# The Experience of Older Adult Couples Living with Chronic Illness at Home: Through the Lens of Health as Expanding Consciousness

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### Boston College Connell School of Nursing

# THE EXPERIENCE OF OLDER ADULT COUPLES LIVING WITH CHRONIC ILLNESS AT HOME: THROUGH THE LENS OF HEALTH AS EXPANDING CONSCIOUSNESS

a dissertation

by MARY T. ANTONELLI

submitted in partial fulfillment of the requirements
for the degree of
Doctor of Philosophy

#### Abstract

The Experience of Older Adult Couples Living with Chronic Illness at Home:
Through the Lens of Health as Expanding Consciousness
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As the United States population ages, knowing and understanding the older adult couple's experience living with chronic illness at home is significant to inform new strategies of care, and planning of resources for the improvement in the health and well-being for a potentially vulnerable population. The purpose of this qualitative study was to better understand the older adult couple's experience while living with chronic illness at home by answering the following research questions: What is the life pattern manifested by an older adult couple living with chronic illness at home? Are there common themes across the life patterns of older adult couples living with chronic illness living at home?

The theoretical framework guiding this study was Margaret Newman's Health as Expanding Consciousness using a hermeneutic-dialectic phenomenology method. The study's sample consisted of 14 married older adults (≥ 65 years of age) couples living together at home. The research method explored the experiences of the older adult couple through dialogue within the context of their social environment in all its complexity. This approach gave voice to the older adult couples' experiences and their meaning from their perspective, which facilitated insights about each older adult couple as well as common themes across the older adult couples.

Three themes emerged from the study, (1) an unfolding pattern of living meaningfully as an older adult couple with chronic illness while moving through life transitions, (2) couple interconnectedness strengthens the bonding within the older adult couple and promotes self-growth, and (3) a resonating process within the couple promotes movement toward expanding consciousness. Conceptual models are proposed. The findings suggest older adult couples living with chronic illness at home strive to live meaningfully while experiencing multiple life transitions embedded in a resonating process that facilitates change.

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#### 1

#### **Chapter 1: Statement of the Problem**

In the United States (U.S.), a contemporary understanding of what "wellbeing" means to the older adult (OA) (≥ 65 years of age) population is required as a new generation of OAs, the Baby-Boomers, are challenging the stressed, fiscalhealth care management and care delivery models (Center for Medicare & Medicaid Services [CMS], 2016). One facet of well-being needing to be better understood is the experience of OA couples managing their health while living at home. Today, fifty-seven percent of the OA population is comprised of couples living together at home, with chronic illnesses (Administration on Aging [AOA], 2014; US Census Bureau [USCB], 2013). While managing chronic illnesses, OA couples are facing a multiplicity of health challenges, not only related to the influence of the aging process, but managing their health within a fragmented healthcare delivery system (see Elhauge, 2010).

A growing body of research speaks to the needs of OAs and the management of their illnesses, but less is known about the experiences of aging as a couple and living with chronic illness in the home setting. Developing new knowledge that informs health care providers about the process can lead to new inquiry to foster interventions to promote and optimize care delivery models that may enhance OA health, while living as a couple with health challenges. This chapter briefly describes the problem of this gap in knowledge, its significance, and the purpose for study regarding the experiences of OA couples living with chronic illness at home.

#### **Problem Statement**

Current knowledge about aging in OA couples addresses the decline of health from a psychological, physical, disease orientation (Kane, 2015; Kiecolt-Glaser & Newton, 2001; Vassilaki et al., 2015). To date, there is an insufficient understanding of an OA couple's living dynamics related to managing daily life when one or the other or both suffer from a chronic illness (Kane, 2015; Revenson, 1994). This lack of information hinders effective design for innovative care strategies to address the contemporary challenges faced by OA couples within their environments. Gaining new insights into the OA couple's living dynamics and how the OA couple understands and manages their health and wellbeing, is a necessary first step in informing the development of effective strategies to support this population and facilitate their ability to remain in their homes and communities over their life span (Colby & Ortman, 2014; Hudson, 2014; Kane, 2015; Vassilaki et al., 2015).

#### **Significance of the Problem**

The significance of the problem is multifaceted and involves the individual, families, society, and has global implications (Hudson, 2014; Sugar, Riekse, Holstege, & Faber, 2014). The growing number of OAs in the U.S. is disproportionate to other age groups placing new demands on health care overall (Colby & Ortman, 2014). The nature of being an OA couple, especially when faced with chronic health conditions in one or both spouses, raises new challenges for all concerned. The vulnerability of the OA population, along with the inherent challenges of aging, requires care delivery models to adequately support the

complexities surrounding health while aging (Kane, 2015; Vassilaki et al., 2015). New models of care need to be developed by nursing and others that can address the complexity of health demands faced by the aging couples earlier in their trajectory (Mason, Jones, Roy, Sullivan, & Wood, 2015).

#### **Older Adult Population Growth**

The OA U.S. population is projected to increase 65% from 21.7 million in 2010 to 38.6 million in 2030 (Baker et al., 2014). With an increase in life expectancy there is an additional growth in the population age of 75 and over. By 2040, the population of 75-84 year olds is projected to reach 30.1 million, and those 85 and older are estimated to reach 14.1 million (Baker et al., 2014). The impact of this population growth is anticipated to continue through 2060, creating controversies and conflict with other age groups regarding healthcare costs, and the allocation of resources, including expansion of health care services, programs, and family caregiving supports (Hudson, 2014). As a result, there is an urgent need to develop effective care strategies and policies to support healthy living in the community, and generate effective care delivery models for the OA that are informed by contemporary evidence and understanding (Colby & Ortman, 2014; Federal Interagency Forum on Aging-Related Statistics [FIFARS], 2012; Hudson, 2014; Settersten, 2011).

#### Influence of Being a Couple on their Health

Within the growing OA population, 72% are reported to be married, and of those non-institutionalized persons, 57% live with their spouse or significant partner at home (AOA, 2014; USCB, 2011). The literature reports there is an

association between the characteristics of a couple's relationship dynamics and the status of their health and well-being (Kiecolt-Glaser & Newton, 2001). This dynamic is related to the continuous influence of each person's behavior, life choices, and personal attitudes on the other (Kayser, Watson, & Andrade, 2007; Kiecolt-Glaser & Newton, 2001; Lyons, Zarit, Sayer, & Whitlatch, 2002). The influence of the couple's relationship dynamics on health can be so profound that morbidity and mortality are affected (Kiecolt-Glaser & Newton, 2001).

The influence of the couple's relationship dynamics on health and well-being is generally more significant for OA couples when compared to those of younger adult couples (Kiecolt-Glaser & Newton, 2001). Hoppmann et al. (2016) explained OA couples tend to have a longer history of shared experiences over the years; each knows the other's attributes well, and the couple tend to share many activities together. The OA couple also is inclined to experience the loss of social roles that may mitigate stress, have less financial, physical and psychological supports, and are less likely to use formal supports (Pinquart & Sorensen, 2003). These characteristics and experiences of the OA couple often facilitate a mutual support of one another, or place the OA couple in a distinctly more vulnerable position than is generally experienced by younger adult couples (Hoppmann, Michalowski, & Gerstorf, 2016).

#### Older Adult Couple's Vulnerability to Health Risks

As aging occurs, each spouse is susceptible to an increase prevalence of chronic illness and disability. The increasing prevalence of ill health and illness, increases their vulnerability to other health issues, and may lead to disruption

within the OA couple's usual patterns of living. This is especially true if the OA couple lack the skill and resources to manage life's complexities (Michalowski, Hoppmann, & Gerstorf, 2016; Ording & Sorensen, 2013; Ruel et al., 2014; Vassilaki et al., 2015).

The combination of social role disruption that often accompanies aging and increased complexity of daily living related to the existence of compromised health, places the OA couple at high risk for having to manage the care of one or both partners. Factors such as managing the delivery of multiple medications, addressing complex home regimes, use of emergency services and hospitalizations, add new stressors to the OA couple living. Decreased quality of life, higher out-of-pocket expenses and a higher risk of developing dementia are added threats to the experience (Vassilaki et al., 2015). These factors can create a need for adjustment in daily living. Unsuccessful adjustments may lead to a deterioration in the couple's relationship (MacLeod, 2011; Walker, Holling, Carpenter, & Kinzig, 2004). Consequently, it is critically important to understand the OA couple within the context of their environment to identify risks and vulnerabilities, and seek ways to support the couple toward achieving goals.

#### **Inadequate Health Care Models**

The current health care delivery and care management models available to the OA couple are inadequate to address the distinctive challenges facing this population. Kane (2015) reported contemporary disease management programs are, for the most part, designed to focus on the individual with a single chronic condition. Such an approach is inadequate to account for the complexity and

ambiguity present within an OA couple's life and potentiates the risk for health management errors (Kane, 2015; Revenson, 1994; Vogeli et al., 2007). Failure to acknowledge the importance of the illness experience within the entire context of an OA couple's life, as a whole, places the OA couple at risk for unnecessary diminishment of health and well-being.

#### **Theoretical Framework:**

#### Margaret Newman's Health as Expanding Consciousness

This study is framed within Margaret Newman's theory of Health as Expanding Consciousness (HEC) (Newman, 1979, 1999, 2008). A brief overview of HEC is provided below. The method is discussed in detail in chapter two, followed by the rationale for use and how the method used applies to answering the research questions.

Rogers' Science of Unitary Human Beings (1970, 1980, 1994) was used by Newman to develop the theoretical framework of health as expanding consciousness. It is a theory of health that places a person as the central character. It is proposed that this person manifests a unique pattern through movement, time and space and is characterized by meaning (Newman, 2008). Health is not viewed as dichotomous, health and disease, but is viewed as an evolving pattern of the person, as a whole, within their environment that also includes disease. Consciousness is the "informational capacity" of the person and is revealed in the evolving pattern (Newman, 2008, p.6). The ability for reflection and understanding of one's relationships with their environment offers the opportunity for expanding consciousness.

This framework was selected to study OA couples living with chronic illness at home because of its focus on exploring pattern over time to uncover meaning and complexity within the experience of the OA couples within their environment. The dialectical process, an important component of the framework and guided method of HEC, is significant to the purpose of this study and to answering the research questions, as it provides an opportunity to capture new insights that other method designs do not offer. Within the dialectic process between the nurse and the participant/s there is an uncovering of the human experience through the life journey, an attention of meaningful events and relationships, an unfolding pattern of the whole over time and an opportunity for reflection on the lived experience that enhances awareness and meaning and promotes choices that can provide change toward transformative living. Nurses facilitate this process through the mutual dialogue, as clinicians and researchers, gaining new insight and discovery from knowing the person or participants through a nursing perspective.

#### **Purpose of the Study**

Family research established the importance of knowing and understanding the OA's experiences of living with chronic illness (Johnson et al., 2013; Kane, 2015; Kim & Waite, 2014; Lyons et al., 2002; McPherson, Wilson, Chyurlia, & Leclerc, 2011). Up until now, there was a lack of contemporary evidence about the unique experiences of OAs, as a couple, living with chronic illness at home. This evidence is needed to adequately inform future health care delivery from a holistic perspective. Considering that meaningful life experiences, care delivery

models and assessment tools are needed to adequately care for this growing population, this current study was important. As the U.S. population ages, the challenges surrounding the delivery of health services to the OAs will continue to escalate. New knowledge accessed by nurses can inform a contemporary, integrated, holistic approach to uncover strategies that can be used to respond to this changing population. Therefore, the purpose of this study was to come to know the OA couple's experience as they live at home with chronic illness using Margaret Newman's of Health as Expanding Consciousness (HEC) using hermeneutic-dialectic phenomenology.

#### **Assumptions**

For this study, the following assumptions were:

- Chronic illness and the management of the health condition/s has a disruptive effect on lives of OA couples.
- 2. These disruptive effects are different than those experienced by people living alone or who are not in a couple situation.
- The OA couples are the most knowledgeable about their experiences and will share their experiences willingly and honestly to enhance the uncovering of the meaning.
- 4. The OA couple's dynamics influences their health and well-being.
- 5. The nurse researcher can invite the participants to discuss meaningful life events and relationships to uncover the pattern of their life experience over time.

- 6. The recognition of the life pattern creates an opportunity for choice, action and transformation linked to new awareness and expanding consciousness for the individual OA couples.
- 7. The process of identifying life patterns across OA couples can reform approaches to care and change policies needed to provide care at home for the older adults.
- 8. The knowledge gained from the study can influence the development of care models for this OA population and guide educational programs in developing curriculum content focusing on care of the older adult.

#### **Research Questions**

For purposes of this investigation, two research questions were constructed. They are (a) what is the life pattern manifested by older adult couples living with chronic illness at home?, and (b) Are there common themes across the life patterns of older adult couples living with chronic illness at home?

#### **Chapter One Summary**

In this Chapter the reason for the study was explained and defended. A brief background was provided with the focus of inquiry, the research significance, the study's purpose, the theoretical framework, and assumptions underlying the study. Finally, the research questions were delineated.

#### **Chapter 2: Review of the Literature**

This chapter presents the relevant literature regarding the contextual background for studying the older adult (OA) couple living with chronic illness at home. This review includes an overview of the theoretical framework, Health as Expanding Consciousness (HEC), along with a discussion of prior related research conducted using HEC. Additionally, a review of the major concepts regarding the topic of interest: aging, the OA population, chronic illness, family caregiving, OA couple, and health care delivery challenges is completed.

#### Theoretical Framework

#### **Unitary-Transformative Paradigm**

Martha Rogers theory of the Science of Unitary Human Beings introduced the concept of human beings as being unitary-transformative (UT) in nature, in the 1970's (Rogers, 1970, 1980, 1994). It is a distinct perspective on human nature also referred to as a paradigm or world view. The UT paradigm reveals a shift from the traditional scientific approach to an inquiry that explores phenomena as isolated parts then adds the parts together to understand the phenomenon, as a whole. A phenomenon, under this view, is the whole as being a sum of its parts. In contrast, the UT paradigm gains understanding through exploration from within the phenomena that uncovers the whole from within the context of a person's being, experiences, and their environment. There are no parts as such, rather the whole is understood as greater than the sum of the parts. There is a continual, mutual dynamic interaction creating a rhythmic flow between the person and their environment manifested in a pattern and creating a rhythmic flow (Newman, Smith, Pharris, & Jones, 2008). Within the UT

paradigm, the individual is viewed as a unitary human being (UHB), an irreducible whole, that is one with the universe, only separable for purposes of discussion. Energy is manifested in human and environment field, is varying in intensity and without boundaries. The dynamic interaction between the human field and the environmental field is manifested in pattern, which is observable. The unfolding pattern for Newman is reflected in flow over time.

From the UT paradigm, health and illness are conceptualized as a unified rhythmic fluctuation over the life span (Rogers, 1970). It is through the process of recognition of the UHB's life pattern that the human experience is revealed or uncovered (Picard & Jones, 2007; Rogers, 1970, 1980, 1994). Exploration of the UHB cannot be fully understood as distinct from their environment, since the mutual interaction between the two is dynamic, continuous, evolving, and changing over time.

#### Newman's Theory of Health as Expanding Consciousness (HEC)

Newman's theory emerged from Rogers' basic conceptualization with three assumptions, (1) health is an evolving unitary pattern of the whole, including the pattern of disease, (2) life-pattern reflects the human-environmental process, characterized by meaning, and (3) consciousness is the informational capacity of the whole, the ability of the system (individual, family, society) to interact with its environment that is revealed in the evolving life pattern and affords the potential for action (Newman, 2008). These assumptions shift the orientation of health and illness from a dichotomous state to a continuous flow of pattern.

Newman's theory of HEC creates opportunities for nursing to engage in research that seeks to uncover the uniqueness of person within the context of health and engage in relationships that promote health and well-being of the whole. When health is viewed as the totality of one's life, in constant motion, the opportunity to gain increasing awareness of one's life pattern can provide benefits to support change and promote healthy living. Focusing on the OA couple living with chronic illness at home through the lens of HEC can uncover new understanding to inform and guide innovative care delivery. Engaging in dialogue guided by HEC provides an opportunity for the OA couple to recognize their life pattern for an opportunity to determine which actions are likely to support change that may have a transformative impact on their lives. Their recognition can then be used to take on actions that support change to improve and living. The nature of the experience, then, can be considered a transformative.

Main concepts. The theory of HEC has four main concepts, health, pattern, consciousness and relationship (Newman et al., 2008). Newman's concept of health is conceptualized and defined as an evolving unitary pattern of the individual, where disease and non-disease is one entity. Health is viewed as the evolving process of interaction with the environment toward increasing awareness, and as a "transforming process to higher levels of consciousness" (Newman et al., 2008, p.364). The expanding consciousness is significant since it provides the person/s with an understanding of their lives or situation that allows for informed options for actions to improve health and well-being. This view of

health not only allows the nurse to concentrate on what is currently being experienced but also the meaning of the experiential process, as it is unfolded, for both the nurse and the individual. The uncovered meaning fostered by the process between the nurse and the individual potentiates an opportunity for recognition of one's life pattern that then provides an opportunity for effective, sustainable change supported by the nurse.

Patterning depicts the individual's interaction with their environment and provides an understanding of the meaning of that interaction (Pharris, 2002). "Pattern describes relationships, relationships of the person and relationships with other people and the environment" (Newman, 2008, p. 5). The pattern is the expression of the whole person that is without boundaries. The pattern is ever changing in the direction of increasing complexity and reveals the meaning of their life (Newman et al., 2008). It is the pattern of life that identifies the distinctiveness of the human being. It is through the mutual process of the nurseindividual relationship that life pattern recognition is accomplished. Health as expanding consciousness evolves as individuals become aware of their unfolding life pattern and how they recognize the existence of a range of possible choices. Pattern recognition permits understanding for choice of action that will create an opportunity for change that can be transformative (Picard & Jones, 2007). This transformation offers new opportunities for new discovery of the experiences and the meaning of health for that individual, family or community.

HEC shifts the perspective of health from merely the treatment of the disease and symptoms to a searching for the life pattern and its meaning to

potentiate change to promote health and well-being (Newman, 2008). "It is a reexamination of disease and disruption that eliminates the negativity associated with these concepts and redefines them as essential parts of the self-organizing process of the expanding consciousness" (MacLeod, 2008, p. 59). Health as expanding consciousness reinforces the purpose of nursing. It is the nature if the nurse-patient caring relationship that is the catalyst for the mutual process and its meaning for appropriate actions. Nursing is not only to address the concerns of disease but to assist the individuals within their environment to become aware of their own life pattern of expanding consciousness that can provide more influence over their health and well-being (Macleod, 2008; Picard & Jones, 2007).

Background of Health as Expanding Consciousness. Newman's concept of consciousness emerged from her early research regarding the relationship between time, space and movement (Newman, 1979). Her thinking was further influenced by Itzhak Bentov. Bentov (1977) conceptualized life as the process of expanding consciousness, ever evolving over time. Newman merged Rogers' conceptualization of health and Bentov's conceptualization of consciousness to create a new understanding of as health as expanding consciousness over the life span (Newman, 2008).

Consciousness is viewed as a characteristic of human nature that evolves over time. Bentov defined consciousness as the "informational capacity of the system" (the person), and is the "ability of the system to interact with the environment" (Newman, 2008, p.3). Consciousness includes all forms of information, physiological, mental and emotional. Expanding consciousness is

achieved as the individual becomes aware of his or her own life pattern, which provides an opportunity to act with the potential to move to a transformative state of understanding (Picard & Jones, 2007). The transformation creates greater opportunities for new discovery about the experiences and the meaning of health and well-being for that individual.

Arthur Young's (1976) theory of the evolution of consciousness also influenced Newman's conceptualization of the process of human movement to an expanding level of consciousness (Newman, 2008; Picard & Jones, 2007). Young's conceptualization of the stages of consciousness offered a theory of the process of expanding consciousness. Young's theory suggests how an individual might move toward expanding consciousness through various choice points; a shift in perspective is needed, because the "old processes" are not working. It is through recognition of the awareness that leads to the ability to make choices resulting in a greater self-awareness (Jones & Antonelli, 2017).

Young's (1976) theory pinpointed the role of life pattern recognition for Newman. Young's ideas provided Newman the impetus for her to integrate the basic concepts of her new theory, including movement, space, time, and consciousness, into a dynamic portrayal of life and health (Newman, 1999). Newman incorporates Young's (1976) conceptualization to facilitate the identification of the expansion of consciousness as the unfolding pattern is presented (Figure 1) (Newman, 2008; Picard & Jones, 2007).

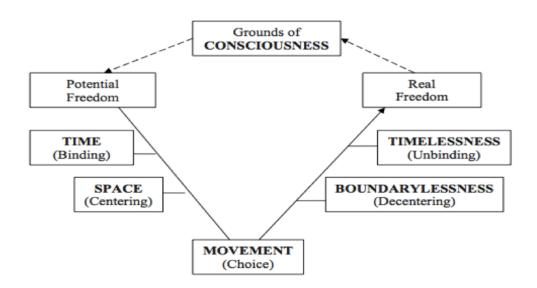
Figure 1 reflects the integration of Newman's and Young's conceptualizations as an illustration of expanding consciousness as a process of

health through the movement of stages, binding, centering, choice, de-centering, unbinding and real freedom. The staging starts with a Potential Freedom which is then followed by Binding (at birth), a stage when there is no sense of self as an individual and decisions are made for the person. Newman depicted this stage as a concept of time. Over time, as the person experiences movement they become more aware of their world. The third stage is Centering when individualism is developed as a sense of self-identity and consciousness. This stage reflects a break from authority. Newman conceptualizes this stage with space where the person may gain a control. The next stage, Choice, is a stage of reflection to respond to a situation. It is a turning point that promotes expansion of consciousness and is related to the concept of movement. The fifth stage, Decentering, occurs after a choice is made, with a movement to growth and development. Newman related this stage as a sense of being boundary-less. The stage of Unbinding is described as when the person is freed from bonds of time and are to be fully present in the moment. It is a time when the person is awareness of their consciousness. The last stage of Young, Real Freedom, may rarely be experienced, which requires transcendence. Newman relates this stage with love and a unity where the person is focuses beyond themselves to more meaningful relationships with others (Newman, 1999).

Over time, Newman's HEC research method advanced and evolved. It has come to be known as research-as-praxis or the hermeneutic-dialectic method, where theory, practice and research are integrated and viewed as one process, each influences the other (Smith, 2011). The application of Young's (1976)

illustration of expanding consciousness evolved to be less prescriptive in movement through the staging. Movement toward expanding consciousness is a process that comes to a choice point for action. The process is iterative and forward moving, where the individual is never in the same level of consciousness as previously experienced (M.A. Newman & D.A. Jones, personal conversation, Sept. 5, 2016). This forward movement allows for increasing awareness toward expanding consciousness.

Figure 1 Interrelationship of Newman's Basic Concepts and Young's Stages of Evolution



From A Developing Discipline: Selected Works of Margaret Newman (p.132), By Margaret A. Newman, 1995, New York: National League for Nursing. Reprinted with permission.

#### 18

#### Past Research Using Health as Expanding Consciousness

The use of Newman's HEC in nursing research is international and diverse. Over 180 articles are published documenting the use of the HEC method in research, how HEC can be used in education, in nursing practice and/or to guiding the distribution of community resources or influence policy. Moch's (1990) publication was the first study to use Newman's theory, exploring women's experience with breast cancer. Since that time, modifications to the theory were made that extended the applicability of the theory to research in many areas (Smith, 2011). One modification was the incorporation of the use of artistic modes (e.g., drawing, poems, dance) by the participant/s as an option to share their meaning of their life pattern (Neill, 2002; Picard, 2000; Smith, 2011). The application was also extended from an individual-focused application to small groups such as families and couples (Endo et al., 2000; Falkenstern, Gueldner, & Newman, 2009; Litchfield, 1999; Picard, 2002; Smith, 1995; Tommet, 2003), to the community (Pharris, 2002), and then also to the inclusion of health policy (Musker & Kagan, 2011). However, through the advancements, the key tenets remain the same. The modifications strengthened the ontological and epistemology alignment with the unitary-transformative paradigm through engagement with the participant/s as active members of the process through the expression of their experiences and its meaning (Smith, 2011).

#### Family Research & Health as Expanding Consciousness

As the theory of HEC evolved the research-as-praxis method was applied to various populations and health concerns. This evolutionary

progression informed the need and the ability for life pattern recognition to extend beyond the individual within groups, such as families. Schmitt (1991) researched the experience of the giving and receiving of social support from the spousal caregivers and to their spouses. This was one of the first studies that used HEC to research the couple or family as the unit of analysis. The results of the study uncovered the complexity of social support situations for these groups and the importance of identifying the interaction within the family, between the family members and to others outside of the family to understand the situation and what is needed for adequate support (Schmitt, 1991).

Litchfield (1999) further extended the use of HEC by studying families. Litchfield found that families with children who had repeated hospitalizations experienced issues that went beyond just the events of the child's illness. A more encompassing issue emerged that had to do with "the meaning of the health patterning in relation to each family's unique experience" (1999, p.65). This discovery revealed, "the pattern of the family was itself a construction of the research process, unfolded within it, creating a framework for health patterning, which represents pattern recognition as a whole movement of a process within the partnership parameters" (Litchfield, 1999, p.65). The pattern recognition led to a more "comprehensive, abstract grasp of the family situation and finding a new identity as a family unit" (Litchfield, 1999, p.65). From this conceptualization, Litchfield articulated a framework of the family within HEC as follows:

A partnership...had parameters of entry and closure where its timing was a phase of disruption in family life and the practitioner-family encounter had an informing capacity. An evolving dialogue...was a continuous flow of unfolding and enfolding of meanings embedded in the social/political/health system context. The recognizing of pattern...occurred as incidental revelations in the conversation leading to a more comprehensive insight as the potential for action. Increasing connectedness...could be seen as a sense of inclusion as family members and citizens, interdependence in health care and transformation in family living. (Litchfield, 1999, p.65)

Yamashita (1999) findings reinforced those of Litchfield (1999).

Yamashita (1999) conducted a study with family caregivers of relatives with mental illness using HEC. Findings suggested the caregivers experienced uncertainty and frustration. It was also noted that the caregivers could reach turning points that allowed them to move beyond their limitations. Caregiving was not so much a burden, as a transformative experience through which understanding and acceptance of the mental illness could occur, "when one comprehends the whole, knowledge of the parts becomes meaningful" (Yashmita, 1999, p. 78).

The family as the focus of analysis. Since the 1990's numerous nurse scholars and researchers applied the theory of HEC to various healthcare topics and populations involving the family or family members collectively, as a focus of analysis (Endo et al., 2000; Falkenstern et al, 2003; MacLeod, 2011; Picard,

2002; Smith, 1995; Tommet, 2003). Endo et al. (2000) explored the caring partnership between the nurse and families experiencing cancer using pattern recognition. Study results suggested that through the caring partnership "the family members began to have insight into their own individual pattern in relation to the family's pattern, and the meaning of the family was revealed" (Endo et al., 2000, p.609). Along with this new family meaning, expressions of care and trust were demonstrated as a new form of connectedness.

The transformation from a lack of connectedness, which had been maintained throughout their family life, to the connectedness evidenced by caring, trusting overtures moved them from the chaotic situation first encountered by the nurse to a new level of stabilization and vision for the future. The families, who had been focusing only on the present difficult situation, made a connection to their past lives and gained insight regarding their future... (Endo et al., 2000, p.609)

Picard (2002) studied the experience of the sudden death of her brother with her family members. The family members explored their perception of the experience as a family and individually leading to an increased personal awareness. Through this exploration, the family members validated the feelings of sorrow and suffering. Exploring the experience together allowed for an increased feeling of family connectedness after the individual's death.

Falkenstern et al. (2003) used HEC to explore the experiences of families that included children with special needs. In this research, the interview question focused less on the individuals in the family and more on uncovering perspective

of the experience as a family, "Who are the most meaningful persons in your life as a family?", and "What events were the most meaningful in your life as a family?" (Falkenstern, et al., 2003, p.45). The study reported that a mutual process of a partnership emerged, which was integral to nursing's practice and research. The Falkenstern study created a precedence for the use of HEC as a guide to uncover family patterns and experienced commonalities. The new approach allowed for a new use of HEC in uncovering family pattern to broaden the scope of understanding the phenomena and to further guided research.

Tommet (2003) advanced the knowledge of family caregiving by assisting "the family to understand the evolving life pattern through an authentic shared relational experience" (p. 240) via the exploration of the nurse-parent interaction in families with children who were medically fragile. The nurse-family interaction facilitated and empowered families to engage in a partnership in order to achieve innovative change and growth. Tommet (2003) found that "families changed from trying to gain control of their uncertainty to learning to live in the uncertainty, as they evolved through an initial period of disruption and disorganization to organization to another level" (p.239).

MacLeod (2011) used HEC study with a sample of 12 spousal caregivers of post-cardiac surgery patients. This research focus was on the spousal caregivers, but the findings of the across the participants uncovered significant relational dynamics between the spouses and the family members. Macleod (2011) found a dyadic relationship pattern between caregivers and spouse that impacted the caregivers' role and responsibilities. High levels of mutuality

presented barriers for the caregiver to act outside of the couple-dyad to ask for assistance. This experience challenged the communication between the spouses and enhanced distrust of those outside of the dyad. The study also found the caregivers' recognition of their life pattern allowed for an awareness of new understanding of the meanings of their lives, opportunities for new choices and insights about their life left to be lived.

#### Other Research using of Health as Expanding Consciousness

Other studies using HEC as the theoretical framework for research investigations explored the meaning of staying healthy for families, and older wife-husband caregiving (Brown & Alligood, 2004; Brown, Chen, Mitchell & Province, 2007; Smith, 1995). Smith (1995) used Newman's conceptualization of health through a phenomenological analysis to reveal the meaning of staying healthy for 10 low-income rural African American families. The study found that staying healthy was more like as a process than a state of being. Staying healthy meant the family moved through events taking on new ways of doing and being.

Awareness of staying healthy for the participants centered on an internalized sense of being able to survive whatever pattern of health or illness they experienced. Staying healthy meant the family experienced life events as times of learning that were dynamic and individualized. When the families shared experiences of staying healthy, the structural patterns revealed person-environment interactions that were dynamic in nature and could not be placed on a linear continuum scale. (Smith, 1995, p. 20)

Smith's (1995) findings reinforced the premise that a family's conscious awareness of life's dynamics influence health, and facilitates action that permits sustained health and growth over time.

Brown & Alligood (2004) and Brown et al. (2007) utilized a combination of HEC theory and Grounded theory method in their studies. Though this synthesized approach provided an alternative research application of Newman's theory in combination with other qualitative methods, the methodological design differs from one that is purely HEC, complicating the analysis, interpretation of the findings and thus its application in practice. Therefore, these studies are presented as exemplars as to the multiple existing applications of HEC, rather than as a substantiation or validation of this current study's methodology.

For the current study, the OA couple, is the unit of analysis as a holistic entity. As identified by MacLeod (2011) an influential dyadic pattern emerged within the couple. The life pattern of the couple living with chronic illness at home becomes the focus of interest and the pattern conceptualization and its meaning is the emphasis. Newman's framework of HEC was chosen to undergird this current research study because of its capacity to explore the dyad's experience and pattern as a whole. Using the HEC research design creates the opportunity for the understanding of the meaning of health, well-being and life pattern and within a research context. Data gained from this study may validate and extend the theory that may offer new information into the older adults and couples studied that can guide intervention for the aging population.

#### Aging

Aging is defined in many ways depending on the perspective of who is defining the term. Aging incorporates an amalgamation of processes including genetic, behavioral, and social factors that is often expressed in negative terms such as degeneration, injury, or decline (The Free Dictionary, n.d.). Depending on how the concept of aging is defined, aging is a phenomenon that generates unique and challenging situations for societal structures that starts at birth and continues over the life span (Settersten, 2011). These challenges are both diverse and complex, and are created by the variations that occur within the context of social and environmental dimensions of one's life (Settersten, 2011). Understanding the connections between the social and environmental dimensions of aging can offer insight into the life experience and the pathways that are taken by an individual.

Health care is one of those social structures that play a significant and intimate role in the aging phenomenon. It is responsible for the well-being of individuals, families and society (Hudson, 2014). Hence, there is an ethical mandate for healthcare professionals to act in the best interest of the aging person and society. In order to act in the best interests of the aging population, scholars in nursing and other healthcare disciplines have to continue to develop their knowledge about the particular needs of this population.

#### **The Older Adult Population**

An intensified interest in the older adult (OA) population occurred during the latter half of the 20th century related to the impeding shift to an increase in

age of the U.S. population. This shift reflects a combination of factors including an increase in longevity and the "Baby-boomer" cohort (Colby & Ortman, 2014; Settersten, 2011). The large baby boomer cohort population, born between 1946-1964, was the result of increased and sustained levels of births that occurred post-World War II (Colby & Ortman, 2014). As the "Baby-boomer" population moves into the 65 and over age group, 20% of the U.S. population will be 65 years of age or older by 2030 (FIFARS, 2012). Though the size of this cohort will diminish over time, the impact will last until 2060, when it is expected this segment of the population will reduce to 2.4 million (Colby & Ortman, 2014). Until that time, this shift to an older population will create many challenges for society and governmental services overall, including health care.

Generally, the OA population is viewed as financially vulnerable, disabled and needing special assistance from family or governmental agencies based on chronological age alone (Hudson, 2014). However, in the aggregate, this perception of the OA is incongruent with the current reality of the population. Since the enactment of public policies early in the 20th century and the changes in social structures, the OA population's composition is different from years past, influencing a new perspective from a health care, societal, and governmental viewpoint.

#### **Older Adult Population Health Determinants**

The determining factors for OA healthy aging and a sustainable quality of life are multifactorial and are the same as other age population in the U.S. (Hudson, 2014; Kindig, 2010). Determinants of health, such as individual age,

genetics, behaviors, social-economic factors, and physical environment all contribute to one's health status as does access to supports and resources. Each of these determinants influences, to varying degrees, health within a population (Kindig, 2010). The study of health of the OA population's offers a unique opportunity to understand the influence of historical, social and economic opportunities the OAs experienced over their life time. This information can provide identified actions and policy that contributed to the OA population's improved health. Examples of such improvements from social and health policy enactments over the last 50 years have been lauded for the better standard of living and health for the current OA population compared to the past populations (Chernof, 2015; Hudson, 2014).

Age categories. The OA population is not homogenous. There is diversity, just as in any other age group population. One differential characteristic is the defined age ranges of people who are 65 years of age and older. There are three age categories that comprise the OA population. Each has defining generalizable features that require different considerations related to healthcare (Sugar et al., 2014). The first is the young-old, ages of 65 through 74, the largest segment of this population and 7.6% of the overall population (approximately 22 million) (USCB, 2013). This group is comprised mostly of the "Baby-boomers." The young-old cohort is healthier, more mobile, continues to be in the labor force and may be providing care to aging parents (Sugar et al., 2014). It is this young-old cohort that currently has the largest effect on the growth of the OA population.

The middle age range, currently referred to as the aged, is comprised of those whose age is between 75 through 84. They currently represent 3.3% of the population (approximately 13 million) (Sugar et al, 2014; USCB, 2013). Those in the aged category exhibit the start of an increase in the incidence of chronic conditions. Such conditions include heart disease, sensory impairment, a decline in mobility and a slowing down of participation in leisurely physical activities (Schoenborn, Vickerie, & Powell-Griner, 2006). The last category is known as the oldest-old. This group of persons are 85 years of age or older, and make up 1.6% of the US population (approximately 5 million) (USCB, 2013). This is the fastest growing segment of the OA population percentage wise (Sugar et al., 2014). The number of oldest-old persons is estimated to reach 19 million by 2050 (FIFARS, 2012). Substantial improvements in life expectancy are thought to be due to better treatment of chronic conditions and the promotion of better health and quality of life at the older ages (Schoenborn et al., 2006; Sugar et al., 2014). However, it is also this age group that tends to suffer higher levels of disability and frailty and individuals in this group are more likely to live in a nursing home or need assistance in the home (Sugar et al., 2014).

Race & ethnicity. In general, the U.S. population is becoming more diverse (Sugar et al., 2014). Americans under 65 years of age are less than two-thirds non-Hispanic whites, defined as people who reported as white and no other race, (FIFARS, 2012), and one-third comprised of Blacks, Hispanics and Asian descent (Treas, 2011). Though future estimates note the aging population will continue to be mainly non-Hispanic white, the percentages persons of non-

Caucasian ethnicity will increase in the OA population creating a more diverse composition by 2060. The largest gains in population percentages are predicted to those of Hispanic ethnicity (FIFARS, 2012; Treas, 2011). The proportion of non-Hispanic white persons in the population is estimated to decrease from 80% currently to 58% by 2050. Persistent gaps in the health and longevity of OAs continue for those of different race and ethnic groups, such as the white-black gap in health and life expectancy.

Marital status and gender. Marital status and gender have been shown to influence levels of income (Hudson, 2014; Sugar et al., 2014). A larger proportion of older men than older women tend to be married. There are several postulated reasons including the fact that men often marry women who are younger than them, and women, in general, have a longer life expectancy (Sugar et al., 2014). As of 2010 seventy-eight percent of older men in the 65 -74 age categories were married compared to 56% of women2010 (FIFARS, 2012). Though the marital percentage decreases as aging occurs, older men proportionally have higher marriage rates than women, even at the oldest old age group (FIFARS, 2012).

From an economic perspective, marriage generally favors woman over those who are not married. The "traditional" social roles that women hold within society, e.g., child care, caregiving, employment discrimination, impacts their ability to have an income equal to or beyond their partners (Sugar et al., 2014). Marital status or cohabitation does influence the ability to have various life-choice options during aging (Hudson, 2014; Sugar et al., 2014).

Education and economics. The OA population, as an aggregated group, experienced a rise in education levels over the last 40 years (FIFARS, 2012; Hudson, 2014; Sugar et al., 2014). Substantial gains were made between 1970 and 2015 in the percentage of OAs who had completed high school. Rates increased from 28% in 1970 to 84% in 2013. Likewise, the numbers of those with bachelor degrees increased from less than 10% in 1970 to 26% in 2013 (AOA, 2014; AOA 2016). Though all race and ethnic groups experience gains in educational preparation, sizeable variations between the groups were noted. Non-Hispanic whites had the largest gains followed by those identifying as Asian, African American, American Indian/Alaska Native, and Hispanic (AOA, 2016). Percentages having completed high school diplomas as reported in 2010 were similar between older men (80%) and women (79%).

Higher educational levels usually are related to higher rates of employment with better incomes, which provides a higher standard of living and more opportunity for choice throughout the life span (FIFARS, 2012; Hudson, 2014; Sugar et al., 2014). As the Baby-boomers become 65 years of age, this overall trend of will continue. However, due to the recession of 2007 and changes in pension funds, more and more OAs continue to work due to financial considerations (Anderson, Richardson, Fields, & Harootyan, 2013; Hudson, 2014; Sugar et al., 2014).

**Living arrangements.** Income, health status and caregiver availability are all influences on OAs' living arrangements (FIFARS, 2012; Sugar et al., 2014). The nature of living arrangements for those in the aging population can

significantly affect the quality of life and whether engagement and socialization with others are supported (Sugar et al., 2014). A variety of living arrangements have been documented in the literature. Overall, older Americans live in housing that is affordable and adequate for their needs (FIFARS, 2012). However, the quality and the variety of options available to meet needs and quality of life are linked to income (Anderson et al., 2013; Sugar et al., 2014).

The variations of OA living arrangements include living with a spouse, living alone, living in an intergenerational unit or living within an institution, such as a nursing home. According to the AOA, in 2014, 57% of OA lived with a spouse. Men (72%) live with a spouse more than women (46%). With increasing age, the percentage of couples living together decreases. Especially for women, only 32% of women 75 years or older live with a spouse. Contrary to common perceptions, only a small percent of the OA population resides in a institution, 3.4%. However, this rate increases with age, from 1% of the 65 - 74 age range, to 3% in the 75 - 84 age range, to 10% in the 85 year or older population (AOA, 2014).

A popular trend in the US is to "age in place" (Sugar et al., 2014, p.126), meaning to age in one's current residence. The aging in place concept provides many advantages for the OA, such as promoting and maintaining social engagement with the community, supporting the ability for family caregiving, increasing quality of life, and assisting in the control of long term care costs (Hudson, 2014; Sugar et al., 2014). Aging in place also has challenges related to housing cost burden which is the most prevalent when a person is living on a

fixed income (FIFARS, 2012; Sugar et al., 2014). In 2012, out of pocket expenditures were over 30% of the household income, and were even higher for the intergenerational households (FIFARS, 2012, Sugar et al., 2014). A portion of household dwellings also lack adequate maintenance, 2.7% of the private residences reportedly had problems with plumbing, heating, electric and kitchen upkeep (AOA, 2015). For those OAs who share living space, crowding can also be an issue.

Overall the US aging population is healthier, more financially secure, more educated, more active, and living on their own in larger numbers than ever before. This is not the image of a dependent population requiring such rich agespecific governmental programs or one of vulnerability. Commentators attribute the current status of the aging population's independence and health to successful governmental programs such as Social Security, Medicare, and Medicaid. This model of policies and programs may be used as an exemplar for other improvements of social concerns (Hudson, 2014). Some may use this success to substantiate a reduction in the fiscal funding of these programs as a solution to cut governmental expenditures (Hudson, 2014).

Caution is recommended in generalizing the data reported above as there is also evidence of continued disparities experienced by people who have not had the access to existing supportive programs and services. Further analysis on the population-specific data is required due to the number of diverse social structures that impact the lives and well-being of people. From the data reported above significant inequalities between groups across age, gender, race and ethnicity,

marital status and income are noted. Though many aging adults have a better quality of life than their predecessors, there are still millions are still at risk from inadequate basic resources (Hudson, 2014).

#### **Chronic Illness**

Conceptualizations of chronic illness have changed over the years (Corbin, 2003). The evolution of understanding about what is a chronic illness is related to the advancement of health care. Shifts have occurred in the fact that most causes of illness and death were attributable to infectious diseases and some cancers earlier in the 20th Century, whereas now with biotechnological and other advances there are increased survival rates and more people who would have died from an acute illness are now living with a chronic illness (CDC, 2015; Corbin & Strauss, 1985; Thorne & Paterson, 2000). For example, HIV/AIDS was once conceptualized as an acute illness. Now it is characterized as a chronic illness with an extended trajectory because of pharmacological and treatment advances (Thorne & Paterson, 2000).

Another related contributing perspective to the changing conceptualization of chronic illness is the distinction between disability and chronic illness (Gordon, Feldman, & Crose, 1998). Previously, healthcare providers and researchers thought of disability and chronic illness as the same sorts of issue. As a result of the disability advocacy movement, chronic illness became known to be different from and incomparable with disability (Gordon et al., 1998; Thorne & Paterson, 2000). This new awareness creates a further complexity as to the determination of what defines a chronic illness. Though disability and chronic illness may be

conceptually different in one aspect, there are other aspects where there is an overlap. For example, there are those with disability who also have a chronic illness and those with chronic illness who develop a disability related to the illness. For such reasons, those who are engaged in knowledge development activities and interventions targeted to these population and healthcare issues need to be cautious about generalizing.

The perception of health that an individual holds also adds to the complexity of what defines a chronic illness. An individual without any or with limited symptomology may not think of themselves as having a chronic illness. However, if one's chronic illness creates pain, suffering or limits their abilities to enjoy life, then their perception changes (Corbin, 2003; Thorne & Paterson, 2000). Corbin (2003) examined how the body may influence health and illness. Corbin (2003) postulated that it is from the body that the meaning of life is derived, it is "from being able to do, to look, to experience life in ways that the self comes to expect" (p. 258). It is this meaning and understanding of life that the person is working toward a self-identity. Though the body may be the modality to sense, it is the mind and awareness of self that determines how the person identifies as being ill or not.

But just having a diagnosis of chronic illness doesn't lead to a construction of being ill. Constructing an illness identity takes more than that. Constructing an illness identity comes from a fear that one is losing control over one's body and/or that one can "no longer do" what one could do before, and also from the fact that one can no

longer understand the body's language or trust it to act as it should. It doesn't matter if one has cancer, AIDS, multiple sclerosis, or Parkinson's disease; as long as one "feels good" and "can do" what one wants, then one might not necessarily see oneself as ill. (Corbin, 2003, p. 266)

Thorne and Paterson (1998) conducted a systematic analysis on the elements of chronic illness reviewing 158 qualitative studies from 1980 through June of 1996. Findings supported a shift from the experience of loss and burden to a conceptualization of "health within illness, transformation, and normality" (p.174). This shift is attributed to a change in the relationship between the healthcare provider and person in need of assistance, from viewing the individual as a patient to viewing the individual as a partner in his or her care. Thorne and Paterson's analysis suggests that a more existential perspective of chronic illness is needed. This contrasts with Corbin's more descriptive perspective. The existential perspective moves away from the concept of constructing an "illness identity" to illness viewed in the context of a whole. From Thorne and Paterson's (1998) findings the individual embraces the chronic illness and takes control of what health means for themselves, rejecting labels that may be placed upon them as the patient.

