Life Review as an Intervention to Facilitate the Grieving Process

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SECTION I.

Statement of Purpose

The purpose of this project was to explore a unique end-of-life respite program in order to obtain an understanding of the type of care that enhances the quality of life for individuals near death and their family members. This included exploring interventions to assist dying persons and their loved ones, gaining experience working with hospice caregivers, and learning techniques to handle the special needs of the dying individual. Included in this project was an in-depth analysis of life review as a method of developing coping skills for the patients as well as the family members. Participation in this project began in September 2008 and is ongoing.

The experience of death and dying has changed significantly over the past century. For a variety of reasons, death has become a taboo subject that no longer represents an accepted progression of life but something unnatural to be wrestled against. Through further study of loss and coping and implementation of validated techniques, this author is optimistic that change in the perception of death can occur. To facilitate change in perception, life review was chosen for analysis.
Organizational Context

Setting of Practicum Site

Clarehouse is a non-profit 501c (3) corporation dedicated to providing a loving alternative for end-of-life care. Clarehouse is nestled in a residential area of Tulsa, Oklahoma. Its appearance is not unlike any of the other homes in the neighborhood. Beautifully landscaped and well maintained, Clarehouse is a welcoming and friendly place before even entering the door. Because Clarehouse occupies a traditional residential structure, the home-like atmosphere is successfully accomplished. Inside, each guest room and living area has been tastefully decorated in a manner that promotes a feeling of peace and tranquility. The staff members at Clarehouse are respectful of the sensitive nature of their business and perform their duties with professionalism and poise. Established in October 2003, Clarehouse was able to accommodate three guests and have twice since expanded, allowing for services to be available to eight guests and their families (see Figure 1).
Figure 1: Capacity Days of Care

An organization of this nature is unprecedented, with no like agencies known in America. It began as a grass-roots response to a need that was personally observed by a group of individuals that were passionate about easing the burden of the dying population. The mission statement of Clarehouse (see Figure 2) establishes their commitment to excellence in their service to the dying. Clarehouse staff members are constantly seeking new knowledge regarding the dying experience and how they can further assist families and guests during this transition. They are receptive to new ideas and encourage their staff and volunteers to take the initiative to implement new programs. They have seen an increase in demand for their services and a rise in their charitable contributions, indicating community support of their philosophy.
Mission Statement

The Clarehouse mission is to provide a loving home, quality end-of-life care and access to hospice services to people in need.

Figure 2: Mission Statement

The entire operating budget of Clarehouse is received from charitable contributions. There is no charge to guests or their family members for a stay at Clarehouse. Funding comes from individual gifts, memorials, grants and support from civic organizations and faith communities. Fundraising is a critical aspect of operations at Clarehouse and there is one paid staff member devoted to this task. Clarehouse’s extensive volunteer team assist with keeping overhead costs low by donating their time to care for the landscaping and yard, clean the interior of the home, and run errands that otherwise would be performed by paid staff.

History and Background

The history of Clarehouse begins with the history of hospice care. The concept of hospice care originated in medieval times when shelter was provided for weary or ill travelers. The term’s modern application began in 1967 when it became associated with specialized care for the dying, when a British
physician, Dame Cicely Saunders, founded St. Christopher’s hospice in London, England. The concept rapidly spread to America by way of a lecture series presented by Dr. Saunders. This exposure led to increased publicity and attention from the medical community that attended these lectures. In 1978, a U.S. Department of Health, Education, and Welfare task force reports that “the hospice movement as a concept for the care of the terminally ill and their families is a viable concept and one which holds out a means of providing more humane care for Americans dying of terminal illness while possibly reducing costs. As such, it is the proper subject of federal support” (“Hospice: A historical perspective”). As a response, hospice care became a Medicare benefit in 1986, with almost every state opting to include it in their Medicaid programs as well. In the late 1990s, major grant-makers poured money into funding for research, program initiatives, public forums, and conferences to transform the culture of dying and improve care at the end of life. The ever increasing attention and support of hospice care has prompted the palliative community to appraise what services they provide and how they deliver them.

