adolescents. In addition, there are several research studies conducted on living in a household with terminally ill children or

adolescents and the effects on parents, but none on the effect on children with terminally ill parents (Barling, Stevens, & Davies, 2014; Pei-Fan, Ching-Ching, Pei-Chi, Pao-Chen, Ling-Ya, Mei-Yin, & Yi-Wei, 2014).

The focus on the proposed study was to investigate the experience of adolescents' involvement with the medical spectrum and the impact this has on their grieving process. The impact of adolescent involvement in the medical spectrum may have on the grieving process - or to show the way in which involvement in the medical spectrum influences the grieving process for adolescents. The goal of this study was to discover similarities among experiences and determine its effects on grieving periods.

Methodology

Participants Recruitment and Data Collection

Participants were recruited for the study through a variety of methods. Local marriage and family therapists, as well as current marriage and family therapy students at the University of Nevada, Las Vegas, were contacted and briefed on the research study. These therapists were asked to identify potential participants and contact them with an invitation to participate in the study. Researchers also distributed flyers around private practices and agencies, the UNLV student union, and the Lied library. Social media avenues such as Facebook, Instagram, and Twitter were utilized. A post on the UNLV Research Pool was made as well. Recruited participants were also asked if they knew any other qualified participants and then share the research information with them.

The lead researcher contacted interested participants to determine if they met the research criteria and if they did a time and place to conduct the interview was scheduled. Six participants agreed to participate in the study; four identified as female, and two identified as male. All participants were over the age of 18, ranging from 18 to 24 years old. Four identified as Caucasian, one identified as African-American, and one identified as Hispanic. It is important to note that two of the six participants were students in mental health programs. All participants experienced the loss of a parent during their adolescent years. The death of the parent of all participants occurred more than a year before the time of the study. All participants had contact with medical staff during the time of the parents' diagnosis and treatment. Each of the participants experienced the illness and death of a biological or adopted parent which was caused by a terminal illness, which was some form of cancer for all the participants.

Table 1. Participant Information

Participant	Gender	Ill Parent	Illness	Prognosis	Family Support	Age of participant when death occurred
Participant 1	Female	Mother	Brain Cancer	Few months	No father, 1 older sibling	18
Participant 2	Female	Mother	Small Intestine Cancer	Few months	No father, no siblings, distant family	16
Participant 3	Male	Father	Cancer	Two Years	Mother, 2 siblings (twin and older)	18
Participant 4	Male	Both	Breast & Brain Cancer/ Throat Cancer	Was not told	Father, no siblings	13/16
Participant 5	Female	Mother	Brain Cancer	Was not given	No father, 1 younger sibling	13
Participant 6	Female	Mother	Melanoma	None given	Father, 1 older sibling	17

Philosophical Underpinnings

Motivation for this study stemmed from wanting a deeper understanding of the challenges adolescents face during the time of parental terminal illness. The study also aimed at understanding how the adolescents' involvement in the medical decisions impacts the grieving period during the illness of the parent and after the passing of the parent. Because the focus of

the research was on the participants' experience, it was determined that a qualitative

methodology would be appropriate for the study. As Jones (1995) described, qualitative methods

are aimed to study phenomena in terms of the meaning that people create from their experiences.

Additionally, qualitative methods are particularly suited to give researchers an in-depth view of

the phenomena being studied.

A qualitative approach helped researchers explore answers to the research question

through the unique perspective of individuals who have experienced the loss of a parent to

chronic illness. As McClement, Degner and Harlos (2003) described, "a qualitative research

approach can explore social processes inherent within human interactions" as well as "uncover

the practices, beliefs, and behaviors of individuals or groups as they normally function in life" (p.

738).

This study utilized heuristic inquiry, an approach to qualitative research that emphasizes

the personal experience of both the researcher and the participants. Researchers were guided by

principles of heuristic inquiry in the analysis of the transcribed interviews. Heuristic inquiry

requires two components; the researcher must have had personal experience and interest in the

study, and the research assistants must also have interest in the phenomenon of the study

(Douglass & Moustakas, 1985). Heuristic inquiry places importance on "personal experiences,

reflections, and insights of the researcher" (Patton, 2002, p. 108). With this experience the

researcher is capable of understanding phenomena of interest through reflection and inquiry.

Because of the understanding of the researcher, a unique type of connection forms during the

interviews with the participants and the analysis of the data. Heuristics differ from other forms of

phenomenological inquiry in that it acknowledges the connection of the researchers with the

topic of the study, derives meanings from both the researchers' and participants' experiences,

and includes the researcher's intuition as well as tacit understanding of the experience (Patton, 2002).

When heuristic inquiry is "used as a framework, it offers a disciplined pursuit of essential meanings connected to everyday human experience" (Douglass & Moustakas, 1985, p. 39). Heuristic research searches for deeper meaning and conceptualization of important human experiences. Although heuristic inquiry is not directed by a set standard of rules, it requires commitment and passion from the researcher. When interviewing participants, the researcher must know "when to probe deeper, when to shift the focus, when to pause to examine the inmost layers of meaning, when to reflect, and when to describe" (Douglass & Moustakas, 1985, p. 41). Therefore, researchers are not bound by a single set of interview questions that must be uniformly asked in every interview. Making meaning, being aware of, and discovering the core of human behavior is what drives heuristic research. The idea that methods and guidelines are irrelevant when it comes to understanding the experiences of humans was introduced by Polkinghorne (1982), who believed that research was not about sticking to set rules and regulations of research, rather the understanding of human experiences. Heuristic research thrives on making meaning, being aware of, and discovering the core of human behavior.

When talking about heuristic inquiry, tacit knowing is an important factor to remember. Tacit knowing is often described as the "inner essence of human understanding, what we know but cannot articulate" (Patton, 2002, p. 108). Two types of tacit knowing have been identified: codified and indwelling. Codified knowledge is knowledge that can be conveyed in proper themes that come from the human experience. Indwelling knowledge refers to turning into deeper insight to understand human experiences (Kenny, 2012). Another important process to heuristic inquiry is self-dialogue, which is described by Moustakas (1990) as the researcher's

process of moving between the internal and external worlds they live in. Self-dialogue is composed of two qualities: 1) the researcher must understand the self deeply before trying to comprehend the experiences of others, and 2) the researcher must be open to others, which allows for a deeper and more authentic connection between the participant and researcher (Kenny, 2012).

Heuristic inquiry suits this study because of the primary researcher's personal experience of losing a parent during adolescence and being involved in the medical setting during her parental illness and talking with the doctors about what the diagnosis of the parent meant and what treatment options were available. The researcher was able to connect with the participants on a deeper level to inquire about the participants' unique experience, explore what meaning was made out of the experience, and how it hindered or helped their grieving process. The research also looked at how the experience shaped the participants into the persons they are today. The connection helped participants feel comfortable sharing their experiences, knowing that it was not a distant topic to the researcher. Heuristic inquiry also assisted in analysis of the data, as Patton (2002) explained, rigor is achieved when "systematic observation of and dialogues with self and others" is retrieved (p. 108).

It is important to remember that the researcher used heuristic inquiry as a guide only to connect deeper with the participant and inquire about the meaning the participants derived from their experience. The results were not solely based on the researcher's experience and bias towards the medical profession. The research team ensured that the data was broken down and organized in a way that fit the participants' experience. The results and identified themes were grounded in the participants' experiences, rather than the experiences of the researchers.

Role of the Researcher

The role the researcher undertook in this project was influenced by the personal experience with her parent passing away from a terminal illness and the influence the hospital setting had on her understanding of the disease and grieving process. Second, the researcher was influenced by her role as a marriage and family therapist and her interest in finding a more effective way for therapists to work with adolescents who are grieving. Additionally, it was hoped that the study would be useful to medical professionals to improve proper communication with the family members, especially including the children of a terminally ill patient. Third, the researcher was interested in illustrating how little is known about the impact of the hospital setting on adolescent's view and understanding of their terminally ill parent, as well as grieving process. And finally, the researcher hoped to further establish ideas about bridging the gap between the mental and physical health fields.

