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Family Involvement within Assisted Living: Care- Receivers' and Caregivers' Roles and Relationships

Rachel Vineet Solomon

University of Denver

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FAMILY INVOLVEMENT WITHIN ASSISTED LIVING: CARE-RECEIVERS’ AND CAREGIVERS’ ROLES AND RELATIONSHIPS

A Dissertation
Presented to
the Faculty of the Graduate School of Social Work
University of Denver

In Partial Fulfillment
of the Requirements for the Degree
Doctor of Philosophy

by
Rachel V. Solomon
June 2011
Advisor: Jean East, Ph.D.
Abstract

Family systems providing informal care and support to their aging relatives, who were residing in assisted living systems and receiving formal care were central to this study. A broader understanding of family involvement, with respect to exploring both care-receiver and caregiver roles and relationships, within the regulatory and environmental context of assisted living was sought through a qualitative research process. This study employed a phenomenological approach to conduct in-depth interview sessions with eight pairs of participants, comprising elderly residents in five assisted living facilities and their respective caregiving family members, typically a daughter or son and, in one case, a close friend, all of whom were personally interviewed. A total of 16 participants were interviewed individually. The three dominant themes that emerged from care-receivers and their caregiving relatives’ experiences, which characterized and impacted their family involvement, were (1) Coping efforts and attitudes that characterize the aging, the care-receiving, and the caregiving processes; (2) Enduring and changing roles and relationships in family systems; and (3) The paradox of institutional long-term care, as it created both relief and stress for elderly care-receivers’ and their caregivers in family systems. A systems/ecological framework is applied to explicate these findings, and policies pertaining to assisted living, and their economic implications for the long-term care process are also discussed.
Acknowledgements

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Chapter One: Introduction

Statement of Research

Those concerned with health and social administration must, at every stage, treat old people as an inseparable part of a family group, which is more than just a residential unit. They are not simply individuals, let alone cases occupying beds or chairs. They are members of families and whether or not they are treated as such largely determines their security, their health and their happiness.

(Townsend as cited in Tanner & Harris, 2008, p. 44)

This qualitative study focused on the family involvement of elderly individuals who reside in assisted living facilities and their family caregivers. To this end, the experiences of a family were viewed broadly, including both the efforts of the care-receiving elders and their caregiving family members. This study examined how elderly care-receivers and their family caregivers were able to maintain their emotional and relational ties, and sustain their respective roles after an elderly family member moved into an assisted living facility. In this study, the systems/ecological framework was applied to understanding how family systems can continue to function as a close-knit family network, sustaining relationships and mutual interdependency through roles and contributions, despite the institutionalization of elderly family members in assisted living facilities.

For most family units, relationships between family members are lifelong and significant. Family units have continued to persist and adapt in response to social, political, and cultural changes, as well as ongoing internal changes, as generational units
are formed and mature (Morgan & Kunkel, 2001). Despite the changes that take place, all families are characterized by family relationships that provide continuity and family norms, which are passed from one generation to the next. Elderly family members are part of a complex system of roles and multigenerational relationships that are a primary source of support and interaction for most elders (McInnis-Dittrich, 2002). Traditionally, families have been the first line of support to provide the needed assistance to any members unable to take adequate care of themselves due to physical or circumstantial factors. Family networks constitute the backbone of the caregiving system, because family members continue to stay involved by trying to meet the many emotional, mental, physical, financial, and social needs of their institutionalized elderly relatives (Caro, 2006; Feinberg & Newman, 2004; Thompson, 2004).

Caregiving literature has categorized caregivers and care-receivers based on a hierarchy of obligations, responsibilities, and position in the lifecycle, often leading to informal rules and expectations concerning family caregiving roles (Hoff & Tesch-Romer, 2007; Greene, 2008). Although it is commonplace for family caregivers to remain actively engaged in caring for their institutionalized elderly, it is less recognized that many older adults residing in assisted living facilities possess the capacity to provide critical family roles, such as emotional, relational, and financial support, in addition to working hard to adjust to the facility in order to alleviate stress on their family members (Cox, Green, Seo, Inaba, & Quillen, 2006).

Much research has already been conducted on the caregiving process, and the caregivers’ responsibilities and stress, whereas the care-receivers’ experiences and perceptions of their care, both at home and in long-term care settings, such as assisted
living, remain largely unaddressed (Chou, Boldy, & Lee, 2003; Cox et al., 2006). To attain a more balanced view, this qualitative, phenomenological study not only gives importance to the perspectives of family caregivers, but also focuses on the experiences of the care-receiving residents of assisted living facilities regarding their roles and relationships. In this study, the terms long-term care facilities, and institutional or institutionalized elderly care were used interchangeably to include both nursing homes and assisted living arrangements, each of which refers to a specific form of residential care.

**Organization of This Dissertation**

The subsequent sections in chapter 1 describe the purpose and rationale for this study, the significance of the study, followed by important conceptual definitions. This chapter also discusses the systems/ecological framework, which was chosen as the overarching theoretical framework guiding the study. A systems/ecological framework was particularly relevant to this study, because it allows for a comprehensive assessment of how the interrelated systems of the care-receiving residents, their families, and the assisted living system as a whole are functioning and interacting with each other.

A growing elderly population who are well informed and well educated to a greater extent than the previous generations, and who are also increasingly diverse, has several important implications for our aging society, which are discussed in Chapter 2.

This chapter identified major areas of research on caregiving families, and elderly care-receivers living within institutionalized long-term care settings. A historical perspective has been utilized to not only examine the changes in family structure and ideals, but also discuss the development of the long-term care system in the United States, with special
reference to assisted living facilities. Implications of the changing structure and role of families; the contribution of female caregivers; theoretical perspectives that have widely contributed to the aging and the caregiving processes; along with past and present trends in family caregiving research were examined. This is followed by a description of the varied long-term care needs, and family involvement of elderly residents, along with a discussion on assisted living facilities, which provide the context for this study. Policy implications for older adults and their families as well as a detailed analysis of financing residential long-term care options have also been included. Hence, this study recognized the important role of assisted living facilities, which need to become increasingly affordable and culturally competent for older adults, irrespective of their racial and ethnic backgrounds.

Chapter 3 focuses on the methodology of this qualitative research study and elaborates on the tradition of phenomenology, which was used to conduct this study. Research findings that are based on the experiences and perceptions of elderly care-receiving participants and their respective family caregivers are addressed in Chapter 4. Finally, chapter 5 discusses the findings in relation to the systems/ecological framework, and implications for policy, and social work research and practice.

**Purpose and Rationale for the Study**

The overarching purpose of this qualitative study was to explore the nature and extent of the relationships between care-receivers and family caregivers, and their respective roles within an assisted living context. The perceptions and opinions of elderly residents and their primary family caregivers regarding their family involvement were emphasized throughout the course of this study. The four main purposes of this research
study were to (a) explore care-receivers’ experiences, relationships, and roles within their
families after their transition into an assisted living facility, as well as their perceptions
regarding their primary caregivers’ and other family members’ level of involvement;
(b) explore the primary family caregivers’ experiences, relationships, and roles in caring
for their institutionalized elderly relatives, as well as their perceptions regarding their
elderly relatives’ level of family involvement; (c) explore the factors that affect family
networks and social ties for care-receivers and caregivers; and (d) provide
recommendations for how family units can sustain their mutual relationships and roles,
and continue to function as a family network as normally and productively as possible.

This study primarily examined roles and relationships between family members
and elderly residents from both the care-receivers’ and the caregivers’ perspectives.
Adapting to an assisted living care environment provided the context for examining the
nature of care-receiver and caregiver interactions and exchanges. Even though the
assisted living staff members were not interviewed during this research process, this
study emphasized the role and impact of the assisted living system on care-receiving
residents’ and their caregiving family members’ mutual involvement.

Assisted living facilities are considered a viable substitute for nursing homes,
because they permit greater autonomy and choice, and are thought to attract a
sociodemographic sector that includes families’ participating to a greater extent in the
care process, and in ways different from family involvement in nursing homes (Port et
al., 2005). Family caregiving roles within some emerging residential care models, such as
assisted living, may differ from the family assistance that can be provided in more-skilled
nursing homes and facilities. Gaugler and Kane (2007) have suggested that because
assisted living facilities are neither designed nor organized to provide more intensive health care, family involvement within such environments may be more diverse, with family members’ being able to provide a range of assistance to elderly relatives.

Many service professionals have been directing attention to developing and appraising programs and interventions that improve not only health care but also the social status and networks of older adults and their caregivers (Hudson, 2008). Meaningful roles emerge from such relationships and networks, which allow elderly residents and their family members to continue to stay involved with each other. However, very little is known about these roles, and the social and emotional connections and relationships of family caregivers and their elderly relatives residing in an assisted living setting (Regnier & Scott, 2001). A limited number of research studies that have examined family involvement have mainly studied the caregivers’ involvement in the care process, instead of also considering the involvement of elderly care-receiving family members. Phenomenological research efforts that have investigated care-receiving residents and their primary caregivers’ family involvement with respect to their roles and relationships, within the context of an assisted living environment, are rare. Consequently, this study was designed and conducted to address such a gap in care-receiver and caregiver research.

**Significance of the Study**

Family members are presently, more than ever, confronted with the pressures of caring for their frail and disabled elderly relatives in a profit-oriented health care system. Many elders and their family caregivers have been experiencing the need for supportive long-term care services and professional assistance (Cohen-Mansfield, Besansky,
Watson, & Bernhard, 1994; Robertson, Zarit, Duncan, Rovine, & Femia, 2007; Rudin, 1994). Placing an elderly family member in an institutional care setting impacts involvement within caregiving family systems, and such experiences were described in this qualitative study by elderly residents in assisted living and their primary family caregivers.

The process of transitioning to a residential long-term care setting generates many stressors and establishes relationships that have to be negotiated with staff, residents, and families of other residents (Whitlatch, Schur, Noelker, Ejaz, & Looman, 2001). As most seniors age and live within a long-term care facility due to medical and physiological conditions, family caregivers and their elderly relatives have to adapt and adjust to new roles and relationships, which are yet to be assessed comprehensively. Hence, this research study has significant benefits to helping care-receiving relatives and their family systems maintain their psychosocial well-being and satisfaction, which are determined by their roles and mutual interactions. Information from this study is highly useful in helping social workers assess the situation when working with caregiving families and their elderly relatives in long-term care settings. Such an assessment can lead to identifying care-receiver and caregiver needs; evaluating risks to their personal, social, and emotional well-being; and subsequently developing intervention outcomes or strategies (Tanner & Harris, 2008).

Most significantly, this study provided elderly residents with a medium to voice their opinions and suggestions, and focused on discovering the experiences of elderly residents in their own words, which should be the starting point of any research work concerning elder care. This study also reinforced the need and value of elderly care-
receivers’ relationships, as well as the importance of their unique contributions, roles, and position within their families and assisted living facilities.

A basis for developing and applying a systems/ecological framework to examining factors that facilitated or inhibited greater family involvement and participation was also realized through this qualitative inquiry. Furthermore, this study’s findings can help to understand the institution-based role of care-receivers and their family caregivers within the context of an assisted living facility, because of its potential to influence and improve policy measures regarding institutionalized long-term care. This study also recognized the important need for making residential communities, such as assisted living, more affordable and accessible to elders who are wait-listed, or who do not qualify for public assistance.

It is therefore, highly beneficial and in the professional interests of gerontologists and social workers to conduct research efforts, such as this study, to identify ways and means to maintain familial relationships that constitute the primary support network for elderly residents, as well as facilitate more cooperation between formal care providers and informal family caregivers. Study findings can also educate research and policy-development efforts that can lead to better planning, development, and implementation of feasible interventions that support family involvement, all of which can be helpful to family caregivers, elderly care-receivers, and their formal care providers.

**Important Definitions**

The most fundamental and universal attribute of almost all human relationships is care itself. Caring is essential to our human nature. According to Tanner and Harris (2008), care is an intrinsic part of the interpersonal relationships between the elderly and
those in their informal networks. Some researchers have defined *caring* as a positive and loving attitude towards an elderly person, which is differentiated from the challenges that *caregiving* may entail (Moroney et al., 1998). The act of caregiving if limited to merely providing services and support without any compassion or concern is not truly caring.

The care needs of older adults, who tend to suffer from some physical and functional limitations, are met both informally and formally. McKenry and Price (2005) defined a *caregiver* as anyone who offers assistance to someone who is physically or psychologically impaired and is therefore dependent on others. Family members and friends, such as spouses, children, and neighbors, are central to providing *informal care* to their elderly relatives and are classified as *family caregivers* in this study. *Formal care* is provided by paid caregivers in long-term care facilities that offer specialized care and skilled assistance to older residents, who are defined as the *care-receivers*.

**Family.** Biological familial relationships are not entirely voluntary and cannot be denied, because each of us are born into our families of origin and are related to a given set of people by definition and not by choice (Beckerman & Tappen, 2000; Park, 2009). According to Chibucos and Leite (2005), even as attempts to define a *family* have evolved throughout the twentieth century, there exists a lack of consensus regarding a common functional definition of families. Defining families is important to our understanding of how they function, prevail, and care. Traditional notions of family as being very household centered have undergone a change due to the increasing plurality of family forms, as more and more families are being considered a network of different generations living in multiple households (Hoff & Tesch-Romer, 2007).
Families are broadly defined and not restricted to a nuclear notion of what constitutes a family unit or a system. The term *family* is understood as not being exclusively applied to conjugal or nuclear families, but to almost any grouping of two or more adults living together (Zimmerman, 2001). Seccombe and Warner (2004) defined families as being a relationship by blood, marriage, or affection, in which members may care for each other, may cooperate economically, and may consider their identity to be intimately connected to the larger group. White and Klein (2002) differentiated families from other social groups based on their duration and nature, because families last longer, are intergenerational, and comprise of both biological and affinal relationships, while also being part of a larger kinship network.

Hence, families can refer to any group of individuals either sharing a common ancestry, or residing under the same roof, or to a unit comprising one or more adults living together, engaged in rearing their own or adopted children (Zimmerman, 2001). For the purposes of this study, *families* have been defined as social institutions and networks that have expanded to include members that are not only related by blood and marriage, but are also connected through friendship, affection, and mutual interest (Hirschfeld & Wikler, 2004; Mintz & Kellogg, 1988).

**Family caregiving.** Family caregiving has existed and continues in response to illness and disability among older adults. Family members have chiefly continued to provide informal (i.e. unpaid) care to their elders (Lehning & Austin, 2010; Lund, Utz, Caserta, & Wright; 2009; Whitlatch & Noelker, 1996). It is therefore imperative to define the nature of *family caregiving*, which is viewed as a complex construct. To date, a single agreed-upon definition of family caregiving has not been established (Cicirelli, 1992;
Much of the literature conceptualizing family caregiving has seemed unable to move beyond the physical dimensions of caring (Parker & Lawton, 1994). Given and Given (1991) noted that a primarily instrumental approach to defining family caregiving has failed to capture its dynamic nature. Wenger, Grant, and Nolan (1996) recommended understanding caregiving in terms of its purpose and aspect, rather than task.

Marks and Lambert (1997) attributed this ambiguity to the difficulty in distinguishing between family members who regularly engage in routine activities of social support and those who, in addition, engage in caring activities that are demanding and complex. When describing caregiving (applicable also to family caregiving), this term was often found to refer to what the caregivers were trying to accomplish and what activities were encompassed in their caregiving processes to achieve those goals (Caron & Bowers, 2003).

Several researchers have identified family caregiving as careers that include various transitions from the onset of family care to institutionalization, along with progression and change in the care needed (Gaugler & Teaster, 2006). However, the most popular approach that has been used to define and measure caregiving is based on the need for care and assistance due to functional disability. For example, Marks and Lambert (1997) defined caregiving as supplying not only a higher level of continuous personal care, but also,

Help with routine activities of daily living which is provided to a family member or friend due to a long-term mental or physical condition, illness, or disability that makes it difficult or impossible for them to take total care of themselves. (p. 8)
This definition does not include other aspects of caregiving, such as emotional factors, financial contributions, the role of care-recipients, or frequently, the caregivers’ efforts to create partnerships with paid formal caregivers (Marks & Lambert, 1997). Caron and Bowers (2003) identified two categories of caregiving purposes: (a) interrelational, wherein the caregiver’s view of the care recipient’s sense of self and the caregiver/care-receiver relationship are protected and sustained, and (b) pragmatic, which ensures hands-on provision of care and comfort.

**Long-term care.** Many families are frequently involved in caregiving activities even before their elderly relatives begin to need a higher level of managed care. Family members are often, persistent in their role, opting for institutionalization only as the last resort (Montgomery & Kosloski, 1995). *Long-term care* constitutes the support given to individuals suffering from chronic illnesses or disabilities that limit their ability to live independently (Moody, 2009). Long-term care is typically provided to older adults who are functionally limited or disabled to perform basic self-maintenance and other activities of daily living. The American long-term care system is a vast collection of various care arrangements that provide needed services to frail and weak older adults. Nursing home care, along with care in a wide variety of settings, including congregate housing (e.g., assisted living facilities, group homes, and private homes), are all part of long-term care (Kane, 2001).

**Assisted living.** Assisted living encompasses a diversity of residential settings and has been defined in various ways. Assisted living is an industry term for multi-family housing with formal care services and can also be referred to as residential care, congregate care, or even board care (Jurkowski, 2008). *Assisted living* facilities have
been defined as “nonmedical, community-based living arrangements that provide housing, food service, one or more personal services, and 24-hour protective oversight to frail elders and others with physical and mental disabilities” (Ball et al., 2004, p. 468).

Assisted living facilities that aim to provide support and services tailored to individual needs in a normalized and homelike setting are patterned after a residential model of care. A residential assisted living setting has mostly been preferred to a medical model, because its focus is upon promoting autonomy, developing interdependence among residents, and maintaining each resident’s individuality and privacy (Regnier, Hamilton, & Yatabe, 1995). However, there is no consensus over the environmental features that would promote privacy in assisted living facilities, setting them apart from other forms of residential care (Hawes & Phillips, 2007).

Assisted living facilities are developed and controlled at the state level, and because each state responds to the interests of local stakeholders independently, differentiating assisted living from all other forms of residential care has become a confusing process (Stone & Reinhard, 2007). There exists inconsistency from state to state with regard to how assisted living as an institution should function, be categorized, and defined (Hawes & Phillips, 2007; Namazi & Chafetz, 2001). Some states have developed a separate assisted living licensing category, whereas others have set stringent rules that require an additional license for nursing services, or a higher level of care (Zimmerman et al., 2003). In Frank’s (2002) words, “Assisted living not only changes its name from state to state but it also varies by licensure category and definition” (p. 133). Hawes and Phillips (2007) reported that as of 2002, 32 states have a licensure category or a statute that uses the term assisted living.
To sort through the plethora of definitions describing assisted living would be an equally challenging task. A single federally mandated definition of what represents an assisted living facility does not exist. As a consequence, varying definitions across states regarding what constitutes assisted living make it harder to estimate the total number of assisted living facilities in United States (Hawes & Phillips, 2007). The Assisted Living Federation of America, which was founded in 1991 and is responsible for promoting the interests of the assisted living industry and the quality of life of its residents, candidly acknowledged that defining assisted living could either be the biggest obstacle or catalyst to the development of assisted living (Assisted Living Federation of America, 1999). Nevertheless, assisted living is a rapidly growing market due to its perception as a lucrative development opportunity that provides a combination of housing and services.

**Family involvement.** Most families want to continue to assist and care for their elderly relatives following admission to institutionalized long-term care settings (Szinovacz, 2003; Williams & Guendouzi, 2005; Wolff & Kasper, 2006). Researchers have discovered that family caregivers continue to provide care and assistance to their institutionalized relatives beyond merely visiting them (Kane & Penrod, 1995; Reuss, Dupuis, & Whitfield, 2005). Family involvement has been defined as care planning, financial monitoring, and advocacy, as well as care provision and general involvement of family caregivers (Port et al., 2001). Recent research has described and quantified family involvement in terms of family visits, provision of socio-emotional support, and personal and instrumental care, following an elderly relative’s move into a residential long-term care facility (Gaugler & Kane, 2007).
Lately, there is a growing emphasis on caregivers’ and care-receivers’ interactions and satisfaction, and on including and partnering with care-receiving residents and their families, who are being increasingly recognized as a credible source of information on the provision and quality of care within residential long-term care facilities (Ejaz, Straker, Fox, & Swami, 2003; Williams, Desai, Rurka, & Mutran, 2008). The next section discusses the systems/ecological framework, because it offers a useful approach to analyze and understand the complex nature of involvement between care-receivers’ and their caregiving family systems, within an assisted living setting, and because it also prescribes ways to provide more collaboration between interrelated systems and facilitate changes within each of them. Such collaboration and facilitation can help meet the interactional, relational, psychosocial, and cultural needs of the care-receivers, as well as their caregiving family members.

The Systems/Ecological Framework

Theoretical perspectives that have been developed and applied to understanding family involvement; family caregiving; family relationships; institutional care; and family, resident, and staff interactions and roles in long-term care settings are gradually evolving. Many of these theories have offered developmental, bio-psychological, and social contexts for understanding either implicitly or explicitly how older adults relate to their environments (Hooyman & Kiyak, 2004). However, very few efforts have been made to develop a theory that provides explanatory insight into the roles and relationships between family caregivers, their care-receiving residents, and the assisted living care system.
A combination of systems and ecological perspectives provides an overarching integrated framework that offers an eclectic and a unified approach to organizing knowledge about the roles, partnerships, and interrelationships of people with each other and with their environments. Some theorists have argued that a systems framework focuses on the structural ordering of systems and variables and is completely different from an ecological framework, which considers relationships and exchanges between individuals and their environment as important (Ambrosino, Emeritus, Emeritus, & Ambrosino, 2005). At the same time, the ecological perspective is criticized, based on its emphasis on *evolutionary adaptation*, which promotes adjustment instead of bringing about a change in the environmental conditions (Kemp, Whittaker, & Tracy, 1997).

Despite these limitations, for the purposes of this study, a systems framework was applied in conjunction with an ecological perspective to conceptualize and guide the exploratory nature of this qualitative research study. The following section elaborates on the systems component of this framework, focusing on how a systems approach can be applied to examining critical family relationships and roles that are shared within and between the care-receiving, family caregiving and assisted living care systems.

**Systems framework: Development and relevance.** A systemic approach to understanding individual behaviors and relationships is a key component of the systems/ecological framework. A systems perspective suggests a contextual influence on individuals where other systems, such as social groups and institutions that respond to individual behaviors, are also evolving (Payne, 2005). A systems approach also values the interrelationships among the various social systems, emphasizing the process behind how interactions and transactions between systems take place (DuBois & Miley, 2007).
Herbert Spencer’s organic and evolutionary perspective on society and his work in social Darwinism towards the end of the 19th century proved to be a major foundational influence on systems theory (White & Klein, 2002). In addition, the ecological school of Chicago sociologists in the 1930s, and social survey research in England in the late 19th century were some other antecedents to the systems perspective (Payne, 2005). Early proponents of the systems framework also believed in “it’s potential to provide scientific credibility to the profession and to develop an integrated theoretical foundation that would capture the central elements of social work practice in all its varied forms” (Gordon as cited in Healy, 2005, p. 134).