As a result of hospice care being introduced to the American public, there have been opportunities extended to the
dying that have not existed before along with the return of a philosophy that has been absent for a century or more. Hospice’s desire is that terminally ill individuals experience end of life pain-free and with dignity. They accept the challenge of aiding family members to embrace this same philosophy. They implement this mission by providing support to the patient and family, primarily from the home setting. Hospice teams consist of medical professionals (i.e. nurses, home health aides, physicians, therapists) as well as social workers and clergy. The team’s responsibility is to manage pain symptoms, provide drugs and supplies, and assist with emotional, psychosocial, and spiritual support for the dying and their family. Families participating in hospice care are typically ones that have the resources to stay at home and be the primary caregivers for their dying loved one, knowing that hospice staff will be making scheduled and on-demand visits to assist with care.

Clarehouse has identified an area of service to ease the burden of those dying in need. If a terminally ill individual is not able to remain in their home due to a lack of care-givers, care-giver ability, or any other resource, Clarehouse fills that need by providing a home environment and compassionate care giving. Clarehouse is not a hospice. Clarehouse is unique in
that they provide services that hospice does not provide—the routine care that is required as death nears. All guests of the Clarehouse are serviced by a hospice agency of their choice. By collaborating with these hospice agencies, Clarehouse is able to act on behalf of family and provide the care necessary to allow the dying to remain in a home setting during their final days.

Families are welcome and encouraged to participate in the care of their loved one to whatever degree they are able and comfortable. During their first year of operation, Clarehouse had serviced more than 65 guests and their families, demonstrating that a need was being met and lives were being affected.

Clarehouse offers services that come in addition to providing physical care for the terminally ill guest. Clarehouse employs a Director of Support Services (DSS) who is an ordained minister. Her responsibilities include providing assistance to the guest and family in developing their coping skills. It is the goal of the staff to educate families regarding the death process in order to alleviate fear of the unknown. Often, staff will engage family in conversation about the loved ones life story as a way of reflecting on the meaning and purpose of their life. This counseling can facilitate the acceptance of death by
transferring focus from the pain of loss to the celebration of a life. The DSS spends a great deal of time training staff and volunteers and would like to see a more formal approach to life review implemented at Clarehouse.

Scope of the Problem

One theory of psychosocial development that is relevant to this project is Erik Erikson’s final stage of development which addresses ego integrity versus despair. Bonadaptive resolution of this crisis would present as an acceptance of ones death, absent of regrets, with a knowledge and understanding of the meaning of their life. Maladaption of this crisis would reflect despair in the life that was led and the inability to relive it. This theory is particularly relevant to life review, as this technique assists the individual in reflecting on the past and achieving a sense of coherence and unity.

Other theories, or models, of coping are relevant to this project as well. George Vaillant’s work identifies several areas of adaptive defenses that affect the aging person’s perception of the meaning of their life. A list of these characteristics includes: altruism, humor, suppression, anticipation, and sublimation (Papalia, Olds & Feldman, 2007). Through the use of these traits, especially in younger years, a person has
established a frame of reference with which to gauge life events. When these traits are present, adaption following crisis favors personal growth and positive mental health.

Elisabeth Kübler-Ross has also provided a model of experiencing grief over the loss of life that is widely referenced. This model includes stages of denial, anger, bargaining, depression, and acceptance. Kübler-Ross noted that people may not experience emotions in this order and may not experience all stages. Other theorists have expanded the application of this model to include various types of losses such as the disintegration of a marriage, the loss of a career, or the loss of a physical function.

Abraham Maslow hierarchy of needs also plays a role in the dying person’s ability to adapt to the losses associated with impending death. Maslow’s theory asserts that a human’s needs exist in an order of significance and that basic needs must be met before the individual can give their attention to the higher needs. This applies to the dying individual’s psychological wellbeing because the dying process involves changes on multiple levels of the hierarchy and prioritization becomes critical.

Finally, Viktor Frankl’s contribution to the existential theory recognizes man’s desire to find meaning in life as the
basis of all human motivation. This theory is supported with research explored later in this document.

Significance of the Project

Death is a part of life. No one will escape it. In the field of counseling, there will be untold numbers of clients that are experiencing grief from loss. Knowledge in the area of grieving a loss is invaluable. Coping with the death of a loved one is a skill to be acquired by all, regardless of gender, age, or race. As universal as death is, it is unfortunate that our society has worked so hard to deny its role in living.

Through studying the benefits and outcomes of life review, the author will gain experience and insight into a technique that can be put into practice in a wide number of settings. There is potential for the same technique to assist during the recovery from a divorce or the loss of a job. By participating in a practicum that provides concentrated opportunities for being present with the dying and their loved ones, a better appreciation will be achieved for the array of responses and coping skills that can be developed during times of crisis.

