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LOMA LINDA UNIVERSITY
School of Behavior Health
in conjunction with the
Faculty of Graduate Studies

Resilience and Complicated Grief

by

Les Bishop

A Dissertation submitted in partial satisfaction of
the requirements for the degree
Doctor of Philosophy in Marriage and Family Therapy

June 2018

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Each person whose signature appears below certifies that this dissertation, in his/her opinion is adequate, in scope and quality, as a dissertation for the degree Doctor of Philosophy.

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ABBREVIATIONS

DSM5	Diagnostic and Statistical Manual 5 th edition.
CG	Complicated Grief
RESM	Resilience Ecological Stress Model
NHPCO	National Hospice and Palliative Care Organization
ICG	Inventory of Complicated Grief
PTSD	Post-Traumatic Stress Disorder
EEA	Engineering Ecological Adaptive Framework
IFCR	Individual, Family, Community Resilience Profile
BCM	Brief Cope Measure

ABSTRACT OF THE DISSERTATION

Resilience and Complicated Grief

by

Les Bishop

Doctor of Philosophy, Graduate Program in Marriage and Family Therapy
Loma Linda University, June 2018
Dr. Brian Distelberg, Chairperson

This study surveyed 155 family members or caregivers of patients who had died between twelve and thirty months prior to this study. These patients had been on hospice at the time of their death. The purpose of the study was to assess the prevalence of hospice defined risk factors for complicated grief. Medical records provided patient demographics information and a verbal (telephone) survey was used to measure the following risk factors: lack of social support, lack of expression of faith, lack of adequate coping skills, multiple losses, substance use, and relationship to the person who died. Descriptive statistics were used to assess the prevalence of risk factors and linear regression was used to evaluate the potential of risk factors to predict complicated grief. Results indicated that coping skills were a highly significant predictor of complicated grief. To a lesser extent, the gender of the patient was also a significant predictor of complicated grief. Pragmatic, clinical and theoretical implications of these results are discussed.

CHAPTER ONE

INTRODUCTION

Grief is universal. It is a common occurrence, a normal part of the human experience. It is not unusual for people to struggle while grieving, and the pain of grief can sometimes seem overwhelming. It is not unusual for people to be depressed and find re-entry into life rather difficult at the loss of a loved one (Simon, 2013). This is normal acute grief. Most people find that, ultimately, these painful feelings subside and they are able to resume their lives (mayoclinic.org., 2017). When these feelings fail to subside, complicated grief is determined (mayoclinic.org., 2017). Therefore, the symptoms for normal acute grief and complicated grief are the same. The distinguishing factor is the length of time that symptoms persist. If these symptoms continue for a year or more, complicated grief is diagnosed (American Psychiatric Association, 2013). Complicated grief is emotionally and mentally debilitating. The presence of complicated grief increases the possibility for suicide. (Baker, et al. 2009). The personal pain, and individual loss suffered by the grieving individual is multiplied by the cost in productivity to the community, and financial cost to society.

Hospice is an organization designed for those who are experiencing an incurable disease and who have been determined by a physician to have six months or less to live (Bonebrake, et al., 2010). Hospices focus on end of life, with the goal of making it less painful, physically for the patient, and emotionally for both the patient and the patient's family.

Hospices work specifically and exclusively with the dying, and the bereaved. Hospice professionals acknowledge that complicated grief cannot be diagnosed at the

time of a person's death. It can only be determined over time. They do, however, look for risk factors, which are considered predictors of the potential for complicated grief (Vitas Healthcare, 2012). The purpose of this study is to test these risk factors in order to determine the potential for complicated grief in hospice patient families. Understanding risk factors and their place in predicting complicated grief will enhance the work of hospice professionals and grief therapists. To understand the risks for complicated grief and to know how to avoid it will have the dual benefit of helping both the grieving individual and society.

Background

Hospice is designed for those who are experiencing an incurable disease and who have been determined by a physician to possibly have six months or less to live (Bonebrake, et al. 2010). Hospice is an organization dedicated to assisting people who have been diagnosed with a terminal illness to receive care and comfort for the last six months of their lives (Izumi, et al., 2012).

Hospice is sanctioned, governed and financed by Medicare and is therefore obligated to follow specific guidelines in offering care to its constituency (Connor, 2007; Buck, 2009). Because working with end of life issues includes working with the patient's family, Medicare requires that the hospice team address bereavement issues. Chaplains and social workers are trained in recognizing symptoms of complicated grief and are required to address these symptoms. Working in a hospice environment requires working with grief. This study is undertaken in the context of hospice, studying those who have experienced the grief that losing a primary relationship brings.

Although grief is a common and universal life experience, successfully navigated by the majority of the population (Jordan & Litz, 2014; www.Vitas.com), occasionally it becomes a complex experience with ongoing symptomology that significantly impedes the bereaved person's physical and/or emotional health (Mancini & Bonanno, 2012). This is referred to as complicated grief or prolonged grief disorder and affects from seven percent of the population (Simon, 2013) to as high as 20% of the population (Bonanno, et al., 2005). The DSM5 refers to complicated grief as persistent complex bereavement disorder, diagnosed if the bereaved individual continues to experience life inhibiting symptoms of grief after twelve months following the death of a loved one, or six months following the death of a loved one for children (American Psychiatric Association, 2013).

Hospice bereavement professionals look for risk factors in anticipating the possibility of complicated grief. Among these risk factors are: 1) inadequate spiritual health evidenced by the lack of an expression of faith; 2) the lack of a good support system; 3) inadequate emotional health, evidenced by inadequate individual coping skills; and 4) multiple losses in the past five years, 5) financial issues, 6) substance abuse, and 7) relationship with the person who died. (Vitas Healthcare, 2012).

A good support system can consist of family members, friends, work or school associates and/or others. An expression of faith (varying religions and faith expressions), helps many people cope with the death of a loved one and is indicative of the spiritual health of the individual. The quality of personal coping skills will influence how well a person is able to recover from the loss and is indicative of the emotional health of the individual. Recent prior losses increase emotional strain and therefore increase the possibility of risk for complicated grief, especially if these losses are unresolved.

Financial issues and substance abuse issues are stressors to healthy family functioning, and therefore are risk factors for complicated grief. The relationship of the caregiver with the person who died may affect the grieving process. If warranted by risk factors present at the time of the patient's death, hospice will follow the family closely and, if necessary, intervene (through regular visits, referral to grief therapists and other grief professionals, and being personally available to grieving family members) in order to help the family through the bereavement process. This study will predict the prevalence of these risk factors, thus allowing hospice workers and others involved in the bereavement process to be aware of the need for potential interventions.

Historically, grief has been viewed from a pathological perspective (Hedtke, 2010). In the mid-1940's, it was even suggested that grief be dealt with only by qualified grief professionals, those with sufficient psychiatric training (Granek, 2010). Traditional sources for comfort for the grieving, including clergy were discredited and determined to be insufficiently trained and therefore incapable of offering adequate support. Their role was relegated to guiding the grieving toward seeking professional psychiatric treatment (Granek, 2010). These psychiatrically trained, certified grief professionals were to monitor the grief experience, in order to determine whether the grieving individual was grieving too much, or possibly too little. Either extreme was seen as potentially leading to psychosis (Granek, 2010).

Although the last seventy years has seen a relaxing of the drive toward treating grief exclusively as a potential psychiatric condition, the power of the medical model has prevailed. Grief continues to be viewed as something to be cured, so that those who are grieving can get back into normalcy as soon as possible (Granek, 2010). This desire for a

return to normalcy is seen in the way society deals with grief. People often make statements to their bereaved associates in an attempt to lessen the grief (Fuerst, 2014), which do not take into consideration the grieving process. Grieving is seen to be abnormal, and too much grieving is considered to be pathological. Integral to this study is the assumption that normal acute grief is not pathological. Grief is part of life, and therefore cannot be avoided. It is not the intention of this study to cure normal acute grief, but rather to identify the potential for complicated grief.

Complicated grief cannot be determined by an analysis of present symptoms. The immediate symptoms of complicated grief and normal acute grief are the same (American Psychiatric Association, 2013). Complicated grief is determined after a year of continuing symptomology (American Psychiatric Association). Therefore, the only way to predict the potential for complicated grief is in the identification of specific risk factors. It is the intention of this study to test the risk factors determined by hospice to predict complicated grief, and to determine which of these risk factors are more prevalent in those ultimately determined to be experiencing complicated grief.

Objectives

This study will evaluate the prevalence and presence of risk factors for complicated grief in families who have recently received hospice services. The importance of these risk factors in relationship to complicated grief is theoretically relevant. However, to date insufficient empirical evidence has been provided to support these theoretical assumptions. If there is no connection between these risk factors and complicated grief, then hospice professionals need to turn their attention elsewhere. If

specific risk factors are better predictors of complicated grief than other risk factors, then hospice professionals are to give these areas greater attention.

Resilience studies have determined that certain factors are evident in managing traumatic life events (Carver, 1997; Distelberg, et al., 2015), and therefore may be beneficial in buffering the negative effects of these factors in the grieving process. There are several measures in place, which have been developed to measure resilience. This study will use two of these measures.

The objective of this study is to measure the existence of these risk factors in hospice recipients as well as to assess how and if these factors predict complicated grief. The purpose of this study is to help hospice providers and grief therapists to identify early risk and protective factors. These risk and protective factors can be assessed and addressed while the patient and family are receiving hospice services thereby reducing the risk of complicated grief after the family leaves hospice. This finding will benefit hospice professionals by allowing them to prepare for complicated grief in their clientele, and create interventions to address this potential experience.

Rationale

There has been a lot written about grief. Theories concerning the cause and treatment of grief have been debated and have undergone serious change in the past century. Grief has been seen as a pathology (Hedtke, 2010; Granek, 2010), to be monitored and treated by qualified professionals (Granek, 2010). It has also been seen as a normal response to normal environmental happenings (Granek, 2010), requiring no treatment whatsoever (Mancini, et al., 2015).

The universality of the grieving experience coupled with the pain to the individual, the loss to the community and the cost to society that is accompanied with complicated grief, makes this study relevant and therefore significant to the profession of couple and family therapy.

It is not possible to determine the potential for complicated grief based on the initial behaviors, emotions, and responses of the grieving individual at the time of the loss (American Psychiatric Association, 2013). The emotional responses and behaviors considered normal at the time of loss may be the same emotions and behaviors a person will experience in complicated grief. The difference is not in what the behaviors and emotional responses are, the difference is how long those behaviors continue to manifest (American Psychiatric Association, 2013). For example, outward manifestations of emotion (e.g. crying, screaming, etc.), or inward manifestations of grief emotion (e.g. depression, yearning, despair) are very normal at the beginning of the grieving experience. They are symptoms of complicated grief only if they continue to exist in a way that inhibits normal life functioning for longer than a year. Therefore, grief therapists and hospice professionals are called upon to find ways of determining the potential for complicated grief in order to give relief to their clientele before complicated grief is officially determined, and to possibly prevent its occurrence.

CHAPTER TWO

CONCEPTUAL FRAMEWORK

Complicated grief is experienced when someone is unable to adequately navigate the grieving process effectively after the loss of a loved one resulting in an inability to efficiently function (Mancini, et al., 2015). The goal of this study is to understand ways in which complicated grief can be avoided.

Hospice organizations focus on end of life issues and bereavement. One of the tasks of hospice is to recognize the potential for complicated grief in families of patients who have died. Hospice has identified seven risk/protective factors, which they consider predictors of the potential for complicated grief. These seven factors (viewed as risk) are: poor spiritual health evidenced, lack of an adequate support system, multiple previous loss, poor emotional health evidenced, substance abuse, financial issues, and the relationship with person who died (Vitas, 2015). This study will examine these risk factors in the context of resilience theory. This chapter is about resilience theory and complicated grief.

This chapter will define both resilience and complicated grief. Several resilience theories will be discussed. The specific resilience theory to be used in approaching the problem of complicated grief in this study will be described and the application of this theoretical framework to the problem of complicated grief will be reviewed.

Complicated Grief

Complicated grief has been referred to as prolonged grief disorder. In the current version of the DSM (5), it is referred to as persistent complex bereavement disorder

(American Psychiatric Association, 2013). The terms used vary, but the experience is still the same. Complicated grief, (or prolonged grief disorder or persistent complex bereavement disorder) is the experience of yearning and emotional pain because of the loss of a loved one through death that continues for more than a year in adults, six months in small children (American Psychiatric Association, 2013), and inhibits functioning (Mancini, et al., 2015). In this study, this experience will be referred to as complicated grief. The current version of the DSM (5) differentiates between normal acute grief and complicated grief. It refers to the former as uncomplicated grief, describes it as a normal response to loss. The latter is considered abnormal and potentially a pathology (American Psychiatric Association, 2013).

Traditional grief scholarship has been dominated by theories that emphasize “letting go” of the relationship with the one who has died (Hedtke, 2010), and building new relationships with others. The focus is always on the individual who is grieving. The person who has died is considered no longer present, and the bereaved are counseled to acknowledge this “non-presence” (Hedtke, 2010). The conceptual framework or theoretical structure for this study rejects the need for letting go of the relationship and emphasizes the reality of the continuing relationship. Grieving the loss of a loved one is seen from a systemic perspective, in which the person who died continues to be joined spiritually to those grieving the loss, and therefore continues to be part of the system through remembrances, and stories about them that continue to be passed on (Walsh & McGoldrick, 2004).

Traditional grief studies have viewed grief as a pathology (Hedtke, 2010; Granek, 2010) as opposed to a natural and appropriate response to death (Granek, 2017). Grief has

been considered a disease, and the manifestations of that disease have been referred to as “symptoms” (Simon, et al., 2011). This tendency toward pathologizing grief, in traditional mental health studies, stems from a methodology focused on the individual (Granek, 2017), as opposed to an acknowledgment of the systemic. This study assumes that symptoms of grief are not pathological symptoms to be cured, but normal occurrences within the life of the bereaved. The focus is not on healing the illness, but rather on finding meaning in the experience. Inherent in the resilience models utilized in this theoretical framework is the focus on finding meaning (Walsh, 2016, 2012; Henry, et al., 2015; Walsh & McGoldrick, 2004). Therefore, rather than pronounce symptoms and experiences of the bereaved individual as generically and universally somatic, fantasy or pathology, this study views such experiences within the context of their environment, thus honoring the experience of the individual, and acknowledging reality of the continuing relationship.

Definitions of Resilience

Resilience studies have gained momentum over the past few decades, and have been the focus of a myriad of both conceptual and research studies (Henry, et al., 2015). Multiple disciplines, including Social Work, Family Therapy, and Psychology have embraced models of resilience (McCleary & Figley, 2017). Specific resilience studies have evolved which address various populations in our society including the military, police, adolescents, sports (Fletcher & Sarker, 2013), children, Native Americans and others (McCleary & Figley, 2017).

Resilience is the ability to bounce back from adverse experiences (Buzzanell, 2010). The majority of the population possesses sufficient resilience to avoid complicated grief (Mancini, et al. 2015). To this end, about 45% to 60% of the population (Mancini, et al. 2015), will adjust to a loss adequately without any outside intervention. About 15% to 25% of the population will take longer to adjust, and may need minimal outside intervention, but will “bounce back” within about a year (Mancini, et al., 2015). A much smaller percentage of the population, about 10% to 15% (Mancini, et al., 2015) will fail to adjust, and will continue to experience the debilitating and painful feelings of yearning and emptiness that inhibit effective or even adequate functioning (Mancini, et al., 2015). It is this group that suffers from complicated grief (Mancini, et al., 2015). An assumption of this study is that adequate resilience prevents complicated grief.

Resilience stems from the Latin word “resiliens”, which originated between 1620 and 1630, which means to “spring back or rebound” (Dictionary.com Unabridged. Website: www.dictionary.com, 2018). Resilience is the capacity or capability of the original form of something to be restored after being flattened, bent, or expanded; there is a sense of pliability or flexibility (Dictionary.com Unabridged. Website: www.dictionary.com, 2018) in the dictionary definition of the term. In science, resilience has to do with a stretched or twisted mass regaining its appearance and shape after being distorted (Fletcher & Starker, 2013). Human resilience, then is the capacity to “bounce back” or re-assimilate back into life following challenging life events (Buzzanell, 2010).

Resilience has been defined as the capacity of an individual, family or community to adapt after experiencing hardships and adverse life events (Walsh, 2016; Ungar, 2015; Distelberg, et al. 2015). George Bonanno (Southwick, et al., 2014) defines resilience as

“a stable trajectory of healthy functioning after a highly adverse event” (p. 3). Grafton and Gillespie (2010) see a universal characteristic in resilience suggesting that there is a form of resilience in everyone to a greater or lesser extent, the effects of resilience being to cope with, recover from and grow because of hard times (Grafton & Gillespie, 2010). Froma Walsh (2003) defines resilience as “strengths forged through adversity” (p. 1) and suggests that resilience be viewed through a strengths based perspective (Walsh, 2003). Resilience has been likened to regulation (McPhee, et al., 2015), in that regulatory processes are activated in order to establish stability when families face hardships or significant life changes (McPhee, et al., 2015).

What all of these definitions have in common is that adversity is coupled with adaptation. Most contemporary definitions of resilience rely on the experience of adversity followed by the resulting positive adaptation (Fletcher & Sarkar, 2013).

In most of these examples, adversity is seen in a negative sense, as a trauma or tragedy, and resilience is the capacity to bounce back after experiencing such a hardship. However, positive or even desirable life changing events (e.g. marriage, change of employment, significant move, etc.) also require an element of resilience in order to produce positive adaptation (Fletcher & Sarkar, 2013). Resilience, then can be defined as any difficult experience, whether a positive, exciting life changing event, or a traumatic, adverse, undesirable happening in which a person, family or community is able to successfully adapt (Fletcher & Sarkar, 2013). Successful adaptation ultimately results in healthy functioning (Mancini, et al., 2015) and potentially, personal growth (Grafton & Gillespie, 2010).

Resilience Theories

Several resilience theoretical frameworks based on these definitions have been developed and continue to be used in resilience studies. These theories help to understand the place and power of resilience in navigating and successfully recovering from difficult life experiences. The following is an overview of a few of these theoretical perspectives.

Initially, resilience was viewed in terms of resilience traits, inner characteristics that empowered individuals to recover and refocus (Distelberg, et al., 2015) and to adapt to hardships in order to function (Masten, 2016). Those who enjoyed trait resilience were able to adapt to difficult or traumatic events. Those who did not have trait resilience were not able to adapt. Theories were developed that viewed and defined resilience from the individual trait resilience perspective.

The Risk and Resilience Approach

The Risk and Resilience Approach focuses on trait resilience. This framework came into being in the late 1970's (Anthony, et al. 2009), and further developed in the middle of the 1980's (Jenson, 2007). This theoretical perspective was developed in the context of elementary school children. Basic to this model is the notion that problem behaviors in children can be mitigated by specific social interventions directed toward these problem behaviors (Jenson, 2007). There are three aspects to this theory. The first is the identification of risk factors. Risks are defined as things that happen, or are experienced in a child's life. These risks increase the likelihood of problem behaviors being intensified (Anthony, et al., 2009). The second aspect of this theory is the belief that these risk factors are mitigated by protective factors which are either in the child

(trait resilience) or in the environment (resources) that decrease the effectiveness of these risk factors (Anthony, et al., 2009). The third aspect of this framework is the child's capacity (trait resilience) to successfully adapt during incidents of difficulty and risk (Anthony, et al., 2009); success is defined as avoiding undesirable behaviors (Anthony, et al., 2009). According to this model, risks are identified, then factors are put in place to counter these risks (Bryan, 2003). The objective of this model is to identify traits in children who exemplify resilience, and then work to create those same traits in others who do not (Bryan, 2003). The goal is to create or enhance trait resilience.

The Engineering, Ecological, Adaptive Framework

Another theoretical framework based on the notion of trait resilience is the Engineering, Ecological, Adaptive (EEA) framework (Maltby, et al., 2015). This framework assumes three realms of trait resilience: engineering, ecological, and adaptive (Maltby, et al., 2015). Engineering is resilience in terms of regaining equilibrium following an individual or systemic disruption (Maltby, et al., 2015); ecological is resilience in terms of a system's capacity to withstand and maintain in the presence of distress, thus preserving stability with regard to function and purpose (Maltby, et al., 2015); and adaptive is resilience in terms of the system's capacity to cope with and adjust to change (Maltby, et al., 2015). These three factors interact to produce trait resilience.

Although the development of trait resilience in children and adults continues to be regarded as desirable, trait resilience is no longer the sole focus of resilience studies. Resilience theories have evolved from a focus on individual trait resilience to viewing resilience terms of outcome, to the current view in resilience literature that resilience is a

process (McLeary & Figley, 2017; Fletcher & Sarker, 2013).

The advent of family systems thinking influenced resilience theory (Walsh, 2012). The focus changed from static individual resilience factors, to an emphasis on dynamic adaptive processes (Masten, 2016). As systems thinking became incorporated into resilience thinking, it became obvious that trait resilience is not the only factor to be considered in determining resilience. Rather, an individual's capacity for resilience is impacted by both the family and the community (Taylor & Distelberg, 2016; Ungar, 2015).