Interview Procedure

The study consisted of a four part semi-structured interview which addressed the following: 1) basic demographic information, 2) medical involvement during illness of parent, 3) the grieving phase, and 4) relevant resources such as peer groups, family, and religion, which were available to the adolescent after the death of the parent (see Appendix A for the semi-structured interview protocol). All interviews were recorded with a digital recording device and later transcribed by the researcher and members of the research team. The interview was conducted by the same researcher throughout the study to maintain consistency, while allowing flexibility to obtain important information through follow up questions.

Data Analysis

Data analysis was conducted by a team of four researchers: Dr. Stephen Fife, faculty advisor, assisted in developing research protocol, analyzing data, and organizing the results. Dr. Fife has over 10 years of experience conducting and publishing human subject's research at the University of Nevada, Las Vegas. Dr. Fife is a licensed marriage and family therapist who has been providing therapy services for over 15 years. Hannah Goodman, marriage and family therapy graduate student, assisted the author in writing, transcribing data, and analyzing the data. Triston Neeson, marriage and family therapy graduate student, assisted the author in writing, participant recruitment, and analyzing the data.

The research team met to receive training on how to use grounded theory methods to analyze data. Each interview was transcribed after it was conducted. Upon completion of the transcriptions, grounded theory principles were applied to examine the transcribed interview recordings using Strauss's (1987) methods of data analysis: open coding, axial coding, and constant comparison. The data was broken down and analyzed until no new themes were being generated, thus reaching theoretical saturation.

During the open coding phase the data was broken down into isolated parts and thoroughly inspected, while comparing for resemblances and variances. Through the data analysis, the research team utilized a process of constant comparison: "coding an indicator for a concept, one compares that indicator to the previous indicators that have been coded the same way" (Larossa, 2005, p. 841). Indicators were words, phrases, and sentences in the data that were analyzed in light of the primary research question. A concept was the name or label linked with an indicator. During open coding, categories were developed, which stood represented conceptual elements of the phenomenon being studied (Glaser & Straus, 1967, p. 36). This

process required grouping similar but not identical concepts, as well as unrelated yet linked ideas under a more abstract label. In addition to categories, properties were also formed. Properties were defined as "a concrete feature of an idea, thing, person, event, or activity that can be conceptualized" (Strauss, 1987, p. 21). A property is a "characteristic of a category, the delineation of which defines and gives its meaning" (Strauss & Corbin, 1998, p. 101).

The next step of axial coding required the analysis to be done around one category at a time. The categories were then broken down into subcategories, "which answer the questions of when, where, why, who, how, and with what consequences around a focal category" (Strauss & Corbin, 1998, p. 125). Glaser (1978) titled these specific coding procedures as "theoretical coding" and described them in three processes: "(a) looking for causes, contexts, contingencies, consequences, covariances, and conditions around the focal category; (b) building process into the analysis (i.e. stages and phases); and (c) paying attention to people's strategies, tactics,…maneuverings, ploys,… dominating, and positioning" (p. 74 - 76). During axial coding the researcher ensured that the subcategory were not a category underneath another category, rather a category that was related to a focal category (LaRossa, 2005).

Qualitative analysis procedures and the credibility of findings of a qualitative research study can be improved through triangulation. Research triangulation is described as "using multiple data sources, multiple data collections and analysis methods, and/or multiple investigators" (Moon, Dillon, & Sprenkle, 1990). Triangulation was sought for in this study through the use of multiple researchers throughout the study: through the process of formulating the research question, developing the semi-structured interview questions, and analyzing the data. Research team members strived to enhance the credibility of the findings by clearly articulating the data collection and analysis methods used; conducting a rigorous analysis of the

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data; describing in detail the triangulation activities, theme development, and connections between the proposed research question; and reporting the results thoroughly, which provides readers with the opportunity to make their own judgments about the findings (Anfara, Brown, & Mangione, 2002).

Findings

The purpose of this study was to understand what factors influence an adolescents' involvement in the hospital during a parents' terminal illness and the impact involvement in the medical setting has on a grief. The qualitative analysis conducted by the research team resulted in a deeper understanding of the participants' experience during a parental illness, in particular being present at the hospital and hospice, while having the opportunity to talk to medical professionals, as well as how the grieving process was affected by that experience. The results were organized into two broad categories: factors that influenced participants' involvement within the hospital setting, such as talking to medical professionals or attending classes about treatment with the ill parent, and factors that influenced the grieving process.

The factors that influenced the extent of hospital involvement describe the adolescent's particular involvement in the hospital setting, such as talking to the medical professionals, taking their ill parent to classes, and joining the parent during their treatment or stay at the hospital. The factors that influenced the grieving process describe what has helped or hindered their grief, such as knowing the prognosis of the parent, having support, the hospital environment itself, and accepting the loss of the parent before the actual death.

After analysis of the factors that influence hospital involvement, four main themes were found to influence involvement of adolescents with medical professionals, and fives themes that helped the participants process and grieve the death of the parent. The four themes identified to influence hospital involvement were family structure, type of communication, age, and the realization of the disease (see Figure 1). The five themes identified to influence the grieving process were the hospital environment itself, the involvement in the hospital setting, social support, prognosis, loss of the parent before the actual death, and need for more education.

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Figure 1. Factors Influencing Adolescent Hospital Involvement
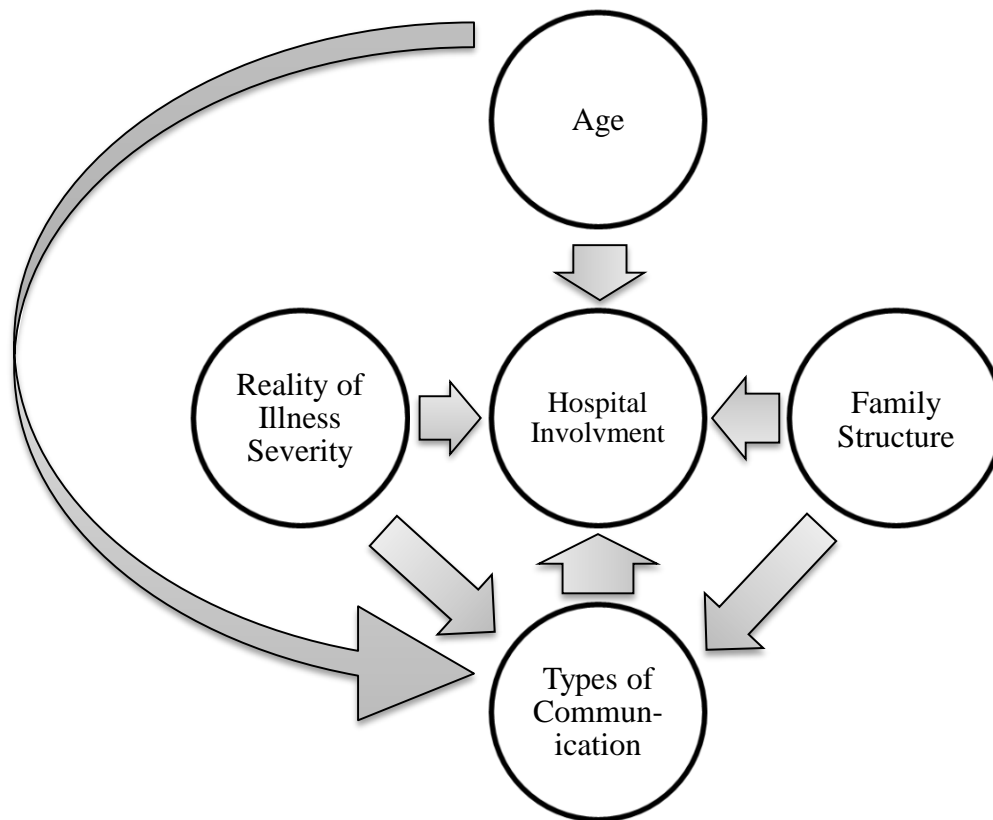
Factors Influencing Hospital Involvement

Age

All six participants describe age-related difficulties or challenges. Age often affected the

type of communication the adolescent had with medical professionals. Some participants were

reluctant to talk to medical professionals because they felt their previous attempts to speak to

them resulted in being disregarded because of their age: "We knew, because of our age they were

just not talking to us, because we were so young. So we went through a lot of problems not being

taken seriously." Participants learned quickly that their input might be disregarded or dismissed

because of their young age. Some participants who pushed through the age limit and tried to be involved felt like they were not being taken seriously. Often, the participant described an experience of what the researchers labeled as 'limited self because of their age.' The participants talked about how they feared to speak up when they felt like they needed to because they recognized that their age would limit the interaction with the medical professionals. As one participant described: "I appreciated their [doctors] willingness to talk to me but at the same time I recognized I was only 15 and knew that whatever I would say, they would not take serious". Another participant recalled being seen as a child, even though she was 16 and had taken on many adult like responsibilities when her mother was diagnosed.