The evolving understanding of what counts as chronic illness is exemplified by changing definitions of the concept over time. The definition of chronic illness or disease evolved from a focus on the ongoing biological dysfunction of the body, to the inclusion of the psychological and social aspect of

living with the illness (Rosa, 2011). A current definition stated by the MacColl Institute for Healthcare Innovation (2016) is any healthcare condition of an individual that requires ongoing adjustments by the individual with interactions with the healthcare system. This definition is broad and general to allow for inclusion. Contextual and other specificities are needed when using the term chronic illness in research or the development of interventions in order facilitate health from a nursing perspective.

## **Impact of Chronic Illness**

Along with longer life expectancy, the prevalence of individuals living with chronic illness has increased. Chronic illnesses such as heart disease, stroke, cancer, type 2 diabetes, obesity, and arthritis are among the most common, costly, and preventable of all health problems (CDC, 2016). In 2010, seven of the top ten causes of death were from chronic illnesses associated with heart disease and cancer leading the list, and accounting for 86% of all healthcare spending (CDC, 2016).

The consequences of chronic illnesses increase health risks, and diminish quality of life, generally related to a long period of decline, disability associated with the illness and costs (AARP, 2009; CDC, 2015; Christ & Diwan, 2008). Individuals with chronic illness report better health than 20 years ago, partially due to health screening and early diagnosis (AARP, 2009).

**Multiple chronic illnesses.** Often the terms multiple chronic illnesses (MCI), comorbidity, and multi-morbidity are used interchangeably. Yet, the terms are be defined differently (Violan et al., 2014; CDC, 2015). As an

aggregate the different nomenclatures refer to an individual with 2 or more chronic illnesses. Caution is needed to ensure the understanding of the exact definition of the term when critically evaluating the research on the topic. The subtleties between the defined terms can make a difference in the depth of understanding of the phenomena. The term multiple chronic illnesses is helpful in defining an individual with 2 or more chronic conditions requiring adjustments in living by the individual and ongoing interactions with the healthcare system (Vassilaki, et al., 2015; Ruel, et al., 2014; Ording & Sorensen, 2013).

As aging occurs, the prevalence of an OA having MCI is more likely to increase (CMS, 2012; Vogeli et al., 2007; Ward & Schiller, 2013). The risk of having any chronic illness increases from 70% to 92% between the ages of 50 to over 85 and the risk of having 5 or more almost triples between the ages of 64 to over 85 (AARP, 2009). In the U.S., the prevalence of MCI is growing.

Specifically, for the OA population, three out of four OAs have MCI, making it a primary health concern (CDC, 2015; Violan et al., 2014). Also, there is strong association of MCI with gender, age, lower socioeconomic status and mental health conditions (Barnett et al., 2012; CMS, 2012). Multiple chronic illnesses vary little across race and ethnic groups within the OA population (CMS, 2012).

Living with multiple chronic illnesses. Having multiple chronic illnesses places additional strain on persons over those with a single chronic illness. The complexity of management increases with number of illnesses and time experienced. The complexity of living with the illnesses significantly impacts the OA community since it affects day-to-day functioning (Boltz, 2012;

CDC, 2015; Ward & Schiller, 2013). Examples of such effects are: decreased physical mobility and accompanying lessening of independence, difficulty managing poly-pharmaceuticals, changes in cognitive functioning, and a decrease in quality of life (Kane, 2015; Fabbi et al., 2015; FIFARS, 2012). An increase in use of healthcare services is also correlated with OA MCI, such as frequent hospitalizations and emergency room visits, additional need for home care visits and post-acute services (CMS, 2012).

Facilitating quality of life as long as possible for the OA requires adequate and appropriate care models and programs that address the social and health behaviors over life transitions. The capacity to manage health requires social supports, access to health care and information on healthy behaviors (Christ & Diwan, 2008). Current strategies tend to focus on management of single chronic illness (Barnett et al, 2012; Vogeli et al, 2007; Ward & Schiller, 2013). As the prevalence of MCI increases with age, focusing on managing a single chronic illness becomes ineffective, new modalities that account for complexity are needed. Strategies that focus on treating and managing a singular chronic illness fails to provide the best diagnostics, care, treatment and resources for the individual with multiple illnesses. The families of these OAs are also affected. Epidemiologic studies continue to identify the most common MCI combinations within various socio-demographic groups allowing for the development new treatment strategies (Parekh, Goodman, Gordon, & Koh, 2011). However, these studies, focused as they are on treatment strategies for the management of the illnesses, tend to fall short of accounting for the individual living within their

social contexts.

# **Family Caregiving**

Care provided by family members is known as family caregiving (FC), or informal caregiving. Family caregiving is defined as unpaid care or assistance provided to someone with a disability or chronic illness by a family member or friend (Family Caregiver Alliance [FCA], 2007). The family is significant to caregiving since spouses and other members of the family provide most of the home care (80-90%) for OAs, (Sugar et al., 2014). Due to the large percentage of care provided by the family, FC is considered the "backbone" of the U.S. longterm care policy (Levine, Halper, Peist, & Gould, 2010, p.116). The family is also the primary structure for the OA's emotional, and financial well-being. The family member who generally provides most of OA care is the spouse or significant partner (FIFARS, 2012; Selected Caregiver Statistics [SCS], 2012; Sugar et al., 2014). Spousal or significant partner caregiving supports aging in place, which has demonstrated an increase in quality of life, control of long-term care costs, and reduction in the likelihood of institutionalization (Hudson, 2014; Sugar et al., 2014).

Family caregiving shares common challenges across age groups. For the OA population, there are unique challenges associated with the age of the caregiver (CG), the aging process, and the relationship of the CG to the care receiver (CR). Evidence demonstrated risk of physical and psychological strain related to FC that impacts the CG's health negatively, which can in turn interfere with caregiving activities (Lyons et al., 2002; Pinquart & Sorensen, 2003; Roth,

Fredman, & Haley, 2015; Schulz & Beach, 1999; Sugar et al., 2014). This evidence is significant for the OA couples since each are aging, increasing the potential risk of vulnerability to the maintenance of health.

There many contributing circumstances to the success of spouses and families in caregiving. MacLeod (2008) found that health status trajectory (acute or chronic) of the CR and CG, the frequency of care required, the nature of the care (routine or crisis), fiscal resources, and the socio-environmental are just a few of the circumstances. These multidimensional dynamics pose various challenges for the management of care and to the welfare of the CG, CR and the family.

# **Couple Caregiving**

Marriage or cohabitation is a significant relationship for most adults. The couple can be viewed as a dyad. For a couple or dyad, this relationship occurs in a small group made of two people. A dyad is considered a special form of a group, the nature and characteristics of which are different from the nature and characteristics of the individuals in the dyad. It involves the particularities of their relationship and interactions with each other (Coser, 1977). George Simmel, a sociologist, argued that the dynamics of dyads dynamics are qualitatively different than groups consisting of more than two individuals in the relationship are confronted only by the other (Coser, 1977). The very existence of the dyad depends on both individuals interacting in some way. The removal of one individual or the non- participation of one of the individuals will end the relationship. The fact that a dyad depends on the other creates an "intense

absorption" between the individuals where they both are responsible for any action taken (Coser, 1977, p.186).

Various relationships can comprise a caregiving dyad, each of the dyad's dynamics are qualitatively different reflecting nature of their relationship. One of the most significant caregiving dyads is the spouse-spouse or partner-partner dyad. The significance is in the difference of the interaction between the spouses, than which is present with other family relationships. The difference is embedded within the intimacy of the relationship of the married or cohabitating couple. The relationship dynamics are created as a couple, which is defined as encompassing the mutual experience of the combined influences of personal, social, environmental and societal factors that shape the life and its understanding as a couple. The characteristics of the couple's dynamics are demonstrated to have a significant contribution toward both positive and negative consequences regarding health and quality of well-being for each (Choi, Yorgason, & Johnson, 2015; Kiecolt-Glaser & Newton, 2001; Lyons et al., 2002; Revenson, 1994).

Examining the interactions of OA couples is meaningful since most primary caregivers living in the home are spouses or partners who provide most of the care (FIFARS, 2012; SCS, 2012). Many of caregivers (CGs) of OAs are spouses with an average age of 63 years, and 33% are in fair to poor health themselves (FCA, 2007). Women continue to shoulder more of the care for their spouse or partner, though the percentage of male CGs is increasing. The disproportion of female-male caregiving within a couple starts to even out as the couple ages. The care receiver's (CR) average age is 69 with 59% having a

chronic physical condition, 35% with a short-term physical condition and 26% with a memory condition (AARP, 2015). As aging occurs, 37% of CRs will develop more than one chronic condition.

Caregiving studies tend to collectively define the primary caregiver, and do not differentiate between the primary caregiver being either the spouse, an adult child, or relative/friend (Archbold, Stewart, & Greenlick, & Harvath, 1990; Lyons et al, 2002; Roberto & Jarrott, 2008; Schulz & Sherwood, 2008; Young, 1994). This lack of differentiation, ignores the confounding influences of the various the relationship on the responses to and experiences of the caregiving. It is the very nature of the relational differences between the individuals (parent-child, adult-parent, spouse-spouse) that may create a difference in the response or experience, which then should not be aggregated as findings (Carr & Springer, 2010). This is especially true when generalizing the results to establish the influence of the health of both individuals depending on the context of the caregiving (Kiecolt-Glaser & Newton, 2001; Lyons et al., 2002; MacLeod, 2011).

The understanding of the influence of the OA couple's dynamics is a significant factor when managing chronic conditions. It is significant since inherently health status fluctuates creating a cycle where the stress events will influence the OA couple's dynamics, and in turn the OA couple's dynamics will influence the event in a constructive or adverse manner (Kim & Waite, 2014; Johnson et al., 2013; Park et al., 2013; McPherson et al., 2011; Lyons et al., 2002). The understanding of the cyclic influence will offer insight to what strategies may be supportive to minimize disruption in the OA couple's lives.

#### **Couple's Influence on Health**

Evidence shows the morbidity and mortality is lower for married or cohabitating individuals with several acute and chronic conditions (Kiecolt-Glaser & Newton, 2001). The dynamics of a given relationship influences health over time, specifically related to chronic condition management (Kiecolt-Glaser & Newton, 2001). As aging occurs the incidence of chronic conditions increases. The chronic progression of the condition creates the likelihood for couple dynamic disruption and caregiver uncertainty (MacLeod, 2011) requiring a resilience to adjust to a different way of life and meaning of the relationship (Walker et al., 2004).

The OA is also especially vulnerable to the exacerbation of symptoms related to physiological and psychological stressors when experiencing a distressed couple dynamic (Umberson, Williams, Powers, Liu, & Needham, 2006; Miller, Hollist, Olsen, & Law 2013). Evidence strongly suggests that a distressed couple's dynamics produce a steeper rate of decline over the continuum of health for OAs compared to their younger counterparts (Umberson et al., 2006). In contrast, when examining the influence of positive couple dynamics, health benefits were noted, but this was only noted significantly in the OA. This difference may be related to the effect of experiencing couple distress, physiologically and psychologically, as an accumulative effect over time (Umberson et al., 2006). Consequently, the distressed effects emerge and can be more readily found in the OA population compared to the younger cohorts.

The OA couple dynamics may become further complicated as aging occurs related to the dynamic that both partners may become the caregivers at various times over their life span together (FIFARS, 2012; SCS, 2012). This unique shifting of the caregiving role creates a complexity to understand the caregiving demands and difficulties. The significance for understanding the couple's dynamics is to inform the most effective means to sustain health, personal wellness, and reduce costs over the life span, for both partners (Allen, Goldscheider, & Ciambrone, 1999; Jackson, Shahsahebi, Wedlake, & DuBard, 2015; Johnson, 1983; Kiecolt-Glaser & Newton, 2001; Lum, Lo, Hooker, & Bekelman, 2014; Meleis, 2010; Park & Schumacher, 2013; Trivedi, Piette, Fihn, & Edelman, 2010). To more specifically evaluate the OA couple dynamics related to caregiving and its influence on health, the understanding of the couple's dynamics becomes significant.

### **Couple Research**

Past research studying couple's health tended to study the individuals separately and then aggregate the findings as a couple. Thompson and Walker (1982) stated studying only one individual's perspective within a dyad repudiates the complexity of the dyadic dynamic, suggesting that couple research should study both individuals. Recent research shifted the approach to couple research to include both individuals in the relationship, as a unit, to better understand how the interaction between the two individuals influence health and well-being over the life span (Berg & UpChurch, 2007; Hoppmann et al., 2016).

Generally, relationship research findings are conceptualized as causal

influences to demonstrate how the quality of the relationship influences health (Kiecolt-Glaser & Newton, 2001; Kim & Waite 2014; Lum et al., 2014; McPherson et al., 2011). Further research conducted highlights evidence that the dynamics involved within the relationship are too complex and multi-directional in nature to determine a unidirectional, causal effect (Lyons, Sayer, Archbold, Hornbrook, & Stewart, 2007; Thompson & Walker, 1982). The complexity is explained by the cyclical influence the social and environmental spheres has on life; the couple's relational dynamics influence health, and the dynamics of health influences the couple. Given this evidence, it is necessary to understand the OA couple's dynamics within the context of their social-environment in order to capture the intricacies of the dynamics.

One of way of capturing the intricacies is to explore the couple as the unit of analysis, (Lyons et al., 2007; Thompson & Walker, 1982). The study of the couple, as a dyad, produced an awareness of relational concepts, such as reciprocity, mutuality, uncertainty and coping adjustment, that significantly influenced the couple's experiential dynamics. Examples of such influence are that mutuality in a relationship can act as a protective factor that fluctuates over time and supports coping, especially during stress situations (Kayser et al., 2007; Lyons et al., 2007). When couples demonstrate higher levels of reciprocity and mutuality there is an associated decrease in stress and care burden, even when the care receiver's condition deteriorated (McPherson et al., 2011). Over time, though, and with increasing caregiving demands, the caregiver can experience the effects of the demands on their physical and mental well-being (McPherson et al.,

2011; Roberto & Jarrott, 2008; Trivedi et al., 2012). These relational concepts influence the assessment of the couple and furthers the understanding of the couple's dynamics related to the physiological and psychological impact on the overall couple's health (Dalteg, Benzein, Sandgren, Fridlund, & Malm, 2014; Goodwin, Swank, Vaeth, & Ostwald, 2013; Kayser et al., 2007; Lyons et al., 2007; McPherson et al., 2011; Park & Schumacher, 2013).

The couple's perception of the illness and the potential illness' uncertainty has an influence on the couple's dynamics on how caregiving burden and stress is experienced (Dalteg et al., 2014; Mahrer-Imhof, Hoffman, & Froelicher, 2007). Mahrer-Imhof et al. (2007), in their phenomenological study of 25 couples post myocardial infarction, found that if the couple views the situation as a positive transformative experience in their lives, it brought them closer together, compared with the experience of those couples who viewed the experience as a threat or were fearful. Those couples seemed to be more burdened. Nine of the couples perceived the event as a "second chance in life", viewed recovery and life changes as a "mutual task", were "more attuned to each other" resulting in better communication, "became more mature and reliable", and were "able to reconnect better with each other" through the experience (Mahrer-Imhof, 2007, p.516). These couples perceived themselves as taking on the challenge of the condition resulting in the improvement of their relationship. The couples that viewed the experience as a threat and were fearful expressed a shared experience but continued to have insecurities and uncertainty about the future. Five couples had experiences where the patient perceived the partner and health care professionals

as overstating the illness and returned to previous daily behaviors. This perception of the situation created incongruent expectations between the spouses resulting in arguments and a withdrawal for each other.

Kayser et al. (2007) spoke to the coping adjustment that influences the CG-CR relationship depending on the acuity or chronic onset of the condition. An acute onset of life threatening events, such as myocardial infarction, cardiac surgery, and cancer, create unexpected changes in a couple's life and caregiving expectations creates uncertainty and limited time for adjustment (Mahrer-Imhof et al., 2007; Park et al., 2013). However, after the acute stress of the event ends, the coping in regards to the caregiving demands assumes an iterative cycle and the perception of the chronic illness adopts the persona as the "we disease" (Kayser et al., 2007, p.1). This persona provides the couple an approach to the illness, together as a couple, using coping strategies to adjust to the care demands and life changes. Relational coping is demonstrated by behaviors that manifest mutuality, reciprocity and open communication. Kayser et al. (2007) identified this type of relational coping as a component that built strength and resilience in the relationship enhancing the couple's emotional closeness. Couples that did not engage in relational coping and used avoidance were more likely to appraise the caregiving as a stressor.

The significance of the understanding of the relational concepts within the context of the dyad is further substantiated when applying a holistic perspective to the dynamic itself. Walker et al. (2004) reported "the stability of all linked systems of humans and nature emerge from three complementary attributes:

resilience, adaptability, and transformability" (p. 1). The couple's dynamics is a system when faced with events that change the nature of the system, reliance and adaptability are required to transform the system to a different state (desirable or undesirable). In this situation, resilience is the capability to manage and reorganize the disturbance to the system, and adaptability is the ability of the couple to avoid an undesirable state. Understanding the capability for transformation becomes a key factor when studying and caring for couples with chronic or acute conditions.

More studies are being designed to examine social concepts as significant influential aspects within couple's dynamics related to health, such as mutuality, congruency of expectations and health goals, social control, adaptation and adjustment (Godwin et al., 2013; Checton, Greene, Magsamen-Conrad, & Venetis, 2012; Lyons et al., 2002). Essentially, these concepts may act as moderators within the couple dynamics by affecting the strength and direction of the dynamics over the health trajectory, and may produce insight into strategic approaches to improve health as continued understanding is obtained.

#### The Older Adult Couple and Family

The family, defined as a group of people who are related to one another including close friends, provides a significant social network to the OA couple, especially when one is older with a chronic illness requiring care at home (Tucker, 2002). Though the primary caregiver is someone who provides and coordinates most of the care for the OA, 67% of the primary caregivers are supported by someone within their social network (Aging and the Family, n.d.).

The engagement of other family members can be very important to the OA couple's dynamics regarding the safety and the quality of the informal care (Kemper, Blackburn, Doyle, & Hyman, 2013). The other family members' involvement and the frequency is related to the gender, marital status, relationship quality to the couple, and their living proximity (Aging and Family, n.d.). It is important to conceptualize the caregiving within a form of a social network context and not in isolation of only the couple.

Not to conceptualize the OA couple within their broader environment would ignore the further complexities of the contextual nature of the experience and may limit the development of effective strategies (Levine et al., 2010). The awareness of the context of the OA couple's environment becomes more significant because the family structure has changed over time. Since the 1900s the family structure shifted from a pyramid structure with the grandparents in smaller numbers at the top to a larger grand-child base, to more of a lopsided rectangle, where the number of grandparents is slightly larger than the number of grand-children (Gillen, Mills, & Jump, 2010). This diagrammatic structure is projected to be shift again by 2030 to reflect an upside-down triangle reflecting a larger number of grandparents at the top and the smaller number of grand-children at the bottom. These shifts in generations impact the roles of family members, where the older generation may be available to help raise the grand-children, but also there are more older adults requiring care and support.

Living arrangements for the OA couple was also changing. Twenty percent of older adults are living in a multigenerational household, which is an

increase of 3% from 1990 and a change from the 1940s, when OAs tended to live alone (Pew Research Center, 2010). The cause for the return of the OA living with family members is multifactorial, such as the recession of 2007 causing economic struggles, and the need for caregiving (either for children or OAs) (Pew Research Center, 2010). Multigenerational households can provide a benefit between the generations but can prove to have challenges as well, such as cultural differences, roles related to family and living arrangements, social norms, attitudes and behaviors.

The living arrangements differ across race and ethnic groups. Asians, Blacks and Hispanics are more likely to live with multi-generations in the same household than non-Hispanic Whites. This living arrangement lends itself to higher caregiving demand. Asians tend to provide more care for an older relative than Hispanics (34%), Blacks (28%) or Whites (19%) (Pandya, 2005). However, most of the care provided and the challenges to caregiving are the same across the cultures, but may vary depending on specific circumstances and income levels.

#### **Gender Difference within Couple Dynamics**

Evidence regarding how gender influences responses to various relational situations is inconsistent. It is postulated that women experience poorer health outcomes related to a couple dynamic quality. Umberson et al. (2006) found no gender difference in the effects of couple quality of health based on gender. The study noted with continuous coupled adults, when socio-demographic characteristics and age are accounted for, the differences between the responses to couple quality based on gender are negated. Other studies do not support these

findings. Additional research found even though both spouses experience distressing physiological responses, women experienced more dramatic physiological responses to distressed interaction within the couple than men (Kiecolt-Glaser & Newton, 2001; Ingersoll-Dayton & Raschick, 2004; Rohrbaugh, Shoham, & Coyne, 2006). The men's physiological responses to other stressor situations outside of the couple were more intense than those of women (Kiecolt-Glaser & Newton, 2001). This contrast in findings alludes to the question of whether other factors within or about the dynamics are influencing the intensity of the physiological or psychological response. Rather than the response being contributed to an isolated gender-based factor, the response may include stronger influencing from social and environmental factors.

## **Health Care Costs and Challenges**

Health care costs continue to escalate placing financial burden on society and the personal finances of the older population. The US national health expenditure (NHE) in 2015 grew 5.8% reaching 3.2 trillion dollars, which translates to \$9,990 per person and accounts for 17.8% of the Gross Domestic Product. Of that amount, Medicare spending increased by 4.5% to \$646.2 billion, 20% of the total NHE, and Medicaid spending increased by 9.7% to \$545.1 billion, or 17% of the total NHE (CMS, 2016). From 2015-2025, health expenditures are projected to increase at an average rate of 5.8% per year.

The health spending growth is attributable to several factors. The coverage expansion due to the Affordable Care Act, economic growth, and the aging population are the major factors (CMS, 2016). Medicare and Medicaid's

growth is notable as strong enrollment occurs amongst the baby boomers, and higher utilization of services drives increasing costs. The higher utilization costs are related to managing multiple chronic illnesses as an individual ages. Seventy-one percent of health care costs and 93% of the Medicare expenditures are for individuals with multiple chronic illnesses (Anderson et al., 2010; FIFARS, 2012). Medicare, on average, spends \$9,738 per beneficiary. As the number of chronic illnesses increases, health-related costs increase proportionally. For example, a Medicare beneficiary with 0 to 1 chronic illness, has an average cost of \$2,025 per year. Those costs increase to \$5,698 for 2-3 chronic illness, \$12,174 for 4-5 chronic illnesses and \$32,658 for those individuals with 6 or more chronic illnesses, over 140 billion dollars annually (CMS, 2012).

## **Out-of-Pocket Health Expenditures**

In 2015, along with federal health expenditure increases, personal out of pocket expenses, defined as the percent of income spent out-of-pocket on healthcare, grew 2.6% to \$338.1 billion, 11% of the total NHE. Personal health spending for the 65 and older population was \$18,988 per person, 5 times higher than the spending per child (\$3,552) and 3 times higher than a working-age person (\$6,632) (CMS, 2016). The federal and personal out of pocket health costs both share the largest percentages of total health spending, federal government (28.7%) and personal households (27.7%) respectively (CMS, 2016).

Managing multiple chronic illnesses adds to the financial burden for the OA and their families related to the out-of-pocket expenditures (AARP, 2009; Meraya, Raval, & Sambamoorthi, 2015). The interaction among co-morbidities

and the number of medications required, increases the risk of poly-pharmacy which further escalates the cost (AARP, 2009; Meraya et al., 2015). For example, an OA with five chronic conditions will pay out of pocket over \$5,000 per year, compared to an OA with no chronic conditions paying slightly over \$1,000. As well, poly-pharmacy creates a balancing dilemma for the OA, where 10% of Medicare beneficiaries are non-adherent with medication prescription regimes simple because they could not afford the medications (Nekhlyudov et al., 2011).

For the OA couple on a fixed income stream the economic hardship is accentuated. Eighty-four percent of the aging population relies on Social Security as their primary source of income (FIFARS, 2012). A higher percentage of OA couple's annual income is used to fill the gaps in health coverage with purchases of additional insurance and prescription medications. The poor or near poor experience a greater impact from out of pocket expenditures, which results in delayed access to care, affecting health status and quality of life, and reducing resources for other life necessities (FIFARS, 2012; Hudson, 2014).

Challenges are ahead for the economic stability of the OA population. Income is a strong determinant for health and can act as a barrier for overall health and quality of life for the aging population. Changes in pensions, reduced saving from the 2007 recession and political threats to Social Security and Medicare-Medicaid have and will impact the aging population's economic viability, especially the oldest old (Hudson, 2014; Sugar et al., 2014).

As the societal and political support for aged-specific programs are tested, an accurate assessment of OA populations is required to inform decision-making

processes, especially from a health programming perspective. Since family members provide the bulk of the care, which is provided at no cost, there is an incentive to support those family members, which includes spouses and life partners. The study of OA couples with chronic illness at home provides such an opportunity to understand what clinical inquiry is needed to evaluate support systems and resources.

## **Challenges for Health Providers**

Increasingly, partners provide most of the care to their loved one, who are experiencing chronic illness, in the home (SCS, 2012). This growth of OA couples within the home environment creates new challenges, not only for the OA couple but also for the providers of health care. A couple-management concept, where the couple becomes responsible for daily management as they age in the home, challenges the current care modalities for managing the aging and multiple chronic illnesses over the trajectory. The health care professional now is required to consider not only the medical management of aging and multiple chronic illnesses, but also the influence of the couple dynamics within their social network to sustain health and well-being at a financial prudent cost (Barnett et al., 2012). New knowledge is a necessity to inform innovative approaches to support the OA couple and their healthcare providers to address these challenges.

#### **Chapter Two Summary**

This chapter reviewed the relevant literature of the contextual background for this study. An overview of the theoretical framework, Health as Expanding Consciousness (HEC), along with a discussion of prior related research conducted

using HEC was presented. The concepts of aging, the OA population, chronic illness, family caregiving, OA couple, and health care delivery challenges were reviewed.

The future care of the OA population is complex calling for innovative approaches based on strong evidence driven by the voice of the OA population. Development of innovative, effective health programs and resources require an accurate understanding of the aging population within their environment. New knowledge is a necessity to maneuver through the changing political and societal perspectives to best represent and serve the aging population. The precision of the accuracy of the understanding is strengthened when a social approach to aging is utilized (Golden & Earp, 2012), and advocacy for targeted resources are made on the best evidence and current trends. The understanding of the experience of the OA couple and its meaning provides an opportunity to inform strategies to address such complex issues.

The review of the literature demonstrates a need for further investigation and research to guide, inform, and evaluate care delivery based on the changing composition and needs of the future OA population. This exploration requires an understanding of the experience of OA couples living with chronic illness at home, since the majority of the population are couples. Research with a couple-focused approach within the context of their environment will add to the needed new knowledge. Gaining insight into the OA couples experiences through the hermeneutic-dialectic phenomenological approach will uncover a new understanding and meaning that will inform health care service programs for the

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older adult population. Chapter three will address the study's design and methods used in this study.

## **Chapter 3: Design and Methods**

Newman's theoretical framework, Health as Expanding Consciousness (HEC), was used as the guide for this study. Research related to HEC is guided by a hermeneutic-dialectic phenomenology methodologic approach to uncover the human experience, life pattern, and meaning for transformative change. This study aimed to answer two research questions: (a) what is the life pattern manifested by OA couples living with chronic illness at home?; and (b) what are the common themes across the life patterns of the OA couples living with chronic illness living at home?

This chapter presents the philosophical underpinnings of the method: phenomenology, hermeneutics, and hermeneutic-dialectics. The study's design and sampling procedures are explained along with setting, recruitment and retention strategies. Finally, procedures for data analysis, maintaining rigor, validity, and ethical integrity are described.

#### Phenomenology

Since phenomenological methods are diverse, an understanding of the philosophical underpinnings of each is required to ensure congruence in application (Fleming, Gaidys, & Robb, 2003). Phenomenology is distinguished in two ways, as a philosophy of the mind (consciousness) to understand meaning of reality and as a discipline that provides a structure of study and methods for use to uncover the meaning of a phenomenon that is experienced from the first-person's point of view (Woodruff-Smith, 2013).

The philosophical underpinnings of phenomenology have roots dating back to Plato and Kant. Edmund Husserl's (1859-1938) philosophical efforts to

understand the essential structures of human consciousness provided the basis for the development of modern phenomenology as a method of inquiry (Woodruff-Smith, 2013). Husserl was interested in understanding what the essential features of consciousness are as experienced by an individual. He wanted to describe phenomena in the way they are experienced by the subject, and in the absence of preconceived ideas or prejudices about those phenomena. Thus, he thought phenomena could be revealed in their purest, most essential forms, including a person's own self-conscious experience, experiences with other people, objects and events (Husserl, 1964, 1965). To understand the nature of the phenomenon of consciousness as experienced by the subject in its most essential form, one must suspend one's own prior knowledge and judgements. Husserl was not looking for scientific certainty, but rather he wanted to understand the conditions for the possibility of knowledge and these lie in human consciousness. Without consciousness, there is no knowledge. His most basic insight is all consciousness is consciousness of something.

Heidegger (1962), a hermeneutic phenomenologist, extended the interpretative aspects of phenomenology with his thinking that humans are embedded within their socio-political contexts, which connects their realities to their experiences within the world or being in the world. Heidegger's perspective meant that human perceptions could not be viewed in isolation from the context of the world of which they are a part. Moreover, human beings are interpretive. They have the capacity to interpret the meaning of their lives and the meaning that objects in their world hold for them, including the meaning of their existence as a

conscious entity. Thus, interpretation of the reality provides an understanding of the meaning of the reality to the individual. However, Heidegger was not explicitly developing a research method, but was explicating the nature of being.

In the context of phenomenological research the idea of interpretation has evolved from concerning only the individual in question and their understanding of self, to understanding the meaning of phenomena as experienced by others to improve their lives. Understanding a phenomenon as proposed by contemporary phenomenological researchers is gained through interpretive interdependence between the researcher and the participant/s, where the known parts of the experience become the whole of the understanding and the meaning by being in the world (Dowling, 2004; Fleming et al., 2003). Each interpreted experience is unique and different from all others. However, there are essential aspects that may be experienced in common.

### Hermeneutic Phenomenology

Hermeneutic is defined as the study of the methodological principles of interpretation of text, especially of scripture with origins from the Greek word hermeneuein, meaning to interpret (Merriam-Webster Dictionary, n.d.). The researcher using a hermeneutic phenomenology method focuses on the interpretation of the essential meaning of a phenomenon within its context that may not be apparent from direct investigation, analysis, or description (Omery, 1983). This interpretive focus adds an increasingly deeper, layered reflection with the use of rich detail through descriptive language (Kalfe, 2011). Van Manen (1997) described a good phenomenological text as

...the effect of making us suddenly "see" something in a manner that enriches our understanding of everyday life experience. This seeing of meaning is not merely a cognitive affair. The production of insight must proceed through the creation of a research text that speaks to our cognitive and non-cognitive sensibilities. (p. 345)

Within the context of this method, meaning is uncovered through an interpretative process of understanding of not only what is being said but the mantic meaning of the text or how the text speaks (van Manen, 1997), as told by the participant/s' unique perception of the lived experience (Creswell, 2013; Munhall, 2012; van Manen, 1997). Both forms of meaning are methodologically important to hermeneutic phenomenological inquiry (van Manen, 1997).

# Hermeneutic-Dialectic Phenomenology

Gadamer (1900-2002), a German philosopher, advanced interpretive phenomenology by examining the ability for understanding and what knowledge is used to form the understanding (Gadamer, 1960/1989). From Gadamer's perspective one's historical knowledge is a required prerequisite for any basis to understand a phenomenon or its meaning, since no one can truly understand without a historical knowledge. Self-understanding of the phenomenon and others understanding of the phenomenon are linguistically shared through a reciprocal process of dialogue. It is through the reciprocal process where reality is explored and a consensus is reached regarding a common understanding (Gadamer, 1976; van Manen, 1997).

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Hermeneutic-dialectic inquiry is an interpretive process seeking understanding through a dialogue. Dialogue, that is a reciprocal process of articulation between two or more persons aimed at uncovering contradictions to come to a new understanding through synthesis resulting in a new understanding of the phenomenon (Guba & Lincoln, 1989). A hermeneutic-dialectic phenomenology method can attain an understanding that Gadamer proposes, since the method incorporates a reciprocal dialogue to come to a shared understanding. The dialogue allows the historical knowledge to come to the forefront to be addressed along with what is to be understood. It is an iterative process that seeks the meaning of the phenomenon as a whole, and then examines the whole through the particular parts leading to a new understanding of the whole. The new understanding of the whole then affects how the parts are understood (Gadamer, 1976; Steeves & Kahn, 1995). The iterative process is dynamic to understanding change over time that can only be viewed within the context of that specific moment. The interplay between the researcher and the participant leads to a truer interpretation of the phenomenon and its meaning, a consciousness being determined by a synthesis between the researcher 's and participant/s' worldviews including each other's historical knowledge (Gadamer, 1976; Fleming et al., 2003).

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## Phenomenology as a Discipline

The use of phenomenology as an inductive research method provides the opportunity to explore the human experience of living as a "dynamic whole" (Omery, 1983, p.49) to discover the understanding and the meaning of participant/s' reality (Creswell, 2013; van Manen, 1997). The human experience of a phenomenon is shared through stories that are analyzed by the researcher through an interpretive process to uncover the embedded meaning. The purpose of using a phenomenological method is to explore and describe all aspects of the phenomenon of interest, as a single entity, to be understood in the richest and fullest depth of the phenomenon's meaning from the foci of human consciousness. The phenomenon is approached with a priori naivety and is not seeking to validate specific categories or theories (Omery, 1983). The approach to the research is without premeditated expectations or operational definitions.

A hermeneutic-dialectic inquiry extends the interpretive process seeking to understand through a dialogue, which is a reciprocal process to uncover contradictions to come to resolution through synthesis resulting in a mutual understanding of the phenomenon (Guba & Lincoln, 1989). The method is iterative, dynamic process that seeks the meaning of the phenomenon within its entirety, as a whole, and then explores the whole through the particular parts leading to a new understanding and meaning of the phenomenon. The new understanding of the phenomenon can then affect how the various aspects are understood within the context of the moment (Gadamer, 1976; Steeves & Kahn, 1995).

A phenomenological research design defines the method of data collection and analysis within the philosophical tents of the approach (Cohen, Kahn, & Steeves, 2000). All data, objective and subjective, are collected and analyzed to discover and understand the meaning of the phenomenon from the participant/s' position. Van Manen (1990) expressed phenomenological research as a human scientific study of phenomena, in which the human experience of a phenomenon is shared through stories that are analyzed by the researcher through an interpretive process to uncover the embedded meaning.

## Newman's Health as Expanding Consciousness and Hermeneutic-Dialectic Phenomenology

Newman's theory of HEC was used as the theoretical framework that guided the design for this study. The theory emerged from the unitary-transformative paradigm that views the nature of reality within its entirety, and the nature of change as transformative and simultaneous over the life span (Newman, 1997; Newman, Sime, & Corcoran-Perry, 1991; Pharris, 1999). The synthesis of the key philosophical underpinnings from the both the unitary-transformative paradigm and hermeneutic-dialectic phenomenology are the basis the Newman's protocol (Newman, 1999). Newman uses dialectics as the process through which the mutual process between the participant/s and the researcher unfolds and produce a story reflecting individuals or groups human life experience. It is through the mutual process that the life pattern unfolds through awareness and recognition (Newman, 2008). Newman considers her approach, research as praxis, which reflects the mutual process of inquiry with the

participant/s that integrates theory, research and practice into a unified concept (Newman, 1990; Smith, 2011).

Newman's analysis centers on the unfolding awareness and recognition of the life pattern through dialogue to find the meaning within the experience. The life pattern is manifested as rhythmic fluctuations that reflect health through the life process. It is within this process that the life pattern reflecting the human experience emerges and meaning is found (Newman, 1999; Rogers, 1970, 1980, 1994). The researcher invites the participant/s to participate in a dialogue, within a mutual process between the participant/s and the researcher. Mutuality is established in the moment, where the researcher is intentionally present and is an active member within the dialogue. The experiential meaning is revealed through a dynamic mutual process between the researcher and the participant/s. The researcher then interprets the experience that unfolds to understand the experience and reflects on its meaning (Creswell, 2013; Newman, 2008). Later, these reflections and perceptions are validated with the participants. Data analysis is focused on the evolving life pattern, "the process is the content" (Newman, 2008, p.9). The researcher dwells with the data to uncover meaningful life experiences. The personal awareness is intrinsic to the process and can provide insight into the participant/s, leading toward previously unforeseen actions as options, to potentiate a transformative experience for the participant/s.

Newman's (2008) theory of HEC is predicated on three synthesized assumptions, (1) health is an evolving unitary life pattern that encompasses disease and non-disease, (2) consciousness is the informational capacity of the

whole and is revealed in the evolving life pattern, and (3) life pattern identifies the human-environmental process and is characterized by meaning (pg.6). The recognition of a life pattern and its meaning to the person provides an opportunity for change that can be transformative leading to improved health and well-being. It is from this basis that HEC and research as praxis, offers a unique opportunity to uncover a new understanding and meaning of the OA couple's experience living with chronic illnesses. In this study, this experience was revealed in a dialogue between the OA couple and the researcher, in a dynamic interaction within their environment. This approach offered an opportunity to uncover new meaning of important life events and relationships as told in an unfolding story revealed in dialogue and focused on the OA couple's experiences and opportunities for life transitions and change.

#### **Recruitment & Retention**

The recruitment site was a geriatric primary care clinic within an urban academic medical center. The clinic was staffed by a team consisting of four physicians and two nurse practitioners specializing in geriatric primary care. The clinic provided health services to a diverse geriatric population and focused on the special needs of both individual and the geriatric population.

After IRB approval and prior to the start of recruitment, the researcher conducted an introductory education session with the health care providers (HCP) involved in recruitment. The clinic's management staff also attended the session so that all staff understood the purpose of the study, the researcher's role and the recruitment process. The education session included an explanation of the study,

criteria for participation, the recruitment process, role expectations, and contact information.

The recruitment occurred in two ways: face-to-face contact or through written contact information left in a locked box located in the clinic. The face-to-face method had 2 phases. In the first phase, the HCP identified an OA patient-couple who met the criteria for participation. The HCP provided a general explanation of the study and asked the OA patient-couple if they wanted to speak with the researcher. If the patient-couple expressed interest, they were provided a study fact sheet (Appendix B).

The second phase of recruitment was initiated when the interested patient-couple was directly introduced to the researcher by the HCP or clinic staff. The researcher then further explained the study and reviewed the fact sheet with the participant/s. If there was interest expressed by the patient-couple to participate in the study, a date was scheduled for the first interview. If a spouse was interested in participating but both spouses were not present, a follow-up phone call was made by the researcher to confirm the other spouse 's interest. During that phone call, a date was scheduled for the first interview. If the patient-couple wanted time to think about the participation, a follow-up phone call by the researcher was made and a date scheduled for the first interview was made if indicated.

When the researcher was not in the clinic, recruitment was obtained through the Authorization to Contact form that was placed in a locked box located in the clinic (Appendix C). The initial contact was made by the HCP as

previously described. If there was interest, the Authorization to Contact form was completed by the patient-couple and placed in the locked box. The Authorization to Contact form met the organization's Health Insurance Privacy and Portability Act (HIPPA) standards. When the researcher obtained the contact information, a phone call was made by the researcher to review the study's purpose and general information with the interested OA couple. A scheduled date was then set for the first interview.

The retention strategies were initiated upon first contact with the participant/s. The researcher first established a relationship with the OA couple at the time of recruitment by facilitating engagement and trust with the OA couple to reinforce a commitment to the study. All the interviews were conducted in the OA couple's home per the couple's request. Any follow up interviews were scheduled at the end of each interview session. A confirmation phone call was made by the researcher a day before each of the interviews. A \$30 gift card was given after the completion of the first interview and a \$40 gift card was given at the last interview. All interviews were completed within 5 weeks from the initial interview.

#### **Informed Consent**

The informed consent document was guided by and was aligned with Boston College's (BC) requirements, including the general purpose of the study, the design procedures, any potential risks and the participants' rights including to withdraw at any time (Appendix D). The consent explained how confidentiality was maintained for all information. A detailed review of the study was conducted

prior to obtaining informed consent. Informed consent was obtained in-person prior to the first interview. A copy of the signed informed consent document was given to the participants. Verbal consent was obtained before each interview to affirm the participants' continued consent. The participants were informed the interview could be terminated at any time at the request of either participant without any compromise to their health care. For this study, no interviews were ended prematurely. The researcher was attentive to the participants' responses during each interview for signs of abuse or neglect that may require reporting. Approval by the Institutional Review Boards of Boston College and the participating academic medical center was obtained prior to the data collection process.

## **Sampling**

A purposeful sample was recruited with a potential for a diversity across age, socioeconomic status, sexual orientation and race-ethnicity (Creswell, 2013; Sandelowski, 2000). The inclusion criteria were any older adult (≥ 65 years of age) married or cohabitating, heterosexual or same sex couple that were living together independently, where one or both partners had at least one chronic illness, as defined by the U.S. National Center for Health Statistics, as a health condition lasting three months or longer (National Health Council, 2014).

The sample included 14 OA couples. The sampling size was determined by the ability to capture rich, in-depth detail about the OA couple's experience living with chronic illness at home. Exclusion criteria were established to ensure the participants had the capacity to provide information-rich data and could

complete the study. The exclusion criteria used were as follows: (a) either partner had a diagnosis of dementia by their clinical practitioner that interferes with activities of daily living; (b) either partner could not participate in an interview for approximately 1 hour; (c) the acuity of the chronic illness impaired either partner's ability to complete the study, (d) either partner does not want to participate, (e) either partner was not a patient at the clinic, and (f) either partner is non-English speaking.

#### **Data Collection Procedures**

Two face-to-face interviews with the OA couple were conducted. Both interviews were audio-recorded with the permission of the OA couple. The first interview was scheduled at the convenience of the participants, either in person at the clinic or via a phone call from the researcher. Prior to the start of the data collection, informed consent was obtained after an overview of the study and the informed consent form. Verbal consent was also obtained before each recorded interview, to confirm ongoing agreement to participation. The participants were told they could end the interview or have the recorder turned off at any time during the interviews without consequences. Demographic information was collected via an intake form (Appendix E). The demographic data was entered in to an excel spreadsheet within a password protected computer. Hard copies were stored in a secured cabinet with restricted access to only the researcher.

Prior to the interviews, the researcher took a few moments to prepare herself for the intentional dialogue with the OA couple. The first dialogue was opened with an invitation to the OA couple to participate with the question, "Could you tell me about the most meaningful people and events during your life as a couple?" This question allowed the OA couple the freedom to unfold their experience at any point, and allowed the OA couple to have more control of the interview process. The researcher actively participated in the dialogue by being involved in the process through active listening, clarifying, and reflecting upon the data to decide when branching questions were needed for richer explication of the detail or the need for clarification (Newman, 1999, 2008). The researcher made notes after the interview of key moments and thoughts at the time. The length of the interviews was from 45 minutes to approximately 1 hour and forty-five minutes. The couple determined the end of each interview by indicating that they shared what they wished. The second interview was scheduled at the end of the first and occurred 1- 4 weeks. Immediately following each interview, the researcher privately documented notes about her observations or thoughts about the interview process.

## **Transcription**

Audio-recordings of the interviews were uploaded in to a password protected computer for transcription purposes. A master code spreadsheet was created listing each OA couple with the identifiable information along with an assigned pseudonym information. The identifiable information was kept separate from all the coding and stored in a password word protected computer. The assigned pseudonym was then used for all transcription, coding, and consultation with my advisor. Twenty-seven interviews (first and second interviews) were transcribed for a total of 35 hours of recordings (1.5 hours average per interview).

One couple chose not to complete the second interview and did not offer an explanation. This was the only non-Caucasian couple.

Each transcription was completed within 1 week. Once the text was transcribed, the researcher reviewed the transcription for accuracy, highlighted insightful text, and dwelled with the data from each OA couple. This marked the beginning of the first data analysis phase. The audio-recording were secured in a locked cabinet with access only by the researcher and will be erased at the time the findings are reported or after 3 years.

## **Data Analysis Procedures**

When using a hermeneutic-dialectic design, data collection and analysis are an iterative process due to the dialectical nature (Cohen et al., 2000). As a result the data collection can overlap with along with the data analysis. To answer the two research questions, two phases of analysis occurred, which followed Newman's suggested protocol (Newman, 2008). The first phase was data analysis to answer the first research question, "What is the life pattern manifested by older adult couples living with chronic illness at home?" The second analysis phase answered the second question, "Are there common themes across the older adult couples living with chronic illness at home?