The systems framework has been successfully utilized in social work, but it was not until the 1960s that a focus on person-in-environment gained prominence (Healy, 2005). Although systems’ thinking was mainly applied to biological and technical systems, it was first introduced to social work in the 1930s and since then has been applied to social systems, such as groups, organizations, families, and communities (Payne, 2005). The systems framework has had considerable influence on social work practice to promote the social order, interactions, and exchanges within and across multiple social systems that contribute to individual and community well-being (Healy, 2005). Moreover, as a comprehensive approach, it has incorporated psychological theories within its wide framework, and has also been extensively applied to human and social development work (White & Klein, 2002).

A system has been considered to have holistic properties that are not found separately within the parts, but rather are the result of the relations taken on by the parts, forming the whole (Andreae, 1996). An individual’s behavior is mutually determined by
interaction with others, which suggests that human systems influence their environments and are in turn influenced by them (Miley, O’Melia, & DuBois, 2004). A **system** is technically defined as an organized whole composed of subsystems and environments that distinctively interact and endure over some period of time (Anderson, Carter, & Lowe, 1999). A **social system** is simply defined as a “structure of interacting and interdependent people” (Miley, O’Melia, & DuBois, 2004, p. 45), in other words, a group with a pattern of relationships and shared social and personal characteristics, which separates it from other groups in the environment.

Regarding the relevance of systems theory to the topic of this study, it is common knowledge that elderly residents do not live in isolation, but are influenced by other human systems within the environment. The systems framework focuses not only on individuals as part of, but also inclusive of, other systems and their interactions, which is useful in analyzing how individuals interact with each other in their families, communities, and organizations (Payne, 2005). Within the systems framework, all systems have a certain organized **structure** and are characterized by the concepts **reciprocal influence** and **circular causality**, which allow all the parts of the system to affect each other in a manner that an effect is influencing its own cause (Ridley, 2003). All social systems, for example, families and the assisted living system are distinguished by human relationships and transactions, which are determined by either the level of **closeness** and **power** or a system **hierarchy** (DuBois & Miley, 2007; Miley, O’Melia, & DuBois, 2004). Closeness within the system is assessed in terms of open and closed **boundaries**, which conceptually allow or regulate the interaction and exchanges between and within systems (Ambrosino, Emeritus, Emeritus, & Ambrosino, 2005). Hierarchy
within the system establishes power, and the notion of feedback is used to address disruptions and maintain a system’s equilibrium (Agass & Preston-Shoot, 1990).

The long-term care system, which is synonymous with a formal or professional system of care, represents a range of residential care facilities, such as the assisted living system, which provides housing and ongoing monitoring and assistance to their elderly care-receiving residents. Institutionalized living becomes a reality for many elders due to disability, failing health, and lack of resources, causing drastic changes and environmental adjustments to which care-receivers and their family members must adapt.

This study asserts that despite institutionalized living, care-receiving residents are a contributing and a vital part of the family system. The systems framework can help to examine how a family system, comprising the care-receiver, the caregiver, and other family members maintain equilibrium through a variety of resources employed to meet new environmental demands and diverse adaptations (White & Klein, 2002). Subsumed under the umbrella of a systems framework is family systems theory, which is discussed in the following section.

**Family systems theory.** Systems perspectives have been applied to the realm of family therapy, and more specifically to family systems, where the fundamental unit of study is not the personal characteristics of an individual but rather the entire system as a whole, which includes family members who are studied in terms of their interactions with each other (Andreae, 1996). A family “is a social system comprising a number of people united by emotional ties and by some form of regular interaction” (Greene, 2008, p. 131).

Family systems theory, in existence since the 1960s, describes a system as a set of interrelated elements, characterized by a boundary and common characteristics (Chibucos
& Leite, 2005). A family system is viewed as a self-regulating system of interconnected and interdependent individuals, in which changes in one or more members or relationships can have a profound impact upon the entire family (White & Klein, 2002). Family systems theory suggests that families, as systems (which in this context also include the elderly care-receiving members residing in assisted living) influence their environments and are in turn affected by the circumstances and contexts around them (McKenry & Price, 2005).

Family systems that provide care to elderly family members do not exist in isolation but rather are part of the larger social context (Connidis, 2001). Accordingly, a family system is made up of many subsystems and environments, and can itself be a subsystem of a larger system in the environment. In this context, family members within the family system are also coexisting within different environments (i.e., systems), which include neighborhoods, schools, work sites, and institutions, such as assisted living. Family systems theory has mainly been used within family research to study family communications, marital interaction, family conflicts, and family therapy (White & Klein, 2002). However, it can also be applied to study the interactions between the care-receiving and the caregiving members of the family, and the family’s interaction as a whole with the assisted living staff/administration.

Assigned roles, rules for behavior, organized structural hierarchy, and the overt and covert forms of communications present within family units represent some of the characteristics of a family system (Goldenberg & Goldenberg, 1991). Family systems are primarily focused on maintaining boundaries, and social and spatial relationships
between dyads within the family, as well as keeping the family system linked with other external systems within the environment (Pillari, 2002).

Family systems theory is relevant to the focus of this study, because health and developmental challenges faced by even one of the family members (e.g., the elderly member) can affect the roles and relationships of the entire family system. Family systems that include institutionalized elderly relatives need to be increasingly supported in regard to their roles within the assisted living system and their relationships with the assisted living staff and administration.

Many postmodern theorists have criticized a universal systems approach to understanding family structure, organization, and communication patterns, and instead placed value on localized experiences and multiple perspectives (Greene & Blundo, 1999). Such perspectives include an emphasis on ecological and developmental models for examining areas such as family adaptation and resource management. Complementing the systems framework, the ecological framework, described next, emphasizes the person-in-situation approach, which examines the environmental exchanges and context of social functioning.

**Ecological framework: Development and relevance.** *Ecology* as a biological science was introduced by Charles Darwin, who established the interrelationships between living organisms and their physical and biological environments (DuBois & Miley, 2007). The notion of *human ecology*, on the other hand, was first presented by Gregor Mendel, which led to further research on uniting “ontogenetic development with environmental interaction” (White & Klein, 2002, p. 204). The ecological framework emerged in social work during the 1970s with the aim of helping social workers
customize their interventions to the person, the environment, or the interaction between
the two (O’Donoghue & Maidment, 2005). Since then, the ecological framework has
been readily implemented to extend social work’s understanding of individuals, families,
and organizations, with respect to their reciprocal relationships, and environment. The
ecological framework provides essential perspectives regarding how various
environments affect people and conversely, the ways in which people affect their
environments (DuBois & Miley, 2007).

According to the ecological framework, individuals and institutions have an
impact on the environment in which they are embedded, as well as by any future changes
that may occur over time. Rowe and Kahn (1997) note that the social, cultural, and
environmental contexts have more influence upon the experiences and circumstances of
the elderly than biology or genetics. From an ecological standpoint, individuals continue
to interact with their physical-social-cultural environment in processes of mutual
reciprocity and complementary exchanges of resources (Miley, O’Melia, & DuBois,
2004). Concurring with this perspective, Andreae (1996) explained that from birth, the
environment is in every person, and individuals create their own environment through
their choices and social transactions, which are, in turn, a response to the opportunities
and deprivations presented to them.

Ecological concepts, including ecosystems, were introduced to social casework by
Germain and Gitterman (1995), because such concepts were considered a better fit for
comprehending human experience, and “promoting individual and family health, growth,
and satisfying social functioning” (p. 816). Ecological perspectives and concepts have
drawn attention to the physical and social environments, along with culture, all of which impact and are influenced by individual functioning and adaptation.

White and Klein (2002) identified the concept of *ecosystem* as central to an ecological approach, defining it as “the arrangement of mutual dependencies in a population by which the whole operates as a unit and thereby maintains a viable environmental relationship” (p. 208). According to Rothery (2008), the ecosystemic framework is a contemporary effort according equal importance to the individuality of people and to the social environments that do so much to determine their well-being. The external environment within which families are embedded has also been referred to as the ecosystem (McKenry & Price, 2005). The family ecosystem consists of the historical, cultural, economic, genetic, and developmental influences, which affect the family members (Boss, 2002). A care-receiving and a caregiving family’s ecosystem is in constant interaction with its environment, which would encompass other systems, such as the assisted living system.

The ecosystemic perspective, which has mainly been applied to casework situations within social work practice, views individuals and environments as complementing each other rather than being separate. The ecosystems perspective is therefore a useful and relevant approach, because it draws attention to the quality of relationships and the nature of transactions that develop among families, care-receiving residents, and the assisted living staff within an institutionalized care environment. Such exchanges take place across different levels of an ecosystem, which have been emphasized by Urie Bronfenbrenner in his human ecological theory (Bronfenbrenner, 2001).
**Human ecological theory.** Human ecological theory was formulated by Bronfenbrenner to explain the impact of the environment on human development. The following discussion on human ecological theory describes and applies Bronfenbrenner’s human ecological model (also known as the ecological systems model) to this study of the roles and interrelationships between the family caregivers, aging residents, and staff/administration within an assisted living system care environment. Bronfenbrenner’s model considers the ecosystem to consist of “multiple interdependent levels that interact with and influence individual behavior and development” (Chibucos & Leite, 2005, p. 346), which are envisioned as a series of concentric circles, with the individual at the center.

Bronfenbrenner defined four levels of nested systems that affect human development and behavior: the microsystem, the mesosystem, the exosystem, and the macrosystem (Bronfenbrenner, 2001), to which he later added a fifth dimension, the chronosystem (Bronfenbrenner, 1986), all of which are applicable and relevant to the topic under study. **Microsystems** refer to the immediate environment where an individual experiences and creates day-to-day reality (Bronfenbrenner, 1977). Accordingly, the care-receiving residents’ microsystem would be the assisted living facility, whereas their caregivers’ microsystem would be the family system. The overlap between two microsystems, such as the family system and the assisted living system, creates a mesosystem. The **mesosystem** is characterized by the interrelations of two or more microsystems (Bronfenbrenner, 1977).

The **exosystem** includes the systems that are not in direct interaction with an individual but have indirect effects on the individual’s micro-or mesosystem (Ambrosino,
Emeritus, Emeritus, & Ambrosino, 2005). Hence, the exosystem affects the microsystems but does not involve individual participation. In the context of the topic under study, the exosystem refers to the government institutions and regulatory mechanisms that influence the development of the assisted living system, including its structure, services, and environment.

The **macrosystem** provides the general cultural context in which the other economic, social, educational, legal, and political systems operate, of which the microsystem, mesosystem, and exosystem are the concrete manifestations (Bronfenbrenner, 1977). Even though the macrosystem level is the most removed from an individual, it also includes cultural beliefs and values reflected in policies and regulations relating to community collaboration, decision making, and funding in communities (DuBois & Miley, 2007).

Bronfenbrenner’s fifth dimension, the **chronosystem**, recognizes that “development within the person and within the environment occurs over time” (Chibucos & Leite, 2005, p. 347), thereby suggesting the importance of specific life transitions, and the cumulative effects of these changes throughout life. From this perspective, people’s lives are characterized by transactions and transitions from one stage to another.
When considered altogether (see Figure 1), these levels of interrelated systems recognize the environmental impact on individual development and the interactions among, between, and within human systems. In particular, Bronfenbrenner’s human ecological theory is important and relevant to this discussion, because it presents a theoretical model that helps in understanding how the environment and interactions within the assisted living system can influence the relationships among and between all who are involved in the long-term care process. In this context, family involvement is
complex and dynamic in nature, because it involves multiple contributions by multiple individuals to care-receiving residents and their family members. Bronfenbrenner’s model can help to extend our understanding by reflecting the boundaries and intersections between caregiving and overall involvement by a network of individuals, as opposed to just a caregiving dyad (Greene, 2008).

Bronfenbrenner’s model also presents a multi-level assessment for identifying resources that may strengthen older adults and their families. Assessment has been defined as “an ongoing process to understand people in relation to their environment; it is a basis for planning what needs to be done to maintain, improve, or bring about change in the person, the environment, or both” (Coulshed & Orme, 1998, p. 21). A combination of both the systems and the ecological perspectives, therefore, emphasizes the need for assessment and effective interventions for older residents and their family caregivers.

**Strengths and Weaknesses of the Systems/Ecological Framework**

The systems component of the systems/ecological framework recognizes the complex configuration of nested and interlocking systems as they influence their environment, human behavior, and functioning; whereas the ecological component emphasizes the environmental transactions and their impact on elderly individuals and their families (Miley, O’Melia, & DuBois, 2004). This framework offers a systemic approach to viewing individual behaviors as being organized in response to those around them resulting in groups forming systems, which in turn organize their behaviors in response to other systems to form much larger systems (Hargrave & Hanna, 1997).

The systems/ecological framework recognizes the internal and external functioning of care-receiving and caregiving family systems, the larger environment, its
component parts, and the relationship between all of these aspects (DuBois & Miley, 2007). Applying the systems/ecological framework to residential care, such as assisted living systems, can help in understanding the interactions between elderly residents and their families, as well as explain the different ways in which residents can manage their complex relationships with each other and with those in the assisted living system (Payne, 2005). The systems/ecological framework is particularly compatible with the value base of social work practice and can be applied to restoring the balance between people’s adaptive capacities and their social and physical environments, when faced with stressful life transitions, maladaptive interpersonal processes, and unresponsive environments (Kemp, Whittaker, & Tracy, 1997).

From a systems/ecological standpoint, when a family system of caring for elderly members and a professional system of care overlap, there exists the potential for conflict in such situations, which needs to be clarified and addressed for meaningful partnerships and collaboration to take place. Relationships that link individuals to their social and physical environments can be understood from a “goodness of fit” standpoint (Rothery, 2008). Problems that may arise because of a poor fit between an individual’s environment and his or her needs, capacities, rights, and aspirations can be identified and corrected within the ecological framework (Greene, 2008; Healy, 2005).

With regards to the notion of goodness of fit between care-receivers in an assisted living setting and their physical environment, many older residents have indicated that along with independence and privacy, they also value environmental autonomy. A certain level of autonomy allows them to personalize their private space, arrange furniture, bring in adequate storage for valued possessions, prepare snacks, and in some cases, keep a pet.
(Hawes & Phillips, 2007). This fosters self-identity and a sense of belongingness among the care-receiving residents. Elderly residents get accustomed to living in an assisted living care setting, which is where they want to remain, in spite of their increasing physical frailties and constraints.

Despite its value, the systems/ecological framework has been criticized for being too inclusive, complicated, and hard to test empirically (O’Donoghue & Maidment, 2005). The systems framework has been described as being too abstract in nature, which limits its application to diverse ideas and contexts, whereas the ecological framework has been criticized for offering a very tautological logic for the process by which change occurs (Greene & Blundo, 1999; White & Klein, 2002). Some critics claim that this comprehensive framework fails to offer a concise and prescriptive model for social work practice, which would include guidance on intervention and social work methods. In answer to these criticisms, this researcher contends that although the framework does not change the outcome of a particular crisis, it is highly invaluable in identifying and understanding the factors that are causing the crisis, which is vital for change to take place. Overall, the systems/ecological framework is critically important to this study, because it allows for a comprehensive analysis of the familial (informal) and the professional (formal) networks around the care-receiving residents and their respective caregivers, including relationships with the community and the environment as a whole.
Chapter Two: Literature Review

Demographic and Social Trends and Their Implications for an Aging American Society

It is well known and widely documented that America’s elderly population is living longer and continues to grow at a steady pace (Albert, 2008; Kinsella & Phillips, 2005; Matcha, 2007; McKenry & Price, 2005). Hence, several imperative social, political, and economic implications of an increasing elderly population are an important context for this study. The Administration on Aging (AOA, 2007) estimated that there were around 37.3 million elderly persons, 65 years or older, in 2006. However, as the youngest members of the baby boom generation who were born between 1946 and 1964 begin to turn 65, the older adult population is predicted to more than double to 80 million by the year 2050, resulting in one in five Americans being elderly (Greene, 2008; Institute of Medicine, 2008; U.S. Bureau of the Census, 2004).

This boost in numbers, which has increased the proportion of older adults in the population, is attributed to a consistent decrease in the death rate for those 65 and over, an increased prevalence of fewer children per family, and an increased life expectancy at birth, which is significantly higher now than in the past (Matcha, 2007). Whereas it was 47 in 1900, life expectancy by the end of the 20th century was 76 (Jurkowski, 2008). Research studies have increasingly shown that improvements in medical care, nutrition,
and hygiene, as well as lifestyle choices, which have been associated with good health in old age, have helped in extending life expectancy for most seniors (Carman, 2009).

Prolonged life expectancy has important physical, socio-emotional, and economic implications for elderly care-receivers and their family members. However, longer life spans do not prevent or delay disabling conditions. Advances in biomedical technology and treatment have not been able to prevent an epidemic of chronic diseases and conditions among older adults (Albert, 2008). According to a report by the Institute of Medicine (2007), some of the most common conditions that are linked to activity limitations among those 65 and older include arthritis, hearing, and vision impairments, diabetes, hypertension, musculoskeletal conditions, and cardiovascular and other circulatory problems. A high prevalence of chronic and acute health concerns in mid or late life that require long-term care, also referred to as aging with disability, have been frequently described to limit older adults’ abilities to perform routine care activities, such as showering, dressing, cooking, shopping, doing laundry, and managing personal finances (Putnam, 2007).

It is also estimated that 80% of older adults suffer from at least one chronic condition, which substantially increases the demand and utilization of more long-term care services (Institute of Medicine, 2008). Longer life spans also increase the likelihood that a growing number of elders will be afflicted by dementia and Alzheimer’s disease. This alarming trend suggests that by the year 2050, 16 million Americans could be diagnosed with Alzheimer’s disease (Pruchno & Smyer, 2007). Some major causes of death are now found to be cerebrovascular, cancer, and heart-related diseases that often
involve an extended period of disability and need for caregiving before death (Covinsky et al., 1994; Richardson & Barusch, 2006).

Future projections have also indicated that the demographic characteristics of elderly Americans are likely to differ from those of previous generations primarily with respect to race, family structure, socioeconomic status, and education (Institute of Medicine, 2008). Presently, an important demographic feature of older Americans that cannot be overlooked is their diversity. Estimates have suggested that between 1999 and 2030, because of continued immigration, minority groups of elders, 65 and older, will increase by 217%, and the number of older African Americans is expected to increase by 131%, compared with a growth rate of 81% for the elderly White population (Ball et al., 2005; Greene, 2008). Elderly Hispanics are expected to number 13.4 million by 2050, becoming the largest elderly minority group (Richardson & Barusch, 2006).

Demographic and cultural shifts in the United States have led some researchers to predict that the percentages of older adults belonging to different racial and ethnic minority groups will increase at a much higher rate than White elders over the next 50 years (Dilworth-Anderson, Williams, & Gibson, 2002; Redfoot, 2003). By the year 2050, the total number of Whites age 65 and over will double, the number of elderly African Americans will more than triple, and the number of elderly Hispanic and other minority populations will increase 11-fold (Cohen, 2004). Overall, the total population of older adults belonging to minority groups will grow from 6 million in 2003 to 20 million in 2030, and to 33.5 million in 2050 (Markides & Wallace, 2007), which, therefore, increases the demand for culturally sensitive and competent services. The level and
extent of disability from aging, determines the need for caregiving and care-receiving, which is also influenced by an elderly family member’s ethnic orientation, culture, values, experiences, and expectations. However, irrespective of racial and ethnic differences, family members continue to be the most important resource and support for their aging relatives, providing emotional, social, physical, and financial assistance and care.

Increased life expectancy provides an extended period of time and numerous opportunities for older adults and their family members to stay mutually involved, or even to re-establish ties, which can help to promote solidarity within families. In 2000, 76% of individuals age 30, who were likely to have their own children, had at least one living grandparent; moreover 60% of 40 year olds had both parents living (Conner, 2000). Within a decade, these percentages will have increased further. As older adults are advancing in age, their families are also aging, which has extended many family roles and established new intergenerational relationships with living grandparents and great-grandparents. This has important implications for family involvement among families of all racial/ethnic backgrounds in this present day and age.

Among the aged, the fastest growing segment is expected to be those over the age of 85, who would also most likely be in need of health care, instrumental assistance, and institutionalized long-term care (Chen, 2003; McKenry & Price, 2005; Moody, 2009). Moreover, the most rapid increase in the oldest old population, comprised of those 85 years and older, will occur between 2030 and 2050, because the aging baby boom generation will then join the ranks of the oldest old (Gonyea, 2005). The 85+ population
is projected to increase from 9.6 million in 2030 to 20.9 million by 2050 (Wacker & Roberto, 2008). Despite the value placed on independence by many older adults, those in the 85+ group in particular are increasingly finding themselves in need of some long-term care services in the form of help with personal care and household chores, which are typically provided by a spouse or child (Ball et al., 2004; Institute of Medicine, 2008).

Remarkably, the U.S. Census Bureau reported that there were approximately 65,000 Americans age 100 or older in 2000, predicting that number to increase to 131,000 centenarians by 2010, 381,000 centenarians by 2030, and 834,000 by 2050 (Gonyea, 2005; Jurkowski, 2008). Among the oldest old, an increased prevalence of debilitating conditions, therefore, results in not only the loss of independence but also a corresponding rise in the level of care needed. The last century has therefore witnessed a radical change in terms of the global load of family dependency, which has begun to shift from meeting the needs of young dependents to addressing the increasing needs of older dependents (Marks & Lambert, 1997; Moody, 2009; Szinovacz & Davey, 2008).

Changes in the American Family Structure and Ideals

Families are age-old institutions that help socialize and care for individuals. Families provide a basis for multiple relationships, shared experiences, exchange of resources, and mutual solidarity that lasts over a life course (Hoff & Tesch-Romer, 2007). The notion of family as a dynamic social institution is deeply embedded in historical processes (Zimmerman, 2001). Family systems can be understood through studying the numerous changes they have undergone in history. American families have undergone several “domestic revolutions, which have profoundly altered family life, repeatedly
transforming their demographic characteristics, organizational structure, functions, conceptions, and internal dynamics” (Mintz & Kellogg, 1988, p. 45). During the early colonial era, the American family constituted the fundamental economic, educational, political, and religious unit of society, performing many functions (Carman, 2009). Labeled as “little commonwealths,” families in colonial times performed many functions that have since been consigned to non-familial institutions (Zimmerman, 2001).

Family in the late 18th century was described as a haven in the harsh, aggressive, and selfish world of commerce, and a core upholder of morality and tender feelings (Mintz & Kellogg, 1988). However, the elderly members in families were viewed as without skills to contribute successfully. Referring to that era, Heumann and Boldy (as cited in Frank, 2002) explained, “Industrial society devalues non-productive people, thus when human beings are no longer productive, they become expendable” (p. 186). Those economically disadvantaged elders who were without skills and available family members or connections were unfortunately consigned to the “poorhouse,” as communities distanced themselves from having to take care of them (Matcha, 2007).