The limitation of self, caused some participants to not attempt to be involved in the hospital setting at all, concluding that they would be dismissed:

> We were just invisible basically. I mean, we were always there, but we were always treated as plants or balloons that you bring to loved ones, rather than actual humans. I always felt like I shouldn't be talking. Even though I had valid things to say. And I was more expert at my mom's house, than they were at the time, but they didn't treat it like that.

Recognizing their age, many participants recalled the experience of feeling lonely. Understanding that their peers are not experiencing the same burden of a dying parent, often left participants feeling like they could not talk to them: "I felt like I really was alone, because I was only 15, and all my other friends didn't have to go through what I was going through. So I didn't feel like other people understood me." Feeling like no one else understood them, they were alone in the situation, and having no support from their peers led the participant to become more involved in the hospital setting. In the hospital, they felt like they were kept in the loop and were

surrounded by people who understood the process and stressors of having a terminally ill parent, often forgetting the barriers of their age.

Family Structure

Looking at factors that influence involvement of an adolescent while their terminally ill parent is hospitalized, the researcher noticed that family structure had a significant influence on the level of involvement that participants had with the hospital and medical professionals. Family structure was defined as presence or absence of the healthy parent, siblings, grandparents and other family members, such as extended family. In particular, participants were significantly influenced by whether or not they had a healthy parent present. In situations where the healthy parent was not present, due to divorce or previous death, the adolescent seemed to step into a caregiving role, feeling obligated to take on more responsibility. Not having a healthy parent present also pushed participants toward more direct involvement with the medical professionals, such as speaking to them about the diagnosis and treatment. One participant of the study reported:

> We didn't have dad in the picture; we didn't have any other parents. We were the
> children, and so that position is a one down, and I think…even though my mom wasn't
> competent to take care of her own needs at that point she was seen in society as being
> competent.

This often led the adolescents to feel lonely because they were left to handle many things on their own and felt like no one could relate, "I really was alone because I was only 15, and all my other friends didn't have to go through, what I was going through. So I didn't feel like other people understood me."

In cases where the other parent was present, the adolescent often felt as if the parent was trying to protect them by guarding certain information in order to prevent them from the painful truth: "Whenever the doctors did come around, my dad was like a shield towards us, where he would stand in front of us so we wouldn't really hear or understand what the doctors said." In addition, when the adolescent did receive information about the illness, it was often wrong or deluded: "One doctor would tell us, [my father] will probably have like two years, and then like he just dies in three months. I just don't know how you couldn't see that."

Types of Communication

Another important category related to the involvement of adolescents in the hospital setting was communication. Four types of communication styles were identified that influenced hospital involvement. Two types of communication were identified to have impacted the adolescents' involvement with their parent's diagnosis and treatment. Two types of communication were identified for both the adolescent and the medical professionals. Participants' experiences as adolescents included open communication and limited communication. Medical professionals' communication was described by instructive communication and neglectful communication.

Open communication: Open communication from an adolescent was identified when an adolescent was free to ask questions as well as open to receiving information from the medical professionals. For example, open communication resulted in the adolescent feeling comforted, heard, and ensured proper understanding of the diagnosis. One particular participant was very eager to receive information and as a result researched the disease to further understand it:

I was at the hospital every day, asking this and that, and then with his kidney, I was like

'okay, what are we doing about this?' And I actually, I did my own research, so I was

proposing my own ideas to the doctor.

This type of communication made the participant feel included and informed. Without this

communication, the participant imagined that he would have processed the information of the

parent being terminally ill in a completely different way:

I wouldn't have known what was going to happen. And with my mom, I would've just

been out of the loop. And as little kid, I would have still thought that cancer wasn't that

serious. I think it [communicating] definitely helped me, because it gave me a knowing of

what was...I was falling and I was able to put padding under me, before I fell. But if I

hadn't, I would've just hit the ground."

This experience was seen throughout the data and was labeled by the researcher as a soft

landing. The soft landing describes the benefits of open and instructive communication by

talking to medical professionals in order to understand the diagnosis and to be informed of what

to expect in the near future: "It was kind of like, geared me up to being prepared for that [death].

I'm really happy that I was involved and my family allowed me to be involved." Another

participant said:

The doctors at the hospice were more geared towards like helping me land softly. Them

like giving me specifications on what was going on, it was kind of like everybody knew it

was going to happen so they were just kind of like helping me land softly.

Limited communication: Although each of the participants described experiences with

open communication, several also discussed times when their communication was limited or

constrained. Limited communication was identified when the adolescent did not want to talk to

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medical professionals, for reasons such as, not knowing what to say or how to say it, or being in

denial.

A participant recalled the day she was being informed about her mother's relapse and not

talking to anyone about it:

I did not feel comfortable talking to her [mother] about the scary questions I had. And

at the hospital, the doctors and my family, who were all nurses and doctors, tried talking

to me, but I did not want to, I just did not feel comfortable.

Another participant recalled limiting her own communication because she did not feel

comfortable with the medical professionals: "I would not have listened to the doctors anyway. I

didn't know them and they were strangers to me."

Limited communication was also influenced by denial. Participants recalled being

uninterested in talking with any medical professionals because they did not want to hear the

reality of the diagnosis: "I tried avoiding the doctors whenever I was at the hospitals because I

just did not want to know the truth." Another participant recalled: "I didn't really ask questions

because I really didn't think that my mom was going to die. I didn't believe what the doctors

were telling me."

Instructive communication: Medical professionals used instructive communication in

order to keep the adolescent informed by taking the time to explain thoroughly what the

diagnosis meant and what will happen when treatment starts. This type of communication was

identified by the participant as positive, keeping them well informed, and feeling included: "I

just had a lot of information on what's happening." Instructive communication was also

exhibited in a non-verbal ways, for example, one participant recalled her mother's doctors

always being available to her, checking in on her, and providing her with information as well as

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food in order to keep her informed and happy, "When she [mother] was getting chemo, he

[doctor] would bring me food and drinks. He was open to talking to me any time and so he really

answered a lot of my questions." Instructive communication was also exhibited by the

availability of classes that the diagnosed patient and family members could be a part of. One

participant explained how that helped him be informed not only about the diagnosis but what he

should be expecting during the time of the illness: "They inform you on what's going to happen

to your body when you go through the different treatments and they tell you 'your body is going

to experience this so don't worry.'" Participant 6 talked about feeling like the doctors

specifically, avoided her and only communicated with the ill and healthy parent, leaving her with

questions and concerns and no consolidation. The participant recalled an experience with a nurse

instead, who made her feel better and more positive about the future:

> So the nurse sat down next to me and rubbed my back until I calmed myself. And she
>
> said something like 'I know it is hard but it will be okay" and it just made me feel like
>
> FINALLY! Someone with some good… or decent news.

Neglectful communication: On the other hand, neglectful communication was identified

when the medical professionals tried avoiding the family members, did not spend sufficient time

with the family, and left the family members feeling like they are just another family in the

hospital. This type of communication left the adolescent misinformed, disregarded, powerless,

and helpless: "They didn't really tell me anything. The doctors didn't even try to talk to us".

Another participant recalled feeling unimportant to the medical professionals:

> I know they have a lot of other patients, but they threw off the vibe that they did not care.
>
> Like he [father] would be in his room and need something, we call them and it would

take them a long time to answer, and provide him with what he needed. And that made

me feel like, they are not sensitive to family's feelings.

Another participant described a similar situation, needing assistance from medical professionals

but not receiving it:

My mom was like 380 pounds, just had brain surgery, and was hallucinating and wanted

to leave the hospital. I went out to the hallways and yelled for help, for a doctor or a

nurse, and literally no one came.

