# STRUCTURED LIFE REVIEW AND ITS IMPACT ON FAMILY INTERACTIONS

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**Title**

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The Supervisory Committee certifies that this ***disquisition*** complies with North Dakota State University's regulations and meets the accepted standards for the degree of

**DOCTOR OF PHILOSOPHY**

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## ABSTRACT

Communication has been deemed by Nelson, Schrader, and Eidsness (2009) as critical to the ability to provide quality end-of-life care. While past research has focused on communication between healthcare professionals and the patient/family unit, this qualitative study explored the impact of a life review technique on family interactions. Structured life review interviews were conducted with fifteen residents of a skilled nursing facility in the presence of family members. Follow-up interviews were conducted with elders and family members to determine the impact of the intervention on family interactions as well as individual effects. Using qualitative methodology, open-ended questions were employed to enhance our understanding of the participant's experience through the life review process. Themes that emerged included: affirmation of prior knowledge, living legacy, new information, opened communication, enhanced understanding, affirmation of the older adult, testimonials, and bridging distant family relationships. Two articles for publication were produced as a result of the project. The first article defined and reviewed all of the themes identified in the study. Along with the discussion of themes, its potential as a tool to improve communication and family interactions was explored. The second article focused on the psychological impact of the life review process experienced by the individual as well as the family system. In addition, the implications for social work practice with older adults were examined and recommendations for implementation were reviewed. Possible direction of future research was also discussed.

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## DEDICATION

The completion of a doctorate cannot be accomplished by one individual. I believe singular efforts in this world have little merit or meaning. This written work like those of many others has been completed as a result of a number of people. I would like to take this opportunity to dedicate this work to them.

To **my friends and family members** who so frequently heard, "Sorry, I can't make it. I am working on my dissertation." Thank you for not only your patience and understanding, but also your support and encouragement.

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## CHAPTER ONE. INTRODUCTION

This current research project explored some of the dimensions associated with communication at end-of-life in an attempt to enhance those dimensions. The research question of how a structured strength-based life review conducted in the presence of the family would impact communication patterns related to end-of-life was examined. Did modeling open communication impact family communication, relationships or ability to make end-of-life decisions? What understanding did this form of guided life review create of values and beliefs of the older adult so as to guide future decisions by the family? How did the older person and family experience the life review process in regard to consensus building in their decision making process? Two articles were produced with the findings revealing the findings and the potential of this form of intervention with families. The first article discussed the themes that emerged from the project and the various impacts of the life review process on the participants and their interactions with one another. The second article focused on the themes of "Creating a Living Legacy" and "Affirming the Older Adult". The individual impact of boosting the older adult's self-regard through the reflection involved in a life review and the production of a living legacy through the DVD of their life review was reviewed. In addition, the impact on the family of having a living legacy was also be explored. The role of social work in implementation of this intervention and potential use in nursing facilities was also discussed.

The U.S. older adult population will crest between 2030 and 2050. As the baby boomers generation reaches the age of 65, the anticipated number of older adults will increase from 35 million in 2010 to 72 million in 2030 (Federal Interagency Forum on Aging-Related Statistics, 2010). Our aging population adds emphasis to a call for change in end-of-life care. Ira Byock (1997) suggested the baby boomers would transform the dying process in the same manner in which they have influenced the various life stages they have encountered. He interjected the

notion of de-pathologizing the process as they did the birthing process; thereby, bringing the notion of "health" into dying and humanizing the entire process.

While longevity is transforming these years, the advances in healthcare have transformed the quality of life for individuals (Werth, 2002). Werth identified how these changes have called for attention to focus on the needs of elders and strategies to meet those needs. Advances in healthcare technology and treatment regimens resulted in individuals facing challenging situations forcing decisions unknown to past generations (Werth, 2002). Terminal illnesses have, at times, been transformed to chronic conditions (Berkman, 1996), which then carry with them the need to adapt or accept the changes these chronic conditions may create. Some of these diagnoses may now result in an individual living a fragile existence, with challenged functioning and an impaired quality of life. While these changes may have added longevity to life, it has also added years to the phase of life in which the older adult is frail and dependent. For some older adults, this adds to their concern of being a burden to their families (McPherson, Wilson & Murray, 2006).

End-of-life care has gained attention in the literature as healthcare professionals struggle to provide the highest quality care possible to those entering the final stages of life (Marco, Buderer, & Thum, 2005). Steele, Mills, Long and Hagopian (2002), Rodriguez and Young (2006), and Gauthier (2008) revealed we continued to struggle in this arena with family and patient satisfaction rating our interventions as lacking. Frequently, death is seen as a failure of the medical machine to intervene in a disease process; rather than as another phase in the cycle of life. This serves to inhibit communication until a crisis demands it takes place. The experience has gained the interest of researchers in their effort to understand the process and the components that comprise it in today's culture. These studies mirrored the concerns addressed

by Steinhauser, Christakis, Clip, McNeilly, McIntyre, and Tulsky (2000) who found many patients continued to receive undesired medical treatments and die after prolonged, painful, and invasive care. While studies have shown patients would prefer to die at home in the comfort of familiar surroundings, Munn and Adorno, (2008) reported a significant number of deaths continued to occur in healthcare facilities surrounded by medical technology and interventions. What is at the root of this disconnect between patient desires and the medical outcomes experienced?

Communication, or the lack thereof, has been suggested as one cause for this disconnect between our wishes and the reality many face at the end-of-life (Steinhauser et al., 2000; Marco et al., 2005; Wiegand, 2006; Barnato, Llewellyn-Thomas, Peters, Siminoff, Collins, & Barry, 2007). Nelson, Schrader & Eidsness (2009) characterized end-of-life communication as a dance between three dyads – family members and the patient; healthcare providers and the patient; and healthcare providers and the family. Their research suggests choreographing this dance requires a shared understanding of the diagnosis, prognosis, treatment options, and patient's values and beliefs. While sound in reasoning, their work maintained a focus on the medical aspect of the dying process.

Perhaps first, we must explore what we mean by a "good death". Weisman and Hackit (as cited in Steinberg & Younger, 1998, p. 13) discussed the concept of a "good death" as being one in which the individual is "pain free, operates at as optimal a level as possible, recognized and resolves residual conflicts, satisfies realistically possible wishes, and yields control to trusted others. In addition, Byock's definition called for obtaining closure to one's relationships, attending to one's worldly affairs, exploring the meaning of their life, and accepting the mortality of human life and the inevitable unknown that this brings to their awareness (Byock, 1997).

Ira Byock (1997) presents the nature of dying as an experiential process versus a sequence of medical problems to be addressed. Past research has focused largely on medical outcomes rather than a personal journey explored and psychosocial needs met (Byock, 1997). While we have advanced our technology and biological treatment of the dying, our understanding, communication, and support to those whose lives we touch have not kept pace with the needs. If we are to achieve greater congruence between patients' desires for end-of-life care and the medical treatment provided, improved communication may be the first step. Byock suggested that we must journey with them to where they are emotionally and psychologically. While an interesting perspective, the next question would be, do we have the tools or mechanism in place to do this?

Once a definition of "good death" was defined, the question became how we assist individuals in securing this self-determined life closure. The Patient Self-Determination Act of 1990 (P.P. 101-508) was an attempt by the federal government to start this process. The basic premise of this legislation was to education the public about the use of advance directives to enhance the decision-making process. The act required information on advance directives to be provided to every individual upon entrance to a medical facility. In addition, states have passed laws to create procedures to establish durable power of attorney for health care and living wills. The healthcare community has implemented protocols for cardiopulmonary resuscitation directives. With these mentioned directives, presently in the United States there exist three formats by which an individual can make their wishes known for end-of-life care.

Unfortunately, passage of the act and subsequent procedures has not resulted in an avalanche advance directives being established. Boyle, Miller, and Forbes-Thompson (2005) found 41% of all deaths occurred in the hospital setting with 95% of these lacking advanced

directives in place. While it would be inconceivable to anticipate every older adult to have initiated an advance directive, this data would suggest significant work remains. Simply providing information does not seem to start the conversation about advance directives and end-of-life care. Boyle et al. (2005) and Byock (1997) challenged the timing of the introduction of this material. Materials are presented to patients upon their admission to a facility. With the myriad of procedures taking place at this critical time and the heightened anxiety on the part of the patient and family, one argument has been this is a poor time to engage patients and their families in discussions regarding end-of-life care.

Nelson et al. (2009) presented the idea of a three party dance in which patients, family, and healthcare providers must learn to communicate to improve healthcare outcomes. While these are the parties involved in many care decisions, their study also reflected the focus of much of the research in this area. The importance of communication between healthcare providers and the family has garnered much attention and justifiably so. When end-of-life decisions are needed, quite often the patient is unable to communicate with the care providers involved (Rose and Shelton, 2006). Family members often struggled with those decisions because prior communication regarding the wishes of the patient had not taken place. While a three-person dance may be the ideal outcome, perhaps the first steps in this dance need to occur within the family system.

While family communication has been studied and analyzed in many respects, the elephant in the room for many family gatherings continues to be end-of-life wishes (Griffie, Nelson-Marten, & Muchka, 2004). Momento mori, Latin for "remember our mortality", will be the backdrop for exploring the impact of an intervention whose intent is to bring the elephant into the discussion.

## CHAPTER TWO. REVIEW OF THE LITERATURE

Through a variety of venues, our daily lives are confronted with depictions of death. DeSpelder and Strickland (2005) argued, while it would be difficult to deny that death was a natural part of life, our ability to practice avoidance of the real and personal meaning behind death has been enhanced by many mechanisms in our culture. Changes in the funeral home industry, removal of healthcare and funeral process from the home, and the development of various institutions for the delivery of care to the dying have distanced individuals from the dying process (DeSpelder & Strickland, 2005). In addition, the technology involved in the provision of medical treatments and the physical settings of our healthcare facilities have literally distanced us from the dying process (Williams, Dawson, & Kristjanson, 2008). Medical equipment, radiation exposure risks, and medical personnel have become obstacles at a time when patients need their families close. These changes have sent the subliminal message that dying and death are something "other", something to be avoided. This distance has impacted our ability to communicate openly on a topic that requires conversation for the myriad of decisions to be made (DeSpelder and Strickland, 2005). Without the ability of the family to discuss end-of-life care and the desires of the aging individual, the ability to improve end-of-life care has been stymied. Improved understanding of family communication, and identification of interventions that can successfully break down barriers in communication, is needed.

This literature review will examine research on communication and its impact on end-of-life care. The pressure for change in how we approach end-of-life care will be defined to establish the motivation for further research in this area and create a foundation for the ensuing discussion. Next, family communication and potential barriers to communication will be explored to provide an understanding of the dynamics involved in end-of-life conversations. In

response to the developing premise, the potential skills and abilities of social workers to impact these issues will then be reviewed. The social work profession demands evidence-based practices to insure effectiveness of interventions. To conclude the literature review, life review will be investigated as a possible intervention. Along with its theoretical foundation, research on the use of life review in various arenas will be reviewed.

## Pressure for Change

The baby boomers' voice has been felt with each phase of life they have encountered (Byock, 1979). Byock reflects on their impact of the birthing process and suggests similar transformations will be experienced when they reach their later years. With their entry into older adulthood, Werth and Blevins also predicted the status quo will be challenged (2002). This new generation brings with it a different relationship with the healthcare community and an enhanced consumer perspective. Werth and Blevins (2002) project the future may reveal patients entering the physician's office more informed and assertively advocating for their needs to be met. They identified the need to establish mechanisms to improve communication and enhance consumer satisfaction with services as a significant future demand. These strategies would stimulate conversation about the patient's wishes for end-of-life care and need to be analyzed for their effectiveness. Werth (2002) called for research to turn its lens to how people are dying. Earle, Neville, Landrum, Ayanian, Block and Weeks (2004) found "22% of all Medicare patients start a new chemotherapy regimen in the last month of life, and treatment within two weeks of death has increased from 13.8% to 18.5% (p. 377). Wright et al. (2008) reported a correlation between advance directive and less aggressive care. They also noted that aggressive care was closely linked with a reduction in quality of life. With one-third of all healthcare expenditures spent on those sixty-five and older (Perry, 1995), the call for examination of this topic and potential

strategies for impacting the process has been heard from varied arenas. Strategies to change the direction of our medical-model oriented healthcare system are less apparent or researched.

## Family Communication

Glasser and Strauss' (1966) seminal work on communication at end-of-life remains a template for discussions regarding family communication related to the awareness of the dying process. These researchers found communication in the family faced with terminal diagnosis transformed from previous patterns to a construct influenced by the knowledge of the pending death. Glasser and Strauss (1966) identified four patterns of as playing a role in family communication. These were Closed, Suspicion, Pretense, and Open Awareness.

In "closed awareness", the patient was not informed of their prognosis, but family and healthcare providers were aware. The information was kept from the patient for one of two reasons: 1) it was believed to be an act of protecting the dying from harm; or 2) there was an unwillingness to share the information (Glasser & Strauss, 1966). Barclay, Blackhall and Tulsky (2007) reported that most physicians lack training for this type of conversation and that, for most, this was still the most challenging conversation with patients and families. Add this to the struggling family functioning in a closed awareness pattern and communication is further impaired.

In the second type of communication pattern, "suspected awareness", families adopted a stance of withholding the information from the dying individual, but the dying individual suspected the prognosis (Glasser & Strauss, 1966). This suspicion diminished the quality of communication between the patient and family members/healthcare professionals, as the patient struggled to define the intention behind the deception based on past relationship issues.

The third pattern was "mutual pretense" in which all parties were aware of the prognosis, but information was not shared with one another. This form of response required a great energy to maintain the veil of falsehood between members involved (Glasser & Strauss, 1966). This response also impacted the family communication negatively in relation to the development of advance directives. To continue the "mutual pretense" eliminates the potential for honest reflection on treatment options, prognosis and future planning. The use of this "pretense" was reflected as well in McPherson, Wilson, and Murray's work on the perception of being a burden to one's family (2007). They reported the use of pretense to evade discussions that might be perceived as emotionally charged or result in another form of burden to the family and patient.

Glasser and Strauss (1966) found the final family communication pattern type of "open awareness" to be the most effective communication pattern to achieve individual wishes and relationship resolution. In this response, all parties shared information freely between one another and dialogue of its implications to the family system could be brought forward for discussion. The implications and practicalities of the present health situation were reviewed by family members and healthcare providers to consider and deliberate as part of the decision-making and life closure process. Glasser and Strauss (1966) also found the element of time in creating effective communication was vital. Timing of the conversation as related to the course of the illness, as well as time to develop a level of trust with those involved in the conversations was considered critical. These findings were consistent with Rosenbaum, Garlan, Hirschberger, Siegel, Butler, and Spiegel (2006) whose project also noted the impact of timing on the establishment of trust and communication.

Rando (1993) utilized Glasser and Strauss' work in her examination of complicated mourning and anticipatory grief. Her work found a relationship between the pre-death

communication patterns and the subsequent bereavement process for the families. She equated the open awareness model as a healthy behavior and established a relationship between this model and an easier post death bereavement process. She also acknowledged that impaired communication pre-death resulted in relationship strain between family members (1986). The strain of these relationships later resulted in an emotional upheaval between family members and care providers. Her perspective and findings confirmed Glasser and Strauss' position that open communication created healthier functioning within the family system.