#### Phase One: Individual Older Adult Couple Analysis

Once the interview was transcribed and verified by the researcher for accuracy, a narrative diagram and life pattern construal were developed. The narrative diagram and the life pattern construal were developed through in-depth readings of the text and the researcher's field notes. The narrative diagram cites

meaningful events, key statements, and relationships over the OA couple's life span. The events were organized in the phases of the OA couple's life, prior to being a couple, early years, middle years, later years, and the present. The nature of the meaningfulness of the relationships during each of those periods were represented by lines and arrows drawn from the partner-couple to the person in the relationship. The relationship's meaningfulness was described by the use of arrows and lines as follows: (1) bi-directional arrow reflected an open free flowing meaningful relationship, (2) uni-directional arrow reflected a one-way relationship in the direction of the arrow, (3) a neutral relationship was reflected by a straight line, representing a connection to the party is present, but not meaningfully, and (4) a blocked relationship was reflected by a dotted line, representing no communication between the parties (see key at bottom of narrative diagram).

As the data were analyzed, the life pattern emerged for each spouse-couple, noting choice and transformational points represented by a fluctuating line drawn from the years before being a couple, each spouse with their own life pattern, through to the present years, which was represented as one fluctuating line after marriage. The fluctuating line was used to denote flow, important events, and interruptions or shifts in the pattern that represented meaningful moments.

During the second interview, the narrative diagram was shared first with the OA couple then the life pattern construal was reviewed. Upon the review of the narrative diagram, the OA couple was asked for further reflection and clarification, if any. Once the OA couple had nothing more to share or discuss, the life pattern construal was presented for reflection and to validate the accuracy of the researcher's interpretation of their experience. At this period in the dialogue, life pattern recognition occurred for the OA couples.

The researcher clarified and verified any specific points or explored an area of question for better understanding. Any additional clarifications were noted with revisions made to the narrative diagrams and life pattern construals. A third interview was not requested by any of the OA couples.

At the end of the life pattern construal reflection, three general questions were asked. The questions were generated during the researcher's reflection on the data from the first three OA couples that were interviewed. These questions were asked in the following order, "When you look back and to the present, has being a couple influenced your health?", "As you look forward in life as a couple, what will be the most meaningful?", and "What was your experience of participating in this study as a couple?". The questions provided further opportunity to gain insight about the OA couple's thoughts about health, future perspective and their experience of engaging in the study. The end of the second interview was the official closing of the data collection phase.

Data analysis after the second interview. The transcripts for both interviews were read together and referenced many times, text was highlighted, and notes taken of new insights by the researcher. Any changes to the narrative diagram or life pattern construal suggested by the OA couple during the second interview were completed in the narrative diagram and life pattern construal. At

this point in Newman's (2008) research protocol, Young's (1976) spectrum of consciousness was attempted on the first three OA couples. The researcher was unable to apply Young's staging and decided not to apply this protocol to the remaining OA couples (see chapter 5 for details). A narrative summary of each OA couple's story was then written that captured the OA couple's experience, followed by their life pattern recognition and the researcher's pattern analysis. An interpretative narrative summary statement was written for each of the OA couple that captured the essence of their experience.

## Phase Two: Examining Life Patterns Across Older Adult Couples

The second phase of analysis identified the common themes across the OA couples through continued comparison of each of the OA couple's life pattern construal. This phase began with the researcher's re-immersion with each couple's narrative diagram and life pattern construal, focusing on the pattern and descriptive text (Newman, 1997, 2008; van Manen, 1997). Core themes began to emerge across OA couples. These themes were further explored, refined and additional insights developed through the re-immersion. Each theme was listed with corresponding supportive quotes as the interviews were reviewed. Once all the interviews were reviewed and coded, each theme was identified and defined. The quotes were included to support the emerging themes. The synthesized themes were documented in a notebook to aid further contemplation through the review of the data from each OA couple in comparison to the synthesized themes and concepts. Comparison was then conducted across the OA couples, identifying any commonalities that may emerge. Corroboration was completed

through direct quotes and examples from the text and re-examined to ensure substantiation and relevance. The corroborated themes are illustrated in a model that represented the meaningful experiences and influences that emerged.

## Accuracy, Credibility & Rigor

The accuracy and credibility of the data were safeguarded by the close rapport developed between the researcher and the participants. Open communication and trust was critical to obtain rich, interconnected detailed information that was articulated and reported to allow for peer review's full understanding of the setting and findings. The establishment of the trusting relationship between the researcher and the participants was strengthened the theoretical underpinnings of HEC and the methodologic approach used to uncover meaningful data.

Accuracy and credibility were further enhanced by allowing the participants to review the data (member checking), to clarify and to validate accuracy of the narrative diagram and the developed life pattern construal. The member checking included a rich dialogue of the current OA literature, the OA couple's perspective on the literature in relation to their experiences, the use of the use of the researcher's field notes. The inclusive use of resources as a part of the analysis strengthens the corroboration of the data reinforcing accuracy and credibility of the findings (Corbin & Strauss, 2015; Creswell, 2013).

Expert researchers in the Newman's approach to inquiry were consulted to ensure the data collected supported the themes and related findings. The researcher's biases and interpretations were held in check throughout the analysis,

and the findings were substantiated by the data. Regular meetings were held with my advisor to discuss the processes, reinforcement of the Newman's theory, the review of the interviews and emerging themes to ensure consistent methodologic application of health as expanding consciousness. The dissertation committee's feedback and direction acted as peer review for confirmability.

Rigor was maintained due to the well-designed and executed qualitative method. The researcher adhered to the design along with the use of constant comparative analysis (Corbin & Strauss, 2015: Creswell, 2013). Rigor was further strengthened in this study since the theoretical framework was aligned with the methodology. Selection criteria were created and followed to ensure the participants' characteristics provided accurate and rich data to answer the research questions fully. The participants were active members in the research process and in-vivo technique was used to substantiate the interpretation and the findings (Saldana, 2016).

#### **Chapter Three Summary**

In this chapter the philosophical underpinnings of Newman's Theory of Expanding Consciousness and the hermeneutic-dialectic phenomenology were reviewed. The study's design and sampling procedures were explained along with setting, recruitment and retention strategies. Finally, procedures for data analysis, maintaining rigor, validity, and ethical integrity were described. In chapter four the findings are reported.

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## **Chapter 4: Findings**

The purpose of this study was to come to know the experience of the older adult (OA) couple living with chronic illness at home within the framework of Margaret Newman's theory of Health as Expanding Consciousness (HEC), using a hermeneutic-dialectic phenomenological method. The two research questions answered by this investigation were: (1) What is the life pattern manifested by OA couples living with chronic illness at home? (2) Are there common themes across the life patterns of the OA couples living with chronic illness at home? Chapter four presents findings from the study in three sections: (1) a review of sample demographics; (2) phase one analysis of the individual OA couples including the narrative summary, narrative diagram, reflection on their life pattern construal, and the life pattern analysis; and (3) phase two analysis comprised of the researcher's insights from the re-immersion in the data across all the participating OA couples with emerging statements of common themes.

#### Sample

The study's sample consisted of 14 married OA (≥ 65 years of age) couples living together. The OA couples all lived at home without assistance within the same county. Of the 14 OA couples, 13 lived together alone, while one OA couple lived with their daughter and granddaughter. One OA couple elected not to complete the personal or the couple demographic forms. With respect to the OA couple who did not complete the demographic forms, there were data gathered through the interview. These observations were included in the sample

analysis. Table 1 presents a summary of the demographic characteristics of the sample.

## Sample Demographics

The length of time the OA couples were married ranged between 25–66 years (M = 51, SD  $\pm$ 12). This marriage was a first for all of the spouses except one. All the participants were 72 years of age or older (M = 81), with more than half of the participants between the ages of 75-85 (54%, 14/26). Seventy-three percent (73%) of the sample earned some college credits or obtained graduate degrees. The participants who only completed a high school education were between the ages of 75-94, and were evenly divided between genders. Within the OA couples who participated, 46% of the OA couples had different education levels between the spouses. Fifty percent (50%) of the OA couples lived in a fullservice retirement community, while the other 50% owned a single-family home or lived in a condominium in a 55 or older community. Most of the OA couples had children (M = 2; Range: 1-4), except for one OA couple who had no children but had extended family actively involved in their lives. Eighty-six percent (86%, 24/28) of the spouses were retired and 14% (4/28) worked part-time or oversaw their businesses. With respect to annual income, 55% percent (6/11) of the OA couples reported annual income of \$80,000 or higher, two OA couples declined to provide income information. As noted earlier one OA couple declined to complete any demographic information. Though an effort was made to increase diversity, the sample was homogenous with 93% of the couples being Caucasian (7% Indian, 1/14), and all the couples were in heterosexual marriages.

Table 1. Participating Older Adult Couple Demographic Characteristics

Demographic	Sample											
Number of Older Adult Couples	14*											
Marital Status	100% Married											
Years Married	Range: 25-66 years											
	$M = 51$ , $SD \pm 12$											
Age	23% (6/26), 72-74 years old											
	54% (14/26), 75-85 years old											
	23% (6/26), 86+ years old											
	Range: 72-94 years, $M = 81.25$ , $SD \pm 6.4$											
Race/Ethnicity	93% (13/14), Caucasian											
	7% (1/14), Asian (Indian)											
Education	27% (7/26), High School											
	42% (11/26), Some college/Bachelors											
	31% (8/26), Graduate Degree											
Employment	14% (4/28), Semi-Retired											
	86% (24/28), Retired/no employment											
Living Arrangements	29% (4/14), Single family Home											
	21%(3/14), 55+ Community											
	50% (7/14), Retirement Community											
Number of Persons/Household	2.1 (30/14)											
	93% (13/14), Lived only with spouse											
	7% (1/14), Couple lived with family											
Income	46% (5/11), \$41-\$60,000											
	18% (2/11), \$81-100,000											
	36% (4/11), over \$100,000											

Note: 13/14 couples completed the demographic form.

## **Health Demographics**

Seventy-three percent (19/26) of the participants had four or more chronic illnesses (Table 2). The most common chronic conditions reported related to cardiovascular disease—including hypertension (77%), atrial fibrillation /heart failure (50%), hyperlipidemia (42%)—followed by hearing impairment (46%) and cancer (35%). All but one of the participants reported hearing impairment wore hearing aids. The reported number of prescription medications taken per

participant was between 2–27 (Mdn = 6), with 69% (18/26) of the participants using an over-the-counter medication. The number of over-the-counter medications taken ranged between 1–11 (Mdn = 2). The average out-of-pocket expenditure for prescription medications was \$816 per year or \$68 per month. All the participants were covered by Medicare with a supplemental coverage, either with private insurance or military benefits (Table 2).

Table 2
Participating Older Adult Couple Health Demographic Characteristics

Health Demographic	Sample
Number of Chronic	19% (5/26), 1-2 chronic conditions
Conditions/Spouse	58% (15/26), 3-5 chronic conditions
	23% (6/26), 6-7 chronic conditions
Most Common Chronic	77%, Hypertension
Conditions	50%, Heart disease
	46%, Hearing impairment
	42%, High cholesterol
	35%, Cancer
Number of Prescription	Range 2-27, $Mdn = 6$
Medications Taken/Spouse	_
Number of Over the Counter	69% (18/26) use OTC Medications
Medications Used/Spouse	Range 1-11, $Mdn = 2$
Average Out of Pocket	\$68/month or \$816/year
Medication Expenditure/Couple	

## **Sample Demographic Summary**

The study sample was homogenous, composed of 14 heterosexual, married couples who were an older, well-educated, and financially secure group. Most of the OA couples lived alone with their spouse managing chronic illnesses, the most prevalent of which was cardiovascular conditions. All the OA couples had children or extended family who were active participants in their lives. All

the OA couples in the sample used prescriptive medications, with approximately 70% using over-the-counter medications (e.g., various vitamins and health supplements, Miralox, Tylenol). The out-of-pocket expenditures were required for the prescription medications, even though all participants had health insurance coverage.

## Phase One: Data Analysis of the Individual Older Adult Couple

Newman's (2008) research protocol as outlined in Chapter 3 was applied to answer the first research question: "What is the life pattern manifested by OA couples living with chronic illness at home?" Phase one of data analysis was an opportunity for the unique life pattern of each OA couple to be revealed. The presentation of each OA couple's life story is included as a narrative summary, followed by a narrative diagram that reflects key events and significant relationships, the OA couple's life pattern construal and their response after viewing their life pattern, and the pattern analysis by the researcher. From the researcher analysis, a narrative interpretive summary statement was developed that best represents the theme of the OA couple's story.

The narrative diagram denotes relationships' quality by four different lines and arrows, including (a) a bidirectional arrow representing an open relationship with equal engagement by the parties; (b) a unidirectional arrow indicating a one-sided relationship with one party more open in the relationship than the other; (c) a neutral, straight line, representing limited engagement by either party in the relationship; and (d) a blocked, dotted line, reflecting a lack of engagement between the parties (see the key located at the bottom of narrative diagram). A

free coiling line was used in the life pattern construal depicting fluctuations reflective of times of instability (amplitude changes) with new emerging movement toward a new pattern.

All data of the OA couples were analyzed using the same process. Stories from 3 of the 14 OA couples are included in the discussion to exemplify how the data were analyzed to reflect the life pattern of each OA couple. The narrative summary, narrative diagram and life pattern construal for the remaining 11 OA couples are reserved for review in the Appendices.

## **Exemplar One: Couple A's Narrative Summary**

"Knowing-self and the other while moving forward through life transitions as a couple"

Couple A, both in their early 80s, were married 25 years, having met one another at a single's group and marrying within 3 months at the age of 55. This is the first marriage for both and they have no children. They lived most of their lives in a single-family home and had a vacation home for the weekends. They travelled extensively, reflecting a common curiosity to explore and learn.

Couple A share common backgrounds. Ms. A was the third child of four, having an older sister, an older brother, and a younger brother. Her mother lost a pregnancy after the second child, but this was not shared openly. Her mother became severely depressed after a miscarriage that "affected the family forever," requiring the family to move to their grandmother's (paternal) home for family support. Ms. A was very close to her grandmother who served as a role model in her life. "I have her bad heart. I have her scoliosis, but I know that she made it

work [living] and I can make it work." Ms. A's relationship with her older sister was close until conflicts occurred. "She thought she should run everything." Her younger brother had "mental issues" and was "a problem." Her older brother lived out-of-town, limiting contact. Ms. A became a teacher with a graduate-level education. Ms. A explained that—because she was single, or as she put it did not have "family commitments" arising from marriage—she was the primary care provider for her parents with little support from her family. Her father died years before her mother. Her mother's "mind had gone," and at that point Ms. A became her mother's "whipping boy" and perceived the family blamed her "for everything." Ms. A cared for her mother until she said, "I'm out," which resulted in her mother being moved to a nursing home. Freed from the responsibility of caring for her mother, Ms. A acquired more time to socialize.

Mr. A was the oldest of four children, two sisters, and a brother who was a twin with one of the sisters. His mother also lost a pregnancy (between Mr. A and his sister), but he perceived it did not affect the family. Mr. A's mother also did not talk much about the loss but would cry when she went to the gravesite. Mr. A was influenced by his grandfather to join the Army, completing his tour-of-duty as an officer in the rank of Captain. He earned two Masters degrees, worked as a journalist, then worked for the county, and was the primary care provider for his parents until they died. Mr. A was involved in a tragic motor vehicle accident resulting in the death of his sister's husband. His sister blamed Mr. A for the accident, and has not communicated with Mr. A since that time. Other conflicts developed in his family, in one case, arising from perceived inequality in the

distribution of his parent's estate upon their deaths. Mr. A explained the tension eventually resolved as it was "worked out."

Early in their courtship, Mr. A disclosed to Ms. A the traumatic event in his life, as he put it: "I killed my brother-in-law." He then explained the circumstances to Ms. A. Ms. A reflected upon this, inquired whether Mr. A was drinking in connection with the accident. He told her alcohol was not involved. Ms. A summarized how she understood the gravity of this event on Mr. A and how it impacted them as a couple: "There was no malice about it. But he was very disturbed by it. That's a big thing to deal with as you're getting to know a person."

After visiting Mr. A's brother and sister-in-law in New Zealand, Mr. A proposed marriage to Ms. A. "Apparently, he had been talking with his brother and sister-in-law about the marriage proposal." Ms. A was surprised. For her part, Ms. A was hesitant, wanting to be clear that marriage was the right decision, whereas Mr. A was without reservation. When they married, they invited all their siblings and family to the wedding because Mr. A believed it necessary. Mr. A's sister's family did not attend because she continued to hold a grudge against Mr. A for accidently "killing" her husband.

The early years of Couple A's marriage was filled with travel and little worries since, as they put it, they "did not have children or in-laws to argue about." They both owned homes at the start of their relationship, but eventually Ms. A sold her home, and Mr. A sold the vacation house where the catastrophic automobile accident occurred that resulted in the death of Mr. A's brother in law.

Knowing that the vacation home symbolized a traumatic event, Ms. A supported Mr. A's decision to sell the vacation home, explaining—"I was just as happy to get rid of it. I could notice the tension as soon as we got to the road going to it. It was always there." Their financial stability allowed for a secure future and flexibility, as the couple explained, they "could do what they wanted." Eventually, the couple bought another vacation home; demolished it; and built a new vacation home that they planned to use in their retirement years.

Couple A continued their travels, but as they approached their late 60s, health changes prompted life changes for the couple. Mr. A was diagnosed with diabetes and atrial fibrillation, which required a pacemaker. While managing their health concerns, they struggled with finding consistent, quality care since many of their previous providers retired. The couple's experience with the new providers was disappointing. The health care providers had either poor technical or communicators skills. As the health changes impacted their physical stamina, the maintenance of two households became increasingly difficult and overwhelming. They could no longer swim, which reduced the motivation to travel to and maintain the vacation home; harsh winters resulted in further burden upon them in the maintenance of the vacation home.

It was in the context of these health changes that Ms. A broached the idea of selling the vacation home. Mr. A was resistant for a period, but he eventually agreed. He explained he came to agree through a process of continued discussions with Ms. A and his own private thought. They enjoyed Mr. A's family, but Ms. A's family did not include them during this time.

In the later years, Ms. A experienced a back injury that left her with severe scoliosis requiring use of a walker. She also experienced atrial fibrillation, a pacemaker and two hip replacements. The couple continued to travel while living in their single-family home, although they disclosed that a recent trip proved to be physically taxing. During the trip Mr. A experienced two falls, including one in an airport requiring medical attention. Though they would like to continue to travel, they think this may have taken their last trip.

In recent years, maintenance on their home became difficult and time consuming. Ms. A was interested in changing their living arrangements. The couple looked at many different living options, even though Mr. A did not want to move. As part of the future planning, they made their burial arrangements to ensure they were buried as per their wishes. The couple observed that their siblings also began to experience failing health, and this provided further insight into their discussions about moving.

Mr. A had a heart attack on his daily walk. He was found unconscious, rushed to the hospital, and a stent was placed. Ms. A drove to the hospital herself. She expressed concern about the difficulty of receiving information, specifically recalling—"One doctor said, 'You don't need to know that.' and the other said, 'If she wants to know it, let her have the information." After the stressful time recovering in the hospital, Mr. A went to a rehabilitation facility, then to a nursing home. Ms. A visited Mr. A daily, and once Mr. A. was discharged home, Ms. A was the sole driver in the household.

A short time after Mr. A returned home after his heart attack, Ms. A had an appendectomy. Reflecting his deep concern for Ms. A while she was hospitalized, Mr. A took a taxicab back and forth daily to visit Ms. A because "strange things happen to people when nobody checks on them." Once Ms. A was home, her sister-in-law and niece visited to help with recovery. During the visit Mr. A's niece spoke with him about making different living arrangements. Soon after, Mr. A announced at the dinner table they are moving. This shocked Ms. A and her sister-in-law because Mr. A previously was adamantly opposed to moving. Mr. A explained the reason for changing his decision about moving was that it was "just time" to move. Ms. A asserted, "I think he was worried about another heart attack and dying." Mr. A demurred saying, "but I don't think I am now [going to die], though."

At present, Couple A moved into an apartment in a full-service retirement community. The transition to the retirement community was difficult due to the management of all their belongings collected over the years. Ms. A was attached to her long-held physical possessions, as they reminded her of memories that bore so much meaning, but the couple continues to strive towards resolving the dilemma.

Socially, Ms. A does not miss her old community as many of her friends died. Mr. and Ms. A met other couples and have dinner every night in the dining room. Mr. A. remarked, "it can be depressing at times, since they see people with visible physical challenges." The couple was getting accustomed to the "rules of the house." Ms. A does the driving. Mr. A gets confused at times since the heart

attack. His care provider suggested he should be screened for cognitive function.

The cognitive function results may be sent to the state, so he declined to be screened until he learns whether his confusion subsides. Couple A was happy with their care providers at the geriatric clinic.

As their global travels may be over, the couple still talk about day trips. "We've got everything planned. We're just making sure it's [death or disability] not too soon. I have to say we've been pretty lucky health-wise though. …But we get to do the things we want a lot. We're not stuck in bed somewhere." In Table 3, Couple A's narrative diagram is presented.

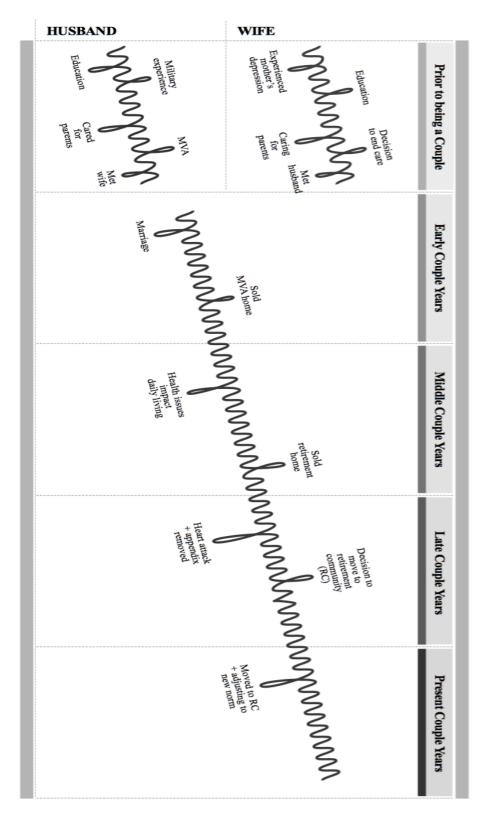
# Couple A's Response to the Life Pattern Construal & the Life Pattern Analysis Summary

When both the narrative diagram and the life pattern construal were presented to Couple A, they recognized the life pattern as their own saying—"[I]t was tough going through all of it. But we survived. Things are getting down to normal, and being okay." Their reflection on their lives prompted interest and awareness regarding the way they managed events and challenges in their life together, saying—"[It is] interesting. Some of the things that have happened in our lives, and how we've dealt with it. Everybody has different things in their life, and we're not any different from most people." Figure 2 represents Couple A's life patte

Table 3
Couple A's Narrative Diagram

B W F GM	Married at age 55	talk to her.	longer care for her mother. Siblings did not	After father's death, she decided she could no	0	sibling's support	for parents for a number of years without	commitments which may her available to care	Single for many years without family		brother had emotional issues.	when caring for their mother. Younger	Older sister tried to control life situations		Educated as a teacher		influence on her life.	loss of pregnancy. Grandmother was a strong	Mother experienced severe depression after	WIFE (1)	Prior to being a Couple
S — H GF		Married at age 55		inequality of parent's belongings.	Tension with brother about perceived		Cared for parents until their death		brother-in-law's death	vehicle accident (mva) resulting in	Lost relationship with sister after a motor		journalist & for the county	College educated and worked as a		Joined the Army after college		seemed sad about.	Mother lost a pregnancy that she	HUSBAND (2)	a Couple
8-2 S-2 W&H		interested in genealogy.	with friends. Husband	Wife was an active card player		home	together as a retirement	Rebuilt vacation home		MVA occurred	Decision to sell home where		moved into husband's home	Wife sold her home and		secure	children and were financial	Little worries. They had no		Enjoyed travelling	Early Couple Years
FR 5:1		brother.	Husband reconnected with		to hardship to maintain,	home prompted by wife due	Decision to sell retirement		quality health care.	Struggled to find consistent,		and heart condition.	Husband managing diabetes		impact daily life	Health conditions began to		events.	engaged in husband's family	Continued to enjoy travel &	Middle Couple Years
B-2 W&H	living. Burial plans made.	Decision made to sell home and		family helped during this time.	recovery. Husband's brother 's	the wife's appendix during his	attack followed by the removal of	Husband experienced a heart		Wife's friends are dying.		both went to look at options.	retirement community living and	Wife started to discuss		issues for both.	became difficult due to health	replacement twice. Travel	required pacemaker with	Wife had a back injury and	Late Couple Years
FR	Satisfied with their health care.	belongings.	decisions about personal	single-family home and make	Need to sell one of the cars, the		husband is on hold.	Return to driving for the		older adults doing very well.	community but there are also	challenges at the retirement	with physical or mental	Can be depressing to see others		Making new friends.	and "rules" of the house.	Adjusting to retirement living		Travel limited to day trips	Present Couple Years

Figure 2
Couple A's: Emerging Life Pattern



The life pattern analysis revealed the spouses had similar life experiences, except for the tragic death event that was experienced by Mr. A. The couple's relationship with Ms. A's family was limited, but they were very close to Mr. A's family, except for his one sister due to the accident. The couple also remained very engaged with their friends. Ms. A supported Mr. A successfully to become at peace regarding the traumatic event involving the death of his brother-in-law and facilitated other adjustments in their lives requiring choice and action. Their relationship helped their decision-making process, as a couple, especially considering choices with family relationships. Each spouse, at different times, initiated their personal perspective to the other that guided thinking and decisions, whether it was Ms. A thinking about future living arrangements or Mr. A suggesting all family members be included in the wedding invitations. Decisions were made jointly, but always with each spouse sharing their thoughts and perspective. Actions were never taken until both agreed. Summarizing this point Ms. A stated: "We work well together. We have our differences, but we talk."

## **Exemplar Two: Couple F's Narrative Summary**

"Recognizing and embracing meaningful life moments as self and the other"

Couple F are both in their early 70s. They have been together for 54 years and married for 50 years. In the beginning of their relationship they were classmates in college and shared a common devotion to social activism. They carried this throughout their lives, demonstrating an openness and curiosity about

life that is consistent with the couple's shared, social justice ideology. The couple has two sons. The couple has lived in their current home for most of their marriage. They love travel and exploration of many subjects, an interest they share with their family.

In the years before they were a couple, Mr. and Ms. F shared a strong passion for the same world outlook, through similar but different paths. Ms. F's father left the family when she was born. He never wanted children and was never a part of her life. Her mother was a nurse and raised her as a single parent. Ms. F elaborated, "[i]t was the two of us." From the age of seven Ms. F and her mother had an understanding that her mother worked, as Ms. F took care of the home: "I did it and I liked it and she [her mother] liked what she did and so— we were a team." When Ms. F was four years old a man came into their lives; eventually he became her stepfather much later in her life. Ms. F shared, though he was a stepfather, he was "emotionally" her father. Ms. F's grandparent and godparents were involved in her childhood. She spent time in Ireland where she experienced her heritage and came to know her extended relatives. Ms. F met Mr. F while in college, and after graduation began her career as a social worker.

Mr. F was the oldest of three siblings, with two younger sisters. His father served in World War II and was present at the liberation of the Nazi concentration camps. Because of his father's service, Mr. F's father was not present in Mr. F's life until Mr. F was three-and-half years old. Even upon the return of Mr. F's father from service in World War II, Mr. F never developed a close relationship with his father. Rather, Mr. F explained he developed a father-son like

relationship with his grandfather, as he spent most of his time living with his grandparents in a small home that his grandparents built in the woods. Mr. F was devastated at eight years old when his grandfather died. Even when Mr. F lived at home—before and after his time with his grandparents—he spent little time at home through his childhood, spending more time at his friend's home and playing sports. Throughout Mr. F's life he came to know his father, but their relationship was strained and fraught with arguments. These early challenges became a prelude for a life in which Mr. F became independent, including working at a young age at his family's construction company, and later attending college with financial assistance from the government.

Mr. F first noticed his wife when she gave a speech at the university to support the civil rights movement. He was enamored with her:

I have never seen a woman like this before in my entire life. . . I mean she was obviously bright; she was strong; she was assertive; and she was gorgeous. Absolutely gorgeous. So I wanted to meet her.

They became increasingly acquainted through their interests and attendance at seminars and political activities. It was not until Ms. F's college graduation party that Mr. F finally asked Ms. F out on a date. He knew he wanted to marry her, but Ms. F's response indicated they were off to an inauspicious start, as she told him: "You know, I like you fine. You're a very nice guy, but, I am not interested in marriage. I have things to do, and it [marriage] just isn't anything I want." Notwithstanding Ms. F's rebuff of marriage, her relationship

with Mr. F grew. They moved to New York City to earn their masters degrees and lived together in an apartment off campus, during which Mr. F proposed to Ms. F three more times. The third time was the charm. Ms. F agreed. Even then they could not marry immediately since Ms. F's eligibility for government education funds was conditioned upon her remaining unmarried and without pregnancy. After Ms. F received her last check from the government they were married.

Mr. F's parents were not close to the couple. His father "hated" his wife and her mother, and was disruptive at their wedding rehearsal dinner. The opposite was true for Ms. F's mother and her boyfriend. They were very close to the couple. Ms. F's boyfriend married Mr. F and Ms. F. Later, when Ms. F's mother finally married her boyfriend, Mr. F and Ms. F participated as the best man and matron-of-honor (at that point, the boyfriend becoming the stepfather of Ms. F, as referenced below).

A year after they were married, Mr. F was drafted into the military but within a year he was honorably discharged due to a cholesteatoma, which affected his hearing. He had treatment that improved his hearing, but he required surgery for correction a few years later. During this time, they had two sons. The first son was adopted, since they were told they could not have children. They had a second son through pregnancy. The first 13 years went very well with the children, but then the adoptive (older) son became involved with substance abuse and dysfunctional behavior, causing stress and turmoil in the home.

During the middle years, their older son and his partner had two daughters. His son could not afford childcare. Mr. F was working on his dissertation while teaching at the university. Since he had the time, he cared for his first granddaughter. When the second grandchild was born, it became too much to care for the children and write the dissertation. Mr. F decided to not finish the PhD. "That's the best decision I ever made in my life. I could have this wonderful granddaughter . . . or have something hanging on my walls."

Ms. F had a benign brain tumor surgically removed that left her without hearing in one ear. Ms. F's hearing loss created problems for her with the directionality of sound. Within 5 years, she had a successful cochlear implant.

Mr. F started to reconnect slowly with his father and he and his father first began to talk about family while visiting at the beach. His father's social perspective was changing and they found common ground. As he explained: "I think we both changed around that time, whatever the catalysts were for that."

The later years were filled with loss and many joys. Ms. F's mother and stepfather died. The couple shared how they advocated strongly to ensure her stepfather's last wishes were honored. They appeared before the hospital's ethics commission and challenged the physician's advice. The couple finally brought her stepfather home where the couple cared for him, per his wishes, until his death five months later. Both Mr. F and Ms. F were present with Ms. F's stepfather until his death. Ms. F reflecting upon this: "That's the past generation, but they both were very important to us. Very supportive." Mr. F was also with his father

when he died. By that time, they reconnected. His father asked for only him to stay by his side.

Their second son successfully followed in the social advocacy role of his parents and was married. Their son and daughter-in-law had a son and daughter, who are very close to them, through visits, phone calls and emails. The couple experienced the joy of traveling Europe and visiting their family roots through the eyes of their two older granddaughters. They reached out again to their older son, but could not sustain a relationship. Ms. F was steadfast in attempting to support her older son for years, but eventually the stress of the relationship became overwhelming, creating physical health issues for her. Ms. F described her and Mr. F's separate decisions to release from their difficult relationship with their older son:

He [husband] gave up before me. But I got to a point where I said, "It's my health," and doctor, she said to me, "Your blood pressure. . . .I can't control your blood pressure with this going on," and I said, "You know what? It's affecting my health. I have to say enough is enough." It was the hardest decision I ever made, but it was the best decision.

Mr. F's health started to decline as he aged. He was overweight with cardiovascular conditions that required a pacemaker and implantable defibrillator. He experienced a cardiac arrest at home that was not witnessed. The implantable defibrillator activated and saved his life. He had a procedure to upgrade his pacemaker that made him feel more energetic and improved his ability to be active. He made a goal to lose weight, 120 pounds by his wife's 73rd birthday.

The weight goal was the same weight when he first met his wife. He went to his wife and asked her for help to lose the weight. She supported him throughout the weight-loss process.

Life is "busier than ever" for the couple. They are catching-up on yard work and cleaning-out the house. Ms. F is retired. Mr. F is still working 20 hours a week, but plans to retire soon. His hearing declined, requiring bilateral hearing aids. The impairment makes communication difficult at times, personally and professionally. The couple remains very close with their youngest son and his family, and their two older granddaughters, with visits and other forms of communication. Throughout their home are family pictures, past and present. They expressed there was little change in their neighborhood for years, but more recently younger families are replacing older neighbors that have died or moved. The couple is now meeting new people in the neighborhood "for the first time in years."

Mr. F's health improved considerably. He lost the 120 pounds and met his goal for Ms. F's birthday. Both are feeling healthy and are committed to making the most of life. They decided to take an extensive trip, a trip they have thought about for 25 years. "Because you're not positive how long you have. Not obsessing about it. Just living, and living as intently as we can."

The first stop on the trip is to see their youngest son and his family. It will be the first time that Mr. F can enjoy activities with his grandchildren and the family due to his new, improved health. Expressing enthusiasm about this, Mr. F reflected:

Yeah, so it'll be fun. It'll be fun. And the whole family is neat. They're all very different people, and they're all very unique, and within that constellation they're all encouraged to be that way, so it's just so nice to see it.

Mr. and Ms. F's narrative diagram is shown in Table 4.

## Couple F's Response to Life Pattern Construal & the Life Pattern Analysis Summary

When both the narrative diagram and the life pattern construal were presented to Couple F, the couple noted, "I just think it is what it is." Both spouses had very close relationships early in their lives that influenced them throughout their lives. For those relationships that were closed (oldest son & Mr. F's father), they moved through the conflict to resolution for themselves.

Through further dialogue additional reflection was shared. The couple did not talk much about their youngest son and the influence he and his family had on their lives together. Mr. F excogitated:

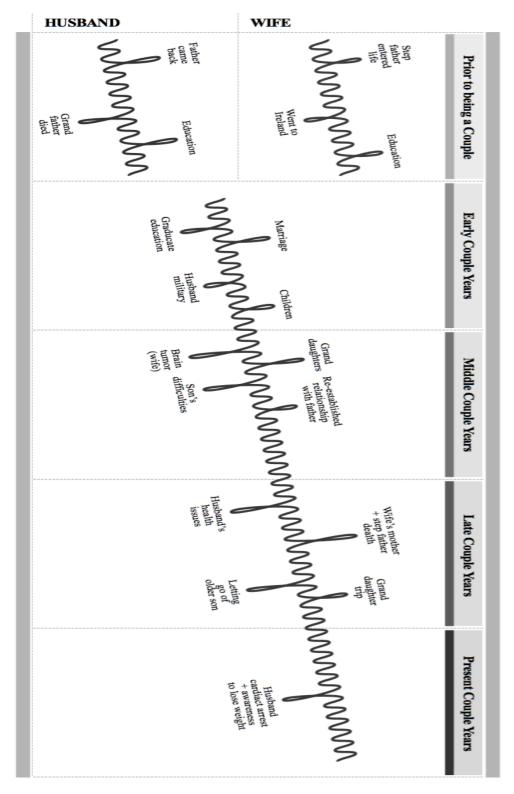
The role of him [the youngest son], and the relationship with him, and what he meant and does mean to us, with his children, and in some ways, the event in our life with him were docile, or not that earth shattering when you compare with dealing with . . . his older brother.

The couple went on to share stories about their second son and his family demonstrating the meaningfulness of their relationship with the son's family.

Table 4
Couple F's Narrative Diagram

friends,	n, GD=granddaughters, GC=grandchildren, FR= friends, Numbers:1=wife, 2=husband	AS=adopted son, S=so -> =bidirectional	Relationship Key: W= wife, H= husband, M=mother, F= father, SF=stepfather, Sr=sister, AS=adopted son, S=son, =neutral =n	e, H= husband, M=mother, F= fa	Relationship Key: W= wife, F
Sr-2 M-2	GC		GDs Sr-2	FR	₩ (
S W&H GC	AS	M.& F2	FR W&H	Ţ	↑ P W ↑ FR
→ FR	M-1 SF-1 S	AS	M-1 SF-1 S	N Sr	→ M GdP
Husband's mother in nursing home.	Husband reconnected relationship with father and was present at his death.		within family over the years.	of marrying.	on the state of th
friendships.	death.	Active politically.	Adopted son had an addiction with	Metwife & had intention	political activists.
Wife continues book club and	Advocacy for the control of wife's stepfather's	father.	pregnant with another son.	Earned a Masters degree.	freshman & both were
neighborhood.	Wife's mother died.	relationship with his	Adopted a son and then became	Very athletic.	-
know new people in the	with him for over 4 years.	Husband started to	Were told they could not have children.	construction business.	Earned a Masters in social worker.
arts, friends & neighborhood	k out. No co		correct hearing loss.	Worked in family	
Enjoy traveling, gardening, the	Provided last opportunity to help and support	corrected loss.	Years later, husband had surgery to		of family.
	manny masony and so apparation and open	implant that	1935	devastating.	relatives. Gave her history
near future.	family history and to experience Europe	received a cochlear	Honorable discharge due to nearing	be was 8 It was	went to Ireland for the
hrs/wk, but may retire in the	Horizontal and the second description of the second	hearing was in one	marriage, but then enlisted in Air Force.	"father figure".	
Wife matired Husband works 20	Their second son married and daughter and son.	brain tumor. Lost	Husband drafted after 1 year of	Grandfather was his	influence in her life.
son and all grandchildren.	device implanted that improved his health.	Wife experienced hearing loss due to	Not close to husband's parents.	met his father.	Grandparents and Godparents were important
Close relationships with second	Husband started to lose weight and had new CV			years old when he first	
professionally & personally.		grandchildren.	stood up for them.	early years. He was 3.5	stepfather entered her life.
difficulty in communications,	while removing show, which had an impact on his physical health.	be with the	Mother married stepfather. Couple	was in the military for his	At the age of four, her
Husband's hearing loss creates	implanted. Had cardiac event with defibrillation	PhD. Then decided to	Wife's stepfather married the couple.	Raised by his	model, raised her.
	Husband had pacemaker and defibrillator	while he studied for			who was a strong role
activity. Lost 120 pounds.		provided childcare	marriage.	younger sisters	she was born. Her mother,
device improved his physical	other issues. Fitted for hearing aids.	Adopted son had 2 daughters, Husband	Living together while attending out of state college (masters) prior to	Oldest of three, two	Father left the family when
Husband's new cardio-vascular				HUSBAND(2)	WIFE(1)
Present Couple Years	Later Couple Years	Middle Couple Years	Early Couple Years	ng a Couple	Prior to being a Couple

Figure 3
Couple F's Emerging Life Pattern



Mr. F contemplated, saying that the youngest son "had a huge effect on us really, and how we thought about things, . . . different ways that we tried to look at things. It's a relationship that lasts until today." The couple recognized over the years they did not share as much detail about their youngest son and his family. It appeared they wanted to make sure their youngest son was not overlooked, as he might have been during his childhood. The additional dialogue seemed to reflect a correction of the past to ensure recognition of the meaning that the younger son and his family have brought to them.

Ms. F offered an insight about what may have triggered her husband's forgiveness of, and reconnection to, his father. She noted a connection from life pattern construal that she had not perceived before. The passing of her own stepfather coincided with Mr. F's reconnection to his father. Ms. F reflected and commented to Mr. F in this regard as follows:

I think that's when you really started to kind of forgive him, and just dealt with the here and now and say, we ought to have a relationship. I didn't think he'd [her husband] would ever do that [forgive and reconnect with his father]. And then he just resolved it. . . all of the stuff was there, but he could overcome it.

Following this comment, Mr. F offered more of his past, stating—"I made it through. I made it. I made it through pretty well. I went to college, . . . then I met [my wife] and all the people we met." (Figure 3)

The life pattern analysis revealed that Couple F's openness to seek understanding was what created an opportunity for the couple to recognize life's

meaningful moments, and how their action during those moments shaped each other's lives, their own lives, their family, and society. The life pattern revealed how this couple, through their own continued self-discovery as individuals within their relationship, managed life together as a couple. Each spouse was free to bring to the couple's relationship, their own perspectives on situation that was an issue and together could form a new perspective that was transformative and meaningful. This process was revealed by key decisions regarding choice points; the decision to marry, "letting go" of the oldest son to sustain their own health, the reconnection with Mr. F's father, the determination to improve health with and for the other, and the decision to take the lifetime trip together. Ms. F offered her own poignant summary of how choice influenced life:

always been [talked about] individually, and this is the first time we thought about it as our little family at this point, how it impacted us . . . and you change so much. It [the life pattern] puts it in some kind of context. It is so much more meaningful.

#### **Exemplar Three: Couple M's Narrative Summary**

"Choices made during life transitions offer the opportunity to live meaningfully"

Couple M has been married 65 years. They had three daughters and a son. Ms. M is 85 years old and Mr. M is 90 years old. Their earlier life was full and active. The couple loved to travel, socialize and dance. They built a "dream" home in a community they loved and were very involved. Life and retirement was a joy until they experienced a situation where choice was taken from them abruptly, leaving them with memories of their life in the past.

Before they married, each spouse was raised in very different social stratus. Ms. M was the second oldest in a family of three siblings. She was raised with her older brother. Her younger sister was born 17 years after Ms. M, and she lived with her younger sister for only a few years before Ms. M moved out of the home. Explaining her thoughts about her younger sister Ms. M said, "I don't think of her as a sister." She added, she may not know her sister well, but she "loves her." Money was scarce in her family. Ms. M was very close to her father and remembered he used his "tips" for special treats, but she had a "hard time" with her mother. They had a close extended family that included both sets of grandparents. Ms. M reflected on her childhood as a "happy" time.

Mr. M's parents emigrated from another country, were not literate, but worked very hard. Mr. M was born in the family home and was the youngest of four children. He had an older brother and two sisters. His older brother fought in World War II. The war adversely affected his brother psychologically, causing dysfunction in the home after his brother's return from the war. Mr. M considers himself an "impatient" person, explaining he developed this characteristic as a result of having little guidance in his younger years, and uses that to explain why he did not complete high school. "I could have done better educationally," but he was anxious to get out of school and work to move on in his life.

Mr. M first saw his wife while she was working in a bank. He worked at a jewelry store at the time and would see her when he was making routine deposits for the business. Mr. M did not know her, but he said he knew "she was the one [he] wanted to marry and be the mother of [his] children." Although Mr. and Ms.

M did not socialize in the same circles, there came a time when they both went to a dance. Each of them was on a date with another person, but Mr. M eventually approached Ms. M and asked her to dance. They were together for the rest of the evening, leading Ms. M to comment—"There were two people who left very unhappy . . . my boyfriend and his date." Mr. M was five years older than Ms. M and wanted to marry her right away, but Ms. M was not sure she wanted to marry at that time. Even after they were engaged to be married, Ms. M showed hesitation with marriage, changing the date of the wedding three times. After Mr. M insisted that there be no further cancellations of the wedding, Ms. M agreed because "she didn't want to lose him"—and so they married a year after first meeting, she 20 and he 25 years old.

At the outset of their marriage Ms. M continued to work at the bank until their daughter was born one year later. Mr. M wanted Ms. M to stay home and care for the children while he worked and earned the family income. Ms. M seemed fine with this arrangement, but soon became aware she was not ready for marriage and all the responsibilities. Ms. M stated she missed some life experiences but she "loved being a mother." The couple eventually had three more children. The first two children were born close together. The second two births were spaced apart. As their marriage continued Mr. M made a career change that made him very successful. The couple enjoyed life and continued their love of dance that was the catalyst of a relationship that spanned 65 years. Their family and extended families were very close.

Early in the middle years of their marriage Ms. M's father died and Mr. M's parents died. Within a few years, Ms. M's mother remarried an old friend who was disliked by the family. Her mother and stepfather moved out to California. The marriage did not last. Ms. M's mother returned and moved into the home of Mr. M and Ms. M. At that time their son was still at home. These living arrangements created conflict between Mr. M and Ms. M's mother, such conflict eventually being resolved when Ms. M's mother moved into another home.