The 19th century transformed the family into a value-oriented, democratic, private refuge, wherein family relations were structured around the principle of “separate spheres,” with each family member having a special role and domain, based on age and gender (Zimmerman, 2001). Yet, increased urbanization added to the disenfranchisement of the economically disadvantaged elderly from communities into the poorhouses (Matcha, 2007). During this period, nuclear family units emerged, which added to the isolation and exclusion experienced by many elderly family members.
Due to high divorce rates and changes in the position of women, morals, and manners, the 20th century saw the rise of a companionate family ideal, which centered relations within the family on friendship, affection, and mutual interest, rather than patriarchal authority (Mintz & Kellogg, 1988). Experiences of economic hardship and loss during the 1930s and 1940s influenced the middle-class family ideal. After the Great Depression and World War II, the combined effects of increasing wages, couples marrying early, and women bearing more children made “family togetherness” the cultural norm (Mintz & Kellogg, 1988). Regrettably, such changes also removed elderly workers from the workforce at a younger age, because strength became the criteria for employment (Matcha, 2007).

Over the past decades, family arrangements have continued to evolve due to the sociopolitical and cultural changes that have taken place. Increased emphasis on self-fulfillment, autonomy, and personal freedom in choosing careers, as well as couples cohabitating outside of marriage were some of the trends occurring during the late 1950s (Zimmerman, 2001). Even as married couples with children are still the most common family type, the rise in divorce rates plus an increasing diversity in family living arrangements, along with singlehood, single parenthood, and unmarried-couple households, have distinctly characterized American family life since the 1960s (Hoff & Tesch-Romer, 2007).

As a consequence of globalization, geographically separated family networks, and increasing demographic and economic changes, family systems are changing in both form and meaning. The plurality of family forms has influenced the relations between
elderly parents and their adult children, between grandparents and their grandchildren, and between aging marriage partners who are now more likely to divorce at an advanced age (Hoff & Tesch-Romer, 2007). Increasing urbanization has helped introduce alternative sources of identity and status, contributing to the process of “institutionalized individualization” (Gilleard & Higgs, 2005, p. 125). Such changes have important implications for institutionalized older adults, their family members, and the long-term care system. It is therefore important to focus on the changing family dynamics among families of all racial/ethnic backgrounds, and their impact on family composition, intergenerational relationships and roles, and caregiving and care-receiving patterns.

Current scholarship has associated changes in family structure with pivotal life events experienced by individual family members, whereas changes in family roles regarding the support of elderly members have been linked to redefined family functions (Hoff & Tesch-Romer, 2007; Zimmerman, 2001). Families have constituted an integral force, crucial to enhancing the quality and quantity of care and support for aging family members. The family’s structure and development, as well as its history of caring relationships, have a significant impact upon family members’ involvement in family caregiving tasks. Family norms and values, along with the roles ascribed to positions within a family system, impact the practice of family caregiving. Smaller families, loosened economic relationships between family members, and a growing aging population have an impact on family roles and relationships (Morgan & Kunkel, 2001). Typically, roles within families are age and gender specific. Caregiving duties have been
predominantly assigned to women, which is why the role of female caregivers is central to this discussion (McKenry & Price, 2005).

**Female caregivers.** Researchers have frequently indicated that caregiving is largely provided by female family members, who are highly motivated by attachment, obligation, and traditional and cultural norms of filial responsibility (Sims-Gould, Martin-Matthews, & Rosenthal, 2008). Moreover, many of these caregivers are women who still have children under 18 living at home (Conner, 2000). After the industrial revolution, caregiving responsibilities assumed by women became central to their life’s work, which introduced the ideology of separate spheres, where women would nurture and develop empathic relationships, and men would be the breadwinners (Hooyman, 1990). This gender bias also resulted in socializing women to feel more responsible for caring for their older family members. The changing role of women has also altered their family and professional lives. Women in professional roles were underpaid and undervalued, but were still expected to fulfill their caregiving roles. Moreover, women who sought institutionalization or in-home help for their elderly relatives were branded as being selfish or unloving (Moen, Robison, & Fields, 1994).

Thus, women caregivers provide more intensive assistance than their male counterparts, a trend that is most commonly observed among adult children (Montgomery, 1999). Typically, the female members in families are viewed as being the “softer sex,” naturally endowed with nurturing and caring qualities when compared to their male counterparts. However, feminists have argued for gender equality in everyday tasks and responsibilities to resolve the disproportionate burdens many mothers,
daughters, and wives carry in families (McKenry & Price, 2005). According to Hooyman and Kiyak (2004), an American woman is estimated to spend an average of 18 years caring for an elderly family member, compared to 17 years for her children. The Family Caregiver Alliance (2003) posited that 75 to 80% of care provided to elderly family members in the United States is by women, because they outlive men and have more nurturing responsibilities. Research literature has, therefore, emphasized the importance of including older women, who may be interested in caregiving careers, as a strategy for developing the caregiving workforce (Stone, 2003).

Women have had to work in professional capacities to financially provide for their family members. Participation of married women in the labor force has been growing since World War II. The traditional value of women assuming the role of family caregiver often conflicts with the more current value that most women ought to compete successfully with men in the labor market (Brubaker & Brubaker, 1992). Nevertheless, when compared to men, women are more likely to face social and familial pressure to be primary caregivers, because their employment is often viewed as less important, and they are less likely to receive any supplemental assistance (Pinquart & Sorensen, 2003). This tension between paid work and family care, which is keenly observed today, has existed in the United States since the 19th century (Abel, 1995).

Currently, about 70% of women are working full time while assuming caregiving responsibilities that are in conflict with their work schedules (Szinovacz & Davey, 2008). This presents a role conflict for working women, which may detract from effectiveness at work, and at times, result in cessation of employment in order to provide more
comprehensive care to family members (Morgan & Kunkel, 2001). Caregiving families need to be provided with fundamental solutions to address the issue of caregiving roles and responsibilities that are divided along gender and economic lines. However, limited research concerning this process exists and specific theoretical constructs to guide practice require further development. Women alone should not have to sacrifice themselves to meet all the needs of their family members, including caring for their elderly relatives. Male members in such caregiving families can be helpful and supportive of the female members by assuming a more equal share of the responsibility in providing care and instrumental assistance.

**Major Theoretical Approaches to Aging and Caregiving**

All families are characterized by intergenerational ties and reciprocal relationships. Many theoretical contributions have been developed and applied to families and aging, which include the role theory, life-course theory, and social exchange theory. Although these theories have often been applied to caregiver burden (Morgan & Kunkel, 2001), they have also provided a context for caregiving and care-receiving relationships and role changes. Role theory, life-course theory, and social exchange theory are briefly discussed below, because they are relevant to this study, which examined the impact of developmental and psycho-social changes, and life-course transitions on the care-receiving and caregiving processes within family systems.

**Role theory.** Role theory was applied to late life, specifically, to widowhood and retirement, in the early 1970s (Richardson & Barusch, 2006). Role theory offers a framework, which can be utilized to explain how individuals adjust to aging and
subsequent role changes (Hooymann & Kiyak, 2004). Role theory is also relevant to examining age-related stereotypes regarding elderly individuals’ competence, abilities, and behaviors (Kite, Stockdale, Whitley, & Johnson, 2005). Roles exist in relationship to other roles and are defined as a set of activities and responsibilities expected of individuals who occupy particular positions in life (Morgan & Kunkel, 2001). Each role is comprised of numerous activities that are emotional, physical, social, and spiritual in nature. Role theory has explained roles as a series of relationships and transactions that are dynamic and reflect changing family circumstances (Berg-Weger, 1996). Role changes can be stressful for family caregivers who have to assume additional responsibilities, as well as for the older care-receivers who have to contend with loss of power and roles due to retirement, declining physical health, and a lower financial status (Hargrave & Hanna, 1997).

Role theory has, therefore, established that most caregivers have multiple roles that either cause strain or create conflicts in time and energy, or in other cases, lead to better health, lower psychological stress, and increased self-esteem and well-being (Berg-Weger, 1996). Such research findings, while conflicted, suggest that caregiving responsibilities are more complex, because they comprise several tasks and behaviors. Nevertheless, role theory has helped to examine reciprocal and complementary family roles, the rights and obligations among family members, and the continuous interplay between individuals and their social experience (Greene, 2008).

**Life-course theory.** Life-course theory is a holistic approach to examining the interaction of historical events and early life experiences, along with personal decisions
and opportunities in determining later life outcomes (Quadagno, 2005). A life-course is a sequence of age-graded roles and transitions, which are embedded in social institutions and history (Putney, Bengtson, & Wakeman, 2007). Life-course theory, hence, views institutionalization as one of the phases or stages in the life span of an individual, which may come at a specific time in an elder’s life course (Caron as cited in Hargrave & Hanna, 1997). This theory helps consider:

- The developmental timing of transitions into and out of caregiver role, the intersection of other roles in relation to the caregiving role, the changing historical context for enactment of the caregiving role, and the cumulative patterns of caregiving across the life courses of varying birth cohorts (Moen, Robison, & Fields as cited in Marks & Lambert 1997, p. 21).
- A life-course analysis is a longitudinal perspective that is characterized by an institutional structuring of lives, and the entry and exit from social roles that are influenced by age norms (Morgan & Kunkel, 2001). Life-course perspectives are also useful in understanding roles and reciprocal relationships between generations (Moody, 2009). Nevertheless, it is also highly important to consider the impact of culture, ethnicity, gender, and socioeconomic status on the individual meaning and experience of aging, which incorporates successive roles and relationships.

**Social exchange theory.** Social exchange theory emerged out of the philosophical traditions of neoclassical economics, utilitarianism, and behaviorism, and has been applied in the family sciences since the 1960s (Chibucos & Leite, 2005). Social exchange theory posits that family caregiving relationships “are characterized by a high degree of mutual exchange, including financial, instrumental, and emotional support” (Hoff & Tesch-Romer, 2007, p. 73). Exchange is expected in family networks, because family members are bound by solidarity, role rights, and obligation (Quadagno, 2002).
Social exchange theory encompasses the concepts of intergenerational reciprocity, responsibility, and identity, which are rooted in morals, familial expectations and rules, and parental needs and desires (Berg-Weger, 1996).

Social exchange theory has also attempted to examine familial relationships and social interactions by arguing that individuals choose behaviors and interactions that maximize their benefits and promote self-interest (Matcha, 2007). In the case of the elderly, these exchange networks are activated in times of need, or when a life change, such as institutionalization, is imminent or in progress. However, this implies that older adults have diminished resources and relationships, and instead of contributing, are largely only receiving assistance and support (Wilmoth, 2000). Older adults internalize such negative messages and become more vulnerable to future losses (Richardson & Barusch, 2006). Social exchange theory, when applied to exchanges mostly material and economic in nature, provides a very limited account of the roles and relationships between older adults and their family members (Seabrook, 2003). However, this study focused on a comprehensive approach to exploring the nature of exchanges between care-receivers and caregivers, and also emphasized the roles and relationships of elderly care-receiving residents.

**Family Caregiving and Care-Receiver Research: Past and Present Trends**

Traditionally, family caregiving has existed and continues in response to illness and disability among older adults. *Family caregiving* has been described as caring for older adults, and has also been referred to as informal support, caregiving, and eldercare (Putney et al., 2007; Sims-Gould, Martin-Matthews, Rosenthal, 2008). Demographic
changes that were mentioned earlier emphasize the importance and need for family caregiving networks. Extensive research on family systems, including multigenerational households, has established that kinship solidarity, affection, and exchange of resources and services have continued to increase, despite the many social changes that have taken place (Putney, Bengtson, & Wakeman, 2007). Researchers have also examined family composition and functioning, and explored the nature of available relationships as sources of informal support (Ajrouch, Akiyama, & Antonucci, 2007; Conner, 2000; Putney, Bengtson, & Wakeman, 2007).

Older Americans have continued to receive regular support from family, friends, and neighbors in carrying out activities of daily living (Gaugler & Kane, 2007; Uhlenberg & Cheuk, 2008). Unpaid informal caregivers are a critical support for their aging family members, because they provide between 70 to 80% of care to their elderly relatives (Conner, 2000). Research studies have consistently highlighted the important role of family and friends in helping their elderly relatives with functional limitations to maintain their independence for as long as possible, and remain in the community rather than moving to a long-term care facility (Keith, Wacker, & Collins, 2009). This, however, does not diminish the provision and influence of familial involvement within the context of institutionalized care.

Research literature on family caregiving has been dominated by studies that have examined caregiver burden, in relation to how it impacts family caregivers’ mental health and their well-being (Berg-Weger & Tebb, 2004; Iecovich, 2008; Wallhagen & Yamamoto-Mitani, 2006; Whitlatch, Schur, Noelker, Ejaz, & Looman, 2001). Giving
constant care to elderly persons who are frail, sick, and dependent has been established as being stressful and often burdensome for family members (Pratt, Schmall, Wright, & Clelland, 1985; Robertson, Zarit, Duncan, Rovine, & Femia, 2007). Family members, who provide care well beyond their experience and ability, suffer from considerable stress and burden (Aneshensel, Pearlin, & Schuler, 1993). Caregiving family members experience caregiver burden, when they are undergoing a loss of resources, freedom, privacy, mobility, energy, and time (Greene, 2008). Hence, caregiving, which is mostly a personal family matter, has become a growing public issue, because an increasing number of family members providing informal care to their aged relatives continue to struggle, offering assistance at a significant cost to themselves.

A number of researchers have suggested that there is a lack of longitudinal research efforts that contribute to a better understanding of how caregiving and care-receiving roles and relationships have changed over time (Given & Given, 1991; Opie, 1994; Taraborrelli, 1993; Thompson, Fellerman, Gallagher-Thompson, Rose, & Lovett, 1993). In addition, numerous research studies have focused on individual caregiver stress and burden, but have paid little attention to examining roles, responsibilities, and relationship dynamics of multiple family members involved in caring for their elderly relatives (Sims-Gould, Martin-Matthews, Rosenthal, 2008). Also, further research is needed on how female and male caregivers’ experiences differ, regarding the nature and type of tasks associated with caregiving.

Limited references to elderly family members and their needs have been made in long-term care research (Cox, Green, Seo, Inaba, & Quillen, 2006). Very few studies
have delved into exploring the experiences and perspectives of family caregivers and their care-receiving relatives living in residential long-term care facilities, such as assisted living. It has been suggested that interactions among residents, and roles and relationships between residents and their family members may have been given little attention due to the focus on care-receiving residents as patients and merely consumers of provided services (Moran, White, Eales, Fast, & Keating, 2002; Zimmerman et al., 2003).

Institutionalization of elderly persons has typically been described as being steeped in isolation and despair for most residents and their family members (Lyons Zarit, Sayer, & Whitlatch, 2002; Whitlatch, Schur, Noelker, Ejaz, & Looman, 2001). Gerontological literature in this area has been based on a medical model of care, with an over-reliance on nursing homes that accommodate elderly clients who are too frail and poor and vulnerable to advocate for themselves (Fahey, 2003; Levine, 2004; Vladeck, 2003). There is ample empirical evidence that caring for an elderly family member with Alzheimer’s disease or dementia is associated with compromised mental health functioning, and stressors, such as severe emotional, financial, and work strain. There is also stress related to placing an elderly loved one in an institutional long-term care facility and negotiating new relationships and interactions with the staff and administration (Dobrof & Ebenstein, 2004; Levine, 2004; Whitlatch, Schur, Noelker, Ejaz, & Looman, 2001; Whitlatch, Judge, Zarit, & Femia, 2006).

Hence, families and their elderly family members are presently, more than ever before, being confronted with making decisions about how to acquire the necessary long-term care as disability occurs and progresses. There has been a gradual shift from
focusing on a medical model of caring for the elderly to a growing need and emphasis on community-based care and services, and residential long-term care, such as assisted living. This shift in focus has been due to a gradual change in values that has resulted in emphasizing dignity, community, and participation, as well as advocating for environmental, cultural, and regulatory changes within residential care facilities, which include both nursing homes and assisted living (Kehoe & Heesch, 2003; Levine, 2003; Redfoot, 2003).

Lately, some researchers have started to focus on more strengths-based and empowerment-oriented approaches to family involvement and caregiving, by emphasizing the psychological well-being, quality of life, and social support and engagement of elderly residents and their families (Chappell & Reid, 2002; Lyons, Zarit, Sayer, & Whitlatch, 2002; Williams & Guendouzi, 2005). Hence, meaningful research activity, along with government and community-based measures need to prepare family networks to adequately take care of their elderly care-receivers without excessive strain and burden.

**A Historical Overview of Institutional Long-Term Care in the United States.**

The long-term care system in the United States is observed to have had deep historical roots in its welfare policy. At a custodial, intermediate, or a skilled care level, long-term care services provide medical and social support to older adults who are unable to independently perform basic and other instrumental activities of daily living. These services can be provided either at home, in a community, or in an institutional care...
setting, such as a nursing home or an assisted living facility (Mering, 1996). However, historically, long-term care was not always set up according to this description.

During the mid 1700s, people over 60 years of age comprised less than 2% of the general population, because the average life span was between 30 to 40 years (Sussman, 1995). In the 18th and 19th centuries, the public welfare system used community taxation, private fees, and charitable giving to fund questionable institutional facilities, also called almshouses or public poorhouses, to provide care only to those residing in their jurisdiction, if they were poor and did not have any family members who could take care of them (Carman, 2009). However, the long-term care movement changed significantly during the 20th and 21st centuries, because of longer life spans among individuals. Religious charitable groups and local organizations developed boarding homes for the aged, and as the elderly population grew and urbanization modified family networks, functions, and relationships, the demand for developing more long-term care options also increased.

Before the 1950s, long-term care represented largely a residual policy area, wherein the provision of this care was viewed as an expression and a response of public or private altruism towards the less fortunate and needy families to provide care to their elderly family members (Hennessy, 1996). Some of the general criticisms of traditional long-term care services were directed at questioning the appropriateness of this form of care for elderly who were not in need of constant nursing care and who had indicated an overriding desire to remain in their own homes if possible. This resulted in the expansion and specialization of home care services, improved long-term care housing arrangements
for the elderly, and the extension of government-sponsored cash support made available
to low-income and disabled elderly. The government developed policies, such as the Medicare and Medicaid programs, that provided the foundation for financing long-term care for older and disabled Americans.

As a result, charitable almshouses gradually became transformed into modern, innovative, bureaucratic service businesses, such as senior community care and adult day care centers, meals on wheels, hospice, and other institutionalized long-term care facilities (Ball et al., 2005). Long-term care institutions emerged from public poorhouses for chronically ill and poor elderly. Board and care homes, which had helped impoverished older adults who were unable to live alone by providing them with basic care and assistance, gradually evolved into nursing homes (Carman, 2009). After World War II, a 1950 amendment to the Social Security Act allowed funding and loan programs to help develop the nursing home industry (Holstein & Cole, 1996).

During the first half of the 20th century, frail elderly individuals were viewed as financially needy and desirable tenants who were also in need of housing assistance, (Pynoos & Nishita, 2005). Also, it was recognized that elderly persons who were disabled would be in need of other housing options. Hence, in 1959, the National Housing Act, Section 202, created a special housing program for disabled and older adults, thereby laying the foundation for developing more housing projects for ambulatory and independent elderly persons (Pynoos & Nishita, 2005). The 1965 enactment of the Medicare and Medicaid policies led to the conversion of many homes for the aged into certified nursing facilities, which were based on a medical model of care (Wilson, 2007).
Hence, many privately owned, profit-oriented nursing homes were widely constructed with very limited regulation and oversight by the government, which resulted in poor care and quality of service, and numerous allegations of abuse and neglect. Changes in government reimbursement measures, such as the Balanced Budget Act of 1997 that imposed overall financial regulations on Medicare and other payments to such nursing homes, led to an accelerated demand for a new form of residential care (Smith, 2003).

Nursing homes of yesterday are presently being viewed as nursing and rehabilitation facilities, which are catering to elderly residents whose needs are now much more medically complex (American Health Care Association [AHCA], 2009). Current challenges for the institutionalized long-term care industry could include reimbursement decreases, new regulatory burdens, employer requirements, and possible new costs for insurance (Gay & Morton, 2010). The three dominant themes critical to the long-term care discussion include a description of (a) elderly consumers and their long-term care needs, (b) family involvement in institutionalized long-term care facilities, and an examination of the (c) current long-term care costs and their financing mechanisms, with special reference to assisted living facilities.

**Long-Term Care Consumers and Their Needs**

According to a report by the Institute of Medicine (2008), just over two-thirds of the elderly population will require long-term care services at some point in their lives, which will be largely provided by their family and friends. An estimated 12 million adults 65 or older will need long-term care services by 2020 (U.S. Department of Health and Human Services, 2007). By 2050, the oldest old, who are age 85 and older and most
likely in need of long-term care, are projected to increase in number to almost 19 million Americans (Gonyea, 2005). It is estimated that those over age 85 are four times as likely to live in a nursing home, when compared to those aged 75 to 84 (Institute of Medicine, 2008). Long-term care has gradually become a viable option for care-receivers who prefer to move into a residential care facility, instead of becoming a burden to their family members. It is also a preferable option for family caregivers who are not skilled and equipped to care for ailing and frail family members within the confines of their homes (Reuss, Dupuis, & Whitfield, 2005). Hence, the long-term care needs of frail elders and their family systems have to be understood within a functional, economic, socio-emotional, and a culturally diverse context.

Current literature has suggested that the economic and social costs of maintaining home care for elderly family members have continued to escalate (Sinclair, 2008; Szinovacz & Davey, 2008). Two-thirds of those not institutionalized and in need of assistance with activities of daily living rely exclusively on family and friends, whereas the remaining one-third supplement family-care with services from paid providers (Lui, Manton, & Aragon, 2000). 78% of older adults receiving long-term care at home rely solely on family members to provide regular assistance (Thompson, 2004). If unpaid family caregivers were paid, the additional cost of providing long-term care would range from $45 billion to $95 billion per year (Mandy, 2009). An increased demand on family caregivers, especially working caregivers, has caused many to need formal resources. Furthermore, this demand often requires careful monitoring on a 24-hour basis, exacerbating the need for institutional care.
Increased frailty and dependence is subsequently accompanied by an elder’s inability to maintain self-care without assistance from formal paid care providers in supportive residential care environments, which involves high costs and a variety of coping mechanisms (Fahey, 2007). Older adults are considered to be the primary users of hospital inpatient admissions, pharmacy services, and physician visitations (Albert, 2008). Frail and disabled older adults incur three times the medical expenditures of those without any long-term care disabilities or chronic diseases (Bowen & Gonzalez, 2008).

Many critics believe that age-segregated housing environments would only isolate the elderly from the rest of the society. Moreover, elderly family members do not wish to live the rest of their lives in a nursing home. They are a valuable resource to their families and communities. Changes in family structure, function, and relationships have created opportunities for a mutual and more equal exchange of support between generations. More efforts, therefore, need to be made to not only support and help institutionalized elderly residents to return to their homes with adequate care, but also increase services in their communities to prevent institutionalization in the first place (Jurkowski, 2008).