While Glasser and Strauss' work provided a template for understanding family communication at end-of-life, current research has moved their attention away from this model and has explored family communication from the perspective of communication in the healthcare environment. Focus has been largely directed toward the relationships between family and healthcare professionals rather than communication within the family system. Glasser and Strauss' work becomes less valued in this context. However, with this shift we have lost the importance of the conversation beginning within the family. This creates a gap in the literature toward our understanding of family dynamics at end-of-life. Could turning our focus on family members' understanding of values, beliefs and wishes related to end-of-life care improve communication? As this project will address communication within the family system, the Glasser-Strauss template provides a model for understanding the dynamics of various family systems and the impact of their chosen pattern of communication upon the family members involved.

## Barriers to Communications

### Search for Information

The struggle to secure the information needed to make informed decisions has been found to be a significant barrier for both patients and family members; especially, at a time when they were capable of hearing the information (Royak-Schaler, Gadalla, Lemkau, Ross, Alexander, and Scott, 2006). Royak-Schaler et al. reported the intent may not be to keep the patient uninformed, however, communication about palliation continued to be less than optimal (2006). The emotional stage on which these communications were delivered also presented an obstacle to understanding or integration of knowledge. While patients reported a desire to have information regarding their care (Nelson, Schrader, and Eidsness, 2009; Royak-Schaler et al., 2006; Barclay et al., 2007) their ability to integrate the information shared was influenced by their emotional readiness to hear such news about their future.

### Cultural Dynamics

While ethically, in the era of informed consent, healthcare providers are required to provide such information, the need for presentation and re-presentation of information was underestimated by the healthcare professionals. Cultural dynamics involved in this delivery were also examined. Americans of European descent and African Americans were found to value having all information presented to them; while, other cultures have been found to perceive such truth telling differently. "For example, for Bosnian immigrants, nondisclosure is seen as benevolent and protective and traditional Navajo believe disclosure of truth causes bad outcomes" (Barclay et al., 2007, p. 962). With delivery of "bad news" (Barclay et al., 2007) being considered difficult, and with time constraints, work demands, and the need to re-deliver the news, it is no wonder effective communication does not always occur.

**Medical Professionals**

Barnato, Llewellyn-Thomas, Peters, Siminoff, Collins, and Barry (2007) also addressed the informational aspects about end-of-life communication. With the advancements made in healthcare delivery, the technical language employed by professionals proved to be a barrier to those they serve. Jargon served as an obstacle to understanding for the patient and family. At times, even with the greatest of efforts on the part of the healthcare team, the complexities of treatments, diagnostic procedures and prognosis projections can be difficult to comprehend. If the thrust of our efforts remains on the technical/technological aspects of the dying process, as presented by Byock (1997) our focus is maintained on "medical problems" to be solved versus the meaning of the personal experience.

The ability of medical professionals to navigate the communication waters within the family contributed to the congruence between the patient's wishes and medical interventions provided. While training of medical professionals has been improving in this aspect (Royak-Schaler et al., 2006) further development of knowledge and skills in this type of communication was called for in order to improve the provision of end-of-life care. Many medical residents continued to complete their studies with a singular course or minimal exposure to practice the skills of communication at end-of-life. This fostered the potential for conflict between parties involved in the care of the dying individual. Barclay, Blackhall, and Tulsky (2007) conducted a meta-analysis of studies on family communication. They identified communication conflicts centered on the families perception of a lack of meaningful information being presented to them, perception of not being listened to, and a need for privacy for these important discussions. Ineffective communication patterns leave healthcare providers and family members stressed and conflicted (Boyle et al., 2005). This breakdown in communication between involved parties

impacted the patient and family's perception of the quality of care they received. Once again, the need for improved communication strategies was identified.

**Family System Impact on Communication**

Family members are involved in many aspects of care giving at end-of-life, whether the dying individual resides in a home setting or healthcare facility. Research by Haley, Reynolds, Chen, Burton, and Gallagher-Thompson (2002) revealed that family members preferred to make end-of-life decisions within a family system rather than as an autonomous agent for the dying patient. This finding was validated by Rosenbaum et al. (2006), who found interventions which afforded the family system the opportunity to participate jointly in the decision making process fostered a positive outcome as well as strengthened their relationship with the healthcare providers involved in the care of their loved one. Heyland, Dodek, Rocker, Groll, Gafni, and Pichora (2006) also found that, in assessing quality of end-of-life care, much of the research available had not focused on the patient or family's perspective. Their research focused on the patient and family's perspective and found that communication proved to be a vital link to insuring family satisfaction with end-of-life care and decisions.

Fear of causing additional stress was found in number of studies to minimize healthcare providers' communication and their contacts with the dying (Callanan & Kelley, 1992; Jenko et al., 2007; Rosenbaum et al., 2006) and thus, created a sense of isolation of the dying individual. For many, facing a terminal illness or chronic disabling conditions resulted in an increase in their sense of social isolation, at a time, when social support was critically needed.

As Rosenbaum et al. (2006) reported, however, timing played a pivotal role in this effort to improve communication. Their research found that earlier interventions assisted in the establishment of trust and improved communication. Paired with Glasser and Strauss' work that

identified the diagnosis of a life-limiting diagnosis as transformative to a family's communication, it would prove critical to time an intervention targeted at improving communication carefully.

### Fear of Being a Burden to Family

In addition, the patient's fear of becoming a burden to the family caregivers may have resulted in an intentional isolation adding to the dysfunctional pattern of communication, at a time, when free flowing information is essential (McPherson et al., 2007). In their study on the dying patient's perception of being a burden on their family, McPherson et al. (2007) found 65% felt they were a significant burden to their families and this related to a loss of dignity, suffering, and a perception of experiencing a "bad death". Results also indicated the dying were hesitant to confide this in family members for fear of causing an additional burden. Focus groups with family members and patients discovered that feeling they were not being a burden was a primary indicator for patients in defining a "good death"; whereas family members identified symptom management as a primary component for a "good death" (McPherson et al., 2007). Communication is influenced by these differing values and perceptions compounding the decision-making process.

## Multi-dimensional Approach to Communication

### Spiritual Concerns

Spiritual concerns were noted as paramount to the dying while healthcare providers continue to emphasize their efforts toward the physical realm (Heyse-Moore, 1996). Addressing these spiritual concerns has a profound impact on the quality of life during the dying process and influences the decisions made by both patient and family. Heyse-Moore (1996) found spiritual pain was expressed through "physical and psychological symptoms, disorders of relationships

and specifically spiritual symptoms (meaninglessness, anguish, duality and darkness" (p. 297). The issue of finding meaning to our lives, seeking reconciliation with others, and resolving a personal life story became critical at end-of-life. Heyse-Moore's work also demonstrated spiritual pain could also impede family communication.

**Medical Model versus Multidisciplinary Approaches**

A life-limiting prognosis has been found to impact many aspects of the life of the patient. Their spiritual, physical, emotional, and social concerns affected their overall quality of life and decision making process at end-of-life (Connor, Egan, Kwilosz, Larson, & Reese, 2002). In order to meet the complex and diverse needs of the dying and their family members, an interdisciplinary approach to care has been felt by many to be the optimal approach to care provision. Connor et al. (2002) found that, while hospice care has embraced this team approach to care, many healthcare institutions have continued to struggle to implement the team concept. The medical model, with its focus on the physical aspects, limits energies and efforts being expended to address spiritual, social, and emotional aspect. Like birthing strategies have transformed in recent decades, a call was issued to revise our dying strategies (Callanan & Kelley, 1992).

A systems approach to end-of-life discussions was seen as a distinct advantage because, although studies have continued to demonstrate the importance of pain control to patients at end-of-life, many studies have found patients and families place high value on psycho-social-spiritual concerns at this time of life as well (Steinhauser et al., 2000; McPherson et al. 2006; Rodriguez & Young, 2005; Barnato et al., 2007; Nelson et al., 2009).

**Social Work Role**

Barclay et al. (2007) felt that the social work profession might serve as a mediator in these situations; serving as a bridge between healthcare professionals and the clients they hope to serve. While conversant in medical jargon, a medical social workers' training offered the ability to focus on the bio-psycho-social-spiritual perspective. The accreditation of social work education calls for knowledge and skills in the areas of interviewing, human behavior across the life span, competence in working with individuals, families, groups, and organizations (Council on Social Work Education, 2008). The profession has called for practice competence in individual and family assessment and interventions. Evidence based practices have become the profession's standard to insure professional interventions with client populations have been evaluated for their effectiveness and impact on target goals. A systems approach to care has been fundamental to the social work profession and meets the needs of the older adult and family when facing end-of-life care. Munn and Adorno (2008) found social workers were typically responsible for presenting advance directive literature and obtaining completed forms. This activity would lead them to be the logical professionals to continue this conversation further with the patient and family.

Social workers are engaged in practice in nursing homes, hospitals, home health agencies, hospices, and many agencies that provide support and assistance to older adults. These professionals were identified by Hobart (2001) as being uniquely qualified and placed to provide assistance to older adults at end-of-life. They were identified as professionals who are present in the lives of older adults at a time when end-of-life issues and decisions were being addressed. Social work training in bio-psycho-social-spiritual assessments, communication, and family interventions were seen as assets to the work of improving end-of-life care (CSWE, 2008).

While healthcare professionals debate whose role it is to educate the patient about end-of-life options (Hobart, 2001), the social work principle of client's right to self-determination brings with it a perspective of empowerment that enhanced the client's potential of a self-determined life closure.

Hobart conducted an ethnographic study with 12 women to explore their shared perspectives on end-of-life decision-making (2001). The sample was comprised of culturally and ethnically diverse older women. While there were many variables in their response to decision making, they shared the perception that decision-making was not a simplistic process and the gaps between advance directive tools and the emotional aspects of the dying process needed to be addressed. Hobart argued social workers possess the skills to provide a vital role in addressing these gaps. Their ability to assess and develop intervention plans was noted, but the evaluation of said interventions has been less explored. She called for the profession to expand the social work role with end-of-life care and to find ways to assist our society to eliminate our "ignoring, denying, or avoiding of issues related to death and dying" (p.190). Older adults fear losing themselves in the medical system and experiencing a de-humanized dying process (Hobart, 2001). Her call for the profession to assume a level of advocacy to change the system also carried with it the need to discern effective tools with which to do so.

Since their inception, hospice programs have attempted to provide holistic care for patients facing end-of-life care. Hospice programs viewed the complex needs of the dying patient as requiring the skills and talents of a diverse and multi-disciplinary team. Reese and Raymer (2002), however, proposed that, with the introduction of the Medicare Benefit and the economic realities that followed, the role of social work was fading in hospice programs. They found that, when social workers saw patients only on an "as-needed" basis when called in by the

nurse, their role was diminished to the point of ineffectiveness. Their National Hospice Social Work Survey revealed that a heightened role of a social worker was closely linked with reduced need for nursing visits, medications, and positive patient outcomes (Reese & Raymer, 2002). Their recommendation was for social workers to engage with clients prior to crisis as a prevention and holistic approach to the dying process. This process suggests interventions at the beginning of the case that would enhance the patient's wellbeing and functioning. This call was mirrored by Hobart's (2001) proposition that social workers need more than their knowledge of the aging and dying process, but also need "service delivery and overall best practice standards" (p.182).

Changes in reimbursement systems have resulted in a transformation in the medical social work role in recent years (Snow, Warner, & Zilberfein, 2008). In the world of prospective payment systems, the importance of discharge planning has become foremost in the responsibilities of social workers. This has left the worker with limited time to establish relationships with their patients and families or to address the psycho-social needs that may have arisen related to their end-of-life care. With nursing assuming greater influence in role definition in medical settings, the social work role has been restricted further limiting their interaction with patients and families. The burgeoning numbers of older adults entering the healthcare system, however, may result in a renovation of roles and interventions.

Snow et al. (2008) reinforced the need to create evidence-based interventions for implementation at end-of-life. They called for future research to evaluate these interventions for their effectiveness with older adults and their families. Rose and Shelton (2006) also identified the need for further research on ways to improve family communication at end-of-life. They encouraged the social work profession to identify strategies that remove barriers to

communication and, subsequently, end-of-life decision making within the family system. Miller et al. (2007) felt that, with specific interventions and tools, social workers' attempt to intervene with older clients and their families would be more beneficial. However, these interventions and tools must bear the scrutiny of research to justify their use in practice.

Prior to changing our delivery system with older adults, evidence-based practice would require a theoretical basis to support said changes. Theory informs research then research may inform practice.

## Life Review

### Theoretical Framework

Erik Erikson's theory of development addressed a period in which the individual faces a crisis of ego integrity versus despair (1959). Erikson viewed this crisis as the individual's struggle to search for meaning in their life experiences and seek resolutions in areas of struggle. He suggested this phase of the life cycle to be a time in which the individual comes to terms with his/her mortality and achieves a level of peace or one of disillusionment with their life's story. Life review was perceived in his theory to be a naturally occurring activity in this stage of life.

Erikson presented a framework by which one's individual identity was formed while encountering various life crises over the lifespan. Butler (1970) suggested this phase of Erikson's theory presented two processes. The first process was viewed as "restorative" as it afforded the opportunity to resolve conflicts and attribute meaning to one's life events. The second process was "resolutive" as the individual confronts their approaching death. This phase fosters a natural life review process according to Butler and Erikson, but Butler (1970) also lifted the idea of creating an "identity beyond the grave" (p. 123). The formation of an identity that will survive beyond the death brings forward the concept of lasting legacy.

While Butler (1970) agreed that life review in older adulthood is natural and free flowing; he also suggested that when one enters his or her final chapter in life, the ability to communicate one's experience as well as one's history can become conflicted. Sharing one's present experiences is complicated when the experiences involve the ending of one's life. This poignant time of life is impacted by cultural beliefs about death and dying, a family's previous pattern of communication, and our present health challenges.

While Erikson's attention was on those who viewed their life as limited, Fillett and Butler (2009) also introduced the concept of a frailty identity to broaden the scope to include those who encounter their first awareness of dependence on others. The term "frailty identity" was used by Butler to describe a psychological response marked by the transition from independent living to one of recognized dependence. He discussed a myriad of challenges associated with this stage of life that included "regrets, sadness, and depression that often complicate physical frailty and can result in untoward medical outcomes, greater caregiver burden, and potentially avoidable costs to the healthcare system" (p. 348). The costs to caregivers and the healthcare system were noted to be increased risk of hospitalization or institutionalization, use of healthcare services, and death.

**Functions of a Life Review**

Westerhof, Bohlmeijer and Webster (2010) provided an overview for the varying uses and occurrences of life review across the lifespan. They suggested the value of understanding the use or purpose of life review activities to better evaluate the impact on the human experience. To understand the dynamics involved in life review activities, one must define what purpose the life review is serving in any particular context in order to discern its origins and resulting consequences.