Definition of Terms

Hospice- a program designed to provide a caring environment for meeting the physical and emotional needs of the terminally ill.
End-of-Life- Within thirty days of death, as prognosed by a physician (as defined by Clarehouse).

Palliative- is any form of medical care or treatment that concentrates on reducing the severity of disease symptoms, rather than striving to halt, delay or reverse progression of the disease itself or provide a cure.

Primary Caregiver- for the purposes of this document, primary caregiver will refer to the patient’s family and loved ones (as opposed to professional caregivers).

SECTION II.

When reviewing literature related to the dying experience, several themes emerged. There is an enormous body of information regarding the physical changes that occur during active dying but there is much less information available that relates to the distress that is known by the dying and their loved ones. Often, this distress can lead to feeling of indignity and psychological anguish.

There is a growing amount of research that addresses the psychological interventions that have been implemented to decrease the distress felt by the dying individual and their family. Finding meaning in life events and reviewing the life in total have been shown to assist in achieving acceptance of
death. For these reasons; a review of literature relating to
distress, dignity, meaning and life review will be explored.

Distress

“All commend patience, but none can endure to suffer.”

Thomas Fuller

The process of dying is naturally difficult and most people
lack the experience of assisting another person through the
journey. Due to this inexperience, the dying individual and
their caregivers encounter distress (Emanuel, Bennett &
Richardson, 2007). One of the central objectives in palliative
care is to enhance the quality of life for the dying person and
their family. This includes the belief that the care recipients
are the patient as well as the family (McClement, Chochinov,
Hack, Hassard, Kristjanson & Harlos, 2007). Health care
providers can be mislead into thinking that patients and
caregivers are appropriately prepared for the impending death,
due to the number of hours spent providing care. However, a
patient’s or caregiver’s perception of their preparedness is a
better indicator of their readiness (Hebert, Prigerson, Schulz,
& Arnold, 2006). Preparedness is accomplished by having key
information regarding bodily changes during the end of life
(physical), processing feelings of grief and loss (emotional),
and keeping close contact with family and friends (social) (Hebert et al., 2006). Robert Zalenski has suggested an adaptation of Maslow’s hierarchy for use in the hospice and palliative care setting. In this model Zalenski includes adequate pain control, freedom from fear, feeling valued and other needs specific to the dying (Zalenski & Raspa, 2006).

Physical distress is one of the primary concerns of the palliative care team when assessing a patient. When considering Maslow’s hierarchy of human needs, relief of pain would fit into the category of basic physiological needs. Untreated pain dominates the mind, therefore hindering any ability to address higher needs (Zalenski et al., 2006). Unbearable physical pain was identified as one of four “critical events” that would cause a dying individual to wish for a hastened death (Schroepfer, 2007). According to Bill O’Neill, science and research advisor for the British Medical Association, “over 80% of cancer pain can be controlled with the use of inexpensive drugs that can be self administered by mouth” and there are further options to aide in the control of the remaining 20% (O’Neill & Fallon, 1997). Collaboration between all members of the multidisciplinary team can result in effective pain relief and allow attention to be focused on meeting higher level needs.
Social distress associated with love and belonging play a part in a higher tier of needs in Maslow’s hierarchy adapted for palliative care (Zalenski et al., 2006). McPherson cited multiple studies where 40-84% of dying individuals report feeling like a burden to their families or as a source of hardship to others (McPherson, Wilson & Murray, 2007). These feelings of burden are exacerbated by fears about things ranging from physical safety to the fear of death itself because they require the presence and emotional support of others to overcome (Zalenski et al., 2006). The lack of independence that occurs with the dying process becomes burdensome as well. The dying person is acutely aware of their inability to continue in their current role and fears a lack of respect from their family (McPherson et al., 2007). The accommodations that the dying individual must face will also have an impact on their sense of emotional well-being.