From a research and policy perspective, expanding home and community-based services (HCBS) has become a major focus of the federal and state governments, because older people strongly prefer HCBS to institutional care, seeking to avoid institutionalized care even if 24-hour assistance is needed (American Association of Retired Persons [AARP], 2003).

Overall, home and community-based service expansion is supported for four reasons, including (a) a strong preference of older people to avoid institutional settings,
(b) the documented need for community-based care due to increasing numbers of
disabled elderly, (c) the superior quality of home and community-based services when
compared to institutional care, and (d) more assumed savings as a result of using home-
based services versus institutional service costs (Wiener & Brown, 2004). Results from
numerous cost-related studies in this area, however, emphasize the complexity of the
level of care needs and the availability of unpaid family and/or informal caregiving
assistance as important variables that affect the costs of home-based care and supplement
home and community-based services.

Presumptions about older adults as being merely helpless and dependent prevent
them from articulating their needs and preferences for care. For an older adult, personal
autonomy “means having the capacity to make and execute deliberated decisions to
satisfy needs and attain goals in a manner consistent with one’s values” (Cicirelli, 1992,
p. 14). Elderly adults with higher incomes and access to material resources have greater
control over long-term care decision making and have more residential care facilities and
communities to choose from, as opposed to poor elderly residents who can only afford
smaller, low-income facilities (Ball, Perkins, Hollingsworth, Whittington, & King, 2009).

Policy debate regarding institutional long-term care has emphasized the
inadequacy of financing long-term care needs and services, including assisted living.
However, the economic feasibility of such programs is affected by the rapid increase in
health care costs in United States. Most aging experts argue that long-term care is given
low priority in this debate (Sinclair, 2008), while the Administration on Aging and other
aging organizations continue to emphasize the need for a better balance between acute
care and community-based programs (Brodie & Castora, 2008). These issues are being argued in order to find probable funding options and solutions to this dilemma.

Another important issue is the growing diversity of long-term care consumers. Presently, America’s elderly population is becoming more ethnically and racially diverse, and includes an increasing number of immigrant elders who undergo many environmental and lifestyle changes that place them at considerable risk for chronic diseases (Okafor, 2009). Older adults from Hispanic, African-American, Asian, American Indian, Alaska Native, and other Pacific Islander and Hawaiian origins are estimated to constitute 40% of the 87 million older adults by 2050 (He, Sengupta, Velkoff, & DeBarros, 2005). African-American elders, followed by Hispanic elders are highly prone to suffer from multiple chronic conditions, such as arthritis, diabetes, hypertension, and other functional disabilities, and continue to experience poorer health as a result of delayed care and poor management of chronic conditions (Farmer & Ferraro, 2005). Overall, older adults’ values, traditions, and culture play just as important a role as their health, when it comes to planning long-term care for them.

Age, gender, race, and familial and marital status have also been linked to disability, poor health, and a consequent need for long-term care and health services for most minority elders (Bowen & Gonzalez, 2008). Qualitative research findings have suggested that cultural values that rely heavily on familial and gender–based roles, along with religious and spiritual coping may explain why elders from Hispanic, Asian, and African-American backgrounds underutilize long-term care services (Herrera, Lee, Palos, & Torres-Vigil, 2008). Minority elders from Asian, Hispanic, and African-American
backgrounds prefer to live in larger families, and continue to be institutionalized at much lower rates than non-Hispanic White elders (Markides & Wallace, 2007). Social Security is the main source of income for many minority elders, and African-American and Hispanic elders reflect the highest percentages for living below the poverty level (Borrell, 2008). Language barriers, inadequate health insurance, clinical uncertainty, lack of knowledge about available services, stereotypical behavior, and racial discrimination have been identified as some of the structural barriers to accessing and utilizing long-term care services among minority elders (Cox, 2005; Herrera, Lee, Palos, & Torres-Vigil, 2008).

Moreover, institutional long-term care is facing culture changes, not only with respect to its consumers, but also within its organization, care management, and its environment. There is an increasing demand for diversification of services, because elderly consumers and their families prefer a more homelike, resident-controlled environment in institutionalized facilities and a less institutional approach to long-term care services and supports (Gay & Morton, 2010). Long-term care facilities are comprised of both staff members and older residents who may belong to different minority groups and who, therefore, influence service delivery and other policy and program decisions. A cultural shift in such institutionalized settings also reflects an overarching emphasis on elderly residents, their needs and their psychosocial well-being.

**Family Involvement Within Institutional Long-Term Care**

Family involvement has been considerably influenced by the demographic, cultural, political, and economic context of American society (Ball et al., 2005; Olson,
Historically, many factors have been recognized as having an impact on family involvement. These factors include family and household organization, gender differentials, epidemiology, and a health care delivery and financing system that has used public resources sparingly (Levine, 1999). Research literature on family caregiver and care-receiver’s mutual involvement within an assisted living system is severely limited due to the number and nature of studies that have mainly focused on caregiving family members’ involvement in caring for their elderly relatives, who live in nursing homes (Feinberg & Newman, 2004; Port, 2004). Recently, a few research studies exclusively focused on the nature and types of family involvement within assisted living facilities (Gaugler, 2005; Gaugler & Kane, 2007; Kelchner, 2008). However, further research is required to assess experiences of both caregivers and elderly care-receivers regarding their family involvement, a perspective that has been largely ignored and unexplored.

Studies on caregiving stress have helped to identify predictors of family involvement in nursing homes (Gaugler, Anderson, & Leach, 2003; Mitrani et al., 2006; Whitlatch, Schur, Noelker, Ejaz, & Looman, 2001). Family units constitute the backbone of the caregiving system, because family members continue to stay involved by trying to meet the many emotional, mental, physical, financial, and social needs of their institutionalized elderly relatives. Overall, the relationship between a caregiver and care-receiver may change with respect to the caring role after placement in a residential long-term care facility, but the bonds that have been established over a period of many years do not change significantly (Gilhooly, Sweeting, Whittick, & McKee, 1994; Szinovacz, 2003). Most families want to continue to assist and care for their elderly relatives.
following admission to institutionalized long-term care settings (Szinovacz, 2003; Williams & Guendouzi, 2005; Wolff & Kasper, 2006).

A majority of those who visit their elderly family members in a long-term care facility are adult children, followed by other relatives, which confirms the important role family members play by visiting and staying involved (Gaugler, Anderson, & Leach, 2003). Research studies have identified that frequency of family visitations, provision of personal and instrumental care and monitoring, as well as socio-emotional support have helped determine the different forms of family involvement (Gaugler & Kane, 2007; Port, 2004; Port et al., 2001). There is ample evidence that family members continue to maintain extensive contact and close emotional ties with their elderly relatives after institutionalization, along with renegotiating their role and actively assuming responsibility for certain care tasks that require less skill (Dempsey & Pruchno, 1993; Gaugler, 2005; Gaugler, Anderson, & Holmes, 2005; Schwartz & Vogel, 1990). In fact, research studies have indicated that family caregivers, while engaging in the caregiving process, have progressed towards considering themselves as vital members of the health care team (Duncan & Morgan, 1994; Kelchner, 2008; Williams & Guendouzi, 2005).

However, when compared to nursing home facilities, many older adults and their family members prefer a housing option involving the delivery of professionally managed supportive services in a group setting that is not overtly medically oriented (Pynoos & Nishita, 2005). The percentage of elders living in nursing homes declined from 21% to 14% between 1985 and 2004 due to alternative residential care options, which have become increasingly popular, because they are more homelike in character.
and appearance (Institute of Medicine, 2008). This leads into the subsequent discussion on assisted living facilities and continuing care retirement communities, which are described as such options.

**Evolution and Need for Assisted Living Care**

Within the continuum of care, assisted living represented the first attempt to fill the gap between independent senior housing and nursing homes (Zimmerman et al., 2003). Twenty-four-hour home care is extremely expensive and a nursing home is not the appropriate level of care required by an elder with a moderate level of care requirements, including mild dementia. Assisted living facilities encompass diverse care, resident independence, and new ways of combining housing and services (Golant, 2008).

Long-term care in the United States has witnessed the emergence of assisted living facilities due to the individual, financial, and communal needs of the elderly. As a housing model for the elderly and disabled, it has represented a response to the need to develop a happy medium between congregate residential care and skilled nursing care (Regnier, Hamilton, & Yatabe, 1995). Accordingly, assisted living settings were developed through the 1990s to become an established long-term care option for older adults (Kane & Wilson, 1993). However, assisted living as a residential care option is not a recently evolved phenomenon. Historically, assisted living facilities existed as smaller public housing arrangements that offered comparable services in the form of “board and care homes, domiciliary homes, personal care home facilities, and adult foster care homes” (Namazi & Chafetz, 2001, p. 1).
Assisted living is a growing industry when compared to other housing models. Both the demand for and supply of assisted living is escalating. A recent survey of American states reported that 36,451 assisted living facilities were licensed to serve almost a million residents in 2004 (Ball, Perkins, Hollingsworth, Whittington, & King, 2009). As of 2007, state governments have regulated 38,373 assisted living facilities in the United States (Golant, 2008). In 2004, the average age of residents within assisted living was 85, with 79% being women and 99% being Caucasian; and residents’ average length of stay was reported as being 2.5 to 3 years (Carman, 2009). Higher poverty rates among minority elders have led to their under-representation in newly modeled larger assisted living facilities (Sikorska-Simmons, 2006). Consumers of assisted living facilities are expected to more than double, to 2 million, by 2030 (Ball et al., 2009).

Since its evolution, several aspects of what comprises and defines assisted living have been questioned by researchers, which is why consensus has not been reached on what constitutes assisted living and what its role is (Hawes & Phillips, 2007). Reflecting several typologies, assisted living models have been categorized as public housing alternatives, freestanding facilities, and units in continuing care retirement communities, with each type differing in its target populations, funding, organization, and delivery of services (Mollica, 2001). As a result of state regulation in the 1990s, assisted living was classified as institutional board and care, housing and services, and service-oriented facilities (Frank, 2002). Assisted living has also developed a medical model of care, which views such facilities as health care environments that are designed to adapt to skilled nursing and serve as an extension of nursing homes (Regnier et al., 1995).
medically oriented model prioritizes medical service delivery and views older residents as patients (Frank, 2002). The question as to whether it is the role of assisted living to focus on the health care needs of its residents has been widely debated (Hawes & Phillips, 2007; Hawes, Rose, & Phillips, 1999).

The overarching philosophy of assisted living reinterprets senior care by offering its residents dignity and the chance to maintain their remaining functional independence in a more supportive, homelike environment. According to Kane (2001), assisted living facilities offer elderly residents opportunities to combine long-term care services with continuing their lives in the most normal, meaningful, and independent way possible, which accounts for their gaining in popularity as an alternative housing model. Frank (2002) suggested that an emphasis on providing health care and personalized support services, in order to meet the individual needs of seniors requiring help with activities of daily living and instrumental activities of daily living, is what sets apart assisted living from other residential care models. Assisted living is, therefore, an increasingly popular option that has continued to emerge.

Certain assisted living establishments are also relying on outsourced home care assistance, which is brought in to cater to very impaired elderly persons who would then not have to relocate to another setting, such as a nursing home (Golant, 2008). Some home and community-based services can also be accessed by assisted living residents to a certain extent, but these services do not provide adequate income support to older residents and their families to maintain living in an assisted living facility (Jurkowski, 2008). However, many facilities do not allow outside services to be provided, which may
necessitate the relocation of an ailing elderly resident to a more skilled care setting. Moreover, assisted living facilities that offer high-acuity care in luxurious quarters and upscale neighborhoods are costlier, and are, therefore, occupied by residents who are able to afford such accommodations (Ball et al., 2005). Consequently, attention needs to be directed to such potential barriers to accessibility and affordability, in order to strengthen the role of assisted living facilities within the continuum of long-term care.

Research within assisted living also requires adequate attention, because assisted living facilities are assuming more importance in the long-term care sector and are serving an increasing number of the elderly. Research findings from large longitudinal studies have just recently started to become available, but provide merely a classification of the types of assisted living/residential care facilities in some communities that differed from each other, based on the number of residents, their mental and physical health conditions, and the type of accommodation (Hedrick et al., 2007).

A limited number of qualitative studies have delved into how homelike assisted living environments, their administration, and the regulatory structure can impact residents’ independence and influence their ability to establish and sustain social ties that include family relationships and participation (Ball et al., 2004; Gaugler, Anderson, & Leach, 2003; Sikorska-Simmons, 2006; Regnier & Scott, 2001). Very few research studies have focused on resident and family perspectives on assisted living, and even fewer have tried to study residents’ satisfaction, preferences, and concerns regarding assisted living care (Chou, Boldy, & Lee, 2003; Levin & Kane, 2006; Yee, Capitman, Leutz, & Screigaj, 1999). Therefore, research studies need to exclusively focus on elderly
residents’ perspectives regarding their involvement in their families, and in their assisted living facilities.

**Economic Implications for Long-Term Care Consumers and Their Families**

American policies have been shaped by a value system that has emphasized individualism, self-sufficiency, and the omniscience of the market place (Karger & Stoesz, 2002). Social welfare policies are influenced by the dominant belief systems, values, ideologies, and traditions of the cultural and political elites in power, who usually lobby for their own interests (Estes, 2001).

Traditionally, a dominant political ideology has emphasized caregiving as mainly the family’s responsibility, expecting the state to step in only as the last resort. Normative standards, as well as the threat of public disgrace of a family’s failure to care, motivated families to be responsible for their aging relatives (Conner, 2000). Some family historians have suggested that family care patterns emerged because it is a family’s inherent moral obligation to care for their dependent elderly, whereas others have argued that this notion of family responsibility was encouraged to sustain policies that were motivated by economic gains and political concerns (Montgomery, 1999). The value of family responsibility is strongly associated with the lack of support for valuing a resident or citizen’s right to health care, along with the hesitancy to demand government responsibility in any area of provision that may interfere with the interests of private enterprise (Navarro, 2008). It was, therefore, noted that family responsibility as a family value was encouraged to protect the public purse and minimize the financial responsibility of wealthier classes (Jacobson as referred to in Montgomery, 1999).
Most family members have eventually had to resort to providing residential long-term care for their elderly loved ones, depending upon the severity of the care-receiver’s health and functional status. In a positive light, as more and more elderly individuals require extensive health care, popular support for attention to long-term care provision is rising, especially among middle-income families who are hit the hardest. Because they are not able to qualify for public assistance—by not being poor enough—they must pay for nursing home and assisted living expenses out-of-pocket.

Escalating long-term care costs and an outdated institutional regulatory system has continued to alienate and demoralize many care-receivers and their family caregivers. Such costs have devastating financial, emotional, and physical repercussions for not only the elderly member, but the entire family (Moody, 2009; Sinclair, 2008). Many families who care for elders requiring long-term care have found themselves under pressure to pay more direct costs, provide hands-on complex care, and forgo many educational and social opportunities, which subsequently impact care-receiver and caregiver roles and relationships.

Hence, a debate over whether long-term care costs need to be incurred chiefly by care-receivers and their families, or should be shared solely or partially by the government continues on (Knickman & Snell, 2004). The complexity of such issues experienced by older residents and their family members are directly influenced by governmental support and policy interventions, which need to be discussed in the following sections, because they provide the larger context for this study. Financial repercussions of terminally ill and disabled elders, even when they had private long-term
care insurance, have had devastating consequences for family members (Covinsky et al., 1994). This next section provides a brief overview of private long-term care insurance.

**Private long-term care insurance.** Catastrophic financial risks not only stimulate an expansion of public financing, but also this long-term care financing challenge has led to the demand for private insurance, or both (Novak, 2006). Accordingly, the growing interest in securing protection against the high costs of nursing home care resulted in the emergence of the private long-term care insurance industry in the mid-1980s. Private long-term care insurance typically covers the cost of care provided in nursing homes and assisted living facilities, as well as in-home personal care services (Cohen, Miller, & Weinrobe, 2001). However, financial repercussions for families of terminally ill elders, even when they had private insurance, were documented by a support study on end-of-life decision making as being devastating (Covinsky et al., 1994).

Some proponents have argued that privatized long-term care insurance may help finance long-term care expenses in the future. However, according to Hennessy (1996), a review of this form of insurance suggests that the issue of affordability, denial of risk, and wrong information pose barriers on the demand side, whereas the unpredictability of the overall cost is a barrier on the supply side. Private long-term care insurance may severely impact minority elders, including African-American and Hispanic elders, who primarily depend on social security as their main source of income, and are known to have the highest percentages for living below the poverty level (Markides & Wallace, 2007). Another major handicap foreseen in the future is the lapse rate of such insurance policies. The U.S. industry norm is to assume that not counting those who will die before
needing long-term care, approximately half of all insured people will lapse their policies within 5 years of purchase and about 75% will lapse within 15 years (Wiener, Illston, & Hanley, 1994).

In short, private long-term care insurance is not a very viable option for many older adults. Such policies are highly expensive and have many conditions for providing coverage, depending on individual circumstances (Novak, 2006). However, the following sections examine the contribution of Medicare and Medicaid regarding their impact on long-term care, especially their role and potential role in assisted living developments, and suggest recommendations for change. Medicare and Medicaid programs were selected for a more comprehensive analysis because they provide the core of health care provision available to older adults.

**Medicare and Medicaid Programs**

Prior legislation led to the creation of Medicare and Medicaid that established very narrow eligibility criteria (pertaining to income level) for frail elderly citizens who wished to obtain state-sponsored care and support services. Relevant to the long-term care financing challenge, Medicare and Medicaid are the only government-sponsored policies that were developed in response to the health care needs of the elderly in the United States. Skilled nursing and congregate residential facilities have increasingly become the principal source of institutional care since the inception of Medicare and Medicaid policies (enacted in 1965 as Title 18 and Title 19 of the Social Security Act) (Mollica, 2001; Vierck & Hodges, 2003). Both Medicare and Medicaid have, therefore,
had the most significant impact on assisted living, and its residents and their families (Jurkowski, 2008).

**Medicare.** Medicare is the primary federal health insurance program for individuals 65 years or older; however, it is very limited in its coverage of long-term care expenses. A political bidding process in 1965 resulted in creating Medicare’s two-part structure, which provides a mandatory hospitalization insurance (HI) or Part A coverage, and a voluntary supplementary medical insurance (SMI) or Part B coverage, which requires participants to pay a premium (Shaviro, 2004). The financing of acute care and long-term care is set up as being separate (O’Brien & Flannery, 1997). Although Medicare covers 55% of the acute medical expenses for older adults, it only pays 20% of the long-term expenditures incurred by the elderly (Feder, 1999). Clearly, Medicare is structured in a way that suggests a lack of focus on home care and long-term care coverage. The more recent 2003 Medicare Modernization Act (MMA) includes a prescription drug benefit that requires beneficiaries to pay premiums that cover about 23% of the cost, making Medicare’s coverage a little more comprehensive, but very costly (Rettenmaier & Saving, 2007).

Medicare’s overall expenditures will continue to grow much faster than the economy, and were projected to total $244.8 billion in 2001, due to the growth in expenditures per enrollee and demographic factors (Shaviro, 2004). Medicare’s growing burden implies potentially devastating repercussions that can lead to a reduction in government funding, which subsequently can affect the eligibility criteria for obtaining health insurance and long-term care coverage (O’Brien & Flannery, 1997).
**Medicaid.** Medicaid is a tax-funded program that was established to cover health and long-term care expenses for the poor and disabled, and is currently the single largest payer of long-term care services (Senate Special Committee on Aging as referred to in Administration on Aging, 2004). Medicaid is a means-tested entitlement program to assist elderly individuals who are impoverished; it is viewed as the last resort to help finance long-term care costs, because there is no other universal public insurance program for health care and long-term care (Moody, 2009). Medicaid, enacted by Congress in 1965, is a joint government program supported by both federal and state funds, making it the primary government mechanism that pays for two-thirds of nursing home residents and for long-term care for the disabled (O’Brien & Flannery, 1997).

Medicaid community care programs include the home health care and the waiver program. In 1980, Medicare was amended to extend benefits to home health care agencies; and in 1981, a Social Services Block Grant (SSBG) was established and the Home and Community-Based Long-Term Care Services (HCBS) Waiver option was included under Medicaid (AOA, 2004). In 1987, the enactment of a new HCBS waiver, Section 1915(d), permitted states to take a Medicaid block grant for institutional long-term care, to be used at the state’s discretion to provide services to those meeting Medicaid eligibility requirements (O’Brien & Flannery, 1997). Medicaid HCBS waivers are carefully monitored, because federal regulations require states to have a quality assurance plan, although the content of these plans is left entirely to each state’s prerogative (AOA, 2004). Nationwide, such waiver programs have expanded to an
approximate total of 250, catering to almost a million participants, at an annual expenditure of almost $18 billion (Doyle & Timonen, 2007).

In order to qualify for institutional long-term care and be covered by the Medicaid program, however, an individual or couple must be extremely poor, possessing very few or no assets at all. Older persons who are found ineligible for Medicaid coverage have to either struggle to get home-based care, or spend down accumulated assets to become impoverished and then qualify for government assistance. Thus, elderly individuals who are too well off financially to be eligible for Medicaid payments have engaged in voluntary spend downs, which are attained through transferring assets to children or relatives in order to qualify for coverage (O’Brien & Flannery, 1997). Hence, the Medicaid program, designed for the truly poor, faces issues that have grave monetary and economic implications for the government, the elderly care-receivers, and their family caregivers. The practice of having to spend down has mostly had an impact on middle-income families who, while trying to meet their long-term care needs, are gradually depleted economically of all their resources, possessions, and entire life savings. This puts a considerable strain on the entire family, on mutual relationships and roles, and is therefore a very serious policy issue that needs to be addressed.

**Analysis of the Impact and Role of Medicare and Medicaid on Long-Term Care**

With the cost of long-term care increasing rapidly, paying for institutionalized care has become an American dilemma. Criticism of the U.S. long-term care system has broadened to include the financial concerns of elderly people with incomes and savings above Medicaid eligibility levels, as discussed above. Older people are in need of some
protection against “catastrophic” out-of-pocket costs for nursing home care (Hennessy, 1996), or more preferably, assisted living care. Also, Medicaid reimbursement rates are not always consistent with the cost of delivering services, which is why health care providers are often uncertain about providing services to elderly individuals on Medicaid (Jurkowski, 2008).

The three areas of criticism that are often raised by policy experts, after reviewing the Medicare/Medicaid efforts that most directly target assisted living and family relations and the involvement of assisted living residents include (a) lack of adequate funding to support institutional care, including the discrepancies in coverage between nursing home care and assisted living care; (b) lack of or extremely limited mental health coverage; and (c) the strong emphasis on acute institutional care versus chronic and preventative care options due to the great imbalance that exists between acute institutional care and home and community-based services (Jurkowski, 2008; Moniz & Gorin, 2007).