The Socioecological Model of Family Resilience Determinants

This model considers the systemic perspective in determining factors that produce resilience. According to this theory, resilience is multidimensional and socioecological (Taylor & Distelberg, 2016). Resilience as multidimensional suggests that there are several factors that work together to determine individual resilience as opposed to simply the presence and development of individual resilience traits. Resilience as a socioecological construct suggests that there are levels of influence beyond the individual, including family, environment, community, etc. that impact an individual's capacity to bounce back from adverse or difficult situations (Taylor & Distelberg, 2016). Higher levels of socioecological influence have an effect on lower levels of socioecological influence (Taylor & Distelberg, 2016; Ungar, 2016). This means that the environment affects the community, which has an effect on the family, which affects the individual with regard to the capacity for resilience. The community can be a resource for the family, and the family can be a resource for the individual; public policy, and

community circumstances can create (or alleviate) family pressure, thus influencing family process, which will have a bearing on individual capacity for resilience (Taylor and Distelberg, 2016; Walsh, 2016). According to this theoretical perspective, the capacity for resilience is not simply based on individual trait resilience. It is a product of systemic influence, which suggests that it is not simply the individual that be the focus (i.e.: creating trait resilience), but rather the system (i.e.: the family, community and environment) that be considered in the creation and maintaining of resilience.

The Resilience Ecological Stress Model (RESM)

This model utilizes the same ecological and systemic foundation (Greene, 2014), as the Socioecological Model of Family Resilience Determinants. The RESM uses an ecological systems outlook, often referred to as the “person-environment” perspective to explain how resilience is achieved and maintained (Greene, 2014). It considers the environment as well as the individual in determining how resilience manifests (Greene, 2014); and this includes consideration of the multiple systems which influence people’s lives (Greene, 2014). This approach assumes an ecological outlook that considers the individual and the environment as a system in which each has an influence on the other. People interact with the environment reciprocally; a “goodness of fit” between the individual and the environment determines how nurturing the environment is for the individual and therefore impacts the potential for resilience (Greene, 2014). This theoretical framework considers resilience from an eco-systemic perspective, and suggests that resilience is not found in the focus on individual resilience traits, but rather

multilevel and multidimensional systems contribute to the development of resilience (Greene, 2014).

The Resilience Framework for Complicated Grief

The conceptual framework for this current study acknowledges the need to view resilience from a systemic perspective and to incorporate ecological factors into that understanding. This study will utilize a Family Resilience Model as the theoretical framework and will draw from Key Family Processes in Resilience (Walsh, 2016), and Family Resilience: Moving into the Third Wave (Henry, et al., 2015) in order to conceptualize this framework. A Family Resilience Model is one in which resilience is viewed from a family systems perspective, acknowledging the influence of ecological factors on the system as well as identifying individual characteristics which are produced by the system and also help to create the system.

The Family Resilience Model (Walsh)

The Family Resilience Model, (Walsh, 2016) views resilience from a systemic perspective in order to create a relational view of resilience (Walsh, 2016). The Family Resilience Model acknowledges the presence of ecological factors in the development of resilience (Walsh, 2012). With the family are other social structures, including school, peers, work and community which enhance and reinforce resilience (Walsh, 2012); there are multidimensional factors that exist which put the family in a peculiar and complicated position, and these multidimensional factors are considered in the creation of a family resilience theoretical framework (Walsh, 2012).

This Family Resilience Model developed by Walsh acknowledges the existence of ecological pressures which confront families; resilience is created as families interact with these pressures (Martin, 2011). Walsh insists that these pressures have the capacity to make families stronger (Martin, 2011). Walsh believes that unrelenting difficulties, catastrophic happenings, and unsettling changes empower families, making them stronger, more resourceful, better able to fully love and be more competent in family life (Walsh, 2012). The Family Resilience Model does not define resilience as an individual trait, nor is it desirable to strive for individual hardiness exclusively. Rather, resilience is cultivated in relationships (Walsh, 2016). There is strength in collaboration, such that mutual support is key to conquering life's adversities (Walsh, 2016).

The Family Resilience Model has identified three specific key family processes as strengthening the potential for family resilience: 1) shared belief systems, 2) family organizational processes and 3) effective family communication (Walsh, 2016). Each of these family processes work to strengthen families and their capacity to withstand hardships and move successfully toward effective family functioning.

Shared Belief Systems

Belief systems are basic to family or individual resilience (Walsh, 2016). There are three aspects of belief systems identified by this theoretical perspective. The first is making meaning, which views resilience from a relational perspective (Walsh, 2016), acknowledging the presence of loyalty, mutual reliability, and dependability in the family system (Walsh, 2016). Meaning making includes normalization of the crisis, viewing it as manageable (Walsh, 2016).

The second is seeing life through a positive lens, which includes the presence of hope, mutual encouragement and the acknowledging of strengths (Walsh, 2016). It is not the present difficulties that are to be the focus. It is the confirmation of present strengths that are to be at the center of a family's consciousness.

Third, belief systems acknowledge spirituality and transcendence (Walsh, 2016). There is the ever present awareness that there is something beyond who we are (Walsh, 2016). Spirituality includes purpose, values, and the potential for personal growth (Walsh, 2016). It also includes faith, contemplation and connection with nature (Walsh, 2016).

Family Organizational Processes

Organizational processes are the relational and structural supports to resilience (Walsh, 2016). This theoretical perspective has identified three aspects of family organizational processes. The first is flexibility. This includes the ability to rebound and reorganize. The ability to rebound allows a family to adapt to meet new and inevitable challenges (Walsh, 2016). The ability to reorganize creates the potential in a family for maintaining steadfastness and constancy (Walsh, 2016).

The second is connectedness. This includes mutual advocacy, mutual allegiance and working together in a context in which the work of the other is viewed with respect (Walsh, 2016). Connectedness allows for differences which are not only accepted but honored. When there is disconnect, the system works to reconnect (Walsh, 2016).

The third is the mobilization of social and economic resources, which includes tapping in to social, community and structural supports as opposed to being steadfastly

individualistic; creating economic well-being; and successfully interacting with greater systems (Walsh, 2016).

Effective Family Communication

Reliable communication enables every part of a family's capacity to effectively function and be resilient (Walsh, 2016). This theoretical perspective identifies three aspects of effective family communication. The first is clarity, which includes both the sending of messages that are easily understood, and seeking to clarify in messages that are not easily understood. Clarity is seen in both what is said and what is done (Walsh, 2016).

The second is open emotional expression, which includes the expression of both pleasant and uncomfortable emotions; good feelings and hurtful feelings (Walsh, 2016). It is important in open emotional expression for individuals to own their own feelings and to respect the feelings of others (Walsh, 2016).

The third is collaborative problem solving, which includes the practice of sharing ideas; working together to brainstorm and find resources (Walsh, 2016); making decisions together and exchanging relational reactivity for relational proactivity (Walsh, 2016); working toward goals, accepting and learning from obstacles; planning and preparing while moving toward the future (Walsh, 2016).

The Family Resilience Model proposed by Walsh is systemic, acknowledges the socio-ecological, and recognizes that resilience is made up of multidimensional factors.

The Family Resilience Model, Third Wave (Henry, et al.)

This perspective, developed by Henry, et al. (2015) suggests that family resilience thinking has progressed through two waves of theoretical thinking and stands ready to move into the third wave (Henry, 2015). According to this perspective, during the first wave of family resilience scholarship, family resilience was seen as a family characteristic (Henry, et al., 2015). Some families are resilient, and others are not, in much the same way that trait resilience views some individuals as having resilience as personality trait, while others do not. The first wave of focused on a family's capacity to adjust to hardships and the assets that empowered them accordingly, within the frameworks of which these families are a part (Henry, et al., 2015).

Second Wave

The second wave moved forward with an emphasis on conceptualization, scholarly exploration, and how to apply these results to families (Henry, et al., 2015). The second wave did not do away with the idea of families possessing resilience as a trait; rather, it incorporated the notion of “process” into the mix (Henry, et al., 2015). The authors of this particular perspective would view the Family Resilience Model described by Walsh as part of this second wave. There are obvious conceptual advances inherent in the Walsh Family Resilience Model. Conceptual advances are a characteristic of the second wave (Henry, et al., 2015).

The second wave includes an emphasis on the wider ecological system (Henry, et al., 2015). The Family Resilience Model presented by Walsh acknowledges an ecological perspective (Walsh, 2012), taking a biopsychosocial systems orientation, acknowledging

the “interaction of life experiences, social contexts, genetic and neurobiological predispositions...” (p. 402). These are influenced by sociocultural assets and hindrances (Walsh, 2012).

The second wave emphasized protective factors and processes. Protection consisted of a family’s abilities and capabilities that would empower a family to face an entire range of difficulties from daily stresses to considerable threat (Henry, et al., 2015). The second wave also addressed specific risks which included both vertical (continuing) and horizontal (single event) family stresses (Henry, et al., 2015).

Third Wave

Family resilience studies are moving into the third wave according to the authors of this theoretical framework. Third wave theorists continue to be systemic and to acknowledge presence and importance of the wider ecological system. The Family Resilience Model they propose consists first of intensifying four basic elements which were found of the second wave: risk (a crisis which threatens family homeostasis), protection (which assists families in the restoration of stabilization following the crisis, and which may guard against risks to equilibrium in the future), vulnerability (which increases the possibility of increased risks or multiple risks) and adaptation (adjustment happens in the immediate future, being able to adapt happens in the long term), and adding to this the interaction of Family Adaptive Systems (Henry, et al., 2015).

According to the authors of this perspective, second wave resilience theorists and practitioners, looking for ways to protect families from risk, overlooked an important distinction: the distinction between promotive (enhancing proficiency when there are not

any risk factors present) and protective (enhancing proficiencies in the presence of considerable risk factors) processes in the family (Henry, et al., 2015). The third wave is looking toward further research into these distinctions.

Third wave theorists also mention cascades and trajectories, present in individual resilience studies for a long time, but not as well developed in family resilience studies (Henry, et al., 2015). Trajectories are routes through life development that include or lead to adaptation; cascades refer to risk as well as adaptation and depict the course of risk, protection and adaptation processes (Henry, et al., 2015).

Family Adaptive Systems

Family Adaptive Systems are a major focus of the Family Resilience Framework defined and described by the third wave authors. Family Adaptive Systems stem from family exchanges from within the larger ecosystem, and become part of everyday family life, in which stressors are faced and conquered (Henry, et al., 2015). Family Adaptive Systems work to produce healthy family functioning (Henry, et al., 2015), are based on a systemic perspective, and are viewed as relational patterns in the family system as opposed to the total sum of interactions of various family members (Henry, et al., 2015). Family Adaptive Systems operate on a continuum, in which positive adaptation is at one end, and negative adaptation is at the other end (Henry, et al., 2015), the family functions accordingly along this continuum. At least four systems are considered basic Family Adaptive Systems: emotion, control, meaning and maintenance systems.

Emotional adaptive systems have to do with emotional control, reactivity, emotional cycles, triangulation and scapegoating (Henry, et al., 2015). A major focus of

this adaptive system is the regulation of emotions (Henry, et al., 2015). Inappropriate expression of emotion can become an adversity, something which requires resilience to withstand (Henry, et al., 2015).

Control adaptive systems have to do with power, structure and decision making. (Henry, et al., 2015). In a family system in which control systems are not functioning, there is chaos or inappropriate rigidity (Henry, et al., 2015). Poor family control systems may impede the utilization of necessary family assets required for adequate resilience (Henry, et al., 2015).

Meaning adaptive systems are vital to resilience and are foundational to enhancing family resilience (Henry, et al., 2015). There are three levels of family meaning systems: family world views; family identity; and family perceptions of how hardships and resilience are to be navigated (Henry, et al., 2015).

Maintenance adaptive systems provide the capacity within the family to fulfill expectations and functions in society. Competence in this area empowers families to make appropriate changes when necessary in the presence of crisis in order to continue to function adequately (Henry, et al., 2015).

This study incorporates both the Family Resilience Model developed by Walsh and the Family Resilience Model developed by Henry, et al.

Table 1. The Family Resilience Model

Family Resilience Model (Walsh, 2016; 2012)

1. Belief systems
 - a. Meaning making
 - b. Encouraging perspective – hope
 - c. Over and beyond ourselves – spirituality
 2. Organizational processes
 - a. Flexibility
 - b. Connectedness
 - c. Extended family; social and financial means
 3. Communication processes
 - a. Well – defined information
 - b. Emotional input
 - c. Collaborative problem solving
-

Family Resilience Model (Henry, et al., 2015)

1. Four Basic elements
 - a. Risk (a crisis that threatens homeostasis)
 - b. Protection (restoration of stabilization, guard against future risks to equilibrium)
 - c. Vulnerability (which increases the possibility of increased risks or multiple risks)
 - d. Adaptation (adjustment: immediate future, adaptation: long term)
 2. Identification of Promotive and protective factors
 3. Family Adaptive Systems
 - a. Emotional: regulation of emotions
 - b. Control: power, structure and decision making
 - c. Meaning: world views; identity; perceptions of how hardships and resilience relate
 - d. Maintenance: expectations and functions in society
 4. Cascades and Trajectories
-

Application of Theoretical Framework

This study is about risk factors and complicated grief. There are seven risk/protective factors explicitly identified by Vitas Hospice (Vitas, 2012), which are used to determine the potential for complicated grief. Current hospice practice is that if any or all of these risk factors are present at the time of the patient's death, hospice will follow the family closely and, if necessary, intervene (through regular visits, referral to grief therapists, other grief professionals and support groups, and being personally available to grieving family members) in order to help the family through the bereavement process. This study will evaluate the prevalence of these risk factors, thus allowing hospice workers and others involved in the bereavement process to be aware of the need for potential interventions.

Risk factors and protective factors identified by hospice are the same, at opposite ends of a continuum. For example, hospice considers the lack of an expression of faith to be a risk factor. Therefore, to have an expression of faith is considered a protective factor. The lack of an adequate support system is considered a risk factor, having an adequate support system is a protective factor. To have poor coping skills is considered a risk factor, having good coping skills is a protective factor. To have experienced multiple previous losses is a risk factor, to have not experienced multiple previous losses is a protective factor. Having financial issues is a risk factor; not having financial issues is a protective factor. The type and quality of the relationship with the person who died is both a risk and protective factor. Substance abuse is a risk factor; no substance abuse is a protective factor. Hospice bereavement professionals look for these seven risk/protective factors in anticipating the potential for complicated grief (Vitas Healthcare, 2012).

A good support system can consist of family members, friends or others. Several studies have concluded that the negative effects of bereavement can be mitigated by the presence of an adequate support system (Valente, et al., 2002). This study looks at social support from three dimensions: family support (relatives), social support (friends and associates) and community support (people from the wider community).

An expression of faith (from varying religions and faith traditions) is indicative of spiritual health. Transcendence and spirituality are part of a belief system that creates hope and enables one to make meaning of the loss (Walsh, 2016). The belief in something beyond this life has given hope to many, and helps make meaning of the experience of loss.

The quality of personal coping skills will influence how well a person is able to recover from the loss and is indicative of the emotional health of the individual. Resilience traits have been acknowledged as buffers to loss (Anthony, et al., 2009), and Hospice professionals look for resilience traits, in the form of coping skills as protective factors for complicated grief.

Multiple recent losses are believed to increase the likelihood of a bereaved person to experience complicated grief (K. Kaufman & N. Kaufman, 2007). Recent losses (within the past five years), especially unresolved losses are believed by hospice professionals to increase vulnerability and therefore increase the risk for complicated grief (Vitas, 2012).

Use of substances has been shown to increase difficulties with emotional awareness and articulating and explaining emotions (Carton, et al., 2010). Hospice considers substance abuse a risk factor for complicated grief (Vitas, 2012).

Financial security and the use of resources to attain financial security is considered a significant process in maintaining family resilience (Walsh, 2016), and the lack of financial stability is considered by hospice to be a risk factor for complicated grief (Vitas, 2012).

The relationship a primary caregiver had with the person who died is considered in determining the potential for complicated grief (Vitas, 2012). This study does not address the quality of relationship a person had with the person who died. This study does address the type of relationship (spouse, daughter, etc.) of the person who died with the caregiver.

These risk/protective factors will be investigated in the context of resilience theory. The Family Resilience Model developed by Walsh (2016; 2012), together with the Family Resilience Model developed by Henry et al. (2015) form the theoretical framework for this study.

Four basic elements of the Family Resilience Model developed by Henry, et al.: risk, protection, vulnerability and adaptation apply directly to this study. Risk (to family equilibrium) is the loss by death of a loved one and the potential for complicated grief. Protection and vulnerability are the same factors, at opposite ends of a continuum. Protection (restoration of equilibrium) is the presence of protective factors. Vulnerability (which increases the potential for multiple risks) is the presence of risk factors. Adaptation is ultimately avoiding complicated grief.

Table 2. The Four Basic elements of the Family Resilience Model (Henry, et al.)

Risk
<ul style="list-style-type: none"> • Crisis: the loss of a loved one by death • Concern: complicated grief
Protection
Protective factors
<ul style="list-style-type: none"> • A good support system • An expression of faith • Coping skills • No recent unresolved loss • No Substance abuse • Financial health • Good relationship with the one who died
Vulnerability
Risk factors
<ul style="list-style-type: none"> • Inadequate support system • No expression of faith • Poor coping skills • Recent unresolved loss • Substance use • Financial issues • Poor relationship with the one who died
Adaptation
Adjustment: the process of adjusting to the person's death
Adaptation: ultimately avoiding of complicated grief

The Key Processes in Family Resilience (belief systems, organizational systems and communication processes) in the Family Resilience Model developed by Walsh

(2016; 2012) correspond to the Family Adaptive Systems (world view, perceptions of resilience, structure, emotions, etc.) in the Family Resilience Model developed by Henry, et al. (2015). And these theoretical frameworks broadly correspond with the risk/protective factors identified by hospice and examined in this study.

Table 3. The Family Resilience Model and Hospice Risk Factors

Family Resilience Model: Walsh	Family Resilience Model Henry, et al.	Hospice risk/protective factor
Belief systems		
<ul style="list-style-type: none"> • Meaning • Hope • Spirituality 	<ul style="list-style-type: none"> • Identity • Perceptions of Resilience • World Views 	<ul style="list-style-type: none"> • Social Support • Coping Skills • Expression of Faith • Resolving Previous Loss • Expression of Faith
Organizational processes		
<ul style="list-style-type: none"> • Flexibility • Connection • Resources 	<ul style="list-style-type: none"> • Structure • Function in Society • Maintenance 	<ul style="list-style-type: none"> • Family Support • Relationship with the one who died • Social Support • Financial Resources • Avoiding Substance Abuse
Communication processes		
<ul style="list-style-type: none"> • Information • Emotion • Collaboration 	<ul style="list-style-type: none"> • Decision Making (Control • Regulation of Emotions • Function in Society 	<ul style="list-style-type: none"> • Family Support • Coping Skills • Community Support

The focus of this study is on the risk/protective factors identified by hospice as predictors of complicated grief. This study is to be done in the context of resilience theory. The goal is to assist hospice professionals and other grief counselors to determine the potential for complicated grief.

Table 4. Hospice Risk Factor and the Family Resilience Model

Hospice Risk/Protective Factor	Family Resilience Model Walsh	Family Resilience Model Henry, et al.
Coping Skills	Meaning Emotion	Regulation of Emotion (Emotion) Identity (Meaning)
Family Support System	Flexibility Information	Structure (Control) Decision Making (Control)
Community Support System	Collaboration Connection	Function in Society (Maintenance) Emotion
Social Support System	Connection	Emotion Meaning
Expression of Faith	Hope Spirituality	Perception of Resilience (Meaning) World Views (Meaning)
Multiple Losses	Hope	Perceptions of Resilience (Meaning)
Substance Use	Resources	Maintenance
Financial Resources	Resources	Maintenance
Relationship with the one who died	Connectedness	Structure (Control)

Each of the risk/protective factors identified by hospice relates broadly to the Family Resilience Model developed by (Walsh, 2016; 2012) and to the Family Adaptation Systems, which is part of the Family Resilience Model developed by Henry, et al., (2015).

- Coping skills: Meaning making in Walsh (2016) is characterized by ways of dealing with trouble. A family's ability to regulate emotions (Henry, et al., 2015), describes a family's ability to cope.
- Family support system: Flexibility has to do with family structure (Walsh, 2016), and therefore, relates to the family support system. Structure and decision making are part of the family control system (Henry, et al., 2015), and relate to family support.
- Social Support: Connectedness is mutual support; meaning making is relational (Walsh, 2016); both relate to Social support. The emotion system (Henry, et al., 2015) includes interactions that enhance relatedness, and show support, encouragement and cooperation.
- Community support relates to collaboration and connectedness. Collaboration described by Walsh (2016) is shared decision making; connectedness is reciprocal advocacy and honoring of differences (Walsh, 2016).
- Expression of faith: Hope and spirituality (transcendence) as described by Walsh, both relate to an expression of faith. A world view (transcendence) and a perception of resilience (hope) are both subsections of meaning in the model developed by Henry, et al., and both have to do with spirituality.