Once all the children left home, the couple sold their house and built their dream home near the water in the community where the couple had grown up as children. They were very happy to be near their church, their friends, and Ms. M's part-time job. The couple traveled extensively after Mr. M retired and continued to dance.

After Mr. M retired, the couple bought a villa in the South to live during the winter season. They socialized with a group of friends and continued to enjoy the freedom of life. This all ended when the couple contracted food poisoning at their villa. Ms. M "waited it out" but Mr. M "due to his impatience" went to the hospital where the treatment "caused" Mr. M to develop clostridium difficile. He was hospitalized for six weeks. Ms. M and her family did not know whether Mr. M would survive. Mr. M stated, "I made peace with death." This was a very stressful time for Ms. M as she was recovering from a knee replacement, while deeply concerned she would lose her husband. Ultimately, her husband survived, and lived in a rehabilitation facility for a year as he recovered from the incident.

In the past, Mr. M made life decisions with Ms. M. Due to the acuity of the Mr. M's health, the couple's children began making a series of decisions that fundamentally altered the couple's living arrangements, causing the couple to feel a deep loss of independence. Ms. M recalled hearing her children talk about her, rather than with her. She recalled her children discussing ways to resolve their parent's living situation. "What are we going to do with Mom," her son said at one point, making Ms. M feel that she was a "problem now."

It was in this context their children decided the couple's "dream" home would be sold, and the couple would be moved into a full-service retirement community into an apartment selected by the children. The children divided their parent's cherished belongings between them, packed the parent's possessions that were left, and relocated their parents to the apartment. During this time, Mr. F was too severely ill and Ms. F was too emotional distraught to engage in the situation.

It took Mr. M one year to fully recover, but he never returned to his earlier physical health. The children made a further judgment—one that profoundly deepened the couple's sense of loss of independence—deciding their father should have his driving license revoked, stripping the couple of mobility.

Moving to the retirement community 11 years ago was an abrupt change.

Mr. M and Ms. M felt resentful for not having the choice about where they would live for the later years of their lives. Though the couple understood the circumstances, they expressed intense bitterness about how the changes were made without them. Neither one of the spouses could engage in the discussion

well at the time the decisions were made. Ms. F was not only under extreme stress of the moment, but also may have felt incapable of participating in the discussions or decision-making, since she may have never made such important decisions without her husband.

Since Mr. M's illness and the move, Mr. M has been treated for depression. He struggles to find the good in life. He mournfully admits that he "wants to die" because his life is getting more "narrow." This despondent and somber outlook of Mr. M has introduced strain and conflict in the couple's relationship. Ms. M attempts to encourage Mr. M and she does not accept Mr. M's thinking. Even so, Ms. M candidly joins in Mr. M's disdain for their imposed, living arrangements, longing for the memories of their previous life's activity and dancing.

The couple struggles for common ground and "quarrel" often. Commenting on this Mr. M said:

[The quarrelling] has to stop. That is the most important thing. When I sit down with her, even when I quarrel with her. And I quarrel—we quarrel. We have high points in life, and we have low points.

Mr. M also resents Ms. M increasing independence over the years. The couple are thinking of hiring a companion for Mr. M to increase his independence and aid him in his exercises. Mr. M nonetheless showed resilience, observing—"But we have stayed the course. There's a lot of people who don't stay the course."

The past year was difficult for Couple M. The couple continued to see their children and grandchildren but not as much as they would like. One of their grandsons does not speak to them due to a disagreement. This limited their ability to see their great granddaughter. Their two daughters have conflict. The conflict impacted the couple's opportunity to see and enjoy their daughters. In addition, the couple began to have frequent health concerns that have reduced strength and mobility. They can no longer dance as a couple, but the couple made a goal to dance on New Year's Eve, 2018. Reflecting on this goal, Ms. M offered—"as we get older and older and older, maybe that's what we're still holding onto, that last gasp from your past that you're holding onto for the finality of life." Mr. and Ms. M's narrative diagram is shown below in Table 5.

## Couple M's Response to the Life Pattern Construal & the Life Pattern Analysis Summary

When the couple reviewed their narrative diagram and the life pattern construal, the couple recognized it as their own. They saw the experience as an opportunity of, "having it [life] all laid out" for them. As they reviewed the information the couple reflected on the past, taking time to look at life experiences and connections and what was meaningful regarding their current life together. "We've done it. Now we know we did it…[its] crystallized and made it to what it is…it's revealing…the break is right here [indicting to the time of his illness on the life pattern]…this is a new life."

Table 5
Couple M's Narrative Diagram

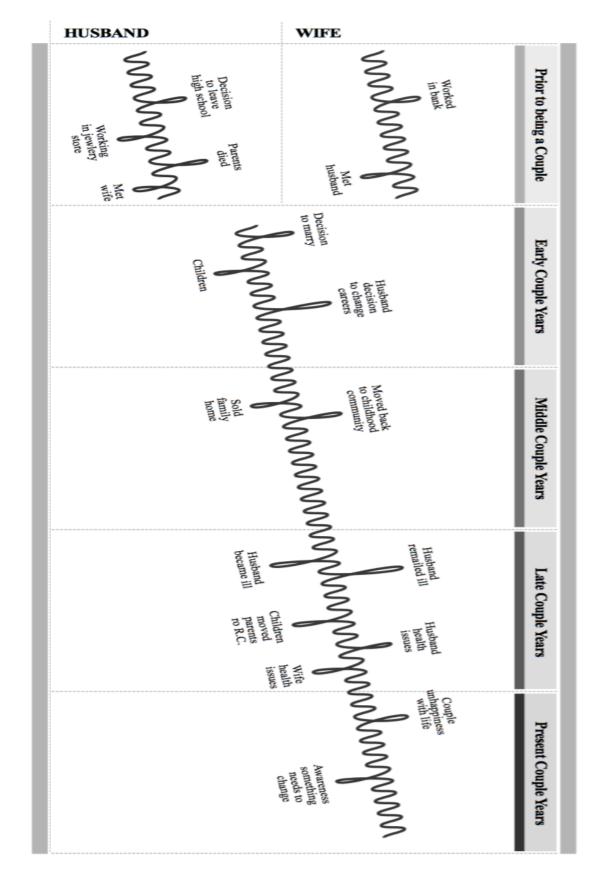
Sr W M	Married at 20	didn't want to lose him.	to get married, but	Worked in a bank.	grandparents.	Very close with her father and	the younger sister.	Did not grow up with	Was not close with her mother.	17 years younger.	three, older brother and a sister that was	WIFE(1) Second oldest of	Prior to being a Couple
B H Sr	Was ready to "settle down". Married at 25.	store.	Worked at a jewelry	Loved to dance. Danced 3 times a week.	life.	school. Stated he was impatient to start his	Did not finish high	mental illness after the war.	<ol> <li>a brother and 2 sisters. Brother had</li> </ol>	He was the youngest of	immigrants from Portugal.	HUSBAND(2) Parents were	ng a Couple
M-1 F-1 M-2 F-2 W&H  S  Ds	and father (65) died. Wife's father died.	Husband's mother (66)	Couple loved to dance.	wife and he became successful.	salesman in insurance with the support of the	Husband became a	Missed experiences of growing up.	aware that she not ready for marriage at the time.	Overtime, wife became	a bank then quit once she had children.	Wife continued to work in	Had 4 children, 3 girls and a boy (the youngest)	Early Couple Years
SF-1 S Ds	ended.  Husband retired.	remarried. Did not like stepfather. Marriage	Wife's mother	Danced when they went out.	friends there.	nearby, wife worked part-time and had	happy in their community; church	Wife and husband very	community they grew up. Wife's dream home.	children out of college and moved to	Sold family home after	Enjoyed traveling and life together.	Middle Couple Years
M-1 S Ds W&HGS FR GC	Continue to love dancing, Danced in RC shows. Recently have not danced in years.	Children decided they shouldn't drive anymore. Left the couple feeling isolated.	grandenlidren. Had a falling out with one of the grandsons.	Daughters tend not to get along. Have 6 great	located outside of their community. Both have resentment about the move and the impact on their happiness.	Children decided the couple's home was to be sold and the couple was moved to the retirement community (RC)	recovery.	Wife had both knees operated on during husband's	never returned to his baseline health causing both to loose their independence.	almost died, followed by depression. Husband made peace with death. It took 1 year to recover. Husband	Couple became ill due to food poisoning in SC. Wife recovered but husband became very ill with C. diff., he	Wife's mother died.	Later Couple Years
GC W&H GS	It has been a difficult year due to health concerns for both.	due to strengthen and mobility issues.  Goal is to dance on NYE.	Have not been able to dance together	Strained relationship with grandson, which is hurtful.	exercise.	Hiring a companion for husband to be more independent and to aid in	they get together for holidays.	Miss the companionship of their children, grandchildren. However,	husband.	The couple does not like living at the RC, feels like a "prison" to the	common ground.	The couple does not like what is going on in their lives. Struggling to find	Present Couple Years

Relationship Key: W= wife, H= husband, M=mother, F= father, SF=stepfather, Sr=sister, B=brother, S=son, D=Daughter, GC=grandchildren, GGC=great-grandchild, FR=friends, =neutral =neutr

-----=blocked

- =neutral

Couple M's Emerging Life Pattern



The couple offered the following comments.

It [the dialogue] got things out that I think about sometimes. I felt like I was confessing because I've said things I probably wouldn't have said in front of him. I might not be that honest with him about my feelings or something because he has a great way of hurting your feelings, mine especially. (Ms. M)

Before ending the dialogue, Mr. M. said:

But I feel that we haven't strayed—and I'm talking about her, too. She's never strayed too far from her life with me. I haven't strayed too far with her. I might be angry with her. But I still love her. This is the way it works. Yeah, you figure there's a lot of life right there [indicating to the life pattern].

#### Ms. M. then replied:

I think it's [the reflection] maybe even brought us a little closer right now because -- I don't even get a hug out of him anymore. Maybe now he'll think about it and say, gee, maybe she would like a hug.

Mr. M. poignantly stated, "Okay, I'll start hugging you."

In Figure 4, Mr. and Ms. M's emerging life pattern is presented.

The pattern analysis revealed when people are not part of decisions as a couple, there can be resonating repercussion, like quarreling, that can compromise moving forward and finding new meaning in life. For this couple, not participating in choice about their life affected their movement forward. They were not able to engage in "their process", but were subjected to someone else's

process. The couple lost control of their life, something that was very important to Mr. F. The couple had control until abrupt life changes compromised their ability for movement forward. The couple seemed to be striving for balance with their environment as well as within their relationship. This was demonstrated through both Mr. M and Ms. M's struggle to accept their current living arrangements, even though they admitted other options are no longer available. This created relationship dynamic challenges and "quarrels" that fueled the potential for discontentment and depression. Ms. M states, "I miss him because he's not the man I married. And I really miss that man, very much, very much." The couple shares a love of one another, which keeps them seeking to create a new meaning as a couple.

### **Phase One Data Analysis Summary**

The answer to the first research question—"What is the life pattern manifested by OA couples living with chronic illness at home?"—was uncovered through a focused dialogue between the OA couple and the researcher. The findings reflect meaningful events and people who have influenced the OA couples' life pattern and opportunities for choice that impacted their life pattern. By reflecting and recognizing their life pattern, the unique story of the OA couple was revealed at that moment in time, and provided a time for reflection and insight. Table 6 provides a list of the OA couple's narrative interpretive summary statements for each of their stories.

#### Phase Two: Data Analysis Across the Older Adult Couples

All the study data were analyzed across the OA couples through an exploration of the unique life pattern of each OA couple. The narrative summary interpretative statements (Table 6) from the OA couples were further contemplated and analyzed using a qualitative analysis to explicate the overarching themes manifested across the OA couples' stories (Saldana, 2016). The OA couples' recognition of their life pattern offered insight and was viewed as validating a natural day-to-day flow that addressed challenges and life opportunities. Each couple expressed their own story and meaningfulness, which they identified as their own.

The analysis across the OA couples revealed three themes. The themes offered new insight into the meaning of health, illness, and life, in an OA couple, and how their relational process with each other and other individuals influenced life choices and changes over time. The themes provide new insights into the OA couples' reliance on one another for identity, socialization, and management of daily living, even in the face of chronic illness. The themes are presented as follows: (1) an unfolding pattern of living meaningfully as an OA couple living with chronic illness moving through life transitions; (2) couple interconnectedness strengthens the bonding within the OA couple and promotes self-growth, and (3) a resonating process within the OA couple promotes movement toward expanding consciousness.

Table 6 Older Adult Couple Narrative Summary Interpretative Statements

Couple	Narrative Summary Interpretative Statement
A	Knowing-self and other while moving forward through life transitions as a couple
В	Struggling for understanding within the couple
С	Feeling the presence of the other as momentum to propel the couple through life experiences
D	Relating to the other within the relationship to survive the struggles of life and experience meaningfulness
Е	Awareness of being in the context of family and living in the moment
F	Recognizing and embracing meaningful life moments as self and the other
G	Mutual sharing with the couple gives ease and peace to being
Н	Staying in the moment and never giving up as an individual and as a couple
I	The dynamic presence of the other in the relationship reinforcing the value of commitment
J	The bond of the couple as strength to continue through adversity
K	Maintaining the "self" to enrich choice and the meaning of the couple
L	A partner's experiences and insights are shared within the couple to further meaning and awareness, as a couple.
М	Choices made during life transitions may offer the opportunity to live meaningfully
N	Awareness of self and the other is an opportunity to find greater meaning of life as a couple

Theme One: An Unfolding Pattern of Living Meaningfully as an Older Adult Couple with Chronic Illness while Moving through Life Transitions

The first theme is a synthesis of data from three interrelated components that were revealed by the OA couples. The first component relates to the OA couple's description of living life meaningfully. The second component addresses the influence of chronic illness on their living. The third component examines the context of the OA couples' living while moving through life transitions. In the following three sections, the components of the theme are discussed, followed by a summary.

Living meaningfully. All the OA couples expressed living meaningfully through discussion of the importance to the looking forward to a "full life" with less attention to their actual chronic health conditions. Their chronic health conditions did impact their lives at times, but the OA couples often appeared to move beyond their physicality, despite the impact of the health conditions on their daily lives. Challenges to aging as an OA couple were often influenced by other social determinants, including family, children, living arrangement changes, social networks, and the chronic illness experience itself. The OA couples expressed a focus on living as having purpose, actualizing themselves with their spouse, and enjoying their families and friends. The following excerpts from the interviews exemplify the OA couples' perspective of living meaningfully in this regard.

I see a lot of people in their nineties. Their minds are as clear as can be. They're enjoying life. And they're dealing with whatever is wrong, and they're making it work. And that's what I keep saying to [her husband]. We're making it work for us too. One day at a time. (Couple A)

Just having this time we didn't think we were going to have, to do things we wanted to do together. We've been talking about this trip for 25 years. And we're at a point where he said to me, "It's time." Because you don't want to go on a trip like this any worse off than we are right now. And neither one of us knows what the future brings. So we are doing things in the yard that we thought we would never do. It's like living everything at the fullest, to cram it in. Because you're not positive how long you have. Not obsessing about it. Just living, and living as intently as we can. (Couple F)

We've reached an age where we have to do those things [manage health issues], but it's not something that is overshadowing our lives. Health is only one piece of this time in our lives; it's not the whole thing by any means. (Couple L)

We're doing everything we've always done forever. Takes us longer. We do it differently. But we still do everything we need to do. We cope by living. You can't define yourself by your diagnoses. That would be crazy. So you just kind of compensate and do what is important to you. (Couple F)

We don't think ahead of time, because you never know what tomorrow will bring, but we're still about living. (Couple E)

Another dimension of the OA couple's living meaningfully was demonstrated by the OA couple's appraisal of their past life as an accomplishment—"We made it." Now their time together was seen as the time to enjoy the "fruits of their labor." The OA couples shared moments of difficulty and stress as they sought balance to family and life's responsibilities. The OA couples expressed an acceptance that they were "doing the best they could" at the time, "letting go" of the past concerns, "living in the moment," and "taking each day as it comes"—as they proceeded to a new enjoyment of living as an OA couple. The following excerpts from the interviews demonstrated the OA couples' appraisal of their life together in this respect.

We've had a wonderful, a fascinating life, with great experiences, both before we met each other and together. We're not simple. It's been crazy, wonderful life, with ups and downs. But that's what life is all about. It's been good. When we reflect about it, the good stuff outweighs the bad stuff. And we are able to go on, and do good things, and not focus on the bad things. (Couple F)

We can enjoy the fruits of our labor now. Where before, there were many struggles. ...take days as they come and enjoy life right now. Because you never know what tomorrow's going to bring. Neither one of us is in

great health...but at our age you're probably looking at 5-6 years down the road, and there'll be only one of us, and so we're going to enjoy our life as we have it right now. Enjoy our life every day, and take it as it goes. And just help each other through the struggle. (Couple D)

The OA couples articulated another facet of the meaningfulness of living as deriving—not only from time with each other—but also from time with their children, grandchildren, extended family, friends, and the community. The breadth of the relationships of the OA couples in this regard seemed to enrich their sense of living meaningfully. They expressed a connectedness to others through the joy of their family and accomplishments, and observed the "progress and achievements" of their children and the grandchildren as sources of great pride and satisfaction. The following excerpts from the interviews exemplify the OA couples' relationships in their lives as contributing to living meaningfully.

We've had a very full life and our biggest enjoyment is being with our kids and grandchildren. We are going to a game there next week. I can't thank God enough for our grandchildren because they think about us all the time. They check on us, but not overly. As far as adventure, we've done everything. We've done the traveling. The only thing we really look forward to the success of our children and our grandchildren. That's the only real thing with any meaning to us. (Couple H)

When you pass, your wealth is not measured by the amount of money in the bank, but by the number of friends you leave behind. That has stayed with me all my life. Friends are important. They are very important. (Couple E)

Volunteering helps a lot. I think that helping other people makes you feel better. In fact, we did that even when we were young. (Couple D)

There's so much love when they are [the children and grandchildren] here with us. You can feel it in the room. (Couple L)

Three couples within the sample shared uncertainty and past regret that tempered their ability to live meaningfully. Those OA couples continued to reflect, to seek understanding of, and to balance their challenges while striving to live meaningfully. Each of the OA couples offered different life experiences in that regard. In two of the three couples, one of the spouses was being treated for depression that may have impacted relationships and challenged the opportunity to live meaningfully. The following are highlights from the three OA couples that shared feelings of this nature.

Couple J had the largest age differential between spouses, the wife 72 and the husband 85 years old. The wife saw a psychologist for depression. She used a wheelchair for mobility and relied on her husband for all transportation or movement when in public. Ms. J expressed a concern about "thinking forward" because she does not "like now much." Her husband thinks about what illness is going to "take over" his life as he ages. The following exchange between them reflects this thought process. Mr. J states, "I kind of just am concerned about the

illness that is going to take over my life—as I grow older. That's about all. I don't worry about it, but I"—Ms. J interrupts, "You do. You do. You worry. What else are we going to have come against us. I worry about him and he worries about me."

Couple B were in their mid 80's with neither spouse reporting a diagnosis of depression. Couple B shared a regret of not being the "perfect parents" which was a goal for them as a young couple. Couple B explained an inability to accept the life styles of their three children. They reflected on strong religious beliefs they held which were rejected by their children. They continue to struggle with resolving this concern:

I think a big disappointment in our life is that somehow we don't have a good relationship with our children, and that bothers me, and it bothers [my wife] an awful lot. (Mr.B)

We do have a pretty good relationship with our children. We do. It's not that. It's just not—they didn't turn out the way we thought they would. We didn't raise the perfect family. We have a daughter that's very concerned with us. She calls me almost every day to check on us, and our [youngest] son, he's nearby. He's near if we need anything, and he calls at least weekly if not twice a week. Our oldest son still keeps in contact with us. They're just doing things we don't want them to do. We're not happy with any of their lifestyles, because it's not like ours probably. (Ms. B)

Maybe our standards morally are too high, but maybe we expect too much of them. Maybe we ought to understand that their failure to see, what forgiveness is. If we didn't accept them we would have just cut them out of our life, so yes, we have I would say it's a degree of acceptance there.

(Mr. B)

If I keep harping on, 'I think you are doing wrong', that kind of cuts down on your relationship with them. You have to kind of just let it go.

Sometimes I think we should enjoy each day, instead of bickering or whatever we do. We should just sit back and relax. (Ms. B)

Couple M are 5 years apart in age (the wife 85 and the husband 90 years old), and live in a full-service retirement community. When Mr. M was 80 years old he suffered an acute catastrophic illness at their summer home. He was near death. At the time, their children made decisions regarding Couple M's living arrangements without the couple's input. Mr. M recovered through a long rehabilitation period. Since the illness, Mr. M was treated for depression. The OA couple continued to express a deep sadness and regret about their current living arrangements. They yearned for their past and continued to have difficulty accepting their current living environment. This impacted their living meaningfully during the past 11 years. The following exchange between Mr. M and Ms. M reflected this difficulty, with Mr. M voicing a struggle with his feelings about living "past his time":

It's not an option [moving to a home they want to live], but it is in my mind constantly. It's too late. It's too late. We wish that we could have

gone home ourselves, and maybe just stayed there long enough for us to decide alone, what did we want to do? Where did we want to go? And, I certainly wouldn't put myself up here in this part of the country I've never been. (Ms. M)

We're isolated here. This is a very, very nice prison that we live in. All of this upsets me. (Mr. M)

Though the three OA couples shared aspects of life that were challenging, each of the OA couples expressed counterbalancing aspects that helped mitigate such challenges. The couples frequently expressed the joy they felt from the relationships and presence of their children and grandchild; such moments offered the OA couples an opportunity to add meaningfulness to their lives, as shown by the following excerpts.

We never knew grandchildren could make an impact -- on your life that they did, just... Oh, it was fantastic. (Couple J)

When they come here [children and grandchildren], I enjoy them. I really do. I enjoy...my son is my best friend. We have a wonderful son. He's special. (Couple M)

Impact of chronic illness. Though the OA couples did not focus on their chronic illnesses, their health did trigger attention creating a need to evaluate their lives. As individuals and as a couple, health management was important. Most of the OA couples reported receiving quality medical care but shared their frustration of being defined by their "illness." Many couples experienced limited

communication and often felt others (in health care) were not listening to them. They described frequently being given pharmaceuticals as the primary treatment option. Several OA couples were frustrated with the amount of time required to obtain medical care. Typically, the OA couples were seen by many specialists while trying to find "good" providers of care. Some OA couples shared how they tried to find alternative treatment around discomfort and mobility, and were challenged to obtain information about these options, leading them to the internet or through their friends. The following excerpts from interviews exemplify the OA couples' perspective about this concern.

I always say to the doctors, if I have an ache or a pain, I want to exercise it out. I can't do the drugs. And I refuse to cow down to stuff like that because they make me so sick. It's just like I don't want pills for every situation I'm in. But I do, like Qigong. It's more geared for the elderly. (Couple D)

They [health care providers] didn't know what to do with me, so they were dishing out drugs. "Well, maybe this'll work. Try this, try this, try this." I diagnosed myself. I got into energy medicine, which is a little bit out there for most people. I've been to chiropractors, acupuncturists, I spent a month at an Ayurvedic clinic in India. We take a lot of supplements, but each thing is something that I researched. I get JAMA, a couple of different JAMAs, I get Lancet, because I don't believe the US. I go to the UK, the New England Journal of Medicine. (Couple J)

The doctor said, "You have so many arthritic and muscular problems, as well as the bones, that I can't do any more for you." I said, "Thank you," and decided I needed a new doctor because if he couldn't do any more for me, there wasn't any point in wasting his time and my time in seeing him. I did some listening around here because nobody has a problem that no one else has here, believe me. (Couple L)

I said to a doctor one day, "You people are so busy saving our lives, you forget to tell us how to die." (Couple M)

When something happens to one of us, we go and we look it up and figure out how to deal with it. You've got to deal with it. That's all you can do. I don't think going to the doctor is a complete picture of what you're going through. I think they only have X amount of time. And then you come out of there with questions and stuff like that. So, we do a lot of research to figure out how to manage it. It's challenging for us, because where I go to so many doctors, everybody has their own little opinion. You find conflicting information. We find that a challenge. We find some of the things that they want to do we don't like. I don't want a pill every time I have a problem. I have conflicts with the medical field on that. I think it's easier for them to push a pill on you...I think they spend a lot more time trying to treat you. There is not a cure for aging. And when they say, well,

this has long-term health effects, who gives a shit? I mean, come on. (Couple D)

Life transitions. The pattern of living meaningfully as an OA couple seemed to unfold while moving through life transitions. The OA couples experienced many life transitions during their older adulthood. Some of these life transitions are planned or expected events, e.g., retirement, and some of the events can occur very abruptly and unexpectedly without planning, e.g. health events. The context of how the event occurred and the frequency of the life events appeared to influence the OA couple's ability to move through the life transition along with its successful integration into their lives.

Life transitions examples that occur in older adulthood include those that are considered developmental or normally occurring, such as retirement, having grandchildren, or situational, such as moving to be close to their children, moving into a smaller home and new community to save money, or health related, such as sudden cardiac arrest or acute illness. To move through the life transitions required the OA couple to experience a series of dynamic processes. The processes required a recognition to evaluate their current lives and to make choices that took into consideration what is needed for new living (daily living after the life event and changes in living occurred) based on what was meaningful to the OA couple. The following excerpts from the interviews exemplify the OA couples' life transitions.

He retired first and I really didn't want to retire. Until one day my daughter said, 'You know mother, you never know.' I went in and gave my notice. And that's when we went to Florida. We were there for 25 years. We always kept the place here, but we went down there for 6 months of the year. (Couple H)

We were the only ones left [in the neighborhood]. I still miss our house and our street. I had a lot of friends and I don't make friends easily. I had a lot of possessions in that house. We were throwing things away, giving things away. That was difficult because it was things that we saved. (Couple J)

When we come to the big decisions, we hammer them out. It doesn't just happen. I mean, you said no, you weren't selling nope, and then all of a sudden, over Labor Day weekend [husband agreed to sell home] -- Things changed. It was after my heart attack. (Couple A)

#### **Theme One Summary**

The new living took on new meaning by the OA couple as they moved through the life transitions. The movement occurred differently across the OA couples; some OA couples moved faster through the life transitioning processes; while others toggled between the life transitioning processes; and for some of the OA couples the movement overlapped among the life transitioning processes.

While moving through life transitions, diverse forms of influences occurred. The

OA couples experienced influences from relationships with family and friends, life style changes, various contemplations to formulate new awareness, memories attached to belongings and personal independence creating a sense of loss. All these influencing factors complicated the movement through life transitions.

Across the OA couples the need of purpose, connection, and engagement were vital. One 80 year-old husband thoughtfully reflected on this, as follows:

I thought when you retire that was it. You just sit down and read a book and do nothing, but it's not like that. You don't even know that yet, because you're not old enough, but if you sit around and do nothing you don't really feel too good at the end of the day, because you don't have that feeling of accomplishment. So, you have to do something. It might be something minor, just a little gesture to help someone or something like that, but you feel good at the end of the day. You have to do that, I think, for the rest of your life. Do something challenging and keep busy, because otherwise you're going to feel opaque. (Couple C)

# Theme Two: Couple Interconnectedness Strengthens the Bonding within the Older Adult Couple and Promotes Self-growth

In this study couple interconnectedness is defined as a bond of partnership between the spouses resulting from a reciprocal dynamic exchange that may foster interdependence, where interdependence is as a mutual reliance on the other for physical, emotional, and economic needs. Couple interconnectedness may be viewed as an artful, delicate balance of interdependence within the OA couple, maintaining a personal and couple identity while living meaningfully. The OA

couples demonstrated their interdependence through companionship, physical and emotional support, and the engagement in living activities.

Shaping dynamics of couple interconnectedness. Couple interconnectedness appeared to be shaped by three relational dynamics: (1) knowing self and the other; (2) reciprocal influence; and (3) the ability to move in and out of the couple-sphere, as defined as a relational sphere where both spouses manifest as a couple. These relational dynamics, along with the aging process, may impact the degree and mutuality of the interdependence between the spouses.

Knowing self and the other. An essential relational dynamic of the OA couple interconnectedness was revealed as knowing self and the other, a dynamic that may be perceived as a conscious self-awareness and expression that extends to include the awareness and understanding of the spouse. The awareness and understanding of each other was developed over time through the experiences of life, continued personal growth and the other spouse's influence.

Many of the OA couples' dialogue revealed couple interconnectedness through knowing self and the other. The dialogue exemplified an influence and support by each spouse, creating rich, profound, in-depth moments, leading to a transformation in their relationship dynamics. The following excerpts demonstrate this viewpoint.

We may have had differences, but it just passed off. When you have to, just gloss over it and carry on. The thing that is really important is we must stay together. That's it, in everything. We share everything. I rely on him for many things, and he relies on me for many things. There's a

lot of give and take. I can't imagine having married anybody else. Nor can he imagine having married some other woman. (Couple G)

I think you learn to grow more together as a couple because of the relationships as they've occurred at various points in time during your life, as you've grown as an adult. (Couple E)

We knew each other for four years before we got married. We had a pretty good idea of what was coming. Even though we have a lot of different interests and things, we match. We can accommodate. (Couple L)

It was difficult, but we were on the same page, bottom line—maybe not on every single thing, while things were going on, but bottom line, we had the same values on education, money and religion. It just made for harmony. We survived. (Couple C)

One thing is you make a vow. I don't want to violate my vows. We had kids to take care for. We enjoyed each other. We enjoyed the kids. We looked for things to do as a couple. So it was an evolving thing.

(Couple I)

We both learned from an early age to be very responsible. We both knew from our experience we had to be responsible and accept them, even if the new ones were difficult. We knew we had to work together to get through all of this. (Couple N)

We've been together forever. It's just like a comfortable shoe now. (Couple D)

There's support and bolstering of each other—existed on both sides. I just appreciate her doing that and vice-versa. There was a lot of work to do.

There was a lot of illness, but we worked together. Raising kids was not the easiest venture. We stuck together. And here we are today. I'm happy. I'm very, very happy after all these years. (Couple C)

Reciprocal influence. The knowing and the understanding of one's own individual attributes, and in turn knowing and understanding the other spouse's attributes offered a basis for reciprocal influence. Reciprocal influence was expressed by each spouse having a degree of influence over the other through the spouse's behavior, presence, or the spouse's thinking. All the OA couples shared stories that exemplified reciprocal influence. The reciprocal influence took different forms that occurred either continuously, simultaneously, or at different moments by each spouse during their life together. The influence could be in the form of being present with the spouse, which offered the security of knowing the other was there for them, and their needs would come first. The reciprocal

influence was manifested as "keeping a watchful eye" on the other to make sure health is maintained by ensuring medications are taken, appointments are made, nutrition is adequate, encouraging exercise and socialization and caring for each other when one is ill. The presence of the other was shared as companionship to experience and enjoy life together, which keeps each spouse engaged and active.

Reciprocal influence also appeared to foster personal growth and development that not only seemed to benefit the individual but of the OA couple over time. The sharing of new perspectives between the spouses helped to balance a viewpoint or response to a situation or was used to promote agreement for action and decision-making. The following excerpts exemplify this finding.

I was asking him [wife asking doctor about her husband's heart attack], so that I could tell him [her husband] afterwards, what happened. And one of the other doctors said, "Oh, you don't need to know that." And the first doctor said, "If she wants to know it, let her have the information." Because he wouldn't know, and I'd want to be able to tell him [her husband]. (Couple A)

I think just being a couple is,in itself, an incentive to stay as healthy as possible, and when things go wrong, having someone available to help out is very beneficial. I can't imagine not being a couple. I would feel very bad for anyone who's alone. I certainly wouldn't want to be alone. I think it's combination of having the other person in mind, and also oneself. I

think it's important to want good health for both, and -- I mean, obviously, it's a lot better than the opposite. (Couple N)

We know the other one is there to help and support, and to be with us as we're going through it [health issues]. Not sure either one can understand exactly how bad it is for the other person, but I think that we both are watching out for each other. (Couple A)

Well if it wasn't for me, he would have had colon cancer. There's no doubt in my mind, I get too bossy about it [follow up]. But, and I say to him, thank God that I was, because he would have had colon cancer, because how many polyps have they removed? And they're all precancerous. (Couple D)

I said, "Okay, now stop putzing and get out here and have breakfast," because actually, he's lost a lot of weight. He was too heavy. He was up to 175; now he's down to probably 140. (Couple B)

They [family members] have their own kids, and those come first. I know that if I need him[her husband] he will be there. Whereas with other people, yes, they'll be there if they can, but we adjust whatever... we'll change plans to be able to be there for each other. (Couple A)

[He is] a lot stronger than I about how things will come out. His glass is half full, and my glass is half empty. We blend very well, because I will look at things realistically, and he'll look at them, "Don't worry about it, it's going to be OK." So, I think we mesh, and it works out just right. (Couple H)

I was more conservative. She was very liberal. Then, it's interesting how that's come together. She gets more conservative as she gets older. For some things, I became more liberal. (Couple I)

I wouldn't have done it on my own [attend personal development sessions]. I really am not outgoing, go out and look for friends, make friends. I mean she pushes me in that direction, to my benefit. (Couple I)

I try to encourage her. I'm always positive about everything and tell her that she doesn't have to worry about money, not in the sense that she can't enjoy life. I would say he's always encouraged me, to be more than what I was I guess, to be more confident. In being married to him, he has pretty much changed my personality. I used to be very quiet, and I'm not so bad anymore. (Couple B)

If it weren't for my husband -- even before we married, he was the best influence in my life. He has a lot more patience. I probably was more

strict -- in my head, anyway -- than he was. But we supported each other, and bottom line, we agreed on things. But we didn't quit. He's a good balance (Couple C)

I don't think you've ever had that kind of introspection happen. I don't think you internalize. I think you always keep it at a distance from you. Husband stated, "Yes, I think you are right. I think I still tend to not look internally, what am I doing, why am I doing it, as much as I probably should. But this got me to do some, and it was difficult a few times to go through [personal development sessions. (Couple I)

Reciprocal influence also appeared to create stress, tension, and feelings of vulnerability. Two couples shared their thoughts and feelings in this regard.

Couple B, the wife 84 and the husband 85 years old, were married 60 years. Ms. B was a healthcare professional and was diagnosed recently with atrial fibrillation. Mr. B was an active man throughout his life and was struggling with maintaining his ability to do the activities he enjoyed. Mr. B's health was declining over the past 5 years and he has been using a walker for ambulation. Mr. B tended to push himself physically, which placed additional responsibility on Ms. B. This situation created frustration in the relationship, as shown in the following excerpt of Couple B's own words:

I've been a burden to her, in a way. I don't think I could live here without her. That's a blessing to have your own personal nurse and actually that's what she is. I guess I have to say I'm not taking getting old well. I always

have been an active person, and I cannot be active any more, and that's one of the reasons I stay up late, is that I think of doing this, and doing that, and doing this, and doing that, I couldn't do during the day because I'm taking care of my health, going to the doctors, doing this, and doing that. (Mr.B)

Being a health care provider is more of a hindrance, because I really feel responsible sometimes. And it's hard, because I listen for him. I listen for falls, and then when something is wrong, you think, what it is and a lot of times you're right. But I don't know. It's difficult being that type of a caregiver. If he would just [clear his mind] -- he's got his mind too occupied all the time with too many projects. I can say to him, "I've nursed you back a few times, but if you don't take care of yourself, and you don't get your sleep, you're going to get sick again, and that means more work for me." I'm not going to get my sleep when you're not, you know, don't have good habits that they're trying to get to bed. That's really the thing that gets me. (Ms. B)

Couple M, (the wife was 85 and the husband 90 years old) have been married 64 years. Couple M has always done "things his way" in life. He was a very successful businessperson and considered himself to "control" his destiny. Mr. M experienced a life-threatening illness and was treated for depression since that time. Since his recovery, Mr. M has had an "indifference" to life. His life was very different from the time before his illness. Mr. M's ambulation was

unstable and slow. He had difficulty hearing. He refused to use a walker or a cane and declined testing for the use hearing aids. He considered use of support devices as a visual reminder of his "inadequacy." Ms. M became more independent from the time of Mr. M's illness. Ms. M wanted to continue to enjoy life on the level in which she could. Mr. M found he was more dependent on her. The conflicting individual needs created tension between spouses and within the relationship over the last 11 years, as reflected in Couple M's own words:

I think there's a time to live, and I've lived. I made peace with God, when I was dying, and my whole life changed afterwards. Because I love my wife very, very much. And, my life has caused me to lose my love, to a degree. Really, that's the biggest thing. We were joined at the hip, and as a result of [the illness]— she's more independent now than she was when our children were younger. I depend on her. It's an admission of inadequacy to buy those things, to use that cane. I think we've got to get rid of this quarreling, really. It's destroying us, like it's a little bit at a time. I'm unhappy. I try to have moments of goodness, but I take a step forward, and somebody pushes me back half a step. We're both unhappy. It's contagious. (Mr. M)

When he did come back [from his illness] -- he's complaining now that he's found me a little more independent than I was before. I said, I had to be. When we first came here he was sick. Then when he went in that deep depression. He came out of it because I went in, and I just couldn't take it

any longer. Our doctor had brought hospice in, said two more weeks and he'd be gone. And I just looked at him and I said knock it off. Get up. There's life. There is life to be lived. And all of a sudden he did start taking care of himself a little better, and he did good. I think it's because of him that's making me unhappy, because I feel that he's not doing enough for himself, and that bothers me, and I keep thinking that if he just would push a little bit, that things would be better. What bothers me there is that he's lost more hearing than he realizes, and it is annoying, having to constantly repeat to him. What bothers me is that he won't do anything — he won't even go see a doctor. This is not like him. (Ms. M)

Ability to move in and out of the couple-sphere. The ability of the spouses to move in and out of the couple-sphere, appeared to impact the contextual quality of the movement, the frequency of the movement or the distance away from the couple-sphere the spouse moved. Movement by the spouse was either physical, such as travel or other activities without the spouse, or the movement was cognitive wondering to explore their individual thinking. The ability of movement appeared to give a spouse an opportunity to have experiences on their own terms before making a choice for themselves, at a time when the spouse was ready to make it, as well as choices as a couple. The following are excerpts that exemplify this point.

He never finished the Ph.D. He can't look at them [the granddaughters] without saying, "That was the best decision I ever made in my life." I said, "Jeez, I could have these wonderful, wonderful granddaughters. Or I

could have something hanging on my walls. He said, "Why am I doing this?" and I said, "I'm not telling you what to do. You do what you want to do." (Couple F)

That's the point they were ready to graduate from high school [the children]. I decided I wanted to go back into nursing. I hadn't done anything for 20, 25 years. (Couple K)

He gave up before me [deciding to let go of trying to have a relationship with their older son]. But I got to a point where I said, "It's my health," It's affecting my health," I have to say enough is enough. So I have given up. I feel terrible about that, but it's absolutely necessary. And I said to my husband, that's the best decision I ever made. It was the hardest decision I ever made, but it was the best decision. I would not be living if he was still in my life. And the girls [granddaughters] would never be as good as they are. (Couple F)

I mean, there was never a, no you can't go or spend the money. No, you can't go and be away. And he said, "Fine, go." A lot of couples, spouses wouldn't --allow. They would try to forbid. (Couple I)

I said, "You know, I like you fine, you're a very nice guy, but," I said, "I am not interested in marriage. I have things to do, and it just isn't

anything I want." So he said, "Oh, okay." So he asked me three times before finally I said, yes. Over a period of 3 years. (Couple F)

The importance of the spouses to return to the couple-sphere before action appeared to reinforce the commitment to the reciprocity of being a couple.

Moving to action before the OA couple had agreement may create discord. There were moments when one spouse moved to action before checking back with the other spouse on agreement with the action. This one-sided action may engender tension and feelings of duplicity, which then may undermine the capacity for common agreement for future action as a couple.

An example of this was shown by the experience of Couple B at a time when they were amending their will. Family dysfunction made the process more complicated. Mr. B wanted to amend the will without letting the children know; Ms. B disagreed. Before the will could be changed, Ms. B told their youngest son about the amendment. This resulted in the will not being amended and Mr. B feeling angry and not respected.

Contemplating loss of the other. Couple interconnectedness appeared to foster interdependence between the spouses. Interdependence allowed each spouse to benefit from the collective support and attributes of the other. The mutual reliance benefitted the relationship, but it could also create fear and anxiety of the perceived threat of being alone. The fear and anxiety appeared to be related to how the remaining spouse would manage living on their own, physically, emotionally, and socially. It seemed to imply the concern, "Who would care about me? And "How would I survive?" These feelings may become

stronger if an unequal balance of dependency between the spouses occurs creating increased feelings of vulnerability during the aging process.

The OA couples shared feelings of the risk of loss of the other and the unknown of life after the loss. For some of the OA couples, this known risk of loss was spoken about practically—not that the emotional intensity of the moment of loss of the other would not be present, but rather as a conviction that either one of them would manage through it. Life would be different but would go on.

Many of the OA couples expressed heartfelt concern about life after the loss of a spouse. It was a concern that was contemplated by the spouses and reinforced as they observed other spouses coping after the death of their spouse. It was a moment during the dialogues that brought such sadness when spoken, it brought tears to the spouses' eyes. The awareness was apparent, but a thought upon which the OA couples did not often dwell.

The thought of losing the spouse or the reminder of its possibility (seeing others that have lost a spouse) brought the most intense emotion from both spouses. It was a moment of sadness and a pause that was transformative in that moment. When OA couples planned for funeral and other arrangement in the event of the loss of one of the spouses, it seemed to give solace to the OA couples. The OA couples appeared to be comforted in knowing the particulars of what would occur during a time that introduced an unknown, potentially catastrophic, life transition into the surviving spouse's life. Though the OA couples stated they do not dwell on those thoughts, the certainty of the moment was present and known. The awareness of time in and of itself, was voiced and

added a meaningful dimension to their lives. The following are excerpts from the interviews that highlight this concern.

I see too many widows here [the retirement community living], and they have too much time on their hands. And that has a bearing on their mental happiness. The widows gather in a group. They eat together. They entertain together. They go out together. The couples, and the widows who are groups, and the poor lonely gentlemen, who we see several, they just eat alone. They come in, they eat, and they go back to their unit. The widowers, at dinnertime, there's one sitting here, and one sitting there, and they don't have the strength of a group. So, I'm just grateful we don't have that. But I absolutely think being alone affects your physical and mental well-being. I think some couples almost are a bit selfish, a little. They have their groups, and maybe they don't want to be reminded they might be a widow or a widower. I think it's very rare to see couples that will ask a single person to eat with them. (Couple H)

As you get older, the circle of friends gets smaller and smaller. It must be very hard when you lose your spouse, and we haven't reached that yet, but it's something to plan for and to think about, and understand—I think about it once in a while. Especially if he's walking slowly or something, or if I'm not feeling good. I think, oh, what'll happen to him? He'll survive and I'll survive, but it won't be the same. (Couple A)

Our lives get narrower and narrower. But I think this is part of the growth of elderness, being elder. You learn to do -- because there's no alternative. What's the alternative? The only alternative is the finality of life. As we get older and older and older, maybe that's what we're still holding onto, that last gasp from your past that you're holding onto for the finality of life. You're at that end. This is what's happening to our lives. It's getting smaller? Smaller and smaller. We can't do this. We can't do that -- smaller and smaller. You die. This friend dies. You get smaller and smaller. We're coping with trying to survive. (Couple M)

The idea of losing a spouse though, I don't even want to think about that. That's probably going to be the worst, I think, if you have a good marriage. I don't like to think about it. I've never woken up with an alarm clock all my life. I said, "I have to go first. He's my human alarm clock!" No, I don't even want to think about that. He wants to stay here. I don't know if I would stay here if I were alone. You know, big house all alone, but cross that when and if you come to it. So, I worry about that. (Couple C)

I don't know what I would be or do without him. I can't -- sometimes I think about it, how will I be? One of our friends here lost her husband, and she said to me, "When do you stop crying?" That was about two, three years ago. And she's -- on the surface she seems to be OK. Now she's

participating and everything. When she walks down the corridor all by herself and goes into her empty apartment, I don't know what her reactions are. But I will never forget when she said, "When do you stop crying?" So, I just, I can't make myself think about that. And then I know that I have to. (Couple H)

What am I going to be doing [after his death]? How am I going to handle all of this? I don't know if I would stay here or not. I would never, ever move in with one of our children. That's not fair to them at all. And I've often thought I'll go back to [back to their community]. But then that can be a big mistake, too. All my doctors now are here. The hospital is here. You've got to start all over again. And now I don't have a car. I'm not supposed to be driving. So, I'm opening a big kettle of worms. It's best just to stay here. We're close in age. How much longer will I be here? I'm not going to worry about it. If it happens, it happens. What can you do? You just hope for the best. You keep yourself busy. My mind is on something else. I'm doing that, whatever it is I'm doing. And so, you just hope for a better day. (Couple M)

#### **Theme Two Summary**

Couple interconnectedness may be viewed as a bonding-partnership between the spouses that allows flexibility for a personal and OA couple identity to be sustained while living meaningfully. There appeared to be three relational dynamics that influenced the OA couples' interconnectedness, knowing self and

the other, reciprocal influence, and the ability to move in and out of the couple-sphere. The couple interconnectedness may foster interdependence which was demonstrated through companionship, physical and emotional support, and the engagement in living activities, and personal growth. Though interdependence may be a support to each spouse as well as a OA couple, interdependence may also generate feelings of vulnerability, in situations when a spouse thinks of the future of being alone. Couple interconnectedness appeared to be a significant factor to the OA couples' experience of living meaningfully as the OA couple moved through life transitions.