Future projections of institutionalized care costs suggest that private pay, and to a certain extent, Medicaid sources will continue to be the largest source of payment for long-term care, unless the United States is willing to prioritize this issue and address the severe impact of such costs on elderly residents and their family members. Sustaining health benefits, programs, pensions, and fixed incomes for the elderly is becoming increasingly difficult in the current political and economic climate. An unprecedented change in the population structure of the elderly, with an expected further increase in the elderly aged 65 and over, has and will continue to result in the high cost of medical care.
It is only logical to assume that Medicare and Medicaid costs will continue to grow in the future as the population of people qualifying for it increases. Nevertheless, during the past few years, every effort has been made to cut Medicare and Medicaid rather than target the gaps in services, with the exception of the addition of the Medicare Part D drug program to subsidize the cost of prescription drugs (Kaiser Family Foundation, 2004).

Both Medicare and Medicaid have significantly contributed to the social and economic welfare of individuals in United States, providing millions of adults and children with health care; nevertheless, this also makes both programs highly expensive (Moniz & Gorin, 2007). Rettenmaier and Saving (2007) calculated the total Medicare debt owed to current and future generations to be a staggering $70.8 trillion, after considering all of the parts in Medicare. In 2001, the overall Medicaid expenditures, which are split between the federal government and the states, amounted to $214.9 billion, after serving 41.7 million beneficiaries (Shaviro, 2004; Wacker & Roberto, 2008). Medicaid expenditures in 2005 were estimated to be more than $300 billion and continue to increase every year (Moniz & Gorin, 2007).

Medicare does not provide coverage for assisted living, and Medicaid is very limited in helping finance assisted living. Thus, a major portion of the expenses incurred in regard to assisted living are directly out-of-pocket. Another reason for such out-of-pocket expenditure is that freestanding assisted living facilities have increasingly been developed and marketed, but have largely remained cost prohibitive for elderly residents with fixed incomes (Stone & Reinhard, 2007).
It is largely up to the states to implement ways to make assisted living more affordable and accessible to elderly clients. Medicaid plays a very minimal role in financially helping lower-income residents living in assisted living facilities. Even though most states have included the funding of assisted living services through Medicaid HCBS waivers, only some states are making use of this option (Stone & Reinhard, 2007). Elderly care-receivers residing in assisted living facilities do not receive the same reimbursements as residents in nursing homes, as shown in Table 1, which presents the long-term care expenditures by funding source, incurred in 2002. Medicaid has therefore become a large and expensive program; and as the number of oldest old in the 85+ population increases, the long-term care expenditures are likely to grow further (Jurkowski, 2008).

Table 1

*Financing for Long-Term Care for Older People, 2002 (dollars in billions)*

<table>
<thead>
<tr>
<th></th>
<th>Nursing Homes</th>
<th>Home and Community Based Services</th>
<th>Assisted Living Facilities</th>
<th>Totals</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medicare</td>
<td>13.0*</td>
<td>11.3*</td>
<td>---</td>
<td>24.3</td>
</tr>
<tr>
<td>Medicaid</td>
<td>35.2*</td>
<td>6.3*</td>
<td>1.0**</td>
<td>42.5</td>
</tr>
<tr>
<td>Out-of-Pocket</td>
<td>18.3**</td>
<td>1.6**</td>
<td>7.7**</td>
<td>27.6</td>
</tr>
</tbody>
</table>

*Note. * = expenditures; ** = Long-Term Care Financing Model projections. Adapted from “Benchmarking the Long-Term Care Financing Model” by the Lewin Group, December 19, 2004 (as referred to in AOA, 2004, p. 4).*

Being extremely expensive, long-term care consumes a much larger portion of the private health care dollar for the elderly than does any other type of expenditure. In 2002, as shown in Table 1, Medicaid was the largest funding source for nursing home coverage, but paid only $1 billion for assisted living coverage. Also, out-of-pocket costs were
estimated to total $18.3 billion for nursing homes and $7.7 billion for assisted living facilities in 2002 and are continuing to rise. Feder (1999) reported that 70% of those who enter nursing homes as private-pay patients reach the poverty level within just 3 months, and nearly 90% are impoverished within a year. Very few families and individuals can afford such costs on an extended basis.

Medicaid insures the largest number of elderly individuals in need of long-term care services, covering “68% of nursing home residents and over 50% of nursing home costs each year” (Namazi, Begen, Jackson, & Chafetz, 2001, p. 195). In contrast to Medicare, Medicaid provides nursing home care past the 100-day Medicare limit and helps finance items, such as eyeglasses and hearing aids (Shaviro, 2004). To a certain extent, Medicaid HCBS waivers help those in need of assisted living services, in-home support services, adult day care, and respite and health care programs (Estes, 2001).

Whereas Medicaid provides nursing home coverage to low-income beneficiaries, it is not as flexible in its provision of comprehensive assisted living coverage, including room and board (AOA, 2004).

Most Medicaid-funded nursing home residents are unable to qualify for any public payment program, because they are believed to possess sufficient income from Social Security or pensions to pay for their housing costs (Mollica, 2001). The costs of nursing home care versus assisted living is a primary focus of current cost analyses by a number of advocates, along with a focus on the use of Medicare and/or Medicaid as a basis for possible expansion of coverage for institutional long-term care (MetLife, 2008). Furthermore, when compared to nursing homes, assisted living facilities are different
because of the health care requirements of their residents and other factors, such as regulation, family involvement, and resident demographics (Franks, 2004).

According to a report released in 2009, many states cumulatively have underfunded the actual cost of providing quality long-term care by approximately $4.6 billion, and the Medicaid payment outlook for 2010 also appears to be very bleak, because the Medicaid stimulus dollars are expected to expire by the end of 2010 (Gay & Morton, 2010). Even as most elderly clients largely prefer assisted living facilities, because they are more flexible in meeting their needs and less restrictive in nature, assisted living care is not very affordable. Thus, newly constructed and modeled assisted living facilities often offer a more appropriate setting than nursing homes, but are also a barely affordable alternative.

Hence, regardless of state-to-state differences in costs the potential use of assisted living facilities to avoid premature nursing home placement is evident, which makes affordability and accessibility to assisted living options an increasingly important issue for older adults and their respective family systems. Many older adults are not able to qualify for public assistance, as discussed earlier, and consequently, must pay for assisted living expenses out-of-pocket. Programmatic preferences and the nature and financing of assisted living facilities have significant implications for family caregivers and care-receivers and need to be further explored. It is, therefore, important to examine the role or lack of role of Medicare and Medicaid policies. The next section provides an analysis of Medicare and Medicaid with respect to their potential and need for expansion to make assisted living a more affordable option, especially for middle-income and poor families.
Financing Assisted Living: A Medicare/Medicaid Policy Dilemma

Assisted living has become increasingly unaffordable, because in 2003, for example, the average annual fee for assisted living housing and services was $32,400, whereas 64% of older adults had annual incomes lower than $25,000 (Heumann, 2004). Public assistance, such as Medicaid-reimbursed services in assisted living, are so low that only a very limited number of beneficiaries are served in this setting (Mollica & Johnson-Lamarche, 2005). Under the Section 202 program, nonprofit organizations can apply for federal funding to own and manage a residential long-term care facility, providing federally subsidized housing in 2004 for more than 381,000 elderly individuals in more than 9,000 facilities. (Pynoos & Nishita, 2005). However, this production is not enough to meet the increased demand due to a growing number of elderly individuals who are facing financial difficulties and long waiting lists.

Whereas assisted living care settings emerged to meet an increased demand, ironically they have been available primarily to upper-income seniors who can afford to pay privately. Long-term care in the United States has been described as being increasingly segregated by income and payment levels, separating private pay from a Medicaid clientele served mostly by nursing homes (Mollica, 2001). Representing a step in the right direction, some states have provided limited Home and Community-Based Services (HCBS) Waivers to fund services in assisted living and have tried to be more flexible in developing alternatives to institutionalized care for older adults who are Medicaid eligible, but this targets only those who are extremely poor (Namazi, Begen, Jackson, & Chafetz, 2001).
Political decisions regarding the changing role of government and the expanding coverage of assisted living strongly impact the role of assisted living within the long-term care continuum. It is important to note that policies from all levels of government, as well as the private sector are involved in the assisted living movement. Assisted living facilities are regulated by states, as mentioned earlier, unlike the nursing home industry, which is federally regulated (Namazi, Begen, Jackson, & Chafetz, 2001). It is the states who largely have the authority to develop policies that influence (a) the extent to which older adults can continue living in assisted living, (b) the admission and discharge criteria, and (c) the number of assisted living facilities that can be built (Stone & Reinhard, 2007). Although federal policies have a limited role in developing assisted living regulations, they have major consequences financially that affect the payment options available to elderly residents (Stone & Reinhard, 2007).

Efforts need to be concentrated on expanding the Medicare and Medicaid programs. Federal and state policy-making processes should develop more generous public funding programs in order to make assisted living care more affordable and accessible to elderly clients. Also, efforts need to be concentrated on making community-based services available to assisted living residents and their families, in addition to elderly who are Medicaid eligible. Under the current political climate and leadership, these two national insurance policies, appropriately modified, have the potential to further improve and effectively meet the health and long-term care needs of a growing number of elderly care-receivers and their families.
Assisted living must, therefore, become a more affordable option. This will require a policy shift. Customized institutional models providing quality care and services need to be made affordable to better serve this country’s aging elders. A policy movement towards making the continuum of care cost effective is also possible, because AOA and other lobbyists for community-based care advocate for Medicare and Medicaid policy decisions to better fit into the continuum of care movement (Kunkel & Lackmeyer, 2008). An essential part of this debate must include opportunity for strengthening the assisted living component of the long-term care system, concerns related to an appropriate level of care, and generating improved funding mechanisms based on older adults’ preferences and potential cost savings. Furthermore, policies that will allow unrestricted choice regarding assisted living options could very well prevent premature nursing home placement and cut Medicaid costs.

Stone and Reinhard (2007) have also noted that federal Medicaid rules permit payment for room and board in nursing homes, but not in assisted living facilities or other residential care options. Medicare, also, does not pay for assisted living expenses, as mentioned above. Whereas nursing home coverage remains an entitlement, a preferable assisted living alternative to nursing home placement cannot be made politically feasible unless middle- and low-income elderly individuals are given adequate reimbursements, which largely depends on the state Medicaid waivers, state funds, grants, and other plan options (Stone & Reinhard). Consequently, it is critical for state governments to have a strong interest in reviewing and changing the existing long-term care efforts. Policy
Interventions (e.g., modifications to Medicaid and Medicare) and advocacy efforts therefore need to focus on creating a better balance in the long-term care continuum.

There is much debate on how to reform the long-term care system. Some policy experts suggest an integration of the acute and long-term care needs. Others, although against privatizing long-term care, propose developing appropriate public-private partnerships that are effective and well balanced, and place emphasis on prioritizing long-term care services. An expensive and expanding American long-term care system has caused many policy experts to argue over whether home care or community-based care for elderly members is a more cost-effective option than resorting to an institutional care environment. Assisted living can provide the solution by becoming a more cost-effective and a viable option within the continuum of long-term care. Instead of focusing on private responsibility as a low-cost alternative and sustaining families’ capabilities to provide care, our government should develop a broader public role in long-term care (Ambrosino, Emeritus, Emeritus, & Ambrosino, 2005). Therefore, public programs should be re-structured to become more flexible in helping elderly clients qualify for assisted living coverage within the continuum of care.

In conclusion, the economic and political dimensions of policy, along with the influence of societal values are critical to the future of assisted living facilities, and consequently the roles and relationships of its residents and their families. At present, many middle-class older adults in need of assisted living care are unable to afford this option, or are required to utilize individual and family resources that cause great financial loss and strain. Therefore, federal and state policy-making processes need to develop
economically feasible public funding programs in order to make assisted living care more affordable and accessible to elderly clients who have fixed or insufficient resources to meet their care needs. As baby boomers continue to get older, family involvement and caregiving efforts are bound to increase, because public funding is currently either inadequate or unable to provide assisted living coverage to every older person who needs it. Hence, public sources will and should continue to bear the major portion of the current expenditure on long-term care for the elderly. Public responsibility for long-term care should be organized to accommodate all elderly clients without any discrimination.
Chapter 3: Qualitative Methodology

Importance of Qualitative Research

Qualitative research has been valued in social sciences because of its comprehensive, explorative, rigorous, and in-depth approach to data collection and interpretation. Biographical methods, case studies, and other descriptive methods have been central to qualitative studies since the early 1900s (Creswell, 1998). The ethnographic and descriptive work of the Chicago school during the 1920s and 1930s established the importance of qualitative inquiry in the social and human sciences (Denzin & Lincoln, 2003). Positivist and quantitative techniques have dominated the research efforts, but since the 1970s, the number of qualitative research studies and monographs on how to collect and interpret qualitative data has steadily increased (Berg, 1989; Bogdan & Taylor, 1975).

Qualitative research efforts have focused on describing life-worlds “from the inside out” (Flick, Kardorff, & Steinke, 2004, p. 3) to obtain a better understanding of social realities, processes, meaning patterns, and structural features. Qualitative methodology offers important approaches that help the researcher build a complex and holistic picture by conducting the study in a natural setting, analyzing words and descriptions, and reporting detailed perspectives of all the participants (Creswell, 1998). As opposed to quantitative research procedures, qualitative inquiry views each participant holistically, as part of a whole, and combines data-gathering methods with various
theoretical perspectives and narrative approaches to obtain comprehensive and authentic analyses (Berg, 1989; Corbetta, 2003; Creswell, 1998). Qualitative approaches are challenging, demanding, and rigorous, and lead to claims for conclusions that are defensible and useful, because they enhance understanding (Morse & Richards, 2002).

**Rationale for Conducting a Qualitative Research Study**

As established in the previous chapter, the increasing pluralization of family structures and functions, along with a growing diversity and individualization of lifestyles has significant implications for the caregiving process, elderly family members’ long-term care needs, and for care-receiver and caregiver involvement. Qualitative research is especially relevant to the study of family relationships and roles within the context of institutionalized long-term care housing and service provision. Many families are being increasingly confronted with the realities of care-receiving and caregiving efforts within residential long-term care facilities, which require further exploration that can provide insight into new and complex familial contexts and social perspectives.

Our day-to-day life is characterized by shared beliefs and perceptions. Qualitative traditions, such as phenomenology, which was used in this study, are very open and do justice to the complexity of a subject under study, by eliciting a variety of subjective practices and perspectives from participants (Flick, 2002). Thus, thick descriptions and their detailed analysis have yielded critical explanations of the roles and relationships of family caregivers and their elderly relatives residing in assisted living facilities. An exploratory qualitative research design was very apt for this study, because it helped derive an extensive depth of understanding, and allowed this researcher to share in the
concerns and experiences of the care-receiving residents of assisted living facilities and their primary family caregivers on a one-on-one basis. This study delved in detail into the complexities and processes that characterize caregiving and care-receiving patterns, relationships, and roles, for which a descriptive qualitative approach is best suited.

In-depth and honest communication is the essence of all qualitative research. Qualitative research procedures, such as phenomenology, produce descriptive data from participants’ own spoken words and observable behavior (Bogdan & Taylor, 1975). Meaning is established through the narrative and the conversational presentation of the participants’ experience (Rubinstein, 2002). Data collection in qualitative research has a communicative dialogic character (Flick, Kardorff, & Steinke, 2004). This was essential, because family members and especially elderly care-receivers’ narratives, in their own voices regarding their needs and experiences, have not been adequately explored in research literature.

Qualitative research work utilizes such thick descriptions to not only depict reality, but also emphasize the unusual or the unexpected in order to offer insight, thereby allowing for further possibilities of self-recognition (Flick et al., 2004). This study provided a detailed description of the nature and quality of the relationships and roles of family caregivers and their elderly relatives residing in assisted living. Qualitative research strategies were, therefore, employed for this study, because they are more open and more involved, and can deliver precise and substantial descriptions from the participants themselves.
Phenomenological Tradition

Qualitative research is an umbrella heading for various approaches that differ in (a) their theoretical assumptions, (b) an understanding of their object, and (c) their methodological focus (Flick, 2002). *Phenomenology* is a qualitative research tradition that is used to analyze the meaning of the lived experiences of several study participants regarding a concept or phenomenon (Miller & Salkind, 2002). Phenomenology is a narrative approach, which helps to identify the broader social meanings of the stories and perspectives shared by study participants, and provide information that can lead to a subsequent change (Tanner & Harris, 2008). Phenomenological inquiry helps to explore the processes and meaning of events, and examine how people behave, experience, and interpret their world. This study, therefore, utilized a phenomenological tradition to investigate how family involvement and participation was sustained and influenced by both family members’ caregiving experiences and care-receiving residents’ lived experiences within an assisted living facility. Phenomenology was chosen because of the explorative nature of this topic, which needs to be adequately and thoroughly investigated.

Phenomenological research can trace its origins from the extensive writings of a German mathematician, named Edmund Husserl, and the philosophical discussions of Heidegger, along with many others, such as Merleau-Ponty and Jean Paul Sartre, who focused on understanding the world as experienced and perceived by individuals (Creswell, 1998). Historically, Husserl’s diagnosis of the crisis in European scholarship resulted from a lack of focus on the human life-world, which was, according to him, the
foundation of scientific theorizing and philosophizing, and essential in achieving an adequate methodological self-awareness (Hitzler & Eberle, 2004). Phenomenological research has developed and maintained the primacy of the life-world as it is encountered in everyday life in relation to the world of science, which would be meaningless without individual experiences and viewpoints (Merleau-Ponty as referred to in Kvale, 1996).

A phenomenological approach offers an engaging, descriptive, reflective, and a particular way of “making sense” by organizing the undisciplined confusion of the events and experiences of all the participants (Morse & Richards, 2002). Phenomenology begins with individual actions and experiences related to a social phenomenon and develops this in a reflexive form by referring back to the subjective meaning of such actions for the individuals themselves (Hitzler & Eberle, 2004). According to Shank (2006), the “task of phenomenology was to move past, or transcend our conscious awareness of the nature of things, to an eventual awareness of things themselves as they really are” (p. 132). Phenomenologists try to capture this process of interpretation by attempting to see things from the participants’ point of view (Bogdan & Taylor, 1975). In qualitative research, phenomenology helps to conceptualize how participants’ experiences, actions, and interactions can relate to the different contexts and ways in which they are being studied (Flick, 2002).

**Assumptions of phenomenological inquiry.** Phenomenology is dedicated to describing and exploring the structures and meaning of human lived experiences as they present themselves to consciousness on a day-to-day basis (Polkinghorne as referred to in Miller & Salkind, 2002). Human existence is meaningful, unique, and always conscious
of something. In a phenomenological research effort, participants’ perspectives and experiences present the evidence, not as it is thought to be, but as it is lived (Creswell, 1998). Morse and Richards (2002) defined experience as “an individual’s perceptions of his or her presence in the world at the moment when things, truths, or values are constituted” (p. 44).

Participants in a phenomenological study can only be understood in their specific contexts. The four existentials that guide a phenomenological study are (a) temporality (lived time), (b) spatiality (lived space), (c) corporeality (lived body) and (d) relationality or communality (lived human relation) (Morse & Richards, 2002). The emphasis is on the lived experiences, because human behavior occurs in the context of the four existentials of relationships to people, things, events, and situations (Miller & Salkind, 2002; Morse & Richards, 2002). Hence, this study utilized phenomenology to examine how the lived experiences of assisted living residents, as well as those of their family caregivers have affected or influenced their family involvement. The following sections elaborate on how family involvement was conceptualized in the study, along with the research questions and the research design that helped to guide the course of this study.

**Conceptualizing Family Involvement**

Recent research has indicated that increasing family involvement in the case of institutionalized residents and their family members must become an important goal of our long-term care system (Gaugler, Anderson, & Holmes, 2005; Kelchner, 2008; Port, 2004). Family involvement is a comprehensive phenomenon, and is, therefore, highly limited if assessed only in terms of visitation patterns or the provision of aid. A broader
understanding of family involvement with respect to both the care-receiver and caregiver roles and relationships that are established within the context of an assisted living facility’s administration, structure, and environment, can be increasingly and thoroughly sought through qualitative research.

Hence, this qualitative study explored ways through which care-receiving residents and their family members can continue to function as family networks by staying mutually involved, within the regulatory structure of an assisted living facility. In this study, the two groups of respondents who were interviewed at length included elderly care-receivers residing in assisted living facilities and their primary family caregivers. Family involvement is conceptualized strictly in terms of each of these two groups’ perceptions of family relationships and their role fulfillment.

Family relationships represented one of the two dimensions critical to studying the family involvement of elderly residents and their family caregivers. Caregiving occurs in the context of a relationship, which is usually close and familial (Szinovacz, 2003; Williams & Guendouzi, 2005). Family units are repositories of shared interactions, exchanges, and relationships that exist over time. Relationships between family members are often characterized by affectional ties and dependencies that play a crucial role in caregiving situations. The focus of this phenomenological study was to investigate how family members continued to mutually sustain their emotional ties, roles, and family relationships after an elderly member of their family network had moved into an assisted living facility due to physical or health concerns. Family involvement is characterized by such relationships. This study examined the nature and extent of involvement with
respect to family relationships, from the perspectives of both the care-receiving residents in assisted living, as well as their primary family caregivers.

*Role fulfillment* constituted the second major dimension for exploring family involvement in this study. One’s gender and position within the family structure, as well as the family’s cultural background determine the various roles, responsibilities, and the kind of participation, and obligations assigned to family members. These roles, including those fulfilled by elderly family members as well as the caregiving roles are neither inclusive nor mutually exclusive; rather, they form a complex and dynamic interrelationship (Estes, 2001). Within the family system, roles are fulfilled in the context of relationships between family members. Hence, this phenomenological research effort studied family involvement by examining the various roles fulfilled by care-receiving residents and their family caregivers.

**Research Questions and Sub Questions**

In this study, the primary research question was sensitive to the process of phenomenological inquiry, and helped to understand the essence of family involvement in the participants’ own descriptions, which is also a form of self-interpretation. This study relied on the *perceptions* of elderly care-receivers and their family caregivers, which constitute the primary source of information and knowledge in phenomenological research. The following primary research question helped guide this study:

What is the experience of family involvement for care-receivers and their family caregivers, when the care-receivers are residing in assisted living facilities?

Because this phenomenological study derived its data from two separate groups of individuals to elicit their perceptions, the care-receiving residents in assisted living were
asked one set of interview questions and their family caregivers were interviewed using another set of questions, both of which are respectively listed below.

**Care-Receiving Residents:**

1. How has living within an assisted living environment affected your roles and relationships with your family members?

2. How has living in an assisted living facility had an impact on your family caregivers’ and other family members’ involvement with you and with each other?

3. In what ways are you able to contribute to your family?

4. In what ways are you able to contribute to your assisted living facility?

5. How has the assisted living staff and administration detracted from or supported your roles and relationships within your family and within the assisted living facility?

6. How can the assisted living staff and administration facilitate more involvement between you and your caregiving family members?

**Family Caregivers:**

1. How has your elderly relative’s residence in assisted living had an impact on your involvement in his or her care process?