- Multiple losses relate to hope (Walsh, 2016), and perceptions of resilience (Henry, et al., 2015). Both of these characteristics have to do with making meaning which is a way of dealing with multiple loss.
- Financial issues and substance abuse relate to activating societal and financial resources, to build financial solvency and to solicit support within the established association (Walsh, 2016). Maintenance has to do with meeting basic needs and protecting the vulnerable (Henry, et al., 2015), thus being able to maintain and function within society.
- The relationship with the one who died can be viewed structurally, part of the control system, as a way the family system is structured (Henry, et al., 2015); and it can be viewed as connectedness, committed relationally, and seeking reconciliation and reconnection when separation occurs (Walsh, 2016).

The purpose of this study is to examine the factors believed by hospice to be predictive of complicated grief. This objective of this chapter is to articulate a resilience theoretical framework through which this study will progress. In this chapter, complicated grief and resilience are defined. Relevant resilience theories are examined. The specific theoretical framework to be used in this study is described, and the application of this theoretical framework is applied to the research problem.

Through this study, complicated grief will be better understood in the context of resilience, ways to avoid complicated grief will be more apparent, and the profession will be better equipped to empower our clientele.

CHAPTER THREE

REVIEW OF THE LITERATURE

This review of the literature will focus on three areas. First it will review the literature about hospice, its beginnings and its philosophy. This study is undertaken in the context of hospice, studying those who have experienced the grief that losing a primary relationship brings. Second, this review will examine the literature about complicated grief. It will define normal acute grief and complicated grief, and identify how they differ. Finally, this review will look at the resilience literature, the work that has been done with regard to risk and protective factors in particular. The ideal is to avoid complicated grief. The discerning of very specific and identifiable risk and protective factors are ways of detecting the potential for complicated grief, thereby treating it early, possibly avoiding it altogether.

Hospice

Hospice is designed for those who are experiencing an incurable disease and who have been determined by a physician to have six months or less to live (Bonebrake, et al., 2010). Hospice uses the phrase “terminally ill” to refer to those who have diagnosed to have six months or less to live (weatherbeeresources.com). Hospice began initially as a volunteer movement in New Haven, Connecticut, with volunteers providing services for those at the end of life.

Today hospice is an organization dedicated to assisting people who have been diagnosed with a terminal illness to receive care and comfort for the last six months of their lives (Izumi, et al., 2012). Patients admitted to hospice will receive care in their

homes or in the facility in which they reside (Connor, 2007). Hospice does not seek to cure the illness (Connor, 2007). Patients receive palliative and/or comfort care only.

Linguistically, the word hospice comes from the same word as “hospitality”. During the Middle Ages, a hospice was a place where travelers could find rest (be shown hospitality) during a long or difficult journey (NHPCO, 2016). The modern hospice movement began in 1963 with the work of Dame Cicely Saunders who applied the term to specialized care for the dying. She ultimately went on to establish St. Christopher’s Hospice in a residential suburb of London (NHPCO, 2016).

In 1963, Saunders visited the United States and lectured at Yale University about hospice (Sullivan, 2008). Florence Wald, the Dean of the Nursing Program at Yale University was impressed with what Saunders had to say. Wald visited St. Christopher’s Hospice in the late 1960’s (<http://www.nursingworld.org/FlorenceSWald>). She returned to the United States and started the first hospice in the United States in Branford, Connecticut in 1974 (Sullivan, 2008). The hospice movement has since grown significantly in both numbers and impact in the American healthcare system (Bonebrake, et al., 2010). The National Hospice and Palliative Care Organization (NHPCO) estimates that about 44.6% of all people who died in the United States in 2011 were under hospice care (NHPCO, 2012). According to the NHPCO, there are over 4700 different hospices in the United States (Bonebrake, et al., 2010), and in 2014, they collectively cared for 1,656,000 patients (NHPCO, 2016). The majority of these patients are served in their homes. A person’s home is the place where the patient is currently residing and therefore may be a nursing facility, a board and care, or the home of a family member or caregiver (NHPCO, 2016), as well as the home of the patient. In 2014, 58.9% of hospice patients

were served in their homes, and 31.8% were served in a residential hospice facility (NHPCO, 2016).

Hospice is sanctioned, governed and financed by Medicare and is therefore obligated to follow specific guidelines in offering care to its constituency (Connor, 2007; Buck, 2009). These guidelines, referred to as the Conditions of Participation delineate what a hospice is required (or allowed) to do or not do (weatherbeeresources.com). A hospice may be a free standing hospice, or subdivision of another healthcare organization (weatherbeeresources.com).

The Medicare Hospice Benefit was created by Congress in 1982. The purpose of this benefit was to provide terminally ill patients the means to pay for financial expenses connected with end of life illness (Vitas.com). This benefit includes providing for medications, medical equipment, and bereavement counseling for families of the terminally ill (Vitas.com). There are requirements that hospice providers must meet in order to receive payment from Medicare for their services (Vitas.com). When a person chooses hospice care, the hospice providing service is required to manage and/or provide all services related to the terminal illness (Vitas.com). Specific guidelines were created to direct this process.

These guidelines include criteria for qualification for coverage by Medicare. Patients who meet these criteria are eligible to receive hospice care that is completely covered by Medicare (vitas.com). These criteria include: 1) eligibility for Part A, Medicare; 2) informed consent to receive hospice care, which consists of palliative and not curative treatment; 3) initial certification by the patient's physician and by the hospice physician that the patient has a terminal illness (prognosis of six months or less

to live); 4) continued medical prognosis of life expectancy being six months or less (Vitas.com). If a person lives longer than six months, they can continue hospice care if their physician deems their condition as continuing to be terminal, continuing to have a prognosis of six months or less (Vitas.com).

Medicare defines hospice care as a wide ranging, all-inclusive series of services, provided for the patient by an interdisciplinary team of professionals who care for the physical, psych-social, spiritual and emotional concerns of the patient and members of their family (weatherbeeresources.com). These concerns are outlined in a plan of care created and maintained by the interdisciplinary team (weatherbeeresources.com).

The interdisciplinary team consists of health care professionals who work together for the benefit of the patient and the patient's family. This team includes nurses, social workers, physicians, hospice aides, chaplains, volunteers and bereavement specialists (Vitas.com). The nurses case-manage the patient's situation, as well as offer direct physical care. Hospice physicians work with the patient's primary care physician in providing care (Vitas.com). Hospice aides assist the patient with hygiene, bathing, housekeeping and errands (Vitas.com). Volunteers are available to spend time with the patient, to offer respite to the patient's caregivers, to do light housework, and to support the family. Chaplains offer spiritual support. Social workers offer emotional support. Although anyone on the team is encouraged to offer bereavement support to family members in grief, much of the bereavement counseling is done by the chaplains and social workers, who are trained to offer bereavement counseling. Bereavement counseling is defined by hospice as offering emotional, psych-social and spiritual support

both prior to and following the death of the patient; addressing issues of grief, and adjustment to the loss (weatherbeeresources.com).

Hospice recognizes that the grief a family member experiences at the loss of a loved one can be devastating. Hospice professionals recognize the potential for complicated grief and seek ways to help their clientele avoid it. For this reason, hospice professionals (chaplains, social workers and bereavement specialists, with the help of the interdisciplinary team) look for risk factors that may indicate the potential for complicated grief (Vitas, 2012).

Because addressing end of life issues includes working with the patient's family, Medicare requires that the hospice team address bereavement issues. Chaplains and social workers are trained in recognizing the potential for complicated grief and are required to address these symptoms. Working in a hospice environment requires working with grief. This study is undertaken in the context of hospice, studying the experience of those who have faced the grief that losing a primary relationship brings.

Complicated Grief

Much has been written about grief over the past fifty years, including articles on the definition, conceptualization and treatment of grief. This focus of this study is complicated grief. Complicated grief is also referred to as prolonged grief disorder, persistent complex bereavement disorder, complicated mourning. This study will refer to it as complicated grief (CG). That CG exists has long been established (The Inventory of Complicated Grief was developed in 1995). The debate concerning CG revolves around its connection with other disorders (e.g. depression, PTSD, Normal Acute Grief, etc.)

This review will define complicated grief, discuss the difference between complicated grief and normal acute grief, and differentiate between complicated grief, depression and post-traumatic stress disorder, and in so doing suggest that all of the above be approached and treated differently by grief therapists and professionals.

Complicated grief is a condition of persistent despairing that continues for at least six months and possibly longer, distinguished by powerful separation upset, invasive and tormenting thoughts about the person who died, feelings of emptiness, an inability to accept the loss and an inability to function adequately (Holland, et al., 2009). In this definition, CG is determined after six months of these symptoms. The DSM suggests the CG be diagnosed a year after the loss in adults, six months in children (American Psychological Association, 2013).

The DSM differentiates between normal acute grief (which it refers to as uncomplicated bereavement) and complicated grief (which it refers to as persistent complex bereavement disorder). The former is considered a normal reaction to a death, the latter a potential pathology (American Psychiatric Association 2013). Normal acute grief is a reaction to a loss in which symptoms occur that are similar to a major depressive episode. However, these symptoms are considered normal, temporary, and are easily treatable (American Psychiatric Association 2013). The DSM mentions depressive episodes accompanying grief symptoms and suggests that this is different than normal bereavement. The former happens in persons who are vulnerable to depression. Depression and bereavement are different (American Psychiatric Association 2013). There are similar symptoms, but the latter is distinguished from the former by the persistent, continued attention to the loss (American Psychiatric Association 2013).

The DSM differentiates between complicated grief and PTSD following a loss. Similar symptoms accompany both. The latter is the result of a traumatic death (suicide, homicide, etc.), and the symptoms revolve around the traumatic event itself. The former is more focused on the relationship with the person who has died and includes thoughts of good times with the person who died as well as the yearning and longing for the person who has died (American Psychiatric Association 2013).

Other studies agree. Depression, PTSD, normal acute grief and complicated grief are different, distinguishable, and are to be treated differently. According to a 2009 study, symptoms of grief can occur as comorbid with other symptoms, such as depression or PTSD. At the same time, symptoms of grief present as their own symptoms, not as symptoms leading to something else. In other words, grieving does not lead to depression. Symptoms of grief and symptoms of depression are separate (Holland, et al. 2009).

Another study addressed specifically posttraumatic stress disorder (PTSD) and complicated grief (CG) in the context of sudden death. In this study, CG and PTSD were addressed, and a specific similarity examined. The purpose of the study was to look at the relationship between CG, PTSD and the peritraumatic stress, and to compare in terms of age, being female, trauma history, being an immediate family member of the one who died and whether or not the deceased died a violent death (Hargrave, et al., 2012). The participants were given the Peritraumatic Distress Inventory, Impact of Event Scale-Revised, and the Inventory of Complicated Grief questionnaires to complete. This study found that people who experience a sudden death are at a greater risk of experiencing CG or PTSD. The stress that accompanied by the sudden death of a friend or family member

is an indicator of potential complicated grief, as well as potential PTSD (Hargrave, et al., 2012). The authors acknowledge the need for a longitudinal study to give further credence to these conclusions (Hargrave, et al., 2012).

Another study directly addressed depression and anxiety and how they related to CG (Boelen, P. A. & van den Bout, J. 2005). The purpose of the authors of this article was to use confirmatory factor analysis to show that symptoms of complicated grief are different from symptoms of depression and anxiety (Boelen, P. A. & van den Bout, J. 2005). The authors acknowledge that earlier studies have suggested that this is true. However, the authors suggest that the problem with the earlier studies is that they used exploratory factor analysis, which precludes comparison of appropriateness of the different models (Boelen, P. A., van den Bout, J. 2005). The previous studies have not shown that their results have held across the various subgroups of people. The goal of this study was to see if the results of previous studies hold true in light of these issues (Boelen, P. A. & van den Bout, J. 2005). The authors gathered data from 1321 grieving people. They used the Inventory of Traumatic grief as their measure. The results of this test replicated the earlier findings. Symptoms of complicated grief are different from grief related symptoms of anxiety and depression (Boelen, & van den Bout, 2005).

According to these studies, complicated grief is to be viewed differently from depression, PTSD, anxiety and other disorders. Although the DSM5 considers complicated grief a condition for further study, it does acknowledge that CG exists, is distinguishable from other disorders (depression, PTSD), and requires particular attention (American Psychiatric Association 2013).

According to the DSM, complicated grief can only be diagnosed after a year of grieving. Although the symptoms begin immediately, they need to continue for at least a year in order for the diagnosis to be made (American Psychiatric Association 2013). In children, the time frame is six months (American Psychiatric Association 2013). The symptoms include persistent yearning and longing for the person who has died, intense emotional pain, being fixated on the person who has died, and constantly thinking about the circumstances surrounding the death (American Psychiatric Association 2013). The potential presence of other symptoms such as bitterness or anger, inability accepting the loss, being emotionally numb, avoidance of reminders about the death, a desire to die to be with the one who died, difficulty pursuing personal interests, sense of personal meaninglessness, difficulty trusting and feeling alone (American Psychiatric Association 2013) are also apparent. These symptoms happen to the degree that it inhibits social, vocational and relational functioning (American Psychiatric Association 2013). The DSM recognizes that grieving practices differ culturally. In those cases, the grief response is more marked and blatant than regular or normal cultural practices would allow (American Psychiatric Association 2013).

A 2012 study examined the symptomology surrounding CG. The purpose of the article was to show that complicated grief (CG) is indeed a syndrome and should therefore be treated accordingly and included as such in the (then) upcoming version of the DSM. In the results of this study, the author was able to develop fourteen different symptoms of CG that clustered into six different categories. The six categories were: yearning and longing for the deceased, being angry and bitter, being shocked and

unaccepting, being disconnected from others, seeing changes in behaviors, and hallucinations and illusions of the deceased person (Simon, 2012).

The fourteen symptoms were yearning and longing, feeling lonely, feeling meaningless, a wish to die to be with the one they lost, intrusive thoughts, frequently obsessing about things pertaining to the person's death, not fully accepting the loss, continual anger and feeling of bitterness, difficulty trusting or caring about other people, the feeling of the pain the person who died would have had as they were dying, emotionally reacting to things that remind them of the one who died, hearing the voice of or seeing the person who died, avoiding reminders of the person's death, and a desire to touch, smell or be near things that remind them of the person who died (Simon, 2012). The author believes that CG is significant and different from normal acute grief. In normal acute grief, people feel the pain of their loss but are ultimately able to assimilate back into life. She acknowledges that CG is a syndrome because these symptoms continue for months and even years, giving the person experiencing these symptoms the feeling of being "stuck". These symptoms cause significant interference with how the grieving individual functions in society and in life (Simon, 2012).

Another study, related to the above, used the Inventory of Complicated Grief to determine how serious the symptoms of CG were in the grieving, diagnosed individual (Simon, et al. 2011). These authors were able to identify symptoms of CG and determine the severity of CG by the existence of these symptoms (Simon, et al. 2011).

The study considers those who are experiencing grief and who are in one of three categories. One category is those who have been diagnosed with mood disorders; the second is those who have been diagnosed with anxiety disorder and the third category is a

group who have not been diagnosed with any disorder (Simon, et al. 2011). The participants took the Inventory of Complicated Grief.

The authors identified six clusters of symptoms: hallucinations, a yearning for the deceased, anger and bitterness, shock and still not believing that their friend or family member is dead, disconnection from others and a change in behaviors on the part of the caregiver or family member (Simon, et al. 2011). One of the most specific clusters of symptoms is the cluster that has to do with hallucinations of the person who died. These hallucinations take the form of feeling the pain that the person who died felt, hearing their voice or seeing them in the room bodily present (Simon, et al. 2011). The authors of this study conclude that looking at the symptom clusters gives insight into how serious the CG is for the patient and therefore how it is to be treated (Simon, et al. 2011).

A 2005 study agrees that CG is a syndrome that needs to be treated accordingly. The authors of this article approach grief in the context of attachment and loss. They acknowledge the emotional pain that is part of the grieving process (Shear & Shair, 2005). They suggest that normal acute grief is normal but complicated grief is not. Therefore, CG must be treated. This article focuses on what is lost when someone dies, drawing on attachment research, animal studies with regard to infant separation (Shear & Shair, 2005). This model suggests that when an “attachment figure” dies, there is the experience of acute grief, which is traumatic. There is usually a modification of the how the person who died is imaged within, which will integrate the fact that the person has died. After this happens there is a resolution of the symptoms of acute grief (Shear & Shair, 2005). In a small minority of the population, about 10% to 20%, the revision does not happen and this portion of the population experiences complicated grief. The feelings

of normal acute grief continue and the symptoms do not disappear (Shear & Shair, 2005). The individual experiencing complicated grief will experience feelings of longing for the person who died; there will be intense anger and bitterness; often there are intrusive thoughts about the death; being interested and engaging in life decreases; and the person often experiences intense and painful emotional times (Shear & Shair, 2005). This study distinguishes between normal acute grief, and complicated grief, showing that they are different experiences.

A 2010 study examined continuing bonds in the light of risk factors in those who are grieving. The purpose of the study is to identify risk factors that may be present for the bereaved (Field & Filanosky, 2010). The risk factors considered in this study included whether or not the death was a violent death, whether or not the bereaved was responsible for the death, attachment issues, and how well adjusted psychologically the participants were based on symptoms of CG, how the grieving person viewed their own physical health and how well they were involved in personal growth grieving (Field & Filanosky, 2010). The study acknowledges healthy grief and unhealthy grief, what may indicate the former and what may predict the latter. The two types of continuing bonds discussed were externalized continuing bonds and internalized continuing bonds. External continuing bonds were identified as hallucinations and illusion. Internalized continuing bonds were identified as expression involving use of the deceased as an autonomy in which secure foundation can be achieved. The former is deemed pathological, the latter is considered healthy grieving (Field & Filanosky, 2010). This study consisted of 502 participants who took a survey over the internet. As would be expected, there was a positive association between hallucinations and illusions and violent death and

responsibility for the death. Internalized continuing bonds negatively associated with these symptoms and positively associated with personal growth grieving (Field & Filanosky, 2010). This article also discusses the place of these continuing bonds in how the bereaved person adjusts and moves back into society (Field & Filanosky, 2010).

Not all premature death leads to CG. A 2011 study of grieving parents who lost a child to death in a pediatric intensive care unit of a hospital (Meert, et al., 2011) sought to investigate the presence of CG. The authors acknowledge previous studies that have confirmed that parents who lost a child in the pediatric intensive care unit suffer serious acute grief symptoms for the first six months after their child has died. Their study concerns parents who lost a child between six and eighteen months prior in a pediatric intensive care unit (Meert, et al., 2011). The authors studied 138 parents of 106 children. The parents completed surveys at six months and again at eighteen months. Included among these surveys were the “Inventory of Complicated Grief (ICG), measures of grief avoidance, attachment, caregiving and social support” (Meert, et al., 2011, p. 207). The results of the tests showed improvement in test scores in the areas of “traumatic death” (Meert, et al. 2011, p. 207) and avoiding the grief (Meert, et al. 2011). Lower scores were prevalent in the areas of “responsive caregiving” (Meert, et al. 2011, p. 207) and “being the biological parent” (Meert, et al. 2011, p. 207). The authors conclude that sometimes there is decrease in the pain in the 6 to 18-month period and sometimes there is not (Meert, et al., 2011). This suggests that experiencing the loss of a child does not always result in CG. The scores also suggest the presence of risk factors (or protective factors), which may impact the potential for CG.

Among the complications connected with CG is insomnia. A 2005 study looked at insomnia and grief in college students. In this study, 815 college students took the Inventory of Complicated Grief survey along with being assessed for insomnia and sleep related disorders (Hardison, et al., 2005). The study found that insomnia was higher in the students who were experiencing grief than it was in other college students. It also worked the other way. Those who could not sleep were ranked higher in the amount of bereavement they were experiencing. Complicated grief symptoms were present for the insomniacs and included dreaming of the deceased, and “ruminating” about the deceased around bed time (Hardison, et al., 2005).

In the literature there was a debate that centered around whether CG was its own disorder (Simon, 2012; Shear & Shair, 2005), or simply an extension of normal acute grief (Holland, et al., 2009). Those who believed that CG was its own syndrome, which needed to be treated clinically accordingly were able to include a series of symptoms which may be used in determining criteria for the diagnosis (Simon, 2012; Shair & Shear, 2005). The other side of the debate insisted that what is referred to as CG is simply the extreme end of normal acute grief (Holland, et al. 2009), and that there is no difference between CG and normal acute grief (Holland, et al., 2009). Their argument was that the symptoms are similar or the same, that in CG symptoms simply exist for a much longer period of time. Ultimately, both complicated grief and normal acute grief were included in the DSM as distinguishable and, to be viewed differently. However, the DSM does leave the door open for further study (American Psychological Association, 2013).