# Theme Three: A Resonating Process within the Older Adult Couple Promotes Movement towards Expanding Consciousness

A resonating process of undulating movement by the spouses in and out of the couple-sphere was found. The resonating process appeared to occur within a cluster of action-potentiating dynamics, which manifested a life transitioning pattern for each OA couple. The resonating process seemed to facilitate the movement through life transitions and or life circumstances. The movement of the spouses exposes each spouse to new information and perspectives to share, inform, nurture, and grow, separately and then together. The movement facilitated a greater awareness for change and choice leading to expanding consciousness.

The four action-potentiating dynamics that were identified as having an impact on the OA couples' life transitioning pattern: (1) freedom of movement; (2) reflection and recognition; (3) new awareness and insights; and (4) co-creating

an "authentic unity" (Newman, 2008, p. 45). The four action potentiating dynamics appeared to be not experienced in the same sequence for each OA couple. Nor were the dynamics expressed in a linear sequence. Examples of the common events and circumstances that were shared by the OA couples revealing a resonating process included increase travel and socialization with others, neighborhood changes, their children and their families' mobility, challenges with the maintenance of homes, health issues impacting life's routine, changing of the circle of family and friends, ongoing coping of different types of loss, and new awareness of meaningfulness. The following is a discussion of the four action-potentiating dynamics.

Freedom of movement. Freedom of movement is a dynamic the OA couple have an independence of control over their time and space to enjoy life as they wanted. The dynamic is experienced as both physical and cognitive freedom. This freedom of movement was manifested as an increase in travel (abroad and local), exposure to new experiences, socializing with friends, enjoyment of family activities, and the ability without hindrance to create their own schedules. Some of the OA couples bought second homes to become "snow birds" or for vacations on the ocean, traveled to areas they always wanted to go, and enjoyed life on their terms. The data also revealed the contextual characteristics of this dynamic may change while aging in older adulthood. The scope of the movement may become limited with the OA couple experiencing a narrowing of options due to changing life circumstances and requiring

adjustments. Yet, the freedom of the movement remains. The following excerpts relate to freedom of movement, in the OA couples' words.

He retired first and I really didn't want to retire. Until one day my daughter said, 'You know mother, you never know.' I went in and gave my notice. And that's when we went to Florida. We were there for 25 years. We always kept the place here, but we went down there for 6 months of the year. (Couple H)

We took them to Europe [the grandchildren]. That was a wonderful trip.

We went to all the places we knew. I wanted to see it through their eyes.

It was probably the best trip we've ever taken. It was just wonderful.

(Couple F)

We owe ourselves a couple of outside trips. We've talked about a Scandinavian cruise. I want to go to the Panama Canal. (Couple I)

It's time to take care of yourself now. And you've done plenty for many, but now it's time to take care of yourself. (Couple E)

We have drinks on the driveway on Fridays in the spring, summer and fall [with the neighbors]. (Couple I)

I am more busy now that I am retired than I ever was with little kids.

Every day is 3 or 4 things. And it's just a matter of keeping up with it.

And he is getting into the groove. He was really worried about retiring, what he'd do, but he's in a different place now. (Couple F)

Our lives get narrower and narrower. But I think this is part of the growth of elderness, being elder. You learn to do -- because there's no alternative. What's the alternative? The only alternative is the finality of life. This is what's happening to our lives. It's getting smaller? Smaller and smaller. We can't do this. We can't do that -- smaller and smaller. You die. This friend dies. You get smaller and smaller. We're coping with trying to survive. (Couple M)

**Reflection and recognition.** Reflection and recognition is a dynamic the OA couples noticed changes occurring in their lives; being confronted with the prospect of events such as downsizing and simplifying their lives; and contemplating these matters prior to (or in conjunction with) deriving new awareness and insights from such reflection and recognition.

For many of the OA couples reflection and recognition was prompted by situations such as (a) the difficulty of managing the single-family home from a financial and workload perspective; (b) neighborhoods were changing with neighbors moving away or dying; (c) the OA couples often noticing they were the "older" people in the neighborhood; (d) the OA couples potentially needing to sell the second home to consolidate funds, as the OA couple no longer were able to

enjoy the second home as they once did; and (e) chronic health conditions triggering the need for adjustments to their daily routines and often a change in their living situation.

The following excerpts of the OA couples show, in the OA couples' own words, how circumstances such as those described above provided an opportunity for OA couples to reflect and recognize what was meaningful, as an individual and as a couple, and to gather options for their appraisal and inventory for choice.

We took a walk one night after dinner [in Florida]. She said, 'Let's go. You know, this place [Florida home] is changing.' Eight-five percent of them were snowbirds. We had a pool...in the middle of our social hour, everybody would be there. It was so popular you would have to bring a chair. But as time went on, people left. They either went back North, living with their children or they expired. At the end, there were only about 7 or 8 of the original people. The new people were mostly locals. They were younger and mostly working. There was nothing to do during the day...on the weekends the place was crowded with people and their kids. She said, 'Let's sell this place and let's sell our home and go to the retirement living community.' It was a joke, but that's what we did. (Couple H)

I have all these little knick-knacks. I just like looking at it. A lot of it is also memories from when we were kids. There's a hot chocolate set over

there. That was my grandmother's wedding present. I just love it. So that's one reason for keeping it. (Couple A)

We ended up here because every time we came back [from their summer home], we'd find another thing wrong with the house; a leaky roof or this or that. One day [the husband] said, 'I think it's time we thought about moving on'. I had no difficulty with it at all. (Couple K)

We were the only ones left [in the neighborhood]. I still miss our house and our street. I had a lot of friends and I don't make friends easily. I had a lot of possessions in that house. We were throwing things away, giving things away. That was difficult because it was things that we saved. (Couple J)

The neighborhood changed, and we were older...though our neighbors were 20, 30 years younger than us. We didn't form too many bonds there. (Couple H)

We don't demand much. It's funny, we love our home. We are lucky to have this. We enjoy being at home. We don't need much. We don't need bright lights. We don't want to go on cruises. The house is like a vacation. Maybe it'll get fatiguing after a while, but now it is a vacation. I love this house. (Couple C)

I got to be so helpless. I couldn't do work around the house anymore.

Gave away almost three-quarters of our life. That was hard, too.

(Couple B)

New awareness and insights. New awareness and insights is a dynamic involving the OA couple coming to a new understanding regarding their life circumstance and then made a choice of action. A "letting go" of meaningful material possessions occurred, that were accumulated over their life together, along with the attached memories. Within this dynamic came an acceptance for some and the loss for others that occurred during life. It is dynamic that fosters a transitioning to a new understanding, a "letting go" of the past, moving on to an acceptance of new living, and new being.

The OA couples described "substituting" past abilities and interests with new abilities and interests as they adjusted to and accommodated new routines.

Many OA couples continued to engage in activities with people either together or separately. They worked to sustain their health through exercise, eating well, and regular health care visits with providers. Alternative health activities, such as yoga, massage, and acupuncture, were incorporated to increase bodily comfort and reduce pain.

The OA couples described thinking about their present and future needs as they planned future living arrangements. Some OA couples decided to move into full-service retirement communities. Others moved to a condominium in a 55 and older community or stayed in their single-family home as long as possible.

Housing decisions varied between being closer to children and grandchildren or living independent of the children's location.

It was a process during which the OA couples had experienced losses and required new awareness for change and adjustment, such as an inability to drive, an inability to ambulate without devices, challenges due to hearing loss, and decreased independence that led to increased reliance on the spouse for daily living support. Physical determinants of independence were challenged. There was also an increased awareness of limited time for living. For some, the risk of losing the other and the fear of what life will be like after that occurred was frequently expressed. Many OA couples sought a stronger alliance on each spouse during this dynamic for emotional and physical support. The following excerpts offer descriptions of new awareness and insights leading to an action in the OA couples' words

I had looked at other places to go when he was sick, because I said I can't do it [maintain the home]. I cannot do everything, then he got better. So now we are saying as long as we can do it, the two of us, but if one of us can't, then we have to look at something else. We're not saying we are going to die in this house, it would be great if we could, but we might not be able to. It's going to depend on our health and how well we are, for how long we are. (Couple F)

I took a painting class. That's another thing I did. (Couple C)

We belong to different clubs. Right now, we're engaged in a theatrical production. We've both got roles in it. (Couple H)

We maintain our health. We'll just continue as long as our health holds out to do the same. We're very pleased with this facility. I lack really nothing. We have spiritual help and medical help if so needed. (Couple K)

The first question is, how much future is there, you know? So, we have to plan to use the time and enjoy it. (Couple L)

If they [healthcare provider] found something wrong [with the cognitive test], they would tell the State about it. And then I would not be able to drive, so we decided we wouldn't do that [the cognitive test]. (Couple A)

I'm becoming too dependent on him. That's my biggest problem. I expect him to have all the answers. But in that way you can lose your independence. That's not good either. (Couple K)

The kids decided he should not be driving a car anymore. So, the car went, and here we are. We both miss it very much. (Couple M)

Life isn't easy. And somehow we struggle together to meet whatever problem there is. The thing that is hard now, too, because we are really at the end of our life, and we know we don't have much time left. And we know it's going to be hard when one of us goes, and what is it going to be like then. You think about all those things, and you should plan for this, you should plan for that. We should plan for our funeral. It's just so much to really think about. End of life decisions. We still haven't got all of that. It seems like we're forever trying to get your life in order, in order to die. (Couple B)

I mean we are very conscious of making sure that our legal and financial stuff is in order. Because we're both very aware that the day has kind of come. -- We want to, make sure that everything is clear, and everything is cleaned out. All the health orders and all of that, and financially. So, we talk about it frequently. And the health stuff, we sort of talk about things on an ongoing basis. I mean with the various health issues that we've had, and talk about sort of a what-if scenario and all of that. So, we both were clear with each other about what we need, what we want to happen. (Couple F)

The biggest loss is driving, because I gave up my car through fear than anything else. It's a big loss for your independence. But as long as I have [my husband], we will manage. (Couple L)

I think throughout our entire marriage, we've accepted where we're at, you know? We just do. I mean, we know that where we're at now, and we discuss it openly about dying. We've taken care of the wills, the trusts, the whole thing, because I just don't want to leave a mess to the children. (Couple D)

We are very fortunate. In our lives we've gone through some really tough situations too. And everything worked out, and time eventually takes care of most things, so. So, we're ready to go for that. (Couple I)

Co-creating an "Authentic Unity." Co-creating an "authentic unity" as an OA couple (Newman, 2008, p.45) is an ongoing action-potentiating dynamic. The co-creating is the evolving process of becoming an OA couple. It is when each spouse brings the other along with them through personal growth and new thinking, resulting in a unity reflecting the true essence of themselves as an OA couple. The resonance within the OA couple fosters the ability to co-create a higher dimension of understanding of knowing and becoming known as a couple. The information generated from the spousal movement is essential to the resonating process to understand the meaning of the experience. The OA couple resonated with the information, individually and together, to move toward a new meaningful understanding of living, and experience, a new awareness of life as expanding consciousness. The spouses each share new information with the other spouse, give their thoughts on various topics to influence the other's thinking. It

is through this process that the OA couple shapes their identity as a OA couple and over time a pattern emerges.

The manifestation of this dynamic was embedded within the essence of OA couples' dialogue. It cannot be extracted, but was expressed in how each spouse can move freely as a person and return to the couple, bring new knowledge and experiences that enrich the lives of both spouses. The following are small excerpts demonstrating this movement of resonating within the whole in the OA couples' own words:

We did not grow equally. Sometimes he went ahead, sometimes I went ahead, and it wouldn't be in the same fields at all. It would be different things that we were involved in. I think we brought knowledge from that different growth to our relationship, and used it. Sometimes he will get more insistent on deciding something and sometimes I will. It's not that we're fighting; it's just that we see it a little differently. I think it comes from this uneven growth pattern. And I don't suppose we've stopped growing at this point, because we're both alive and reasonably well, mentally. We weren't exposed to exactly the same things over the years. And that made a difference. (Couple L)

In terms of making sure we got the right info and the right programs for our daughter, my wife was the leader. She was leading the charge, so to speak. And little by little, I began to see how important that was. So, for me, I kind of learned that's what we had to do, but she was the leader. I had a more passive role, but I helped out. I always helped out. (Couple N)

I said, "We're going [to personal development sessions]." He goes,
"Why?" I go, "I don't know. I am going. With or without you!" "You
want to come, fine. I don't know why, but I'm going." So we went to that
one. And then we continued going through that chain of events.

(Couple H)

I knew we should be looking [for another type of living arrangement]. We should be making plans, because we're both getting too old to take care of all the house, and it ties up all your time, too. I had been thinking for a while before. We looked at different places. And then he had the heart attack, and then he was in the nursing home, and then rehab. And then I had the appendix out. Then suddenly, he says, "I've made a decision. It's time to move. We're going to a retirement community. Well, we almost fainted off our chairs, because he had told his sister the week before on a little private phone call without my knowledge, "She [the wife] wants me to move, and I am not moving out of this house. (Couple A)

Moments of understanding if we maybe have had a misunderstanding, when it clears up and we have a moment of clarity. It's good to be

understanding of each other. When things get cleared up, it's nice; it's comfortable. (Couple N)

I think one thing that cemented our relationship is we both felt the same about [our daughter]. We wanted to keep her with us as long as possible, and we wanted to make sure she was in the best possible program. On that subject, we were always on the same page. I think that gave us a lot of strength. (Couple N)

I think we talked about any decision that we had, and if we were in agreement, it pretty much was very smooth. And I guess that comes with living together over such a long period that you know pretty much what the other person is -- how they think. (Couple K)

I feel we haven't strayed. She's never strayed too far from her life with me. I haven't strayed too far with her. I might be angry with her. But I still love her. This is the way it works. You figure there's a lot of life right there [referring to the life pattern]. But we have stayed the course. There's a lot of people who don't stay the course. You have to work at it, too. I won't do anything. I mean, anything that we've done that's real important, we've done together. (Couple M)

I remember turning 30, and he says to me, oh God, I'll never forget it, he said, "We need to save for retirement." I said, "My God, we're only 30 years old." And he said, "It's going to be right around the corner." And from then on, he insisted that we save. (Couple D)

I guess we don't do things spontaneously. It's when I -- you make a suggestion and dwell a bit to find out in your mind whether you really -- this is what you want. And, I think you just go from there. You think of the positives and the negatives, and when it looks more positive than negative. (Couple K)

Co-creating an authentic unity as a couple was an evolving process, where there were times when the creating went smoothly and others moments the OA couple need to work through perspectives to agreement. Though some OA couples shared difficulties moving through this dynamic, there was one couple that seemed challenged more and over the longest time. This OA couple shared an important unexpected, abrupt acute illness of the husband that quickly propelled the OA couple forward, forcing them into a situation that required quick decisions with the big picture in mind. This experience, as individuals and as a couple, eliminated the time for their reflection on their lives and future planning and limited exploration of options for their future living. The lack of a shared resolution regarding these decisions appeared to disrupt their ability to move forward and experience new life changes to their fullness. The words of Ms. M described this regarding events from 11 years ago:

They [their children] decided they all would look for a place to put me. We ended up in here, because they live in this town. I felt like I was just suddenly picked up and plopped here. I live in an area I've never known before. I don't have a church here. I don't know anybody, other than people here. I moved in here with a lot of resentment, and I haven't gotten over it yet, because I still go down to [the town they lived] to go to the dentist. Here I am, and he's been in and out of being ill, and having problems, which tie us to this place. And then, because of all his illnesses, and so forth, the kids decided that he should not be driving a car.

Mr. M adds. I have a resentment, a real, strong resentment, of -- from the time that we were brought up here, with the kids, her happiness was apparent, was always, you know, in the background. And, I can see her point. The quarrelling has to stop. That is the most important thing. We have high points in life and we have low points.

#### **Theme Three Summary**

The researcher's recognition of the resonating process was embedded within the OA couples' dialogues. The OA couples' interview excerpts that were highlighted demonstrate how the OA couples' resonating process promoted the movement toward expanding consciousness, created new awareness leading to choice points followed by a decision to act on the options available or agreed upon for potential transformative change. Additionally, there were exemplars not only illustrating the influence of internal relationship factors, but as well as external factors, such as family members.

#### Phase Two Summary: Data Analysis Across the Older Adult Couple

The phase two analysis addressed the second research question, "Are there common reflected themes across the OA couples living with chronic illness at home?" Three themes emerged across the older adult couples: (1) an unfolding pattern of living meaningfully as an OA couple living with chronic illness moving through life transitions; (2) couple interconnectedness strengthens the bonding within the older adult couple and promotes self-growth; and (3) a resonating process within the OA couple promotes movement toward expanding consciousness. The themes offered new insight into the meaningfulness of health and life as an OA couple, as well as a better understanding into the relational process of how transformative change may occur as a OA couple.

#### **Chapter Four Summary**

In this chapter, the sample demographics of the married OA couples were presented. Exemplars of the meaning of three couples' life pattern living with chronic illnesses at home were described. An analysis of the comparison across the couple's life patterns was conducted and revealed themes that support the following propositional statements:

- (1) As an OA couple living with chronic illness moves through life transitions, there is an unfolding pattern of living meaningfully,
- (2) Within the OA couple's dynamics, couple interconnectedness strengthens the bonding between the spouses and promotes personal growth, and

## EXPERIENCE OF OLDER ADULT COUPLES LIVING WITH CHRONIC 161 ILLNESS AT HOME

(3) A resonating process between the spouses promotes movement toward expanding consciousness that facilitates life changes.

#### **Chapter 5: Discussion**

The purpose of this research was to better understand the experience of OA couples living with chronic illness at home. In this chapter the study and its findings are reviewed in four sections. First, the research findings are evaluated through the theoretical framework of Newman's Health as Expanding Consciousness (HEC). Second, the research findings are considered in context of current literature. Third, the implications of this study for nursing theory, practice, research, education, and social-health policy, are explored. Fourth, the limitations of the study are identified followed by a discussion of the prospect for future research.

#### The Findings Evaluated through the

### Framework of Health as Expanding Consciousness (HEC)

The participants and the researcher explored how OA couples described their experiences of living with chronic illness together through dialogue with the focus on meaningfulness and relationships. The OA couples identified the meaning of their experiences, the complexity in their lives, the choice points, and the decisions they made that impacted future actions. Through the HEC process new insights were uncovered permitting a richer understanding of the experience of OA couples living with chronic illness than currently exists. Hermeneutic-dialectic phenomenology, allowed the researcher to be immersed along with the OA couple in the process of discovery facilitating an uncovering and understanding of their life pattern as it evolved over time, and facilitated the identification of common themes across the OA couples.

Since the first published study using Newman HEC theory (Moch, 1990), the theory has evolved and its method refined by the many scholars that have applied the theory in research. This has advanced applicability of the theory, the key tenets of which remain, to a diversity of phenomena and patient populations (Ananian, 2014; Endo et al., 2000; Falkenstern et al., 2009; Litchfield, 1999; MacCloud, 2008; Musker & Kagan, 2011; Neill, 2002; Pharris, 2002; Picard 2000, 2002; Rosa, 2011; Schmitt, 1991; Smith, 1995; Smith, 2011; Tommet, 2003). This study contributed to the use of the theory in two main areas. The first was the application to studying a new population, OA couples while living with chronic illnesses, as a unit of focus and analysis. The second was the decision not to include the application of Young's stages of consciousness to the interpretation of the nature of the life pattern.

The HEC's framework supported the conceptualization of movement through time, space and consciousness as an evolving process for the OA couples. The use of the dialectic process was essential for uncovering the OA couple living dynamics, as a couple, including how information was obtained, shared, and processed. The research questions were answered. The richness of the data was enhanced by having both spouses together within their environment during the dialogue—capturing non-verbal movements, tone of dialogue between spouses, and the spouses providing different perspectives throughout. Relational dynamics unfolded through the dialogue. The use of the opening question focused on meaningfulness—"Can you share with me the most meaningful events and people in your lives as a couple?" The question created an openness and full

engagement between the OA couple and the researcher. Many of the OA couples expressed surprise that anyone would be interested in knowing this information. The encouragement of using story telling as a method to capture new insights was very effective with this population. The technique allowed the participants to provide contextual character without boundaries or limitations to their experiences.

The importance of movement involving space and time became very evident as the dialogues developed. The OA couples reported many examples for the need of movement, not only physically but mentally. The need for purposeful stimulation that enriched their living, the space in which they lived and the moments of living, along with the realization of time, both expanding and limiting. These concepts were powerfully presented in all the OA couples' stories.

The decision not to apply Young's (1976) staging to the analysis process was determined after the first three OA couple interviews. Since Smith's (2011) integrative review and personal conversations held with Dr. Newman (M.A. Newman & D.A. Jones, personal conversation, Sept. 5, 2016), the application of Young's stages to the life pattern evolved to be less prescriptive, and has even been challenged as potentially incongruent with the theory because it sets the participants within boundaries (Smith, 2011). Consciousness is an evolving process and suggests that information gained from earlier experiences shape and influence new experiences. To bind the participant/s within a specific stage seems to be misaligned with Newman's theoretical underpinnings.

The researcher attempted an application of Young's staging to the first few OA couples' life pattern analysis. This was unsuccessful for the following reasons. First, placing the OA couples in one of Young's stages seemed to conflict with Rogers' unitary-transformative paradigm from which HEC emerged. In this paradigm people develop in a free-flowing, dynamic, participatory manner. Even though movement occurs among the stages, when trying to apply the staging, it did not seem to align from a theoretical standpoint of HEC which emerged from Rogers' paradigm.

Second, there was difficulty in determining one stage for an OA couple (two individuals). Since two individuals may be at different stages, it was unknown how to collectively determine a correct couple stage. The concern raised from the researcher's perspective was that by placing the OA couples or individuals in a category may compromise the credibility of the findings.

Third, the findings were not limited by the determination not to apply Young's stages. Neither were potential applications of the findings for further inquiry limited by this omission. This procedural change offers an opportunity for new procedural questions to be discussed for future applications of HEC in research. Continued study and discussion is required to address concerns of using Young's staging in future study designs. Nevertheless, Newman's use of Young's stages did aid this researcher's understanding of the method and how it might be useful in facilitating clinical interventions. Figure 1, Interrelationship Newman's basic and Young's stages of evolution, may need to be re-conceptualized requiring further discussion and research.

#### **Individual Older Adult Couple's Life Pattern Recognition**

The reflective mutual process described by Newman (2008) was integral to the proposed research method of hermeneutic-dialectic phenomenology. The process created an opportunity for the OA couple to openly share their life stories with the researcher in dialogue. It also allowed for an examination of the significant relationships and events the OA couples experienced in their lives as a couple, with a shared reflection on the meaning of the experience as a couple and as an individual. The reflective experience of the OA couples were enhanced by two factors: (a) the OA couple's life pattern was reviewed with the researcher's interpretation; and (b) time was provided for reflection on situations that may have influenced their life together as well as individually. This reflective process facilitated new understanding and recognition of the influences of the meaningful people and events in their lives at that moment in time. The new awareness gained by the OA couples provided an opportunity to reflect on life choices and the journey, as a whole. It gave voice to personal concerns that were not previously discussed between the spouses and reinforced feelings of love and caring.

#### **Research as Praxis**

Research as praxis, mutual process of inquiry between the researcher and the participants, was used with the individual OA couples. The mutual process uncovered experiences, reflected on choices, decisions, and identified meaningful people and events that impacted life, resulting in a mutual new understanding of events for opportunities for change, action, growth and transition. Each OA

couple's life pattern was unique and offered new insights into how the OA couples lived with chronic illness at home. Each OA couple, and each spouse, experienced varying degrees of life pattern recognition, and sometimes with new or different understandings of the life pattern. For some of the OA couples, the experience reflected positive experiences. For other OA couples, there was recognition of how they were impacted by choices and moved forward based upon those choices. Many of the OA couples agreed on their life pattern, both spouses remarking on how events and relationships influenced a change in their lives and or their thinking about life. Many noticed new connection of the past life events leading to a new understanding of their spouse and the context of the past event. These OA couples appeared to share a consensus of the meaning of their life pattern.

#### **Life Pattern Recognition and Response**

Some spouses within an OA couple had different responses to the life pattern construal. The depth of the recognition varied within each OA couples and between each spouse. Newman (2008) stated some responses are immediate by people, while other responses require the person to think about the information. One spouse would explain the life pattern construal in concrete terms, where the other spouse would recognize the life pattern construal in a more aesthetic understanding of the pattern. The dialogue would then transition to the spouses expressing their interpretation to the other as they negotiated a common understanding of the pattern. This occurred when one of spouses would have insight about a specific event or how the pattern was evolving. The spouse would

refer to the life pattern construal and express their perspective. In response to this, dialogue would occur with the other spouse agreeing with the point; being enlightened and adding to the point; or not understanding the point fully after a short discussion, then agreeing to continue to move on to another topic.

The dialogue in and of itself was transformative, each spouse sharing their "way of seeing" (Newman, 2008, p.45) to come to a new depth of understanding or awareness, an expanding of consciousness. The new awareness and meaning can strengthen the bond between the spouses and as a couple. Some couples could reach a common understanding at the moment. Some couples needed more time to process the perspectives or did not agree.

The recognition of the life pattern by the OA couples manifested choices for potential to take action that may lead to a transformative change. The OA couples described a change in their awareness about knowing self and each other, their lives and their relationship, which is a potential for transformative change. This was expressed as follows: "you have done us a great service"; "it's the first time we thought about [life] as our little family and how it impacted us"; "it brought out how blessed we are, even through all the trauma"; and "I almost consider it an extension of personal development. It forced me to sit down and think about what is my story, what influenced it, and where does it go from here?" For at least two OA couples, spouses stated they would change their behavior in response to the dialogue; a husband would give his wife a hug every day and another husband stated he would tell his wife what he was thinking more often.

The life pattern recognition revealed an evolving process, which often depends on the "readiness" of the individual or couple to respond to the experience. Litchfield (1999) found life pattern recognition to be an evolving process while studying families of children with repeated hospitalization. She stated the life pattern recognition "occurred as incidental revelations in the conversation leading to a more comprehensive insight as the potential for action" (p.65). The new awareness created new connectedness within the family that became transformative for the family. This suggests a nurse must process the information through a different approach to derive new insights in the care of the older adult. For example, longer sessions over time with the OA couple may be required to understand what is the situation, what is needed to facilitate change.

#### **Couple Resonance**

The dialogue between the spouses reflected a couple resonance, a flowing, fluctuating exchange of influence and movement of the individual spouse and its impact on the OA couple. The resonance revealed the importance of each spouse knowing themselves, which allowed for an expression of their perspective and thinking, and the importance of the spouse knowing the other to incorporate its understanding by the other spouse to make meaningful decisions. The resonance could be considered as a reverberation of understanding between the spouses that manifested their "authentic unity" as a couple.

The couple resonance is conceptually aligned with Newman's (2008) presence of resonance between the nurse-client or nurse-participant relationships where the nurse researcher is fully present with the OA couple and mutually

engages in the dialogue, in discussion of insights, recognition and new awareness (transformation). The nurse researcher journeys with the OA couple, to see events and relationships through the OA couple's perspective. The exchange of information and perspective guides examination of events that can enhance awareness and meaningful insights for all.

It is within hermeneutic-dialectic phenomenological process that the nurse researcher is the catalyst precisely by mutual engagement in the process. The dialogue creates opportunities for exploration and fosters new understanding to emerge. The discovery of new understanding is guided through exploration of meaningful research and knowledge that fosters development about the phenomenon of interest to the discipline.

#### Impact on the Researcher

The nurse researcher is not only a participating member in a mutual, dynamic, unfolding process with the OA couple, but can also be transformed by the process. From the beginning of the data collection until the end, the nurse researcher became aware of the influence of her presence within the dialogue, as well as the ability to help clarify key moments, prompt added comment, and provide silence to allow for deeper reflection and disclosure. The nurse researcher left the experience with a new awareness of the importance of nurses' engagement with people from within their context, as a whole, instead of seeing relationship as a part of the experience. In doing so, the nurse researcher gained new appreciation for the meaning behind the nurse-patient relationship. The process changed this nurse researcher's "way of seeing" by looking

"comprehensively rather than selectively" (Newman, 2008, p.46) at the meaning of the experience of OA couples living with chronic illness at home.

The narrative summary for each individual OA couple reflected Newman's concepts of resonance, movement, time, choice, knowing self and other, and meaningfulness. These concepts are needed for the achievement of pattern recognition, and transformation, with a deeper meaning toward expanding consciousness (Newman, 2008).

#### **Themes Across the Older Adult Couples**

The three overarching themes provide new insight regarding the OA couple's experience while aging. A new understanding emerged stimulating innovative thinking, knowledge, and perspectives regarding the experiences of OA couples, where living meaningfully for the OA couple was a manifestation of health as expanding consciousness.

An Unfolding Pattern of Living Meaningfully as Older Adult Couples Living with Chronic Illness Moving through Life Transitions

Health and well-being was manifested by the OA couple's living meaningfully through choices that lead to action-enhanced freedom and promoted transformative change. Life's meaningfulness was enriched through the OA couples' relationships and engagement with their children, grandchildren, families, and friends. Meaningfulness was also experienced through engaging in activities together, as well as apart. The OA couples voiced the desire to be independent, and to have choice, both personally and as a couple. They worked to maintain control over the decision-making for outcomes that were meaningful,

including engagement, purposefulness, and dignity. The awareness of the meaningfulness is critical for the OA couple to understand their experience as they move through life transitions (Meleis, 2010).

Chronic illnesses did not seem to directly limit the OA couples' ability to live meaningfully and was not discussed as a major focus. There was an awareness expressed that chronic illness was an "inconvenience" requiring attention from time to time. This finding may not be surprising since OAs are healthier than 20 years ago (AARP, 2009), and the view of older adulthood in the United States continues to change. In the past, older adulthood was a time where OAs were viewed as reacting to events happening to them, a time only filled with loss, and less focused on meaning in their lives (Marguis-Bishop & Bishop-Shoemaker, 1987). The OA couples viewed the management of their illnesses as more of a means to an end, as an inconvenience that was tolerated so they could continue to live their lives with meaning. The chronic illness may be considered an interruption in their lives that needed attention. Most of the OA couples considered their health to be good, despite poly-pharmaceutical management, arthritic pain and discomfort, the use of assistive devices, frequent medical appointments, and required adjustments in daily routines.

Corburn (2003) postulated the body is the sensory modality, but it is the mind and awareness of self that determines how the person identifies as being healthy or not. It is this search for meaning and understanding of life for which the OA couple continue to strive as they live as OA couples as continually revealed in the data. Thorne and Paterson (1998) reported people are shifting to a

new conceptualization of "health within illness, transformation, and normality" (p.174). This shifting perspective of health creates a change in the relationship with the healthcare provider (HCP) from the individual as a patient to the individual as a partner. A shift toward a partnership with the HCP may create differences in expectations between the patient or partner and the health care provider. This change in health care expectation was shared by the OA couples. Although the OA couples overall expressed the quality of their health care was adequate, they also voiced an increased frustration with their options for treatment, lack of sufficient communication by providers, not being known as "more than" an individual with health condition, or feeling not understood or viewed in their capacity as a couple.

Recent efforts toward patient or person-centered care (PCC) or relationship-based care delivery models may address the changing expectations by patients who are seeking to be an active participant in their care, and to reject being labeled as the "patient." These efforts may be falling short of the goal. In their review of the literature, Kogan et al. (2015) found a continued necessity to focus on PCC in the outpatient care setting. Though efforts to provide PCC were made, there was a gap in placing patients' preferences and values at the center of the care. Additionally, the study's participants shared that their communications with physicians was, generally, not personalized, failed to account for their wishes, and did not prepare them to make the decisions that were necessary for their care. This study's findings support these perspectives with the OA couples voicing similar concerns and frustrations.

There also may be a tipping point that is experienced in OA health. The concept of a tipping point was identified as an imbalance where the benefits of living are outweighed by the burdens. Circumstances that contribute to the perceived oppressive weight of such burden are—the effort and energy for daily living, exhaustion, impediments to enjoying interests, loss of independence and control of living, and an increased dependence by an individual on their spouse or others. During these times, contemplation of whether life was worth the effort was entertained; and this triggered a need for deeper reflection, and a different support, e.g., nurse engagement, that may lead to new insights for future consideration. Research demonstrated as chronic conditions become acute, there is increased strain and complexity for the patients and providers to manage health for the both spouses. As a result, the joy of living becomes more challenging (Boltz, 2012; CDC, 2015; Ward & Schiller, 2010).

General health decline or specific episodic exacerbation of chronic illnesses can be a stressor on the marital relationship (Kiecolt-Glaser & Newton, 2001). The OA couple's response to the stressor determines the influence of the stressor on their relationship. Yorgason & Choi (2016) presented an integrated model of illness and marriage demonstrating the complexities of internal and external factors to which the OA couple is exposed when health concerns are encountered. The findings from this investigation suggest a need to shift health care to a broader conceptualization of health that focuses on maintaining well-being in this population within a social network that considers all complexities beyond the disease.

# Resonating Process within the Older Adult Couples Promotes Movement Toward Expanding Consciousness

The OA couples' ability to live meaningfully appeared to be informed by a rhythmic resonating flow within the relationship; each of the spouses freely moved away from the couple-sphere to experience an individual response to an experience and then bringing the information back to the couple-sphere. The movement reflects a resonance within the couple as a whole, while engaging in a dynamic way within their environment.

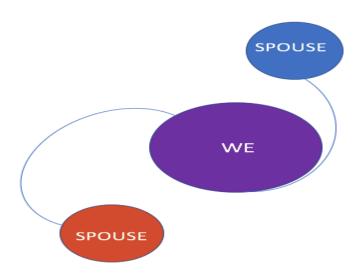
Figure 5, Resonating Process of Older Adult Couples Living with Chronic Illness, presents a model that conceptualizes this process. Within the model, the "We" is seen at the center representing the unity of the couple. Couple interconnectedness is the foundation of the "We." Couple interconnectedness was defined in this study as a bond of partnership between the spouses resulting from a reciprocal dynamic exchange that may foster interdependence, and manifests itself as a united entity of the couple. The filaments that connect the "We" to the spouse may be conceptualized as the partnership-bond that brings the OA couple together again during the resonating process.

The model also depicts the movement of a spouse outside of the "We."

The movement may be physical or cognitive in nature by the spouse. This movement outside of the "We" is to account for personal internal and external influences that shape the experiences from an individual perspective, and allows for the individual to gain new information and insights. When the spouse reenters the "We" sphere, the spouse shares the experiences, creating a potential for new

awareness for choice and growth as a OA couple. It is within the "We" that new information and thoughts are resonated with as a couple to form a "couple" perspective leading to potential transformative change as a couple. The transformative change is a manifestation of expanding consciousness within the couple.

Figure 5
Resonating Process of Older Adult Couples Living with Chronic Illness



The characteristics of a spouse's movement may be shaped by the freedom from controlling influences and the ability to move in and out of the "We" sphere. This resonating within the "We" allows for fluctuation and change in flow to create new opportunities, e.g., engaging in different activities and interests, having different friends, respecting the other's space (Malouff, Mundy, Galea & Bothma, 2015). The movement is dynamic, reoccurring in different forms, and unique for each OA couple and spouse. The distance from the couple-sphere the spouse moves may fluctuate at different points in time during the life span and may vary depending on the circumstances experienced.

Kayser et al. (2007) found an iterative cycle when studying caregiving and responses to illness by couples that took on a persona of a "we disease" (p.1). The "we-disease" persona provided an approach to the illness, together as a couple, using coping strategies to adjust to the care demands and life changes. Lyons and Lee (2017) proposed a Theory of Dyadic Illness Management with illness viewed as a dyadic phenomenon. The theory focused on the dyad as an interdependent team who appraised the illness together, which may influence the dyad's degree of collaboration toward managing the illness together to improve health. The dyad is conceptualized as a "patient-care partner dyad" and should be viewed as the "unit of care" (p.14).

Though the couples were viewed as a team in the previous studies, the OA couple's management of health was embedded within the disease. The findings from this study suggests the "We" persona of the OA couple is to be conceptualized much more broadly than it is proposed, to include all aspects of health from the "We" persona that goes beyond the disease state, supporting HEC theory assumption. Health is conceptualized as being beyond the disease, and encompassing all aspects of life and well-being over the OA couple's life span. This perspective may change as the chronicity of the illness becomes more acute and debilitating. Even then, the broader view of health and its meaning is supported by these current findings, with the illness relegated to being only an aspect of the whole (Newman, 2008).

Walker et al. (2004) provided insight about what may be required for couples to move through events when faced with a challenge or a need for a life

change. The couple's dynamics are pivotal in these experiences since resilience and adaptability are required for them to transform to different state of being. In this situation, resilience is the capability to manage and reorganize; adaptability is the ability of the couple to avoid an undesirable state and progress to a desirable state. Understanding the capability for transformation becomes a key factor when studying and caring for OA couples with chronic or acute conditions. The resonating process model may provide an innovative method for exploration of the OA couple's dynamics to further identify the intricacies of the process involved in health and well-being as an OA couple, where disease management is only one factor among many.

#### **Couple Interconnectedness and Related Influencing Concepts**

Couple interconnectedness is manifested by the OA couple's resonating process, a rhythmic movement in synchrony that reinforces closeness and unity as a OA couple through dialogue and actions. It expressed the meaning of their relationship and may act as a bond between the spouses within the "We." The findings suggested there were additional influencing dynamics occurring that may impact the couple's interconnectedness.

The intricacies of the couple's interconnectedness appeared to be influenced by internal relational dynamics. The relational dynamics, "as knowing self and other" and "reciprocal influence", seemed to occur continuously and simultaneously, creating a dynamic of changing thoughts and persuasion of thinking throughout the process.

The relational dynamics of—knowing self and other as a continuous influence—appeared to present throughout and was integral to an OA couple's search for new understanding and to adjust to life circumstances. Examples of events of how this dynamic was revealed included where and when to change living arrangements, decisions with the children, future planning, or when to have health procedures. The concept of knowing self and other may be considered a distinct self-reflexive consciousness or awareness along with having a reflexive awareness of the other. The common values shared between the spouses provided further cohesion appearing to be an anchor when addressing the differences within the relationship. The knowing self and the other offered strength in the partnership and a commitment to each other and their environment.

Reciprocal influence may be a passive or active influence that was expressed by each spouse having a degree of influence over the other through their behavior, presence, or thinking. It may be an intended opportunity for each spouse to share their perspective, information, and experience to move the OA couple to a common understanding of life events. It also may be present in a passive way—where influence occurs simply by the behavior of presence of the other without intent to influence. Reciprocal influence was demonstrated overtly or covertly by the OA couples, depending on the topic and the dynamics of the relationship. The depth of knowing self and other may shape the ability of reciprocal influence within the OA couple. Those OA couples with an open and diverse ability to influence each other gave the OA couple a synergistic quality when moving toward choices for change.

The reciprocal influence within the OA couple was expressed in various ways. For example, the OA couples shared how being a couple made each healthier and sometimes was viewed as lifesaving. Most of the examples given were related to choices regarding nutritional options, encouragement for exercise and weight reduction, medication management, engagement with others, remembering health and screening appointments, establishing friendships outside of the relationship, emotional support, and personal and couple development.

Another reciprocal influence that was manifested was how decisionmaking over the life span occurred, including timing to sell property, when to
look for other living arrangements, how to manage family relationship dynamics,
and when to change health care providers. Each of the examples facilitated the
movement of the OA couple to the contemplation of options for choice.

Reciprocal influence may provide a better decision for both as a couple than if
either spouse decided alone. Mutual influence offers more options to be explored
when both spouses share their perspectives which may reduce the risk of
vulnerabilities during the life span.

Reciprocal influence can also engender stress and tension that can negatively influence a couple's health when behaviors of one partner has a deleterious affects the other (Kiecolt-Glaser & Newton, 2001). Examples of this were present in a few of the data. When outlooks on life were not aligned and depressive symptoms were present, tension and quarreling were found between the spouses. Those OA couples stated frustration and stress in their relationship and life.

Research also reported both positive and negative health factors related to reciprocal influence. Investigations have shown reciprocity and mutuality in a couple's relationship can be a protective mechanism influencing their physiological and psychological well-being (Archbold et al., 1990; Dalteg et al., 2014; Goodwin et al., 2013; Kayser et al., 2007; Lyons et al., 2007; McPherson et al., 2011; Park & Schumacher, 2013). These interactions can influence morbidity and mortality, specifically related to chronic condition management (Kiecolt-Glaser & Newton, 2001).

Research supported negative effects can be experienced through reciprocal influences depending on the response of the couple to the influence (Johnson et al., 2013; Kim & Waite, 2014; Lyons et al., 2002; McPherson et al., 2011; Park et al., 2013;). As health status fluctuates during aging, it may create a cycle of stress that can influence the OA couple's dynamics; in turn the OA couple's dynamics will influence the response to the event in a constructive or adverse manner.

### Movement through Life Transitions while Living Meaningfully as Older Adult Couples

Retirement is the most common known life transition of older adulthood, and the implications of the retirement-transition issue for the individual and family has been well studied (Van Solinge, 2012). Research and literature has found many life transitions are experienced in older adulthood (Berg, Sewell, Hughes-Lansing, Wilson, & Brewer, 2016; Choi et al., 2015; Schumacher, Jones, & Meleis, 2010; Sugar et al., 2014). Schumacher et al. (2010) proposed a life transition and health framework for gerontological nursing for older adults. In

their research, life transitions are described as processes that occur over time with s flow and movement to them. The life transitions are usually triggered by a various life events and in various patterns. In the presentation of the movement through the transition, following the event, the OA is prompted to recognize a need for a change followed by time for need for strategies or responses, and then coming to a new stage of stability. They propose the use of process indicators can provide a snapshot assessment of the progress through the life transition over time.

This study supports their findings and advances the conceptualization to include insights into the processes that are occurring during the process of life transitioning. This study suggests there are common processes involving action potentiating dynamics that are repetitive as the OA couple manages life circumstances. The resonating process facilitated how the movement occurred while the transitioning unfolds, which manifested the OA couple's life transitioning pattern.

In Figure 6, Life Transitioning of Older Adult Couples Living with Chronic Illness, conceptualizes the OA couple's resonating process within the context of the action-potentiating dynamics as the mechanism by which the movement through the life transitions occurs. The resonating process facilitates the filtration, examination, and understanding of the new information from the spouses as a couple, then allowing action to be taken. This resonating process occurs through the movement among four action-potentiating dynamics — freedom of movement, reflecting and recognition, growth and awareness, and co-

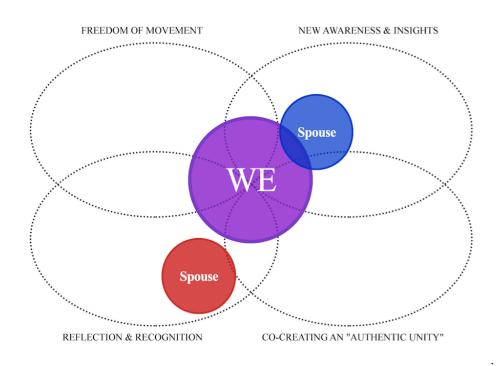
creating an "authentic unity" (Newman, 2008, p. 45), which manifests as a life transitioning pattern (Figure 6).

The freedom of movement offers opportunities for broader exploration and increased frequency of new encounters together or individually, along with socializing with family and engagement in diverse activities. The recognition and reflection of the changing life events supports an evolving understanding toward growth and new awareness and insights with an acceptance or "letting go" of past life norms. co-creating an "authentic unity" is the evolving essence of the OA couple of knowing their persona as a couple and as individuals. The OA couples' resonance with each other and their environment allows for the new and different awareness. This newly shared awareness is then transformed as a perception of the OA couple, where each spouse is reflected within the couple, and the couple becomes a reflection of each spouse (Newman, 2008). The differences of both are understood as unity of the couple.