Emotional distress is associated with the highest levels of needs in the adapted hierarchy. Esteem and self actualization are achieved when the dying individual is able to appreciate their life for what it was and have a sense of cohesiveness (Zalenski et al., 2006). Emotional distress in the end of life often occurs along a continuum with each person reporting
varying degrees of grief, fear and sorrow at different times. However, some individuals may advance to the level of clinical depression (Kelly, McClement & Chochinov, 2006). Emotional distress falls into three major categories near the end of life: anhedonia (which refers to a loss of feelings of pleasure under circumstances that were once pleasurable), demoralization (including feelings of hopelessness, helplessness, and giving up), and grief (acknowledging the hurt experienced with loss). These symptoms can be managed by increasing the individuals sense of control through offering choices, providing an environment of comfort, allowing for emotional expression, and/or providing psychotropic medication (Clarke, 2007). Conversely, when a patient feels they have no choices and lacks a sense of control, loss of dignity can ensue.

*Dignity*

“Dignity is not negotiable. Dignity is the honor of the family.”

Vartan Gregorian

Dignity is the concept that each and every individual has intrinsic value. In the framework of palliative care, dignity refers to the patient’s and the family’s perception of being treated with respect. According to a study of recently bereaved individuals, the participants had a number of questions that
impacted the dignity of their loved one. Questions ranged from how and when to make funeral decisions to how to handle disagreements about treatment options (Hebert, Schulz, Copeland & Arnold, 2008). One means of treating people with dignity is involving patients in the decision making; however, dignity is not achieved by that alone. When study participants reported that they were treated with dignity by their health care providers, many had difficulty citing specific behaviors that lead to their conclusion (Beach, Sugarman, Ege, Shuster & Burgio, 2005). Self reported level of perceived treatment with dignity is an area that would benefit from further research.

Dignity has strong roots in spiritual practices. In the Christian faith, there are several principles that promote the treatment of every person with dignity. These principles include the belief that man was created in the image of God, the teachings of Jesus that advocate loving our neighbor as ourselves, the emphasis on Jesus’ dying for all, and the presentation of God as the father of all people (Cobb, 1990). However, dignity has also been studied from the viewpoint of non-Christians. In a study conducted of atheists, dignity was connected to a respect for their non-belief. Atheists want to be respected as moral individuals that value family and humanity.
and contribute meaningfully to society (Smith-Stoner, 2007).

Poor perception of being treated with dignity can lead to an assortment of problems. In McPherson’s study of terminally ill patients, those that identified themselves as not having dignity also had a higher sense of burden to others and reported lower quality of life. Also related was the finding that self perceived burden is a predictor of loss of dignity that ranks second only to perceived changes in physical appearance (McPherson et al., 2007).

The two most highly reported dignity concerns reported by Chochinov et al. were “not feeling treated with respect or understanding” and “feeling a burden to others”. Chochinov et al. believe that these items refer to an individual’s sense of lack of purpose and meaning in life (Chochinov, Krisjanson, Hack, Hassard, McClement & Harlos, 2006). This finding suggests that health care providers are in a unique position to enhance dignity in their patients through simple acts such as seeking to understand the concerns of the patient and validating their worth as a person.

Patients and families frequently find themselves facing situations that lack dignity when negotiating the health care system, especially when approaching death. The ability to
successfully reframe one’s perception of a problem has been shown to promote stress relieve for both the patient and family. Likewise, “coping strategies that include avoidance, passivity, self-blame, and resignation are associated with greater caregiver strain.” (Redinbaugh, Baum, Tarbell & Arnold, 2003) The reframing subscale of The Family Crisis Oriented Personal Scales (F-COPES) measures family member’s ability to accept problems, describe problems in a manageable way, and successfully solve a problem. Families then identified social support, spiritual support, and accepting help form others as tools to assist the reframing process (Redinbaugh et al., 2003). Being able to reframe difficult situations often leads to an increased sense of meaning associated with the event.

**Meaning**

“We do not just attach and attribute meanings to things, but rather find them; we do not invent them, we detect them.”

*Viktor Frankl*

Finding meaning in life and coming to an acceptance of one’s impending death are significant events in the life of the dying person. Meaning has been defined as a correlation between the facts of a given situation and one’s understanding of themselves (Längle, 2005). Alfried Längle states that “personal...
meaning is a complex achievement of the human spirit” and “is a nonphysical power underlying our conscience, our mind, our capacity to feel and to sense and even our body” (Längle, 2005). More simply stated, meaning is a orientation to life, a personal significance, a mechanism for coping, a causality, and an outcome (Breitbart, Gibson, Poppito & Berg, 2004). Taking ownership of one’s feelings, beliefs and choices lends to genuine connection with the individual and others (Breitbart et al., 2004).