The attempt to differentiate between or connect as the same normal acute grief and complicated grief stems from the same modernist approach that views grief

(complicated grief in particular) from a pathological perspective, which is seen in much of the recent literature (Field & Filanosky, 2010; Boelen & van den Bout, 2005; Shear & Shair, 2005; American Psychiatric Association, 2013; Simon, 2012).

Complicated grief continues to be a concern, especially among those who work specifically with the grieving. The literature defines complicated grief (Holland, et al., 2009; Shear & Shair, 2005), describes complicated grief (American Psychiatric Association, 2013), and differentiates complicated grief from normal acute grief (Simon, 2012); PTSD, (Holland, et al., 2009; Hargrave, et al., 2012) and depression, (Boelen, P. A. & van den Bout, J. 2005). Specific symptomology has been associated with the identification of CG (Simon, 2102). Hospice organizations acknowledge the presence and potential for complicated grief and highlight their endeavor to avoid such a state in their best practice guidance by identifying specific risk (or protective) factors (Vitas Healthcare, 2012).

Resilience

Resilience studies have determined that certain factors are evident in managing traumatic life events (Carver, 1997; Distelberg, et al., 2015), and therefore may be beneficial in buffering the negative effects of these factors in the grieving process. Resilience is the capacity to adapt after experiencing challenging life events. Resilience implies inner strength, competence, being flexible and having the ability to cope with life's challenges (Wagnild & Collins, 2009). Resilience is the concept that refers to the capacity of people to deal successfully with adverse events thus experiencing a positive and satisfying outcome (Connor & Davidson, 2003).

Hospice has identified seven risk factors (protective factors) in predicting the potential for complicated grief. These risk factors are 1) lack of an adequate support system, 2) lack of an expression of faith, 3) lack of adequate coping skills, 4) multiple losses, 5) the relationship with the person who died, 6) substance abuse, and 7) financial issues.

Support System

Social support has been included in resilience studies and has been seen as a resilience factor, thus making lack of social support a risk factor. For example, in a 2011 study of traumatic death, parents of children whose child had died in a pediatric Intensive Care Unit between six and eighteen months prior intended to measure complicated grief in the context of risk or protective factors (Meert, et al., 2011). The study included social support as one of the protective factors measured (Meert, et al., 2011). The study showed that the grief of losing a child sometimes decreased after six to eighteen months and sometimes it did not, suggesting that the presence of protective factors mitigates CG (Meert, et al., 2011), one of which was an effective social support system.

According to a 2014 study, social support is effective in decreasing the pain connected with experiencing sudden loss (Dyregrov, et al., 2014). A good support system helps people who experience loss to have better mental health, superior physical, and longer life (Dyregrov, et al., 2014). Poor social support can make the problem worse, distance friends, and increase illness (Dyregrov, et al., 2014).

A 2016 study that focused on the older adult population found that external connections (social support system) was one of nine protective factors related to

resilience in confronting hardship (Bolton & Praetorius, 2016). A 2017 study of adults who lost a spouse found that one of the strongest predictors of resilience was the sustained participation in regular life events and in social relationships, followed by the belief that they would get support when in distress (Infurna & Luthar, 2017). A 2015 study of grieving spouses found that those who experienced resilience after their loss were those who believed that their support system was interested in listening to their distresses; they were willing to rely on others, and they experienced lower levels of loneliness (Mancini, et al., 2015). Social support in each of these situations was indicative of healthy and successful grieving.

However, there are other studies which suggest that social support may not effectively mitigate CG. Social support in the context of bereavement has also been shown to occasionally have undesirable outcomes (Mancini, et al., 2015). A 2005 study utilized data from the Changing Lives of Older Couples study, which looked at 1532 married couples 65 years old and over and focused on women who experienced loss and bereavement during the course of the study. Although social support showed a significant effect on depression, there was nothing in that study that indicated that social support had a buffering or recovery effect on bereavement (Stroebe, et al., 2005). A 2013 study showed that, although social support was seen as a buffer initially in the grieving process, it did not continue to be significant after controlling for other factors (Allen, et al., 2013). A 2007 qualitative study looked at how people experiencing CG described the support they received through the grieving process (Wilsey & Shear, 2007). Of the 22 persons interviewed in the study, all of them had someone with them at the time of the death, and twenty of them talked about the how the support they received from other people either

helped or hindered their grieving process. Of this group, seven of them reported that the help was completely beneficial, seven reported that the help was completely not beneficial, and six of them reported that the support they received was sometimes helpful and other times not helpful (Wilsey & Shear, 2007). They had stories about both how support was helpful, and how it was not helpful (Wilsey & Shear, 2007). Often, those who are grieving are advised by counselors to choose the right kind of support, which consists of those who are willing to do things, those who are willing to listen non-judgmentally, as opposed to those who have a tendency to be critical (Bottomly, et al., 2017), which implies that not all social support is beneficial. The quality of social support more than the presence of social support is an indicator of its benefit as a buffer to CG. The place of social support in the grieving process, acting as a buffer to CG warrants further study (Allen, et al., 2013). Whether or not people who are grieving actually always desire social support has not been thoroughly investigated (Bottomly, et al., 2017), nor has personality type and social support been adequately addressed.

Although traditional hospice bereavement care has considered social support to be a buffer against complicated grief, the singular effectiveness of social support to mitigate grief continues to remain in question, and its role in palliating grief has not yet been definitively established.

An Expression of Faith

A second risk (protective factor) used by hospice professionals to predict CG is the presence (or absence) of an expression of faith. Spiritual faith has been shown to be a resilience factor. Religious coping is defined as the utilization of religious and spiritual

behaviors in order to handle stress (Wortman & Park, 2008). Examples of this would be praying and attending church. Religious coping has been shown to be beneficial to the grieving process, helping with the adjustment to the death (Wortman & Park, 2008). A 2008 study suggests that an experience of faith does benefit the grieving process by giving hope and/or comfort to the grieving individual if the faith experience is healthy (Edmonson, et al., 2008). The expectation of immortality is a comfort to those at end of life (Edmonson, et al., 2008).

A study of black mothers who experienced the violent gang related death of their children found that at the center of their resilience was a spiritual influence, that the deaths of their children was part of God's purpose (Bailey, et al., 2013), and this belief empowered them in their formation of meaning (Bailey, et al., 2013).

That religion or spirituality moderates CG may be because being a person of faith assumes belief in an afterlife where the person who died is waiting for the bereaved to join them (Van Der Houwen, et al., 2010); or the belief that the person who died is still among the living (Van Der Houwen, et al., 2010). Beliefs appear to act as a buffer to bereavement. However, people of faith are of participants in a faith community. This participation and the corresponding social support potentially may be the buffer to bereavement, as opposed to the beliefs themselves (Van Der Houwen, et al. 2010). The beliefs connected with religion, the social support inherent in community, the intrinsic essence of spiritual experience or some combination of all of them is believed to be a protective factor.

A 2007 study of religion and bereavement acknowledged that the vast majority of studies that have investigated the effects of religion and/or spirituality on bereavement

found that religious/spiritual beliefs have a helpful influence on bereavement (Becker, et al., 2007). However, this study also suggested that most of these findings lacked diversity and were weighed down by design flaws and methodological weaknesses (Becker, et al., 2007), therefore nothing definitive could be determined concerning the influence of religion/spirituality on bereavement (Becker, et al., 2007).

A 2010 study that investigated risk factors and bereavement found that the only thing predicted by spirituality was positive mood (Van Der Houwen, et al., 2010). Higher levels of spirituality produced higher levels of positive emotions (Van Der Houwen, et al., 2010). This study also pointed out that there is a difference between religion and spirituality that most studies fail to control for, which would impact study results (Van Der Houwen, et al., 2010).

Although faith is often part of a person's coping repertoire, not all find spirituality beneficial. Sometimes grief causes a person to become angry at God or at their community of faith or have feelings of being abandoned, or to experience crises of faith (Burke, et al. 2011). A study of African American survivors of homicide found that negative religious coping was related to CG, and positive religious coping had no effect on whether or not someone ultimately experienced CG (Burke, et al., 2011). Although traditional hospice practice advocates for the presence of the religious in working with grieving individuals, and spirituality is used as a predictor for potential CG, nothing definitive has yet been established in the literature concerning the effect of religion on the grieving process. Because of this, some authors suggest that further study on the buffering effect religion with regard to grief is warranted (Van Der Houwen, et al., 2010; Becker, et al., 2007).

Coping Skills

The presence of coping skills as an indicator of emotional health is one of the protective factors considered by hospice professionals in predicting complicated grief, and that resilience as a personality trait will act as a buffer against complicated grief. Recent studies have found evidence to suggest the accuracy of this assumption.

For example, a 2016 study of spousal bereavement examined psychological adaptation of those entering widowhood (Spahni, et al., 2016). They considered trait resilience, marital history and context of death. Of these three, the most effective indicator of psychological adaptation was trait resilience (Spahni, et al., 2016). A 2013 study of bereaved spouses found that trait resilience clearly predicted state hopefulness, distress disclosure and boundary turbulence. The latter two were predictors of life satisfaction, making resilience an indirect indicator of life satisfaction (West, 2013). A 2010 study that pertained to positive emotions and spousal loss found that trait resilience significantly predicted positive emotion in the experience of significant adversities in life (Ong, et al., 2010). Lower levels of trait resilience prior to widowhood were related to lower levels of positive emotion after the loss of a spouse (Ong, et al., 2010).

The studies that have been done about trait resilience have suggested that it benefits positive thought, and thereby assists with the bereavement process. The current study will add to the field by confirming the presence of trait resilience as a mitigating factor with regard to CG. This study will also look at trait resilience in the context of other potential risk (protective) factors in order to determine which mitigating factor appears the most often, and how the mitigating factors relate.

Multiple Losses

The current study survey includes a question about previous losses. Hospice views multiple recent losses and unresolved losses to be a risk factor for CG. Although there is evidence that multiple losses do increase the possibility of CG, and increase the intensity of the grieving process, there has not been as much written about multiple losses as a predictor of CG. For that reason, further study is warranted.

A 2006 study addresses multiple losses, but not in the context of CG (Mercer & Evans, 2006). Twenty-eight people had experienced the death of a family member or friend, or multiple deaths. Many had experienced other losses as well including loss of their own health, family injury, marital and other issues (Mercer & Evans, 2006). This study found that those who had experienced loss soon after a prior loss, grieved the longest (Mercer & Evans, 2006). People mourned losses separately, even if losses occurred at the same time or close in time (Mercer & Evans, 2006). People were affected emotionally, physically, spiritually, and financially by these losses. Sometimes personalities changed (Mercer & Evans, 2006). This study addressed multiple loss, and the devastating effects of multiple loss, but not in terms of CG.

A study concerned with CG and members of the military found that there was a correlation between the amount of loss a member of the military experienced, and scores on the ICG. This suggests that multiple losses may make a member of the military more prone to experience CG (Delaney, et al., 2017). A 2015 study of refugees from war scarred countries who end up living in refugee camps in North America discusses the implications of multiple loss and the potential connection to CG (McLellan, 2015). A 2006 study pertaining to childhood pet bereavement discusses multiple losses in the

context of CG and suggests ways to avoid the latter (Kaufmann & Kaufmann, 2006). These studies suggest that multiple losses within a relatively short period of time are a risk factor for complicated grief. But these studies are few. Further study is warranted. Also missing are a significant number of studies that discuss whether the risk present because of multiple loss is softened by the presence of other protective factors.

Substance Abuse and Financial Issues

Those who experience CG have more mental health issues of which substance abuse is one, than do those who do not experience CG (Ott, 2003). Drug abuse is also a risk for self-harm, CG and loss. A 2016 study looked at the potential for suicide among those who are substance dependent. The study consisted of 196 substance dependent people who had been clean and sober for at least a month who had lost a loved one at some point in their life, but at least a year prior to the study (Masferrer, et al., 2016). Sociodemographic information was considered, and the Inventory of Complicated was administered to the participants. Of the 196 participants, 67 evidenced CG, and 85.1% were at risk of suicide. The connection between drug dependence, suicide and CG is apparent and needs to be addressed.

A study in 1990, showed that life events effected bereavement in older people experiencing the loss of a spouse. Financial issues, were among the life stressors that led to increased bereavement related depression (Norris & Morrell, 1990). This was more significant in widows than in those who lost a parent or a child (Norris & Morrell, 1990). Financial well- being is integral to family well-being (Walsh, 2012); the poverty, stress and trouble brought about by continued unemployment can be disastrous (Walsh, 2012).

Poverty is a stressor that impacts psychological health and negatively affects what people will tolerate and how they function in society (Anderson, 2012). Financial stress is harmful, and a risk factor to successful resilience.

This literature review has looked at some of what has been written about risk factors and the potential for CG. It is apparent that significant research has been done. It is also apparent, however, the literature is not conclusive, as attested by those who have participated in the research, therefore further study is warranted.

CHAPTER FOUR

METHOD

This is a quantitative study. A quantitative study requires appropriate data analysis, which includes establishing a research question and gathering and testing data (Nelson & Allred, 2005). Data will be gathered through the use of a survey. The purpose of a survey is to use questionnaires or brief interviews with a sample of the population in order to create generalizations among the entire population and to determine trends (Creswell, 2014). The survey to be used for this study will focus on complicated grief and resilience. The trends to be determined will be on predictors of complicated grief. The study will result in a publishable paper (as opposed to the traditional dissertation format), to be submitted to a peer reviewed family therapy journal or to a peer reviewed journal with a focus on grief studies, death and dying, Hospice or end of life issues (e.g. Journal of Death and Dying or the American Journal of Hospice and Palliative Medicine or Death Studies). Because this study addresses both diagnosis and treatment, in the context of the family, it is pertinent clinically to the field of marriage and family therapy. Because it deals with the end of life and the grief that it accompanies, it is pertinent to grief therapists and hospice professionals.

Assumptions

When a person suffers with complicated grief, treatment is required, and that treatment differs from the treatment given to those experiencing normal acute grief. This study assumes that the way people respond at the time of a loved one's death is not a predictor complicated grief. Dramatic emotional expressions at the time of a death are not

necessarily indicative of potential complicated grief. Stoic non expressive fortitude at the time of death is not necessarily an indicator of future emotional health. The presence of complicated grief is diagnosed a year following the death (American Psychiatric Association 2013). Therefore, hospice professionals and grief therapists look for possible predictors of complicated grief, (risk factors or protective factors) in order to anticipate the potential for complicated grief. A better understanding of these risk or protective factors will better enable hospice professionals to prepare for and therefore treat adequately this painful condition. It may even be possible to prevent complicated grief. If some risk factors are more common than others for those who experience complicated grief, then knowledge of how to treat it will be enhanced.

Hospice is an organization dedicated to end of life issues. The experience of the end of life brings with it the need to address bereavement issues and grief. Those working with grieving family members have become very aware of how people respond to grief, and are therefore, reticent to allow persons to experience complicated grief if it can be prevented. Therefore, hospice team members regularly discuss the bereavement process of family members in order to prevent complicated grief. Those deemed at “high risk” are given extra attention, and directed to resources that may help alleviate this risk.

The context for this study is hospice. Vitas Hospice has delineated seven risk factors for complicated grief. They are: 1) poor spiritual health; 2) the lack of an adequate social support system; 3) the presence of multiple, recent or unresolved losses; 4) poor emotional health; 5) financial issues; 6) the relationship of the primary caregiver with the person who has died; and 7) dependence on alcohol or other substances (Vitas, 2012). This study investigates six of these risk factors, which are the independent (or predictor)

variables. The dependent (or outcome) variable is complicated grief. This study assumes complicated grief can be predicted by the presence of risk factors (or lack of protective factors) and that the greater the preponderance of risk factors, the greater the likelihood of eventual complicated grief. The measures used in the survey and the questions asked in the survey pertain to these risk factors. We hypothesize that lower risk factors determine higher levels of resilience, and are therefore related to lower levels of complicated grief.

Spiritual health is a concern. As part of their initial assessment, hospice chaplains are required to assess for spiritual distress in the patient and spiritual concerns and strengths in family members and friends of the patient who are involved in the patient's care (Vitas Healthcare, 2017). Included among these concerns are the presence and importance of particular religious beliefs, religious conflict in the family, spiritual disconnection, need for reconciliation and the feeling of powerlessness (Vitas Healthcare, 2017). This study will examine the presence of a faith expression in bereaved individuals, and how this expression of faith was used in the bereavement process. In particular, this study will examine whether people used their faith expression as a way of avoiding complicated grief. This study will use three questions from the IFCR profile and two questions from the BCM, which pertain the expression of faith. From the IFCR, participants are asked how strongly they agree or disagree with the following questions:

- When you face problems or difficulties in your family, you respond by: Attending church services/religious services?
- When you face problems or difficulties in your family, you respond by:
Participating in religious activities?

- When you face problems or difficulties in your family, you respond by: Seeking advice from a minister or spiritual leader?

From the BCM, participants are asked to what extent they participate in the following:

- You've been praying or meditating.
- You've been trying to find comfort in your religion or spiritual beliefs.

Support system is a concern. Hospice professionals assess social support by considering whether the caregiver is lonely or isolated, or declines assistance; and if there are sufficient family members, friends and outside activities to offer bereavement support (Vitas Healthcare, 2017). The lack of an adequate support system in this study was determined by the IFCR and the BCM. Three types of support system were considered: family support (including extended family), community support (friends in the neighborhood and community where the bereaved person lives), and social support (friends and associates, included work, school associates and others with whom the participant socializes), and each was entered as a separate variable. This study investigated how these systems of support are used by the participant or are beneficial to the bereavement process.

Family support is determined using six questions from the IFCR. Participants were asked how strongly they agreed or disagreed with the following:

- When you face problems or difficulties in your family you respond by seeking advice from relatives (grandparents, etc.)
- When you face problems or difficulties in your family you respond by doing things with relatives.
- When you face problems or difficulties in your family you respond by asking

relatives how they feel about problems you face.

- You feel good about yourself when you sacrifice and give time and energy to members of your family.
- The things you do for members of your family and they do for you make you feel part of this very important group.
- The members of your family make an effort to show their love and affection for you.

Community support was determined by asking the participant how strongly they agreed or disagreed with the following six questions from the IFCR:

- When you face problems or difficulties in your family you respond by receiving gifts and favors from neighbors (e.g.: food, taking in mail, etc.).
- When you face problems or difficulties in your family you respond by asking neighbors for assistance.
- When you face problems or difficulties in your family you respond by sharing problems with neighbors.
- People here know that they can get help from the community if they are in trouble.
- People can depend on each other in this community.
- Living in this community gives you a secure feeling.

Social support refers to people that the bereaved individual associates with, including friends from work, or school, or others with whom they socialize; people who are not related and do not necessarily live in the same community, but are people who would be considered friends or associates. This was determined by using four questions

from the BCM and two questions from the IFCR. From the BCM, participants were asked to what extent they participate in the following:

- You've been getting emotional support from others.
- You've been getting help and advice from other people.
- You've been getting comfort and understanding from someone.
- You've been trying to get advice or help from other people about what to do.

From the IFCR, participants were asked how strongly they agreed or disagreed with the following:

- When you face problems or difficulties in your family, you respond by seeking encouragement and support from friends.
- When you face problems or difficulties in your family seeking information and advice from persons in other families who have faced the same or similar problems.

Prior loss is a concern. The concern includes whether this is the first major loss the participant has experienced, and, conversely, whether there have been several losses within a relatively short time span (Vitas Healthcare, 2017). The participant's experience coping with loss is also a concern (Vitas, 2017). This study addresses prior loss by including one "yes or no" question. The participant is asked, "Have you experienced other losses of a close relationship in the past 5 years?"

The lack of emotional health is considered a risk factor for complicated grief. In this study, good coping skills are used as an indicator of emotional health. Hospice social workers and chaplains are required to address coping skills in their initial assessment of the patient, the patient's family and others that may be impacted by the patient's death

(Vitas Healthcare, 2017). Hospice considers healthy coping skills to include: resilience, the ability to compartmentalize, an internal locus of control, having outside interests and hobbies, the ability to personally obtain help, previous experience coping with loss, religious or spiritual support, the ability to continue with life following a loss, and helpful role models (Vitas, 2017). Religious or spiritual support, the ability to obtain help and experience coping with loss are addressed in other areas of this study. This study used eight questions from the BCM in order to determine the coping skills of the participant. Participants were asked to what extent they participate in the following:

- You've been saying to yourself, "this isn't real".
- You've been giving up trying to deal with it.
- You've been refusing to believe that it has happened.
- You've been trying to see it in a different light, to make it seem more positive.
- You've been giving up the attempt to cope.
- You've been looking for something good in what is happening.
- You've been accepting the reality of the fact that it has happened.
- You've been learning to live with it.

Hospice considers the type and quality of the relationship the participant had with the person who died to be a concern with regard to complicated grief. Hospice is interested in the nature of the relationship, including history of ambivalence, abuse, or neglect; the loss of a long term relationship; the closeness of the relationship; how dependent the caregiver was on the patient; and whether the illness was something considered unacceptable by society (Vitas Healthcare, 2017). This study does not address

the nature of the relationship. It does, however, address the type of relationship: how the participant was related to the patient.