Westerhof et al. (2010) analyzed research related to life review in an effort to establish, define, and determine types of life review. Eight different functions were revealed through their research. They were identity, death preparation, problem solving, teaching/informing, conversation, boredom reduction, bitterness revival (a revisiting of a past hurt and rumination over it), and intimacy maintenance. The most pertinent to this report were identity and death preparation. Identity afforded the individual the opportunity to explore and crystalize his/her values, beliefs, and sense of who they were. Death preparation was used to put the past into some perspective that would afford the individual to face a terminal or life-threatening illness with a sense of calm and acceptance of their mortality. This involved re-framing of past experiences through a strength perspective, reconciliation or resolution of past conflicts. Their research would indicate that, at end-of-life, identity and death preparation were most closely related with positive outcomes of interventions (Westerhof et al., 2010).

Their exploration of life review techniques also identified three types of life review: reminiscence, life review therapy, and life-review. Reminiscence was found most appropriate with older adults and was defined as a "sharing of memories" (Westerhof et al., 2010, p. 712) with the main purpose being to reinforce self-esteem through positive recollections.

Haber (2006) explored the various ways in which life review was being utilized as a tool for intervention with various populations. He found that most often life reviews were being conducted by untrained staff unable to evaluate the impact of this intervention or to implement it in a manner that insures the client is free from harm. The role of denial and non-reflection as a defense against emotional harm requires the individual administering the life review process to have adequate training and skill to navigate the process to minimize potential harm to the mental health of the client. Life review processes are quite often used with vulnerable populations

which would require skills and training to insure further trauma is not experienced through the good intentions of a life review (Hobart, 2006).

**Life Review with Special Populations**

Life-review therapy has been most often used and effective when working with populations with mental health concerns such as depression, dementia, and anxiety. The purpose was to "induce self-change and alleviate symptoms of mental illness" (Westerhof et al., 2010, p. 713). The focus was to reduce the bitterness revival and boredom. Bitterness revival was defined as the process of ruminating on a stressful or negative occurrence that results in a depressed mood or impaired functioning. This was accomplished through the strategy of re-framing to stimulate positive reflection and extinguish the negative functions of bitterness revival. Life review therapy was also noted to reduce the occurrence of boredom. This strategy demanded complex interventions and greater training on the part of the professional to understand the mental illness and the impact of the life review process. This intervention was viewed as an individual intervention conducted by the therapist and client with no family involvement (Westerhof et al., 2010).

Westerhof et al. (2010) found the technique of life review was "most suited to people who are struggling to find meaning in life or have difficulties coping with transitions or adversity in their lives" (p. 713). The purpose of life review in these instances was to "enhance aspects of mental health, such as self-acceptance, mastery and meaning of life" (p. 713). The functions of identity construction and problem solving were viewed as primary in this strategy. This review offered the individual the opportunity through life review techniques to gain understanding of their personal identity and using this insight to problem-solve the transition or difficulty facing them.

Those struggling with grief and loss have also found benefit in a life review process. Gilbert (2002) identified the need to tell their story as particularly strong when an individual is grieving. Life review offered a structured mechanism for this storytelling to occur. She argued that in the process of storytelling, we create order to our life's history and through that order can develop meaning and healing in connection to our loss. Whiting and Bradley (2007) also noted the impact of a structured life review in conjunction with individuals who are grieving. They broadened previous discussions on grief to include the myriad of losses experienced by the aging adult. The loss of health, affiliations, relationships and others were identified as benefitting from a life review process which allowed for a reconstruction of meaning in their lives. Whiting and Bradley (2007) found a life review intervention as a successful tool between therapist and client.

Life review was initially conceptualized as a naturally occurring life review as part of the aging process. However, when an individual has been faced with a terminal illness, this process becomes poignant and takes on dimensions beyond those experienced at other times in the life span. Jenko et al. (2007) found a systematic and structured approach provided the vehicle for this process. A life review created a context in which the dying was taking place. It forced the healthcare provider to view the dying as a person rather than a diagnosis and the review offered a context in which the dying process was occurring for this individual (Jenko et al., 2007). While the life review in their review was a task accomplished between the staff and the dying individual, they noted the potential impact on family members. They suggest the life review might benefit the family as they enter the bereavement phase following the death of the client. However, the inclusion of the family as an integral component of the life review was not fully explored by their work.

The Life Tape Project implemented an organized strategy to introduce life review with terminally ill patients and their families (Rosenbaum et al., 2006). Upon the diagnosis of a terminal illness, the patient and family were consulted to determine their willingness to participate in a life review process with a professional facilitator and family present. The life review process utilized in this study was highly structured and guided patient and family through the life story of the dying individual in the clinic setting. Rosenbaum et al. (2006) found the family members involved in this process gained insight to the values and beliefs of the patient and reported they felt better prepared to deal with end-of-life decisions after the life review process. This study introduced the importance of the role of family in the life review process and the impact of the process on the family system.

Patients in the life review process reported improved family communication with emphasis on communication related to the terminal illness (Rosenbaum et al., 2006). The ability to communicate about the illness minimized their sense of isolation and promoted their involvement in end-of-life care decisions. Allen et al. (2008) found that life review and legacy activities (e.g. photo album, scrapbooking, family cookbook with journaling) stimulated conversations, and patients engaged in this form of activity becoming "more talkative across time in comparison with control patients" (p. 1036). With talkativeness defined as a measure of the patient's social engagement, this also represents a reduction in the social isolation earlier identified as a negative consequence for many patients faced with end-of-life care. Jenko et al. (2007) found life review useful as a technique to reduce emotional suffering through establishing a connection with another. This provided a healing for the patient in that they felt "found by another" (p. 160) and their level of anxiety was decreased.

The Life Tape Project found life review was able to reduce anxiety, build bonds between key individuals involved in the care of the dying individual, and create a lasting legacy for family members (Rosenbaum et al., 2006). Patients valued the creation of a videotape of the interview. They viewed the videotape as a keepsake that would allow their values and beliefs to be passed on to future generations and promote a sense of family heritage.

**Life Review Implementation**

Structure to the process seems to be important to its subsequent success with various populations. Jenko et al (2007) strongly encouraged the use of a structured process as it carried with it the best outcomes for positive transition in the dying process. The Agency for Healthcare Research and Quality also found that structured conversations provided the best vehicle for discussions on end-of-life care (2003). Structuring the process initiated the conversation that might otherwise not occur between patient and healthcare providers.

When conducted through a formal interview in a structured manner, Jenko et al. (2007) found life review provided a mechanism for reviewing past events and achieving resolution with one's life. Processing through their life story, the patient was afforded the opportunity to re-frame their life experiences utilizing a strength perspective. This assisted the individual in re-defining their life challenges as opportunities for growth. Life review was perceived as an opportunity to rethink the past as a means of coping more effectively with the future (Jenko et al., 2007). With end-of-life decisions to be made, life review offered a means of clarifying an individual's values and beliefs to provide parameters for those decisions. Haight et al. (2003) found that, for the family member, the benefits of life review related to the improvement in the mood and anxiety of the patient and bonding between patient and family member (when they were also involved in the interview process) as they recalled special times shared together. It

was also found in this study that implementation of life review resulted in a delay in institutionalization of the patient.

When life review takes place within the context of a healthcare team, benefits for the healthcare team have also been identified. These were found to be an increase in rapport with the patient, a holistic vision of the patient and an improved cooperation of the patient with caregivers in two separate studies (Haight et al., 2003; Hirsch & Mouratoglou, 1999). The Life Tape Project also supported these benefits. Rosenbaum et al. (2010) found healthcare providers also shared benefits experienced through the process. Enhanced understanding of the various values and beliefs held dear by the patient, a holistic view of the patient, and an improved relationship with patient and family members resulted in enhanced quality of care. Added to the need for structure, this supports a role for the professional in this intervention to serve as a conduit for the information garnered through the life review process.

Life review has demonstrated itself to be a valuable tool with older adults in providing the healthcare providers with an improved understanding of their values and beliefs which then guide end-of-life decisions related to their care. When facing the end of one's life, decisions regarding treatment options, living arrangements and caregiving opportunities become sensitive and life altering. Family members are involved in many aspects of care giving at end-of-life, whether the dying individual resides in a home setting or healthcare facility. The need to insure meaningful and effective communication between the family and healthcare providers were explored by Haley et al. (2002). Their findings revealed that family members preferred to make end-of-life decisions within a family system rather than as an autonomous agent for the dying patient.

This finding is validated by Rosenbaum et al. (2006) who found interventions which afforded the family system the opportunity to participate jointly in the decision making process fostered a positive outcome as well as strengthened their relationship with the healthcare providers involved in the care of their loved one. Heyland et al. (2006) also found that in assessing quality of end-of-life care, much of the research available has not focused on the patient or family's perspective. Their research found that communication proved to be a vital link to insuring family satisfaction with end-of-life care and decisions. Families and healthcare providers' perception of stress and quality of life have been measured in quantitative studies (Steele, Mills, Long, & Hagopian, 2002; Steinhauser, Christakis, Clipp, McNeilly, McIntyre, Tulsky, 2008). However, an understanding of what makes the communication positive or negative, functional or dysfunctional has not been fully explored.

As previously mentioned, timing is critical for impacting the family and patients' trust level and communication patterns. In 2010, 1.5 million older adults were living in nursing homes (Federal Interagency Forum on Aging-Related Statistics, 2010). For many of those individuals, the diagnosis and admission to the facility marks their transition into what Fillett and Butler defined as the frailty identity crisis (2009). This point on their continuum of care could provide the transformative opportunity to impact family communication patterns and served as the context for this study.

The focus of this dissertation will be the communication that takes place in a family of aging individuals who reside in a nursing care facility. Exploration will center on a structured life review conducted in the presence of family members with a facilitator providing a structured life review process, modeling open communication about end-of-life experiences, values and beliefs, and end-of-life wishes. Evaluation of the family communication after this review will examine

what impact this interviewing process had on the family's communication or understanding of key values to be utilized in future end-of-life decisions.

# CHAPTER 3. USE OF A STRUCTURED LIFE REVIEW AND ITS IMPACT ON FAMILY INTERACTIONS


## Abstract

Communication is vital to our ability to provide quality end-of-life care. Although research has focused on communication between healthcare professionals and the patient/family unit, this qualitative study explored the impact of a life review technique on family interactions. Life review interviews were conducted with fifteen residents of a nursing facility in the presence of family members. Follow-up interviews with participants identified potential impacts on family interactions. Themes that emerged included: affirmation of prior knowledge, living legacy, new information, opened communication, enhanced understanding, affirmation of the older adult, testimonials, and bridging distant family relationships. A review of the themes and potential uses for this technique are discussed.



## Keywords

Life review, family communication, nursing home, end-of-life care


## Introduction

Advances in the medical profession have transformed the aging process. The life span in the United States has increased 30 years in the last century (Werth, 2002). While positive in one perspective, Perry (1995) reported this survival has also brought with it increased rates of disability and dependence on others for care. Berkman (1996) revealed how advances in healthcare have transformed previously fatal conditions into long term chronic illnesses requiring adaptation and adjustments for patients and the caregivers involved in their lives. Battin (1994) projected almost 80% of aging individuals struggled with a degenerative disease that resulted in a prolonged period of decline prior to death. This prolonged period of decline has created challenges for the older adult and family as they journey through the dying process.

Werth (2002) called for research to turn its lens to how people are dying. He found that, whereas, at the beginning of this century, it was not unusual for an individual to die in his/her own home, currently, close to 80% of all deaths occur in an institutional setting. Related to this move for an institutional provision of end-of-life care, Earle, Neville, Landrum, Ayanian, Block, and Weeks (2004) found patients in their final weeks of life continue to pursue aggressive forms of treatment. A relationship between aggressive care and the decrease in quality of life in older adults was noted by Wright, Zhang, Ray, Mack, Trice, Balboni, ...& Prigerson (2008).

In 2010, 1.5 million older adults resided in nursing home settings (Federal Interagency Forum on Aging-Related Statistics, 2010). Lacey (2005) found close to 1000 older adults died in a nursing home each day. In discussing the distancing from death in our society as a result of institutional care, Despelder and Strickland (2005) argued the institution also carries the potential of support and assistance from the professionals employed, if they are appropriately trained.

Based on the prolonged decline of functioning at end-of-life, Fillett and Butler (2009) proposed the Frailty Identity stage as the psychological adjustment required when an older adult faced their first experience of dependence on others. The revelation of their dependency on others was viewed as demanding an adjustment filled with a myriad of challenges which included "regrets, sadness, and depression that often complicate physical frailty and can result in untoward medical outcomes, greater caregiver burden, and potentially avoidable costs to the healthcare system" (Fillett & Butler, 2002, p. 348). The impact of these challenges on the family and healthcare systems demonstrated the need for effective treatment or techniques to enhance end-of-life care provision and improve quality of life. In addition to several other recommendations for healthcare professionals, the suggestion of cognitive behavioral approaches

is note-worthy for those engaged in the care of older adults facing this stage of life (Fillett & Butler, 2002).

Whereas advances in healthcare have resulted in new medical treatment programs and technology, Steele, Mills, Long, and Hagopian (2002), Rodriguez and Young (2006), and Gauthier (2008) found family and patient satisfaction with current interventions lacking. The medical model strongly influencing medical training programs continues to view death as a failure of the medical system rather than a natural consequence of the disease or as another phase of life. This orientation served as an inhibitor to open communication about treatment options. Gauthier (2008) found that, at a time when patients had expressed a desire for open and honest communication, the medical model served as an inhibitor to communication within the family system with confusion about what has been communicated and by whom.

Werth and Blevins (2002) identified the need to establish mechanisms to improve communication and enhance consumer satisfaction with services as a significant future demand. Proposed strategies that would stimulate conversation regarding the patient's wishes for end-of-life care need to be analyzed for their effectiveness. Haley, Reynolds, Chen, Burton, and Gallagher-Thompson (2002) examined the effectiveness of communication between healthcare professionals and family members. Their findings revealed families would prefer to make decisions about end-of-life care within the context of the family system as opposed to an independent autonomous agent for the older adult. Werth (2002) also found families who faced these medical challenges continued to identify psychosocial and societal concerns as the most important issues during this phase of life.

The Federal Interagency Forum on Aging-Related Statistics (2010) reported an anticipated crest of older adults between the years 2030 and 2050 from a reported 35 million

older adults in 2010 to 72 million in 2030. This flow of older adults into the realm of end-of-life will require a response and development of appropriate services and interventions to meet their diverse needs. Byock (1997) suggested that baby boomers touched each phase of the life span altering our previous perspectives and attitudes and suggested a similar impact on end-of-life care. Byock questioned the future impact of this generation on end-of-life care stating their impact on the birthing process might be emblematic of how they will approach their aging years (1997). While improving end-of-life care has been explored in the past decades, this wave of older adults will heighten the need to refine and improve how we care for our older citizens and assist them in dealing with this critical phase of the life span.

**Role of Social Work**

As a profession engaged in the care of older adults, it would seem social workers are well suited to take on this challenge. Rose and Shelton (2006) found social workers possess the training and theoretical background needed to address the complex needs of patients and family members at end-of-life. They noted that conflicts within the family system, at times, create barriers for effective communication. Social workers are trained in theory and interventions for working with families but the need for additional interventions persists. Miller, Frost, Rummans, ...Clark (2007) found the social work component in a multi-disciplinary team intervention with older adults resulted in improved social dimensions of care and a higher quality of life was noted. Munn and Adorno (2008) also noted the fit between social work training and the needs of older adults transitioning into end-of-life care. They called for the profession to clearly articulate what they offer to long-term and end-of-life care. Munn and Adorno also noted too often other disciplines are defining the role and thereby, limiting the interventions employed by social

workers (2008). They encouraged a higher profile for the social work profession in end-of-life care and the need to demonstrate value through outcomes of intervention.