Viktor Frankl believed that the desire to find meaning in life is more than chance, but is a core motivator within man (Breitbart et al., 2004). When in the dying role, patients are acutely aware of forthcoming losses and will begin to adjust psychologically. These adaptations bring about changes in the dying person’s identity and integrate new meaning (Emanuel et al., 2007). Re-examining basic assumptions is part of the adapting and serves to develop a framework that will stand up to the burden of dying (Emanuel et al., 2007). For example, when faced with an imperfect situation, the dying individual is presented with an opportunity to make mental and spiritual adjustments, which results in a change of attitude towards the situation (Längle, 2005). Ideally, this change of attitude will
be integrated into a more positive perception of meaning.

Achieving a strong sense of meaning in life results in a new self image that guides an individual forward in the face of great loss (Knight & Emanuel, 2007). The impact of loss can be lessened through the use of meaning as a coping mechanism. This is accomplished by revising goals, participating in positive experiences and focusing on religious beliefs (Allen, Hilgerman, Ege, Shuster & Brugio, 2008). Enhanced meaning has also been shown to counteract demoralization. When faced with continual helplessness, resulting hopelessness can ensue which leads to the loss of morale. A healthy sense of meaningfulness combined with strong social connection can protect against this decline in morale (Clarke, 2007). Enhanced meaning will not only oppose a decline in morale, but it also plays a role in preventing the desire to hasten death. “Loss of meaning in life” was one of ten contributing factors influencing a dying individual’s desire for a hastened death over living (Schroepfer, 2007).

Spiritual issues also play a part in achieving a full sense of meaning in life. Breitbart et al. state that “any effective psychotherapeutic intervention for meaning should include issues of spirituality” (Breitbart et al., 2004). Observers may notice that as the dying individual experiences physical loses and
independence is not feasible, a more imaginative use of dependence and spirituality becomes apparent (Knight et al., 2007). The integration of spiritual beliefs into meaning can bring understanding to the suffering that accompanies death, therefore leading the dying individual towards acceptance (Breitbart et al., 2004). In an effort to integrate spirituality, religious beliefs becomes so vitally important to patients nearing end of life that approximately half want their physicians to pray with them (Hills, Paice, Cameron & Shott, 2005).

There are several ways that caregivers can assist the dying with developing a sense of meaning and purpose in their life. It is important for the dying to experience daily quality interaction as a means to counteracting hopelessness (Clarke, 2007). Effective listening skills (i.e. being non-judgmental, not avoiding difficult topics, allowing for open expression of feelings) are a key element to facilitating progress in meaning making (Schroepfer, 2007). This concept applies to professional caregivers and family caregivers alike. The degree to which the family is able to accept the adjustments being made by the dying individual influences the stability of the adjustments made (Knight et al., 2007). If end of life care fosters an
environment in which there is open expression of emotions and a gentle challenging of denial and avoidance behavior, the dying and the bereaved will be better equipped to face the task of grieving (Clarke, 2007). One way of fostering open expression of emotions can be reflecting on one’s life story.

*Life Review*

“The unexamined life is not worth living.”

*Socrates*

Life review is a therapeutic tool that uses one’s memories to achieve a sense of significance in life. Socioemotional Selectivity Theory contends that as individuals face the end of life, their focus shifts from future to present. This change in motivation enhances recall of positive information (Allen et al., 2008). One obstacle to accessing this information is that roughly half of dying individuals are reluctant to share their feelings with others out of concern for burdening their caregivers (McPherson et al., 2007). This hesitation seems to be lessened with the use of life review techniques, with patients and caregivers reporting an increase in talkativeness with neither group expressing discomfort with the process (Allen et al., 2008).

Performing life review during one’s final days is an
opportunity to prompt the dying individual to realize the importance of their life and also serves to connect the past, present and future (Clarke, 2007). Those in the dying role often feel compelled to complete legacy work and often experience a sense of “readiness” to die when the task is done (Emanuel et al., 2007). Oftentimes this compulsion centers on reconciliation and resolution with people that are in meaningful relationships with the dying individual (Emanuel et al., 2007). When put into context with Attachment Theory, families that exhibit secure attachment patterns benefit from life review as a supportive activity to facilitate coping not only with the impending death but also the changes of the family unit as a whole (Peterson & Koehler, 2006).