Realization of Illness Severity

The last factor influencing participants' involvement with their parents' illness and the

medical staff was the realization of reality—the reality of the seriousness of their parents' illness

and the reality of their impending death. When the adolescents realized and accepted that their

parent was terminally ill they often experienced the phenomenon we described as *instant*

maturity. Participants often explained how they took on new and more mature responsibilities, of

their own volition. For example, Participant 3 reported: "When you are in that situation, you are

not a kid anymore. I used to be the son in the house, one of the children. But all of the sudden, I

am the man of the house." Participants described a number of different responsibilities that

emerged with their parent's illness, such as the difficult task of taking care of a sick parent,

holding things together at home, or caregiving for their siblings. The adolescent often took on the

caretaker role, whether another healthy parent was present or not. One participant described it as

keeping things as normal as possible and therefore had to take care of the household chores: "I

took on the mom role and tried to keep everything like when she was alive. And taking her

position in any way." Another participant reported that even though they did not want to be at the

hospital they felt that being there will do more good and is the responsible thing to do: "He

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[father] was in the hospital pretty much the whole time....I was there every day." Another

participant recalled:

> So, it was just me and my mom. For quite a while at my mom's house and so I was in, 7th
>
> grade? And so, I just stopped going to school, and I just kind of took care of her full
>
> time.

Participant 6 recalled wanting to be there but it being difficult too: "I went to the hospital, I

really felt like I needed to be there. But it made it really hard too, so I was more of the sibling

who sat on the sidelines."

Factors Influencing the Grieving Process

Through the process of analyzing the data, it became clear that participants also described

several factors that influenced their process of grief. Five main themes associated with grieving

were identified: hospital environment, support, the prognosis, loss of the parent before the death,

and the desire for more education from the medical professionals (see Figure 2).

Figure 2. Factors Influencing Adolescent Grieving Process
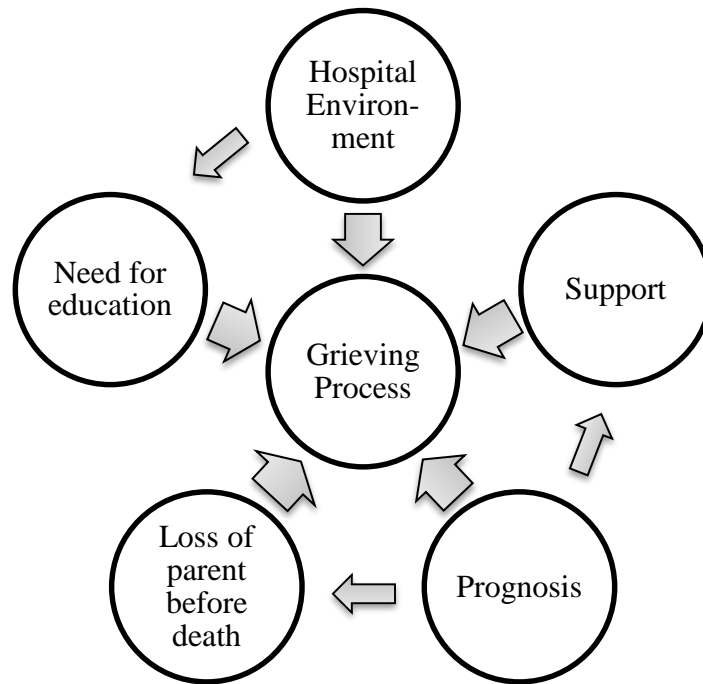
Hospital Environment/Involvement

Being present at the hospital was identified by the participants as aiding them in understanding the diagnosis more, because they had the chance to speak to the medical professionals or overhear them talking to their healthy parent, take the ill parent to classes in which they were explained what cancer means, and learn what treatments were available and what will happen in the future. Such experiences also increased the reality of the situation for participants and helped them accept the illness and their parents' likely death. Also, being present in the hospital helped participants understand the seriousness of the illness, allowing them to prepare themselves for the pain that accompanies death.

Although participants experienced some benefits from their involvement in the hospital setting, there were also some downfalls to being present at the hospital. Some of the participants felt betrayed by the medical system, as well as other organizations aimed to support or assist one during the hard times, such as the mental and allied health providers. For instance, Participant 1

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talked about taking their ill parent to an inpatient mental hospital, "They were like, 'Your mom is fine just take her home,' and my sister was like, 'I don't feel safe driving with her.' And they were like, 'Well then we will lock you up here.'" Not receiving the necessary help from this particular inpatient hospital left the participant feeling hopeless and powerless. This trend was seen throughout most of the interviews of participants feeling inadequate at the hospital, leading them to feel like there was nothing they can do or say to help their ill parent: "No matter what we did, we were ignored, and so eventually we just gave up, because we knew they wouldn't listen to us anyway."

Social Support

Often, the hospital environment made the participants feel powerless and hopeless, leading the participants to reach out to family and peers for support. Social support played a big role in the way that the death of the parent was perceived and grieved. Participants with support from friends and family had a sense of community, in which they knew they could turn to friends or family to talk or receive comfort: "Just like text a friend, like 'hey man, I need to talk, I just need to get everything out.'" Another participant described how her and her best friend had to always cater to her sick mother while hanging out:

> He would drive me places, he would take me to the grocery store to get my mom food.
> We would make our plans to hang out, revolve round anything that I had to get done to
> help my mom and he did it without any hesitation.

Having this best friend who supported her made her feel less lonely. Participant 6 described how having a friend who was experiencing the same thing around the same time helped her cope with the death by talking about the different treatments their parents received:

It was interesting to see the different procedures they did and how it affected their mood

and bodies differently. It helped me understand my mom's journey more, in a way where

I knew the doctors did, what they thought was best for her.

Participant 2 spoke about the community coming together to grieve and be supportive, which

also made her feel less lonely: "The whole community actually was very supportive about the

whole [grieving] process. We sat Shiva together, and it made me feel like I am not alone in this."

On the other hand, participants who felt like they were not supported during that time,

often felt like they had questions, concerns, or other issues that they were left with, but had no

one to turn to:

No one at the hospital contacted us, her doctor came because we called him, and like I

said we were family friends, and he came by when the coroner came, but like that was it.

That was the last time saw him, and so we never saw any of the same people again.

Many of the participants sought out therapy after the death of the parent, or were referred

to therapy by other family members. These participants recalled their memories of therapy as

unhelpful and not beneficial to their grieving process. Reasons included the participant not being

ready for therapy, the therapists being unqualified, or feeling like therapy was conducted in a

manner that was impersonal and too stereotypical:

For somebody to sit there and tell me: 'Oh, you need to do this. This will make you help

feel better.' Like I understand there's like the generalized way that people cope with it.

But I'm like, that's not how I'm coping with it. Like it was easier for me, than

probably anybody in my family. And I hated all of it, I've literally like started to resent

them.

Prognosis

Being present at the hospital often led the participants to receive the prognosis of the ill parent. The prognosis often included the explanation of how long the parent had to live and what treatment will look like. Knowing the prognosis of the parent had a significant impact on grief. Although the prognosis given by the medical professionals was often wrong, if the ill parent received a longer timeline to live, the participant had more of a chance to see their parent in a hospital setting, receiving treatment, and experience the timeline of the illness. This experience gave the participant a chance to come to the realization of the seriousness of the diagnosis, accept the illness, and come to terms with the idea of death and what life may look like after the parent has passed away. Participant 3 recalled thinking about the future after seeing the bad shape of his father: "I just started thinking, I could never imagine life without him. I never thought that, that would be something I would go through like now." Participants who had this opportunity were less shocked and surprised when the death came, compared to participants who received a shorter prognosis, "We have been raised knowing that our mom would die from when we were young. So we had all the conversations. We knew what she wanted and all that stuff, and she did not want to be resuscitated." Those participants who were given a shorter prognosis did not have the chance to conceptualize or come to accept the diagnosis, therefore were left in shock and surprised when the death happened: "I was left wondering how long she actually does have which was very difficult to just sit there and wonder." Participant 2 did not take the prognosis seriously, because their parent had previously survived the cancer and therefore was shocked when the death occurred:

> I didn't think she was going to die though, because I already knew she had other previous forms of cancer, and she fought it. And so, I thought this time as well, that she would fight it and she'll be fine. But when she died, I was very surprised.