2. How has living in an assisted living facility had an impact on your elderly relative’s level of family involvement?

3. How has caring for your elderly relative(s) in assisted living affected your mutual involvement, as well as your involvement with other family members with respect to family relationships and role fulfillment?

4. How has the assisted living staff and administration detracted from or supported your involvement with your elderly family member(s)?

5. How can the assisted living staff and administration facilitate more involvement between your elderly relative(s) and you, as well as other members of your family network?
Research Design

**Sampling procedure, recruitment, and informed consent.** The recruitment of the sample for this qualitative research study was on-going throughout the stages of selection, data collection, and data interpretation. Sampling decisions are highly important because they determine, substantially, what becomes the empirical material in the form of text, which in turn determines the outcome of a qualitative study (Flick, 2002). Good participants represent meaningful cases that are selected and integrated into the sample, because they (a) are willing and available to participate, (b) have the capability to reflect and articulate, (c) and possess the necessary knowledge and experience of the issue being studied (Morse as referred to in Flick, 2002).

In essence, there are two groups of participants in this study: the elderly residents (care-receivers), who lived in assisted living facilities, and their family members (caregivers). Recruitment of the study participants was purposeful. *Purposeful sampling* helped to, intentionally and strategically; select different assisted living facilities, as well as appropriate participants, based on the nature and purpose of this research study (Rubin & Babbie, 2001). Moreover, this sampling strategy provided access to valuable in-depth information within the limited research timeframe.

**Sampling assisted living facilities.** The initial recruitment of assisted living facilities took place in Colorado Springs. In order to identify assisted living facilities in Colorado Springs, a key informant, a social worker with a specialty in gerontology was consulted. This resulted in a list of 30 assisted living facilities, out of which, ten facilities were contacted, based on their different locations within El Paso County. This researcher
directly approached these ten facilities. Two assisted living facilities refused to participate, because they could not acquire permission from their executive board or owners. This process resulted in a total of four assisted living facilities in Colorado Springs that agreed to participate. This researcher was also able to access potential participants from among her social and church network, as well as through referrals from other participants. This led to the recruitment of a large facility in Denver, which generated more participants for this study. Altogether, the sample of assisted living facilities included one facility in Denver and four assisted living facilities in Colorado Springs (see Table 2).

Table 2

<table>
<thead>
<tr>
<th>Assisted Living Facilities</th>
<th>Location</th>
<th>Size</th>
<th>Recruited Participants</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td>Care-receivers</td>
<td>Family Caregivers</td>
<td></td>
</tr>
<tr>
<td>ALF # 1</td>
<td>Colorado Springs</td>
<td>54 bed</td>
<td>3</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>ALF # 2</td>
<td>Colorado Springs</td>
<td>13 bed</td>
<td>1</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>ALF # 3</td>
<td>Denver</td>
<td>200 bed</td>
<td>1</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>ALF # 4</td>
<td>Colorado Springs</td>
<td>16 bed</td>
<td>1</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>ALF # 5</td>
<td>Colorado Springs</td>
<td>18 bed</td>
<td>2</td>
<td>2</td>
<td></td>
</tr>
</tbody>
</table>

Assisted living facilities include a wide range of homelike care settings that provide long-term care and other support services to elders, who do not need constant medical supervision. Assisted living facilities vary in their appearance, features, and management, and are increasingly being designed to accommodate and retain older residents with more demanding impairments and cognitive deficiencies (Golant, 2008).
The five assisted living facilities that agreed to participate in this study differed from one another, based on their size, composition, structure, service-provision, environment, and location. This researcher selected larger, more modern, and newly remodeled, private pay assisted living facilities, along with smaller facilities that catered to Medicaid assisted residents. As shown in Table 2, of the five assisted living settings selected for recruiting participants, two were apartment-style assisted living facilities (ALF # 1), of which one was part of a continuum of long-term care services (ALF # 3), and three were smaller 13 to 18-bed facilities (ALF # 2, ALF # 4, ALF # 5). The two apartment-style assisted living facilities were more expensive and upscale catering to elderly residents, including those suffering from Alzheimer’s who were primarily paying out-of-pocket, and were accommodated in private living units or apartment homes. Two of the three smaller assisted living facilities were decent and well-maintained and offered semi-private rooms, whereas one assisted living, which used to be a board and care home, was in need of renovation and more staff personnel.

**Recruitment.** When this study was initially conceptualized, this researcher had planned to directly recruit elderly participants from the selected assisted living facilities. However, during the recruitment stage, this researcher had to schedule appointments with the representatives and the assistant managers of each of the assisted living facilities in order to explain the nature and purpose of this phenomenological research study. It was necessary to go through these representatives and managers, who then referred this researcher to both specific elderly residents who would be cognitively and physically able
to contribute to this study, and to their primary family caregivers, who would also be willing to participate in interview and follow-up sessions.

In addition, the representatives and managers referred this researcher to their staff members, who provided further assistance and information about the assisted living facilities’ programs and services. This information proved valuable in providing background context for the subsequent interviews. More specifically, the representatives or managers at each of the assisted living facilities were very knowledgeable about each of their clients and their families, and were, therefore, able to direct this researcher to some elderly participants and their family members.

**Sampling study participants.** Purposeful sampling was again utilized to sample the potential participants. The criteria for selecting elderly participants stipulated that elderly residents be American citizens, 65 years or older, who had lived in the same assisted living facility for a period of 6 months or more. Elderly residents were also recruited based on their ability to physically participate and narrate their experiences, and to cognitively understand the rationale and purpose for conducting this study. The criteria for selecting the primary caregiving family member of these elderly residents required that they be available for face-to-face interview sessions, be 18 years or older, and be actively involved in the care process, which was determined by their consistent care provision and assistance, regular and frequent visitation and communication, and advocacy and supervision patterns. Both male and female participants were selected for the sample in as equal a proportion as possible, in order to draw different opinions and
perspectives for this study. This researcher also attempted to select participants from different socioeconomic and racial-ethnic backgrounds.

Following the recruitment and purposive selection of potential participants, this researcher directly contacted the elderly residents, and in turn, their family members, and scheduled appointments to meet with each potential participant separately in order to determine if they met the study’s criteria and were willing to participate. This helped the researcher to establish rapport and gain the trust of family members and their elderly relatives. Two elderly residents who were approached refused to be interviewed, but a total of 8 pairs of elderly participants and their respective primary family caregivers (16 participants) agreed to individually participate in this study. For every elderly participant selected, one of their family caregivers identified by the elderly person, typically a daughter or a son, was also recruited as a participant. In three cases, the elderly participants were married and were living in assisted living with their respective spouses. The care-receiving participant chosen for interview sessions was the one in better health, as identified by the facility. Atypically in this study, the sample of caregivers included a care-receiver’s close friend, rather than a relative, because the elderly resident considered this friend a part of her extended family.

Informed consent. Informed consent was obtained from elderly residents and their primary family caregivers before interviewing any participant (Please refer to Appendix A and B). The informed consent of the elderly residents was obtained at the assisted living facilities in the privacy of their rooms, or in a comfortable and private area in the assisted living facility. Informed consent from caregiving participants was also
obtained at locations that were convenient and comfortable for them. The consent form was given to some participants prior to meeting them for the initial interview session, and to other participants just before the face-to-face interview sessions began. The confidential nature of this research study, which did not use any real names or locations, was discussed with each participant. This researcher clearly communicated to the participants that their participation in this study was completely voluntary, and that they could choose to withdraw at any time or refuse to answer any questions they did not wish to talk about, during the interview, without any negative consequences. After having gone over the consent form, this researcher gave participants adequate time to address any concerns or questions that they might have.

The informed consent forms also included permission from all the participants for being tape-recorded during the interview sessions. In some cases, this researcher had to get the permission of the family members before interviewing and tape-recording any responses from the elderly participants. This researcher asked for each participant’s permission to meet with her for more than one interview session, in order to obtain relevant and authentic individual narratives, as well as to gain clarity and a deeper understanding of the data. The participants were also informed that the information collected from them would only be used for academic research and publishing purposes.

**Epoche**

A phenomenological researcher’s experience of collecting and analyzing data is understood in terms of what Edmund Husserl called *epoche*, which in Greek means to abstain (Creswell, 1998). The process of epoche is central to the phenomenological
tradition and accordingly, played a critical role in all the phases of this research study. A phenomenological researcher begins by setting aside or bracketing all prejudgments, assumptions, and any prior knowledge and experiences regarding the subject being studied, relying on imagination, intuition, and especially the voices of the study participants to arrive at a true and real essence of the phenomenon (Creswell, 1998; Miller & Salkind, 2002). Hence, once these assumptions were identified by the researcher, as outlined in Appendix C, this researcher entered into interviews with the study participants with a fresh perspective. The phenomenological epoche is a process of not only setting aside any prejudices and biases, but also allowing events and people to enter anew into consciousness in order to achieve newer evidence and insights (Moustakas, 1994).

**Data Collection**

An essential, inherent feature of qualitative research is the simultaneous pursuit of complexity and the production of clarity (Morse & Richards, 2002). The strength of a phenomenological inquiry is in the integration of its research question(s), data collection, and data analysis, which do not follow a rigid sequence (Creswell, 1998). In fact, the processes of data collection and data analysis were, to a certain extent, conducted simultaneously in this study. This researcher was respectful and mindful of the participants’ convenience, ability, and availability to meet for interview sessions, and involved the participants throughout the stages of recruitment, data collection, and follow-up.
Qualitative interviewing. Within the phenomenological tradition, the method of inquiry chosen for this qualitative study was face-to-face interview sessions. Interviews are purposeful conversations that provide valid and reliable information. Qualitative face-to-face interview sessions are flexible, iterative, and continuous, and lead to negotiated and contextually based results that encompass the hows and whats of people’s everyday lives (Denzin & Lincoln, 2003; Rubin & Babbie, 2001). Face-to-face conversations are the primary medium for interacting and building relationships. Every interview context is, therefore, interactional and relational, and the nature of the social dynamic of the interview helps shape the nature of the knowledge generated (Denzin & Lincoln). In this study, face-to-face interviews allowed for in-depth information concerning the phenomenon under study, as well as immediate clarification and expansion of the participants’ thoughts, thereby providing this researcher with nonverbal cues, such as gestures and facial expressions (Speziale & Carpenter as referred to in Penner & McClement, 2008).

Before the interviewing began, each participant was asked to fill out a very brief demographic profile. The ensuing in-depth qualitative interviews lasted anywhere between 60 and 90 minutes and focused on the subjective experiences of the participants’ family involvement. The participants could request any relevant information before, during the course of the interview, or after the interview process. One elderly participant seemed a little worried about this researcher’s decision to talk to her family caregiver separately. This researcher reassured the participant that conducting separate one-on-one interviews ensures freedom of exchange, and that family caregivers would, for the most
part, answer the same questions that would be asked of the elderly participants. This elderly participant was also reminded that if she felt uncomfortable at any point, she could completely withdraw from the interview.

This researcher also used a semi-structured interviewing method, along with an open-ended interview guide, comprised of subtopics and areas related to the research questions (Please refer to Appendix D and E). This was also essential to maintain consistency and flexibility in order to obtain more quality, richness, depth, and detail in the data that was generated and collected, because some study participants were interviewed more than once. The interview guide allowed this researcher to elicit responses that introduced relevant topics, which led to the formulation of new questions that helped to fully explore each topic, perception, and experience. This process was repeated in each interview session to generate quality information, and was dependent upon the various experiences and stories that were shared by the study participants. This researcher also focused on listening to the participants and was flexible to allow the participants’ narratives to guide the interview sessions accordingly.

**Audio-taping and field notes.** All the interviews were audiotaped, which allowed this researcher to follow and probe into important cues from the participants, so that the interviews could proceed thoughtfully. This was extremely important, because it freed this researcher to completely focus on the participants and listen to all that was being communicated (Rubin & Babbie, 2001). Audio-recordings help to repeatedly listen to the interviews, which reveal unnoted recurring features of the organization of talk (Denzin & Lincoln, 2003). Tape recording all the interviews verbatim was therefore, ideal and
extremely useful, because it provided highly accurate and detailed information for data analysis (Creswell, 1998; Kvale, 1996).

To further facilitate the data gathering process, this researcher also wrote field notes from every interview to ensure complete and thorough findings. The context of each interview, along with important observations and factors that may have influenced the data collection process, were described in all the field notes (Penner & McClement, 2008). Such observational field notes and analytic memos were most useful in compiling and manipulating data records. Moreover, this researcher was focused and transparent while gathering valuable research information from the family caregivers and their elderly relatives regarding their lived experiences within assisted living facilities.

**Determining saturation.** Each participant was interviewed at length for anywhere between 60 to 90 minutes, which helped to produce detailed narratives of personal and familial experiences. 11 of the 16 participants were interviewed on more than one occasion, because they were reflective and willing to share more, which added to the depth of their narratives. As the interviews progressed across the study sample, commonalities and repetition of themes gradually became apparent. This researcher continued to recruit participants for this study until a data saturation point had been reached. This was determined based on similar data patterns that started to consistently emerge from interview sessions. By the completion of interviews with the sixth care-receiver, caregiver dyad, themes were consistently repeated, and information derived from such interviews was beginning to reach a point of saturation. Hence, data saturation was determined at the completion of the 16 qualitative interviews.
Phenomenological Data Analysis

In his writings, Edmund Husserl established that any phenomenon is a suitable starting point for a phenomenological investigation that needs to be interpreted by explicating its constituents and possible meanings to derive an understanding of the essence of the experience (Moustakas, 1994). During the entire study, but particularly during the analysis phase, this researcher was conscious of the realization that perceptions about family involvement cannot be understood without also understanding the personal meaning of participants’ lives and family experiences. Elderly care-receivers and their present circumstances needed to be explored in terms of their background and past experiences. The participants’ interpretation of events was, therefore, considered within the context of a personal meaning system.

Human social research is a practice of communication, of decoding signs and symbols, and of interpretation (Luckmann as referred to in Hitzler & Eberle, 2004). Interpreting transcribed data is central to qualitative research. A phenomenological approach was utilized to interpret data from the raw materials provided by the participants in the form of audiotaped interviews, which were subsequently transcribed verbatim to produce written data transcripts. Audio-recorded interviews were also used to inspect and re-examine the sequences of utterances, and identify the non-repetitive and non-overlapping statements of the participants’ experience. Hence, this researcher was able to thoughtfully and efficiently transcribe, organize, and analyze the interview data, in order to make sense of all the conversations. When a participant’s experience
corresponded to the correlates of the experience of others in a way that could be typologized, meaning schemata was derived (Hitzler & Eberle, 2004).

A central component of analyzing the data gathered in this study was phenomenological reduction. Generally speaking, phenomenological reduction involves the processes of thinking, intuiting, reflecting, judging, and describing, wherein the relationship between the external perception of objects and the internal act of consciousness, perceptions, and memories are described in textural language (Moustakas, 1994). A narrowing and a selecting from all possible research choices and decisions helps to bring order to the masses of raw materials and data (Patton, 2002). A logical, systematic, and coherent system of reflection provides an analysis of the descriptions of experience. Reflection has been defined as a process “through which the stream of experience, with all its manifold events can be grasped and analyzed in the light of its own evidence” (Husserl as cited in Moustakas, p. 47), leading to a reduction of what is horizontal and thematic. Such themes are identified as patterns that describe and organize possible observations that help to interpret aspects of the phenomenon under study (Boyatzis, 1998). Phenomenological reduction also helps this researcher to remain open to the unexpected insights that might emerge (Patton, 2002).

All phenomenologist researchers need to keep in mind that each individual has his or her own reality and its interpretation, and then construct the essence that captures the common experiences of the study participants and the setting in which they experience the phenomenon (Miller & Salkind, 2002). Subjective viewpoints provide the material to study the course of interactions, which further help to “reconstruct the structures of the
social field and latent meaning of practices” (Flick, 2002, p. 7). Phenomenological data
analysis involves a reconstruction of individual cases, along with summarizing and
contrasting these cases from a generalizing and a comparative viewpoint (Flick et al.,
2004). This above-mentioned approach to data analysis was achieved by using the Van
Kaam method of data analysis, which is described below.

**Van Kaam method of phenomenological data analysis.** Moustakas’s (1994)
modification of the *Van Kaam method* guided the analysis phase of this study, which
primarily involved horizontalization, categorization, and a reconstruction of the essence of
the phenomenon being studied. Prior to beginning the process of horizontalization, even
as the data was being collected and verified, each interview was carefully transcribed.
This researcher sorted through the data records that were created, and initially recorded
preliminary reflections and insight. These processes of continuously reflecting, writing
and re-writing, and sifting helped to “identify similar phrases, relationships, patterns,
themes, distinguishing features, and common sequences” (Morse & Richards, 2002, p.
44).

Creswell (1998) describes horizontalization as a process through which the non-
repetitive and non-overlapping statements of how individuals are experiencing the
phenomenon are sorted out and developed. Every expression relevant to the phenomenon
under study was listed. The data was openly coded and sorted to identify overlapping
themes and patterns, which were organized into more inclusive domains, as suggested by
Denzin and Lincoln (2003). All other vague and repetitive expressions were eliminated,
because the horizons that remained became the *invariant constituents* of the experience
(Moustakas, 1994). Emerging patterns and specific commonalities and differences were extracted for further analysis. These invariant constituents were interpreted or labeled, and subsequently transformed into *core themes* or *clusters of meanings*.

These core themes or key statements that reflected the meaning of experiences, as construed by elderly residents and their family caregivers were carefully analyzed. The individual and subjective perspectives regarding the experience of family involvement were then compared, examined, and subsequently *validated* and organized in preparation for constructing an *individual textural description* for each participant (Creswell, 1998; Moustakas, 1994).

Following the construction of individual textural descriptions for each participant, *individual structural descriptions* were then constructed with the help of *imaginative variation*, which helped this researcher to derive possible meanings through imagination and divergent perspectives, positions, roles, or functions in order to uncover how the phenomenon was experienced, and the way it was experienced, for each participant (Moustakas, 1994).

After having followed all of the above-mentioned steps, *individual textural-structural descriptions* of the essence of the experience were constructed for each participant, out of which emerged a phenomenological discussion of a *composite description of the meanings and essences* of the participants’ experience as a whole. This method led to the formulation of some generalizations and discoveries that are presented in the following chapter.
**Trustworthiness and Credibility**

This researcher employed several procedures that helped ensure the trustworthiness and credibility of this research study’s findings. Creswell (1998) regards *member-checking* as an approach that helps to establish credibility and accuracy in research work. Accordingly, this researcher used member-checking during the interviews and after the interview process as a strategy to help verify data, findings, interpretations, and conclusions. All transcribed interviews were sent to the participants for follow-up and review. Study participants were also provided with a written summary of the study findings and their implications. In addition, *debrieing* with the committee advisor ensured an objective assessment and reporting of the entire research process and the research findings.

**Protection of Human Subjects**

To ensure that this research study was conducted ethically, informed consent and voluntary participation of all the respondents was sought, without endangering or coercing any of the participants. The nature and requirements of this study, ethical issues regarding confidentiality, as well as participants’ rights, including their right to report any concerns regarding the study to the University of Denver Institutional Review Board, were carefully explained to all the study participants before initiating the interviews for data collection. This study was conducted only after obtaining approval from the Graduate School of Social Work and the Institutional Review Board of the University of Denver.
Chapter 4: Findings

Introduction

The main purpose of this qualitative phenomenological research study was to explore institutionalized elderly care-receivers, specifically within assisted living facilities, and their family caregivers’ experiences of family involvement with respect to their roles and relationships. The reconstruction of elderly relatives’ lived experiences as well as their family caregivers’ perspectives points to the complexity of such analyses. This researcher utilized a phenomenological approach to collaborate with 16 participants to create meaning. Eight pairs of participants were purposefully recruited for this research study, including elderly residents in assisted living facilities and their respective caregiving family member, typically a daughter or son and, in one case, a close friend, all of whom were personally interviewed at length.

For the purposes of this study, family was broadly defined to also include extended family friends and close friends, along with biological kin who were involved in caring for institutionalized elderly family members. Older adults who do not have any or very few biologically or legally related family members seem to consider their closest friends as their family. Such friends are also referred to as fictive kin or alternative family members (Connidis, 2001).

In phenomenological research, the data collected from every participant is regarded as unitary and whole (Rubinstein, 2002). Family or family relationships or ties...
are broad terms that represent all the relationships, and each relationship needs to be examined as an entity in its own right (Connidis, 2001). This phenomenological study examined the impact of continuity and change in family relationships and roles from both care-receiving and caregiving participants’ points of view. This was essential because every relationship with elderly care-receivers included not one but two viewpoints and experiences. This chapter presents the findings from participants’ demographic profiles, along with the textural descriptions of 8 pairs of participants, which include the care-receiving residents and their respective family caregivers’ individual experiences of their family involvement, as well as a composite textural-structural description.

**Participant Demographics**

Before being interviewed, each participant filled out a brief demographic profile that provided information about the participants’ gender, age, race/ethnicity, marital status, and relationship to one another. Of the 8 care-receiving participants, six were female, and two were male, whereas of the 8 caregiving participants, seven were female, and only one was male. This breakdown mirrors national trends. A higher proportion of adult family caregivers and elderly family members, who are more likely to be widowed or divorced, and who rely on their extended family networks for care and assistance are female (Markides & Wallace, 2007).

In 2007, a recent report projected female life expectancy to be 80.9 years and male life expectancy to be 75.1 years, suggesting that longer life spans among females resulted in a higher proportion of older women living alone, who were either widowed or unmarried (Wexler, 2008). Hence, it was not surprising to find that of the eight family
members interviewed for this study, seven were female caregivers. Of these, six female caregivers were daughters providing care to their mother or father or, in some cases, both parents, whereas one female participant was a close friend and a caregiver to an elderly resident in the study. One male caregiver was also recruited because of his involvement and support for both his elderly parents residing in an assisted living facility.

Tables 3 and 4 depict the socio-demographic information regarding the care-receiving and their respective caregiving participants. The elderly care-receivers ranged in age from 66 to 90 years of age, with a mean age of 82; and their family caregivers spanned in age from 35 to 78 years of age. The mean age of family caregivers was 55, and the oldest caregiving family member was a 78-year-old extended family member of one of the elderly participants in the study.