The use of life review in the palliative care setting is in its infancy. However, several studies have indicated that life review demonstrates potential for reducing physical distress and symptoms of depression among the dying and their caregivers. In a 2008 study using legacy activities as intervention for end of life stress, caregivers and patients in the intervention group were found to have a reduction in depressive and physical symptoms. This same group of patients similarly reported an increased sense of spiritual meaning (Allen et al., 2008).
Life review can be carried out in numerous ways that vary widely in levels of formality and structure. Patients participating in life review have reported value in its ability to refocus their attention on their positive life events and their connections with people (Clarke, 2007). Questioning is a frequently employed means of initiating life review. According to McClement et al., the goal of life review is “to provide patients a generativity or legacy-making opportunity, in order to decrease their sense of suffering, while bolstering their sense of meaning, purpose, dignity, and quality of life” (McClement et al., 2007). Appendix A offers McClement’s list of interview questions that provide a starting place for opening dialog with the patient and their closest relationships.

Interested listening can facilitate resolution of life experiences. Inviting family and friends to participate in conversations reminiscing with the patient about their achievements, interests and values can enliven feelings of esteem (Buckley, 2004). This effort on the part of family (and even hospice staff) can increase the patient’s ability to enjoy their remaining life and reduce their suffering (Zalenski et al., 2006). Using photographs to aid reminiscence can also be useful and are often enjoyed by hospice staff as a way to
further engage in conversation (Buckley, 2004). Follow up data collected after life review intervention reveals that 95% of participants found it helpful, 78% found that it heightened the patients sense of dignity and purpose, and 78% said it helped the bereaved family during their time of grief (McClement et al., 2007).

Navigating the various tasks required of those dealing with a dying loved one is often uncharted territory. Researchers in the field of death and dying are constantly contributing to the body of knowledge that would make the transition to death easier for the dying and their families. The above research assists in accomplishing the purpose of this document, which was to better understand the type of care that enhances the quality of life for the dying individual and their family members.

Section III.
Overview of the Learning Experience

Clarehouse was selected as a practicum location due to the nature of the services they offer. Clarehouse is recognized in the community as being experts at delivering end-of-life care to the dying individual as well as providing outstanding support to the family and loved ones. This site addressed an area of the researcher’s inexperience. Clarehouse also offered an...
opportunity to reflect upon personal feelings and attitudes towards death and dying. Recognizing the significance that loss has in each person’s life, it was apt for the researcher to select Clarehouse as a site to gather hands-on experience.

Clarehouse is currently located at 7324 E. 49th Place, No. 3 in Tulsa, Oklahoma, 74145. Their website can be accessed at www.clarehouse.org. The phone number is (918)665-7026.

Clarehouse is scheduled to relocate to their newly constructed facility in the summer of 2009. The practicum supervisor was Cindy Ritter, MS, RN, SSD.

There were several learning objectives that were established at the initial meeting with the practicum supervisor. Primary objectives included learning techniques to address the special needs of the dying individual, gaining experience by working with caregivers (both primary and professional), identifying phases of the grieving process and exploring interventions to assist the dying individual and their loved ones. Other goals were achieved as well, including, gaining exposure to a successful volunteer program, developing an overview of the workings of a non-profit organization and becoming familiar with the fundraising responsibilities of a non-profit organization.
During the first meeting with the practicum supervisor, several ideas were discussed as potential projects to undertake during this practicum. The researcher settled on establishing resource materials for guided life review. This was a project that took part in two steps. First, it was necessary for the researcher to perform life review exercises with families. This was followed by the researcher development of permanent resource materials for the facility. Staff and family were encouraged to utilize a constructed set of laminated cue cards that included individual questions to initiate life review. Other duties that were performed by the researcher included assisting caregivers deliver care to the dying individuals (including postmortem preparations), assisting with new guest/family orientation, being present with guests and families, assisting at the annual fundraising event and a variety of other tasks that are common to the daily operations of an organization.

Clarehouse has a library of books that are related to the experience of death and dying. As often as possible, the researcher would spend time reading from these resources. However, two items in particular were worthy of in depth reading. One item titled Gone from My Sight by Barbara Karnes (1986) is a fourteen page pamphlet that addresses the physical
changes that occur before death. This guide was provided to many family members that were having difficulty coping with their loved one’s withdrawal from food or the rattly sounds of their breathing. The other resource (that has been added to the researcher’s personal library) is Final Gifts: Understanding the Special Awareness, Needs, and communications of the Dying by Maggie Callanan and Patricia Kelley (1992). This book is a compilation of the authors’ experiences working in hospice and offers “new insight into the leave-taking process”. This book was found to be a gentle introduction into the realm of death and dying.