Evidence-based interventions are a vital component of social work practice today. This theoretical stance rooted in a strength perspective is particularly conducive to effective interventions with the population of older adults facing end-of-life challenges (Rose & Shelton, 2006). The ability to articulate the value of the social work position will be enhanced through the ability to validate the tools and techniques employed in this work.

This project was designed to evaluate the use of a strength-based, structured, life review process with older adults in the presence of their family. The evaluation was undertaken to determine if this interventions had an impact on the family's interactions with one another. The family system was targeted because, as identified earlier, they are involved in end-of-life care decisions. Communication and understanding of one another were seen as potential consequences, but the qualitative design was chosen to gain a deeper understanding of possible impacts this intervention could bring.

## Methods

### Overview of the Study

#### Design

A qualitative design was employed to gain a deeper understanding into the family interactions that occurred following a structured life review. Merriam (2002) identified qualitative research an attempt to understand "how individuals experience and interact with their social world" (p. 4). As the project explored intervention impacts on interactions within the family system, qualitative strategies were deemed most appropriate to dissect the effects of life review.

The research team consisted of the researcher and two research assistants. The assistants were trained and supervised by the researcher and engaged in all aspects of the project. Prior to the implementation, a pilot study was conducted with two older adults and their family members. This process validated the structure of the life review and follow-up outlines. The experience of the pilot interviews helped to refine instructions, informed consent process, and influenced the timing of the follow-up interview.

Setting and Sample Recruitment

A large nursing facility in the Midwest agreed to allow access to their resident population. This facility provided comprehensive services to older adults ranging from independent living apartments to highly skilled long-term beds encompassing two campuses and several buildings. The administrative and governing board approved the project and coordination of contacts with the researcher was delegated to the director of resident care and the social work staff.

To protect the privacy of the residents, letters of invitation to participate were distributed to residents by the social work staff. Guidelines for recruitment were the residents needed to be cognitively intact enough so that such an interview would not cause distress or frustration. They also needed to be physically capable of tolerating the potentially time-consuming interview process without distress. The availability of family members who would be able to participate was also a requirement. After their receipt of the invitation, residents either contacted the researcher personally or were assisted to do so by the social work staff. Following this contact, the researcher met with the resident and family to further explore the project and answer any questions or concerns they might have. All participants then signed consent forms.

The sample consisted of 15 older adults. There were no commonalities in the diagnoses of the participants with a wide array of medical concerns being represented. All participants had been living in the nursing facility for longer than 6 months. Although the facility offered independent apartment living, all residents were living in a higher level of dependence for their daily needs with only 2 of the 15 residing in a minimal care unit. Their ages ranged from 80 to 98 with a mean of 88.5. Two thirds of the residents were female and one-third male, consistent with the demographic makeup of the facility. Eighteen family members participated with their older adult. The relationship to the older adult was child (n=12), sibling (n=3), spouse (n=2), and granddaughter (n=1). Thirteen were female and 5 were male. Interviews were scheduled at the convenience of family members.

Participants

After participants signed the consent form, a time was agreed upon for the structured life review process. For most participants, this took place immediately following the consent signing. The structured life review process provided a chronological guide for the resident to explore their life's story (Appendix A). A strength perspective was utilized to reframe life challenges or traumatic events into a positive or life transforming episode in their lives. The impact of those events on their values and present personality were explored. This life review was video recorded to afford the participant with a living legacy of their story on DVD. The DVD was created following the interview and presented to the resident for distribution to family members as desired.

This life review process was conducted in the presence of family members who the resident invited. While they were encouraged to ask questions throughout the life review or solicit particular stories they wished to have shared, they were also encouraged not to interject

corrections to details of the resident's recall of stories. The intent was to hear the resident's perspective of their life story versus a factual, detailed reporting on life events.

Follow-up interviews were scheduled and conducted individually with the resident and those family members who had been present. These interviews were conducted with each participant (family member) separately to support the validity of each response as a genuine reflection of that individual's experience. The follow up interview consisted of open-ended questions related to the impact the interview process might have had on family interactions. Using a constant comparative analysis approach (Merriam, 2002), a basic outline was used but, with each interview, additional questions were formed to explore previously identified themes. This represented a total of 33 separate follow-up interviews. These interviews occurred within 2 weeks of the life review. Follow-up interviews were found to have garnered deeper information and responses when done closer to the life review interview. Responses in follow-up interviews that occurred more than two weeks after the life review were not as deep and detailed in content.

**Analysis**

The follow-up interviews were audio recorded and transcribed for analysis. The transcripts were read and re-read by the researcher and one research assistant. Themes were identified and then reviewed for consistency of identification of themes. Discrepancies were discussed and reconciled. If an agreement on coding interpretation was not achieved through discussion of the two reviewers of the transcript, a second researcher reviewed areas of discrepancy for triangulation and validity in theme identification. As themes emerged, a common definition for each theme was identified and accepted by the research team. Nvivo 10 software was utilized to further analyze and manage the data. Transcripts were imported and themes identified. Six major themes emerged in the data and are discussed in detail below.

## Results

### Themes

The six themes were affirming prior knowledge, living legacy, new information, opened communication, enhanced understanding, and affirming of the older adult.

Affirmed Prior Knowledge

This theme was a represented consistently in the follow-up interviews with family members. One can assume during a review of a family member's life, one will hear stories, beliefs and values that one has heard before. This theme related to the comments of the family members that they knew stories shared in the life review and the review validated their understanding and experience with the older adult. Participants felt the interview process had affirmed their understanding of the values of the older adult and would serve to support future decision-making. While spouses and siblings reported they knew these stories, as part of their shared history, children also shared that the interview brought forward information they had known. Participants shared that this process helped the families validate what they knew and that it provided them with reassurance their understanding and belief of the older adults' values were correct. One son of an 80 year-old woman stated, "What I learned just really reinforced what I know about my mom. As far as values and beliefs, I didn't really learn anything that changed what I thought to be true about my mom. The stories reinforced my understanding of her." His mother who has struggled with cancer in recent years had been able to have several conversations with him about her desires about end-of-life care. The interview process affirmed and capsulated those previous conversations allowing him a sense of confidence about future decision making. One 85 year-old gentleman suffered a stroke which left him cognitively impaired to a degree. His daughter shared, "I kind of have always known his values and beliefs

and how he is that way about stuff. It just kind of affirmed...it's just how he is." She reported the life review interview refreshed memories and stories she had forgotten and since they had not been afforded time for end-of-life discussions prior to his stroke would assist her in her future decisions regarding his care.

Created a Living Legacy

Fifty-three percent of the participants identified with this theme which reflected on how the life review process allowed older adults to pass important stories and information on to their children for future generations. It fostered a perception of a living legacy. A living legacy refers to the process influencing the individual's understanding of the impact of the older adult on their generation and generations to come, the passing on of traditions, practices, values, and beliefs (Allen, 2009). While many mentioned faith, others mentioned traditions observed in the family the origin for which they now understood. Older adults and children also identified a sense of value in having this story around long after the future loss of the older adult through the recorded DVD. One gentleman remarked how his grandchildren had only known him as an individual in a wheelchair. He shared for the first time stories about his adventures in World War II in which he had been a vital, athletic, young man. "I'm sure [this story is] something that they will say to their children, we want you to hear this. I really do". Prior to the initiation of the interview, he had mentioned this segment of his life was not something he was willing to talk about. However, as the interview progressed, he voluntarily entered into discussion about it. In follow-up, he remarked that his stories about being a sailor were ones of physical activity that he wanted his grandchildren to hear. His wife reported,

> I think Gus was hoping that this DVD would give a more full picture of him maybe for those grandchildren who only know him in a wheelchair, hearing

the story about the pineapple juice will give an interesting vision of their grandfather climbing up a rope ladder, and...Seeing him in his whole self.

One daughter had shared how they had attempted to produce a similar living legacy piece for her father but he had died before it could be done. She reflected on the DVD, "This is priceless, to have it in her own words while we can visually sit there and see her and hear her. It's priceless." She hoped this was a beginning step to future recordings and that the project would serve as impetus to her family's efforts to capture this family history. Several participants reported they felt the DVD and experience would gain in value when the older adult was no longer with them. Many mentioned the appreciation of having the DVD available in the future so they could continue to hear the older adults' voice and the re-telling of stories.

Life Review Revealed New Information

A dominant theme among family members was identified as "Life Review Revealed New Information". This theme identified how this life review process brought forward information that was new, enlightening or revelatory to the family members. This may have represented historical information about the older adult's life or current health status information. For example, gaining insight that memory deficits have increased, hearing loss is of greater impact than previously thought. This theme revealed the difference between routine conversational patterns of the family versus the structured life review process. This area also demonstrated the varying impact of this intervention depending on the relationship with the older adult. Children by far, revealed with greater frequency that new information had been shared while siblings and spouses reported learning something new with less frequency. It also seemed to be of greater importance for children rather than spouse or siblings who had more of a shared history with the older adult. It should be noted however, that one participant shared information regarding his life

he had previously been unwilling to discuss. This gentleman who shared his WWII adventures was witnessed through his interview by his wife. She expressed great appreciation for the opportunity to learn what happened during this phase of the older adult's life and how that influenced his future life choices. His lack of sharing his experience had caused her to imagine much graver experiences than what he related. Her husband shared a humorous story about climbing a rope ladder to his ship that resulted in a dramatic arrival to the ship's deck. She shared,

> I hadn't heard about that [story about the ship]...we both laughed so hard. I hadn't heard that, and I thought the children and the grandchildren will get a chuckle out of that. Then in a magazine the other day, I just happened to see these sailors climbing up one of these rope ladders, getting into the [ship] and I could see where there was so many of them that going up there and I could visualize it now. Thinking of him doing that brought me to tears. It made me feel closer to him for him having shared those stories.

She affirmed his previous statement that he had never shared this period of his life with anyone and was comforted by the stories for their humor and his pride in telling them.

A son of an 88 year-old woman reported the significance of the interview to his mother's medical treatment. He shared:

> The whole process was rewarding...but perhaps most important was seeing or learning that her hearing was changing so much. I knew she had some problems hearing, but in the process of doing the taping I saw how much it had changed. I visit her all the time, but in our visits never realized how poor her hearing is.

Because of the taping we are taking her to the doctor tomorrow to evaluate her hearing.

Life Review Opened Communication

Many participants reported the life review process had opened their communication within the family system. This theme included how the life review process opened up lines of communication as well as stimulated future conversation and storytelling. During the follow up interviews, many family members mentioned how the resident continued to tell stories after we left. One woman told us that she and her mom went to eat lunch after the life review where she continued to tell story after story of things that happened in her childhood that she forgot to share with us during the taping. This theme perhaps, most strongly, related to the issue of end-of-life communication and the need to stimulate communication within the family system. One son reported that his mother and he "have been talking about this ever since the taping. She keeps saying, wish I had told that story on the tape. We have shared a lot more stories and memories since. It really has stimulated the storytelling in our time together."

Enhanced Understanding of the Older Adult

This theme related to how the life review process helped family members understand the life, values, and beliefs of the older adult. Over half of the family members felt the life review process had this effect on their relationship with the older adult. While spouses' at times felt they gained a deeper understanding, children reported this impact as significant. They felt the life review process revealed history not previously known to them that made sense of the older adult's responses to life events and care decisions. Participants revealed how they had gained understanding of what events had shaped the older adult and how patterns of behavior throughout the generations were brought to light, and allowed the family to hear stories they

knew but from the older adults' perspective. One stepdaughter reported she had always marveled at the open acceptance with which her stepfather had embraced their blended family. In hearing his life story, she stated, "now I see that this is how he has lived his whole life...it is who he is...always open to loving and taking someone into his life." A daughter of an 85 year-old man stated, "I understand now, and he feels he has led a full life, and he is ready to go. When it comes to that time, I think I'll have an easier time letting him go"

Affirmed Older Adult

This theme encompasses the sense of improved self-esteem or confidence on the part of the older adult. While some family members noted the impact on the older adult's self-esteem or confidence, most comments in follow-up interviews related to this personal impact of the life review process came from the older adult personally. This would make sense, as it is a concept best identified by the individual experiencing the affirmation. This process and the manner in which it was conducted allowed the older adult to reflect on their life through a strength-based perspective validating their experiences, increasing their self-esteem, reinforcing their strengths and honoring their successes in life. This theme represents those comments that revealed how the life review process impacted the older adults in their perception of their value and self-esteem. Participants commented about feeling better about their lives and of appreciating being reminded of their successes at a time in life when they are facing challenges were a portion of this theme. Some of the older adults remarked immediately following the conclusion of taping how fast the time had flown. Initially, we had been concerned about the energy required for the interview process. However, participants reflected they were energized and enthusiastic about the process rather than tired or depleted. One participant began her interview with a slouched body language, but ending it sitting tall and stating, "I'm feeling pretty good about myself". One

80 year-old woman reported she felt "it makes me feel important...I think it is good for the soul". One brother who participated said, "Let's face it, when you are telling your story, you're proud of your story. Whether everybody wants to hear your story or not, you're proud to talk about your story."

Another son touched on an issue discovered during the recruitment phase of the project. He said, "This whole process really boosted her self-esteem...Just knowing that people were interested in her story gave her ego a boost. Something about people wanting to hear about your life sends the message that it was an important life." During recruitment, many older adults were willing to participate in the taping of their life history but adamantly stated their families would not desire to be involved. In discussion with staff, the consensus was this perception of unwillingness on the part of the family to be involved was not justified. These residents had actively involved family members who staff felt confident would wish to be involved. However, this perception on the part of the older adult raised issues for future exploration as it relates to sense of identity within the family system.

Offered Opportunity for Testimonial

The research team found that, during the life review recording, many family members and older adults took the opportunity to convey their deep appreciation for the love and care the other had given in life. These testimonials consistently occurred during recording and were shared with great emotion. They were interjected most often out of sequence. In other words, there had been no entreaty by the interviewer for them to share their feelings for one another or it was not the current topic being discussed but rather seemed to be something they felt compelled to share and to have on tape. In the follow-up interviews, family and the older adults often diminished this piece of their recorded interview. Was the opportunity to discuss life events a

catalyst for the sharing of these types of emotions? For some participants, they reported this type of emotional sharing occurred routinely in the family; for others, they reported they had not had conversations such as this before. One daughter reported she had never heard her father speak about her in such a loving manner and that it would be a lasting memory for her. She shared, "he never really told me that stuff before. It seems like he would tell everybody else but never tell it directly to me." Another father responded to a question about his daughter's emotional response to some of his comments. He said, "I think she cried because I was bragging her up, she is very sentimental and I think the fact I was coming out and telling her what a wonderful person she was and how much I did love her brought on the tears."