A short prognosis often lead to uncertainty. The uncertainty drove participant's willingness to take part in the hospital setting, sometimes a simple process such as visiting the ill parent and sitting by their bed side. The uncertainty also drove the participant to be more involved with the parent's terminal diagnosis in a way that they felt they had to be advocates for their ill parent.

Loss of Parent before Death

Whether the prognosis was short or long, participant often described an experience of losing the ill parent before the actual death. While analyzing data, the research team noticed that each participant experienced the loss of the parent before the actual death in one way or another. The loss of the parent before the actual death was seen in various ways, for instance physical or behavioral changes as well as role changes. This loss helped the participant accept the upcoming death of the family member and understand what life will look like without the ill parent. Often this acceptance consisted of recognizing that the parent is not his or her old self anymore. One participant described his father: "It wasn't him anymore it was just a shell of him." Participant 3 talked about his father being an active person who was, all of the sudden, bed ridden: "He was in pain with every breath he took, and that was just not like him. He was always this strong, 6'4", dude and now he can't even sit up straight."

Accepting new roles and responsibilities while the parent was still alive was another way of losing the parent before the actual death. A common new role and responsibility was switching roles with the parent and suddenly becoming the caretaker of the parent, rather than the parent taking care of the child:

It was so hard, just to see that the one who is always supposed to take care of you, and now the roles switched, and you are taking care of them. It was weird. I just had to suck it

up, because I could see that she didn't want me to take care of her either, but so we were

both like hurt by it, by having it to do it.

Another participant stated:

So it was kind of like I would administer her pills. I kind of assumed the adult kind of

role. And you could tell that it really upset her because I mean she was the mom, I'm the

one that should've been taken care of.

Need for Education

Knowing and understanding the diagnosis, being aware of the prognosis, and accepting

the uncertain future, helped the participants cope and process with the death of their terminally ill

parent. Yet, all participants stated the need for more education in several areas. Participant 1

particularly stated that more information was needed about what to expect when taking care of a

terminally ill person: "More education on what helping an ill person looks like. Because it's not

just going to be the spouse or the parents of the ill person." In addition, the researcher found that

educating the entire family on how to process the grief and support each other in a difficult time

would have been helpful to some of the participants:

There should be some part of the medical process that is there for you when the person

they are treating leaves. You are so involved, but once that one common link is gone,

you fall apart. Hospitals, doctors, and any type of medical professional you may see,

should be built in the process; where there is at least a few times of discussion about what

will happen once the ill person dies.

A couple of participants mentioned educating the medical professionals on how to talk to

the entire family, rather than just the spouse. Participant 2 had family members that had a

medical history and therefore felt like the medical professionals assumed the family will educate

the adolescent, which was not the case: "I think then the doctors, my mom's doctors, kind of put their role onto my family, because they figured: 'I don't need to push more information onto the adolescent, because we will have her family talk to her instead.'" Participant 6 reiterated how doctors should be taught to talk to adolescents or teach the ill parent how to talk to their adolescent child, in order to be informed:

> It would have been nice if the doctors would have wanted to talk to my sister and I. Maybe teach the parent how to talk to the children and have them included. Because, it seemed like my parents, at times wanted to tell me what was going on, but were not sure on how to do so.

Discussion

The intent of this study was to gain a deeper understanding of what factors influenced adolescents' involvement in the hospital setting during a parental terminal illness and how that affected their grieving process. The researchers also looked at factors that shaped the way the death of a parent after hospital involvement was perceived by an adolescent. Researchers analyzed data from six qualitative interviews with individuals who lost their parent due to terminal illness. The result of this study posed several implications for medical and mental health professionals who work with family members during and after terminal illness and end-of-life situations.

Results of this study included several factors that influence the involvement of an adolescent in the hospital setting and with medical professionals during their parents' illness. The results of the study suggested that involvement in the hospital also influences the way death is viewed and grieved. The researcher found that family structure, communication type, age, and

realization of the severity of the diagnosis played a role in the amount of involvement the adolescent had in the hospital setting. The hospital environment itself, knowing the prognosis of the parent, availability of social support, loss of the parent before the actual death, and the need for more education all contributed to the way the grieving process went.

Barriers and Bridges

The findings from this study demonstrate there are circumstances from a family member's perspective that both compromised and facilitated their ability to be involved in the hospital setting and communicate with health care professionals. Such reasons included family structure, communication styles, age, and realization of the severity of the diagnosis.

Family structure, especially not having the healthy present, pushed the adolescent to be more involved with the ill parent, such as being an advocate for them and learn about the diagnosis by asking questions and attending classes. Some participants had siblings that they felt like they needed to take care of because the ill parent was not able to do so. Communication styles depended on both the adolescent and medical professionals. Open communication lead the adolescent to be more involved in the hospital setting by asking questions, educating themselves on the diagnosis and treatment. Limited communication left the adolescent feeling alone and inadequate to help their parent. Instructive communication by the medical professionals allowed time and space for family members to ask questions, receive a prognosis and information on the treatment and what to expect in the near future. Neglectful communication by the medical professionals was described as leading the family members to feel unimportant and uneducated about the diagnosis and what to expect. According to most participants, neglectful communication was influenced due to age, which was also a significant factor that influenced the involvement in the hospital setting. In some cases, the participant let the age limit their

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involvement because of fear of not being listened to and recognizing their lack of knowledge when it came to medical terms. In other cases, age was disregarded and the participant tried to be involved as much as possible with the diagnosis of their parent. Finally, the realization of the severity often influenced the participant to be involved, knowing that the diagnosis may take their parents life. This knowledge pushed the participant's want and need to make the parent as comfortable and in any form possible.

Some of the barriers to communication included the adolescent not knowing how to address the medical professionals and feeling inadequate because of their age. Having the healthy parent present and being protected by them sometimes led to not being allowed to engage with medical professionals. Lastly, having a hard time recognizing the seriousness of the diagnosis also led to denial and unwillingness to talk to medical professionals.

Communication was facilitated by the adolescent in an open or limited way. Limited communication occurred when the participant was held back by the factor of age. Understanding their place in the family, as well as in society, participants explained that they did not feel like their input would have been listened to nor considered. Participants often transcribed to the learned helplessness effect and did not attempt to be involved in the care of their ill parent.

Although participants experienced some barriers to communication, in other cases, communication was facilitated through various contributions from the hospital and medical staff. For example, participants reported benefitting from educational classes in which both the adolescent and ill parent received information on the diagnosis and treatment. Some instances of having the medical professional available to answer questions and concerns helped them with understanding the diagnosis were also reported. Having a healthy parent present shielded the adolescents from unnecessary burdens and responsibilities. However, the parent often played a

protective role, which occasionally led the adolescents in being left out in important conversations. Some participants did not let their age affect them and used it to their advantage by asking many questions to become more knowledgeable. Being an adolescent, without a healthy parent present, helped the adolescent become more responsible and take on the caregiving role of the ill parent, as well as others, such as siblings or the household itself. This instant maturity was seen when the participant recalled experiences of knowing that they have to be in charge of their ill parent and being engaged in the treatment process as well as discussing future plans of treatment with medical professionals.

The results of the study suggest that medical professionals can improve the experience of family members of terminally ill patients by learning how to include the entire family system during the diagnosis explanation and inform them what treatment options are available and what each treatment would look like. Additionally, teaching family members about the upcoming changes and what to expect in the near future, may be beneficial to the family. The medical professionals can also improve the experience of family members by teaching the parents how to talk to their children about the diagnosis, treatment, and death. Participants in the study noted that educational classes, which explain the diagnosis and treatment options were helpful. However, these could be enhanced to include information about caregiving tasks and other topics that would be beneficial for family members.

Medical Family Therapy

Medical family therapy is a unique sub-specialty of family therapy in which problems, especially medical problems, are viewed through a biopsychosocial-spiritual perspective. Medical family therapists work through a comprehensive treatment approach, making sure to attend to both physical and mental aspects of the presented problem.