Table 3

*Care-receiver Demographics*

<table>
<thead>
<tr>
<th>Elderly Participant</th>
<th>Gender</th>
<th>Age</th>
<th>Relationship with Family Caregiver</th>
<th>Race/Ethnicity</th>
<th>Duration of Residence in AL</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>F</td>
<td>66</td>
<td>Mother</td>
<td>African-American</td>
<td>1.5 years</td>
</tr>
<tr>
<td>2</td>
<td>F</td>
<td>79</td>
<td>Mother</td>
<td>Caucasian</td>
<td>9.5 months</td>
</tr>
<tr>
<td>3</td>
<td>F</td>
<td>83</td>
<td>Mother</td>
<td>Caucasian</td>
<td>2 years</td>
</tr>
<tr>
<td>4</td>
<td>M</td>
<td>90</td>
<td>Father</td>
<td>Caucasian</td>
<td>9 months</td>
</tr>
<tr>
<td>5</td>
<td>M</td>
<td>84</td>
<td>Father</td>
<td>Caucasian</td>
<td>10 months</td>
</tr>
<tr>
<td>6</td>
<td>F</td>
<td>84</td>
<td>Mother</td>
<td>Caucasian</td>
<td>2.5 years</td>
</tr>
<tr>
<td>7</td>
<td>F</td>
<td>83</td>
<td>Mother</td>
<td>Caucasian</td>
<td>8 years</td>
</tr>
<tr>
<td>8</td>
<td>F</td>
<td>85</td>
<td>Friend</td>
<td>Caucasian</td>
<td>11.5 years</td>
</tr>
</tbody>
</table>
Both male and female participants, as well as participants from different ethnic backgrounds were recruited for the sample in order to draw different opinions and perspectives for this study. One of the care-receiving participants was an African-American, whereas the other 7 elderly participants identified themselves as Caucasian Americans. Among the family caregivers, 1 participant was a South-Asian immigrant and 1 participant was African-American, whereas the other 6 participants were Caucasian Americans (see Table 4). Recently, a U.S. census report on the aging population by county-state estimated that in 2008, 91.9% of the 65+ population residing in El Paso County in Colorado Springs (the primary location of this proposed study) were Caucasian (AOA, 2008).

Similarly, as reflected in these findings, a majority of the participants in this study were Caucasian Americans, who were paying from out-of-pocket for assisted living care and services, because they could not have qualified for any public assistance. However, one elderly participant was on Supplemental Security Income and received some

<table>
<thead>
<tr>
<th>Caregiving Participant</th>
<th>Gender</th>
<th>Age</th>
<th>Relationship with Elderly Participant</th>
<th>Race/Ethnicity</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>F</td>
<td>35</td>
<td>Daughter</td>
<td>African-American</td>
</tr>
<tr>
<td>2</td>
<td>F</td>
<td>54</td>
<td>Daughter</td>
<td>Caucasian</td>
</tr>
<tr>
<td>3</td>
<td>F</td>
<td>47</td>
<td>Daughter</td>
<td>Caucasian</td>
</tr>
<tr>
<td>4</td>
<td>F</td>
<td>63</td>
<td>Daughter</td>
<td>Caucasian</td>
</tr>
<tr>
<td>5</td>
<td>M</td>
<td>53</td>
<td>Son</td>
<td>Caucasian</td>
</tr>
<tr>
<td>6</td>
<td>F</td>
<td>59</td>
<td>Daughter</td>
<td>Caucasian</td>
</tr>
<tr>
<td>7</td>
<td>F</td>
<td>55</td>
<td>Daughter</td>
<td>Caucasian</td>
</tr>
<tr>
<td>8</td>
<td>F</td>
<td>78</td>
<td>Friend</td>
<td>South-Asian</td>
</tr>
</tbody>
</table>

Table 4

*Caregiver Demographics*
disability benefits. As shown in Table 3, data regarding the duration of the elderly participants’ residence in assisted living were also gathered. Length of residence ranged from 9 to 11 months (3 participants) to 11.5 years (1 participant).

A Descriptive Profile of Study Participants

Eight family systems, comprising of 8 elderly care-receivers and 8 family caregivers were recruited in this study. Of the 8 care-receiving participants, one participant was divorced, four (female) were widowed, and three were married and living together with their spouses in assisted living facilities. Of these three couples, in two cases, elderly couples who were providing care to each other, and simultaneously receiving care themselves were also interviewed, even though one person from the couples was chosen as the primary respondent and included in the study sample. A brief description of these 8 care-receiving participants and their respective caregiving participants is provided in this section.

Family A. This family consisted of a married couple who were living together in an assisted living facility and their caregiving son. The elderly couple was an 84 year old husband, who was a retired doctor, but was presently suffering from glaucoma, which affected his sight, and his 82 year old wife, who was a nurse, but had become disabled and unable to speak clearly because of Parkinson’s disease. Even as this couple lived in a private pay assisted living facility, which was part of an expensive, upscale long-term care continuum, they reported perceptions of increasing financial burden, among other experiences. The elderly husband was recruited as the primary respondent along with his
53 year old caregiving son, who was divorced, and both the participants were separately and extensively interviewed on more than one occasion.

**Family B.** The study sample also included a family comprising of a 90 year old veteran, who was living in another assisted living facility along with his wife, because she was suffering from advanced Alzheimer’s. The elderly veteran and his 63 year old caregiving daughter, who lived in close proximity to the assisted living facility, were individually interviewed at length. This caregiving daughter was a married, stay at home mother with numerous responsibilities and relationships, because she had an extended family of her own, which included her elderly parents-in-law, her children, and many grand-children.

Hence, she helped to describe her experiences of negotiating relationships within the family system and the assisted living system, along with sustaining care-receiver roles, while also adapting to new roles.

**Family C.** Another family, which included an elderly couple living together in assisted living and their caregiving daughter, were recruited for this study. The 79 year old wife, who had macular degeneration, while also caring for her 82 year old husband, who used to be a structural engineer, but was suffering from prostate cancer, was selected and interviewed regarding her and her husband’s experiences of family involvement. Both she and her married 54 year old caregiving daughter, who was a linguist by profession, related their perceptions about experiencing loss, isolation, burden, and frustration as they continued to adjust to life within an assisted living facility.
**Family D.** An extended family system, which comprised of an 85 year old widow, who had worked as a nurse, and her 78 year old caregiving friend, who was a retired accountant was also included in this study’s sample. Both the care-receiving and the caregiving participants met in a church event, became close friends, and had remained friends for approximately 11 years. Their participation in this study helped to reinforce the importance of elderly members’ roles, positions, strengths, and their personal experiences, which were related in their own words.

**Family E.** This family system comprised of an 83 year old widowed mother, and her 47 year old married daughter. The elderly care-receiving participant was living in a well-maintained and modern assisted living facility and was able to pay out-of-pocket, because her deceased husband had worked for NASA and had made enough money, which left her well-provided for. The caregiving daughter was a teacher, who lived with her husband who served in the army, and her children, in close residential proximity to the assisted living facility.

**Family F.** Another mother-daughter dyad comprised an 83 year old widow and her 55 year old daughter. The care-receiving participant was a German immigrant, who had married an American army serviceman and had moved to United States about 61 years ago. She was suffering from several chronic ailments, such as diabetes, fluctuating blood pressure, and arthritis. Her caregiving daughter, who was divorced, worked as a receptionist in a doctor’s office, and lived with her two sons in close proximity to the assisted living facility.
Family G. This family system represents yet another mother-daughter dyad, which comprised an 84 year old widow and her 59 year old daughter, who ran her own business from her home. The care-receiving participant had moved into an assisted living facility after she had fallen in her home, where she was lying unconscious on the floor for 14 hours, before someone found her. The caregiving daughter shared that after careful planning and many discussions with her elderly mother, they mutually decided to sell her mother’s home, which would provide the financial help needed to enable her mother to keep living in an assisted living facility.

Family H. Another mother-daughter dyad consisted of a 66 year old mother, who had been divorced for over 30 years, and her 35 year old caregiving daughter, who worked as a cashier in King Sooper’s to earn a living. This care-receiving participant had a GED certificate and had worked in different jobs, over the years. She was suffering from severe health ailments and was, therefore, receiving some disability benefits. This elderly participant qualified for public assistance and lived in an older and poorly maintained assisted living facility, which was originally a board-and-care home.

A Phenomenological Analysis of Family Involvement Within Assisted Living Facilities

This phenomenological study was designed and conducted to understand the nature, extent, and quality of family involvement within assisted living facilities from the perspectives of both the care-receiving residents and their respective family caregivers. Family involvement was conceptualized as family roles and significant relationships that characterized family life. This researcher used neither the names of the assisted living
facilities nor those of the participants in order to protect the participants’ identities, and changed the names of any people referred to by the participants in this study. The term care-receiver referred to any elderly resident of an assisted living facility in the study and was used throughout this study to differentiate the elderly family members from their caregiving family members or family caregivers.

Most participants of this study did not differentiate between family roles and family relationships, because caregiving and mutual support were viewed as essential components of a close relationship, as opposed to separate specific roles. However, two of the primary family caregivers in the study who were functionally available and in frequent contact with their elderly parents shared with this researcher their experiences of role and relationship strain. Also, as mentioned earlier, it is important to note that one caregiver was not a biological family member, but rather a good friend.

In this section, textural descriptions are mainly divided into two parts or sets of themes: the care-receiving residents’ experiences of their family involvement and the family caregivers’ perceptions of their family involvement. Although this researcher had made it clear to the participants that all the interview responses would be kept completely confidential, it became evident from the interviews with some family caregivers that their respective care-receiving relatives in the study had withheld important information regarding their preferences and family relationships. This may have occurred because these care-receivers were guarded or felt shy in sharing their perceptions with a stranger. Therefore, both care-receiving and caregiving participants’ perceptions of each other’s experiences related to their family roles and relationships were integrated into both sets
of themes. These invariant constituents and themes were incorporated to develop a thematic portrayal of this phenomenological research study’s findings. Many overarching and underlying themes were identified and interpreted across the data transcripts, which are presented in the subsequent sections and organized on the basis of the perspectives of both the care-receivers and their family caregivers.

**Overarching Themes and Supporting Themes**

**Care-Receiving Residents’ Experiences and Perceptions**

Theme 1: Caregiving Efforts of Elderly Care- Receivers
- Spousal caregiving
  - Rediscovering new roles and interests
- Providing inter-generational support and caregiving
- Continued symbolic and functional involvement in families
  - Maintaining extended family networks and commitments

Theme 2: Residents’ Adjustment to Receiving Care
- Overcoming denial to acknowledging a need for care
- The need for maintaining self-reliance
- Accepting care and support from family caregivers
- Expectations regarding assisted living facilities
  - Experiencing financial strain
  - Adapting to the physical and environmental aspects of an assisted living setting
  - Relationship challenges
Theme 3: Living with Aging and Loss

- “We can do whatever we want”, to “We can only do what others can help us do”
- Sense of being uprooted
- Loss of familiar roles and activities
- Inability to identify meaningful contributions

Caregiving participants’ experiences and perceptions.

Theme 4: Moving from a Parallel Relationship to a Braided Experience

- Being in the middle
- Feeling responsibility towards elderly care-receivers as their dependence on family members increases
- Arranging and maintaining intergenerational family involvement
  - Being the bridge
  - Balancing the need to maintain intergenerational participation versus independence

Theme 5: Intersecting Caregiving Roles and Relationships in Family Systems

- Sibling involvement
  - Consensus among siblings
  - Conflicting roles and relationships with a sibling’s spouse
- Association between family caregivers’ physical proximity to their elderly care-receivers and their mutual involvement
- Generational and gender influences on caregiving roles - “It’s a male thing”
• Negotiating instrumental assistance and quality of life issues

Theme 6: Caregiver Perceptions of Stress and Burden

• Assuming a supervisory/parental role
  - Efforts to assist without crossing the line
  - Letting go

• Impact of elderly couples’ mutual relationships

• “I am my dad’s lifeline”

• Over-extension of specific caregiving roles

• Role overload – Juggling multiple roles and relationships

• Valuing communication

Care-Receiving Residents’ Experiences and Perceptions

The very nature and task of caregiving implies a caregiver and a care-receiver. This researcher interviewed eight elderly care-receivers in assisted living who described their roles and relationships in families, along with their experiences of aging, loss, and the consequent move to an assisted living facility. 3 married participants who were living with their spouses in assisted living described their primary role in terms of providing companionship as well as emotional and instrumental support to their aging spouses. Perceptions from some adult caregiving children regarding their elderly parents’ family roles and relationships were also included in this section. Other elderly participants reflected on their continued and symbolic involvement with their adult children, grandchildren, and in one case a close friend, despite their physical challenges and associated losses.
Theme 1: Caregiving Efforts of Elderly Care-Recievers. Based on the perceptions and experiences of the elderly residents and their family caregivers, elderly care-receivers were found to not only receive care but also provide care. As part of this theme, sub-themes that included descriptions of certain roles and relationships and specific ways in which elderly care-receiving residents were involved in their families are depicted below (see Table 5) and then elaborated upon in the subsequent sections.

Table 5

<table>
<thead>
<tr>
<th>Caregiving Efforts of Elderly Care-receivers</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.  Spousal caregiving</td>
</tr>
<tr>
<td>- Rediscovering new roles and interests</td>
</tr>
<tr>
<td>2.  Providing inter-generational support and caregiving</td>
</tr>
<tr>
<td>3.  Continued symbolic and functional involvement in families</td>
</tr>
<tr>
<td>- Maintaining extended family networks and commitments</td>
</tr>
</tbody>
</table>

Spousal caregiving. A key caregiving role for elderly couples in assisted living is spousal caregiving. Of the 8 care-receiving elderly participants, three were married and living together with their spouses in the selected assisted living facilities. Of these three elderly couples, this researcher interviewed two male spouses and one female spouse, all of whom indicated that they had preferred to move to an assisted living facility along with their spouses to be physically close to them. Thus, spousal caregiving was facilitated by the elderly couples’ moving together into an assisted living facility. In one case, a family member—a daughter—expressed this sentiment as follows:

Part of the rationale for moving Dad, moving them both in here, into an assisted living was that we thought if we could get the both of them established in a community that when my dad passed on, my mom would already have a support group and she wouldn’t suddenly have to leave her house and have all of that trauma then.
Another elderly resident in the study, who was no longer able to care for her husband in their home, decided to move with him to an assisted living facility that could provide him the care he needed. In this way, she could be free to simply see and visit with her husband every day and take a supervisory role in negotiating her husband’s care until his death. She described the benefits of their move in the following way:

My husband had dementia plus Parkinson-like symptoms, but not exactly Parkinson’s. He got pneumonia, and after he came out from the hospital, they moved him down into the reminiscence part, which worked great because I could be up here. I was here and my husband was taken care of, but yet I could walk away from it and I didn’t have to go out to see him all the time.

The study found that an elderly couple’s adjustment to care provision was affected by their mutual relationship, especially their physical and emotional dependence on each other. In spite of physical and cognitive limitations, elderly spouses in this sample valued their autonomy by preferring to rely on one another, even though they lived in an assisted living facility.

This researcher noted that certain differences in perceptions accounted for different behaviors and expectations among elderly husbands and wives, impacting the nature, frequency, and extent to which elderly family members sought assistance. Female spouses who were being cared for by their husbands felt more like a burden on their spouses, who were also aging and needed care themselves. Perceptions, such as “I wish I could relieve my husband of the stress” and “I feel guilty for not being able to help him more,” were identified by an elderly wife suffering from vision loss due to macular degeneration. Similarly, a caregiving son shared the following:
My mom, she has Parkinson’s, and she feels like she’s a burden on everyone but she’s not. She’s a very strong person. She’s been there for all of us. I mean, her disease is horrible, but she’s been a fighter all through.

This researcher found that of the three elderly married couples, the husbands were a primary support to their wives. Based on this sample, elderly husbands played an active role in securing quality care for their wives and themselves and felt financially responsible for planning for their long-term care needs. Male spouses were observed to be physically and emotionally invested in supporting and caring for their wives. In all three cases, the wives required more care due to advanced disability and health-related constraints, such as macular degeneration, Alzheimer’s, and Parkinson’s that had rendered an 81-year-old wife unable to walk and speak clearly. An elderly husband explained,

I say we are independent, but we are certainly in assisted living. I assist my wife and she assists me. She needs a motorized scooter as she has Parkinson’s. Her little transporter chair is largely for me, to help transport her. I take care of her any way I can.

In addition, this elderly husband’s caregiving son described his elderly father’s efforts to care for his aging wife in this way:

My father is a big reason why my mom is able to live independently to some extent. He’s really the reason that she can. I think he figures also his own physical issues with his glaucoma because his vision is becoming quite restricted—he’s going to lose the ability to drive pretty soon. So far, any going out to dinner and to other things, my dad has to help my mom get dressed, help her shower, wheel her in the wheelchair, take her to doctors’ appointments, go to church, go to Parkinson’s meetings. I mean all those things happen because he is there or she couldn’t do it on her own. Somebody else would have to help her to do those daily functions, and he’s the one right now whose doing those things and helping her to function. And he’s at that point now where what’s burdening him is that he’s realizing that he’s going to need more care, but he is also the caregiver. So what happens when the caregiver becomes fully dependent and becomes the care-receiver, you know, and more so, a care-receiver because of all this.
However, even as some elderly women became the primary care-receivers, they experienced greater anxiety because they preferred to avoid becoming a burden on their spouse and children. Exchanges of support between elderly spouses seemed to help to enhance understanding to address any negative reactions and consequences of excessive care provision.

*Rediscovering new roles and interests.* This researcher observed that elderly participants, including elderly spouses’ attitudes towards their changing circumstances and the subsequent need for formal assistance was critical to their social engagement and participation in assisted living events and activities. According to a caregiving daughter, transitioning to an assisted living facility had freed her dad to participate in activities that he had not been able to engage in earlier.

Dad said, earlier, “I wouldn’t be able to play Bingo”….They have margarita night here, and my dad hasn’t drunk in like 30 years, because my step-mom was against drinking. She has severe Alzheimer’s and has been moved to the reminiscence wing….Well, now he can have his beer, and he has his margaritas. He could never do that before…he could never do Bingo before…he could never go to Target on the bus, because he couldn’t take her. So coming here brought him some freedom, and he’s finally realizing that “I can do whatever I want…like I can go down and play Bingo. I can go down to margarita night…I can go to the little parties that they have.”

Another elderly husband who lived in assisted living with his wife also talked about some of the benefits to moving into an assisted long-term care setting in terms of rediscovering interests and accessing services, as is described in the following excerpt:

One of the other reasons for moving to an assisted living was not only because of food service and health issues. It was so that we would be closer to activities that we knew existed. So now we have an exercise class 5 days a week, and we can easily get to the place in the building. My wife can now participate in a drawing and sketching class, and she has shown me a talent that I did not know she had, and she has done some remarkable sketches of things.
Providing inter-generational support and caregiving. Despite past research that has tried to establish that elderly family members disengage from participating and being actively involved in their families and communities, the elderly care-receiving participants in this study, though limited in their involvement, were found to increasingly value reciprocal exchanges, family ties, and inter-generational solidarity within their families. An elderly resident shared, “I’m over at my daughter’s place at least once a week…We all go to church together, pretty much every Sunday. I go to my grandson’s choir concert. We’re all pretty close and it’s good.”

Grandparenthood is one of the primary familial roles through which elderly family members provide assistance and care to not only their children, but also their children’s children. Such exchanges are important to grandparents, because they view their children and their grandchildren as extensions of themselves. Grandparents who share a good relationship with their children often assist them by baby-sitting their grandchildren. An elderly participant observed,

I sometimes watch my grandson, like when my daughter went to take her oldest daughter to college two years ago…and my son-in-law had a meeting. I stayed with the younger boys, and they are quite close to me. The youngest one is 13, and he kids me all the time. He’s really great.

Elderly grandparents living in close proximity to their adult children were, therefore, able to develop a close bond with their grandchildren and were able to pass on their beliefs and values, which they could share in common with their grandchildren. In this regard, an elderly resident mentioned,

My three youngest grandchildren are here and I see them a lot, but I have a total of eight and you know, the kids are all good kids, and I hear from them; but I see my youngest daughter and her family a lot more just because they are here.
This finding was also reiterated in the words of a caregiving son, who stated,

Well, I think that my kids had more of a relationship with my parents than I had with either of my parents’ parents, because my grandparents didn’t live in the same town as here, but lived in another state; so we didn’t see them periodically. So I think place does matter.

Some relationships between grandparents and their grandchildren were also viewed as less prohibitive, which created an unrestricted climate for expression of any concerns or confidences. A caregiving son and his elderly father’s perceptions of his and his wife’s relationship with their grandson are described below:

Grandfather: Our grand-kids live here in Denver, so we see them pretty regularly...about several times a month, on holidays, you know. Our grandson has remained here and has pursued being a medic, and we have that in common with him. I mean, with my wife having been a nurse and I was a doctor, and so we see him on a very regular basis, like once a week, he’s over here.

Caregiving son: My son really understands, medically, a lot of the things that my parents are dealing with, which is a real common ground for both my parents and he, and so they have good conversation about some of their medical needs, some of their future needs; and I think my parents listen to him almost more than my brother and I, because he may be more knowledgeable, and it may be because he is not their child; he’s their grandson. I think that we have these relationships with our grandkids that are less prohibitive than our own children. Uh, it just is, and so they listen to him and take his advice, you know. He’ll call me and tell me that there are some things that your dad and I talked about, you know. It’s good.

Elderly care-receivers who felt emotionally close and available to even some of their grandchildren, if not all, considered themselves as engaging and involved family members. They reported being more involved when their grandchildren were younger, because they volunteered to watch and engage them, which allowed them to frequently visit and associate with their grandkids.

However, as the grandchildren became teenagers and adults, it was noted that most grandparents expected an inevitable change in their relationship, because more often
than not, due to occupational and residential mobility, grandchildren and, in some cases, great-grandchildren tended to move away, relying on their other friends and personal contacts. “When our grandkids were younger, they used to come over more frequently of course to our house and have dinner with us or whatever. But they are at college now; they can’t do that often.” Hence, based on the experience of those interviewed in this study, this researcher found that although the roles and relationships between grandparents and their grandchildren are subject to change across the life-course, geographical proximity and frequent face-to-face contact seemed to influence closeness in relationships.

**Continued symbolic and functional involvement in families.** This researcher found that the elderly participants in this study had both a symbolic and a functional role in their families. Aging and ailing parents and grandparents are not always able to sustain a one-on-one contact with their children and grandchildren, but they take pride and a sense of accomplishment in recounting their involvement with them and by maintaining *symbolic intimacy* through cataloguing and describing their children and grandchildren’s achievements. Maintaining a sense of contact through talking about their family members’ accomplishments was important to elderly care-receiving participants and was obvious from conversations regarding their grandchildren, such as: “My oldest granddaughter goes to Pepperdine in California; she’s actually in Italy this year,” and “My grandson is going to go to college this fall. He’s just been accepted in Greeley.”

As examples of functional involvement, an elderly female participant who could still cook loved to prepare an occasional snack or dessert to share with her friends and
family. An elderly male participant who preferred gardening was involved by assisting family members in gardening projects at their home. Besides offering companionship and emotional support, one of the elderly participants who had the money, provided financial support, not because her children and grandchildren had needed or asked for it, but because she had simply wanted to share some of her personal resources with her family members, as is described by her in the following excerpt:

I’ve always been there for my children. My middle daughter had a couple of divorces and when she had a lawyer’s bill that she needed help with, I financially helped her out. When my husband died, I gave all of the 8 grandkid $10,000 to put towards their college education and, you know, I’ve got the money, so I figure, I might as well spend it on them, and they are very appreciative, you know; they don’t take any advantage at all.