Bridged Geographically Distant Relationships

Family members, who were scattered geographically, reported the DVD was viewed as a resource to bridge those relationships. Three families with relatives living great distances from the older adult reported the DVD was being sent so they could share in the information that had been shared. In some instances, it was reflected the DVD would enable family members to "get on the same page" in relation to their perception of the older adult's condition and help to alleviate family strain related to differing perceptions of care needs. An 89 year-old gentleman was quite excited to record his life story for his two daughters who lived hundreds of miles away. He had never shared stories from his childhood with them and felt this was a great opportunity for them to learn about his "whole" life. His recording began with his birth and ended at the time of his daughter's births, as he felt confident they understood events that followed their arrival into his life. He had experienced a significant change in his health condition in the past year and felt strongly that he wanted his daughters to have this information in a timely manner. Though his health condition was stable, his daughters had no immediate plans to visit in the coming

months. He reported the recording was part of his "unfinished business" he wanted accomplished. While this may also be viewed as a living legacy activity, the gentleman involved identified his goal to be one of communication with his daughters versus a sense of lasting memory or living legacy to other generations. His concern was this information might assist them in understanding the entirety of his life and thus prepare them for future decision-making. While all participants did not commonly experience this theme, those who identified it felt very strongly about the positive nature of the DVD on their family interactions and sense of resolution.

## Discussion

The project was designed to explore the experience of engaging in a structured life review for older adults and their family members who were present to observe the process. The results revealed the life review process has potential as a tool for use with older adults and their families. There were several effects on individual participants as well as on their interactions within the family system.

Through "Affirmed Prior Knowledge", families members identified the process as validating their understanding of the older adult's values/beliefs and reported this perception would support them in their future ability to make care decisions. While 86% of older adults agreed than advance directive would be positive, few have put them in place (Haley et al., 2002). In these situations, family members are asked to make care decisions without clear, defined direction from the older adult. Participants identified the validation of this process as supporting potential future decision-making. Healthcare providers have worked tirelessly to support family members through the decision making process by providing them information and education regarding disease process and treatment options (Barclay, Blackhall, and Tulsky, 2007). The

component lacking in research efforts has been interventions bringing to light the resident's values and beliefs that guide and inform the decision-making process.

Paired with this sense of affirmation of prior knowledge, participants shared the "Life Review Opened Communication" about the resident's life, values, and beliefs. Reports of ongoing conversations, renewed memories and regrets about various stories that didn't "get on the tape" were shared in the follow-up interviews. Families also reported conversations following the interview took on different dimensions with deeper conversations about care needs and life review components. Older adults have been identified as wishing for open and honest communication at end-of-life (Gauthier, 2008). Life review interventions might provide the catalyst for such conversations to take place. The modeling of open communication that took place in this project's life review interview served as a vehicle for the family's future communication patterns. Several family members noted how the process put things "on the table" so that they felt free to bring them back up for clarification or further exploration.

Marco, Buderer, and Thum (2005) found that without an advance directive, family members and healthcare providers often struggle in the end-of-life decision-making process. "Enhanced Understanding of the Older Adult" of the older adults' values and beliefs could provide greater confidence in the decision-making process and reduced guilt and regret in bereavement (Marco et al., 2005). One family reported that, while an advance directive was already in place, the conversation that took place during the interview enhanced their depth of understanding of what the older adult would like. It also resulted in follow-up conversations that allowed family members to inquire about specific treatments and strategies the older adult might want in regard to future cares.

The actual interview process afforded families the opportunity to see dimensions of the older adults' condition that were not always apparent during routine family visits and conversations ("New Information"). Families who discovered changes in the older adult's condition through the interview process reported they took action following the interview to address these changes and their family conversations had been impacted since. At times, families became aware of stories and family history that aided their understanding of values and beliefs.

Participants' responses reinforced Fillett and Butler's (2009) concept of a frailty identity crisis. In their frailty identity crisis, a threatening of the individual's self-perception was triggered with the occurrence of dependence on others for their daily activities. The majority of older adults identified a sense of affirmation of their life and value to their family through the process. In addition, during the recruitment phase reluctance to participate was strongly linked with a perception of family reluctance. This will be discussed more fully in the next section but relates to this conversation regarding the theoretical foundations of the project. This reluctance supports the concept of a frailty identity crisis which stresses the individual's belief in self-worth and value. The life review process afforded a group setting in which the older adult's existence was validated and his or her contribution to the family was offered for consideration. Family interactions validated the older adult's worth to the family system and the role of the life review process provided the mechanism for these validations. Erickson's (1959) development theory and its discussion on life review were corroborated as participants voiced an improved sense of value and worth following the life review process. This theoretical framework for the project was confirmed by the findings and could serve as a foundation for future implementation of this intervention tool.

**Limitations and Future Research Implications**

This project does have limitations that would raise caution to generalizing its results broadly. The sample size was limited and culturally quite homogenous so as to question its transferability to the wider population. While gender was representative of the facility and community of older adults, the racial makeup of the sample was without diversity. While diagnoses, length of stay in the nursing home, and events that lead to placement (coming from home, hospital, or lower level of care facility) were varied, they were also consistent with the general populations of nursing home residents.

The impact of the relationship with the resident revealed a variable that could merit further exploration. For those sharing generational status (spouse or sibling) the impact of the procedure differed from the children and grandchildren. Shared history might explain a portion of the differences, but further research might explore the impact of generational differences on life review process outcomes.

Interviewers utilized a basic format of questions for the follow-up interview, but further pursuit of concepts that arose in the interview were influenced by the interviewers perceptions and interviewing ability. The transcription and review of transcripts by two researchers minimized the potential for jeopardizing internal validity but its potential is worthy of note at this time as well.

Participants were recruited through a screening process of the social work staff of the facility that may have influenced the selection of participants. While criteria for inclusion in the project were broad, the influence of the individual social work staff on which residents they approached may have influenced the type of participants in the project. Wider implementation might provide a broader sense to the potential impact of this intervention. Implementation of the

life review technique as a standard practice at the time of admission rather than a "special" opportunity could benefit more families and decrease resistance to participation. During recruitment, several potential participants self-selected not to participate and reported a perception of their family not being interested or willing to participate. Were their perceptions justified? While staff tended to disagree, this raises the question of the possibility of affirmation available to residents who may de-value their position in their family or diminish their family's commitment to this process. Exploring this issue as it resonates with the frailty identity promoted by Fillett and Butler (2009) could prove interesting and impactful for residents at this critical time of transition.

This project demonstrated the potential of this technique on the participants involved, but future research should consider the impact if implemented at the time of admission. All participants had been in the nursing home setting for 6 months or longer, which means their initial transition from independence to nursing home care was well underway by the time of this intervention. What impact might this technique have earlier in the process? This would be supported by the concept of the frailty identity crisis which promotes the height of the crisis would occur when initially faced with dependence (Fillett and Butler, 2009). Had some of the adjustment already taken place? This might be suggested as having happened as many of the families participating had already had end-of-life discussions prior to this interview process. Would this process have served as a vehicle for those conversations and perhaps added a depth to the conversations? With a social worker serving as a guide to the discussion it would also serve as providing a link to the healthcare team assisting with the care to enhance communication between all involved parties.

One must also consider the enhanced understanding and opening of communication that occurred. The reports of gaining insight and experiencing ongoing conversations of a greater emotional depth should be explored further. If the modeling of open communication that takes place during the interview can have an impact on family interactions in the future, this process might serve to enhance end-of-life conversations and thus end-of-life care. Longitudinal research to follow participants to the end of their life might offer some insight. In addition, implementing such procedures through the use of technology (such as Skype) might offer geographically distant families a means of connecting through this process.

**Implications for Practice**

As our society strives to improve our end-of-life care, interventions that address needs within the family system must be explored and evaluated for their effectiveness. The purpose of this project was to explore the implementation of this technique in the presence of the family for its potential impact on their interactions and results indicate its potential for improving communication and understanding in family systems encountering end-of-life care.

Social workers engaged in nursing home practice are involved in a variety of roles that address end-of-life care and family system needs (Hobart, 2001). One such practice involves the completion of a social history. The interview process for this history resembles in large part that of the life review. The social work role can be very demanding with multiple demands and time constraints proving challenging for practitioners in this setting. If a life review technique as modeled in this project was implemented in the process of completing a social history interview, this technique might serve more than one purpose and maximize the time spent with resident and family. As social work practitioners explore ways in which to address the myriad of

psychosocial concerns for older adults and their family caregivers, this technique might offer a viable option.

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# CHAPTER FOUR. STRUCTURED LIFE REVIEW AND THE PSYCHOLOGICAL IMPACTS ON NURSING HOME RESIDENTS AND THEIR FAMLIES


## Abstract

Qualitative methodology was utilized to explore the impact of a structured life review process on older adults and their family members. Video recorded interviews were conducted with 15 residents in a nursing facility in the presence of family members. Follow-up interviews were conducted with elders and family members to determine the impact of the intervention on the individual and family members. Themes included: preserving personal history and values, increasing value over time, value to those not present, and boosting the older adult's self-esteem. Resident reluctance to involve family in the process will also be discussed for its implications for future research. Implications for its implementation in healthcare facilities are discussed.



## Keywords

Life review, living legacy, gerontological social work, end-of-life care


## Background and Significance

### Theoretical Framework

The frailty identity crisis was a concept introduced by Fillit and Butler (2009) as the experience of older adults when encountering dependency on others as a result of a debilitating illness. The impact of this transition from independence to dependence on others was viewed as challenging to older adults' psychological wellbeing and their self-image. They recognized psychological challenges such as loneliness, depression, diminished self-regard, regret, and despair as potential negative components of this identity crisis. Social isolation and the loss of informal support networks have been associated with a decline in quality of life and a frailty in the social spheres. Fillit and Butler (2009) promoted the relationship between psychological resilience and the prevention of frailty. They incorporated looking glass theory as a framework

to understand the impact of frailty on the individual's self-image and self-esteem, and encouraged research to focus on the psychological wellbeing of older adults in the context of their physical decline at end-of-life.

Erikson's theory of development (1959) viewed this period of life as a time when older adults review their life in an attempt to find meaning and resolution to past events. He suggested a dualistic process that could result in the individual finding a sense of peace and fulfillment or one of disillusionment and despair. This crisis was identified as taking place in the process of a naturally occurring life review. To maintain a healthy perspective on one's past, challenges or difficulties experienced would be incorporated into the whole picture of one's life as opportunities for growth or personality development (Erickson, 1959).

Glasser and Strauss' (1966) seminal work on communication at end-of-life remains a template for discussions regarding family communication related to the awareness of the dying process. These researchers found communication in the family faced with terminal diagnosis transformed from previous patterns to a construct influenced by the knowledge of the pending death. Their findings revealed that three of the four patterns identified posed communication challenges to the family system inhibiting open communication about important issues related to end-of-life.

A patient's fear of becoming a burden to family caregivers may contribute to isolation adding a barrier to family communication, at a time, when free flowing information would be beneficial (McPherson et al., 2007). In their study, McPherson et al. (2007) found 65% of patients perceived themselves as a significant burden to their families and related they were hesitant to discuss this perception of burden with family for fear of exacerbating its effect. The

impact of this on the individual's perceived worth and value to the family is challenged by this perception of being a burden.

Carstensen, Isaacowitz, and Charles' (1999) work on the socio-emotional selectivity theory addressed the concept that when we perceive our time to be limited, there is a shift in the emotional nature of our relationships heightening their importance and their complexity. The poignancy of this time of life can have a transformative influence on our family interactions. Cartstensen et al. felt the knowledge of limited time would enhance our communications creating meaningful and deeper interactions. Gauthier's study (2008) found that while patients expressed a desire for open communication, the healthcare system served as an inhibitor to communication within the family system. Medical interventions served to distance the aging and dying individual from family members who easily become daunted by medical treatments, technology, and protocols that invade their loved one's daily routines. The physical setting of the healthcare facility also appeared to have a dampening effect on family communication. Being present in a facility also carried with it the potential of having healthcare professionals available to facilitate and enhance the family communication if equipped with effective interventions. The critical factor however, would be the implementation of effective interventions by skilled professionals.

What all these researchers share in common is a sense that when faced with the reality of end-of-life care, our perception is transformed and along with that our interactions with our family members can be altered. This transition brings with it the potential for deep enriching communication or isolation and diminished understanding. The resulting transition plays a role in the individual's self-worth and self-image.

**Life Review as Intervention**

Westerhof, Bohlmeijer, and Webster (2010) provided a meta-analysis of reminiscence literature and an overview of the varying uses and occurrences of life review. They evaluated various life review techniques to better understand their impact on the human experiences in which they were employed. Westerhof et al. (2010) found a negative component of life review to be bitterness revival. When operating in this function, the individual ruminates on past life challenges with the focus on their failures or the failures of those around them. They found this function of life review to have a negative impact on the individual's self-image and were linked with depression and other maladaptive coping strategies. It robbed the individual of the opportunity to use life review as a means of enhancing their sense of meaning and self-worth.

Jenko, Gonzalez, and Seymour (2007) believed a structured life review offered the individual the opportunity to reframe these experiences and achieve resolution to many of life's events. When life events are reframed through the lens of a strength perspective, the individual is afforded the opportunity to gain insight as to how those events shaped their values, beliefs, and future responses to challenges. This redefinition of past failings to opportunities for growth created the potential for healing and transformation.

The use of a life review as a living legacy tool was introduced by Butler (1970) when he expanded on Erickson's theory to explore how a life review process might serve to create an "identity beyond the grave" (p.123). Allen, Hilgerman, Ege, Shuster, and Burgio (2008) defined a living legacy as something that initiates the life review process within the family system and results in a product that will transcend the life of the older adult. Cohen-Mansfield, Parpura-Gill, & Golander (2006) also defined a living legacy as a tool or intervention that celebrates an individual's life creating a sense of continuity of self, self-regard, and pride. Allen (2009) found

legacy activities tended to promote meaningful family communication and improve the patient's sense of meaning. Generativity, the giving of one's skills and talents to the next generation or the sense one's life has had an impact on the next generation, was a concept facilitated through the living legacy activities (Allen, 2009). The impact of a living legacy as a tool to impact the individual's self-worth was a consistent theme in studies exploring living legacy products.

**Role of Healthcare Facilities**

Close to 80% of individuals dying today die in an institution whereas the home was the common site for death at the turn of the twentieth century (Werth, 2002). While studies have shown patients would prefer to die at home in the comfort of familiar surroundings, Munn and Adorno, (2008) reported a significant number of deaths continued to occur in healthcare facilities surrounded by medical technology and interventions. According to Lacey (2005), 1000 Americans die each day in a nursing home. While many espouse the statistic that, at any given time, a small percentage (approximately 5-6%) of older adults reside in a nursing home, studies have found a larger percentage (approximately 30%) of older adults are dying in nursing homes (Pynoos & Golant, 1996; Jones, 2002; Hetzel & Smith, 2001). In light of this, it would appear our research attention and energy should be directed toward nursing homes if our wish is to impact the quality of life in our patients' final days.

Werth and Blevins (2002) called for future research to focus on improved communication through strategies that would stimulate family conversation and for these interventions to be evaluated for their effectiveness. This study looked at a life review technique conducted in the presence of family members to determine if this process could serve a dual purpose as a social history as well as a resident/family intervention. The impact of this process on the older adult's

self-esteem and psychological wellbeing, and the family's perception of the life review as a living legacy were examined.