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Medical family therapists are uniquely poised to address some of the barriers mentioned above and can further facilitate inclusion of family members over the course of treatment planning. Results from a study conducted by Anderson, Huff, and Hodgson (2008) found that families experienced significant benefits from therapy sessions, which included the whole family at psychiatric inpatient units. Specifically, participants stated interventions such as psychoeducation was helpful and taught them an operative way to speak to the biopsychosocial and systemic traits of mental health. The findings in the study corroborated with these findings, with participants who participated in educational classes offered by the hospital or who received education about their parents' illness, reported that they were empowered in their communication with medical professionals. On the other hand, participants in the study who were not as informed stated they needed more education to be informed about the diagnosis, in order to have an informational conversation with the medical providers. Medical professionals can aid adolescents and other family members by bringing them more fully into the treatment process through open communication and education regarding the illness and prognosis.

In addition to the benefits for family members, medical family therapists and other clinicians trained in the biopsychosocial-spiritual framework can attend to patients' needs in a more comprehensive manner and "address systemic factors that may have contributed to the need for hospitalization in the first place" (Anderson, Huff, & Hodgson, 2008, p. 176). In other words, looking at the cause of the patient's reason for being in the hospital from a biological, psychological, social, and spiritual perspective, can potentially positively impact symptomology.

Therapists who do not identify as medical family therapists can also benefit from this information. Combining physician and mental health care has shown to have improved effects for both the patient and cost of services. A study conducted by Crane, Christenson, Dobbs,

Schaalje, Moore, Pedal, Ballard, and Marshall (2013) looked at cost effectiveness and the type of therapy (i.e. family, couple or individual therapy for the treatment of depression). The results showed that family therapy is the most cost effective and the most suitable treatment for clients dealing with depression. Christenson, Crane, Beer, Bell, and Hillin (2014) found similar results while looking at family therapy, cost, and treatment of schizophrenia. Results from their study suggested that careful consideration of interventions implemented during therapy is important when demonstrating the expenses of hospitalization as well as medical services delivered to schizophrenic patients.

Medical family therapists are trained to prepare their patient and their family members to get back on track and into their daily routines, while educating them on health, healing, and exposing them to the change that will be experienced after the death of a family member (Fox, Hodgson & Lamson, 2012). Applying the same principles to patients with terminal illnesses and their families, family therapy sessions should be held in order to address any concerns and questions that the patient and their family members may have. Furthermore, highlighting how the diagnosis and the treatment process will affect their current and future lives. Changes to relationship dynamics can be talked about, as well as coming to terms with death and life after the deceased. The findings showed that having some sort of education about the terminal illness, such as classes about chemotherapy or having the opportunity to directly ask medical professionals questions helped both the process and understanding of the illness and made the grief process easier, in a way that the participant was expecting the death. Those who did not have the same opportunities experienced a more difficult time transitioning into caregiving roles and accepting new responsibilities. They also had a harder time grieving, as they were not expecting the death.

Genograms

The findings in the present study suggest that tracking the onset of the illness from the earliest time and highlighting how the roles and patterns contributed to the family's difficulties and how they inhibited family members from speaking to health care team members could be beneficial to the family members. Tracking the course of the illness could help adolescents to process the diagnosis and understand what helped or hindered the process of adjusting to living with a terminally ill family member. One way of accomplishing this might be through an illness genogram, which is a useful tool in psychotherapy. Introduced to the field of family therapy by Murray Bowen (1978), genograms are intended to supply the basic biological ties between an individual and their family members. At their most basic, genograms provide information about how people in a family are biologically connected; at their most complex, genograms can provide detailed information about the individuals in the family map (i.e., ages, jobs, death dates, diseases, etc.), as well as information on the quality of the relationships between the members and other historical patterns. Over time, genograms have been applied to a variety of populations and presenting problems.

Focused genograms refer to a specific type of genogram developed as the result of a series of specific questions designed to uncover beliefs, patterns, and habits in a particular area of one's life (DeMaria, Weeks & Hof, 1999). A family map genogram may be utilized to illustrate relational patterns, healthy and supportive ones, as well as dysfunctional ones. Unlike basic genograms, family genograms address contemporary interactions of the immediate and extended family, if applicable. Therapists can utilize focused genograms with families dealing with terminal illness to further conceptualize the case as well as help the family process the illness and cope with the outcomes of the illness. The genogram can also point out healthy and

non-healthy ways of coping with the death, at which point the therapist may use psychoeducation to further help the family process the death in a healthy way.

Another type of genogram that may be used and helpful in a family with a terminally ill member is the time line genogram. A timeline genogram can demonstrate the developmental, environmental, interpersonal, and life cycle transitions of a family (DeMaria, Weeks, & Hof, 1999). This becomes particularly important when exploring an illness and its unique challenges and stresses (i.e. how it began, what symptoms were present, who was involved, and how the illness affected the family dynamic itself). An illness genogram would provide MFTs with critical information about changes in the a) family organization and b) each member's sense of agency as the illness progressed.

The final genogram that potentially may be beneficial to the patient and the family is a genetics genogram. Visualizing family history on specific illnesses or diseases may clarify risks to patients that have not been previously pointed out. The genetics genogram may show that an illness may have not been genetically inherited within the family, "the negative health history is just as important as the positive family history of disease in risk assessment" (Tavernier, 2009, p. 223). Some questions on the genetics genogram might inquire the family about the understanding of a disease, the treatment options available, and how it was attended to in the past, i.e. what treatments were utilized, what the prognosis of the patient was, and how they passed away. Once this tracking is accomplished, family members may gain insight into what prevents them from communicating with the health care team.

Family Involvement

"Involving family members in each other's care can be efficient, informative, and influential to the success of treatment plans" (Fox, Hodgson, & Lamson, 2012, p. 230). Together,

medical professionals and family therapists have a better chance to manage multilayered

complexities of health and illness. Dym and Berman (1986) identified the issue of current

collaboration work of physicians and family therapists in which the therapists are still not

included in the diagnosis process, which leads to the exclusion of the therapists in deciding

treatment options as well. This becomes important information for the family to know as a way

to help increase their agency. As found in the results, part of what participants said stopped them

from asking questions was their relative lack of medical knowledge as compared to the

physician. Yet, if psychoeducation is a component of treatment, teaching the family about the

fact that all of these systems interact, family members are more likely to experience a greater

sense of agency.

Communication

Delivering bad news, especially in cases of terminally ill patients, is a daily activity for

most physicians. Oncology physicians specifically, are obligated to fully disclose a cancer

diagnosis to the patient. Many physicians, however, still use language that is not direct or clear,

such as "lump, growth, tumor, mass, and abnormal cells" during the diagnosis of cancer (Shaepe,

2011). Communication guidelines, specific ways and keywords that a physician should use when

delivering a diagnosis to a patient, has been generated from a self-reported data collection and

survey data. Yet, there are no such guidelines on how to include the family during the diagnosis

talk. Families that are suddenly confronted with a life threatening illness are often left distressed

(McDaniel, Hepworth, & Doherty, 1992). This distress can arise due to several factors, such as

changes in family roles.

Communication was a central factor in experience of participants in the study.

Depending on the openness of communication between participants and the medical

professionals, participants felt included and informed within the care of their parents or felt

disregarded and betrayed. Positive communication, in which medical professionals took their

time to talk to all family members, including the adolescents, lead to an overall positive

experience during the hospital visits and added to the process of accepting the diagnosis.

Negative communication, where the medical professionals ignored the adolescent or gave short

answers to family members, lead to feelings of disregard and overall in need for more

information, to fully understand the diagnosis. Participants (who were adolescents at the time of

their parents' illness) reported that they were often left with more responsibilities and worries

than before. Also, family members facing terminal diagnosis struggle individually and together

with lack of motivation to go on and confusion about how to proceed with their identified roles

and set routines. Illness often leaves lives disrupted, leaving families obligated to restructure

their lives (Yeager, Auyang, Brown, Dickinson, Goldstein, Jaffe, Workman, 1999). This was

also noted by the participants in the study and reiterates the importance of the inclusion of the

family during the time of diagnosis, and for it to be handled as carefully and delicately as

possible.

Education

The participants stated that there was a need for more education from the medical

professionals, in order to process the diagnosis, understand what is ahead of them, and how the

roles will change now that there is an ill parent in the household. Participants also stated that

when they did seek counseling after the death, their experience was not beneficial to them.