Hospice considers substance abuse to be a risk factor for complicated grief. This study addresses that issue with two questions from the BCM. Participants are asked to what extent they participate in the following:

- You've been using alcohol or other drugs to help you get through it.
- You've been using alcohol or other drugs to make yourself feel better.

This study will work with Vitas Healthcare. Vitas Healthcare began as Hospice Care Incorporated in 1978 in Miami, Florida. It was one of the first hospice programs created in the United States. Today, Vitas Hospice serves over 15,000 patients daily. There are over 50 Vitas programs in sixteen states (www.vitas.com). Recruitment for participants for the current study will be within the Vitas Hospice program.

Hospice professionals and hospice social work interns and trained hospice volunteers will phone family members and primary caregivers of former hospice patients who died while on service between twelve and thirty months prior. These phone calls will be made from the Vitas office. Information concerning former Vitas patients and their family members will be collected from Vitas medical records. The hospice interns, professionals and volunteers will inform families of the study and ask if they would be willing to participate. This will happen through the informed consent process.

The same survey will be mailed or e-mailed to families of hospice patients who have died on service between twelve and thirty months prior. These responses will be included with those received from the telephone survey in order to form a complete data set.

Participants

The study involves only minimal risk. It may bring up unaddressed emotions. Breach of confidentiality would lead to embarrassment of the participant. Otherwise, this study involves no risk to the participant.

If necessary, should the need manifest, the participant will be referred to Hospice bereavement services. The volunteers and social work interns will have training in identifying potential concerns; they will be able to assess the need for further services and will make referral sources available to provide necessary bereavement services. There is only a minimal possibility of a breach of confidentiality. Information received from Participant by the researcher will be de-identified, collected through a Qualtrics encrypted server to which PI and student researcher has access.

This study will benefit humanity by creating a measure that will help hospice professionals and grief therapists predict the potential presence of complicated grief for those who lose primary relationships through death by identifying the presence and predominance of potential risk factors, which will enhance the quality of work done with the grieving population

Sample

This study will have a sample size of about 200 participants. This study will utilize their responses to the survey. Family members of hospice patients will be participants in the survey. Hospice personnel will administer the survey. Participants in this study will include adults over the age of 21 who have experienced the death of a primary relationship between twelve and thirty months prior. A primary relationship is

defined as spouse, child, parent or sibling. Also included in this study will be significant others, close friends and other family members who acted as primary caregivers or who were close relationally to the deceased patient. Participants must be able to read and speak English. This study will exclude participants who demonstrate a decreased cognitive functioning or significant emotional and/or mental health stress during the initial informed consent process, or throughout the data collection phase. Interviewers are trained social work interns under the supervision of a licensed supervisor, trained hospice volunteers under the supervision of a trained hospice professional, and trained hospice professionals also under the same supervision. They will use their training and refer to supervision in order to assess for severe deficits, and the participant will be instructed to stop their participation at this point. Information concerning decreased cognitive functioning will be available to the interviewer through hospice medical records prior to the interview. Interviewers will be trained to identify emotional stress during the process by the way participants respond to questions asked and reasons given for non-response.

The study target sample size is $n=200$. The sample for this study will be obtained from families of patients who have used Vitas Hospice services and who have died on service between twelve and thirty months prior.

Informed Consent

Informed consent will follow the structure of the Informed Consent Document (appendix). The hospice representative will inform potential participants about the study and explain the purpose, as well as requirements for participation. Individuals that agree to participate in the study will give verbal consent, to the hospice intern, professional, or

volunteer who will then verbally administer a short survey and track the participant's responses in a computer based survey system (e.g. Qualtrics). Although the one conducting the survey will have access to the participant's identifying information, no identifying information will be logged on the computer database which is accessible to the researchers. The research team will have access to only this database and therefore will not have access to the participant's identifying information.

Design (How and Where Data is Collected)

Demographic information and the relationship of the participant to the one who died will be available through medical records. Any demographic information collected will be de-identified and stored with the answers from the survey, which will be logged on Qualtrics and stored on the LLU encrypted server. Once the target sample size is achieved the data will be downloaded by the PI and stored on his computer. This data will contain no identifying information.

Hospice professionals, hospice social work interns and hospice volunteers will phone family members and primary caregivers of former hospice patients who died on service between twelve and thirty months prior. After recruiting for participation and gaining informed consent, the Vitas representative will administer a survey, intended to gain insight into the participant's current grieving process. The phone survey will take about fifteen minutes.

Measures

The survey consists of sixty-seven questions, which includes three measures that

have been established, tested and used. Of these three measures, two will be resilience measures and one will be a complicated grief measure. There will not be open ended responses in the interviews. The goal is not to understand the experience of the interviewees, but to accumulate data that will help best predict the potential for complicated grief.

This study will use the Inventory for Complicated Grief (ICG), the Brief Cope Measure (BCM) and the Individual, Family, and Community Resilience Profile (IFCR) in order to measure the correlation between high levels of resilience and low risk factors for complicated grief.

The IFCR Profile, developed in 2015, is a multidimensional resilience assessment that measures family, individual and community resilience (Distelberg, et al., 2015). It is multidimensional in that it assesses twenty separate dimensions of resilience constructs in order to measure resilience (Distelberg, et al., 2015).

The Brief Cope Measure (BCM), developed in 1997 has been used to help determine an individual's ability to deal with complex and difficult life events (Carver, 1997). The BCM is a brief form of the previously developed COPE Inventory which was developed in 1989 and has been shown to be effective in measuring levels of resilience (Carver, 1997). The Brief Cope excludes two scales of the full COPE and lessens the other scales to two items per scale (Carver, 1997). The Brief Cope is an assessment tool that measures responses that are pertinent to helpful coping (Carver, 1997).

The Inventory of Complicated Grief (ICG) was created in 1995. This 19-item instrument has previous evidence of good internal consistency (Simon, et al., 2011). The ICG assesses a specific group of symptoms that are used to predict continued dysfunction

due to the inability to adapt back into normal life routines because of grief (Prigerson, et al., 1995). This inventory has shown high internal consistency. High test-retest reliabilities were also apparent (Prigerson, et al., 1995). There will be three additional questions on the survey pertaining to recent losses, multiple losses, and whether or not the participant was able to be with the deceased at or near time of death.

Analysis Plan

Data analysis includes determining the relationship between variables and understanding the power of that relationship (Nelson & Allred, 2005). This study is a predictive analysis in that it seeks to determine whether certain risk factors (or lack of specific protective factors) can be used as predictors of complicated grief. Predictive analysis can use path, discriminant function or regression analysis (Nelson & Allred, 2005). This study will use regression analysis.

This is a quantitative study. Strengths of quantitative research are in its generalizability. It uses large sample sizes, effectively utilizes analysis and identifies correlations (Creswell, 2015). Its limitations are that it does not incorporate the words and experiences and contexts of the individual participants (Creswell, 2015).

The analysis will begin by examining the univariate assumptions within the data as well as assess for missing data. We will then evaluate the centrality and variance of resilience and risk factors in comparison to known benchmarks for these measures. This analysis will give understanding to the level of significance and prevalence of risk and resilience factors within hospice populations.

Secondly, linear regression will be used to determine the relationship between levels of risk factors and the presence of complicated grief. Complicated grief will be the outcome (dependent) variable, predicted by independent variables: support system, faith expression, coping skills, relationship to the patient, substance use and recent loss. Linear regression will help to determine how risk factors ascertain the level of complicated grief.

Limitations

This study is to be done in the context of hospice. Grieving in other contexts will not be evaluated. Therefore, this study is limited in its scope. It will not adequately measure risk factors and resilience outside of the hospice environment. It is possible that the presence of hospice mitigates the grieving process. This study will not measure the level of change hospice brings to the experience of grief. Further study would benefit the field by studying resilience and risk factors and complicated grief outside of the hospice environment.

This study is working with one hospice organization in an isolated part of the country. This study does not examine hospices in other parts of the country, and therefore does not measure how the experience of grief differs in other areas of the country. It is possible that grief is either enhanced or mitigated by the environment. Further study would control for environmental factors with regard to risk factors and complicated grief.

CHAPTER FIVE

RESILIENCE AND COMPLICATED GRIEF: TESTING THE PREDICTIVE VALUE OF HOSPICE DEFINED RISK FACTORS

Although grief is a common and universal life experience, successfully navigated by the majority of the population (Jordan & Litz, 2014), occasionally it becomes a complex experience with ongoing symptomology that significantly impedes the bereaved person's physical and/or emotional health (Mancini & Bonanno, 2012). When these feelings fail to subside, continuing for several months or longer, complicated grief is diagnosed (mayoclinic.org., 2017). According to the DSM5 complicated grief is diagnosed after a year of continuing symptomology (American Psychiatric Association, 2013). The symptoms for normal acute grief and complicated grief are the same, the distinguishing factor being the length of time that symptoms persist. Because complicated grief cannot be immediately diagnosed, grief therapists look for risk or protective factors to predict the potential for complicated grief.

This study will evaluate the prevalence and presence of risk factors for complicated grief in families who have recently received hospice services. The importance of risk factors in relationship to complicated grief is theoretically relevant. However, to date insufficient empirical evidence has been provided to support these theoretical assumptions. It would be to the benefit of hospice professionals to understand the quality of these risk factors in order to better attend to their bereaved clientele. Furthermore, if certain risk factors are shown to be stronger predictors of complicated grief than other risk factors, then the field would benefit from this focus.

This study will determine the existence of these risk factors in people who are grieving as well as assess how and if theorized factors help predict complicated grief. This study will help bereavement professionals identify early risk and protective factors, which will benefit hospice professionals by allowing them to prepare for complicated grief in their clientele, and create interventions to address this potential problem.

Background

Complicated grief, also referred to as prolonged grief disorder and persistent complex bereavement disorder (American Psychiatric Association, 2013) is the experience of yearning and emotional pain because of the loss of a loved one through death that continues for more than a year (American Psychiatric Association, 2013), and which inhibits functioning (Mancini, et al., 2015).

The majority of the population possesses sufficient resilience to avoid complicated grief (Mancini, et al. 2015). To this end, about 45% to 60% of the population (Mancini, et al. 2015), will adjust to a loss adequately without any outside intervention. About 15% to 25% of the population will take longer to adjust, and may need minimal outside intervention, but will “bounce back” within about a year (Mancini, et al., 2015). A much smaller percentage of the population, about 10% to 15% (Mancini, et al., 2015) will fail to adjust, and will continue to experience the debilitating and painful feelings of yearning and emptiness that inhibit effective or even adequate functioning (Mancini, et al., 2015). It is this group that suffers from complicated grief (Mancini, et al., 2015). An assumption of this study is that adequate resilience prevents complicated grief.

The literature defines complicated grief (Holland, et al., 2009; Shear & Shair, 2005), describes complicated grief (American Psychiatric Association, 2013), and differentiates complicated grief from normal acute grief (Simon, 2012); PTSD, (Holland, et al., 2009; Hargrave, et al., 2012) and depression, (Boelen, P. A., & van den Bout, J. 2005). Specific symptomology has been associated with the identification of complicated grief, including yearning, loneliness, meaninglessness, a wish to die to be with the deceased, intrusive thoughts, frequently obsessing about things pertaining to the person's death, non-acceptance of the loss, bitterness, difficulty caring about other people, feeling of the pain of the person who died, avoiding reminders of the one who died, hearing the voice of or seeing the person who died (Simon, 2012).

The DSM differentiates between normal acute grief (which it refers to as uncomplicated bereavement) and complicated grief (which it refers to as persistent complex bereavement disorder). The former is considered a normal reaction to a death, the latter a potential pathology (American Psychiatric Association 2013). Normal acute grief is a reaction to a loss in which symptoms occur that are similar to a major depressive episode. However, these symptoms are considered normal, temporary, and are easily treatable (American Psychiatric Association 2013). Complicated grief is determined when these symptoms continue for a year or longer (American Psychiatric Association 2013).

This study is undertaken in the context of hospice, studying the experience of those who have faced the grief associated with losing a primary relationship. Hospices work specifically and exclusively with the dying, and the bereaved. Hospice is designed for those who are experiencing an incurable disease and who have been determined by a

physician to have six months or less to live (Bonebrake, et al., 2010). Patients admitted to hospice will receive care in their homes or in the facility in which they reside (Connor, 2007). Hospice does not seek to cure the illness (Connor, 2007). Patients receive palliative and/or comfort care only.

The National Hospice and Palliative Care Organization (NHPCO) estimates that about 44.6% of all people who died in the United States in 2011 were under hospice care (NHPCO, 2012). According to the NHPCO, there are over 4700 different hospices in the United States (Bonebrake, et al., 2010), and in 2014, they collectively cared for 1,656,000 patients (NHPCO, 2016).

Hospice is sanctioned, governed and financed by Medicare and is therefore obligated to follow specific guidelines in offering care to its constituency (Connor, 2007; Buck, 2009). Because addressing end of life issues includes working with the patient's family, Medicare requires that the hospice team address bereavement issues. Hospice chaplains and social workers are trained in recognizing the potential for complicated grief and are required to address these symptoms.

Hospice professionals acknowledge that complicated grief cannot be diagnosed at the time of loss. It can only be determined over time. Therefore, hospice professionals look for risk factors, which are considered predictors of future complicated grief (Vitas Healthcare, 2012). Hospice has delineated seven specific risk factors (Vitas Healthcare, 2012). The purpose of this study is to test six of these seven risk factors in order to determine the potential for complicated grief in hospice patient families, and to determine which, if any risk factors are more prevalent than others in predicting the potential for

complicated grief. Understanding risk factors and their place in predicting complicated grief will enhance the work of hospice professionals and grief therapists.

Hospice has identified seven risk factors (protective factors) in predicting the potential for complicated grief: 1) the lack of a good support system; 2) poor spiritual health; 3) poor emotional health; 4) multiple losses in the past five years, 5) financial issues, 6) substance abuse, and 7) relationship with the person who died.

Hospice considers social support to be a protective factor, and there is evidence in the literature that supports this idea. According to a 2014 study, social support is effective in decreasing the pain connected with experiencing sudden loss (Dyregrov, et al., 2014). A good support system helps people who experience loss to have better mental health, superior physical health, and longer life (Dyregrov, et al., 2014). A 2016 study that focused on older adults found that external connections (social support system) were one of nine protective factors related to resilience in confronting hardship (Bolton & Praetorius, 2016). A 2017 study of adults who lost a spouse found that one of the strongest predictors of resilience was the sustained participation in regular life events and in social relationships, followed by the belief that they would get support when in distress (Infurna and Luthar, 2017). A 2015 study of grieving spouses reported that their support systems helped them by: 1) being interested, and by 2) listening to their distresses. These same individuals reported that they needed to be willing to rely on others, and if so, they experienced lower levels of loneliness (Mancini, et al., 2015). Social support in each of these situations was indicative of healthy and successful grieving.

However, there are other studies which suggest that social support may not effectively mitigate complicated grief. A 2005 study focused on women who experienced

recent loss and bereavement. This investigation utilized data from the Changing Lives of Older Couples study, which included 1532 married couples 65 years old and over.

Although social support showed a significant effect on depression, there was nothing indicating that social support had a buffering or recovery effect on bereavement (Stroebe, et al., 2005). Similarly, a 2013 study showed that, although social support was seen as a buffer initially in the grieving process, it did not continue to be significant after controlling for other factors (Allen, et al., 2013). Therefore, the quality of social support, more than the presence of social support, might be a potential factor buffering some individuals from complicated grief.

Conversely, social support, in the context of bereavement, has been shown to occasionally be ineffective (Mancini, et al., 2015). Poor social support can make the problem worse, distance friends, and negatively impact health (Dyregrov, et al., 2014). A 2015 study examined the grief trajectories 115 people between one and a half and three years following the death of their spouse. They found that those with symptoms of complicated grief had negative perceptions of members of their support system (Mancini, et al., 2015), and did not experience a willingness of others to listen to their concerns (Mancini, et al., 2015). Furthermore, whether or not people who are grieving actually desire social support has not been thoroughly investigated (Bottomly, et al., 2017), nor has personality type and different types of social support been adequately addressed. Therefore, although traditional hospice bereavement care has considered social support to be a buffer against complicated grief, the singular effectiveness of social support to mitigate grief continues to be a question of relevance. The place of social support acting as a buffer to complicated grief warrants further study (Allen, et al., 2013).

A second risk (protective factor) used by hospice professionals to predict complicated grief is the presence (or absence) of an expression of faith. Religious coping is defined as the utilization of religious and spiritual behaviors in order to handle stress (Wortman & Park, 2008). Examples of this would be praying and attending church. Religious coping has been shown to be beneficial to the grieving process, helping with the adjustment to the death (Wortman & Park, 2008). A 2008 study suggests that an experience of faith benefits the grieving process by giving hope and/or comfort to the grieving individual if the faith experience is healthy (Edmonson, et al., 2008). The expectation of immortality is a comfort to those facing the end of life (Edmonson, et al., 2008).

Although faith is often part of a person's coping repertoire, not all individuals find spirituality beneficial. Sometimes grief causes a person to become angry at God or at their community of faith or have feelings of being abandoned, or to experience crises of faith (Burke, et al. 2011). To this end, a study of African American survivors of homicide found that negative religious coping was related to complicated grief, and positive religious coping had no effect on whether or not someone ultimately experienced complicated grief (Burke, et al., 2011). Although traditional hospice practice advocates for the presence of the religious in working with grieving individuals, nothing definitive has yet been established in the literature concerning the effect of religion on the grieving process. Because of this, some authors suggest that further study on the buffering effect of religion with regard to grief is warranted (Van Der Houwen, et al., 2010; Becker, et al., 2007).

A third risk factor is the lack of adequate coping skills (used to indicate emotional health). Recent studies have found evidence to suggest the accuracy of this assumption. For example, a 2016 study of spousal bereavement examined psychological adaptation of those entering widowhood (Spahni, et al., 2016). They considered trait resilience, marital history and context of death. Of these three, the most effective indicator of psychological adaptation was trait resilience (Spahni, et al., 2016). A 2013 study of bereaved spouses found that trait resilience clearly predicted state hopefulness, distress disclosure and boundary turbulence. The latter two were predictors of life satisfaction, making resilience an indirect indicator of life satisfaction (West, 2013). A 2010 study that pertained to positive emotions and spousal loss found that trait resilience significantly predicted positive emotion in the experience of significant adversities in life (Ong, et al., 2010). Lower levels of trait resilience prior to widowhood were related to lower levels of positive emotion after the loss of a spouse (Ong, et al., 2010).

The studies that have been done around trait resilience have suggested that it benefits positive thought, and thereby assists with the bereavement process. The current study will add to the field by confirming the presence of trait resilience as a mitigating factor with regard to complicated grief.

Another risk factor identified by hospice is multiple previous losses. A study concerned with complicated grief and members of the military found that there was a correlation between the amount of loss a member of the military experienced, and scores on the Inventory of Complicated Grief (ICG). The ICG is a survey used to identify symptoms of complicated grief. This suggests that multiple losses may make a member of the military more prone to experience complicated grief (Delaney, et al., 2017).

Similarly, a 2015 study addressed the multiple losses that refugees from war scarred countries had experienced prior to living in refugee camps in North America and identified the connection between multiple loss and complicated grief (McLellan, 2015). A 2006 study pertaining to childhood pet bereavement discusses multiple losses in the context of complicated grief (Kaufmann & Kaufmann, 2006). These studies suggest that multiple losses within a relatively short period of time are a risk factor for complicated grief. But these studies are few. Further study is warranted.

Substance abuse, is also a commonly agreed risk factor for complicated grief. Those who experience complicated grief have more mental health issues of which substance abuse is one, (Ott, 2003). A 2016 study looked at the potential for suicide among those who are substance dependent. The study consisted of 196 substance dependent people who had been clean and sober for at least a month and had lost a loved one at some point in their life (at least a year prior to the study) (Masferrer, et al., 2016). Sociodemographic information was considered, and the ICG was administered to the participants. Of the 196 participants, 67 showed evidence of complicated grief, and 85.1% of these individuals were at risk of suicide (Masferrer, et al., 2016). This study underscores the connection between substance use and complicated grief.

A study in 1990, showed that financial stress effected bereavement in older people experiencing the loss of a spouse. Financial issues, were among the life stressors that led to increased bereavement related depression (Norris & Morrell, 1990). Widows, facing financial stress experienced greater bereavement related depression, than parents who had lost a child, or adults who had lost a parent (Norris & Morrell, 1990). Financial stress is harmful, and a risk factor to successful resilience.

Methods

Sample

The population from which this sample was taken were family members of hospice patients who died on service. Participants were adults over twenty-one years old, who experienced the death of a primary relationship between twelve and thirty months prior to this study. A 'primary relationship' was defined as spouse, parent, child or sibling. Also included in this study were significant others, close friends and other family members who acted as caregivers to the patient or who were relationally close to the patient. Participants were required to be able to read and speak English.