Principles, Concepts and Generalizations

There were a number of situations during the practicum experience at Clarehouse in which the researcher could make direct application of materials studied in course work of the Family Studies and Gerontology Program at Southern Nazarene University. When entering Clarehouse, one of the first things a person notices is the home like setting. This is a primary goal of in-patient hospice units as well. Understanding Death, Dying and Bereavement indicates that as many as three out of four people would prefer to die in their home (Leming & Dickinson, 2007). Establishing a comfortable environment for the dying
individual and their family helps to relieve stress and worry associated with transitioning to a “final” resting place. The presence of soft music, candles, home-made comforters, and individually designed room décor result in a peaceful atmosphere.

New patients at Clarehouse are often admitted from their homes accompanied by a family member. Families repeatedly spoke of the burden of caring for their loved one and how being at Clarehouse eased that load. This concept correlated with the guilt/resentment cycle that was described in the text, Taking Care of Aging Family Members, which was required reading during the Assessment and Wellness module. When a caregiver begins to feel overburdened, they naturally experience resentment. This resentment leads to limit setting, which brings guilt for not meeting every need. As the limits are discarded, feelings of resentment reemerge (Lusterbader & Hooyman, 1994). Many relationships were improved by allowing Clarehouse to perform repetitive daily care duties and allowing both the guest and their family both to enjoy their final time together.

Mr. Smith was admitted to Clarehouse with the terminal diagnosis of lung cancer. His family had cared for him at home and now felt that his care was requiring more effort than they
were able to provide. While Mr. Smith lay incoherent, his adult daughter recounted a story of her father staying awake all night talking to her by cellular phone as she drove across the country. Her father had bought her an expensive early model cellular phone (one that came with a backpack sized carrying case) because he was always looking out for her safety. *Family communication: Cohesion and Change* (Family Communication Module) states that one of the functions of family story telling is to aid in changes. Stories can also answer the question “Will the family stand behind its members?” (Galvin, Bylund & Brommel, 2004) This daughter was facing the death of her father and was able to reaffirm to herself that her father loved her, even though he was unable to say it at the time.

Another lesson that was integrated during the practicum was learned in the *Introduction to Counseling* module. Existential Therapy proposes that awareness of death facilitates living in the present. *Theory and Practice of Counseling & Psychotherapy* by Gerald Corey suggests that there should be open discussions about death because the fear of death is often present but unspoken (Corey, 2005). This information encouraged the researcher to enter into heartfelt conversations with patients about their impending death.
Marriage was a meaningful value to Mrs. Gonzales as she faced her death. She and her husband had planned to renew their wedding vows for some years but now were dealing with her progressing liver cancer. When Clarehouse staff became aware of Mrs. Gonzales’ desire, they immediately offered their assistance with planning a ceremony. The Family Dynamics Module text Marriages and Families: Diversity and Change discussed commitment as a significant factor in intimate relationships and that marriage serves to fill this need (Schwartz & Scott, 2007). The renewal of vows signified the couple’s dedication to one another and stood as a reminder of their history together. Unfortunately, Mrs. Gonzales died two days before the event was to take place.

One of the recurring themes when talking to dying individuals is their anticipation of the loss of relationships upon their death. The text from the Human Development module states that life review can lead to completion of “unfinished tasks such as reconciling with estranged family members or friends” (Papalia et al., 2007). Ruby’s story draws somewhat from this theory. Ruby was ninety-eight years old and was actively dying. Ruby was mourning the loss of a relationship that had not yet begun – her great-granddaughter was pregnant.
As an act of life review and legacy making, the researcher sat with Ruby on three separate occasions documenting a letter that was written to the unborn child (see Appendix B). Not only would this letter impact the recipient but it had profound meaning to the other family members as well.

Section IV.