## Methodology – a Qualitative Research Design

### Design

Merriam (2002) identified qualitative research as an attempt to gain understanding and search for meaning. In phenomenological design, Merriam defined the focus to be on the "essence or structure of an experience" (p.7). In this project, the focus is on gaining a deeper understanding of the impact on family members and older adults when involved jointly in a life review interview. It was determined therefore, that qualitative methodology would best serve the purpose of this study.

A researcher assisted by two undergraduate students conducted the study. The assistants were social work students who had completed their practice coursework in interviewing and were trained and supervised by the researcher in all phases of the study. A pilot study was completed prior to implementation utilizing two older adults and their family members. The pilot affirmed our basic project design and assisted in refining our communication regarding study purpose, informed consent process, and study timeline. It was the initial intent for follow-up interviews to be conducted one month or longer after the life review interview. However, during the pilot it was noted the recall of events was diminished with longer time from the initial interview process. Responses in follow-up interviews that occurred more than two weeks after the life review were not as deep and detailed in content. The decision was made to conduct individual follow-up interviews with the older adult and family members who had been present for the recording within one to two weeks of the recording.

**Participants and Procedures**

A large non-profit organization providing comprehensive elder care in the Midwest agreed to allow access to their resident population for this study. The facility provided care ranging from independent living apartments to highly skilled nursing care in two separate campuses. Approval was obtained though their administrative team and board of directors. Their Director of Resident Care and Social Work staff was designated to coordinate with the research team in procuring a sample for the study. To protect the privacy of the residents in the facility and in accordance with HIPAA requirements, an invitation to participate in the study was presented to residents the facility's social work staff identified as meeting recruitment criteria. This criterion was for the resident to have the cognitive ability to participate in a life review interview without causing emotional distress or frustration, to be physically capable of the tolerating a possibly lengthy interview, and to have family members agreeable to be present and participate in the life review interview and the follow-up interview.

Residents interested in participating were given directions for contacting the research team or were assisted in connections by the social work staff. Additional information was provided through this phone conversation. Their continued willingness to participate was determined and a time was established for the informed consent signing and life review interview. At that meeting, any further questions were answered for the older adult or family members and the informed consent form signed.

The sample consisted of 15 older adults and 18 family members. All of the older adults had been residing in the nursing facility for longer than 6 months and were diverse in regard to medical diagnoses and progression of events that lead to their placement. While the facility offered a comprehensive range of services, only two of the 15 older adults were living on a

minimal care unit with the others being on highly skilled units. Their ages ranged from 80 to 98 with a mean of 88.5. Two-thirds of the residents were female and one-third male, which is consistent with the demographic makeup of the facility.

Of the eighteen family members who participated with their older adult, the relationships were child (n=12), sibling (n=3), spouse (n=2), and granddaughter (n=1). Thirteen were female and five were male. As the focus of the study was targeted on the interactions between family members, it was crucial for the design for family members to be present during the recording of the life review of the older adult. Therefore, scheduling of the life review interviews was coordinated around the schedule of any family members who wished to be present.

The life review outline provided a chronological guide for the resident to explore their life's story and closely resembles the typical information often requested for social history interviews (Appendix C). A strength perspective was employed which reframed life challenges or traumatic events into a positive or life transforming episode in their lives. The impact of those events on their values and present personality were examined and reviewed with the older adult. The life review interview was video recorded and a DVD was produced following the interview for the older adult to present to family members as they wished.

The older adults were encouraged to invite any family members they wished to have present for the recording of the life review. As previously stated, the study was exploring the impact of this intervention on family interactions and thus, their presence was pivotal. However, their presence was one of observation or minimal participation. While they were encouraged to ask questions or request specific stories be told, they were cautioned at the beginning of the interview that this was an opportunity for the older adult to share their life story. Details, dates, and specifics were not to be viewed as important as the older adult's perception of various life

events as well as the values and beliefs that emerged from their life story. The intent was to hear the resident's perspective of their life story versus an accurate chronology of events. Most interviews were accomplished in 1 to 1 ½ hours. The longest session lasted 3 hours and all were accomplished in one session.

After the life review was completed and the DVD created, a follow up interview was performed individually with each participant of the life review process. With the 15 residents and 18 family members this equated to 33 follow-up interviews. These follow-up interviews were audio recorded for later transcription and analysis. As previously stated, these were accomplished within 1-2 weeks of the life review interview, although there were a couple of exceptions due to family member's schedules that prolonged the time between interviews. It was felt participants would react more genuinely if the interviews were conducted privately and thus insure responses were valid and truly represented for their unique experience and perceptions. The follow-up interview consisted of open-ended questions exploring the impact of the life review on their interactions with the older adult as well as their understanding of the values and beliefs held by the older adult. Employing a constant comparative analysis approach as defined by Merriam (2002), as each interview revealed various themes, subsequent follow up interviews explored potential similar experiences by other participants. Questions were used to delve into those areas with subsequent participants.

**Analysis**

The follow-up interviews were audio recorded and transcribed for analysis. The researcher and one research assistant read each transcript two times each. Themes were identified and color-coded. The researcher then reviewed transcripts for differences in identification of themes. If there were differences, they were discussed by the reviewers of the transcripts and

most frequently reconciled. If a disagreement remained after that discussion, the other research assistant was asked to review and provide her interpretation of the themes. This afforded the analysis process a triangulation and enhanced the validity in theme identification. As each theme emerged, the research team developed a common definition of content for that theme.

## Findings

The impact this process confirmed the ability of a structured life review to impact the psychological wellbeing of participants. Through the life review, both individual and family system impacts were noted and related closely to Erickson's concept of ego-integrity (1959) as well as Fillett and Butler's suggestion of the need to find resiliency when confronted dependence on others (2009). Four themes were identified through the transcripts and include: preserving personal history and values, increased value over time, value to those not present, and boosting the self-esteem of the older adult. A fifth area of interest was the reluctance to involve family by potential participants which is also discussed with our findings.

### Preserving Personal History and Values

In the analysis of transcripts and in concordance with the literature, a living legacy was defined as any statement that referred to the process influencing the individual's understanding of the impact of the older adult on their generation and generations to come, the passing on of tradition, practices, values, and beliefs. This process has been strongly linked with an improvement in the individual's self-esteem.

Over half of the participants identified with the idea of a living legacy which reflected on how the life review process allowed older adults to pass important stories and information on to their children for future generations. An 87 year-old gentleman, who was wheelchair dependent, shared his concern that his grandchildren had only known him since he was in a wheelchair. He

shared humorous stories about his service in WWII when he served on a ship in the Navy. His stories featured his physical abilities and antics and he stated that he was hopeful these stories would allow his grandchildren to see him as the vital, athletic, and physically active person he had been most of his life. He reported he had previously been troubled by the fact his grandchildren had such a one-dimensional picture of their grandfather and this process alleviated that concern. His spouse reported, "I think he was hoping that this DVD would give a fuller picture of him maybe for those grandchildren who only know him in a wheelchair."

Religious beliefs as well as family traditions and practices were also noted. Family members heard the origin of particular family phrases or traditions they had never heard before. This brought enhanced understanding to what and why the family engaged in certain behavior. One daughter shared how this brought insight to what her mother had experienced as a young child and how it still connected to their interactions today. She also stated that it was "not the stories as much as just the little things we do you know like when she says 'you-who'. I didn't realize that that came from my great-grandma. And how it has continued and all the characteristics that have been passed down from generation to generation—and so it's fun to hear the story behind them." Family members shared how listening to the life story of the older adult revealed the background behind family practices and traditions providing them with added insight. One older adult shared,

> It triggers the fact of how important it is to take the time to continue to get together, to take the time to remember that it starts with family and when it's all said and done it's about the love and experience from your family. And so I hope that future generations will continue what our great-grandparents started in that strong family bond.

One family had initiated work on their genealogy and found the study well-timed to their family's efforts. To date, they had found records of documents and pictures, but this DVD provided their first audiovisual preservation of family history. One son shared, "We were kind of prepped for this with what we were doing. I am going to send of a copy of that to [my brother] and told him I would, when we got it, and he said he is going to incorporate that into our [genealogical] study as well."

Older adults mentioned their appreciation in having their story available after their death for future family members. Several older adults had small grandchildren whom they feared would not remember them or would not hear these stories through other means. Many commented on the wonders available to us with technology and how few had thought to take advantage of this to create such a lasting memory.

**Increasing Value over Time**

Several family members brought forward the idea that while the video was considered valuable now; its value would increase substantially when the older adult was no longer there for them to talk to directly. One family member stated, "I think we will use the DVD in the future. Probably won't watch it for a while, but it will mean more as the years go on." Many mentioned the appreciation of having the DVD available in the future so they could continue to hear the older adults' voice and the re-telling of stories. One granddaughter conveyed her appreciation as her grandmother's memory was failing and how these stories would become more valuable each day, as she perceived herself losing her grandmother in other ways due to dementia. She shared, "it was a good day for her and she shared a lot of stories that I know today she might not remember. That makes this recording so much more valuable as I realize she will lose the ability to tell us the stories in the time ahead."

The daughter of an 80-year-old woman shared the family's attempts to gather family history with their father. They had purchased him a book to be completed with his memories on various topics. Her father had barely started the book and she reported she felt it was too daunting a task for him. He died without a page being touched. She identified the recording process as so much easier and its potential for fostering further interactions.

> I think this can be just kind of a stepping stone, it will be a good starter, and hopefully [the family] can gather some questions that they want to ask her and, my hope is that we can sit down and continue the interview. Mom brought up the fact that I had given [Mom and Dad] those books and [Dad] had started to fill out a little bit, but to have [the DVD], this is priceless. To have it in her own words while we can visually sit there and see her and hear her. It's priceless.

The value of the DVD over time was reported by another daughter who said, "We always think we have tomorrow. But if you really deep down think about it, you want to seize the opportunity and don't put off, you know, don't put off tomorrow what you can do today." Her thought was mirrored by several family members who voiced their appreciation for allowing them the opportunity to capture these memories when the opportunity was present.

**Value to Those Not Present**

Participants consistently identified the value of the recorded life story to all those involved in the interview process, but also to those not present. The need for a unified understanding of the older adult's condition has been noted in the literature as a key component for effective end-of-life care and was confirmed by family participants. Generally, participants discussed their intention of making the DVD available to those who had not been able to be present for the recording. One family noted the DVD would help siblings who live distant from

the older adult so they could feel connected to the process and also to keep them abreast of changes in the older adults' condition. One son noted how distant family was struggling in connecting with the older adult. Since he visited with his mother daily, he couldn't understand their difficulty. He stated, "perhaps [most] important was seeing or learning that her hearing was changing so much. I knew she had some problems hearing, but in the process of doing the taping I saw how much it had changed. I visit her all the time, but in our visits never realized how poor her hearing is. Because of the taping we are taking her to the doctor tomorrow to evaluate her hearing." He anticipated the family would have much better phone visits after the appointment.

One son related his sister had been the primary caregiver prior to a work transfer that resulted in her relocation to the east coast. As his father has declined, the son has felt isolated in his role as caregiver. He shared how sending a copy of the DVD to his sister had brought the siblings together and lessened his sense of isolation in the caregiver role. In addition, his father's interview demonstrated:

> I guess it was a somewhat sad process in the sense that one of the things that Dad always liked to do was to tell stories of his life and he was known by all of his friends to have a really good memory for the details etc. And he was struggling to remember kind of some of the basic details of his life, particularly by the time the interview ended. But even at the beginning, uh, it was clear that he was struggling with telling his stories.

The son shared the importance of making this change in his father's condition "real" to his sister as he felt the DVD would be able to do. He stated, "I think what would surprise both my sister and the grandkids [are] probably some of the stories he did not tell. Because some of his favorite stories he did not tell. I think they would be surprised by the lack of memory."

While generally participants indicated this would be beneficial to those other family members, they also commented on the value of being present during the interview and having the ability to ask questions to clarify their understanding or to request a particular story to be told. One daughter, who was one of three family members who attended the recording said,

> It's great to get everybody's perspective because sometimes there's a different perspective to the story that surprises others who were there. You know, something that they didn't see or hadn't heard or whatever. I think it was more value to just be there. My sister will watch, my brother will watch, but I've always felt there's value [in] being there and to be able to interject things or ask things.

**Boost to Self-esteem**

The strength-based interviews appeared to give a boost to the self-esteem of the older adults. Responses that encompassed this concept on the part of the older adult most often came from the older adults participating, although family members also reported seeing a change in confidence or the older adult voiced an improved self-perception. This would make sense as it is a concept best identified by the individual experiencing the affirmation, but is noteworthy that the family members could observe this change as well. For the older adult hearing their family members voice their desire and plans to have copies made and shared with various family members reinforced their value and place in the family system. One 80 year-old woman reported she felt "it makes me feel important…I think it is good for the soul."

The life review interview and the manner in which it was conducted allowed the older adult to reflect on their life through a strength-based perspective. Reframing of difficult, traumatic, or negative aspects of their lives allowed the older adult to re-visit these episodes

through a lens focusing on the positive impact and growth that occurred due to the challenges of their lives. One older adult stated, "even though times were tough, we come out of it okay and we know that's all about living." Participants commented about feeling better about their lives and of appreciating being reminded of their successes at a time in life when they are facing challenges were a portion of this theme. A granddaughter shared,

> You know, we talked about both the positive and negative things that had happened, and I think it was good just for her to kind of remember back and kind of come forward with it. Some of the challenge right now, especially with her age is realizing that most of her life, things have been positive. You know, sometimes she focuses on the negative now...with the age and health, you know, and not being able to be alone in her home. That day especially, she was very sharp and excited and happy to do it...I think to bring back some of the old memories that, you know, can make you smile was a good thing for her. She needed a day like that, not thinking about the day-to-day thing so much, but just thinking back over the long haul and really remembering that there have been a lot of really good times.

This supports the concept of frailty identity crisis and suggests the potential for this intervention in helping older adults mediate the challenge of health concerns and increasing dependence on others.

Some of the older adults remarked immediately following the conclusion of taping how fast the time had flown. Initially, there had been a concern about the energy required for the interview process. Participants were strongly encouraged to inform the researcher if they became too fatigued to continue the interview. Plans were discussed through the consent process to

consider multiple dates if necessary to approach this story telling process in a step process. However, participants reflected they were energized and enthusiastic about the process rather than tired or depleted. One participant began her interview with a slouched body language, but ending it sitting tall and stating, "I'm feeling pretty good about myself". One brother of a 98-year-old participant said, "Let's face it, when you are telling your story, you're proud of your story. Whether everybody wants to hear your story or not, you're proud to talk about your story." Interviews that began with timidity concluded with laughter and sense of energy and enthusiasm. Several family members shared how the conversation continued long after the researcher left.

An 84 year-old woman who was battling cancer appeared weak at the beginning of the interview. At its conclusion, she mentioned how much stronger she felt after discussing the many accomplishments and successes of her life. She related that it was easy to become absorbed in the challenges of today and forget what she had accomplished throughout her life. She revealed, "When battling for your life, it's easy to focus on the negatives of today – treatments and surgeries and the challenges ahead. You lose sight of what you have accomplished at times." The life review offered her the chance to review past challenges and how she had overcome them reframing her life story and creating a shift in her perspective on life. She identified the life review process had created a sense of balance in her life story and impacted family interactions since the recording.