Reasons included feeling like their therapist is not adequate enough to work with a grieving

adolescent, or being pushed to therapy too early by their family members. Educating both the

medical doctor and therapist at the same time would be most ideal to increase collaboration in

order to improve the experience of family members at the hospital during and after the terminal illness of a family member. As mental health providers and physicians are slowly beginning to work together in the caretaking of their patients; it is important to note that more training is needed for both professions. Therapists must learn the language that physicians use, and physicians must include the mental health perspectives when assessing a patient. Patients and their families will benefit from physicians and other health care professional who learn how to effectively communicate with the entire family about the diagnosis and prognosis.

Educated together, physicians and therapists can achieve a level of comfort and understanding about each other's field that does not occur in traditional training programs (Harkness & Nofziger, 1998). A pilot course was held at a training university in Texas, which included Motivational Interviewing, as well as Trans-theoretical model of behavior change in the curriculum of physician assistant students in managing cancer risk behaviors. Evaluation of both the course and the students showed that more knowledge and skills are taught and developed during the course. The students self-reported more confidence in consultation about health risk behaviors, and were able to correctly answer questions about their knowledge of interventions compared to the students who did not take the course (McLaughlin, Fasser, Spence, & Holcomb, 2010). This study is an example of how beneficial it could be to include mental health courses in the medical school curriculums. Medical Students should not only be taught preventative mental healthcare but also other mental healthcare, such as grief counseling.

Adolescent Development

During the adolescence stage, the individual struggles between autonomy while still being under their parents' wings and differentiating between when they should be independent and stand their ground, versus listening to their parent, knowing that they are the authoritative

figure in their lives (Erickson, 1980). With this insecurity still in the picture, adolescents may not

know the appropriate balance when it comes to their terminally ill parent and communication.

They may struggle when it comes to talking to both the parents and the medical providers about

their ill parent. Since some adolescents have not yet established self-confidence in social

settings, they may have difficulties distinguishing between times they should be speaking up and

asking questions, or taking the back seat. This insecurity in speaking up, asking questions, and

absence of involvement may lead to confusion and lack of understanding of the diagnosis,

prognosis and treatment options of their sick parent. This issue goes further than just being

informed about the parent's illness; it leaks into the overall development in security of the

adolescent. If the adolescent does try to speak up and be engaged in conversations about the

illness but gets turned down, it will teach the adolescent that it is not appropriate for them to ask

questions and talk whenever it was deemed necessary, affecting the way they perceive

communication in the real world.

Shared Decision Making

The findings from the study confirmed the idea of *shared decision making* when it comes

to making decisions for a family member that is ill. *Shared decision making* is the idea that all

family members usually tend to want to be involved when it comes to making a decision of what

will happen to an ill family member but are often discouraged when interacting with medical

professionals (McDaniel, Doherty, & Hepworth, 2014). Several of the participants stated that

they developed a learned helplessness attitude because of their experience of being disregarded

by their medical providers. Participants also stated that although they knew what their family

members wanted, they had a hard time expressing it to the medical professionals because of lack

of medical term knowledge. Not being given the time and opportunity to hold a conversation

about the wants and needs of the ill family members was another concern of the participants that led to discouragement, thus hindering a shared process of decision-making.

Limitations

This study was based on the recalled memories of the participants and therefore took a retrospective approach. Retrospective studies are based on events that have already occurred and are usually grounded in participants' memories. In this study the participants were given an opportunity to look back at their experience and recall their memories as clearly as they could remember. However, critics of retrospective studies suggest that individuals cannot accurately recall past events, states of mind, or mental processes due to cognitive limitations (Nisbett & Ross, 1980). Although there are limitations to retrospective methods, they can be effective in learning about people's experiences in the past. For example, a retrospective method that has been found to be more accurate is the critical incident technique in which participants are asked to report their memory of specific salient events rather than general information (Ericsson & Simon, 1980). In this study the participants were asked to recall their experience in the hospital during their parents' terminal illness. Given that the participants were recalling memories of such a traumatic and specific time of their lives it can be assumed that those memories are fairly accurate.

The study attempted to recruit participants' who experienced the death of a parent due to a terminal illness during adolescence. The type of terminal illness was not limited to one specific illness. However, all six participants experienced the death of a parent due to cancer. Therefore, the findings are based on the experience of the participants with a parent who passed away from cancer. Nevertheless, the results may be applicable for adolescents, family members, and health

care providers in situations when treating a parent who is diagnosed with another kind of terminal illness.

It is important to note that other factors, besides the findings of this study, may affect the way illness is perceived and death is grieved. For example, the personality of the adolescent, the relationship they had with the deceased parent as well as the living parent, birth order if more than one child, how long the parent was ill, and attachment styles. Research indicates that attachment styles are associated with characteristic strategies for directing attention and coping with the loss (Pistole, 1996). Death may change or dissolve the attachment that was built during childhood (Nager & Vries, 2004). Wayment and Vierthaler (2002) studied attachment styles and bereavement reactions and found that individuals with a closer attachment style to the departed, expressed more grief than those identifying with avoidant attachment style, who described more somatization. Somatization symptoms are accompanied by the failure to express emotions. Anxious-ambivalent attachment style individuals reported greater risk of depression and grief combined. Securely attached individuals are less likely to interpret the death that has negative implications for self, which would lead to depression. The same study also found that grief was reported more often when the death was more sudden compared to more frequently reported depression when the death was expected.

Time was of an essence to this study. Unfortunately, the research team came across some difficulties receiving timely approval from the Institutional Review Board (IRB). Leaving the researchers with limited time to recruit participants, collect and analyze data, and sufficient amount of time to write out the results in a well thought out matter. Recruitment of more participants would result in more data that would have perhaps led to additional data and richer results. Finally, the study is also in need for more males and more fathers who have passed away.

Mothers are often seen as the primary care taker and therefore the loss of a mother may be more dramatic than the death of a father.

Recommendations for Future Research

Although this study provided some information on the interaction between family members of patients in the hospital setting, there is a significant need for additional research that looks at what factors, policies, and procedures can improve the experience for family members of hospital patients. Furthermore, this study focused only on the perspective of the adolescent children of ill parents. Additional research could focus on the perspective of the ill parent as well as the medical professionals.

This study was limited to participants who were young adults, and therefore was based on the experiences of a death that occurred no longer than five years ago. This resulted in the recollection of how the death made a difference in the most recent years, rather than how it affected their lives, personalities, and relationships over a longer period of time. Additional research including older adults who experienced the death of a parent during adolescents could provide information on how the death has affected their lives, personalities, and relationships.

Research on how any type of death affects the adolescent is also in need. This study limited the participants to experiencing the death of a parent due to terminal illness; however, looking at death that occurred otherwise, such as accidents or tragedies could be useful. The sudden death of a parent does not allow the adolescent to prepare for the death and therefore may lead to a different type of grieving process. Including both causes of death, terminal illness and sudden death, would allow for the comparison of how death is perceived and coped with depending on the cause of death.

Longitudinal studies with prospective designs may also help increase understanding of adolescents' experience with the hospital setting as well as the process of grieving the loss of a parent due to terminal illness. Additionally, extending this study into a longitudinal study would allow for deeper understanding of how death can effect adolescent development beyond young adulthood. Jantzer et al., (2013) studied the risky behavior of adolescents who have experienced the death of a parent due to cancer. Their findings showed that the adolescent's typically adjusted well to the parental illness and did not have increased juvenile risk behavior. Similarly, turning the proposed study into a longitudinal study to measure the effects of the death on development may result in insight for both mental health providers and medical professionals on how to work with an adolescent coping with the illness of a parent, with minimal damage to their development.

Conclusion

This study explored the experience of adolescents during parental terminal illness, particularly in relation to their interaction with medical professionals and hospital settings. The findings illustrate the importance of including adolescents and how certain types of hospital involvement can impact the way the diagnosis is processed and death is accepted. The study allowed the author to interview participants who were willing to share their experiences of hospital involvement during their parental illness. Results showed that many factors influenced the reasons of involvement, or lack thereof. Family structure, communication types, age, and realization of severity of the diagnosis all played a role in the extent of hospital involvement. Meanwhile, hospital environment, presence of support, knowing the prognosis of the disease, accepting the loss of the parent before the actual death, and the need for more education, all affected the grieving process.