Personal Response

My time spent with Clarehouse proved to be enlightening from an educational and personal standpoint. I am currently an active volunteer and function in a similar role as when I was a student. I enjoy being able to serve families that are facing a crisis situation. One of my fondest memories of Clarehouse was crying with Mrs. Gonzales’ family immediately after her passing. I discovered that it is acceptable to display feelings of grief when death occurs. Families appreciate seeing the impact that their loved one had up until their final days. I am now more comfortable with acknowledging death and the feelings associated with dying. This change has become apparent by my increasing ability to discuss the recent death of my grandmother with my mother and grandfather.

I did find it difficult to assist with the preparations of a recently deceased person. This was a new experience for me and
I found myself taking a somewhat mechanical approach to cleaning and redressing the body. I believe that I did that to protect myself emotionally because I sensed my own vulnerability in that situation.

As a learner, I believe that I have become witness to one of the most challenging life changes that humans face — the death of a loved one. I have seen people accept death with grace and poise and I have seen people fight death to an unpleasant end. I now have viewed death in a way that many in American society have not.

Future Application

I believe that this learning experience has many future applications for my career as a counselor. I discovered that many theoretical perspectives can apply to the same situation. Thus far in our education, we have been encouraged to consider theories introspectively. However, I can image that having a thorough knowledge in multiple theories could benefit one’s clientele. Just as each of my cohorts preferred some theories over others, clients may respond uniquely to different theoretical practices.

I have a greater appreciation for the emotional distress involved with caring for a loved one and watching them die. I
also have noticed the range of which people can cope with their feelings of loss. It was gratifying to see people make progress towards resolving the crisis of ego integrity. I was saddened to see people disengage from the dying individual out of fear and pain. I feel that I am in a better position to assist people to cope with and find meaning in their loss.

I have discovered that I have an affinity for the needs of the dying individual. I have enjoyed meeting many dying people and my life has become better through these experiences. I predict that I will continue to volunteer at Clarehouse for the next several years on a regular basis as a way to serve this extraordinary population and as a means to expand my knowledge of the field. I would like to be available to encourage family and support them during their stressful time. I have already begun sending more sympathy cards to my congregation members and actually seeking them out to offer my condolences. I can envision myself developing a specialty in grief counseling as a career goal and donating some time through my church or another charitable organization.

I also believe that I am participating in a grander conspiracy — one that’s goal is to change the current societal perceptions regarding death. I am a supporter of an individual’s...
right to participate in their care planning. I am an advocate of death with dignity, in the sense that every person deserves to be treated with respect in life and in death. I no longer view death as a failure of modern medicine but as a phase of life.

Finally, I believe that I am on a journey to developing an ability to be "present" and listen actively. The emotions associated with losing a loved one are not easily remedied. There is no quick fix or magic pill that can cause the pain to go away. I am learning to hold the hand of the hurting and walk the journey with them one step at a time.
Appendix A

Dignity Psychotherapy Question Protocol

Tell me a little about your life history; particularly the parts that you either remember most, or think are the most important? When did you feel most alive?

Are there specific things that you would want your family to know about you, and are there particular things you would want them to remember?

What are the most important roles you have played in life (family roles, vocational roles, community service roles, etc)? Why were they so important to you and what do you think you accomplished in those roles?

What are your most important accomplishments, and what do you feel most proud of?

Are there particular things that you feel still need to be said to your loved ones, or things that you would want to take the time to say once again?

What are your hopes and dreams for your loved ones?

What have you learned about life that you would want to pass along to others? What advice or words of guidance would you wish to pass along to your [son, daughter, husband, wife, parents, other(s)]?

Are there words or perhaps even instructions you would like to offer your family, to help prepare them for the future?

In creating this permanent record, are there other things that you would like included?
Appendix B

A Letter from Ruby

Dear Sweet Baby,

Great-great Grandma is writing you this letter because I know that I will not be there when you are born. I am so sorry that I won’t be able to see you. I have imagined that when I first saw you that I would hug you and kiss you and whisper to you “You’re Momma’s baby…”

There are many things that I want you to know. I love you. I wanted to spend time holding you and talking to you. I wouldn’t let anyone be mean to you. Above all, I would be good to you.

I want you to be a good, sweet baby. Be an even better baby than I was. Love your Momma and Daddy, they love you dearly. Don’t talk back too much.

I wish that you could see me dance around. I wanted to teach you good manners. I want you to know how much I love you.

Do good in school and learn your lessons. School is important.

Finally, I want you to always be a good Christian. God loves you.
and watches over you. I will be watching over you too.

Love,
Great-great Grandma Ruby

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