Participation in the survey was voluntary. Names of potential participants were derived from the medical records of hospice patients who had died on service between twelve and thirty months prior to the study. They were informed of the survey and invited to participate. If they agreed to participate, an informed consent process was administered. Then a phone survey was conducted. Some participants requested that the survey be mailed or e-mailed to them. Their responses are included with those who took the phone survey.

In this study, the sample consisted of 155 participants. Patients ranged in age from 22 to 95. Most (93.3%) of the patients were between fifty and eighty-nine years old and 63.5% of the patients were between 70 and 89 years old. This reflects the age of hospice clientele. Hospice is an end of life program that works with patients who have an incurable illness, which sometimes lingers for several months or longer. Although younger people do suffer from incurable illnesses (4.1% percent of the patients in our study are under forty years old), the potential for life debilitating illness increases with

age. For this reason, hospice is populated (mostly, but not exclusively) by older patients. Because of current life longevity, the number of patients on hospice decreases as patients move into their nineties. In our study, there is only a small percentage of patients (1.3%) in their nineties, and there are no centenarians.

Information was collected about the patient's gender, marital status and ethnicity from hospice medical records. Most (58.9%) of the patients in this study are women. The majority of patients (68.9%) are white or Hispanic (18.2%). Asian and African American patients together accounted for 12.8% of the study. Most of the patients in the study were either married (42.4%) or widowed (32.6%) at the time of death, and 25% were either single or divorced. Thirty-two participants (20.6%) were the spouse of the patient; twenty-seven participants (17.4%) were the son of the patient; and forty-four participants (28.4%) were the daughter of the patient. Of the demographics collected identifying the gender of the participant, more than twice as many women (68.9%) as men (31.1%) participated in the survey. Participants were limited to those grieving a loss by death that had happened 12 to 30 months prior. The majority of participants who took the survey had experienced the loss of their loved one between twenty-four and thirty months prior (90.4%).

Table 5. Demographic summary of sample

Characteristic	F (%)	Characteristic	F (%)
Patient Gender		PCG Gender	
• Male	61 (41.2)	• Male	42 (31.1)
• Female	87 (58.8)	• Female	93 (68.9)
Patient Marital Status		Patient Ethnicity	
• Married	61 (42.4)	• White	102 (68.9)
• Widowed	47 (32.6)	• Hispanic	27 (18.2)
• Single/Divorced	36 (25.0)	• Other	19 (12.8)
PCG Relationship		Patient Age at Death	
• Spouse	32 (26.0)	• 20-39	6 (4.1)
• Son	27 (22.0)	• 40-59	20 (13.6)
• Daughter	44 (35.8)	• 60-79	58 (39.2)
• Other	20 (16.3)	• 80-95	64 (43.2)
Months Since Death			
• 13-19	5 (3.4)	• 25-26	35 (23.6)
• 20-22	2 (1.4)	• 27-28	35 (23.6)
• 23-24	31 (20.9)	• 29-30	40 (27.0)

Measures

The survey consisted of sixty-seven questions from three previously published and widely used measures. Two were resilience measures: the Individual, Family and

Community Resilience Profile (IFCR) and the Brief Cope Measure (BCM). The third measure was the Inventory of Complicated Grief (ICG).

The *IFCR*, developed in 2015 is a multidimensional resilience assessment that measures family, individual and community resilience (Distelberg, et al., 2015). It is multidimensional in that it assesses twenty separate dimensions of resilience constructs in order to measure resilience (Distelberg, et al., 2015). The IFCR displayed strong reliability among inter-item reliability coefficients, with the alpha between a low of .71 and a high of .83; it also presented convincing predictive proficiencies (Distelberg, et al., 2015). Our study used the portion of this measure related to family, social and community support. In each scale, a higher score indicates a higher level of resilience.

The *BCM*, developed in 1997 has been used to help determine an individual's ability to cope with complex and difficult life events (Carver, 1997). The BCM is a brief form of the previously developed COPE Inventory, developed in 1989, shown to be effective in measuring levels of resilience (Carver, 1997). The BCM excludes two scales of the full COPE and lessens the other scales to two items per scale (Carver, 1997). Reliability tests showed that the alpha values exceed .50 in all scales, supports the internal reliability of the BCM (Carver, 1997). The BCM has fourteen categories of coping with two questions each (Carver, 1997). This study used eight of those categories. A higher score indicates a higher level of coping.

The *ICG* developed in 1995 is a nineteen item survey used to assess specific symptoms to predict a bereaved person's inability to adapt back into normal life routines (Prigerson, et al., 1995). Each question has five possible answers: never, rarely, sometimes, often or always. These questions are scaled 0 (never) to 4 (always). The

lowest possible score for the ICG is 0, and the highest possible score is 76. A score over 25 indicates complicated grief (Prigerson, et al., 1995). The ICG has previous evidence of good internal consistency (Simon, et al., 2011). The ICG is used to determine the presence of complicated grief in persons who have been grieving the death of a close relationship for more than a year. A higher score indicates greater complicated grief.

Demographic information was collected from medical records, specific to the patient who died. This information was de-identified prior to analysis. Demographic information collected included: age, gender, marital status, ethnicity, and religion of the patient; the patient's hospice diagnosis; and the length of time since the patient had died. Also collected was the relationship of the person who died with the participant taking the survey and the gender of the participant taking the survey. Also included in the survey were three "yes or no" questions which pertain to previous losses, whether or not the death was sudden or unexpected, and whether or not the caregiver was able to be with the patient prior to the patient's death.

Analytic Strategy

The independent or predictor variables in this study were six of the seven risk factors identified by hospice as predictors of complicated grief. Five of these risk factors (spiritual health indicated by an expression of faith; the lack of an adequate support system; emotional health indicated by adequate coping skills; substance use) were determined using the Individual, Family and Community Resilience Profile and the Brief Cope Measure. For this study, three types of social support were identified: family support, social support and community support, and each of these were included as a

separate independent variable. In addition, multiple losses (binary variable) and the relationship to the deceased were added as additional variables.

In order to determine how well hospice determined risk factors predict complicated grief, a stepwise multiple linear regression was performed. Pre-test assumptions were shown to have been satisfied. Scatterplot tests and P—P plots show that assumptions of linearity and homoscedasticity were satisfied, and the assumption of normality was met. The specification of relationship between independent variables and the dependent variable was correct. Tolerance and VIF scores show that assumptions of collinearity were satisfied. The Durbin-Watson statistic shows that the assumption for independence of residuals has been satisfied. The independent variables were chosen based on theory, thus insuring their relevance to the study.

In this study, good coping skills are used as an indicator of emotional health. Hospice considers healthy coping skills to include: resilience, the ability to compartmentalize, an internal locus of control, having outside interests and hobbies (Vitas, 2017). This study used eight questions from the BCM in order to determine the coping skills of the participant. Participants were asked to what extent they participate in the following: You've been saying to yourself, "this isn't real". You've been giving up trying to deal with it. You've been refusing to believe that it has happened. You've been trying to see it in a different light, to make it seem more positive. You've been giving up the attempt to cope. You've been looking for something good in what is happening. You've been accepting the reality of the fact that it has happened. You've been learning to live with it.

Hospice considers spiritual health to be a concern (Vitas Healthcare, 2017). The presence of an expression of faith is an indicator of spiritual health. This study examined the presence of a faith expression in bereaved individuals, how this was used in the bereavement process, and in particular, if people were able to use their faith expression as a way of avoiding complicated grief. This study used three questions from the IFCR profile and two questions from the BCM, which pertain the expression of faith.

The lack of an adequate support system in this study was determined by the IFCR and the BCM. Three types of support system were considered: family support (including extended family), community support (the neighborhood and community where the bereaved person lives), and social support (friends and associates, including work, school associates and others with whom the participant socializes), and each was entered as a separate variable.

Family support is determined using six questions from the IFCR, community support was determined using six questions from the IFCR and social support was determined by using four questions from the BCM and two questions from the IFCR.

Prior loss is a concern. The concern includes whether this is the first major loss the participant has experienced, and, conversely, whether there have been several losses within a relatively short time span (Vitas Healthcare, 2017). The participant's experience coping with loss is also a concern (Vitas, 2017). This study addresses prior loss by asking the participant one "yes or no" question: "Have you experienced other losses of a close relationship in the past 5 years?"

Hospice considers the type and quality of the relationship the participant had with the person who died to be a concern with regard to complicated grief (Vitas Healthcare,

2017). Our study does not address the nature of the relationship. It does, however, address the type of relationship: how the participant was related to the patient.

Hospice considers substance abuse to be a risk factor for complicated grief. This study addresses that issue with two questions from the BCM. Participants are asked to what extent they participate in the following: You've been using alcohol or other drugs to help you get through it. You've been using alcohol or other drugs to make yourself feel better.

Results

The Inventory of Complicated Grief scores ranged from 0 to 56; the median score was 15.5; the mean was 13.5. The results indicated that 28 people (18.1%) scored in the range of complicated grief. This prevalence rate is comparable to what has been written previously (Mancini, et al., 2015; Simon, 2013; Bonanno, et al., 2005). For example, a 2015 study found that about 10% to 15% of the population fails to adjust after the loss of a close relationship (Mancini, et al., 2015), thus experiencing complicated grief. Other studies have suggested that complicated grief is as low as seven percent of the population (Simon, 2013), to as high as 20% of the population (Bonanno, et al., 2005). The results of our study, showing 18.1% of the participants experiencing complicated grief is very similar to what other studies have found.

Next, multiple linear regression models were fit to estimate the value of each risk and protective factor. Predictor variables entered for Model 1 were the demographics: the age of patient, the number of months since the patient's death, the patient's gender, the participant's gender, the patient's ethnicity, the patient's marital status and the

relationship of the patient to the participant. The dependent or outcome variable was complicated grief. This model explains 24.2% ($R^2 = .242$) of the variance ($F_{(11, 105)} = 3.043$). The demographics predict 24.2% of the level of complicated grief.

For Model 2, a multiple linear regression was performed and additional independent variables were entered as a stepwise function to model 1 (above). These new variables in model 2 were: social support, community support, family support, coping skills, an expression of faith, recent multiple losses and substance use. Of these seven predictors, only one significantly improved the model: the lack of adequate coping skills. Model 2 shows that the demographic predictors and lack of adequate coping skills are significant predictors of complicated grief.

Model 2 explains 27.9% of the variance ($R^2 = .279$). This is an increase in the variance explained by 3.8% over Model 1 (R^2 change = .038). This change is significant ($F_{(1, 104)} = 5.417$; $p = .022$). The addition of this variable (coping skills) enhances the predictability of the model.

Table 6. Model Summary^c

Model	R	R^2	Adjust. R^2	R^2 change	F change	df 1	df 2	Sig F Change	Durbin Watson
1	.492 ^a	.242	.162	.242	3.043	11	105	.001	
2	.528 ^b	.279	.196	.038	5.417	1	104	.022	1.786

a. Predictors: (Constant), relationship to patient, patient's gender, patient's ethnicity, time passed since patient's death, patient's marital status, participant's gender

b. Predictors: (Constant), relationship to patient, patient's gender, patient's ethnicity, time passed

since patient's death, patient's marital status, participant's gender, coping skills

c. Dependent Variable: complicated grief

As is shown in table seven, when coping skills increase, complicated grief scores decrease ($\beta = -.219$), which indicates that coping skills significantly predict complicated grief ($p < .05$). The other variable that was significant in this model was the gender of the patient. As is shown in table 3, when the gender of the patient is male, complicated grief decreases ($\beta = -.238$). Conversely, when the gender of the patient is female, complicated grief increases. This model shows that the patient being a woman significantly predicts the potential for complicated grief ($p < .05$).

Table 7. Coefficients Model

	Model 1			Model 2		
	B	Std. Error	β	B	Std. Error	β
(Constant)	34.763	12.366		52.828	14.387	
Age of Patient	-.168	.086	-.209	-.123	.086	-.153
Months since death	-.088	.382	-.021	-.078	.374	-.018
Patient's Gender	-4.293	2.392	-.189	-5.386	2.390	-.238*
Participant Gender	6.230	3.804	-.260	-6.866	3.736	-.286
Ethnicity (Hispanic)	.476	2.568	.017	1.294	2.540	.046
Ethnicity (Other)	4.504	3.058	.135	3.484	3.027	.104
Marital Status (Widowed)	-1.381	3.136	-.060	-.306	3.107	-.013
Marital Status (Other)	2.295	3.535	.086	3.113	3.481	.116
Rel. to Patient (Son)	-2.638	4.734	-.096	-5.227	4.769	-.189
Rel. to Patient (Daughter)	.822	3.731	.035	-2.094	3.863	-.090
Rel. to Patient (Other)	-5.283	4.145	-.197	-6.551	4.072	-.221
Coping Skills				-.740	.318	-.219*

*p<.05

Discussion

The purpose of this study was to investigate the risk factors used by hospice to predict the potential for complicated grief in the families of hospice patients. Hospice identifies seven risk factors, which they train their staff on, and gear screening and resources towards. Six of these risk factors were tested: poor spiritual health as indicated by a lack of expression of faith, lack of an adequate support system, poor emotional health, as indicated by a lack of adequate coping skills, previous losses, substance abuse, and the type of relationship with the patient. Data was collected through a phone survey. Participants in the survey were family members and/or friends of persons who had died on hospice twelve to thirty months prior. The survey consisted of two resilience measures: the Brief Cope Measure (BCM) and the Individual, Family and Community Resilience Profile (IFCR); and one complicated grief measure: the Inventory of Complicated Grief (ICG). Three additional questions (about previous loss, being present during the illness, and whether or not the patient's death was expected) were also included. Data was analyzed using a multiple regression in order to determine the prevalence and value of these risk factors as predictors of complicated grief. Demographic material was also included in the linear regression. Only one of the six risk factors, the lack of adequate coping skills, was shown to be significant. One demographic factor, not previously considered by hospice to be a risk factor, was also shown to be significant: the gender of the patient.

These findings agree with much of what has been written (Spahni, et al., 2016; Mancini, et al., 2015; Walsh, 2003). For example, a 2016 study of spousal bereavement (Spahni, et al., 2016) showed that trait resilience was an effective indicator of

psychological adaptation, more so than other factors considered (Spahni et al., 2016). Resilience has been viewed through a strengths based lens (Walsh, 2003), which may be broadly interpreted as a skill or a strength personally acquired, not contingent on outside resources. Resilience has been identified as something that everyone has (Grafton & Gillespie, 2010), which lends to the interpretation that resilience is a skill personally owned, not dependent on other factors. These definitions describe coping skills, confirmed in this study to be a significant factor in predicting complicated grief. Because most people have sufficient resilience to navigate loss and avoid complicated grief (Mancini, et al., 2015), and because of the significance of the correlation between coping skills and complicated grief, it can be assumed that coping skills are normal, common and necessary.

The theoretical framework for this study draws from the Family Resilience Model developed by Walsh (2016, 2012), and the Family Resilience Model developed by Henry, et al. (2015). Included in the model presented by Walsh (2016), is the concept of making meaning. In Walsh's perspective, meaning making is characterized by ways of dealing with trouble (Walsh, 2016). Furthermore, Henry, et al. (2015) includes perceptions of how hardships and resilience relate in describing meaning making as part of the Family Resilience Model (Henry, et al., 2015). A family's ability to regulate emotions (Henry, et al., 2015), describes a family's coping skills. Walsh (2016) believes that unrelenting difficulties, catastrophic happenings, and unsettling changes empower families, making them stronger, more resourceful, better able to fully love and be more competent in family life (Walsh, 2012). Walsh insists that these pressures have the capacity to make families stronger (Martin, 2011). For Walsh, coping skills are not only an effective way

of confronting crisis (bereavement), but also a path toward greater family competence.

The presence of an adequate support system was not shown to be a significant predictor of complicated grief. This agrees with other studies previously mentioned in which there was no evidence that social support mitigated bereavement (Stroebe, et al., 2005), or continued to mitigate grief after controlling for other factors (Allen, et al., 2013). The quality of the support system determines its effectiveness (Dyregrove, et al., 2014; Bottomly, et al., 2017).

This study did not assess the quality or desirability of a support system, but rather whether or not it existed. Because of this, and because of the studies that have shown the effectiveness of social support when utilized appropriately (Infurna and Luthar, 2017; Bolton & Praetorius, 2016; Dyregrove, et al., 2014), the value of social support is not to be discounted. In addition to this, the theoretical framework for this study supports the desirability a support system in facing family crisis. Resilience is cultivated in relationships (Walsh, 2016). There is strength in collaboration, such that mutual support is key to conquering life's adversities (Walsh, 2016). Support system was viewed as family support, community support and social support, each being considered independently. Although, in our study, none of these were shown to be a significant predictor of complicated grief, further study as to the effectiveness and proper utilization of social support is warranted.

The lack of an expression of faith was not shown to be a significant predictor of complicated grief in this study. This result agrees with the studies which show that religion can have no buffering effect on grief (Burke, et al., 2011), or a negative effect on

the grieving process (Burke, et al., 2011). Therefore, faith can be useful in some cases, but coping traits are likely a universal and stronger predictor of grief overtime.

Questions that assessed the level of religiosity asked about church attendance, participation in religious activities, prayer and meditation in the context of family difficulty or grief. Many participants are not religious and responded accordingly, lack of participation was indicative of a lack of religiosity. Many other people, however are very religious and participate in some or all of those activities on a regular basis. Such activities are part of life and are not a response to grief or crisis. Some very religious people, who attend church on a regular basis, may have indicated that they did not attend church in order to help them deal with bereavement, because their attendance is not based on seeking help with grief, but their attendance is based on life style. This study was not an adequate measure of the level of the religiousness of the participants. This study measured whether participants used their religion as a buffer to bereavement. Both religious and non-religious people reported that they did not. Our study shows that faith, by itself, may not be an effective buffer to bereavement.

The theoretical framework of this study includes spirituality as integral to confronting crisis. Both Walsh (2016) and Henry, et al. (2015) acknowledge the presence of the spiritual. Walsh believes that shared belief systems includes the concept of spirituality, that there is something over and beyond ourselves that empowers and therefore enhances resilience (Walsh, 2016). She also emphasized the need for hope (Walsh, 2016). Henry et al. (2015) talked about meaning making, and world views (Henry, et al., 2015).

Our study did not differentiate between spirituality and religion, something indicative of most studies of religion, spirituality and bereavement (Van der Houwen, et al., 2010). It is common in the literature view religiosity and spirituality interchangeably (Van der Houwen, et al., 2010). Our study looked at religious activity (church attendance, participation in religious activities, prayer, meditation, etc.). Viewing spirituality on its own terms, separate from religiosity in the context of our study may yield different results.

Substance use was not found to be a significant predictor of complicated grief. This is in direct conflict with a 2016 study that found a direct correlation between substance abuse and complicated grief (Masferrer, et al., 2016). The population from which that sample was taken was substance dependent people in recovery. The population from which the sample for our study was taken were families who had used hospice services, with no stipulation concerning prior or current substance abuse. Most of the participants surveyed said they did not use alcohol or other substances to help them get through the bereavement process. Subsequently, there were few responses from people who admitted to using substances as a way of coping with loss. A different population, or larger sample size may have yielded different results.

Our study measured responses from spouses, sons, daughters and other relatives of patients who died, and found that the type of relationship did not significantly predict complicated grief. Although the type of relationship was not a significant predictor of complicated grief, the gender of the patient was a significant predictor. If the patient is a woman, the caregivers, and relatives are more likely to experience complicated grief.

There have been a myriad of studies concerning spousal coping and illness (Berg

& Upchurch, 2007), and the distress suffered in the face of spousal illness. According to the literature, women utilize coping skills more successfully than men. A 2002 study used meta-analysis to show that women had a stronger likelihood than men to utilize coping methods (Tamres & Janicki, 2002). There was a stronger likelihood for women to express themselves verbally and pursue encouragement from others. They were more likely to reflect on their issues, and utilize self-encouragement (Tamres & Janicki, 2002). Women are more open about their discomfort, more willing to talk about their issues, and more likely to seek support from friends or professionals (Altschuler, 2015). A 2005 study of male and female graduate students showed that female students had better coping skills than their male counterparts (Matheny, et al., 2005). Inadequate coping skills were seen as indicative of increased vulnerability to illness for both male and female students, however, the coping resource effectiveness of women graduate students was significantly greater than that of male graduate students (Matheny, et al., 2005). These studies suggest that women are better at cultivating supportive relationships, and utilizing coping mechanism outside of themselves. Therefore, when women experience loss of a partner, they are better equipped to cope. Men have a tendency to present and practice as independent, whereas women are more given to interdependence (Berg & Upchurch, 2007). A 2015 study addressed gender identities, and observed that the current dominate approach places boys and men as sturdy and self-sufficient and girls and women as caring and nurturing (Altschuler, 2015), and this informs how each gender responds to stress. Men are more likely to attend to problem solving, being private about their distress, fearing helplessness and loss of power (Altschuler, 2015). A 1998 study observed the benefit of women talking with their spouse versus talking with peers about their illness.

Women diagnosed with cancer spoke with their partners about their illness. They then spoke with other cancer patients. Trained observers found the latter to be more supportive, and more beneficial than the former, although the patients themselves found both types of conversation helpful (Pistrang & Barker, 1998). Women, who are able to talk about their illness, are better able to face their illness.