The life transitioning pattern is intricately folded, dynamic, and twisted creating a heterogeneity of patterns across the OA couples. Some OA couples in the study moved more quickly through their life transitions, and while others seemed to be toggling between the action-potentiating dynamics, as the OA couple works to a new understanding. The experience of the process depends on the health of the OA couple and the characteristics of their relationship. The OA couples' awareness and understanding of the movement between the action-potentiating dynamics in relation to the OA couples is significant, since it offers insight into their living, environment, and challenges as they age together over

time. It is from this standpoint the OA couple and the individuals within the OA couple are considered unique and their health care can be understood and individualized.

Figure 6 Life Transitioning of Older Adult Couple Living with Chronic Illness



Understanding the life transitioning pattern among the action-potentiating dynamics within the context of an extended living experience is significant for nursing. This is so because the living experience becomes more complex for the OA couple as their health declines, and social network and environment become narrow. Multiple changes are occurring simultaneously, physically, mentally, and socially. The ability to move through the life transitions may be interrupted or disrupted. Moving through the action-potentiating dynamics may have an impact on each spouse and on the OA couple's identity, their roles within and outside the

relationship, which all may stimulate emotional responses to the changes (Robertson, 2014).

Life circumstances that impact the OA couple disproportionately are fluctuations in their family and friend relationships related to relocation or death, caring for their OA parents, inability to maintain their home creating a need for relocation, increased dependence on others, loss of independence, and health changes that may lead to mobility issues or disabilities. It is the process of how the movement occurs, the form of the movement and the characteristics of the movement that may add to the contextual difference between younger and the older adult couples. The processes are occurring while both spouses are aging during older adulthood, each managing their personal and the other's health. Importance of Social Engagement to Living Meaningfully as Older Adult

# **Couples Living with Chronic Illness**

This study also supports the significance of socialization within the OA couple's network. Marsh-Ryerson (2018) reported social networks and social supports deepened the meaningfulness of living for the OA couples and were determined to be central to maintenance of physical and mental health. The OA couples revealed the importance of relationships beyond that of just the spouses; including relationships with the couple's children, grandchildren, extended families and friends. These further relationships provided purpose, love, and feelings of belonging for the couples interviewed. Social networks and support tend to be disrupted as people age (Dupuis-Blanchard, Neufeld, & Strang, 2009). Social networks became smaller either from deaths of family and friends, frailty,

inability to drive, change in living arrangements, and their families' active life style that limits their availability. Re-establishing social connections is important and social engagement is necessary for maintaining and making new connections to others, especially when in a new community (Dupuis-Blanchard et al., 2009). Continued social engagement is helpful for establishing new friendships, encouraging casual interactions with others, and supporting feelings of belonging.

The loss of spouse of the OA couple was described as a vulnerable time requiring the forging of a new self-identity, adaptation to a different life, and trying to find meaning at a time when options are narrowing. Many of the OA couples shared their concern and fear of what life will be like once a spouse dies. Those moments of dialogue were the most emotional and profound. The loss of a spouse creates an increased probability the surviving spouse will experience anxiety and depression (Carr, 2004). The anxiety and depression can be enhanced by social isolation from living alone, a decrease in activities of engagement, and having a smaller social network than when they were younger (Cornwell & Waite, 2009; De Jong Gierveld & Broese van Groenou, 2016). The many nuances to the responses to this event requires further research to better understand the context of the dynamics involved; it should also be a topic of discussion that nurses are prepared to have with OA couples.

#### **Implications**

#### **Nursing Theory**

This study augments nursing science by leveraging new insights and understanding of the OA couples' experiences related to health and well-being to enhance the knowledge of care delivery for OA couples and to the OA population in general. The two proposed models, Resonating Process of Older Adult Couples Living with Chronic Illness and Life Transitioning of Older Adult Couple Living with Chronic Illness, provide an innovative theoretical conceptualization of the experiences of OA couples that may generate new ideas and questions for care programing and delivery to be explored by research and clinical inquiry. Nurses may use the conceptual underpinnings presented to understand how OA couples may process information, how life transitions may be experienced, and how the meaning of the living can influence care planning and interventions. There is also insight into the understanding of nursing practice with a focused approach on meaning in OA couples' lives through relationship-based care.

At a time when the value and recognition of nursing theory is being questioned (Barrett, 2017; Grace, Willis, Roy, & Jones, 2016), this study reaffirms the critical importance of embedding nursing research endeavors within a nursing theoretical framework to guide the inquiry to support nursing's metaparadigm of nursing, health, environment and the well-being of the people. Through the understanding and knowing the OA couple's experience and its meaning, within the context of their unique experience, further defines the

discipline to better prepare future nurses from a contemporary state of nursing science to care for the older adult population. Newman's HEC theory provides such an opportunity for nurses to explore the person within a relationship and their environment from a different perspective that adds rich and dynamic discovery of a phenomenon, as well as a different and profound domain of understanding and meaning.

An additional implication of this study is the advancement of a nursing method that embraces nursing's discipline-specific underpinnings. Since the inception of Newman's HEC with its roots in the unitary-transformative paradigm, nursing researchers who have used the theory advanced its application, as well as reinforced the critical evaluation of the alignment of theory with the theoretical base (Neill, 2002; Picard, 2000; Smith, 2011). It allows for nursing knowledge and theory development to evolve ontologically within a framework of relationship. This study provides a tested change to HEC's protocol, which is an exemplar for further discussion and testing.

#### **Nursing Research**

This study provides an opportunity to generate further research in multiple areas to explore effective, innovative interventions for clinical inquiry to improve the health and well-being of OAs and OA couples. The study's findings and proposed models spawn new questions and areas for research, such as how to best support OA couples as they age in place, rethinking care delivery designs to better address what is meaningful to the OA couples, testing the underpinnings of the proposed models with diverse OA populations, and re-evaluating current

assessment routines that are OA couple and individually focused—addressing all aspects of health, living, social network, and the impact of interdependence and aging. The generation of new research to address these questions acts as the vehicle that transforms the new knowledge into actionable practice through the testing and application of the nursing phenomenon of concern advancing the science.

This research augments the use of Newman's HEC theory to a new population, the OA with a focus of the OA couple as a unit of analysis. It also adds supporting evidence as an effective qualitative method design for research. The application of the HEC to the OA couple provided an opportunity to capture intricate, rich data for analysis using research as praxis that created opportunities for unique disclosures. The application uncovered new challenges related to the protocol—e.g., how to diagram and interpret a life pattern of a OA couple, is Young's application required for nursing research application, and can HEC be used as an intervention, and if so in what form. The new challenges provide new areas for testing and discussions to ensure method modifications are aligned with the theory.

#### **Nursing Practice**

This research has major implications for nursing practice when caring for the OA couple and the OA population. The findings support the OA couples want to be viewed more than their medical conditions. The OA couples are asking for care beyond the disease, with a focus of well-being that places them in the center of care. For the OA couple to be known, a shift from a disease-focus to a healthfocus is required; this includes the OA couple's broader context of health and living. This shift to a health focus model creates the opportunity for the OA individual to be cared for within the context of the OA couple and their broader social network. This approach also reinforces the continuity of care through all life events, whether as an OA couple or as an OA individual. By socially embedding the OA individual and as an OA couple, the limitations of aging may be minimized and the negative responses to the health changes abated (Marsh-Ryerson, 2018).

Nursing is essential to the care delivery environment where such a healthfocus approach can be provided. Nurses are required to be free to fully develop a
partner-relationship with the OA couple to sustain health and well-being across
the life transitions as the OA couple ages. For this approach to be effective,
nurses need to be consistently available to this population and to have the time
within the practice model to develop partner-relationship based care.

Accessibility of nursing and nurses to provide care and support requires an
extension to the community where the OA populations are living and socialize.

This may require nurses to partner with private businesses, public agencies, and
health facilities to create innovative access points for nursing practice and
services to support the OA population.

Another implication for nursing practice is the need to discuss and assess the vulnerability of risks that may be associated with the loss of a spouse, knowing this event is filled with emotion and uncertainty. The incorporation of regular discussion points in nursing practice with the spouse and the OA couple

related to the potential loss is required. Discussion and preparation for such an event may reduce the shock and uncertainty. When the loss occurs, the surviving spouse needs to be embraced to ensure the person is seen within an appropriate time to support the healing and transition to a new self-identity.

This study, as well as others, demonstrates the effectiveness of Newman's HEC as a potential intervention that should be considered. By using Newman's HEC in practice, along with the understanding of the proposed resonating process model, the nurse can facilitate recognition of life patterns, options for choice, and strategies for action—all of which leverage the dynamics of the OA couple to support change to what is meaningful to the OA couple. Understanding the capability and process for transformative change may be a key factor for nurses in care planning to improve health and well-being.

There are also ethical implications that arise from this study for nursing practice and organizational policy. The autonomy of choice-making as an OA individual, as an OA couple, and as a family becomes complicated due to complex social influences involved during life-changing events that may create uncertainty and emotional instability. Nurses need to be aware of and assess for specific cultural, ethnic, religious, and relationship circumstances to ensure the OA spouse and OA couples rights are protected and appropriate resources are made available when life-changing events occurs, or as needed.

#### **Nursing Education**

The study reinforces the unique nature of the OA couple's experience and informs the significance for nursing curricula to incorporate course work specific

to gerontology. Understanding of the health for this population becomes critical as the United States shifts to an older population along with their changing health needs. Future nurses will require specific knowledge to best support and care for this special population.

This study also exemplifies the value of the unitary-transformative (UT) paradigm, along with the nursing theories branching from it; by its preservation of nursing's unique approach to health and well-being. A nursing curriculum that is focused on the engagement in a mutual process with the individual or others, within the context of the environment, family, community and society, aligns the purpose of nursing with its education. The nurse-individual relationship allows for the opportunity for reflection, and the understanding of the significance of what is meaningful. From this understanding the nurse can then better facilitate the promotion of health and well-being in nursing practice. Ignoring the contribution of the UT paradigm in nursing curricula imposes limitations on the ability of nursing to fulfill its ethical mandate to society. A successful integration of this approach requires curricula at all the educational levels of nursing, baccalaureate through Ph.D., to add continuity and reinforcement to the foundation of the discipline's principles.

Newman (2008) expressed the responsibility of nursing educators is to "ground the nursing education in the discipline while at the same time offering relevant knowledge from other disciplines" (p. 73). The philosophical crossroads does not need to be a choice of one path or another, but rather understanding both paths and the difference between them. This approach in turn fosters an approach

where knowledge is complementary, non-competitive, with an understanding of the differences, yet distinct as a discipline (Newman, 2008). Nursing education becomes "transformative learning" by moving "personal transformation in to nursing curriculum" (Newman, 2008, p.74), through the mutual process of the expanding consciousness of the faculty and the student (Bova, Perry, Kane, Morris, & Fain, 2018). If nursing education is predicated on the UT perspective, it allows the student to become where they need to be to contribute to the discipline, to research, and to practice innovatively from any education level (Newman, 2008).

#### **Social and Health Policy**

This study demonstrates that to sustain health and well-being of the OA population requires both social and health policy initiatives. When comparing as an aggregate the well-being of past generations of OAs, to the current status of the OA population, the improvement of quality of life and health coincides with the enactment of key legislation, such as social security, Medicare and Medicaid, technological developments, and long term care services (Chernof, 2015; Hudson, 2014). This success supports the continued need for social and health policies that leverage the gains of the new generation of OAs, who are more educated, more financially secure, healthier with access to health care, and more active, to create innovative policies for future generations (Hudson, 2014).

This study also suggests that nursing and nurses are essential for the reforming of health policy related to care delivery models, practice environment, and reimbursement. Such involvement may ensure health care being provided

within a health-focused paradigm, which allots more time for the nurse to encounter the OA and OA couple, fostering relationships and knowing the people. For nursing to impact health reform, awareness and engagement in both health and social issues is needed to continue and spread the gains across the OA population to address the inequities for those who have not benefitted from the gains.

#### Limitations

The major limitation of this study relates to the homogeneity of the sample. The homogeneity was significant in three areas, race/ethnicity, income, education, and health care insurance coverage. Ninety-three percent of the sample were Caucasian, which is not representative of the County or State percentages for which the OAs lived, 77% and 72% respectively (CMS, 2017). The entire sample's average income was higher than the County average, \$21,000, as compared to most of the sample earning more than the State's median income of \$42,000 for older adult households (CMS, 2017). The sample was also highly educated. Of the sample, 73% had college level education, which is higher that county, state and national percentages (USCB, 2016). Additionally, the entire sample had supplemental insurance to cover the gaps in Medicare that provided a security of having health care available when needed. The lack of ethnic and sociocultural diversity creates a limitation on the opportunity to fully extrapolate from the findings beyond the sample in the study. Having a diversity of sample may have broadened the experiences shared and uncovered additional findings, allowing greater opportunity for such extrapolation.

Another limitation relates to the self-selection of the OA couples to participate, which increased the likelihood of the OA couples to openly share their experiences, more than other couples who chose not to participate. The participants did not have acute exacerbation of illnesses, mental cognition conditions, disabilities, or severe mobility issues, which may limit the application of the findings. Time and financial constraints limited the ability to conduct more interviews beyond two interviews per each of the 14 OA couples in the sample. This limitation may have constrained the discovery of other insights that may have added to the data and findings. In addition, this study was the researcher's first exposure to an application of Newman's theory and use of the method, which may have limited the ability to uncover richer meaning and reflection by the OA couples.

#### **Future Research**

Replicating this study with diverse samplings, including same-sex couples, would test the findings and the proposed models for the OA couples. Further study would better inform the contextual understanding of these findings across diverse age groups and other socio-economic determinants for clinical application and inquiry other groups of older adults and couples that have not benefitted from the gains.

Interventional studies are needed to develop nursing knowledge for practice and health care delivery improvements. The options for intervention development are diverse. The findings offer new insights and understanding to foster innovative opportunities for alternative care delivery options, accessibility

to nursing, and health information, and alternative options for living resources through partnerships within communities. The findings may also be used to develop an OA couple assessment tool to guide health care providers in the care and management of health and well-being from the perspective of the individual and OA couple. Newman's HEC may also be designed as an intervention that establishes the meaning of health and well-being for relationship-based care delivery in primary care settings. Longitudinal studies would provide new insights to better understand the scope of impact between the couple's resonating process within their environment on decision-making, with a comparison to their health outcomes over time.

The use of Newman's theory provided an opportunity to identify potential procedural changes. Further study is needed to explore Smith's (2011) proposed limitations of Newman's method and the procedural change noted in this study. This new evidence will add to the methodology of HEC's application in the advancement of nursing research.

#### Conclusion

In conclusion, this research study explored the experience of OA couples living with chronic illness at home using Newman's theory of Health as Expanding Consciousness as the theoretical framework. The study discovered an emerging pattern of living meaningfully across the OA couples within the context of moving through life transitions. The pattern of living meaningfully was discerned through the uniqueness of each couple's life pattern and experiences. The emerging themes from the data provides new insight into the experiences and

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resonating process of the OA couple as they age together. The new insights uncovered significant implications for nursing in many areas that can support and improve the health and well-being of the OA couples, including further research into generalization of the findings to more diverse populations. The study's findings add to the body of evidence for Newman's Health as Expanding Consciousness and demonstrated the continued advancement of its use in research.

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### EXPERIENCE OF OLDER ADULT COUPLES LIVING WITH CHRONIC 222 ILLNESS AT HOME

#### **Appendices**

#### **Appendix A: Copyright Permission**



On behalf of Dr. Janice Brewington, NLN Chief Program Officer

Dear Ms Antonelli:

I am writing in response to your email, dated April 11, 2018, in which you requested permission to include a figure from an NLN Press book in your dissertation to be submitted to your graduate school. You requested permission for the following.

The figure, "Parallel between Newman's Theory of Expanding Consciousness and Young's Stages of Human Evolution (Figure 11.1)," which appears on page 132 of the book noted below, may be included within Mary Antonelli's dissertation.

Newman, M.A. (Ed.). (1995). A developing discipline: selected works of Margaret Newman. New York: National League for Nursing Press.

In granting permission to include the figure noted above, it is understood that the following assumptions operate and caveats will be respected.

- The figure will be included only in the print and/or electronic dissertation completed by Mary Antonelli;
- The figure will be included in its entirely, labeled as it now appears, and not modified in any way;
- The dissertation in which this figure appears will acknowledge that it has been included with the permission of the National League for Nursing, Washington, DC;
- The National League for Nursing owns these rights being granted; and
- No fees are being charged for permission to include the figure.

I am pleased that material published by the NLN Press is seen as valuable and that we are able to grant permission for its use. Thank you.

Respectfully, Janice G. Brewington, PhD, RN, FAAN Chief Program Officer

#### **Appendix B: Recruitment Fact Sheet**

# Fact Sheet for a Research Study: The Experience of Older Adult Couples Living with Chronic Illness at Home

You and your partner are invited to participate in a research study about older couples (65 years of age or older) living with chronic illness.

The more that is known about the life at home of older adult couples from their point of viewpoint helps with decisions to better support health and well-being.

The study involves 2 to 3 interviews with you and your partner over a 4-6week period. The interviews can be done in your home or anywhere you both feel comfortable. All interviews are conducted by a doctoral candidate from Boston College School of Nursing.

For more information and to answer any questions, please call 508.683.9279 and ask for Mary. You will receive a follow up phone call to also answer any questions you may have about the study.

Thank you and look forward to hearing from you.

#### **Appendix C: Authorization to Contact Form**



#### Docket Number:

#### The Experience of Older Adult Couples Living with Chronic Illness at Home

Please complete this form if you would like someone to contact you about the research.

Name:	
Signature:	
Date:	
Telephone	number:
Email Addr	ess:
Best way to	contact you (over the phone, over email):

I authorize the UMass Memorial Medical Center to disclose the protected health information on this form to:

Mary T. Antonelli, PhD(c), RN who is the Principle Investigator for this study

The principle investigator will use the information to contact me with more information about the study.

I do not have to sign this Authorization. If I decide not to sign, it will not affect my treatment, payment or enrollment in any health plans, or affect my eligibility for benefits. This authorization does not have an expiration date. I have the right to revoke this authorization at any time by sending a written letter to Mary T. Antonelli, contact info: 508-683-9279 or email <a href="mailto:antoneme@bc.edu">antoneme@bc.edu</a>.

If I revoke this Authorization, researchers may only use the protected health information already collected for this research study. Any disclosure carries the potential for re-disclosure. Once my protected health information is released, it may no longer be protected by the HIPAA privacy rule. I will sign two copies of this form and keep one copy for my records.

Give a copy of this signed authorization to the potential research subject and give a copy to the researchers for their study files.

#### **Appendix D: Informed Consent**

Boston College Consent Form
Boston College Connell School of Nursing
Informed Consent to be in study
The Experience of Older Adult Couples Living with Chronic Illness at Home
Researcher: Mary T. Antonelli, PhD(c), RN
Type of consent Adult Consent Form

#### Introduction

- You are being asked to be in a research study of the older adult couples (65 years of age or older) living with chronic illness at home.
- You and your partner are being invited to be in the study because you or your partner have a chronic illness and live together at home.
- Please read this form. Ask any questions that you may have before you agree to be in the study.

#### Purpose of Study:

- The purpose of this study is to better understand the older adult couple's experience while living with chronic illness at home.
- It is expected that 10- 15 older adult couples will participate in this study.
- \*Please note that the researcher will not receive money for the results of this study and minimal funding was received for this study by non-profit organizations to complete this study.

#### What will happen in the study:.

- If you agree to participate, the study involves 2 to 3 one-hour recorded interviews with you and your partner. The interviews can be done at your home or at a location where you and your partner feel most comfortable. The interviews should be done within 4-8 weeks. All interviews will be completed by the researcher. You can refuse to answer any question or have the interview stopped at any time without any penalty
- Before the first interview, you and your partner will be asked to complete questions about yourselves, such as your age, who you live with and any illnesses. You may refuse to answer any of these questions.

#### Risks and Discomforts of Being in the Study:

• There are no expected risks. This study will have no more risk of harm to you than what you would have in everyday life. However, there may be risks to participating in the study that are unknown at this time.

#### Benefits of Being in the Study:

• The purpose of the study is to understand the older adult couples' lives while living with chronic illness to improve health and quality of life.

# EXPERIENCE OF OLDER ADULT COUPLES LIVING WITH CHRONIC 226 ILLNESS AT HOME

• You will not have a direct benefit from taking part in this research study. However, you may have good feelings About sharing your experiences and to know it may help healthcare research.

#### Payments:

You will receive the following payment for being in the study: A gift card of \$30 will be given after the first interview and the second gift card in the amount of \$40 will be given at the last interview. The gift cards are given to each couple, not each individual. If you begin the interview and decide to discontinue your participation prior to the completion of the interview, you will still receive the full amount of the gift card for that interview.

#### Costs:

• There will not be any charge to you as part of this study. However, depending on where the interviews are located you may need to pay for transportation or parking fees.

#### Confidentiality:

- The records of this study will be kept private. In any sort of report we may publish, we will not include any information that will make it possible to identify you. Research records will be kept in a locked file.
- All electronic information will be coded and secured using a password-protected file. The audio recordings will be uploaded to electronic software and then erased from the recorder by the researcher. The researcher will be the only person to have access to the recordings. The recordings will be erased once the research has been reported or within 3 years.
- In the unlikely event that the researcher uncovers abuse, neglect, or reportable diseases, this information will be disclosed to appropriate authorities.
- Mainly just the researchers will have access to information; however, please note that a few other key people may also have access. These might include government agencies. Also, the Institutional Review Board at Boston College and internal Boston College auditors may review the research records.

#### Choosing to be in the study and choosing to guit the study:

- Choosing to be in this study is voluntary. If you choose not to be in this study, it will not affect your current or future relations with the University or your healthcare provider.
- You are free to quit at any time, for whatever reason.
- There is no penalty or loss of benefits for not taking part or for quitting. Your care at the clinic will not be affected.
- During the research process, you will be notified of any new findings from the research that may make you decide that you want to stop being in the study.

#### Getting Dismissed from the study:

# EXPERIENCE OF OLDER ADULT COUPLES LIVING WITH CHRONIC 227 ILLNESS AT HOME

• The researcher may dismiss you from the study at any time for the following reasons: (1) if either of you or your partner decides to stop the study, (2) if you or partner cannot complete the study, or (3) the researcher is unable to complete the study.

#### Contacts and Questions:

- The researchers conducting this study is Mary Antonelli, RN. For questions or more information concerning this research you may contact her at 508.683.9279 or email antoneme@bc.edu.
- If you believe you may have suffered a research related injury, contact Mary Antonelli at 508.683.9279 who will give you further instructions.
- If you have any questions about your rights as a person in this research study, you may contact: Director, Office for Research Protections, Boston College at (617) 552-4778, or irb@bc.edu

#### Copy of Consent Form:

• You will be given a copy of this form to keep for your records and future reference.

#### Statement of Consent:

• I have read (or have had read to me) the contents of this consent form. I have been encouraged to ask questions. I have received answers to my questions. I give my consent to be in this study. I have received (or will receive) a copy of this form.

Signatures/Date	2S	
Study Partic	cipant (Print Name):	
Date		
Doutioinant	Si am atama.	Data
Participant	Signature:	Date

#### **Appendix E: Sample Demographic Forms (Personal & Couple)**

	Personal Demographic Info	
The Experience of O	lder Adult Couples Living w	with Chronic Illness at Home
Identification Code:		
		r that best describes you. You
	that you choose not to answ	er it.
Age:		
Gender: Female	Male Write In:	
Race/ Ethnicity: Am	erican Indian /Alaska Native	e Asian/ Other Pacific
Islander		
Black/African Amer	ican Hispanic/Latino M	Middle Eastern /North African
Native Hawaiian	White/Caucasian Write In:	Prefer Not
to Answer		
Employment: Employment	oyed Retired Semi-	Retired
	High School diploma H	
	ollege Bachelor Degree	
	_	e Medicaid Supplemental
	Massachusetts State Coverag	ge No Coverage
Darganal Haalth Histor	ner:	
Personal Health Histor	•	e diagnosed by a health care
provider	iidi collaidoli tilat you wel	e diagnosed by a nearth care
Asthma	Blood condition	Ulcerative colitis
Bipolar mood	High blood	Depression
Dipolai mood	pressure	Depression
Heart condition	High cholesterol	Oral health
	mgm emeredeer er	concerns
Kidney condition	Thyroid condition	Cancer
Lung condition	Multiple sclerosis	Osteoporosis
Crohn's disease	Parkinson's	Alcohol-Substance
	disease	
Diabetes	Rheumatoid	Hard of hearing
	arthritis	8
Seizures	Lupus	Blindness
Other:		
Do you take any prescr	ribed medications? No	Yes
If so, how many?:		

# EXPERIENCE OF OLDER ADULT COUPLES LIVING WITH CHRONIC 229 ILLNESS AT HOME

# Medication Record Please

Medication Name	How Often Do You Take Medication

Do you take any over the counter medications regularly?	No	Yes	
If so, how many?:			
How much do you spend on medications (over the	counter	& prescription	ı)
per month?			

# EXPERIENCE OF OLDER ADULT COUPLES LIVING WITH CHRONIC 230 ILLNESS AT HOME

Couple Demographic Information
The Experience of Older Adult Couples Living with Chronic Illness at Home
Identification Code:
Please mark the correct box or write in your answer that best describes you as a
couple. You may skip any question that you choose not to answer it.
Relationship Status:
Married Living Together
Number of Years Together:
Participant 1: This is your first, second or more marriage or live-in
relationship?
Participant 2: This is your first, second or more marriage or live-in
relationship?
Source of Household Income: Social Security Personal Savings
Pension Investments Other:
Household Income: $$20 - 40,000/\text{Year} < $20,000/\text{Year} $ \$41-60,000/Year
\$61 - 80,000/Year $$81 - 100,000/Year$ >
\$100,000/Year
Living Arrangement: Rent Own
Live with spouse/partner only
Live with spouse/partner and others
Daughter Son
Grandchildren Son
Sibling
Friend
0.1
Other

#### Appendix F: Couple B's Narrative Summary, Narrative Diagram, and Life Pattern Construal

Narrative Summary:

Struggling for understanding within the couple to move forward.

Couple B met 60 years ago at a bar and was married within 7 months at the ages of 24 (wife) and 25 (husband). This is the first marriage for both with three children. They lived in many areas throughout their lives to follow the husband's work opportunities. Religion was an important foundation in their marriage and family life.

Prior to Being a Couple

Mrs. B was the oldest of four children, two brothers and a sister. She lived on a farm in Mid-west. Her mother had her when she was 17 years old and they were very close; "more like sisters". Her relationship with her father was distant; "he was different". At the age of 12, her mother lost her vision. Mrs. B became "the boss in my family" and was the "caregiver". Her parents thought she would be a "good nurse", but she wanted to be a teacher. She followed her parent's wishes and earned her nursing diploma. At school, she met her life—time girlfriend. She practiced for a short time before moving to a new area with friends.

Mr. B was the youngest of two, a brother. He was born at home and grew up on the East coast. His father left the family when he was 2 years old and was "in and out" of his life since that time. The family went to live with his grandparents and then with his aunt and uncle; both experiences influenced his life. However, he had little guidance in his life. He had a good relationship with his older brother, but life was focused on survival. He joined the military for the GI bill and went to Korea. After the military, he went to college for engineering.

When they first met, Mr. B was intoxicated. He knew he wanted to marry her within "15 minutes", but she needed to be convinced. However, within 7 months Mrs. B "knew a good guy when she saw one" and he was a "good Christian that you could trust in a marriage". Mrs. B's father refused to walk her down the aisle. "He didn't like to deal with people." Mr. B's family would expect a big wedding, which was not the tradition of Mrs. B. Therefore, they married in a small ceremony with only a good friend of each of them in attendance.

Early Years

The couple shared a common religion, Evangelical Luthern, that was the foundation for their values and world outlook. Mrs. B practiced until they had children, which occurred soon after they were married. The first two, a son and a daughter, were 14 months apart and a third child, a son, followed 4 years after. The family moved across the state a number of times due to the Mr. B's work opportunities. Raising the children was difficult. Mr. B was very involved in his interests, the church, civic and other extracurricular interests.

# EXPERIENCE OF OLDER ADULT COUPLES LIVING WITH CHRONIC 232 ILLNESS AT HOME

#### Middle Years

As the family continued to move, Mrs. B toggled between part-time and full-time work as the children grew. The oldest son had "difficulties" and lived at home until he was 30. He then had a relationship with a girl that had a drug addiction and had two granddaughters. Their daughter was their "pride and joy" and their last son did not give them concern. Mr. B had cardiothoracic surgery when he was 59.

#### Later Years

Mr. B retired from engineering and decided to become a lay minister. He went away for 9 months for the education. During this time, Mrs. B continued to practice and retired once Mr. B was out of school. Both became very involved in missionary work overseas and at home, including their daughter. They often sponsored and cared for (by Mrs. B) many people and families who were in need over the years. During this time, Mrs. B's mother's health declined. She went to visit a number of times to care for her until her death. The mother's passing was a very sad time for Mrs. B.

Her oldest son's two daughters were removed from the home and then adopted by their daughter-in law's sister. However, the couple's youngest son and his wife are very involved in the raising of the children. Their daughter disclosed that she was in a same sex relationship. This was very hard for the couple to accept due to their religion.

During this time both Mrs. B and Mr. B experience health issues. Mrs. B was diagnosed with breast and lung cancer. Mr. B's health more dramatically declined with cardiac procedures, heart attack, pneumonia, congestive heart failure and gait imbalance. Due to the health issues, the couple could not manage in their single-family home. The couple decided they needed to move to retirement community living (RC), but did not select the RC they wanted since it was too far from their youngest son and grandchildren. Their oldest son did help them prepare the home to be sold. Their daughter bought a home close to the RC to be near her parents.

#### Present Time

The couple has lived in the RC for the past 6 years. They enjoy the RC for the security and ease of living it provides. Mr. B started a Bible study group that Mrs. B supports with him. He also enjoys his reading, and music. Mrs. B continues to enjoy playing cards and exercise at a slower pace. She is worried that her sense of direction while driving is becoming a problem. Mr. B's health continues to decline. Within the past year he had a valve replacement. His poor mobility limits his time to follow his interests. "It takes 3 hours to get up and 3 hours to get ready. It doesn't leave much time for anything else." Mrs. B cares for her husband health needs, but worries about him so much that it places a weight of responsibility on her that is stressful. She too is experiencing health issues. She is exercising less due to joint pain and recently was diagnosed with atrial fibrillation. They are rewriting their will (third time), since the oldest son had another daughter. Tension between the couple and their youngest son developed because they want to leave money for the newest granddaughter. The decisions of the will create conflict between the both of them, which is related to

# EXPERIENCE OF OLDER ADULT COUPLES LIVING WITH CHRONIC 233 ILLNESS AT HOME

their belief system and the love for their children (oldest son and daughter's lifestyle). Mr. B wants to apply forgiveness and move forward with the inclusion of all family members, but will not tell their youngest son. Mrs. B told the youngest son the plan without speaking with Mr. B, resulting in conflict and , at this time, no change in will until the issue is resolved by the couple.

Response to Pattern & the Pattern Analysis Summary:

When both the life pattern construal and narrative diagram were presented to Couple B, Mrs. B recognized the life pattern as a negative experience, "pretty much all bad things happened". When the positive was pointed out she agreed, but then commented, "we don't have anything good." Mrs. B shared that she is out of her comfort zone when sharing her thoughts, feelings and life events. "I find it really difficult...it's hard for me to talk about things like that." However, Mrs. B did find it was "fun looking back on your life, with the fun things. I think it was easier to tell it than it is to read it. I didn't like it on black and white." Mr. B's enjoyed the exploration overall but came to an awareness that he has not dealt with aging well. "I'm not taking getting old well."

The data were analyzed from the lens of Newman's theory through a pattern analysis and the development of the couple's narrative diagram. The analysis highlighted the continued conflict between the partners regarding how to manage the relationships with their children, which created discomfort between them. The strong alignment of their religion to their value base may have contributed to an unrealistic lens for their children as well as themselves. The couple may interpret their children's lifestyle choice as a reflection on them as parents and as a form of rejection. This is demonstrated by the lingering conflict of accepting their children's chosen lifestyle and outlooks, which differs from their own.

The couple continues to seek the answers and meaning within the bible. However, Mrs. B is contemplating that maybe "we should sit back and relax...to let it go." When Mrs. B acted on this perspective without Mr. B's knowledge, it created conflict. The couple is at a cross road in deciding how to resolve their lingering concerns. "Life isn't easy. And somehow we struggle together to meet whatever problem there is...because we are really at the end of our life, and we know we don't have much time left. It's just so much to really think about, end of life decisions."

# Couple B's Narrative Diagram

granddaughter, FR=friends, CH=church sband	Relationship Key: W= wife, H= husband, M=mother, F= father, GF=Grandfather, U=uncle, A=aunt, B= brother, S=sister, D=daughter, S=son, GDs= granding = neutral = uncle = plocked = bidirectional = sidirectional = sidirectiona	ndfather, U=uncle, A=aur =blocked	ther, F= father, GF=Gran	wife, H= husband, M=mother, F =uni-directional	Relationship Key: W=
	D D	¥ FR-1	D 🕹	4	FR YS
	3		,	A&U	
	S + W&H S	s	<b>↑</b> ₩&H	<b>→</b> (H)F	wF
	FR-1 CH-FR	CH-FR	B:2	<b>├</b> √	<b>S</b>
	•		M-1	M B	8 B
			Wife worked part-time until they had children.		
	complications.		interests.	engineering.	Chicago & then Wisconsin.
	Husband's brother had major stroke and died later due to		extracurricular	in mechanical	Worked as a nurse in
study. Wife likes to play cards.			civic interests and other	Earned a college degree	
Husband enjoys reading, music and bible	imbalance).		involved in the church,		be a teacher.
(	started a chain of a declining health (stents, heart attack,		The husband was very	GI bill.	diploma, but wanted to
concerns regarding her sense of direction.	Husband had major surgery with complications which	surgery.		Joined the Army for the	Earned a nursing
The wife continues to drive but has		cardiothoracic bypass	due to husband's work.		
	Daughter is in a relationship with a woman.	Husband had	times (across states)	life.	the family.
weight of responsibility on her.			Moved a number of	Had little guidance in his	caregiver and boss in
and worries about him which places a	Support given by their younger son and his wife.	drug addiction.			with the family; was the
Wife cares for her husband's health needs	home and then adopted by their daughter- in-law's sister.	girlfriend who had a	raising the children.	grandfather his father.	She helped her mother
	Oldest son had two daughters who were removed from the	relationship with	Had a difficult time	He considers his	
shoulder pain and a cardiac irregularity.		Oldest son had difficult			12.
Wife is exercising less, developed	Wife diagnosed and treated for breast cancer.		and a son 4 years later.	aunt/uncle.	one eye when she was
		them until he was 30.	were 14 months apart	short time with his	Mother lost her sight in
daughter.	Wife flew to visit/care for her mother often until her death.	Oldest son lived with	son and daughter who	his grandparents and a	
conflicts. Oldest son recently had a			Had three children, a	Family went to live with	like sisters.
Concern over their will due to family	were in need, over the years.	financial needs.			were very close, more
	Opened their home to a number of people/families, who	worked based on	were devote followers.	time.	she was 17 yrs old. They
Recently had a valve replacement.	home.	part and full time	religious beliefs and	"in and out" since that	Mother had her when
mobility limiting his time for his interests.	Both were very involved in missionary work overseas and at	Wife toggled between	Shared the same	early in his life and was	
Husband has declining health and poor				His father left the family	and one sister.
	the husband was out of school.	demands.	both sides.		children, two brothers
for the security and ease of living.	back to school to become a lay minister. Wife retired after	jobs based on industry	were family issues on	Had an older brother.	The oldest of four
Enjoys living in a retirement community	Husband retired from mechanical engineering and went	Husband held various	They eloped since there	HUSBAND(2)	WIFE(1)
Present Couple Years	Late Couple Years	Middle Couple Years	Early Couple Years	Prior to being a Couple	Prior to be

# **Emerging Life Pattern: Couple B**

HUSBAND	WIFE	
Father left inved with extended Education Education Met Military wife	Mother Education Vision Education Moved Helped Care for family	Prior to being a Couple
Children	Moving for work	Early Couple Years
Old son difficulties	Husband + wife + wife + wife + wife health issues health issues health issues health seases for work  Marriage  Moving for work  Marriage  Moving Husband Husb	Middle Couple Years
Husband Missionana Daughter retired Work came out	Husband  + wite  + wite  + wite  health  mother decline  Went to  Afficial  Ministry school	Late Couple Years
	Continued decline husband's health health health for the provide the provided the provi	Present Couple Years

#### **Appendix G:** Couple C's Narrative Summary, Narrative Diagram, and Life Pattern Construal

Narrative Summary:

The attributes of each created the bond of resilience and acceptance.

Couple C met 52 years ago while attending college. They married within a year. This is the first marriage for both and they had two children. They were very close to and involved with their extended families. They raised their family in a small home in a young and lived there most of their lives until recently. They share a joy of song, music, movies, and humor.

Prior to Being a Couple

Couple C share common values and backgrounds "as far as parents and up bring...solid people that worked hard and had values". Mrs. C has one sibling, an older brother that was 6 years older than her. At the age of 12, her grandfather and uncle moved in to live with the family. The uncle became an alcoholic over time which created tension in the home. Her family set an expectation for the children to do well in school, attend college to become a teacher. "I followed that mold." She was active in the booster club during college and enjoyed her studies.

Mr. C was the second oldest of four children. He had an older brother. and a younger brother and sister. He was very close to his mother and admired her. Mr. C's family did not expect the children to go to college. His parents valued a strong work ethic. Mr. C joined the Air Force after high school for 4 years. It is during that experienced he decided he could complete college and enrolled after serving. He worked to pay for his education while he lived at home.

Mrs. and Mr. C attended the same college where Mrs. C first "noticed" Mr. C. "He was older and so good-looking". He called and they started dating. Mrs. C admired Mr. C's work ethic and found him to be "the best influence in my life". Mrs. C graduated from college before Mr. C. and got a teaching position. Since she was working, she bought Mr. C a new jacket for an interview. She also bought his senior ring and pictures since Mr. C was "dead broke". He thought that "was just fantastic". He "loved her before then and loved her even more after that". They married within a year after they started dating. Early Couple Years

Mr. and Mrs. C's parents got along very well. They had many family gettogethers at the beach, "It was like happy days." They both were working after having children for the first five years, then Mrs. C went part-time. They lived in a small home with a small yard, and no garage. Raising the children was "difficult", but would "never show their disagreements in front of the children." They both valued education, a need "to having a budget in the home", and religion. During this time tensions grew related to Mrs. C's uncle's alcoholism, which "was a problem". Her grandfather had a stroke requiring help with his care until his death. Mr. C was "right there" which was an "immense help". Mr. C's father died during this time. They both were very close to Mr. C's mother and

talked with her regularly. Mrs. C describes herself as a worrier. At the time, there were no teaching positions. Therefore, she learned to type and held various office jobs to contribute to the finances. In Mrs. C twenties, she started to experience joint pain in her shoulders and neck that did not impede her mobility but was a chronic discomfort. She also had difficulty sleeping. Middle Couple Years

The middle years were filled with stress due to having full responsibility for care giving for Mrs. C's parents, who were experiencing a number of health issues, helping with their grandchildren and balancing financial responsibilities with both working. Mrs. C's brother lived out of state which resulted in her being the primary person to manage and provide care. Mrs. C's mother developed many health issues that affected her mobility. Her father developed Alzheimers. As the condition progressed, the couple increasing supported her parents resulting in the decision for placing him in a nursing home. "It was the first person in our family ever to have to go into a facility." After Mrs. C's father death, her aunt, who was a hoarder, also had Alzheimers. They became responsible for her care and management of her estate. Eventually they needed to move her to a nursing. Mrs. C's brother died and Mr. C's older brother died. Mrs. C's joint/nerve pain continued. Mr. C retired as a school administrator.

Late Couple Years

The later years were also filled with additional family care responsibilities. Mrs. C's mother became wheelchair bound due to her declining health. The care of her was laborious until her death. Mr. C's brother died of melanoma as well. They then decided to move to a new house for ease of living especially as they get older. While caring for her parents, their daughter's and son's marriage ended. They stepped in to help with their daughter's children. At some point their granddaughter died which they "could not talk about" since it was too emotional. They are not sure how they did it but they "stuck together" to make it work.

Their son lives near and visits often. Their daughter moved to Hawaii "livin' la vida loca" and hear from her often. Their daughter wants them to visit but "the thought of the trip repulses both of us" since it is a long trip. They are also very close to their grandson that lives in the area. Mr. C's mother's health started to decline after she had a broken hip requiring her to move into a nursing home. They visited her often over three years until her death at 102. This was a huge emotional loss, especially for Mr. C. However, Mr. C stated Mrs. C "was there tremendously" for him.

Mrs. C's chronic joint/nerve pain became worse over the years impacting her mobility and activities. She sought out many physicians to get a diagnosis so she "can deal with it", but the doctors thought it was "psychosomatic" since she had been complaining for so long, which was frustrating. Mr. C experienced acute renal failure due to a newly found allergy to sulfur which was induced by medications he was taking. His health was affected for years after. It was a very "frightening" and a "scary" time.

Present Couple Years

At the present they are enjoying their home. They "don't want to go on cruises" since the house is "like a vacation." They keep busy with small projects,

their hobbies, sitting on the porch, and watching television shows. He "loves to cut the lawn", and she paints. They share a love of music and will sing together. From time to time they go to see live theater. "She has transformed me. When I say transformed, that's what I mean. I just love to go to see these musicals and stuff." They "stay up to date" with current events, locally and nationally. They are enjoying their family; their son will come over on Sundays to make breakfast, visits with their grandson and talks with their daughter. They eat out more often and keep in touch with friends. Though they mention that their friends are starting to die.

Mrs. C continues to have pain and discomfort that limits her ability to walk distances and to garden. In the next month she is scheduled for a knee replacement, which she hopes to provide her with some relief. Mr. C considers himself "healthy". He recently got hearing aids and has three chronic conditions that are controlled with medications. Though they complain about going to too many medical appointments, which is "a full-time job", they consider themselves "very lucky".

#### Response to Pattern & the Pattern Analysis Summary:

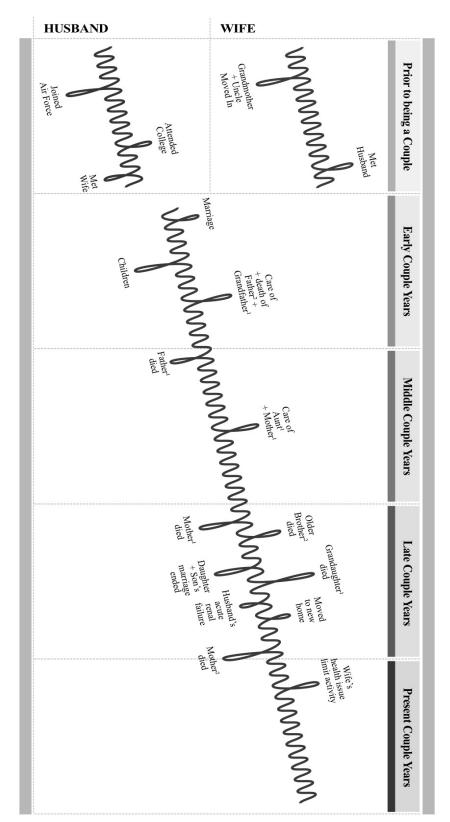
When both the life pattern construal and narrative diagram were presented to Couple C, it took some time to understand the pattern. Mrs. C stated, "I think this captured it [their life]." They have been so involved with the doing of life they have not had time to absorb what has occurred in their life together over time and the influence of those experiences; "We're at the stage now that we—haven't had time even to look seriously". The both view their life together as being lucky.

The data were analyzed from the lens of Newman's theory through a pattern analysis and the development of the couple's narrative diagram. The analysis revealed their experiences as a couple brought them very close and they depend very heavily on each other for their socialization and engagement in activities. The meaning of being a couple is very significant. Both became very emotional when talking about the other. They continue to look forward to enjoying their interests together and the children/grandchildren.