These findings can aid both mental health providers as well as medical professionals understanding on how to interact with adolescents who are present in the hospital environment during the illness of their parent. Learning how to work together, mental health providers and medical professionals can enhance the experience of an adolescent in the hospital. Open communication, being available, and taking the adolescent seriously, regardless of age, can result in the adolescent feeling comfortable enough to speak up whenever necessary in addition to feeling knowledgeable about the diagnosis, prognosis, and treatment.

Mental health providers and medical professionals may utilize the results when working with families who are coping with a terminally ill family member, especially those that have adolescent-age children. Understanding the stage of development of an adolescent, should guide

the professionals to understand the importance of including them during a time of such great

change and difficulty.

Appendix A: Semi – Structured Interview Protocol

Part One:
1. Name:
2. Current Age:
3. Gender:
4. Ethnicity:
5. Age when parent died:

Part Two:
1. Which parent died?
2. How old were you?
3. What illness was your parent diagnosed with?
4. How long was your parent given to live?
5. Who told you about the diagnosis?
6. Were you able to talk to doctors and/or nurses about the diagnosis?
7. Tell me about your experience?
    a. What feelings did you have?
    b. What were your thoughts?
    c. What are some of the things you did to cope with the news?
8. What type of questions did you have?
    a. Whom did you turn to, to get answers?
9. Did you feel like all your questions were answered about the diagnosis?
10. On a scale of 1-10 how much do you think you understood what the diagnosis meant?
11. Tell me about your experience of how the diagnosis changed your everyday life?
    a. Roles at home
    b. Responsibilities
    c. Relationships within the family dynamic as well as others such as friendship
12. Were you explained what treatment options were available to your parent? If so, by whom?
13. Did the treatment options make sense to you? In other words, were they properly explained and broken down into what the treatment may mean in regards to length, side effects, and outcomes?
14. Were you allowed to be part of the decision making process of which treatment will be utilized? How was that for you?
15. How do you think your grieving process would have differed had you not had the experience of being involved with the doctors, the explanation of the diagnosis, and being part of making the decision of which treatment will be used?
    a. What are some of the feelings you had during the experience of your parents' illness?

Part Three:
1. What resources were available to you after the death of your parent?
2. What are some things you can think of that may have helped you grief but was not available to you?

Debriefing: Thank you for your time and participation. Here is a contact number in case these questions have brought up any undesired memories or emotions and you feel the need to further talk to someone.

UNLV Marriage and Family Therapy Program

RESEARCH PARTICIPANTS NEEDED: *HAVE YOU EXPERIENCED THE DEATH OF A PARENT DURING ADOLESCENCE?*

Death has the potential to be traumatic for every member of the family, particularly the adolescent. Conversely, some adolescents' gain coping skills and resiliency as a result of their parents' death. The experience of hospital involvement of an adolescent during parental illness has the potential to impact the way the death is perceived and coped with.

In an effort to understand the way hospital involvement during parental terminal illness affected the grieving period, Dr. Stephen Fife and Vaida Kazlauskaite are interviewing adults over the age of 18, who experienced the death of a parent during their adolescent years (between the ages of 12 and 18) due to a terminal illness from natural causes. The interview will take approximately 60-90 minutes.

The focus of the interview is your experience of how being involved in the hospital setting, (i.e. talking to nurses, doctors, other health care providers to understand the diagnosis of your parent) has helped or hindered your grieving process. We are committed to protecting your confidentiality and to create an interview environment that is safe for all involved.

Your experience is a valuable resource to new as well as experienced therapists who seek to better treatment models for adults impacted by the death of parent during their adolescent years. Thank you for your consideration.

TO PARTICIPATE:
Please contact Vaida Kazlauskaite via phone or email
(301) 667-0623
Kazlausk@unlv.nevada.edu.

Questions regarding this study may be addressed to Dr. Stephen Fife at stephen.fife@unlv.edu or Vaida Kazlauskaite at Kazlausk@unlv.nevada.edu

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project with radiation oncology. *Families, Systems, & Health*, *17*(4), 427-436.

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<div align="center">**Curriculum Vitae**</div>

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<div align="center">**Home and Work Addresses**</div>

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<div align="center">**Education**</div>

Master of Science Degree - Anticipated Graduation is December 2015
University of Nevada, Las Vegas
Marriage and Family Therapy Program
https://www.unlv.edu/mft

Master of Science Degree Thesis – Anticipated completion in December 2015
"Experiencing Parental Loss during Adolescence and Factors Influencing Hospital Involvement and the Grieving Process." This thesis is comprised of a phenomenological study using a Grounded Theory protocol with six participants.

Bachelor of Science Degree - May 2013
Towson University
Major: Psychology
http://www.towson.edu/psychology/

<div align="center">**Research Experience**</div>

Thesis Research: Marriage and Family Therapy Program, University of Nevada, Las Vegas, April 2014 – December 2015. Title: Experiencing Parental Loss during Adolescence and Factors Influencing Hospital Involvement and the Grieving Process.
- Thesis comprised of phenomenological methodology using a Grounded Theory protocol with six participants.

<div align="center">**Academic and Professional Positions**</div>

Graduate Assistant - January 2015 to Present
The Lincy Institute; UNLV Mental and Behavioral Health Coalition
http://www.unlv.edu/lincyinstitute/
Supervisor: Sara Hunt, Ph.D.
Duties include:

Graduate assistant position and all duties performed were under the Community Mental Health Block Grant received by the Nevada Division of Public and Behavioral Health:

- Assisted with planning professional workshops
- Reviewed research literature for grant proposals and projects, course planning, and community collaborations
- Assisted in developing graduate-level Integrated Health Care Course; served as Teaching Assistant
- Assisted with grant project data collection via online and face-to-face surveys
- Created SPSS data files, coding and entering variable data
- Recorded meeting minutes and drafted memos
- Assisted with HRSA Social Work Student orientation

Grant Awarded to The Lincy Institute:

Substance Abuse and Mental Health Services Administration (SAMSHA) – Screening, Brief Intervention, and Referral to Treatment (SBIRT) Student Training Project. Awarded September 2015. An evidence-based practice used to identify, reduce, and prevent problematic use, abuse, and dependence on alcohol and illicit drugs. The SBIRT model was incited by an Institute of Medicine recommendation that called for community-based screening for health risk behaviors, including substance use.

Project Director and Coordinator – Ramona Denby-Brinson, Ph.D. and Sara Hunt, Ph.D.
Duties included:

- Outlining grant
- Literature review
- Proof reading

Practicum Student - May 2014 through May 2015
UNLV Center for Individual, Couple and Family Counseling
https://www.unlv.edu/cicfc
Supervisors: Katherine Hertlein, Ph.D., Stephen Fife, Ph.D., Colleen Peterson, Ph.D.
Duties included:

- Providing high quality, low cost therapy to children and adults in Southern Nevada
- Utilization of an eclectic selection of therapeutic modalities to meet the needs of clients
- Providing information and referral to collateral agencies and organizations

Psychosocial Rehabilitation Provider - August 2013 through December 2014
Shining Star Community Services
http://www.shiningstarlv.com/
Supervisor: Diana Wade
Duties included:

- Working one-on-one with individuals to provide rehabilitative interventions that target specific behaviors in clients age 3 and above
- Providing behavioral management and psychosocial counseling services
- Teaching interpersonal skills, and conflict resolution and anger management skills
- Intervening with schools and social services systems on behalf of clients
- Providing self-management, parenting, and family training counseling

- Providing community transition and integration assistance

Publications

Hubble, M., **Kazlauskaite, V**., Taylor, S., Sheffield, E.S. (2013). "Preschoolers in Pairs: Working Together Increases Memory for Problem Solving." Poster session presented at the meeting of the Association for Psychological Science, Washington, D.C.

Professional Trainings/Memberships/Affiliations

American Association of Marriage and Family Therapy Conference, attendee in October 2014
American Association of Marriage and Family Therapy, member since May 2013
Delta Kappa Zeta, Marriage and Family Therapy Honor Society, member since May 2014
Delta Kappa Zeta, Marriage and Family Therapy Honor Society, Treasurer since October 2014

References

Available Upon Request