**Reluctance to Involve Family**

One issue we encountered in the recruitment process was reluctance on the part of the older adult to involve their family initially. There were more residents interested in participating than those who finally agreed to join the study. Upon the initial interview, many reported their

family would not be interested in the project and they would not be willing to ask if they would like to participate. Facility staff when interviewed did not share the perception of the family's lack of interest in such a project, as they viewed these families as having significant involvement with the older adult. Potential participants were encouraged to at least discuss this with their family members, but several did not feel it was even worth bringing up to their family. Since family participation was critical to the study, this resulted in our not being able to include these individuals. While this might relate to the work of McPherson et al. (2007) regarding a perception of being a burden, the perception of family disinterest could also be related to the perceived value of the older adult's story and their importance to the family system. One son addressed this by saying, "This whole process really boosted her self-esteem…Just knowing that people were interested in her story gave her ego a boost. Something about people wanting to hear about your life sends the message that it was an important life." Older adult perceptions of the family unwillingness to participate have implications for future exploration as it relates to sense of identity, self-worth, and role within the family system.

**Discussion and Limitations of Study**

The themes that emerged in this study support previous work on life review, living legacy activities, and their impact on older adults. The enhancement of self-regard in the older adult and the clarification of life meaning as explored by Jenko et al. (2007), Allen et al. (2009), and Cohen-Mansfield et al. (2006) were validated through this study in the themes of "Boosting Self-Esteem" and "Preserving Personal History and Values". While those studies found life review and living legacy tools impact self-esteem, Fillett and Butler's (2009) work on the frailty identity affirms the value of such work in creating resiliency during this critical transition in an older adult's life. They identified its importance in fostering a positive and healthy transition. This

study revealed the life review process provided a mechanism for this important work to be accomplished. Participants related the process proved stimulating and enhanced their self-esteem. An intervention having this type of impact with individuals whose self-image and value are being threatened by significant life challenges and transitions would be valuable to those hoping to improve the quality of life for older adults.

The value of the intervention to the family system was revealed in the themes – "Increasing Value Over Time" and "Value to Those Not Present". These themes portray the importance and impact of the DVD on the family and their interactions. Families reported the perception of its present value and conjectured about its increasing values over time. They also reported its impact on stimulating subsequent family conversations. Carstensen et al. (1999) discussed the idea of how our perception of limited time would deepen and enrich our communications. Participants shared that prior conversation had not contained this depth or intimacy. Following the intervention, participants revealed conversations had taken on a new dimension and they felt its importance in strengthening family relationships. The significance of sharing the DVD with other family members was consistently brought forward in discussions and the strengthening of family relationships that would occur as a result.

In the struggle to improve end-of-life care, the ability to enhance the older adult's self-esteem and thereby, their resiliency to deal with the health and life challenges they face will be critical. Additionally, our ability to foster effective and meaningful communication within the family system will serve to support the older adult and strengthen the family system for their role in the care delivery process. Decision making and coordination of services is best accomplished by a family system with effective communication patterns who share an understanding of the older adult's values, beliefs, and needs. This intervention tool demonstrates its ability to address

both the older adult and the family system's needs and prepare them for interactions with the healthcare system.

Limitations of the study included the recruitment process. While our sample represented the gender make-up of the facility, the selection of participants was in some degree controlled by the social work staff and may have influenced the composition of the sample. Future studies could consider making this a standard practice at time of admission to eliminate such a creaming or selective process. In addition, implementing the life review process would also create uniformity in the timing of the individual's exposure to this intervention. Participants had been residents in the facility for at least 6 months. Of interest is the timing of this intervention. At admission might reach older adults earlier in their transition to dependency and thus, have an impact on their development of a frailty identity.

Additionally, the research team also evaluated the timing of the follow-up interview. Often, at the end of the recording session, family members and the older adult shared their immediate responses to the process. These interactions were often rich with detail and emotional depth not captured in retrospection during the audio-recorded follow-up interview. If replicated, this research team would likely audio record what was said following the video recording and then again at the follow-up session. Literature and logical applications were behind the idea of giving the family and older adult time between the life review and the follow-up session. This would allow time for additional family conversations and integrating what the process had meant to them since the recording. With cognitive impairments, this meant some data was lost from the older adult whose recollection of the process while not lost was diminished.

Themes were quite consistent across family relationship status, with subtle differences between spouse/sibling and younger generations. Saturation occurred quite early but of interest

would be a greater sampling of family members. For each older adult there was generally only one family member present. What interactions might have taken place if more family members had participated? There were three occasions where more than one family member attended. What impact might have occurred if more were present and a fuller family picture developed?

## Implications for Practice

Recent literature has focused on end-of-life care as healthcare professionals seek to improve their care interventions with individuals entering this final stage of life (Marco, Buderer, & Thum, 2005). Steele, Mills, Long and Hagopian (2002), Rodriguez and Young (2006), and Gauthier (2008) revealed we continue to struggle in this arena with family and patient satisfaction rating our interventions as lacking. Nelson, Schrader, and Eidsness found only one-third of families identified their end-of-life care experience as positive (2009). Rosenbaum, Garlan, Hirschberger, Siegel, Butler, and Spiegel (2006) found that interventions affording family participation fostered positive outcomes and enhance relationships with the healthcare team. Improved understanding of family communication, as well as identification of interventions that can successfully break down barriers in communication, is needed. Munn and Adorno (2008) defined social workers as having the skills and training needed to address the psychosocial needs of their aging residents as well as the challenges facing family communication.

Munn and Adorno (2008) reported the greatest challenge in deploying these skills is the staffing levels and demands on the social worker's time in the nursing home setting. While skilled nursing facilities are required to employ social workers, assisted living and lower levels of care facilities are not. In addition, regulations requiring the employment of social workers do not provide clear staffing guidelines that result in large caseloads minimizing the ability to

provide adequate attention at times (Munn & Adorno, 2008). Emphasis is placed frequently on documentation and assessment requirements demanded by the states that drive reimbursement, thus creating a documentation-driven care atmosphere (Hobart, 2001).

In addition, changes in reimbursement systems have resulted in the transformation of social work role in recent years (Snow, Warner, & Zilberfein, 2008). Discharge planning has become a primary responsibility for many social workers. This has left limited time to establish relationships with residents and families through which one could address the psychosocial needs that may have arisen related to their end-of-life care. Snow et al. (2008) submitted that with other disciplines having greater influence in defining the social work role, the profession has found its role diminished to the point where effective use of their skills and training is being hampered. This restriction in the role has resulted in a further limiting of their interactions with residents and families. Hobart (2001) reinforced the role advocacy has played in the social work profession for its clients. Perhaps this is a time for social workers to advocate for their profession, subsequently benefitting their clients.

Snow et al. (2008) reinforced the need to create evidence-based interventions for implementation at end-of-life that would allow the articulation of that role. They called for future research to evaluate these interventions for their effectiveness with older adults and their families. Rose and Shelton (2006) also identified the need for further research on ways to improve family communication at end-of-life. They encouraged the social work profession to identify strategies that remove barriers to communication and, subsequently, end-of-life decision making within the family system. Miller et al. (2007) felt that with specific interventions and tools would be more beneficial when social workers attempt to intervene with older clients and

their families. However, these interventions and tools must bear the scrutiny of research to justify their use in practice.

Reese and Raymer (2004) found increased social work involvement resulted in decreased drug costs, higher quality of life, and reduced nursing time spent with patients and families. While their study was performed with hospice patients, the parallels with end-of-life care in the nursing home should be explored. Their work enabled an articulation of the social work role to justify the expenditures needed to maintain this valuable component of the healthcare team.

The impact of this study on the older adults' resiliency to transition through the frailty crisis demonstrates it potential as an effective intervention for use in the nursing home setting. The strength-based feature of the life review also demonstrated its effectiveness to support the resiliency of the older adult as they face the challenge of increasing dependence and potential end-of-life decisions. This empowerment of the individual is an integral component of all social work interventions and merges well with the life review process (Hobart, 2001). This strength-based component delineates a difference between this life review process and a reminiscence group facilitated in the activities department.

In addition, the structured life review outline used for this study mirrored substantially the data sought in typical nursing home social histories. It featured a bio-psycho-social assessment approach to reviewing the resident's life in a chronological order. If this interview were conducted at the time of admission when social history interviews are conducted per regulatory requirements, might this serve multiple purposes – documentation compliance, individual support and affirmation, and the production of a living legacy with its stimulation of family conversations? These concurrent activities would address the need for efficiency in the

face of time constraints, as well as, effectiveness of interventions and their value to the residents and families.

## Conclusion

Evidence based interventions are needed to insure the psychosocial needs of older adults and their families are being addressed as they enter the phase at end-of-life and healthcare facilities. Social workers possess the skills and training to implement these interventions but have struggled in the past to articulate their role in the nursing home setting. To use these interventions, social workers will need to find their voice and advocate for their role with administration. Using the most efficient and effective tools available will reinforce their value to the team and more importantly will enhance the delivery of quality end-of-life care. Continued research needs to explore additional tools to provide evidence based practice throughout the dying process supporting residents and family members alike.

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# CHAPTER FIVE. GENERAL CONCLUSIONS

The purpose of the current study was to explore the impact of a structured life review process conducted in the presence of family members on family interactions. After an extensive review of the literature, it was noted an increasing number of individuals entering their later years of the lifespan have generated growing interest to better understand this phase and evaluate interventions that would serve its complex needs. The medical profession is grappling with its ability provide high quality end-of-life care in the face of ever changing technology and medical regimens. Even in the face of these advances, studies have found patients and family are not satisfied with the care they receive at end-of-life. Many studies (Steinhauser et al., 2000; Marco et al., 2005; Wiegand, 2006; Barnato, Llewellyn-Thomas, Peters, Siminoff, Collins, & Barry, 2007) have suggested communication as an avenue to enhance the potential to improve interventions. Much of the research has focused on the communication between healthcare professionals and the patient/family relationship. This study looked at family communication as the first link in the communication chain. This study explored the potential of a structured life review as a means to enhance the interactions and communication within the family system with the potential impact this might have on future end-of-life decision-making.

Two articles were produced for publication with data from this research. The first article focused on themes that emerged from the interviews with participants. These themes were – affirmed prior knowledge, enhanced understanding, opened communication, living legacy, affirming older adult, and new knowledge. The second article was centered on the psychological impacts of this process on the older adult as well as family members. The link between living legacy products and an improved sense of meaning and increased self-esteem has been noted by Allen (2009); Westerhof et al., (2010); and Allen et al., (2008).

The potential of the use of this intervention for both the individual and family impacts are explored. In addition, the role the social work profession could play in bringing this tool forward in interactions with families was examined. Fillett and Butler (2009) would identify any intervention that positively impacts the older adult's self-esteem during the critical period defined as the frailty identity crisis would result in a resiliency and improved well-being. This improved psychological status could result in a reduction in physical and emotional decline (Fillett and Butler, 2009). Fostering a resiliency would appear to be a significant first step in improving the quality of life for older adults facing health challenges. Doing so through a vehicle that stimulates family interactions, deepening them to a level of meaningful substance also addressed the need to improve communication at end-of-life. Nelson et al. (2009) encouraged the pursuit of mechanisms that would enhance our communication in order to impact the decision-making process at end-of-life. The findings from this project found life review conducted in the presence of family as one such mechanism. The ability to drive family communications from the mundane to a deeper level is vital in our efforts to improve end-of-life care. The affirmation of the older adult's values and beliefs guide and inform family members as they face future challenges of making informed decisions regarding end-of-life care.

As a theoretical framework for the study, socio-emotional selectivity theory (Carstensen et al., 1999) as well as, the frailty identity crisis as introduced by Fillett and Butler (2009) served to inform and guide our selection of the target population and research project. Nursing home residents were selected as they could be considered as struggling with the frailty identity crisis due to their introduction into a nursing facility as a result of increasing dependence on others for their care. In addition, the diagnoses that resulted in the admission to the facility could also have triggered the perception of a limited time left in their lifespan triggering the socio-emotional

selectivity theory's concept of transformation of interactions due to recognition of limited time remaining. The findings validated this theoretical foundation with participants affirming the value of the project and the enhancement of family interactions they experienced. Responses from transcripts affirming the older adult reinforced the idea of a frailty identity crisis. Participants shared the challenge to self-esteem of accepting their dependence on others and the value in recalling the accomplishments of their lives. The improved self-esteem was so notable that even family members witnessed the improvement in their older adult family member. Additionally, the perception of limited time and therefore, the importance of communication at this time of life, were reinforced by participants as well. Their reflection on the value of the life review process and the projected increase in value over time supported the concept of socioemotional selectivity theoretical assumptions (Carstensen et al., 1999).

As our focus was to gain deeper understanding of a procedure's impact on family interactions, a qualitative methodology was selected. Qualitative literature consistently defines this methodology as conducive to probing for deeper meaning, and Merriam (2002) and Cresswell's (2007) work was utilized for guidance in the formation of this study. They described qualitative research as providing a deeper understanding to the personal experiences of various events. Open-ended questions were employed during the follow-up interviews to explore the impact the structured life review process may have had on their family interactions. A qualitative approach allowed the researcher to engage participants open to their interpretation of their own experience and probe for an understanding of their individual as well as family response to the intervention.

Previous research on life review has focused on specific populations struggling with various diagnoses such as depression, dementia, and grief (Bohlmeijer, Valenkamp, Westerhof,

Smit, & Cuijpers, 2005; Gilbert, 2002; Jenko, Gonzalez, & Seymour, 2007). This current study explored the potential of life review as an intervention tool with nursing home residents. While previous research has primarily focused on the individual implementation and impact of a life review process, this study examined its impact when implemented in the family group setting and thus, the exponential impact of the intervention (Westerhof, Bohlmeijer, & Webster, 2010). This study demonstrated the potential of a life review process for impacting family interactions, individual self-regard, and its potential for communication with distant family members.

Findings revealed participants experienced both individual and family impacts. Individual impacts or experiences were included in the themes entitled enhanced understanding, affirmed prior knowledge, new information, and affirmed older adult. In enhanced understanding, affirmed prior knowledge, and new information participants addressed the factual information or deeper understanding they now have about the older adult's life, values, and beliefs. General consensus among participants was that the enhanced understanding and knowledge gained would be of benefit in the future as they interact with the older adult. Affirming the older adult was a theme reflecting the personal and intimate impact of the process on her/his self-regard and confidence. Having a positive impact on the individual at a time when identity is being threatened by increased dependence on others is significant to the search for quality interventions. While this theme was experienced individually, its impact was visible to the family system. Family members noted the physical and emotional transformation they witnessed during and after the life review process. For a personal change to be visible in our interactions with others reinforces the strength of its impact.

Family impacts were reflected in themes entitled living legacy, opened communication, testimonials, and bridging distant relationships. These themes reflected impacts that were

interpersonal between the family members. The themes of living legacy and testimonials both address a desire to create a lasting memory. Participants shared their appreciation for having a DVD documenting the life story of the older adult and the interview process also served as a catalyst for family members to share deeper expressions of appreciation and affection. Prior research found communication to be an important factor in our efforts to improve end-of-life care (Steinhauser et al., 2000; Marco et al., 2005; Wiegand, 2006; Barnato, Llewellyn-Thomas, Peters, Siminoff, Collins, & Barry, 2007). The theme of opened communication demonstrated this intervention has potential to improve communication within the family system by stimulating ongoing conversations about the older adult's life, values, and beliefs. Bridging distant relationships explored the possible uses of the life review process as a means for connecting with family members who are geographically distant from the older adult. The creation of a DVD represents the combination of the life review process and technology to provide meaningful connections with family members unable to be present to such conversations.