Couple C's Narrative Diagram

anddaughter, FR=friends	Relationship Key: W= wife, H= husband, M=mother, F= father, GF=Grandfather, A=aunt, U=uncle, D=daughter, S=son, Sr=sister, B=brother, GS=grandson, GD= granddaughter, FR=friends = unit-independent	A=aunt, U=uncle, D=daughter, S= d	d, M=mother, F= father, GF=Grandfather, A==uni-directional	wife, H= husband, M=m > =uni-d	Relationship Key: W= =neutral
S	R-2 CS GD	B-2 A-1 GS GD	GF-1 U-1		GF
FR R-2	M-1 M-2	M-1 F-1 M-2	M-1 F-1 M-2 F-2	B S	S T
Husband rekindled relationship with younger brother.	Husband developed interest in musicals from wife.				
Going doctor appointments more often.	Decided to move to new home for future needs as they get older.		Wife learned new skills to work in various jobs.	attending college.	was finishing college.
Tend to eat out more. Friends are beginning to die.	Husband's mother broke hip leading to placement in nursing home and died at age 102.	Husband retired.	Wife started to experience joint discomfort and had difficulty sleeping due to bodily comfort issues.	Became a teacher.	rather study something else.
their daughter.	and grandson.			himself.	teacher but would
grandchildren and talks with	Hawaii. Hears from her regularly. Close with son	placement in a nursing home.	Wife worries about children and life.	college to support	College educated as a
Spending time with their son (lives down the street).	helped with the daughter's children.	wife's aunt, who had Alzheimer's, lived alone. The couple became	Couple was very close with the husband's mother and spoke regularly.	service.	Was close with her grandfather
shows, and current events.	Daughter's and son's marriages ended. They	After wife's father died	until nis death.	applied to college after	
movies, engaging in TV	Husband's older brother died. Wife's brother died.	in a nursing facility.	Wife's grandfather health declined	it through college during the military and	became an alcoholic which created tension
activities, e.g. painting, word	death.	Alzheimer's, requiring the couple to manage the care and placement	Husband's father died.	Decided he could make	Uncle progressively
Enjoying their home and	resulting in her being in a wheelchair until her	Wife's father developed	as it became worse.	4 years.	the age of 12
month.	Wife's mother's health continued to decline	for after surgical procedures.	Helped to manage Uncle's alcoholism	Joined the Air Force for	moved in with family at
knee replacement for next	allergy.	issues (severe arthritis) and cared	Raising the children was difficult.	sister.	
and enjoyment in waiking and gardening. Wife planning	Husband experiences acute renal failure due to	wife's mother multiple health	Had two children, a son and daughter.	younger brother and	brother.
which now limits her ability	long distances and garden. Experiencing pain.		and provided support.	The second oldest of	Youngest of two
Wife continues to have pain	Wife's joint/nerve pain impacts her ability to walk	Wife's joint discomfort continues.	Very close with each other's families	HUSBAND(2)	WIFE(1)
Present Couple Years	Late Couple Years	Middle Couple Years	Early Couple Years	Prior to being a Couple	Prior to bei
				Couple C's Naffative Diagraffi	Couple C S IN

# **Emerging Life Pattern: Couple C**



### EXPERIENCE OF OLDER ADULT COUPLES LIVING WITH CHRONIC 241 ILLNESS AT HOME

#### Appendix H: Couple D's Narrative Summary, Narrative Diagram, and Life Pattern Construal

Narrative Summary:

Connection and engagement within relationships to survive the struggles of life.

Couple D were married at young ages of 19 (wife) and 20. They have been together for the past 56 years with four children. They consider being married a "full-time job". Most of their life together was deeply embedded within the military community with strong ties still; they vacation in the winter on a military base in Florida. They remain engaged and active in the community and with their family. Pets have been an enjoyable and important part of their family throughout their life together. They carry a positive and practical outlook on life and the future.

Prior to Being a Couple

Couple D shared some common experiences in their childhood. Mr. D grew up on a farm with 2 sisters and 2 brothers with very little money, "My parents did not make enough money to even file taxes." However, the family worked hard together. His father was in the Navy in WWII. Mrs. D grew up in a small town with 2 sisters. Though she had a less austere upbringing, the war made impression on the family to save and not waste resources. Her father was in the Army in WWII. Mrs. D's mother was a strong influence in her young years and would be so throughout her life.

The couple met through a friend while Mrs. D was still in high school and Mr. D was enlisted in the Navy. While they were first dating, Mrs. D was afraid to tell her parents she was dating a "sailor". They married within three years of first meeting.

Early Years

The early years were busy. Since Mr. D was in the Navy, he was at sea a majority of the time and his work exposed him to hazardous metals. He would get leave for 2-4 weeks then off to sea again for sometimes close to a year. They moved many times and lived on military bases across the U.S. They had 4 children close in age and a miscarriage during this time. Mrs. D had support from the other military families that were stationed on base with them. "It was our life. The people that we were surrounded with were our family. And everybody supported each other. There wasn't this anger that there is nowadays. There was total support of brotherhood." There were times when they lived with her parents if did not leave on military base, and spent time during the summers at their parent's summer home.

Since Mr. D was out of the country most of his time in the service, letters and tape recordings became very meaningful to them and the family as a means of communicating. There would be times when they would have mail for over 3 months. "I still have every letter he sent." Through his service, Mr. D was promoted a number of times. Mrs. D helped him with his studies that supported his success. Mr. D retired as a lieutenant.

# EXPERIENCE OF OLDER ADULT COUPLES LIVING WITH CHRONIC 242 ILLNESS AT HOME

### Middle Years

After 20 years of service in the military, Mr. D became a civilian but continued to work on military contracts. They bought a home in a non-military neighborhood, which took some adjusting. The children were in high school. They also "adopted" a friend of their son's. He "ran the streets" and would basically live at their home. So they decided to give him a bed.

As the children grew and married, they enjoyed a beach home during the summer spending time boating and fishing. They enjoyed traveling together. Mrs. D worked in an industrial job during this time also working with hazardous metals, but the "pay was good." Mr. D went to work for Coke-Cola once his contract job ended.

### Later Years

When Mrs. D's father died, her mother lived with them. They would travel together and got along very well enjoying each other's company. AS her mother aged, she developed Alzheimer's. Care became difficult, as Mrs. D was the primary provider until they made the decision to place her in a nursing facility for safety. Mrs. D's mother lived there until her death.

Mrs. D fell down the steps at her home and broke her neck requiring surgery. She was placed on disability and retired at 62 years of age. Mr. D. retired the following year. They sold their home and bought the home they are living in currently. During retirement they remained active. They volunteered and went to Key West each winter and camped on a military base (had a motor van) to be with friends. They were also very active with the grandchildren, with 2 grandsons joining military service.

### Present Time

At the present, Couple D is enjoying living in their new town with fresh air, lower taxes, access to farm food and watching nature from their back porch. The winter trips to Florida continue but they now travel to Tampa to be closer to medical facilities, since Mr. D is at high risk for stroke. Over the years, they are noticing a reduction in medical care coverage and have to pay more out of pocket for services and for treatment. They have 2 daughters living close by that they visit with from time to time. They remain active in the community, volunteer at the Senior Center and take rides to farms for fresh food.

Mr. D is experiencing hearing loss that interferes with their communications. He will be exploring hearing aids. Mrs. D had a recent diagnosis of congestive heart failure with a recent frustrating hospitalization. She also had cancerous skin lesions removed from her hands.

### Response to Pattern & the Pattern Analysis Summary:

When both the life pattern construal and narrative diagram were presented to Couple D, they recognized the life pattern as their own, "Yeah. That's about it." They reflected on their life together and concluded that "retirement has been the richest for them besides having children. "...retirement for ourselves has been the most meaningful... we can sit back and enjoy the fruits of our labor. Where before, there were many struggles."

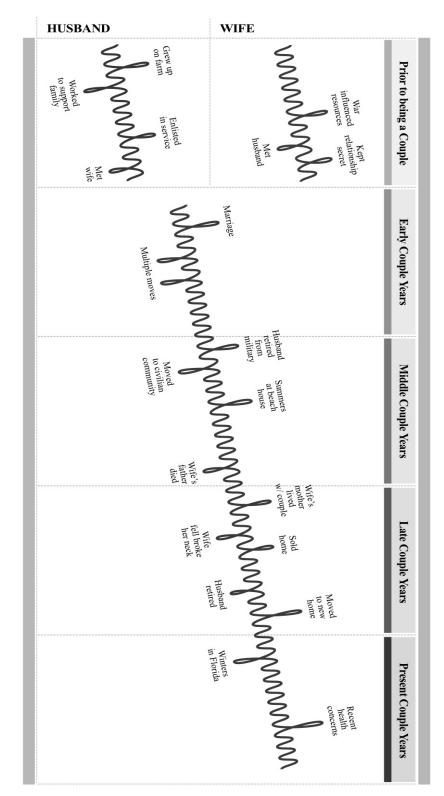
# EXPERIENCE OF OLDER ADULT COUPLES LIVING WITH CHRONIC 243 ILLNESS AT HOME

The pattern analysis revealed that Couple D was able to endure life apart for many years through the connection and engagement of each other along with their family, military community, and volunteerism with various organizations. Their life was influenced by the war and the common experience of austerity that provided a model of how to adjust to make it through the struggle with those people closest to you. They extended themselves beyond the family to give back and make it a little easier for others who may need help and may be struggling. They are committed to "enjoy our life as we have it right now…every day, and take it as it goes."

Couple D's Narrative Diagram

Military friends, FR= friends, P=pets	friend, GC=grand children, MFR=Numbers:1=wife, 2=husband	her, D=daughter, S=son, SFR=son's	Relationship Key: W= wife, H= husband, M=mother, F= father, S=sister, B=brother, D=daughter, S=son, SFR=son's friend, GC=grand children, MFR=Military friends, FR= friends, P=pets = neutral =	N= wife, H= husband, =neutral	Relationship Key: \
SFR MFR P		SFR	D D D	B ►	<b>←</b> (
S WRH GG		S W&H Ds	S WRH MFR	± € €	\$. ₩ ← \$. **
→ <sup>S</sup>		P M-1 MFR	M-1 F-1	Z	<b>→</b> ≤
cancerous skin lesion removed from hands.	Continue to volunteer.		Maine at wife's parents home.		
Wife recently dispressed with OUR & had	Grandsons in the military, Navy and Marines	Sold beach home. Enjoy traveling.	Very close with wife's parents, would live with them off and on. Spent summers in	Married at 20	Married at 19
issues with communication. Needs hearing aids.	With friends from key West.	son joined the Navy.	with the children and daily needs.	WWII	WWII.
Husband has hearing deficient which create	active duty friends. Keeps in touch		Military families would help each other	Father in the Navy in	
	military base with retired and	grandchildren, boating, fishing.			her life.
Military health care coverage is reducing.	Spent winters in Key West on	the summers. Spent time with the	missions. Getting the mail was special.	ends meet.	strong influence in
and of the second collection.	nome they are living in today.	יייייייייייייייייייייייייייייייייייייי	each other and with the children but	tagether to make	Lor mother was
enjoy the rides together	Sold family home and bought the	in the neighborhood.	Would write letters and tape messages to	:	dating a sailor.
	Husband retired from Coca-Cola.	Raised a child that "ran the streets"		food for other items.	parents she was
community.	Deliner of or of	are more Refer to ambrine managemen	societal views.	Family would trade	Was afraid to tell
Continues to volunteer and are active in the	placed on long term disability.	military community. Wife paid off	military base. During Vietnam war it was	enough money to file	was hard for her.
to be closed to illegized actitions.	her neck. Had surgery and was	Transition for children to a non-	Moved a number of times and lived on a	Parents did not make	and had to save. It
spend winters on military campgrounds now	Wife fell down the steps and broke	time retiring from military.	0	material of circumstay.	They did not waste
Drives down to Tampa in motor van to	for safety. Wife's mother died.		Had five children, lost one in a	Ohio without running	The war made an
	be placed in a nursing care facility	Cola.		Grew up on a farm in	
visits from time to time.	Eventually the mother needed to	contracts. Then worked at Coca-	very involved with the children		years).
Two daughters live close with grandchildren	primary caregiver for her mother.	and worked as a civilian on military	time but when he was home he would be	brothers.	during WWII (lean
CHE COVER	got older. The wife was the	Husband retired from the military	Husband was at sea the majority of the	sisters and 2	town with 2 sisters
ower taxes	was difficult at times as the mother	G. C.	and to provide a measurement	One of 5 children, 2	Grew up in a small
Enjoy living in their new town, fresh air,	Wife's mother lived with the	Both worked in jobs with exposure	Husband enlisted in the Navy and retired	HUSBAND(2)	WIFE(1)
Present Couple Years	Later Couple Years	Middle Couple Years	Early Couple Years	Prior to being a Couple	Prior to be
					].

# **Emerging Life Pattern: Couple D**



# EXPERIENCE OF OLDER ADULT COUPLES LIVING WITH CHRONIC 246 ILLNESS AT HOME

### Appendix I: Couple E's Narrative Summary, Narrative Diagram, and Life Pattern Construal

Narrative Summary:

Contentment through knowing self and the other in the context of family

Couple E has been married for the past 48 years and had one son. Their life together is strongly rooted within family, friends, and community. Mrs. E's father business, and later her own business, provided an opportunity to meet many different people leading to many strong friendships and community connections. Mr. & Mrs. E are very comfortable as a couple, as well as being individuals, with Mrs. E enjoying her love of travel, while Mr. E is content to stay at home enjoying his interests.

Prior to Being a Couple

Mrs. E grew up in a closely-knit family with one younger brother of 13 years. Her mother had a number of miscarriages between her and her brother. Her family was known and very involved in community due to her father having a limousine service, in which the entire family and extended family had a role. Mrs. E had many strong friends throughout her childhood. Mrs. E went to secretarial school and started her working career in an insurance company. Mr. E was the oldest of three, a younger sister and brother. His family life was also close. He attended college where he met people that would be his long-lasting friends.

The couple met at a party. They dated for a year before they knew they wanted to be together and then wanted 7 more years before getting married. They wanted to save money for a house and furnishings. Mr. E proposed and a special family party was planned to celebrate. Mrs. E was 26 and Mr. E was 27 years old. Early Years

Their wedding was a big event with 500 people attending. They bought a home in the community where they both grew up. Mrs. E's father worked with Mr. E to renovate the home over time. They had a son and were very close to both sets of parents and their many friends
Middle Years

The middle years were more difficult. Their son married and had a son, but soon after divorced. The couple supported the son emotionally and financially through a custody dispute. Their son eventually settled with visitation resulting in the couple being with their grandson every summer at their lake home until he was 22. Mrs. E went into business with her close friend. She became very involved in the business and traveled to conference throughout the U.S.

Mrs. E's father died suddenly from a heart attack at the age of 53. This was emotional devastating for the family. Her brother took over the business. Mrs. E managed the business' finances. Her mother went to live with Mrs. E's grandmother in a older age community home. Mr. E's mother died also leaving a gap in the family.

# EXPERIENCE OF OLDER ADULT COUPLES LIVING WITH CHRONIC 247 ILLNESS AT HOME

### Later Years

The later years were filled with more transitions and adjustments. Their son remarried. Mr. and Mrs. E are very close to the couple and have an excellent relationship with their daughter-in-law. The couple decided to transition to a new living community to reduce the burden and workload of maintaining a house as they were having physiological issues. They sold their home to their son, and also sold the summer home. They bought a condominium in a 55-older community. They became activity on committees, and joined in on the featured activities that interested them. They met new people who became close friends, as well as continued their relationship with their life-time friends.

Mrs. E's mother fell at home and died of a intra-cranial hemorrhage. Mr. E's father died the same year. A few years later, Mrs. E's brother died of renal complications. It was a very emotionally time for them. Mrs. E's brother asked Mrs. E to watch over his daughter and sons. She took this request very seriously and remained in their lives. Toward the end of this period, Mr. E's brother died.

Mrs. E loves the beach. She bought a timeshare and let her husband know she would be spending time their with her friends, and son and daughter-in-law. Mr. E was content to have her enjoy her time, since he was not a big fan of the beach. Mr. E remain close with his college friends and celebrated a 50th class reunion.

### Present Time

Mr. and Mrs. E are enjoying their life in the community and their home. They want to stay in their home throughout their time together and make adjustments to the home as their health needs dictate (a chair lift was installed to the upstairs). Though they both are experiencing physical problems, e.g. hip replacement, chronic back pain, arthritis, they continue enjoying life through engaging with their friends and family. Mrs. E is traveling, cooking, and running two businesses. Mr. E following his interests in sports, reading and computer work.

Within the last few weeks, he nephew died suddenly due to diabetic complications. This was an especially sad time since this was Mrs. E's brother's son and her nephew was engaged to be married. Their family and friends came together for support.

### Response to Pattern & the Pattern Analysis Summary:

When both the life pattern construal and narrative diagram were presented to Couple E, they recognized the life pattern as their own, "I think you captured it. It seems to flow well. It's everything that has happened. There's a mixture because that's what life is...it's a lot of happiness and various events that occurred over the years...[the pattern proves] the ability to look back and say I did what I could. They expressed how they could see the connections and the relationships over time, an awareness that gave them insight into their value and meaning of living. "You don't stop and think about these things, that there's a connection... brought our life right before our eyes." "You've refined and defined the connection of the interconnection, the relationships, one to another, that have existed and do exist, and continue to, as we go forward." It's like live

# EXPERIENCE OF OLDER ADULT COUPLES LIVING WITH CHRONIC 248 ILLNESS AT HOME

for today because nobody's promised tomorrow. Yesterday has passed. Tomorrow's not here. Today's the present. Enjoy it."

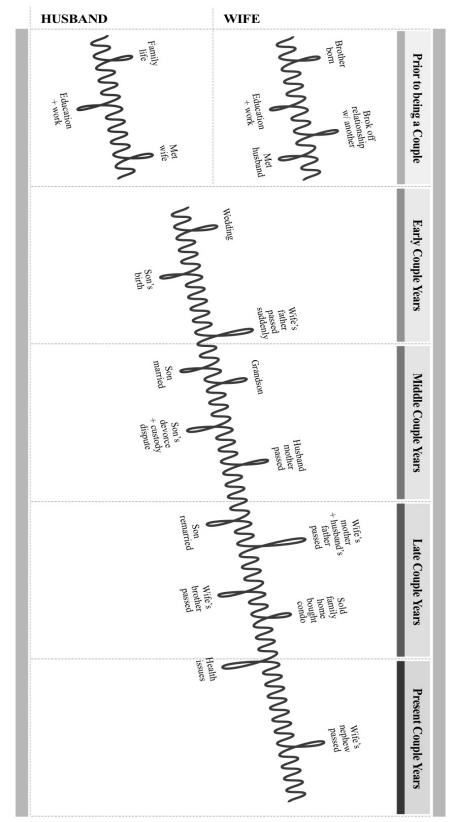
The pattern analysis revealed that Couple E has a strong foundation of support through their family and friends. The value of relationships was seeded during childhood and reinforced throughout their lifetime. The couple has expectations of a relationship and lives by them, where the boundary of friendship blurs into family. "A good relationship is two-sided." Both parties in the relationship are "willing to give of themselves in many ways" that "mimics actual family." "When you pass, your wealth is not measured by the amount of money you have in the bank, but by the number of friends you'll leave behind. That has stayed with me all my life, and probably will until I pass. Friends are important...they're very important."

The pattern analysis also revealed the ability to be a couple, yet maintain individual interests that reinforces or generates contentment within the couple over time. "Just his demeanor, he so caring and loving...this is what I want." Mr. E expressed happiness for Mrs. E's time at the beach and content with his ability to follow his interests, "to each his own."

Couple E's Narrative Diagram

rs, FR= friends,	Relationship Key: W= wife, H= husband, M=mother, F= father, Sr=sister, B=brother, D=daughter, S=son, DIL=daughterinlaw, GS=grandson, N=nieces & nephews, FR= friends, = neutral = unj-directional = blocked = blocked = blocked = blocked   numbers:1=wife, 2=husband	er, Bebrother, Dedaughter, Seson, DILeger =blocked ====================================	M=mother, F= father, Sr=sister,       =uni-directional	V= wife, H= husband, N =neutral	Relationship Key: \
N C-15	GS \$\int_{Sr-2}\B-2	FR 5r-2 B-2	5r-2 B-2	<b>←</b>	₩ (
S&DIL W&H	M-1 F-2 FR  S&DIL  W&H  → R-1	M-1 F-1 M-2 F-2  W&H B-1	M-1 F-1 M-2 F-1	Ç S	<b>₹</b> ←→ 3
Wife's nephew died.	Husband's brother.				
They do not have any plans to move again.	Wife bought timeshare and enjoys time with friends and DIL.				
an answering service too.	Wife's brother died at 53 due to kidney failure. Very difficult emotionally.				married at 26.
Continues to run an insurance	6	Husband's mother died.			home before getting
working on the computer.	Wife's mother died after a fall due to internal bleeding. Husband's father died at 96 the same year.	close friend and traveled for business.	Had a son.	after he proposed.	Dated for 8 years to save money for a
reading, watching sports, and		Wife owns an insurance agency with a		Planned a special party	
Husband enjoys being at home	had a successful laminectomy due to constant pain.		father helped to renovate.		company.
Wife loves to travel and cook.	experiencing back problems and knee issues. Wife	her father died.	Bought a house and wife's	one."	an insurance
	Husband had his hips replaced. The wife is	grandmother in an elderly facility after	parents.	knew she was "the	school and worked in
with results.	friends.	1000	Very close to both sets of	relationships, but when	
Wife has arthritis. Had	Husband celebrated 50th anniversary with college	business' finances.		Did not have many	limousine service.
		business. The wife managed the	father's limo service.		Father had a
daughter-in-law and her family.	(over 55 community). Enjoying the community and the people. Activity on committees.	Wife lost her father (53 years old) due to heart attack. Brother took over	with close roots to the community fostered by	Attended college and met close friends.	Very close family.
Very close with son and	They both enjoy the home they are living in now		Developed strong friendships		miscarriages.
Approx.		Had a summer home on a lake.		Close to his family.	Mother had multiple
and open to mendships or all	law.	c	they both grew up.		0
continues to be very society	family home was sold to their son and daughter-in-	Saw grandson every summer until 22	lived in the community where	brother	Volinger
Continues to be constantially	Sold both their family and summer home. Their	Son divorced. The couple supported their son through a custody dispute.	over 500 people in attendance.	vounger sisters and a	brother 13 years
community.	their friends.		Had a very large wedding with		
Enjoy living in their home and	Son happily remarried. The couple is very close to	Son married and had a son.		HUSBAND(2)	WIFE(1)
Present Couple Years	Later Couple Years	Middle Couple Years	Early Couple Years	Prior to being a Couple	Prior to b

# **Emerging Life Pattern: Couple E**



## EXPERIENCE OF OLDER ADULT COUPLES LIVING WITH CHRONIC 251 ILLNESS AT HOME

### Appendix J: Couple G's Narrative Summary, Narrative Diagram, and Life Pattern Construal

Narrative Summary:

Movement through life as a couple with commitment and mutual sharing gives ease and peace to being

Couple G has been married for 61 years. Their parents arranged their meeting and marriage, which is the Indian tradition. They have two children and have grandchildren, both living in the U.S. and in India. They lived happily in the U.S. and in India. Currently they live contently with their daughter, who provides all living, finance, and health needs.

Prior to Being a Couple

The couple shared the same religious and ethnic background. Their childhoods were filled with friends, fun activities and sports while living in India. Mr. G was the oldest of 5 children, 2 sisters, and 2 brothers. Mrs. G. earned a Masters degree in English literature and Mr. G earned a degree in chemical engineering.

Early Years

After marriage they lived in an apartment with a balcony throughout their time in India. They had two children, a son and a daughter. Life was made comfortable since they had servants and other services to support daily living routines. Due to Mr. G's work assignment, they were relocated to the U.S. for a year. They enjoyed the opportunity and were able to travel to see other areas in the U.S.

Middle Years

Their children moved the U.S. to earned graduate degrees. Their son studied electronic engineering and has a business in India. Their son resides in India with his wife and children. Their daughter became a physician and is also advancing her education in engineering. During this time the couple traveled to the U.S. to visit their children and grandchildren often and then stayed to care for the daughter's child.

Later Years

Once their grandchild was in school, their daughter wanted her parents to be near her as they aged. So the couple decided to sell their home in India and move permanently to the U.S. Before settling in the home they are today, they moved to different areas with their daughter. They learned to live life without servants or additional services for daily living. The enjoyed taking walks together. Mrs. G had surgery to remove a benign stomach tumor. During this time, their daughter took care of all their health needs. Their daughter managed all care coordination and follow-up with recovery.

Present Time

Currently they live with their daughter in a newly built home that is designed to support their daily routines. Their daughter, a physician, cares for all their health, finance and living needs. The couple is usually alone in the home

# EXPERIENCE OF OLDER ADULT COUPLES LIVING WITH CHRONIC 252 ILLNESS AT HOME

during the day and manages daily activities together. Due to their declining balance, the couple does not leave the home without having assistance. Also, at this time, Mr. G's siblings all passed, except for a sister, who he skype's from time to time.

Mr. C was hospitalized recently due to a tick bite, which affected his leg and knee. His mobility is very limited. Mrs. C, though she walks very slowly, is active in the home. She likes to read, quilt and knit. Mr. C loves to garden and has a view of the flower garden close to his seat. The couple does not have acquaintances outside of their family. He likes his solitude.

### Response to Pattern & the Pattern Analysis Summary:

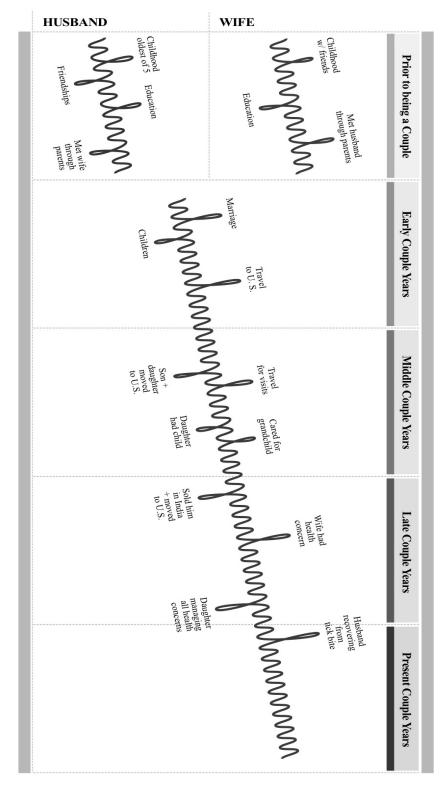
Couple G chose not to continue with the second interview. They did not want to share the private information listed on the demographics and was not comfortable with the interview process. Therefore, the life pattern recognition could not be conducted. The withdraw from the second interview was not surprising to the researcher. The couple voiced many questions about the use of the information and why it was needed, both at the time of recruitment, at the informed consent, and during the interview. The unease to engage in the process may be a cultural response related to privacy and trust.

The pattern analysis revealed a commitment to being a couple from the moment they "sat down and said our prayers during the wedding ceremony." The commitment to each other was demonstrated through mutual sharing of activities and respect, which from their perspective "makes life easy." All living, finance, and health needs is managed by their daughter who is a physician. They recognize how fortunate they are (Mr. G became very emotional when sharing how his daughter cares for them) to have a daughter who cares for them so well. "But for us, we feel that she has done everything possible for us." To Mr. and Mrs. G, "life is full".

Couple G's Narrative Diagram

	Relationship Key: W= wife, H= husband, B= brother, S=sister, D=daughter, S=son, GC= grandchildren, FR=friends, N=Niece & Nephews  =neutral = uni-directional = blocked = bldirectional Numbers: 2= husband	eblocked +	ther, S=sister, D=daught	wife, H= husband, B= brother, S  =uni-directional	Relationship Key: W= =neutral
	oc ec		D	S / B	FR T
	S ← W&H ← D	‡ \$\bigset{1}{2}{2}{2}{2}{2}{2}{2}{2}{2}{2}{2}{2}{2}	₩&H	S	8
Husband enjoys solitude.	•		\$	Ð	
Husband hospitalized last month due to a tick bite. Continues to have complications. Limits his mobility.					
Get together with and skype with husband's sister and nieces and nephews that live in US.					
would like to have someone to read to her due to her declining eyesight.	Son lives in India with his wife and children.		and stay in the US.		
Husband enjoys gardening. Wife enjoys reading, knitting, and quilting. Wife	Learned to use washing machine and dishwasher. They don't miss the daily services they had in India as much.		Husband's work	Followed India tradition of an arranged marriage.	
without support over the past 2 years.	Husband's siblings died, except for one sister.	Had a grandchild.	throughout their time in India.	companies.	marriage.
by daughter), and daily activities together. Unable to leave home	Wife had surgery on a benign stomach tumor.	often to see their children.	Lived in an apartment with a balcony	Educated as a chemical engineer with petroleum	Followed India tradition of an arranged
Couple stays in the home together all day. Manage their medications (set up	Would take walks together.	Would visit the U.S.	and daughter.	sports and friends.	Had a group of friends.
Controlled State of S		parents.	Had two children, a son	Activity childhood with	Enjoyed her childhood.
everything they need including health care and daily living needs	Daughter wanted the parents near her as they aged and they cared for her child.	their education with loans and money from	daily living.	2 brothers	literature.
in her home. Their daughter provides		to the US to continue	services to support their	Oldest of 5, 2 sisters and	Has master's in English
Present Couple Years	Late Couple Years	Son and daughter came	Had servants and	Prior to being a couple	WIFF(1)
Propert Parcels Vance	Lata Canala Vanna	satually County Vonce	Take Canala Vance	in a second	0112111

# **Emerging Life Pattern: Couple G**



### Appendix K: Couple H's Narrative Summary, Narrative Diagram, and Life Pattern Construal

Narrative Summary:

Knowing self and the other supports and strengthens the couple

Couple H has been married for 67 years and had one daughter. They major of their life together focused on being financially stable. Though they both worked hard, they were happy together through all the moments. Prior to Being a Couple

Mrs. H was the oldest of four children. She had 3 younger sisters and they all were very close. They grew up during the Depression, which had an impact on Mrs. H. She remembers seeing so many people that did not food or shelter. Though their family had more than most, she still remembers there were limitations. Mr. H was also the oldest in his family. He had 2 younger brothers and sisters. His family grew up in a metropolitan city. His father and his uncles were immigrants from Russia. They started a produce business that he eventually worked. Mr. H's family was not close, but were "there for each other". "Contrary to her family, my family... we seemed to be more private to each other, we didn't... celebrate birthdays and stuff like that. I mean, we were there for each other...But just,...not very emotional". Mr. H served in WWII.

They met each other at a party, where they were the only non-married people there. "All they talked about was babies and the diapers and the dishes. And so right after the meal, he said to me, "Let's get out of here." They dated for three months before they were engaged and then married 6 months later. "My father said, "You go out with so many other nice boys, what do you see in him?" I said, "Daddy, he's really nice. He's a nice guy." Early Years

The early years were hard years. Mr. H started his own produce business. He worked very long hours many days of the week. Mrs. H was also working as a secretary. In the evenings, she would do the accounting for the business. The business struggled for a number of years with amounting. The business ended with the couple owing a large debt. Mr. H worked odd jobs and worked long hours. Mrs. H contributed her salary too to help pay down the debt. During this time Mrs. H became pregnant and 6months into the pregnancy her father died suddenly. It was a difficult time, but their joy was the birth of their daughter. "...so that was really a hard time in our lives. But we did it. We worked hard. Buddy never got to see our child as a young child very much because he was working 20, 24 hours a day. But you know what? We can hold our heads up. We don't owe anybody anything. And nobody helped us. We did it on our own." Being financially stable was very important to Mrs. H. It made feel more secure and worry less about life.

Middle Years

The middle years were brighter. The couple purchased a franchise cleaning company that did very well. Mrs. H continued to keep the business'

books, while maintaining a fulltime job that she loved. Their daughter married and had 3 children. They were very close to her family through the childhoods of the grandchildren. They both retired at the ages of 64 & 65, and bought a home in Florida to enjoy during the winters. They slowly renovated the home. They met many new people that they shared common interests. During this time one of Mrs. H's sisters died of pneumonia.

The later years were filled with more transitions. They decided to sell their Florida home since the "people were changing" and their family home since the "neighborhood was changing". Their friends were either leaving the area or dying. Younger couples moved in to the neighborhoods that they did not share common interests. They moved into the retirement community with ease and comfort.

One year after moving into the retirement community, Mr. H was hit by a car suffering extensive and serious injuries. He required extensive surgeries, hospitalization and recovery time. Mrs. H was devastated. "I went into the bathroom, and I started to cry. And I kept saying, "It can't be. It can't be." And it was just awful for me ... I don't really know what we would have done without our daughter." Their daughter took a leave of absence from her job to support the couple and stayed with her parents for three months until they could manage on their own.

### Present Time

Later Years

At the present time, the couple is financially secure and overall "healthy". They consider themselves "lucky." Mr. H continues to do well after the accident. He and Mrs. H work with a physical trainer to maintain mobility and balance. Mr. H continues to drive. However, they tend to stay at the retirement community most of the time. Socializing and helping to care for Mrs. H's two sisters that live in the same community home. They also maintain a close relationship with their daughter and grandchildren.

They enjoy living at the retirement community and have made new relationships. The couple is active both together and individually in different clubs and activities offered at the home. They take each day at a time, making life choices that maintain their health, which is very important to them. "I just hope our health stays up." Mr. and Mrs. H feel as though they have lived a full life, looking "forward to the success of [their] children and grandchildren", which is "the only real thing with any meaning" to them." "We have enough money to see us through, our daughter is well taken care of, everything is in order. We have a will, ...everything should go smoothly. We even have cemetery plots. So, my main concern is to keep the status quo."

### Response to Pattern & the Pattern Analysis Summary:

When both the life pattern construal and narrative diagram were presented to Couple H, they seemed unimpressed with the life pattern, "...we've done everything, we've done the traveling." They recognized it as their own; they lived it, without a need for validation of it. They are content in life, financially secure and physically health. "...no couple married 67 years would go without an

# EXPERIENCE OF OLDER ADULT COUPLES LIVING WITH CHRONIC 257 ILLNESS AT HOME

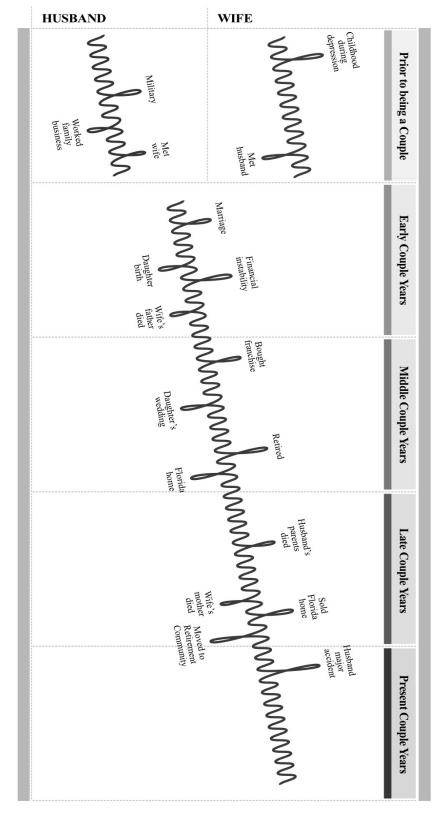
argument, but it's over like that...we're okay...there is nothing to fight about." The focus is maintaining their health together. However, Mrs. H does worry from time to time about being without Mr. H. "I don't know what I would be or do without him. I can't -- sometimes I think about it, how will I be?"

The pattern analysis revealed that Couple H managed life together as a couple as well as individually, using their individual strengthens to benefit the couple and then supporting the other to minimize their limitations over their life together. "He is a lot stronger than I about how things will out come out. His glass is half full, and my glass is half empty...we blend well, because I will look at things realistically, and he'll look at them, "Don't worry about it, it's going to be OK...it works out just right."

Couple H's Narrative Diagram

	FR=friends Numbers: 1=wife, 2=husband	Relationship Key: W= wife, H= husband, M=mother, F= father, D=daughter, S;r=sister, B=brother, GC=grandchildren, FR=friends = uni-directional =	d, M=mother, F= father, D=daughter, Sr=siste = <u>uni</u> -directional	wife, H= husband, M=m >=unj-di	Relationship Key: W=
	Sr-1 VFR	FR GC	<b>↔</b>	В / Усг	<b>←</b>
↑ <del>SR</del> -1	W&H AC	Sr-1 (W&H) Sr-1 Sr-1	W& H	E E	N St
7	M-1 D	M-1 D	M-1 F-1		
Husband's siblings had all passed			Daughter educated as a physical therapist.		
Husband and wife have physical trainer since car accident.	recovery for both parents		books for their business.		
	Daughter was a strong support		Wife employed in an office and kept the	Was in military, WWII.	
theatrical productions, go to gym, history club, card club.	rehabilitation.	Wife's sister died of pneumonia.	meet.	with his brothers.	through mutual friends.
retirement community, e.g.	hospital including surgery and		Husband took old jobs to make ends	grandfather started	Met her husband
Active in different clubs at the	serious injuries requiring extensive	enjoy during the winter months.		business that his	
	Husband was hit by a car with	Had a home in Florida and fixed it up to	Birth of daughter.	wholesale produce	dating him.
grandchildren.	Wife's mother died.	lite can be unpredictable.	Couple was close with her mother.	Worked in the family	her relationship with her husband while
Close with daughter and		wanted to retire but decided to since		hours.	Her father questioned
concinent continuity	was seamless.	business. The wife was not sure she	months pregnant.	His father worked many	
retirement community	Transition to retirement community	Retired at age 65 and 64 after selling	Wife's father died when they were 6	"head of household".	were very poor.
200	into retirement community.			His mother was the	saw many people who
Wife socializes with her 2 sisters	Sold single family home and moved	Birth of grandchildren (3).	social life.	Family was not close.	had the basics but she
			Worked very hard to pay off debt. No		depression. Her family
friends	demographics.	marriage.		Grew up in the city.	up due to the
community and have many	moving in were of different	Marriage of their daughter. Has a good	amount of money.		Life was hard growing
Enjoy living in the retirement	friends moved or died. The people		and they were in debt for a large	2 younger sisters.	
	Sold the home in Florida since their	the books.	industry changed. The business folded	2 younger brothers and	sisters.
healthy.		did very well. Wife continued to keep	business with a partner. Produce	The oldest of 5 children,	The oldest of 4, all
Secure financially and physically	Granddaughter's marriage.	Bought franchise cleaning business that	Financial stability was tough. Had a	HUSBAND(Z)	WIFE(1)
Present Couple Years	Late Couple Years	Middle Couple Years	Early Couple Years	Prior to being a Couple	Prior to bei
,	1.1.0	Wildlian Complete	Talk Assault Value		

# **Emerging Life Pattern: Couple H**



### Appendix L: Couple I's Narrative Summary, Narrative Diagram, and Life Pattern Construal

Narrative Summary:

The influence of each other through the fluctuations of movement and diversity brings a new life dimension of being as a couple.

Couple I has been married for 47 years. They have three children, 2 sons (one adopted) and a daughter. The family traveled extensively together, even living in other countries for periods of time. The couple attributed this experience for their openness and understanding of difference in others and ways of thinking. Though they both are experiencing health concerns, they continue to enjoy the family and look for new opportunities.

Prior to Being a Couple

Mr. and Mrs. I had different backgrounds and experiences while growing up. Mrs. I was the youngest of two sisters. She was dyslexic and was bullied in school, with even the teachers creating embarrassing situations for her. "Something like that makes an impression on you." Her family was Jewish and very liberal politically. She went to college and studied computer programming. She married, in an appearance to be a "good girl", since they had sex while dating. However, the marriage ended in a short time. Mr. I was the oldest of three, two younger sisters, and brought up in a politically conservative household. His father was from "high society", and his mother enjoyed the lifestyle. The family situation changed once his father became ill and then moved to a farm. The majority of Mr. I's life was spent on the farm. His mother became disengaged with the family, and created her own life outside of the family. This created a distance between himself and his mother. Mr. I also attended college and studied Internet technology. After college he became a reservist in the military to avoid the draft.

Mr. and Mrs. I met as neighbors. They dated on and off, until expectantly Mr. I proposed, which was after he broke off another relationship and quit smoking. "If he smoked, we would not have been married." Mrs. I was 26 years old and Mr. I was 31 years old when they married. "Both families [did give the marriage a chance], because we had different religions, we had gross family political differences." Sometime before they were married, Mr. I's father died. Early Years.

The early years were very stressful. They experienced 5 miscarriages and 17-month stillborn birth, without an understanding of the cause. Mrs. I was experiencing health symptoms that were vague. "...I had a 7-month still born and 5 miscarriages and a 6 month baby in the 70's. We knew something was wrong with every muscle, which showed up on the EMG's, we had the top EMG specialist in the world." They eventually had three children, 2 sons (one was adopted), and a daughter. The daughter, as an infant, was misdiagnosed with a potential brain dysfunction, which reinforced Mrs. I mistrust of medicine. All the children had a form of learning disabilities; the adoptive son was the most severe.

The family lived abroad for many years and traveled. Once back in the States, they bought a home on 3 acres surrounded by nature that was their home for 37 years. Mrs. I would walk to reduce her stress and manage her symptoms. Mrs. I also struggled with advocacy for resources for her children's learning disabilities. Though there was little help from the families with the children, they did have a very close couple for support. Mr. I's mother died. His 2 sisters said, 'she should have died when dad died."

### Middle Years

During the middle years, Mr. and Mrs. I both earned Masters degrees. Mrs. I was working part-time and Mr. I was fulltime in the technology industry. It was also a time where the majority of the focus was spent on understanding Mrs. I's health issues. She vigorously researched and sought out specialists across the world. Mr. I was very supportive of Mrs. I exploration. Through her research, she was introduced to the supplements and nutritional changes that improved Mrs. I's symptoms. Mr. I retired from the technology industry and they both started a nutritional business prompted by the need to improve their health.

The couple was also supporting their middle son who was struggling with finding a path in life. Mr. I and the middle son were not close. Their son thought that Mr. I treated him differently.

### Later Years

As Mrs. I continued her search for a diagnosis and effective treatment, she became interested in energy work, which lead her to think she had chronic Lyme disease. She was tested and the diagnosis was verified. It was also during this time that her co-workers suggested she go to a personal development course since she had a tendency to be "angry". Mrs. I was so moved by the experience, she encouraged Mr. I to attend further courses with her. Also, all their children attended at least one of the courses as well.

Their children started to marry and have children. The middle son is in a relationship and found a job he enjoys. Since that time Mr. I and his relationship with his son is more "comfortable". Health concerns for Mr. I began. He experienced a stroke at his daughter's wedding followed by another one not too long after. He was diagnosed with sleep apnea and a malformation in his heart. Mrs. I cared for both her mother and father when necessary until their deaths.

As their friends moved and the home became too large and expensive for them, they decided to sell the home and move closer to their grandchildren in another state. Their daughter's family soon moved again to this state.

Present Time

Mr. and Mrs. I decided to follow her daughter's family to be near them. They bought a 55 or older condominium 2 years ago with a limited backyard and areas of nature. Mrs. I is frustrated with the lack of nature for her walks. Mrs. I is not as happy with the condo community as Mr. I. However, they are meeting people and becoming involved in local activities. Mrs. I said she has not found a connection with people, where Mr. I is fine with the level of connection.

Both are experiencing health concerns. Mrs. I was recently diagnosed and treated for atrial fibrillation and breast cancer. During a recent scan, a small "spot" was found on her pancreas. Mr. I was diagnosed and treated for skin

# EXPERIENCE OF OLDER ADULT COUPLES LIVING WITH CHRONIC 262 ILLNESS AT HOME

melanoma and is having difficulty swallowing. Due to recent health issues they have not traveled as much outside of the country but still are vacationing. They are looking forward to spending time with their children, grandchildren, volunteering and travelling as much as possible.

### Response to Pattern & the Pattern Analysis Summary:

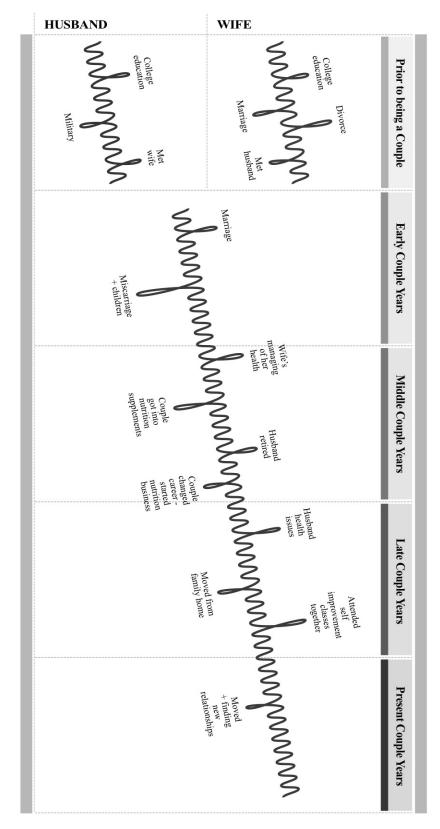
When the life pattern construal and narrative diagram were presented to Couple I, the response was one of contemplation. As a couple they reflected and noticed how their life had more conflict earlier than it does now, "I think we get along together, we live together, more easily today than we did 40 years ago". They then put it into context of life and what was occurring at the time, "...it's a lot different when you're dealing with 3 kids, and tension, and working, and everything else that was involved. And there were political differences back then that are not as dramatic today. Certainly money was more of an issue."