Our study, however, was not limited to spousal relationships. Our study measured responses from spouses, sons, daughters and other relatives of patients who died, and found that when the patient was a woman, the possibility of complicated grief increased. Women traditionally have more close relationships than do men, although this does not always lead to more happiness (Antonucci, et al., 1998), but it does indicate that there will be more people affected by a woman than by a man. Family members depend on women. A 2002 study acknowledged that the caregiving function is currently in the domain of women (Hagedoorn, et al., 2002). Taking care of family members, and continuing to cultivate social relationships is in the purview of women (Hagedoorn, et al., 2002). It is this caregiving identity that determines the level of distress women feel when their partner is ill. Because of the inherent nature of caregiving in women's identity, women feel more distress in the face of spousal illness than their male counterparts when they feel unsuccessful at caregiving. When women do not feel unsuccessful at caregiving, the level of distress is the same (Hagedoorn, et al., 2002). Women are more involved as caregivers for all members of the family than are men (Altschuler, 2015). For this reason, it is possible that the caregiving activities of women are inherent in the loss family members and friends feel when a woman dies, thus increasing the potential for complicated grief.

Women also identify themselves in terms of emotional relationships; characteristics such as understanding, sensitivity, affection are ascribed more to women than to men (Hagedoorn, et al., 2002). A study in 2000 suggested that women respond to stress with a “tend and befriend” pattern in addition to the traditional “fight or flight” pattern (Taylor, et al., 2000). Tending includes nurturing, protecting behaviors, intended to foster security and decrease stress. To befriend is to establish and nurture friendships and associations that will help with the tending behaviors (Taylor, et al., 2000). For this reason, women cultivate more intimate relationships with friends and family members than do their male counterparts. It is the loss of this closeness that is felt when a woman dies, thus increasing the potential for complicated grief.

Our study also asked if participants had experienced other losses in the past five years, and found that multiple losses were not a significant predictor of complicated grief. Given the results of our study, present coping skills may be more effective than past experience in mitigating complicated grief. While inadequate coping skills will impede a person’s ability to cope with loss, adequate coping skills may enable a grieving person to cope with multiple loss.

Implications for Practice

Hospice professionals have traditionally looked for risk factors in order to predict the potential for complicated grief in the families of patients who have died on service. Recognizing the risk factors that are significant will enable hospice professionals and grief therapists to be more precise in identifying the potential for complicated grief. This study has shown that many of the risk factors currently identified by hospice

professionals may not adequately predict the potential for complicated grief.

Pragmatically, this study suggests how hospice professionals can best assess the needs of their clientele in order to better predict the potential for (and possibly avoid) complicated grief. For example, this study has shown that it might be more beneficial to assess for the adequacy of coping skills in family members of patients, than to assess for previous loss, an expression of faith or type of relationship with the person who died. The results of this study also show that the lack of a support system may not significantly predict complicated grief, thus possibly decreasing the emphasis on the universal benefit of social support.

Clinically, this study suggests that hospice bereavement specialists and grief therapists to focus more on the adequacy of the coping skills of their clientele, and to put more emphasis on building or enhancing coping skills in family members of patients who are dying. Often, people know whether or not they have good coping skills. When the initial clinical assessment indicates that a family has adequate coping skills, clinicians should work to enhance those skills. A clinical assessment indicating a lack of adequate coping skills would allow the clinician to immediately create a plan of care that would address complicated grief. This plan of care should have a dual focus. First, a focus on grief and bereavement therapy to address the issue clinically. Second, the creation of a system to care for the patient who will, potentially be experiencing these debilitating symptoms. Ideally, all of this would begin with assessment at the beginning of service, as opposed to a year following active symptomology, when complicated grief is diagnosed.

Theoretically, this study confirms and enhances aspects of the family resilience theory developed by Walsh (2016) and Henry (2015). It confirms the theory by the

connection of coping skills to various aspects of the theory. In Walsh (2016), coping skills connects with: normalization of the crisis as one of the shared belief systems; the ability to rebound and reorganize, which is one of the family organizational processes; and collaborative problem solving, which is part of effective family communication.

In Henry, et al. (2015) adequate coping skills connect with the four basic elements of resilience: risk, protection, vulnerability and adaptation; coping skills also connect with meaning adaptive systems, which include family perceptions of how hardships and resilience are to be navigated. This study enhances aspects of the family resilience theory by emphasizing the importance of adequate coping skills. Since lacking adequate coping skills was significant as a predictor of complicated grief, more significant than any other factor tested, it may be that more emphasis needs to be put on adequate coping skills in the areas where it is discussed in the family resilience model.

Limitations

This study was done in the context of hospice. The sample is a convenience sample in which most of the participants were family members or friends of people who died on service. This study worked with one hospice organization in one part of the country. Therefore, it does not adequately measure risk factors and resilience outside of the hospice environment. It is possible that the presence of hospice mitigates the grieving process. This study did not measure the level of change hospice brings to the experience of grief, nor did it examine hospices in other parts of the country. It is possible that grief is either enhanced or mitigated by the environment.

Suggestions for Further Study

Further study would benefit the field by studying resilience and risk factors and complicated grief outside of the hospice environment, and in other parts of the country in order to assess the difference, if any that the community environment has on the grieving process. Further study would also more closely examine some of the specific risk factors traditionally used by hospice, which were not significant in our study. With regard to social support, for example, further study would focus on its desirability; and on the effectiveness and relationship of social support to personality types. It is possible that social support for the extrovert is significant, but for the introvert is not, something our study did not test. The effect of an expression of faith on the grieving process needs further study, specifically the level of religiosity or spirituality as opposed to whether or not it is used by the individual or family as a buffer to crisis.

Conclusion

This study has shown that the most significant risk factor in identifying the potential for complicated grief is the lack of adequate coping skills. Understanding this will enable hospice professionals and grief therapists to more adequately assess for the possibility of complicated grief in their clientele, and to offer appropriate clinical interventions. This study is also beneficial to family therapists working with individuals and families who are facing end of life issues, to help guide the therapy. Finally, this study can be used as a basis for further research on how to predict and possibly avoid complicated grief.

CHAPTER SIX

SUMMARY

Use of the Information

The information gained through this study will enable hospice professionals and grief therapists to better understand complicated grief, how complicated grief differs from normal acute grief, and how to identify potential risk factors for complicated grief. This study will also be used by family therapists who are treating the bereaved among their own clientele. A therapist will be able to differentiate between complicated grief and normal acute grief and will be able to treat their grieving clients accordingly. Therapists will also know how to identify risk factors for predicting the potential for complicated grief in clients whose family members are currently facing end of life issues.

Grief is common; the distress to the person, the hurt to the community and the expense to society that accompanies complicated grief are considerable. Therefore, this study is both pertinent and appropriate to the business of couple and family therapy.

Determining the likelihood of for complicated grief based on the initial responses of the grieving individual at the time of the loss is not possible (American Psychiatric Association, 2013). The diagnosis of complicated grief only happens after a year of continued symptomology (American Psychiatric Association, 2013). Therefore, it is the responsibility of grief therapists and hospice professionals to find ways of predicting complicated grief prior to its diagnosis, to adequately treat and possibly prevent it.

Hospice professionals look for predictors of the likelihood for complicated grief (Vitas Healthcare, 2012). The purpose of this study was to test hospice determined risk factors in hospice patient families. Understanding risk factors and their place in

predicting complicated grief will enhance the work of hospice professionals and grief therapists.

This study interviewed family members, caregivers and/or close friends of hospice patients who had died between twelve and thirty months prior, using two resilience measures (the Brief Cope Measure and the Individual, Family, and Community Profile) and one complicated grief measure (the Inventory of Complicated Grief).

The predictor variables in this study were six of the seven risk factors identified by hospice as predictors of complicated grief. In order to clarify whether these factors adequately predict complicated grief, a stepwise multiple linear regression was conducted. The results of this study show that lacking coping skills is a significant as a predictor of complicated grief; none of the other hospice determined risk factors were significant. Also significant was the gender of the patient.

Implications in Relation to This Topic

This study has shown that many of the risk factors currently identified by hospice professionals do not adequately predict the potential for complicated grief. This implies need for further study concerning predictors of complicated grief. It also implies that hospice professionals and grief therapists redirect their focus away from traditional predictors in order to assess predictors shown to be significant.

Pragmatically, this study suggests how hospice professionals and grief therapists can assess the needs of their clientele in order to better predict the potential for complicated grief. It also gives grief therapists and hospice professionals the tools to help their clients to possibly avoid complicated grief. The results of this study show that the

lack of a support system does not significantly predict complicated grief. Understanding this will decrease the emphasis on the universal benefit of social support. This study has also shown that it would be more beneficial to assess for the adequacy of coping skills in family members of patients, rather than to assess for previous loss, an expression of faith or the type of relationship with the person who died.

Implications for the Field of Couple and Family Therapy

Practice

Clinically, this study suggests that hospice bereavement specialists and grief therapists work to build or enhance coping skills in family members of patients who are dying. Often, people know whether or not they have good coping skills. The clinical assessment includes questions to the individual or family about the adequacy of their coping skills. When the clinical assessment indicates that a family has adequate coping skills, clinicians work to enhance these skills. A clinical assessment indicating a lack of adequate coping skills would allow the clinician to immediately create a plan of care that would address and treat complicated grief. This plan of care would have a dual focus. First, it would focus on grief and bereavement therapy to address the issue clinically. Second, it would create a system to care for the patient who will be experiencing these debilitating symptoms. All of this would begin with assessment at the beginning of service, as opposed to a year following the death of the patient, and active grief symptomology, when complicated grief is diagnosed.

Theory

Theoretically, this study confirms and enhances aspects of the family resilience theory. It confirms the theory by the connection of coping skills to various aspects of the theory. In Walsh (2016), coping skills connects with: normalization of the crisis as one of the shared belief systems; the ability to rebound and reorganize, which is one of the family organizational processes; and collaborative problem solving, which is part of effective family communication.

In Henry, et al. (2015) adequate coping skills connects with the four basic elements of resilience: risk, protection, vulnerability and adaptation; coping skills also connects with meaning adaptive systems, which include family perceptions of how hardships and resilience are to be navigated. Since lacking adequate coping skills was highly significant as a predictor of complicated grief, far more significant than any other factor tested, it may be that more emphasis needs to be put on adequate coping skills in the areas where it is discussed in the family resilience model.

Research

This study confirms research that questions the usefulness of many of the traditional predictors of complicated grief. The field would benefit from further research that more closely examines some of the specific risk factors traditionally used by hospice, which were not significant in our study. With regard to social support, for example, further study would focus on its desirability; and on the effectiveness of social support with different personality types, specifically how an introvert responds to social support verses how an extrovert responds to social support. It is possible that social support for

the extrovert is significant, but for the introvert is not, something our study did not test. The effect of an expression of faith on the grieving process also needs further study, specifically the level of religiosity or spirituality of the individual or family as opposed to whether or not it is used by the individual or family as a buffer to crisis.

Since the gender of the patient was a significant predictor of complicated grief, further study would be beneficial, to assess whether gender of the patient is significant for adults in all age groups, is limited to specific age groups. Further study would also focus on other factors that may influence this variable, such as the relationship between the gender of the patient, and the gender of the PCG; or the relationship between the gender of the patient and the relationship of the PCG to the patient.

REFERENCES

- Allen, J. Y.; Haley, W. E.; Small, B. J.; Schonwetter, R. S.; Millan, S. C. (2003). Bereavement among hospice caregivers of cancer patients one year following loss; predictors of grief, complicated grief, and symptoms of depression; *Journal of Palliative Medicine*; Vol 16(7); 745-751. Mary Ann Liebert, Inc.
- American Nurses Association (2017). <http://www.nursingworld.org/FlorenceSWald>.
- American Psychiatric Association (2013). Diagnostic and statistical manual of mental disorders, (5th ed). American Psychiatric Publishing.
- Anthony, E. E., Alter, C. F., Jenson, J. M. (2009). Development of a risk and resilience-based out of school time program for children and youths; *Social Work*, Vol. 54(1), 45-55. Oxford University Press.
- Antonucci, T. C., Akiyama, H., Lansford, J. E., (1998). Negative effects of close relations; *Family Relations, And Interdisciplinary Journal of Applied Family Studies*; Vol. 47(4), 379-384. Blackwell Publishing.
- Bailey, A., Hannays-King, C., Clarke, J., Lester, E., Velasco, D. (2013). Black mothers' cognitive process of finding meaning and building resilience after loss of a child to gun violence. *British Journal of Social Work*, Vol. 43(2), 336-354. Oxford University Press.
- Baker, A., W., Goetter, E. M., Bui, E., Shah, R., Charney, M. E., Mauro, C., Shear, M. K., Simon, N. M. (2009). The influence of anxiety sensitivity on a wish to die in complicated grief. *Journal of Nervous and Mental Disease* Vol. 204(4), 314-316. Lippincott, Williams, and Wilkins.
- Becker, G., Xander, C. J., Blum, H. E., Lutterbach, J., Momm, F., Gysels, M., Higginson, I. J. (2007). Do religious or spiritual beliefs influence bereavement? A systematic review. *Palliative Medicine* Vol. 21(3), 207-217. Sage Publications.
- Berg, C., & Upchurch, R. (2007). A developmental-contextual model of couples coping with chronic illness across the adult life span; *Psychological Bulletin* Vol. 133(6), 920-954. American Psychological Association.
- Boelen, P. A., & van den Bout, J. (2005). Complicated grief, depression and anxiety as distinct postloss syndromes: a confirmatory factor analysis study; *The American Journal of Psychiatry*, Vol. 162(11), 2175-2177. American Psychiatric Association.
- Bolton, K. W., Praetorius, R. T., Smith-Osborne, A. (2016). Resilience protective factors in an older adult population: a qualitative interpretive meta-synthesis; *Social Work Research*, Vol. 40(3); 171-182. Oxford University Press.

- Bonebrake, D., Culver, C., Call, K., Ward-Smith, P. (2010). Clinically differentiating palliative care and hospice, *Clinical Journal of Oncology Nursing*, Vol.14(3); 273-275. Oncology Nursing Society.
- Bonanno, G. A., Moskowitz, J. T., Papa, A., Folkman, S. (2005). Resilience to loss in bereaved spouses, bereaved parents and bereaved gay men. *Journal of Personality and Social Psychology*, Vol. 88(5); 827-843. American Psychological Association.
- Bottomley, J. S., Burke, L. A., Neimeyer, R. A. (2017). Domains of social support that predict bereavement distress following homicide loss: assessing need and satisfaction; *OMEGA—Journal of Death and Dying*, Vol. 75(1); 3-25. Sage Publications.
- Buck, J. (2009). ‘I am willing to take the risk’: politics, policy and the translation of the hospice ideal; *Journal of Clinical Nursing*, Vol. 18(19), 2700-2709. Wiley-Blackwell Publishing, Ltd.
- Burke, L. A., Neimeyer, R. A., McDevitt-Murphy, M. E., Ippolito, R. R. Roberts, J. M. (2011). Faith in the wake of homicide: religious coping and bereavement distress in an African American sample; *International Journal for the Psychology of Religion*, Vol. 21(4), 289-307. Taylor and Francis.
- Bryan, T. (2003). The applicability of the risk and resilience to social problems of students with learning disabilities: response to Bernice Wong; *Learning Disabilities Research and Practice*, Vol. 18(2); 94-98. Blackwell Publishing.
- Buzzanell, P. M. (2010). Resilience: talking, resisting and imagining new normalcies into being; *Journal of Communication*, Vol. 6(1); 1-14. Wiley-Blackwell Publishing, Ltd.
- Carton, S., Bayard, S., Paget, V., Jouanne, C., Varescon, I., Edel, Y., Detilleux, M. (2010). Emotional awareness in substance-dependent patients; *Journal of Clinical Psychology*, Vol. 66(6); 599-610. John Wiley and Sons.
- Carver, C. S., (1997). You want to measure coping but your protocol’s too long: consider the brief COPE; *International Journal of Behavioral Medicine*, Vol. 4(1); 92-100. Lawrence Erlbaum.
- Connor, S. R. (2007). Development of hospice and palliative care in the United States; *Omega, Journal of Death and Dying*, Vol. 56(1), 88-99. Baywood Publishing.
- Connor, K. M., Davidson, J. R. T. (2003). Development of a new resilience scale: the Connor Davidson resilience scale (CD RISC); *Depression and Anxiety*, Vol. 18(2); 76-82. John Wiley & Sons.

- Creswell, J. W. (2014). *Research design: qualitative, quantitative and mixed methods approaches*. Los Angeles: Sage Publishing.
- Delaney, E. M., Holloway, K. J., Miletich, D. M. Webb-Murphy, J. A., Lanouette, N. M. (2017). Screening for complicated grief in a military mental health clinic; *Military Medicine*, Vol. 182(9); e1751-e1756. Assn of Military Surgeons of the US.
- Dictionary.com, Unabridged (2018). Website: www.dictionary.com.
- Distelberg, B. J., Martin, A. S., Borieux, M., Oloo, W. A. (2015). Multidimensional Family Resilience Assessment-The Individual, Family and Community Resilience Profile (IFCR); *Journal of Human Behavior in the Social Environment*, Vol. 25(6); 552-570. Taylor and Francis.
- Dyregrov, K., De Leo, D., Cimitan, A. (2014). Peer support and self-help groups; in *Bereavement after traumatic death: helping the survivors*; De Leo, D (ed), Cimitan, A. (Ed), Dyregrov, K. (Ed), Grad, O. (Ed), Andriessen, K. (Ed); 137-142. Cambridge, MA, US: Hogrefe Publishing.
- Edmondson, D., Park, C. L., Chaudoir, S. R., Wortmann, J. H. (2008). Death without God: religious struggle, death concerns, and depression in the terminally ill; *Psychological Science* Vol. 19(8); 754-758. Wiley-Blackwell Publishing, Ltd.
- Field, N. P., Filanosky, C. (2010). Continuing bonds risk factors for complicated grief, and adjustment to bereavement; *Death Studies*, Vol. 34(1); 1-29. Taylor and Francis.
- Fletcher, D., Sarkar, M. (2013). Psychological resilience: a review and critique of definitions, concepts and theory; *European Psychologist*, Vol. 18(1); 12-23. Hogrefe Publishing.
- Fuerst, T. (2014). Ten things you should never say to a grieving person; *Ministry Matters.com*.
- Grafton, E., Gillespie, B., Henderson, S. (2010). Resilience: the power within; *Oncology Nursing Forum*, Vol. 37(6); 698-705. Oncology Nursing Society.
- Granek, L. (2010). Grief as pathology: the evolution of grief theory from Freud to the present; *History of Psychology*, Vol. 13(1); 46-73. Educational Publishing Foundation.
- Greene, R. R. (2014). Resilience as effective functional capacity: an ecological-stress model; *Journal of Human Behavior in the Social Environment*; Vol. 24(8); 937-950. Taylor and Francis.
- Hagedoorn, M., Sanderman, R., Buunk, B. P., Wobbes, T. (2002). Failing in spousal caregiving the identity-relevant stress hypothesis to explain sex differences in

- caregiver distress; *British Journal of Health Psychology*, Vol. 7(4); 481-494. The British Psychological Society.
- Hardison, H. G., Neimeyer, R. A., Lichstein, K. L. (2005). Insomnia and complicated grief symptoms in bereaved college students; *Behavior Sleep Medicine* Vol. 3(2); 99-111. Lawrence Erlbaum.
- Hargrave, P. A., Leathem, J. M., Long, N. R. (2012). Peritraumatic distress: Its relationship to posttraumatic stress and complicated grief symptoms in sudden death survivors; *Journal of Traumatic Stress*, Vol. 25(3); 344-347. John Wiley and Sons.
- Hedkte, C. L. (2010). Folding memories in conversations: remembering practices in bereavement groups (doctoral dissertation). Taos Institute, University of Tilburg.
- Henry, C. S., Morris, A. S. Harrist, A. W. (2015). Family resilience: moving into the third wave; *Family Relations: An Interdisciplinary Journal of Applied Family Studies*, Vol. 64(1); 22-43. Wiley-Blackwell Publishing, Ltd.
- Holland, J. M., Neimeyer, R. A., Doelen, P. A., Prigerson, H. G. (2009). The underlying structure of grief: a taxometric investigation of prolonged and normal reaction to loss; *Journal of Psychopathology and Behavioral Assessment*, Vol. 31(3); 190-201. Springer.
- Infurna, F. J., Luthar, S. S. (2017). The multidimensional nature of resilience to spousal loss; *Journal of Personality and Social Psychology*; Vol. 112(6), 926-947. American Psychological Association.
- Izumi, S., Nagae, H., Sakurai, C., Imamura, E. (2012). Defining end-of life care from perspectives of nursing ethics; *Nursing Ethics*, Vol. 19(5), 608-618. Sage Publications.
- Jenson, J. (2007). Research, advocacy and social policy lessons from the risk and resilience model; *Social Work Research*, Vol. 31(1); 3-5. Oxford University Press.
- Jordan, A. H., Litz, B. T. (2014). Prolonged grief disorder: diagnostic, assessment and treatment considerations; *Professional Psychology: Research and Practice*, Vol. 45(3), 180-187. American Psychological Association.
- Kaufman, K. R., Kaufman, N. D. (2006). And then the dog died; *Death Studies*, Vol.30(1), 61-76. Taylor and Francis.
- McCleary, J., Figley, C. (2017). Resilience and trauma: expanding definitions, uses and contexts; *Traumatology*, Vol. 23(1); 1-3. Educational Publishing Foundation.
- McLellan, J. (2015). Religious responses to bereavement, grief and loss among refugees; *Journal of Loss and Trauma*, Vol. 20(2); 131-138. Taylor and Francis.