While findings from this study support prior research on life review, it offers an expansion on our understanding of its impact on the family system. This impact suggests the potential of life review as a tool to improve family communication at a transformative phase in life.

## Strengths of Study

As the focus of this study was to gain deeper understanding and meaning, qualitative methodology was the method of choice. The strength of this methodology was uncovered as first-person accounts captured through individual follow-up interviews revealed the personal experience of each participant. This process allowed participant responses to be probed for

clarification to create a clear picture and thorough understanding of impacts this intervention on participants individually as well as those impacts on the family system.

The portion of the sample composed of nursing home residents represented the nursing home population in large in regard to gender with one-third male and two-thirds female. The age range of older adults was 80 to 98 years of age with an average of 88.5. The older adults resonated well with the theoretical framework employed as these individuals had faced significant health decline and thus, had dealt with the dependence reflected in the frailty identity crisis. Additionally, the concept of recognition of our limited time involved in the socio-emotional selectivity theory was exemplified in the older adult participants in the sample. The family members who composed the rest of the sample participants brought diversity in relationship, age, and gender. There were 13 female and 5 male participants with relationships to the older adult including – spouse, sibling, child, stepchild, and grandchild. Their ages ranged from the mid 90's to early 30's and allowed them to approach the study with a mature perception of end-of-life care and its impact on the family system.

This study sheds light on life review as a family intervention. The individual and family system impacts were noteworthy and consideration for further research is revealed in the findings. Serving as an intervention to stimulate family communication and enhance the depth of conversations, this tool bears further exploration for its ability to have a meaningful impact on older adults and their family as they transition to end-of-life care.

## Limitations of Study

Limitations of the study include the small homogenous sample of participants. The sample of older adults represented the gender make-up of the nursing facility. They were not diverse culturally. All participants and family members were white middle class residents in a

Mid-Western community. The recruitment of participants may be viewed as a potential limitation of the study. Participants were solicited for their involvement in the study by the facility's social work staff and, while the criteria for involvement in the study were open, staff may have been drawn to specific residents for other reasons. Not all residents who responded positively initially participated, as they did not wish to include their family members. Generally, the inclusion of family was viewed by the resident as "too much to ask" or that their families were "too busy" to be involved in such an activity. This exclusion of the family by the older adult resulted in their inability to be included, but a different method of recruitment, such as initiating original contact through the family member might have secured their family members consent. Privacy laws and administration preference provided the structure by which residents were recruited. Alternative methods might have drawn a different pool of participants.

All participants had been residents in the nursing home for over 6 months. This afforded them and their families the previous opportunity to explore and converse about end-of-life care decisions. Many expressed the process by which advance directives had been developed or conversations had taken place about their wishes and desires related to end-of-life care. Moving the introduction of this intervention to the time of admission might prove of interest for future research to determine if it might act as a catalyst to those family conversations.

It was felt saturation of themes was reached within the sample, but this does not necessarily constitute relevance to practice and future research. While findings demonstrated the potential of this intervention with families, the potential for alternative results may occur when changes in the protocols or sample process are made.

Another limitation of this study is the unknown component of how this intervention might impact the family in the future. When end-of-life decisions need to be made, will this

knowledge learned from this process influence, guide, or support them at that time. While the DVD offers a lasting memento of the older adult's story, will it provide enough information to serve as a guide to family decisions? A longitudinal study would provide the means to answer this question.

## Implications for Future Research and Practice

The positive impacts of this intervention on the family and older adult are noted as implications for social work practice. Finding evidence-based interventions that offer positive impact on the clients served is significant. The fragility of the older adult at the time of admission to a nursing home requires interventions that will not exacerbate the situation. Older adults facing the loss of home, health, independence, and other losses need reinforcement of their value and the continued meaning of their lives to themselves and the family system. This intervention provides such a vehicle for growth and healing. The family system too is in a state of flux at the time of admission and may require modeling for communications in this new environment. Awareness of future decisions may add to family stress and the life review process offers knowledge and opportunity to make that future decision-making process easier.

Social workers engaged in the nursing home setting find themselves challenged in their workloads, being able to articulate their value to a medically dominated team, and defining their role to the client and family (Munn and Adorno, 2008). While currently conducting social history interviews per nursing home regulations, a modification of the social history process to resemble this life review intervention could prove to have a greater impact for all involved. The potential for establishing rapport and solid working relationships with the older adult and family system, thus impacting future interactions, should serve as a motivation for long term care social

workers. As social workers struggle to secure their place on the multi-disciplinary team, this intervention reinforces the substance they bring to the team's efforts to enhance end-of-life care.

Families involved in end-of-life decision making have expressed their desire to better understand the loved ones wishes, values, and beliefs. Findings from this study revealed an enhanced understanding of the history, values, and beliefs emerged through the life review process. In addition, the communication that took place after the life review demonstrated the possibility of this intervention to serve as a catalyst for deeper and more reflective conversations within the family system. As professionals struggle to model effective communication strategies for families at end-of-life, this tool serves as one such vehicle.

The affirmation of an older adult facing the transformative phase of admission to a nursing home and acceptance of dependence on others for care delivery is also reinforced through the life review process. Feedback from the older adult as well as the family noted the positive impact on self-regard and confidence experienced by the older adult. Fillett and Butler's (2009) work on frailty identity crisis reinforces our need to support older adults in the effective transition during this phase of life.

Future research should focus on the long-term impact of this intervention and its potential benefit to families when they face end-of-life decisions. Could this form of intervention reduce the number of caregivers who struggle with guilt and regret after the death of the care recipient? Longitudinal studies that follow families as healthcare needs change and after the death of the older adult could provide a window into understanding if this intervention provided them with the guidance and support needed to make healthcare decisions and their comfort with the decisions made.

Expansion on the sample to include a greater diversity of cultures and age would also add insight and understanding to the broader experience of this tool. Finally, it would be beneficial to professionals engaged in end-of-life care to alter the timing of this intervention to see if there is a moment in the aging process when results could be maximized. This could include time of diagnosis, first expression of need for assistance, or entrance into a facility. Timing could prove to be critical to benefit the older adult and family alike.

## Summary

This study demonstrated the potential of a structure life review with nursing home residents and their family members as a means to enhance family interactions and improve the self-regard of the older adult. The positive impact on the resident and the family members, in the absence of any negative effects, justifies future use of this intervention with older adults and their families. Given the desire to improve end-of-life care, it is vital to discover tools to enhance family interactions and create a level of understanding of the values and beliefs to guide decisions. A structured life review process conducted in the presence of family members appears to be such a tool and is one worthy of implementation and further research.

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## APPENDIX A. LETTER OF INVITATION

Date

Greetings!

Our life's stories are a valuable part of who we are. In some ways, they create who we are today and what we want for our future. For many families, these stories become a family legacy with tales passing from generation to generation. I am writing to invite you to participate in a project about your life story. My name is Laurie Dahley and as a student at North Dakota State University, I am interested in the power of telling one's life story and how these stories affect families. Bethany Retirement Homes has opened their doors to allow their residents to participate in this project. So, let me tell you more about the project.

I would like to interview you about your life's story with any family members you wish to have present. Their presence is important for a couple of reasons. Most importantly, because I want you to feel comfortable in the process.

- This interview may be video or audio recorded, if you wish, producing a recording to preserve your stories for you and your family to keep at no cost to you. Any recording will be your property with no copies remaining outside or your possession.
- Although there is an outline for the interview, you will choose which stories in your life's journey will be explored and how much you want to share
- Your participation is completely voluntary and you may decline to participate at any time.

If you wish to learn more about this project or our interested in participating, I would be more than happy to meet with you and your family to discuss the process. At that meeting, if you decide to participate, we will set up the date and time for your interview

and you would then be able to invite whomever you wish to join you for the life story project.

If you have any questions or would like to meet to discuss your participation in the study, please call:

Laurie Dahley at 371-3120 or email me at laurie.dahley@ndsu.edu .

Thank you for considering taking part in this research.

## APPENDIX B. INFORMED CONSENT

### Informed Consent Information Sheet

**Title of Research Study:** Use of a Structured Life Review and its Impact on Family Interactions

**This study is being conducted by:** Laurie Dahley, MSW and Greg Sanders, PhD

**Why am I being asked to take part in this research study?** We are looking for 15-20 residents and their families to discuss their life's story with us. We want to better understand what impact that life's story might have on you and your family. We are seeking individuals for whom this will not be a physical burden and who are able to share their memories of events past without difficulty.

**What is the reason for doing the study?** Communication within the family is viewed as critical in improving the care provided to older adults. Social histories are commonly done with the social worker and the resident but not necessarily with the family present. We would like to see if sharing the experience with you has an impact on communication, interactions, and understanding of values and beliefs you hold dear.

**What will I be asked to do?**

- Listen to all information presented today and decide if you wish to participate.
- Set up a time and day for a life review interview. You can invite any family members you would like to have present with you that day.
- The life review interview will take approximately 2 hours, but might take longer or less time depending on how much you are willing to share with us.
- Then, within the following month, we would like to meet with you and your family again to hear your feedback on the life review process. This interview will take approximately 1 hour.

**Where will this all take place?** Bethany has agreed to make space available for us to meet with you. We want to make sure that all discussions take place in a setting that is private and comfortable for you. If you wish to conduct the interviews in a family home, we would be glad to meet you there as well, but are unable to provide your transportation to that setting.

**What are the risks or discomforts involved in participating?** Talking about your past can bring up unhappy memories or difficult times. If such a memory comes up, we will be exploring it to learn how you were able to cope or grow through that process. What supports you had, what values guided you through the event, what lessons did you learn? But once again, you have the right to say you don't want to talk about it.

**What are the benefits to me?** The opportunity to have a DVD or audiotape may be viewed by you and your family as a benefit. We also hope there will be benefits from

the interview process, but cannot guarantee that. You may, in fact, experience no benefits from this interview process.

**What are the benefits to other people?** Your participation may provide us with a better understanding of families involved in the aging process. Better understanding may result in better care for our older adults.

**Do I have to take part in this study?** No, your participation is your choice. If you decide to participate, you can change your mind later and stop participating at any time.

**What are the alternatives to being in this research study?** Instead of being in this research study, you can choose not to participate.

**Who will see the information that I give?** The only copy of the recording will be given to you following the life review interview so only you or your family will see it. The follow up interview with you and your family will be audio-recorded to insure we accurately relate the reactions you had to the life review interview. If you select not to be audio-recorded, we will be unable to use your thoughts and ideas in our final project report. We would still like to meet with you but want you to know that without the recording of that interview, your reactions would not be included in the project. We will keep private all research records that identify you. When we write about the study, we will write about the combined information that we have gathered. We may publish the results of this study; however, we will keep your name and other identifying information private. If you withdraw from the project, your information will be removed at your request and we will not collect additional information on you.

**Can my taking part in the study end early?** If you are unable to attend the interviews, we may need to proceed with other participants. We will attempt to be as flexible as possible to make interviews possible, but if due to illness or other conflicts we are unable to meet, we will need to keep the project moving forward and may not be able to wait for our schedules to work out.

**Will I be compensated for taking part?** No, with the exception of receiving the recording (if you choose to have your life review interview recorded), there is no monetary compensation for taking part.

**What if I have questions?** If you have any questions, at any point during your involvement with this project, you can contact the researcher, Laurie Dahley, at 701-371-3120 or dahley@cord.edu

**What are my rights as a participant?** You have rights as a participant in this study. If you have questions about your rights, or complaints about this project, you may talk to the researcher or contact the NDSU Human Research Protection Program by:

- Telephone: 701-231-8908
- Email: ndsu.irb@ndsu.edu

- Mail: NDSU HRPP Office, NDSU Dept. 4000, PO Box 6050, Fargo, ND 58108-6050

The role of the Human Research Protection Program is to see that your rights are protected in this research; more information about your rights can be found at: www.ndsu.edu/research/irb

Documentation of Informed Consent:

You are freely making a decision to participate in this project. Signing this form means that:

1. You have read this form or it has been read to you and you understand its contents
2. You have had your questions answered, and
3. You have decided to be in the study.

You will be given a copy of this consent form to keep.

_____ _____

Your signature Date

_____

Witness if signed by mark

_____ _____

Family member, relationship to resident Date

_____ _____

Family member, relationship to resident Date

_____ _____

Family member, relationship to resident Date

_____ _____

Family member, relationship to resident Date

## APPENDIX C. INTERVIEW OUTLINES

**Structured Life Review Outline**

Family of Origin Information

Where and when were you born?

Tell me about your parents:

Tell me about your siblings, birth order, relationships, activities:

What values did you learn as a child, what were the important lessons you believe your parents attempted to instill?

Childhood

What was life like growing up for you?

What are your favorite childhood memories?

What were some of the strengths your family possessed?

Which relative had the most positive relationship with you and why?

Did you or your family experience any significant challenges or difficulties and how did you overcome them or deal with them? How did these influence your future?

Major Family Illnesses or Concerns

How did you deal with them? What did you learn from this?

How did you lose your parents? What happened and what did you learn from this? Have you lost any of your siblings? What can you tell me about that process?

Education

Tell me about your education. What level did you complete? What was school like for you? What was your favorite subject/activity? Did you have some struggles as well…how did you overcome them?

Any extra-curricular activities?

Spiritual Beliefs

Are you affiliated with a particular spiritual belief: If yes, How have spiritual beliefs impacted your life? How have your beliefs evolved throughout your life?

Cultural Practices

What is your cultural heritage?

What cultural practices/traditions do you practice?

Military History

Did you serve in the military? In which branch? Tell me about your experience. What did you learn from these experiences?

Family of Creation/ Significant Other information

Have you ever been married? To whom and when? Tell me about your marriage(s).

What was something positive you learned about relationships?

What values were important in your family of creation?

Tell me about your children? Who, ages, health

What values did you try to teach your children? What were some strengths that you brought into parenting? Did your family face any challenges or issues? How did you overcome or deal with them?

Peer Relationships

Tell me about friendships. Who were/are your closest friends and confidantes? Who is your life has been most supportive over the years? Are they still in your life? How did they support you?

Employment

Tell me about your occupation? If your employer or colleagues were asked about your strengths as a worker, what would they say?

Personal Attributes

What do you consider to be your strength/talents

Leisure/ Recreational Activities

What were your favorite hobbies or recreational activities throughout the years? Are you still able to participate in these? If not, why?

Health Assessment

How is your current health? What do you understand about your diagnosis?

Have you had any surgeries? Do you have any health/ medication concerns?

What are some of your concerns about your future health treatment? What directions would you give your family regarding your wishes?

**Post "Life Review" Interview**

What impact, if any, do you feel the life review process has had on you and your family related to:

a. Communication
b. Relationships
c. Understanding of values and beliefs about end-of-life care
d. Perception of future decisions