The pattern analysis revealed that the couple's relationship takes place within a fluctuation of movement and diversity, including struggles and joy, each partner influencing the other, coming to a new dimension of life of being, as a couple. "Even with all the trauma that I've had, going back to my education, and then the medical issues and everything else, those all impacted my life, but I still have had opportunity to do so much more than most of the people on the planet...it brought out to me how blessed we really are...I think not only between the two of us, I think we're really blessed as a family unit."

# Couple I's Narrative Diagram

nd	efriends, Ex=ex-husband ectional Numbers: 1= wife, 2= husband	Relationship Key: W= wife, H= husband, S <u>r</u> =sister, D=daughter, S=son, SIL=soninlaw, GC= grandchildren, FR=friends, Ex=ex-husband = neutral = sun; directional = sun;	er, D=daughter, S=son, SIL=sonin tional ====================================	wife, H= husband, Sr=sister, D=	Relationship Key: W=
GC FR	GC D-SIL	D	D	Sr.	EST.
S (W&H)	→ W&H → S	W&H S	\$ (w&H) ↑	H W	w Ex
) <del>  D-SIL</del>	FR M-1	) Z	M.1 M.2 F.1	)	) \ \ \ \ \ \ \ \ \ \ \ \ \ \ \ \ \ \ \
follow up on swallowing.	Husband and middle son's relationship became more comfortable.		Both worked in IT.	He married at 31.	
finding on pancreas. The husband was	area and home 2 years ago.		Husband's mother died.	Dated his wife on and off.	
fibrillation and requires follow up on recent	would live. Moved to Colorado then to this	improve health.	disabilities of all the children.	married.	
Both are managing health issues. Wife	Sold family home and moved to apartment	started nutrition business,	C+ringled +brough lograins	Esthor died hofers asting	
		Couple made a career change,	medicine.	Quit smoking.	got re-married.
travel as much as possible.	Friends in neighborhood moved.		medicine. Started mistrust of		She was 26 when she
Enjoy traveling and want to continue to		last few years.	Daughter misdiagnosed by	draft.	
	Had grandchildren.	Wife didn't enjoy the IT work		military to avoid the	neighbors.
in volunteerism.			that was not diagnosed.	Was a reservist in the	Met her 2nd husband as
Working on building activities and engage	sleep apnea.	consulted.	Wife contracted Lyme disease		
	wedding day. Husband diagnosed with	Husband retired from IBM and		College educated.	politically.
community as the nusband.	Husband had a stroke on daughter's		friends including holidays.		Family was very liberal
rriendships. Wife not as settled in the		symptoms.	Shared family life with close	conservative politically	
starting to meet people and making	needed until their deaths.	supplements to reduce		Family was very	and divorced.
Charling to most poople and making	Cared for wife's mother and father when	Wife changing diet& using	Tokyo for 3 years.		Was married previously
Support of their positions.			Traveled with children. Lived in	Mother was distant.	
nusparte their business	different life outlook.	treatment.	,	Grew up on a farm.	College educated.
Highand Apoc little committee projects and	together. Friends changed due to their	wife's exploration for	from family.	0.00	
Sons are in relationships.	Experienced personal development	multiple testing and seeking	Baicod children without holy	father became ill	in school
	supplements.	of wife's health issues with	a daughter in four years.	,	
years ago to be close to daughter's family.	was verified by lab results. Both takes	Spent years trying to find cause	Had two sons,[1 adopted] and	younger sisters.	sister.
Bought condo in 55 and older community 2	work and self-diagnosed chronic Lyme that			Oldest of three, 2	Youngest of two, a
	effective alternatives. Wife got into energy	Masters.	miscarriages.		
Moving away from life-long close friends.	Wife research's health conditions for	Wife & husband completed	Had 7 month stillborn, 5	HUSBAND(2)	WIFE(1)
Present Couple Years	Late Couple Years	Middle Couple Years	Early Couple Years	Prior to being a Couple	Prior to be
				- 2000	000000000000000000000000000000000000000

# **Emerging Life Pattern: Couple**



### Appendix M: Couple J's Narrative Summary, Narrative Diagram, and Life Pattern Construal

Narrative Summary:

Commonalities that bond the couple provides the momentum to continue

Couple J met at their sibling's wedding and has been married 43 years with two children, a son and daughter. This is the first marriage for each with the husband being 15 years older than his wife. Their life together has been filled with family, a love of traveling on cruises, and fishing. They enjoy the simplicity of life, but have experienced several losses of significant relationships.

Prior to Being a Couple

Mrs. J was the middle child of three. She had an older and younger brother. Mrs. J had an especially close relationship with her younger brother. Her family life was close and happy. She lived was educated as a registered nurse and lived with her parents until she married. Mr. J was the second oldest of four children, an older brother and two younger sisters. He attended college and studied optometry. Soon after graduation he was drafted and served in the Navy like his older brother. His mother died at 46 due to asthma complication. Mr. J's father remarried. He and his sisters did not feel welcome in the home. He moved the sisters to an apartment and lived with them until his sister married his wife's oldest brother. He then bought a house and lived with his other sister until she married. Mr. J was teaching at the university and wanted to be a bachelor.

After meeting each other at their sibling's wedding, they did not see each other until after he was living along in his home, which was not far from his wife's parents home. Mrs. J mother was responsible for the two of them reconnecting. They dated for a month before getting in engaged (on Thanksgiving) and then married 3 months later. He was 44 years old and she was 28.

Early Years

The couple lived in the husband's home that was on a cul-de-sac with surrounding land. Mrs. J practiced as a RN until their first child was born and the second followed. They decided that Mrs. J would stay at home with the children while Mr. J was on a tenure track at the university. Adapting to the marriage was smooth. "We knew what we wanted and had what we needed, so it was not a hard marriage to get adapted to at all. It was nice." The couple enjoyed their neighbors and was very close with Mrs. J's parents. "My mother loved him [Mr. J]. However, Mrs. J's relationship with her younger brother changed and he missed her friendship and companionship. "I would have liked to have done more with him as he would have liked to have done more too. It was difficult to break apart. And then, when he got ill. He was blind. He was on dialysis, and he had both his legs amputated, ...but in a short period."

The middle years started smoothly. The couple enjoyed traveling once the children were older. Mr. J reconnected with his older brother and would visit

with his son. Mrs. J remained involved with her younger brother who was in a nursing facility. Mrs. and Mr. J would take him out on excursions whenever they could. Their children married.

Mrs. J's older brother suddenly died on a vacation in his early forties (who was married to Mr. J's sister). It was a very difficult time for both families. Mrs. J's parent's health declined and both were also in nursing facilities for care. Mr. and Mrs. J visited often.

### Later Years

Mr. J retired as professor emeritus and was home with Mrs. J. They completed major home improvements thinking they would live in the home the rest of their lives. Mrs. J became paralyzed after a back injection and was in rehabilitation for 4 months. She eventually was able to use a walker, but is now using a wheelchair most of the time. Mrs. J was also diagnosed with diabetes, which terrified her because of her younger brother's diabetic diagnoses. Mrs. J quit smoking soon after returning home. Mr. J also experienced health concerns, pancreatitis.

Family and friends were moving away from the neighborhood. Her younger brother, mother and father all died within a year of each other with 2 of the deaths on Thanksgiving. The amount of loss of such close relationships was very difficult for Mrs. J emotionally; it was devastating. Mr. J also lost his oldest brother during this time.

Their children had children, which brought joy to their lives. "You don't know how grandchildren can impact your life." They tend not see their son or his daughter very often. "I lost my son...his family is much close to his wife's family." Their daughter began to talk about them moving closer to her and living in a retirement community. They eventually agreed and moved to where they are living now 6 years ago. Mr. J did not have a concern about giving up their possessions or moving, whereas Mrs. J found it difficult. Mr. J stated, "I had a lot of possessions in that house. It had an attic and a cellar plus the house, and we were throwing things away, giving things away." Mrs. J stated, "That was difficult because it was things that we actually saved."

Mr. and Mrs. J are having challenging times. Mrs. J has been struggling with depression since her parent and brother's deaths, which affects her ability to maximize her physical potential. "I don't do death well." She does see a counselor that helps her see the good in her life. She is wheelchair bound and reliant on her husband to maneuver her when they go out. This had limited their ability to travel on short trips. She also may lose sight in one eye since she did not follow instructions for care. Mrs. J is terrified of going blind and is having a number of procedures to try to correct the problems. Mr. J, 15 years older than Mrs. J, is also experiencing many health concerns that have been ruled out. He considers himself healthy but is slowing down. They use to exercise together, "but stopped one day and never went back."

Their daughter's children bring great joy to them. They sleep over one at a time, so they can give each special attention. The grandchildren love coming to the retirement community and meeting the people. The couple also shares the

# EXPERIENCE OF OLDER ADULT COUPLES LIVING WITH CHRONIC 267 ILLNESS AT HOME

holidays with Mr. J's sisters and their families. Though Thanksgiving is a tough holiday, they "get through it." However, Mrs. J is not as happy living there. She misses their home and has not meet any close friends where they are living. "I really think I was much happier. Partly because I wasn't ill then. I drove my own car, bought my own car, and drove wherever I wanted, -- the time of night didn't matter." Mr. J wonders what will be the condition that ends his life. He does not dwell on it, but knows it could be anything.

Response to Pattern & the Pattern Analysis Summary:

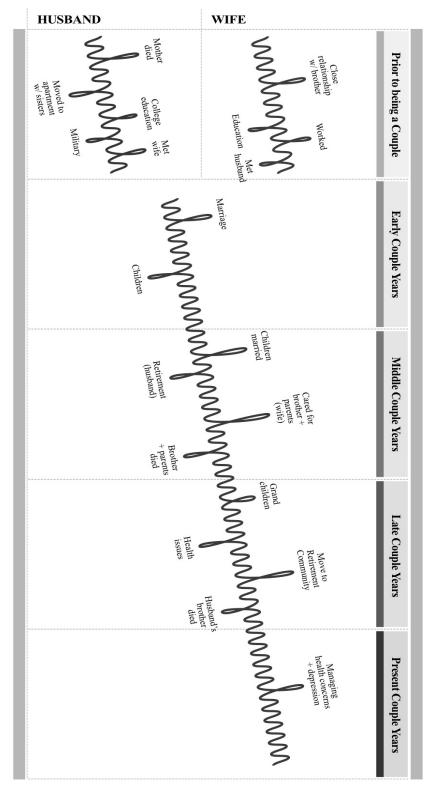
When the life pattern construal and narrative diagram were presented to Couple J, a response by Mrs. J was "It was done really well, as far what was going on." Mr. J never responded directly. However, they both stated that getting married was the most meaningful event followed by the grandchildren. Mrs. J did ask for Mr. J to share what he is thinking or to give her feedback when she tells him something that happened to her. He responded, "Well, I'll see if I can do better."

The pattern analysis revealed that the emotional burden created by the loss of the major relationships in Mrs. J life has created a cascaded of situations challenging the couple's ability to embrace living to the fullest. Mrs. J states, "I don't look forward. I don't like now that much." Mr. J states, "I am ...just concerned what illness is going to take over my life as I'm growing older." Mr. J understands he is her caregiver and maybe concerned for her if he is unable to care for her. However, even with the life challenges, each are there for the other to continue. Mrs. J stated, "It's been forty-some years", and Mr J. said, "Well, let's start another 40 years."

# Couple J's Narrative Diagram

pmother	Relationship Key: W= wife, H= husband, St=sister, B=brother, D=daughter, S=son, SlL=soninlaw, DlL=daughterinlaw, GC= grandchildren, FR=friends, SM=stepmother = neutral = unit daughter = plocked = bidirectional = numbers: 1= wife, 2= husband	son, SIL=soninlaw, DIL=daught	=brother,D=daughter, S=son al =blocked	wife, H= husband, Sr=sister, B=	Relationship Key: W=
<b>₩</b>	<b>↔</b> (	D.SIL FR	D (FR	\begin{align*} \begi	В
D.SIL W&H	D-SIL W&H S.DIL	S.DIL W&H B-1	S W&H B-1	н 5М	× T
GC <b></b>	<b>♣</b> 8-2	M-1 B-2 F-1	M-1 F-1	F 35	A L
Miss their single-family home, was much happier there.	Husband's older brother died.				
pancreas and screening for other health concerns.	Husband didn't mind leaving possessions and moving. The wife found it difficult. Daughter and son-in-law helped with the move.			Married at 44 years old.	
Husband has recurring issue with his	Moved to retirement community 6 years ago.			Wanted to be a bachelor.	Married at 28 years old.
depression.		sister, heartbreaking for family.	Had a son and daughter	and taught at the university.	time at the wedding.
her brother. Wife treated for		was married to husband's		Earned a degree in Optometry	Met husband for first
wife, doesn't want to go blind like		Wife's older brother died, who	the wife's family.		married her brother.
had surgical treatment. Weighs on	Family and friends moved from the neighborhood	retired as Professor emeritus.	street and was close to	ant married	Huchand's sister
wire may nave lost vision in I eye	died within 3 years.	Husband became Professor and	neighborhood, had a	near the wife's parents and	boat.
Wife man based based by a few sections in the	Wife's younger brother, mother and father all		Enjoyed their	He bought a home which was	Bought a corvette, had a
the family and husband's sisters.	Children live in the area, don't see their son often.	with his older brother, visited with his son.	but still close.	with 2 sisters in an apartment.	nursing and practiced.
Counte enjoys the holidays with all		Husband rekindled relationship	younger brother changed,	family. Moved out of the house	Earned a diploma
at a time.	Had grandchildren.		Wife's relationship with	Did not feel welcome in step-	
Grandchildren have sleep overs, one		often.			Family was close.
	Wife diagnosed with diabetes. Wife guit smoking	nursing care facilities & visited	home near wife's family.	Served in the Navy for 2 years	Lived with parents.
helps her.	rehab for 4 months.			father remarried.	together.
wheelchair when they go out and	procedure for back pain. Used a walker after	progressed.	track at the university.	complications of asthma.	brother, liked to fish
Husband maneuvers wife in	aneurysm. Wife was paralyzed due to a	brother's life as his diabetes	Husband was on tenure	Mother died at 46 due to	Very close to younger
	experienced pancreatitis twice. Worked up for	Very involved in younger			
accessibility.	Changes in health started to occur. Husband		after the wedding.	brother and 2 younger sisters	children, 2 brothers
immobility and lack of handicap		Daughter & son married.	which was in a few years	One of 4 children, older,	Middle child of three
difficult to travel now due to wife's	thought they would stay in their home.	enjoyed traveling, cruising.	she had their first child,	HOSBAND(Z)	WIFELL
Present Couple Years	Late Couple Years	Middle Couple Years	Early Couple Years	Prior to being a Couple	Prior to

# **Emerging Life Pattern: Couple J**



## EXPERIENCE OF OLDER ADULT COUPLES LIVING WITH CHRONIC 270 ILLNESS AT HOME

# Appendix N: Couple K's Narrative Summary, Narrative Diagram, and Life Pattern Construal

Narrative Summary:

Maintaining the "self" to enrich choice and the meaning of the couple

Couple K is Canadian born and moved to the United States in their early thirties. They will be married 60 years, have 4 daughters and many grandchildren. Family and faith are a constant thread through their lives together. They are active and engaged fully with others and their surroundings. Prior to Being a Couple

Prior to being a couple Mr. and Mrs. K spent their early twenties obtaining education and working in their careers. Mrs. K 's family was close. Mrs. K was the youngest of 11, 5 sisters and 5 brothers. She admired her mother throughout her life and frequently remembers her advice. Mrs. K attended one year of college before deciding to go to nursing school. At that time university education was not available for nursing. Once she earned a nursing diploma, she became engaged and she practiced in nursing until her brother approached about becoming a flight attendant (at that time to be a flight attendant, you had to be a nurse), which she agreed to do. Eventually, Mrs. K broke off the engagement.

Mr. K was the youngest of 4 children, 2 sisters and 1 brother. There was 11 years between him and his sibling before him. Mr. K attributes his independence and being of an analytical nature to the number of years between him and his other siblings, as well as his parent's relaxed style. He grew up on a farm and was very close with his family. He was the only child that went to college and then worked in the oil industry. He had no intention of getting married.

The couple first met each other in the recovery room of a hospital. Mr. K had an appendectomy and Mrs. K was his nurse. Three years later, they met again when Mrs. K was a flight attendant and Mr. K was flying for work. They dated for two years, Mrs. K knew she wanted to marry Mr. K. Mrs. K had to give Mr. K "a push" to consider marriage. They soon married after. Mr. K stated, "I guess I fell in love", as the motivation to get married. Early Years

They had four daughters and a dog. The couple was active together and faith was a strong family value. Mrs. K cared for the children in the home while Mr. K worked in the oil industry. They decided to move to the US for a better job opportunity when the children were still young. They relocated easily and lived in an active, engaging neighborhood. They also bought a ocean home in Canada, next to Mr. K's parent's home, and visited often. Once the children were in high school, Mrs. K decided she wanted to practice nursing again. She was told she needed to go back to school due to the length of time out of practice. She took it upon herself to study all the required materials on her own, since she could not commit to a nursing program. She passed the licensure exam.

### Middle Years

Mrs. K had a hysterectomy. While in the hospital she spoke to one the nursing supervisors who then offered her a job. She practiced nursing for the next 20 years. Over time, all their daughters got married, "married in the church…no living together."

Later Years

Mr. K retired from the oil industry, but consulted on the side. Mrs. K also retired within 2 months, and they did not have a dog. Now that they both had limited obligations, they traveled and took cruises more often enjoying the time together. They also enjoyed time with their 13 grandchildren. Every June through September the families went to their ocean home. Since the couple split their time between the ocean home and their family home, they decided to sell their family home of 43 years and move to a retirement community. The decision was a easy, since they no longer had to worry about their home when they were traveling. During this time, health issues began with eye concerns for Mrs. K and cardiac issues and prostate concerns for Mr. K.

Present Time

At the present Mr. and Mrs. K have lived in the retirement home for the past 6 years. Mr. K is now fully retired. The living arrangement meets all of their expectations and needs. They are very active in the community home, playing cards, bowling, church leadership and supporting the library. The couple has met other couples they find interesting and keep a full dinner calendar. They don't travel by plane anymore, but they continue to spend the summers on the ocean with their daughter's families and go on short car trips. They attend grandchildren's sporting events, which they say "keeps them young" and the family golfs together. The holidays are always full with all the families getting together.

### Response to Pattern & the Pattern Analysis Summary:

When both the life pattern construal and narrative diagram were presented to Couple K, shared the pattern was their own. However, they had different thoughts about the meaning of the pattern. Mr. K shared that there was no meaning or benefit for him. Mrs. K. shared that she did not learn anything new, but that "when you express words you begin to realize the quality of it all." She said she had to think about why she did what she did and "really did not know." Mrs. K goes on to share it was benefit to review the pattern because "it makes you stop and appreciate...putting it into words is interesting...it's food for thought...because we don't stop long enough to analyze properly, but when you really put it into words you stop and say, yeah, I guess so...we probably did all okay." They consider themselves blessed and very fortunate.

The pattern analysis revealed a conscious effort by Mrs. K to maintain her independence within the relationship currently and over their life together. Though Mrs. K was able to maintain a sense of self throughout their relationship, e.g. worked outside of the home, maintained different interests, the relationship was in context of the traditional male head of household and Mr. K embracing the

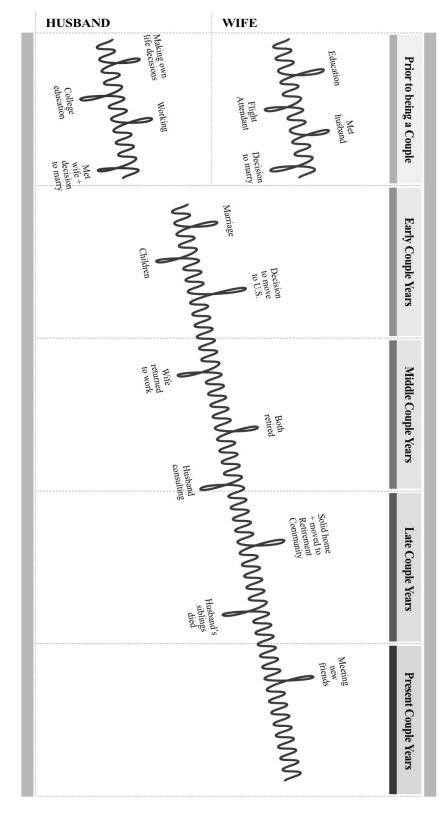
# EXPERIENCE OF OLDER ADULT COUPLES LIVING WITH CHRONIC 272 ILLNESS AT HOME

power and control. Her awareness of maintaining her identity was demonstrated throughout the flow of the dialogue, inserting her life experience and perspective often after the husband's experience. She expressed her concern of being further dependent on Mr. K, since she recently gave up driving. "I'm becoming too dependent on him. That's my biggest problem. I expect him to have all the answers and I, you know. But in that way you can lose your independence because you become dependent. That's not good either." Mrs. K maintains "herself" by "branching out" on her own and doing "things he wouldn't do."

Couple K's Narrative Diagram

	Relationship Key: W= wife, H= husband, M=mother, F= father, Sr=sister, B=brother, D=Daughter, SIL=soninlaw, GC=grandchildren, FR=friends, P=pet  -neutral + united + beligher +	-Daughter, SIL=soninlaw, GC=gra	other, F= father, Sr=sister, B=brother, D=D =ymj-directional	wife, H= husband, M=mother,	Relationship Key: W= w =neutral
FR GC	D-SIL	SO	S	**************************************	S72 By
D-SII W&H D-SII	D-SII W&H TIS-O	W&H	W&H P	ж Т,	<b>E</b>
D-SIL D-SIL	GC D-SII	M-1 M-2 F-2	M-1 M-2 F-2	M TI	
Husband one sister is 95 lives in Toronto.					
Attends grandchildren sporting events.			Lived in a very active, engaged neighborhood.		
Family gets together for holidays and family events.	Husband volunteered at a retreat home.		family.	off a plane. Married 2 years later.	push" to consider marriage.
			Faith is important value of the	Two years later saw he coming	She gave her husband "a
Sept.	Wife doesn't drive due to eve issues.		Played tennis together.	First met wife when he had a surgical procedure.	time.
Earth ages to seem home from line to	and his brother died 8 years ago.				attendant for short
Wife continues to refer to her mother.	Husband's sister died at 95 last year		Husband worked in oil industry.	Never thought of marriage.	Worked as a flight
Doesn't travel much now by plane.	Have 13 grandchildren.	Couple's parents died.	Wife cared for children in the home.	college.	nurse.
	community (RC)	industry job.	children were young.	Only sibling that went to	Had 1 year of college then educated as a
Play golf together and with family.	and moved to the retirement	Husband retired from oil	Canada due to husband's job when	with family.	
	Sold their family home of 43 years		Moved family to the US from	Grew up on a farm and close	Admired her mother
Met new friends at the RC and keeps a social calendar.	Traveled a lot once they retired.	Wife had hysterectomy.	Had 4 daughters	reit like an only child.	Very close family.
powling, and supports the library.	ANIC ICCII CO II CIII II CIII CII	once children were grown.	parent a point.	difference from closest sibling.	5 sisters and 5 brothers.
community church, playing cards,	months before the wife.	Wite studied on her own to	Bought a summer home across from	Volume of A shilling 11 son	V
Enjoy living at the RC. Very active in the	Husband retired from consulting 2			HUSBAND(2)	WIFE(1)
Present Couple Years	Later Couple Years	Middle Couple Years	Early Couple Years	Prior to being a Couple	Prior to
				,	

# **Emerging Life Pattern: Couple K**



### Appendix O: Couple L's Narrative Summary, Narrative Diagram, and Life Pattern Construal

Narrative Summary:

A partner's experiences and insights are shared within the couple to further meaning and awareness, as a couple.

Couple L spent close to half their lives together as a military family, which required travel and living in different areas across the country in other countries with their children. This experience provided them and their children an appreciation and understanding of other cultures and people. Since that time they adjusted to civilian life, and continued to value and enjoyed traveling. Prior to Being a Couple

Mr. and Mrs. L have similar childhoods and the same faith. Mrs. L was the oldest of 3 children, 2 younger sisters. When she was 7 had a concussion due to a fall from the second floor of her home, hitting her head on a step. She spent a week in bed. Her mother was a strong influence in her life, especially regarding her education and development. Mrs. L's mother was an artist and the first to earn a Master's at a liberal arts college. Both Mrs. L's parents expected her to attend college, which she did. She majored in English and minored in education and art. She became a teacher, as she wanted to do. Mr. L was the oldest of 4 children, 2 brothers and a sister. He also wanted to be a teacher and majored in English and minored in philosophy. He lived with his family through college. The draft for the Vietnam War was active at the time. He joined ROTC to ensure he would be an officer if he were drafted.

Mr. and Mrs. L met at a college dance. He asked her to dance and then dated. They decided to marry once Mrs. L completed her degree. While Mrs. L was studying, Mr. L enlisted in the military for 2 years to help save money for the wedding.

Early Years

The early years were very busy. Mr. L was in the infantry at the start of his career, and was not able to come home for long stretches of time. He did not see his first daughter until see was 1 year old. While in Vietnam he was exposed to Agent Orange. After a year Mr. L change assignments to military intelligence. When his military assignment ended, he decided to stay in the military for next 23 years. During that time they had two other children and moved 15 times. Mrs. L tried to teach but found it was very difficult to maintain consistent employment due to the moves and the required volunteerism expected of military wives. The military community became very important to them for support and socialization. "It is very difficult to live with one foot in each society. It doesn't work."

Mrs. L experienced another concussion while out with her in-laws and children, which created headaches and fatigue for a period of time. Mr. L got his Masters and his brother die.

Middle Years

# EXPERIENCE OF OLDER ADULT COUPLES LIVING WITH CHRONIC 276 ILLNESS AT HOME

At the beginning of the middle years, Mr. L retired from his military career and they moved into their family home of 32 years. Mr. L was declared 100% disabled due to his exposure to Agent Orange. The move into civilian life was an adjustment. They noticed differences between the social expectations of military and civilian life. At the time, there were not any teacher positions available. Mr. L then worked in related fields such as security and then retrained to work as a paralegal. Mrs. L also moved into a different career as an accountant. They were social with the neighbors and played bridge with a group they met at a bridge class. Mrs. L loved to garden.

During latter part of this time, they cared for their parents and the children started to marry. Mrs. L's mother moved in with them. Her mother had strokes and developed Alzheimer's toward the end of her life. This was a very difficult time for them. Mr. L's parents were in an assisted living facility. The couple would visit them every Sunday until their death. Their home was busy with the children and their spouses living with them from time to time until they were settled in their own homes.

### Later Years

The later years were the time when Mr. and Mrs. L retired and grandchildren entered their lives. Health issues started to develop. Mrs. L developed degenerative disk disease and arthritis throughout her joints that was very painful. Mr. L had cardiac issues requiring an ablation. The neighborhood started to change with younger couples moving in and the older couples leaving. The home was getting too big for them to manage. They decided to sell their family home and move to a retirement community. Their daughter (a physician) recommended specific specialist as needed. They decided on their own to seek health care from a geriatric clinic when they moved. Present Time

At the present time, couple L continues to enjoy the retirement community and socializing with their friends. Mrs. L has started to paint and Mr. L enjoys water aerobics and watching sports. They follow politics and are very active in a number of committee and activities at the retirement community. They also keep in touch with their bridge club from the "old" neighborhood. The oldest member is 90 and they play at her house every Friday.

Mrs. L is experiencing severe back pain. To relieve the pain and to improve her mobility, she has acupuncture, massage and physical therapy regularly. She "does not dwell" on the health issues but continues to keep moving. Mrs. L considers her faith to be her "backbone." They keep in touch with their children, who live locally, and their grandchildren with great-grandchildren on the way, and their remaining siblings. They feel a loss to not to be able to travel as much alone. However, the couple does take short trips, when they can. They look forward to more memories and special times with their children and their families.

Response to Pattern & the Pattern Analysis Summary:

When both the life pattern construal and narrative diagram were presented to Couple L, Mrs. L recognized the similarity of their patterns before they became

# EXPERIENCE OF OLDER ADULT COUPLES LIVING WITH CHRONIC 277 ILLNESS AT HOME

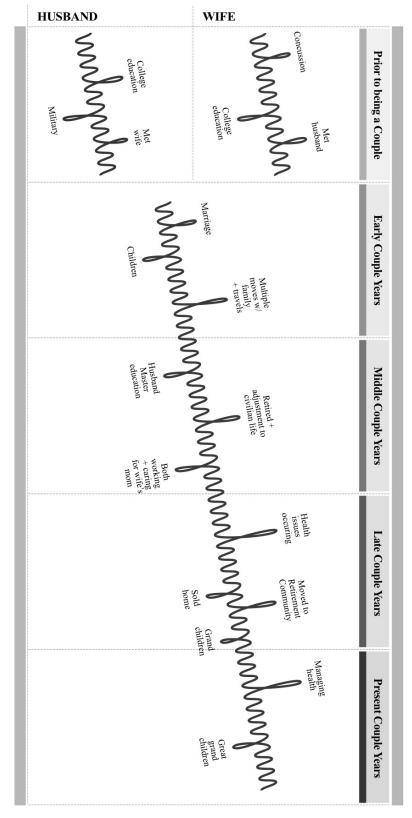
a couple and Mr. L noting that it was the 1950's and "a lot of people in our economic group did pretty much the same stuff." As Mrs. L reflected on the pattern she was quick to add that the influence of the travel was more than just the moving. The travel "opened you up to all kinds of things... an appreciation of the country" and should be better reflected on the pattern. Mrs. L also shared that the health concerns depicted on the pattern "was only a piece of this time of our lives...it's not the whole thing by any means." Mr. L shared what they do to manage the health concerns. In response, Mrs. L tries to reframe her insight for Mr. L that their lives are much richer beyond the health problems.

The pattern analysis revealed a general connection to others about the phases of the life pattern, but the meaning of the life pattern varied. Mrs. L was able to the commonalities between them as well as to the events of others who lived through this time. However, Mrs. L was able to move beyond the diagram of the pattern to what the pattern represented. By doing so Mrs. L became more aware of how travel influenced their thinking, and understanding of the world across their lives, as well as an awareness that their physical challenges should not "overshadow" their lives as a whole. She then shares this new awareness with her husband. This is an example of how the individual brings in new insight to further meaning and awareness to the couple.

Couple L's Narrative Diagram

	ctional	→=blocked	=uni-directional	=neutral ====================================	DIL=daughterinlaw
Relationship Key: W= wife, H= husband, M=mother, F= father, Sr=sister, B=brother, S=son, D=Daughter, GC=grandchildren, GGC=great-grandchild, Sib-siblings, FR=friends, SIL=soninlaw,	=grandchildren, GGC=great-grandchi	r, B=brother, S=son, D=Daughter, GC	=mother, F= father, Sc=siste	V= wife, H= husband, N	Relationship Key: \
GGC K ← FR	<b>←</b> FR	₩ ×	<b>•</b> • • • • • • • • • • • • • • • • • •	<b>K</b>	K
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D-SIL D-SIL S-DIL	D-SIL D-SIL S.DIL	M-1 M-2 F-2	FR →	× ×	<u> </u>
Expecting their first great-grandchild.				get married.	
6			Husband got his Masters.	serve to save money to	
Both keep in touch with siblings.	Husband's brother died.	every Sunday until their deaths.	whe rangiful or short time.	for 2 years of military	marrying iiiii.
visits shared nome in Maine when they can.	Had 8 grandchildren.	double Visited bushand's parents	Wife taught for chort time	college. After	years before
			Wife had another concussion.	Joined ROTC while in	Knew husband 4
Their children live locally.	they moved to the RC.	Wife worked as an accountant.			
	Decided to go to geriatric clinic when		friendship until college.	dance.	a child.
and acupuncture for her back pain.	Daughter helped refer to doctors.	agent orange exposure.	maintaining continuous	Met wife at a college	Had a concussion as
balance. Wife started exercises, yoga, massage,		Husband declared disabled due to	Children had a hard time with		
Wife's back pain affects her mobility and	before selecting this RC.		due to military assignments.		and art.
	Researched a number of places	paralegal.	Family moved many times	teacher.	minors in education
old neighborhood.	the retirement community (RC).	school with a certificate as a		Wanted to be a	English major and
Playing prioge with a rew or the menos from the	Decided to sell home and move in to	military. Husband went back to	throughout life.		College educated,
District heiden with a four of the friends from the		Husband held several jobs after the	Military friends were close	minor in philosophy.	
Grandchildren are getting married.	became too much work.	wile loved to garden.	children, a daughter and son.	English major and	college.
:	Neighborhood changed. Younger		assignments. Had two more		strong influence on
committees and activities supporting the RC.		they met at a bridge class.	old due to military	21 years.	artist and had a
following politics. Both are very active in	Husband and wife retired.	Played bridge with a card group that	daughter until she was a year	Lived with his family for	college educated
			Husband didn't see 1st		Mother was an
Wife took up painting. Husband does water	ablation.	civilian life.		brothers and a sister.	
	arthritis. Husband had a heart	lived there for 32 years. Adjusted to	orange when in Vietnam.	Oldest of 4, two	Oldest of 3, 2 sisters.
Socialization with others.	degenerative disc disease with	military, moved to a family home and	years. Exposed to agent		
Love living at the RC. Enjoying retirement.	Health issues began. Wife developed	Shortly, before husband retired from	Husband in the Army for 25	HUSBAND(2)	WIFE(1)
Present Couple Years	Later Couple Years	Middle Couple Years	Early Couple Years	Prior to being a Couple	Prior to b

# **Emerging Life Pattern: Couple L**



### Appendix P: Couple N's Narrative Summary, Narrative Diagram, and Life Pattern Construal

Narrative Summary:

Awareness of self and the other is an opportunity to find greater meaning in life as a couple.

Couple N has been married 56 years and will be celebrating their anniversary next month. They have 3 daughters. The last daughter is autistic. Their life together was shaped by the care and well-being of their autistic daughter. However, they were able to find time for their love of travel by taking short vacations. Though their past life was busy and stressful, they have navigated to a point in their life where they are enjoying family and friends.

Prior to Being a Couple

Couple N shared a common background of austerity through very different experiences. Mrs. N lived in Germany with her family when WWII started. She was 4 years old. Her father went to serve in the Army. In the meant ime her family with an Aunt were told to leave their home to be relocated further within Germany's borders. They were told they would be able to return in a few days. "When we arrived at the new destination in Germany, we were treated like –like some of the people who come here to this country. "They steal and they do this. Quite discriminations." Her mother found work on a farm. Mrs. N remembers working on the farm as well. They slept on straw and the food was rationed. "We were very hungry at times." Near the end of the war, her father was killed in the line of duty. After the war, they could never return to their home because the borders were redrawn. "We lost everything. We lost our home." They finally moved to an area that offered more economic opportunity. When she was 14, she balanced working and going to school. Her boss made it difficult for her to attend school, but she finished.

Mr. N came from a large family. There was very little money and he had to work to support the family through his teen and young adult life. The family never owned their home or a car. The family got along, but was not close. His father was ill with cancer for many years. Mr. N helped care for him. He dropped out of college when his father died. He had to go to work full –time and "directed most of [his] paycheck into the family for quite a while." Mr. N felt quite lost after his father died since he cared for him so much and for so long.

The couple met when Mrs. N came to visit friends in the U.S. Mr. N was at his sister's painting her house, when Mrs. N came over with her American friends who knew Mr. N's sister. They were married within 7 months. Early Years

Mr. N knew he was to be drafted in to the military. He enlisted to enable him to select where he would be stationed. He selected Europe so they could be close to Mrs. N's family while he served. For three years they lived overseas and were very close with Mrs. N's family and friends. They had two daughters while they lived in Europe. It was very hard for Mrs. N to leave her family and return to

the U.S. Mr. N's family was not close with them. There was little family interaction, and support. Though Mr. N's mother would come over from time to time. English was Mrs. N's second language. She found it hard to express herself because it took longer to process what she wanted to say and how to say it. This concern would follow her through her life.

Soon after they returned to the U.S., their last daughter was born who had autism. The early years were not as difficult. The children and friends did not notice a difference with their autistic daughter. She was taken everywhere with them. However, as the children aged, it became more difficult as other people would make comments to the daughters about their sister, the autistic daughter's behaviors became more pronounced restricting where the family could go with her. This limited them socially. Their daughter required 24-hour care. Mrs. N was the primary care provider and stayed at home with her. Mr. N helped as well. There were also ongoing battles with State agencies and local schools for services and resources to help support the autistic daughter's needs. One town took the parents to court on charges of truancy. "I remember going in there and almost shaking. We went 3 times to court with a lawyer. Now I am getting emotional."

Throughout these years, Mrs. N educated herself on disability rights and on the topic of autism. She found having English as a second difficult when advocating her point and understanding what professionals and governmental agencies told her. Often, professionals and agency representatives disregarded both Mr. and Mrs. N. Mrs. N did find special camps that help their daughter and a special sign language was developed so they could communicate. Middle Years

Mr. N was diagnosed with a treatable form of lymphoma. This event, as well as planning for the future, trigged the exploration of the option for their autistic daughter to live in a group home at the age of 40. They looked extensively to find the right environment for her and found a home that they thought would fit their daughter's lifestyle. However, their daughter lost weight and the home did not seem to provide a caring environment for her. So she returned home to live with her parents. Battles were ongoing for support from the State for appropriate services. Mr. N started to experience hearing loss requiring hearing aids.

Later Years

Soon after Mr. N retired, he became very ill with a relapse of lymphoma. He was hospitalized for 30-days requiring a long recovery. During this time, Mrs. N was very stressed because she traveled to see him every day, sometimes staying the night, along with caring for their daughter. Now that the couple was over 65 years old, they asked the State for additional resources to support their daughter. Once again, barriers were experienced. Their oldest daughter, a social worker, attended meetings to advocate for her parents and sister. "She [the State agency representative] saw a little weak side in us, knowing when she said, well, there are some people there in their 70s, and they still have their kids, and then I felt bad that I would ask for help." After Mr. N's recovery, the daughters encouraged the couple to have their younger sister live with their oldest daughter. "They [the

daughters] kind of pushed us to -- they said, you're not getting any younger, and it's going to get more difficult."

The couple sold their single-family home to move into a 55 and over community in a city. They were not sure they would like the city but they "love it". The city is close to their doctors and commercial locations, and their backyard is beautiful with wildlife.

### Present Time

Their autistic daughter is living with their oldest daughter. The couple has their daughter every weekend and on holidays. This arrangement has worked over the past 5 years. Legal issues continue related to their daughter's care, but the oldest daughter takes the lead. With this added support the couple are enjoying travel, cruises and short trips, when they can.

They maintain a close relationship with all their daughters. They have survived all their siblings. "We are the last of the Mohicans." Mr. N's hearing continued to decline requiring a microphone to be worn by Mrs. N for conversations. Mr. and Mrs. N will be celebrating their anniversary and Mr. N's remission in the upcoming months. They spend time with friends and enjoying games of daily scrabble. They plan on living in their home as they age. "...keep going and keeping our health without having to depend [on anyone]."

### Response to Pattern & the Pattern Analysis Summary:

When the life pattern construal and narrative diagram were presented to Couple N, Mrs. N was struck by seeing what they experienced over their life together," I guess if somebody would have told me ahead of time that all [this] would happen, I would say, I don't know if I would be strong enough to take that." Mr. N responded, "that's why we don't know the future. So we can take it". They recognized that both of their past experiences provided them with the skill and resilience to take on the challenges they faced as a couple. "...we both knew from our experience, responsibility. We had responsibilities and accepted them...we knew we had to work together through all this." Couple N found the experience of sharing their story like a "sedative...A pleasant understanding, accepting. It gave us an opportunity to review our lives...nice that somebody even wanted to hear it...makes us feel important."

The pattern analysis revealed how both partner's past experiences influenced their ability to address barriers and challenges together through their lifetime. They were able to find the love and joy of life through their daughter's autism that brought them closer together, as a couple. Though there were moments of sadness related to the struggles for support and how people with disabilities were mistreated, they did not become resentful. They were able to cut through the stigma and traditions of care together to ensure their daughter had a loving and caring environment. They look forward to the future, to travel, to enjoy family and friends, and after they die they wish their daughters will be happy with each other in the care of their youngest sister. "..it's [health] is a combination of having the other person in mind, and also oneself. ..it's important to want good health for both, and...it's a lot better than the opposite."

# Couple N's Narrative Diagram

essionals Pand	dren, FR=friends, Pro=Professio Numbers: 1= <u>wife</u> , 2= husband	ghter, GC= grandchildr =bidirectional N	Relationship Key: W= wife, H= husband, M=mother, F= father, B= brother, S=sister, A=aunt, D=daughter, GC= grandchildren, FR=friends, Pro=Professionals = unit = wife_, 2= husband = blocked = bldirectional Numbers: 1=wife_, 2= husband	H= husband, M=mother, F  = unj-directional	Relationship Key: W= wife, =neutral
<b>↔</b> (	8C 1		oc D D	Ss. / Bs.	FR V <sub>S</sub>
W&H	D + (1		$\hookrightarrow$	Ī	<b>*</b>
Pro	D		M-1 M-2 Pro	—————————————————————————————————————	<b>S B</b>
togethers due to husband's hearing.			Husband became a marathon runner to manage weight.		met her husband.
Have met neighbors and attend small get-	,			sister's home.	Was visiting the US when she
scrabble daily. Wife goes to a knitting group.	55 & older development in another city.		Enjoy traveling together on a regular basis as an "escape" to relax.	Met his wife at his	school.
for travel, watch movies together and play	and bought a condo in a			family.	the age of 14.Finished high
They spend time reading and surfing the web	Sold single family home		vacations together.	help support the	location. Started to work at
misunderstandings.	parents and advocate.		Both love the ocean with cruising as their favorite	Dropped out of	After war, moved to another
improved communications and reduced	agency to support her	aids.	Husband worked in the plating industry.		others.
microphone for conversations, which has	meeting with State	requiring hearing	Wife worked as assistant teacher with disabled children.	afterward.	child. Were treated poorly by
Husband's hearing loss requiring a	Daughter attended	severe hearing loss		"quite awhile"	Remembers being hungry as a
		Husband developed	services throughout her life, including litigation.	years. Felt lost for	farm to make ends meet.
Close with all their daughters.	health issues.		and information. Had to fight to receive appropriate	him for a number of	had to live and work on a
	manage her and the	with lymphoma.	daughter. Not always helpful. Sought own education	He had cared for	While relocated, the family
month.	ability of the parents to	Husband diagnosed	Sought evaluation, and support from experts for	was 18 years old.	
To celebrate their wedding anniversary next	daughters due to the	0		Father died when he	the war. They lost everything.
	daughter initiated by	Had grandchildren.	Life circumstances limited them socially.	idiliy.	redistricting of territory after
consider him lucky.	delighter live with oldest	credied partiers.	others worked a difference.	family	and could never return due to
since being diagnosed with Lymphoma. They	Decision to have autistic	services, state rep.	artism. It became more difficult in the teen years as	Worked also and	moved out of their nome to a
Planning a celebration of husband's 25 years	time for wife to manage.	appropriate state	Early years were not as difficult managing life with		The family with an Aunt was
d	walk again. Very difficult	Had to fight for		They had very little.	
legal issues related to their autistic daughter.	slow. Needed to learn to		the children close together.	a home or a car.	was 4 years old.
weekends and holidays. Continues to have	days. Recovery was very	her.	last daughter has autism requiring 24 hour care. Had	Family never owned	Father died in WWII when she
daughter. She stavs with the couple on the	and was in hospital for 30	did not work out for	Had three daughters, 2 in Germany, 1 in the States. The		
Autistic daughter continues to live with her	treatment for lymphoma	40. The group home		and 2 brothers.	family lived in Germany.
	Husband required acute	home at the age of	be close to wife's family.	children, 7 sisters	sister and a brother. The
planning more for the future.	nuspario retireo.	living in a group	of service (was going to be drafted). Went to Europe to	Youngest of 10	Youngest of 3 children, a
		Years			
Present Couple Years	Late Couple Years	Middle Couple	Early Couple Years	Couple	Prior to being a Couple

# **Emerging Life Pattern: Couple N**

War + Education relocation Visit Father for U.S. Father met died in war nusband in wife Family Father Wife Father wife Father wife Father father to support to support father father	Prior to being a Couple
Advocating Advocating for to U.S. Had Enlist Children daughter born win military Autism	Early Couple Years
Contine advocating advocating for resources for daughter daughter for daughter for daughter for daughter for daughter for daughter	Middle Couple Years
3 1	Late Couple Years
Moeting new frends + traveling Sold family home + moved to condo	Present Couple Years