- MacPhee, D., Lunkenheimer, E., Riggs, N. (2015). Resilience as regulation of developmental and family processes; *Family Relations: An Interdisciplinary Journal of Applied Family Studies*, Vol. 64(1); 153-175. Wiley-Blackwell Publishing, Ltd.
- Maltby, J., Day., L., Hall, S. (2015). Refining trait resilience: identifying engineering, ecological, and adaptive facets from extant measures of resilience; *PLoS ONE*, Vol. 10(7): e0131826. Doi:10.1371/journal. Pone.0131826. Public Library of Science.
- Mancini, A. D., Bonanno, G. A. (2012). The persistence of attachment: complicated grief, threat and reaction times to the deceased's name; *Journal of Affective Disorders*, Vol. 139(3); 256-263. Elsevier Science.
- Mancini, A. D., Sinan, B., Bonanno, G. A. (2015). Predictors of prolonged grief, resilience, and recovery among bereaved spouses; *Journal of Clinical Psychology*, Vol. 71(12); 1245-1258. Wiley Periodicals, Inc.
- Martin, A. S. (2011). Successful Aging Through A Family Resilience Lens; Doctoral Dissertation; Loma Linda University.
- Masferrer, L., Garre-Olmo, J., Caparros, B. (2016). Risk of suicide: its occurrence and related variables among bereaved substance users; *Journal of Substance Use*, 21(2); 191-197. Taylor and Francis Group.
- Masten, A. S. (2016). Resilience in developing systems; the promise of integrated approaches; *European Journal of Developmental Psychology*, Vol. 13(3); 297-312. Taylor and Francis.
- Matheny, K. B., Ashby, J. S., Cupp, P. (2005). Gender differences in stress, coping and illness among college students; *The Journal of Individual Psychology*, Vol. 61(4); 365-379.
- Mayo Clinic: mayoclinic.org (2017). Diseases and conditions: complicated grief.
- Meert, D. L., Sear, K. N., Newth, C. J. L., Harrison, R., Berger, J., Zimmerman, J., Anand, K. J. S., Carcillo, J., Donaldson, A. E. Dean, J. M., Willson, D. F., Nicholson, C. (2011). Follow-up study of complicated grief among parents eighteen months after a child's death in the pediatric intensive care unit; The Eunice Kennedy Shriver national Institute of Child Health and Human Development Collaborative Pediatric Critical Care Research Network; *Journal of Palliative Medicine*, Vol. 14(2); 207-214.
- Mercer, D. L., Evans, J. M. (2006). The impact of multiple losses on the grieving process: an exploratory study; *Journal of Loss and Trauma*, Vol. 11(3); 219-227. Taylor and Francis Group, LLC.

- Nelson, T. S., Allred, D. D. (2005). Survey research in marriage and family therapy. In Sprenkle, D. H. (Ed.) and Piercy, F. P. (Ed.), *Research Methods in Family Therapy*; 211-237. New York, NY: The Guilford Press.
- National Hospice and Palliative Care Organization (2016). NHPCO.org.
- Norris, F. H., Murrell, S. A. (1990). Social support, life events, and stress as modifiers of adjustment to bereavement by older adults; *Psychology and Aging*; Vol. 5(3); 429-436. American Psychological Association.
- Ong, A. D., Fuller-Rowell, T. E., Bonnano, G. A. (2010). Prospective predictors of positive emotions following spousal loss; *Psychology and Aging*; Vol. 25(3); 653-660. American Psychological Association.
- Ott, O. H. (2003). The impact of complicated grief on mental and physical health at various points in the bereavement process; *Death Studies*; Vol. 27(3); 249-272. Taylor and Francis.
- Pistrang, N., Barker, C. (1998). Partners and fellow patients: two sources of emotional support for women with breast cancer; *American Journal of Community Psychology*; Vol. 26(3); 439-456. Plenum Publishing Corp.
- Prigerson, H. G., Maciejewski, P. K., Reynolds, C. F. III, Bierhals, A. J., Newsom, J. T., Fasiczka, A., Frank, E., Doman, J., Miller, M. (1995). Inventory of complicated grief: a scale to measure maladaptive symptoms of loss; *Psychiatry Research*, Vol. 59(1-2); 65-79. Elsevier Science.
- Shear, K., Shair, H., (2005). Attachment, loss and complicated grief; *Developmental Psychobiology*, Vol. 47(3); 253-267. John Wiley and Sons.
- Simon, N. M. (2013). Treating complicated grief; *Journal of the American Medical Association*, Vol. 310(4), 416-423. American Medical Association.
- Simon, N. M. (2012). Is complicated grief a post-loss stress disorder? *Depression and Anxiety*, Vol. 29(7); 541-544. John Wiley and Sons.
- Simon, N. M., Wall, M. M., Keshaviah, A., Dryman, M. T., Le Blanc, N. J., Shear, M. K., (2011). Informing the symptom profile of complicated grief; *Depression and Anxiety*, 28(2); 118-126. John Wiley and Sons.
- Southwick, S. M., Bonanno, G. A., Masten, A. S., Panter-Brick, C., Yehuda, R., (2014). Resilience definitions, theory and challenges: interdisciplinary perspectives; *European Journal of Psychotraumatology*, Vol. 5, ArtID: 25338. Co-Action Publishing.

- Spahni, S., Bennet, K. M., Perrig-Chiello, P. (2016). Psychological adaptation to spousal bereavement in old age: the role of trait resilience, marital history, and the context of death; *Death Studies*, Vol. 40(3); 182-190. Taylor and Francis
- Stroebe, W., Zech, E., Stroebe, M. S., Abakoumkin, G. (2005). Does social support help in bereavement? *Journal of Social and Clinical Psychology*; Vol. 24(7); 1030-1050. Guilford Publications.
- Sullivan, P. (2008). Florence Wald, 91; started hospice movement in US; *Washington Post. Obituary reprinted in the Boston Globe*.
- Tamres, L. K., Janicki, D., Helgeson, V. S. (2002). Sex differences in coping behavior: a meta analytic review and an examination of relative coping. *Personality and Social Psychology Review*, Vol. 6(1); 2-30. Lawrence Erlbaum.
- Taylor, S. E., Klein, L. C., Lewis, B. P., Gruenewald, T. L., Gurung, R. A., Updegraff, J. A. (2000). Biobehavioral responses to stress in females: tend-and-befriend, not fight-or-flight; *Psychological Review*, Vol. 107(3); 411-429. American Psychological Association.
- Taylor, S. D., Distelberg, B. (2016). Predicting behavioral health outcomes among low-income families: testing a socioecological model of family resilience determinants; *Journal of Child and Family Studies*, Vol. 25(9); 2797-2807. Springer.
- Ungar, M. (2015). Practitioner review: diagnosing childhood resilience – a systemic approach to the diagnosis of adaptation in adverse social and physical ecologies; *Journal of Child Psychology and Psychiatry*, Vol. 56(1), 4-17; Doi:10.1111/jcpp.12306. Wiley Blackwell Publishing, Ltd.
- Valente, S. M., Saunders, J. M. (2002). Nurse's grief reactions to a patient's suicide; *Perspectives in Psychiatric Care*, Vol. 38(1); 5-14. Blackwell Publishing.
- van der Houwen, K., Stoebe, M., Stroebe, W., Schut, H., van den Bout, J., Wijngaards-De Meij, L. (2010). Risk factors for bereavement outcome: a multivariate approach; *Death Studies*, Vol. 34(3); 195-220. Taylor and Francis.
- Vitas Healthcare (2012). Bereavement Documentation: A refresher.
- Vitas Healthcare Corporation (2017). Vitas Documentation Procedure: Psychosocial Spiritual, Initial Comprehensive Assessment.
- Vitas Healthcare: www.vitas.com.
- Weatherbeeresources.com (2018). Weatherbee Resources, Inc.; Hospice Compliance Services.

- West, C. L. (2013). When talking helps: a quantitative study of privacy and resilience after bereavement; *Dissertation Abstracts International Section A: Humanities and Social Sciences*, Vol. 73(10-A)(E). ProQuest Information and Learning.
- Wagnild, G. M., Collins, J. A. (2009). Assessing resilience *Journal of Psychosocial Nursing and Mental Health Services*, Vol. 47(12); 28-33. SLACK.
- Walsh, F. (2016). *Strengthening Family Resilience (3rd ed.)*; New York, NY: Guilford.
- Walsh, F. (2012). Family resilience: strengths forged through adversity. In Walsh, F. (Ed.), *Normal Family Processes Growing Diversity and Complexity (4th ed.)*; New York, NY: Guilford; 399-427.
- Walsh, F. (2003). Crisis, trauma and challenge: a relational resilience approach for healing, transformation and growth; *Smith College Studies in Social Work*, Vol. 74(1); 49-71. Haworth Press.
- Wilsey, S. A., Shear, M. K. (2007). Descriptions of social support in treatment narratives of complicated grievers; *Death Studies*, Vol. 31(9); 801-819. Taylor and Francis.
- Wortmann, J. H., Park, C. L. (2008). Religion and spirituality in adjustment following bereavement: an integrative review; *Death Studies*, Vol. 32(8); 703-736. Taylor and Francis.

APPENDIX A

INFORMED CONSENT DOCUMENT

Procedures

Participation in this study involves answering questions about your experience in a phone survey. This survey takes about 15 minutes to complete. There will be approximately 200 participants in this survey.

The survey asks you to respond to questions about how you dealt with the grief you experienced when someone close to you died and how you have been able to cope with that grief.

Participation in this study is voluntary. Your decision whether or not to participate will have no impact on current or future treatment from Vitas Healthcare. The study is not part of usual follow up care from Hospice, nor is it an expectation of Vitas staff. The short survey will be administered verbally by a Vitas Hospice Social Work Intern, a Vitas Hospice Volunteer or a Vitas Hospice professional. Phone calls will be made from the Vitas office and will be confidential. Those conducting the survey have received training on the elements of grief. Your responses will be entered into a computer based survey system. Although the Hospice Intern, professional or volunteer will have access to your identifying information, no identifying information will be logged on the computer database. The research team will have access to only this database and therefore will not have access to your identity.

Confidentiality and Risks

This survey is confidential and involves very little risk. Information concerning your identity will be removed. All that will be retained will be the answers to the

questions that are asked during the course of the survey. While the risks of this study are minimal, the survey may ask questions that could cause uncomfortable feelings or anxiety. If this happens, the participant will be referred to Hospice bereavement services. Those conducting the survey have had training in identifying potential concerns based on the response of the participant; they will assess the need for further services and will provide referral sources if necessary.

This study will benefit society by allowing Hospice professionals and grief therapists to identify families that might need additional services during their hospice care as well as identify additional services for Hospice.

Questions about the Research

If you have any questions about the research, please phone Les Bishop (909) 386-6000 or e-mail lebishop@llu.edu. You may also contact the Principal Investigator, Brian Distelberg, PhD at (909) 558-4547 or via email: bdistelberg@llu.edu.

APPENDIX B

THE RESILIENCE AND COMPLICATED GRIEF SURVEY

For Each question please answer how often you experience what is described by responding “never, rarely, sometimes, often or always.” *Never = less than once monthly; Rarely = more than once monthly but less than once weekly; Sometimes = more than weekly, but less than daily; Often = about daily; Always = more than once daily*

1. You think about this person so much that it’s hard for you to do the things you normally do.

Never	Rarely	Sometimes	Often	Always
-------	--------	-----------	-------	--------

2. Memories of the person who died upset you

Never	Rarely	Sometimes	Often	Always
-------	--------	-----------	-------	--------

3. You cannot accept the death of the person who died

Never	Rarely	Sometimes	Often	Always
-------	--------	-----------	-------	--------

4. You feel yourself longing for the person who died

Never	Rarely	Sometimes	Often	Always
-------	--------	-----------	-------	--------

5. You feel drawn to places and things associated with the person who died

Never	Rarely	Sometimes	Often	Always
-------	--------	-----------	-------	--------

6. You can’t help feeling angry about his/her death

Never	Rarely	Sometimes	Often	Always
-------	--------	-----------	-------	--------

7. You feel disbelief over what happened

Never	Rarely	Sometimes	Often	Always
-------	--------	-----------	-------	--------

8. You feel stunned or dazed over what happened

Never	Rarely	Sometimes	Often	Always
-------	--------	-----------	-------	--------

9. Ever since s/he died it is hard for you to trust people
- | | | | | |
|-------|--------|-----------|-------|--------|
| Never | Rarely | Sometimes | Often | Always |
|-------|--------|-----------|-------|--------|
10. Ever since s/he died you feel like you have lost the ability to care about other people or you feel distant from people you care about
- | | | | | |
|-------|--------|-----------|-------|--------|
| Never | Rarely | Sometimes | Often | Always |
|-------|--------|-----------|-------|--------|
11. You have pain in the same area of your body or you have some of the same symptoms as the person who died.
- | | | | | |
|-------|--------|-----------|-------|--------|
| Never | Rarely | Sometimes | Often | Always |
|-------|--------|-----------|-------|--------|
12. You go out of your way to avoid reminders of the person who died
- | | | | | |
|-------|--------|-----------|-------|--------|
| Never | Rarely | Sometimes | Often | Always |
|-------|--------|-----------|-------|--------|
13. You feel that life is empty without the person who died
- | | | | | |
|-------|--------|-----------|-------|--------|
| Never | Rarely | Sometimes | Often | Always |
|-------|--------|-----------|-------|--------|
14. You hear the voice of the person who died speak to you
- | | | | | |
|-------|--------|-----------|-------|--------|
| Never | Rarely | Sometimes | Often | Always |
|-------|--------|-----------|-------|--------|
15. You see the person who died stand before you
- | | | | | |
|-------|--------|-----------|-------|--------|
| Never | Rarely | Sometimes | Often | Always |
|-------|--------|-----------|-------|--------|
16. You feel that it is unfair that you should live when this person died
- | | | | | |
|-------|--------|-----------|-------|--------|
| Never | Rarely | Sometimes | Often | Always |
|-------|--------|-----------|-------|--------|
17. You feel bitter over this person's death
- | | | | | |
|-------|--------|-----------|-------|--------|
| Never | Rarely | Sometimes | Often | Always |
|-------|--------|-----------|-------|--------|
18. You feel envious of others who have not lost someone close
- | | | | | |
|-------|--------|-----------|-------|--------|
| Never | Rarely | Sometimes | Often | Always |
|-------|--------|-----------|-------|--------|
19. You feel lonely a great deal of the time ever since s/he died

- | | | | | | |
|--|-------|--------|-----------|-------|--------|
| | Never | Rarely | Sometimes | Often | Always |
|--|-------|--------|-----------|-------|--------|
20. When you face problems or difficulties in your family, you respond by: Seeking encouragement and support from friends.
- | | | | | | |
|--|-------------------|----------|---------|-------|----------------|
| | Strongly Disagree | Disagree | Neutral | Agree | Strongly Agree |
|--|-------------------|----------|---------|-------|----------------|
21. When you face problems or difficulties in your family, you respond by: Seeking information and advice from persons in other families who have faced the same or similar problems.
- | | | | | | |
|--|-------------------|----------|---------|-------|----------------|
| | Strongly Disagree | Disagree | Neutral | Agree | Strongly Agree |
|--|-------------------|----------|---------|-------|----------------|
22. When you face problems or difficulties in your family, you respond by: Seeking advice from relatives (grandparents, etc.)
- | | | | | | |
|--|-------------------|----------|---------|-------|----------------|
| | Strongly Disagree | Disagree | Neutral | Agree | Strongly Agree |
|--|-------------------|----------|---------|-------|----------------|
23. When you face problems or difficulties in your family, you respond by: Doing things with relatives.
- | | | | | | |
|--|-------------------|----------|---------|-------|----------------|
| | Strongly Disagree | Disagree | Neutral | Agree | Strongly Agree |
|--|-------------------|----------|---------|-------|----------------|
24. When you face problems or difficulties in your family, you respond by: Asking relatives how they feel about problems you face.
- | | | | | | |
|--|-------------------|----------|---------|-------|----------------|
| | Strongly Disagree | Disagree | Neutral | Agree | Strongly Agree |
|--|-------------------|----------|---------|-------|----------------|
25. You feel good about yourself when you sacrifice and give time and energy to members of your family.
- | | | | | | |
|--|-------------------|----------|---------|-------|----------------|
| | Strongly Disagree | Disagree | Neutral | Agree | Strongly Agree |
|--|-------------------|----------|---------|-------|----------------|
26. The things you do for members of your family and they do for you make you feel part of this very important group.
- | | | | | | |
|--|-------------------|----------|---------|-------|----------------|
| | Strongly Disagree | Disagree | Neutral | Agree | Strongly Agree |
|--|-------------------|----------|---------|-------|----------------|

27. The members of your family make an effort to show their love and affection for you.
- Strongly Disagree Disagree Neutral Agree Strongly Agree
28. When you face problems or difficulties in your family, you respond by: Attending church services/religious services.
- Strongly Disagree Disagree Neutral Agree Strongly Agree
29. When you face problems or difficulties in your family, you respond by: Participating in religious activities.
- Strongly Disagree Disagree Neutral Agree Strongly Agree
30. When you face problems or difficulties in your family, you respond by: Seeking advice from a minister or spiritual leader.
- Strongly Disagree Disagree Neutral Agree Strongly Agree
31. When you face problems or difficulties in your family, you respond by: Receiving gifts and favors from neighbors (e.g.: food, taking in mail, etc.).
- Strongly Disagree Disagree Neutral Agree Strongly Agree
32. When you face problems or difficulties in your family, you respond by: Asking neighbors for assistance.
- Strongly Disagree Disagree Neutral Agree Strongly Agree
33. When you face problems or difficulties in your family, you respond by: Sharing problems with neighbors.
- Strongly Disagree Disagree Neutral Agree Strongly Agree
34. People here know that they can get help from the community if they are in trouble.
- Strongly Disagree Disagree Neutral Agree Strongly Agree

35. People can depend on each other in this community.

Strongly Disagree Disagree Neutral Agree Strongly Agree

36. Living in this community gives you a secure feeling.

Strongly Disagree Disagree Neutral Agree Strongly Agree

Answer yes or no to the following questions

37. Have you experienced other losses of a close relationship in the past 5 years?

Yes No

38. Was your loved one's death sudden or unexpected?

Yes No

39. Were you able to be present with your loved one during the illness?

Yes No

Each of the following items says something about a particular way of coping. I want to know to what extent you've been doing what the item says. How much or how frequently. Don't answer on the basis of whether it seems to be working or not—just whether or not you're doing it. Try to rate each item separately in your mind from the others. Respond with answers that are as true *for you* as you can. Use these response choices.

1 = you haven't been doing this at all

2 = you've been doing this a little bit

3 = you've been doing this a medium amount

4 = you've been doing this a lot

40. You've been turning to work or other activities to take your mind off things. ____

41. You've been concentrating your efforts on doing something about the situation you're

in. ____

42. You've been saying to yourself "this isn't real." ____
43. You've been using alcohol or other drugs to make yourself feel better. ____
44. You've been getting emotional support from others. ____
45. You've been giving up trying to deal with it. ____
46. You've been taking action to try and make the situation better. ____
47. You've been refusing to believe that it has happened. ____
48. You've been saying things to let your unpleasant feelings escape. ____
49. You've been getting help and advice from other people. ____
50. You've been using alcohol or other drugs to help you get through it. ____
51. You've been trying to see it in a different light, to make it seem more positive. ____
52. You've been criticizing yourself. ____
53. You've been trying to come up with a strategy about what to do. ____
54. You've been getting comfort and understanding from someone. ____
55. You've been giving up the attempt to cope. ____
56. You've been looking for something good in what is happening. ____
57. You've been making jokes about it. ____
58. You've been doing something to think about it less, such as going to movies,
watching TV, reading, daydreaming, sleeping, or shopping. ____
59. You've been accepting the reality of the fact that it has happened. ____
60. You've been expressing your negative feelings. ____
61. You've been trying to find comfort in your religion or spiritual beliefs. ____
62. You've been trying to get advice or help from other people about what to do. ____

- 63. You've been learning to live with it. ____
- 64. You've been thinking hard about what steps to take. ____
- 65. You've been blaming yourself for things that happened. ____
- 66. You've been praying or meditating. ____
- 67. You've been making fun of the situation. ____