In one case, an 84-year-old female resident who had very limited to no contact with her biological family members had retained and maintained her friendships with her extended family network, some of whom had, over a period of time, become her family caregivers. This elderly participant, in spite of her physical and emotional challenges, was available, on a weekly basis, to provide reassurance, comfort, and spiritual support by simply visiting, communicating, and praying with a very close friend who had been diagnosed with cervical cancer and was currently receiving hospice care. In the words of this participant,

My friend Betty was diagnosed with cervical cancer, and a hospice is taking care of her. The doctor has given her from 3 to 6 weeks to live… I’ve known her probably for 30 or 35 years. She’s kinda like the sister I never had. I worked with her; we did home care for different people. We alternated visits and most of the time, we just relieved each other…. We have a wonderful relationship. Betty’s husband does a lot for me. He does little chores for me. He brings me things that I need. They are like family; they have taken care of me, you know, they are there for me. Betty wants me there all day long, maybe once or twice a week. Her husband comes and gets me….I don’t have a car as I don’t drive anymore. I have
to depend on someone else to take me places. We have transportation here but only for medical reasons, and not to go visit somebody. Well, a bus takes us for our grocery shopping. But it’s hard to be away from her.....On Tuesday, she said, I love you. She’s not talking much. She’s sleeping most of the time. I haven’t been physically able to take care of her bodily or anything, but I provide prayer support, and I visit her when I can.

Also, as elderly family members advance in age and experience short-span memory loss and other physical limitations, their functional involvement with their grandchildren might diminish, but that does not necessarily weaken their affectational ties and roles. A caregiving daughter described her dad’s role and position in their family as follows:

Thank God for the stories. He’s a monarchy. He’s still Dad. He is still Grandpa, and he is still Great Grandpa and Great-Great Grandpa. He used to come over and dominate everything, every aspect of anybody’s conversation. It was him telling stories, which the kids, they dearly love Grandpa’s stories. Now he doesn’t remember things. At Christmas, Dad always gives the grandkids and the great-great grandkids $5. And I take care of all the envelopes, mark them with names, and I put them in his lap. He didn’t know what to do with them, this past Christmas. And my kids, you look around, and the kids are crying. Because it’s not Grandpa. You know, Grandpa doesn’t do that; Grandpa starts yelling. He gives them all a hug. Well, I had to tell him, and they all got their hugs. But Dad didn’t know why. You know, he didn’t. He was saying, “I wish I had money to give them. I wish I would have thought of this, but Dad, you did. This is what you do.” Well, I should have done this, and I said, “But Dad, you are doing this. Just call out the names on the envelopes. They’re all here.” And my daughter had to take over and call names. But they all came up and got their $5 and gave him the biggest hugs. We never know what’s going to happen tomorrow. It could be one of us. But no, he will always be the head of our house. We never take that away from him, no matter how bad.

Maintaining extended family networks and commitments. This researcher noted that social engagement and meaningful participation prevented a couple of elderly participants from excessively depending upon their family caregivers and helped to facilitate family involvement and exchanges that were well-balanced and healthy in
nature. It was found that accessibility to a good support system is critical to elderly residents’ overall involvement and development. For one elderly participant, being able to sustain an extended family network along with other commitments had increased his perceptions of self-reliance and integration. He explained it this way:

Well, I would say that one of the things that in a way keeps us from falling into that final pit and depending upon our children all the time is that we have maintained our outside friendships and activities to some extent.

Furthermore, this elderly participant stated,

We have also actively participated with Parkinson’s Association of the Rockies and many of its support groups and its education programs. We have many connections with members in these groups. There are about 15 to 18 Parkinson’s patients within a support group in this community. These are residents here, and so we are participating in that once a month.

Data from the interviews clearly showed that older adults, especially care-receiving residents in assisted living facilities, need to be needed, because most of them, if they are physically able, want to engage in meaningful pursuits and activities. The need for integration, which influenced the physical and socio-emotional adjustment of elderly residents to an assisted living facility, was therefore, regarded as extremely important to family caregivers, as well as a few elderly care-receiving participants, because it helped to extend relationships and conversations within and outside of families. A caregiving son explained,

I do like the socialization that they have up there. They have a lot more opportunities to socialize with other people. I like it that they have many things within the facility….Many activities that they can get involved in at the facility are all good things. And my parents, if they make any decisions, they call and we can talk about it.
An elderly care-receiving participant also observed the following:

If elderly members are more adaptable individuals and if the family keeps close contact and introduces them to more of their family and their social contacts, as well helping them develop their own social contacts here, those are happy uprooted people.

For elderly residents who were involved in reciprocal relationships, and who were able to maintain a balance between receiving care and giving back in some shape or form, their mutual involvement with their family caregivers and other family members was perceived to be more extensive and fulfilling. However, the reverse was true for an elderly participant and her husband who were unable to socially integrate and participate in any activities and were consequently dissatisfied with their lifestyle within their assisted living facility, as is stated below:

They have their own ticket here, and there’s not much we can do about it. There’s nothing that they or we can do actually. They have a lot of different things here, but they are kind of immature. We don’t have any friends here. My husband and I stay together…as long as we’re together, we usually spend most of our time together…when he goes, then I’ll be on my own. I don’t know what I’ll do at that point.

Theme 2: Residents’ adjustment to receiving care. Older adults want to resist becoming a burden on their family members for as long as possible. Care-receiving was perceived as becoming dependent on family members and other professional caregivers by most elderly participants. Sudden developmental and health-related changes may require older adults to adjust to needing long-term care, perhaps for the rest of their lives, which, unfortunately, implies negative connotations of futility and powerlessness for many elders. Elderly study participants’ expectations and responses associated with accepting and receiving care are described under this theme (see Table 6).
Table 6

Theme 2 and Sub-Themes

Residents’ Adjustment to Receiving Care

1. Overcoming denial to acknowledging a need for care
2. The need for maintaining self-reliance
3. Accepting care and support from family members
4. Expectations regarding assisted living facilities
   - Experiencing financial strain
   - Adapting to the physical and environmental aspects of an assisted living setting
   - Relationship challenges

Overcoming denial to acknowledging a need for care. This researcher found that for some of the study participants, there was a letting go of “the way it was” and a subsequent recognizing of the need for care. According to a caregiving daughter, her 90-year-old married father had gone through a period of denial over the fact that his wife was suffering from dementia and consequently had resisted moving into an assisted living facility at first:

My step-mother has severe Alzheimer’s. Dad was taking care of her 24/7 and he didn’t get to do anything or go anywhere without her making a scene in the restaurants, her making a scene in the doctor’s offices, because you can’t take patients like her out of a familiar surrounding, and he kept doing it everyday. He was in denial, didn’t want to move to an assisted living. He would say there wasn’t anything wrong with her; she was just tired. We all saw it, but until he admits that there was something wrong with her, uh, but after the stroke, that was finally the last straw. He couldn’t do it; he couldn’t take care of her anymore. It was just, it was just too much for him.

Some care-receiving participants gradually realized their need for help as a result of their increasing limitations. For example, one care-receiver reflected,

The property which we dearly loved was becoming too much of a burden in terms of outside maintenance and size…but it was home for 37 years…we were coming
to the realization that we probably needed to get into a facility where outside maintenance would be taken care of.

Another elderly participant noted, “I couldn’t do my own wash anymore. I still like to be in the kitchen, but I really don’t feel like cooking. I think I have just come to accept that I need help in my life now.” A caregiving daughter described her perception of her aging mom’s acceptance and adjustment to living in an assisted living facility in these words:

Mom has this situation with her back, and it acts up if she’s on her feet. I think she is realizing her limitations. Because she is so independent…I have to say how proud I have been of her adjustment, because we really expected when we brought her in here that she’d come fighting tooth and nail and that she’d call a cab and drive away; we really expected that, that’s how stubborn she is. But she adjusted beautifully…I think Mom realized its time.

**The need for maintaining self-reliance.** This study confirmed the notion that helping elders maintain autonomy and reciprocity, to the extent possible, helps to preserve their sense of rediscovery, self-dignity, and self-esteem. Being able to not only participate in certain assisted living programs, but also maintain self-reliance by retaining function in daily activities, such as bathing and dressing, also helped to alleviate perceptions of dependency among these study participants. A few of the elderly participants reinforced their ability to be self-reliant by stating “I do my own showers,” and “I dress on my own,” as opposed to other residents who needed hands on care, as was expressed by one participant: “They have girls here who are responsible for administering medicines and giving showers. I don’t need that much help, but they shower 98% of the people, and they get them dressed and get them down for meals and stuff.”
Being able to shower and dress on one’s own and being able to drive was viewed as being independent, without having to depend on the assisted living system for transportation. One elderly participant observed,

There are a lot of people who keep their cars for as long as they can. I see cars that are parked outside that have not moved since I got here. Those are people who are just hanging on to their cars. It’s for the occasion that they can go from here to the grocery store or locally.

Hence, elderly residents’ adjustment to assisted living was not only characterized by their perceptions of dependency, but also by their need to be self-dependent for as long as possible, to avoid becoming a greater burden on their caregiving family members.

Accepting care and support from family members. The elderly study participants desired never to become a burden on their families or others. As evident from some participants’ responses, a few elderly residents hesitated to ask for help, even from a close and supportive family network, because they were constantly trying to balance between the need to impose and what they considered as super-imposing on their family caregivers. An elderly caregiver described her perceptions of her care-receiving friend in these words,

Barbara never wants to ask for any help. You have to pry it out of her. She had to move some boxes out to clear up her place. I had to keep asking her in a round about way by asking more questions to find out what she really needed. That’s who she is as a person; she never wants to impose on others, even though she is in need herself.

An elderly resident also commented, “To feel my daughter has to have me over for dinner, or she has to always take me to my appointments and other things… I try not to be a burden on her at all.” Another elderly participant continued to struggle with imposing on her caregiving daughter, because she did not want to overstep any
boundaries and expected the same from other family members. While talking about her family involvement with her adult children, she responded, “I try not to run their business even if they try to run mine…sometimes, a little more than you’d like.”

One elderly female participant seemed to be comfortable asking and receiving care from an adult child who lived in close proximity to her, as opposed to another child who lived at a distance. A caregiving daughter reported,

   My brother has asked my mom on many occasions to come to Denver and stay with them for a holiday. He’s willing to drive down that day and even drive her back if she doesn’t want to spend the night, and she won’t do that. She’s just not comfortable, and I don’t know why. We can’t figure it out…so we accept that.

Past experiences also helped to determine the nature and quality of some elderly parents’ relationships with their adult children. Elderly participants who were more confident in their relationships with certain children and had relocated from other states in order to be closer to them seemed to be more involved in their families. A caregiving daughter who had willingly sought to help her mother and father relocate to her city to keep them closer to her responded as follows:

   In my opinion, my sister didn’t make the effort, which told me she wasn’t as interested in being with my mom. It wasn’t like a family thing. She just went like she was going through the motions. So I didn’t want my mom to go to Washington. I was like, “no, you have to come here. You owe me to come and be by me and be by my kids,” and I think it got to the point where I pushed it.

*Expectations regarding assisted living facilities.* Before an elderly family member can move into an assisted living facility, care-receiver and family caregiver expectations need to be extensively discussed. This is an essential component of the process behind trying to find the right facility. Need for transportation was a major expectation that was identified by both elderly residents and their family caregivers.
Some assisted living facilities provide transportation services to elderly residents for their medical and shopping needs but are unable to accommodate elderly residents’ social and spiritual needs, such as going to church and other group events. This posed a problem, especially for an elderly resident who did not have any caregiving family members living close to her who were willing and available to help her run her errands and connect with others. A caregiving daughter providing assistance to her elderly parents also explained,

The one thing we didn’t look into when we decided on this facility as opposed to some of the other places around here is the fact that they do not have transportation available…which means that my full-time job is to be a taxi-driver.

*Experiencing financial strain.* An 85 year old elderly participant who lived in the assisted living part of a long-term care continuum with his disabled wife shared his perceptions of the considerable financial strain he was experiencing, and the role that the care facility and the current economy played in this strain:

We had bought the independent living cottage, because this facility had indicated that they would buy back the cottage from us when we moved into the assisted living unit. Now that we are in assisted living, we were told that the facility has four other cottages that they had already bought that are also for sale. So they can’t afford to buy back our cottage…but we can try to sell it on our own, in spite of the market being bad and the competition from the other cottages that are for sale. I understand that the business end of things has to work, but I also feel like there needs to be some kind of an ethical standard here. It’s a great burden financially on us and until it sells, I will keep losing a lot of sleep over this….In the 2008 meltdown, I lost 50% of my retirement account, as did many other people here. And now, the unsaleability of our property adds to our burden. There are many people who are waiting to get in here who are living in a home that they are having a problem selling. You see, they could come if they are able to sell their home and get some equity out of it.

This elderly participant’s financial situation augmented his perceptions of stress, which were associated with his increasing physical limitations and need for more care
himself, as well as his sense of responsibility to physically, emotionally, and financially provide for his disabled wife.

A caregiving daughter also expressed her concern over her step-mother, who had Alzheimer’s, and her aging father’s financial situation to continue living in an assisted living facility,

My dad is 91, and my step-mother is 97. They get no help from the government for living expenses. Sure wish they did. If dad had been broke and had no savings, they would have helped out a little. So they will stay private pay until it’s all gone. I would hate to move them from this assisted living later down the road. This place is there home for now, but for how long.

Hence, unmet expectations regarding assisted living policies and management seemed to exacerbate perceptions of financial burden, frustration, and dependence among elderly care-receivers as well as their family caregivers. Such experiences affected care-receiving residents’ sense of security and prevented them from aging in place and adjusting to their new environment, which consequently influenced their roles and relationships. In this context, a caregiving participant also observed in her interview:

If you go to a care facility, I don’t think you will find happy people in there. They are all burdened with not just their own limitations, expectations, physical pain, and handicap, but they are lacking the help and the caregiving they really need…because quality care comes with a price. To me, that seems to be the bottom line…if you have the money to pay the price to be in good places, people can find good care. It’s the rest of the facilities that provide subsidized care that I am talking about that have become these depressing places.

Adapting to the physical and environmental aspects of an assisted living setting.

While adjusting to an assisted living setting, care-receiving residents also described their experience of negotiating environmental influences and navigating through spatial and architectural aspects of the facility. A male participant explained that “at times I feel
trapped in here…even though I can look outside to this courtyard and see the sunlight.

But I can’t see what the heck’s going on with the street…and to get to outside has also become cumbersome.” Another elderly participant emphatically shared his experience and expectation of being in assisted living by describing it as follows:

We get used to being patternized in routes to things, how schedule of things work, knowing where things are in a grocery store. It is the same thing as finding things in your own apartment. People get used to the pattern of things in where they are and what they do; and when you change that pattern, it is not an incidental thing. It is traumatizing, and we noticed that with our move to the assisted living here. It became very obvious to me that first day that this was going to be tough; everything that used to be on my right side is suddenly now on my left here. This should not be blown over, with “oh dad, it just works this way,” no. The acceptance of moving, that was one thing, but then to be hit with these things on a daily basis and to be really made to change the way things have been is another thing. If you really want to help, try to keep things in the same way as near the pattern that used to exist before. And this should be discussed and outlined prior to moving and being thrown into a new situation.

Yet another elderly resident also noted the need to have a regular pattern by observing how other residents in her assisted living facility were more comfortable with sitting at the same tables during meal times, which became part of their familiar routine. She reflected on how “people, if they go down to the bistro, they have one chair they like to sit in; they figure it’s their chair. It’s not, but they pretty much like to sit at the same tables.” Elderly residents’ satisfaction and willingness to comfortably adjust to their new surroundings and to a new assisted living environment were, therefore, identified as factors in alleviating elderly care-receivers’ stress, as well as family caregivers’ perceptions of guilt.

Relationship challenges. Family and care-receiver expectations with respect to establishing new relationships in an assisted living setting were, in some cases, perceived
as a challenge for the elders. Some resident participants suggested that elderly women were more likely to be able to make more connections with other residents as opposed to elderly men. A female participant voiced her observations in these words:

There are married couples, and they’ll be together. There are a lot more women here, and we tend to couple up or group up to meet for lunch and go to activities together. There are other examples of men who are alone here, and they tend to be by themselves more.

A male resident who lived with his wife added to this finding by explaining, “When you’ve been used to living in an independent home of any size or shape…and now you’re in an apartment type of close space…it’s difficult to adjust.” Another elderly resident explained,

It was hard. I was suddenly thrust into being introduced to a whole lot of new people. My memory circuits are not as acute and accurate as they once were, and people here, they all look the same, talk the same, have gray hair. So it’s quite an adjustment.

An African-American elderly resident described her reasons for not associating with other residents within her assisted living facility in this way:

I don’t have no friends in here. I say hello to them and they’d be staring back at me. I get nothing. I call some of them acquaintances not friends, because they talk too much and then they go back and tell what you said. That’s the reason I stay to myself; they’d be talking about you, because I can hear from right here in my room, you know, I can hear everything I don’t pay any attention to it. I just mind my business, but I talk to my daughter about it.

Relationship challenges and discriminatory attitudes against elderly residents suffering from Alzheimer’s disease and other impairments are an impediment to their social integration and overall involvement in an assisted living context. This researcher interviewed an elderly participant, who shared,
I see our future here in handling my visual difficulty and my wife’s Parkinson’s voice with some optimism. I have to...there are people who don’t understand...and for some of them who are bright enough to understand, I give them more information and they appreciate that.

As illustrated below, Resident 1 narrated his experience regarding his and his wife’s social integration in their assisted living facility. Resident 2, who was cognitively and functionally able to volunteer within the facility, because she felt physically able to participate more than maybe some of the other residents, also voiced her expectation concerning the integration of more cognitively challenged elders with other residents in an assisted living setting. This researcher found it interesting that Resident 2 was of the opinion that assisted living should keep elderly residents segregated based on their physical and cognitive functioning and abilities, even during meal times. The following excerpts from interviews with these two elderly participants describe their perceptions from two different viewpoints, which points to the complexity of this issue.

Resident 1: My wife’s voice is compromised because of her Parkinson’s disease, but she gets this feeling that she can’t participate in a conversation with other people… We feel sometimes that the people are going around us preferring not to sit with us in the dining room, because it’s difficult for them to carry on a conversation with us. So I try to carry on the conversation, and my wife wants to get in on it, and when she’s got something to say, she’s got something to say… So those are some of the things that she and I, we are going to have to deal with the rest of the time we are here, but we’ll deal with it. My wife wants to keep in the conversation, so she tells me what she’s got, I interpret and give it back to them. Now if they don’t like that, that’s their problem, and they can go sit somewhere else. That’s the way we feel about it.

Resident 2: Lately they are taking people in with more dementia than they should. They say to me, it’s assisted living...well what is assisted living? They bring new people in and some of them are really bad. A couple of them were being seated at our table with us. well, my feeling is, and I certainly have lived with my share of dementia, but if we go to eat a meal, that’s the only time you really talk to people; and a couple of times they put people with severe dementia, and they are asking the same thing over and over again every 5 minutes, and we complained about it.
So what we did, and this is not nice, but we pushed our table up against the wall so only three of us could sit there. I don’t think full-blown dementia is assisted living, but I figure it’s all about the money, and that’s the bottom line in this day and age.

**Theme 3: Living With Aging and Loss.** As elderly family members advance in age, their experiences of loss, disempowerment, and perceptions of dependency also increase. Age-related losses evoke different notions and reactions among different people. Older adults’ expectations in relationships, behavioral patterns and attitude, and coping mechanisms determine how well they adapt to loss and dependency. Elderly participants’ experiences of loss with respect to their health, mobility, home, personal belongings, and roles, and consequent notions of dependency in late life are discussed below (see Table 7).

Table 7

*Theme 3 and Sub-Themes*

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<th>Living With Aging and Loss</th>
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<td>1. “We can do whatever we want”, to “We can only do what others can help us do”</td>
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<td>2. Sense of being uprooted</td>
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<td>3. Loss of familiar roles and activities</td>
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“*We can do whatever we want*, to *We can only do what others can help us do.*” This was stated by an elderly participant to suggest the increasing need for support and assistance that is associated with declining physical, cognitive, and socio-emotional changes as elderly residents continue to age. The 8 elderly participants described their experiences of loss and disempowerment, either resulting from either a move to an assisted living facility or as an outcome of physical and/or mental impairments.
For many elders, losing one’s car and the ability to drive represented the loss of mobility, a link to past experiences, self-reliance, and independence. An elderly care-receiver’s comment supported this view:

We feel very limited in what we can do. I have not been able to drive for quite a number of years because of macular degeneration…and now that my husband has lost his driver’s license, he’s kind of bored. We don’t get around too much. We’re just sort of stuck in this facility.

Another elderly participant mentioned, “I can’t go places like I did before. Now I feel restricted in my movements in what I am able to do and not do. I don’t want to always keep asking others to take me here and there.” A caregiving son also reported on the future loss of his dad’s ability to drive,

Loss of car is huge; it’s the loss of recreation on many levels…it’s losing the ability to drive and go meet with friends and do things with them. Once Dad can’t drive and can’t do these things, then someone else will have to help him do it. That will be hard.

**Sense of being uprooted.** For elderly residents who had lived in their neighborhoods for 30 to 50 years, letting go of significant components of their life, including their home, its symbolism, and selling their house to relocate to an assisted living facility was a traumatic phase in their lives. This was evident from the following statement by a caregiving daughter:

We had a home here, close by; we all grew up in that home; Mom owned it. It was completely paid for and everything. She did all her own gardening, she did everything. I sold the home this year in September, and so that was absolutely horrible for her. It has to be an empty feeling for her, to know she no longer has her home. She was in it for 50 years.

An elderly participant’s description of his experience of moving to assisted living is illustrated below:
The moving was, to say the least—even with the help of our family and our extended family—extremely difficult for us. The property which we dearly loved was becoming too much of a burden. We had to uproot what we had established. Over the years we had accumulated all this stuff. The space that we were moving into, in the assisted living, did not allow to keep all that stuff, and we had to get rid of most of it. It was a very difficult process for us.

For other elderly residents, certain situations of dependency evoked perceptions of loss and reminiscence. One elderly woman who was suffering from several chronic conditions, including severe arthritis and osteoporosis, explained,

See, when you move you lose. I had a beautiful apartment, but when I moved, I lost everything. The paramedics said I couldn’t live by myself. It was beautiful. I lost a lot of things, my clothes, my dresses—it was very hard to give up all of that, but I had to do what the doctors’ said.

Such experiences were reported by study participants to constitute a significant loss in the aging process. Another care-receiving participant observed,

I saw this when I was still working in practice as a doctor, that kids would say, “Mom’s got to move out here.” Uproot Mom from all her contacts and bring her out here and she is miserable, she’s absolutely miserable. Like in one of our friend’s case, whose two daughters and a son decided that he really needed to be in a place like this, but then their contact is over. Put Dad in here—they’ve got all these programs in here and the ability to take care of him. So he’s over here, and they forget about it.

**Loss of familiar roles and activities.** All of the eight care-receiving residents were suffering from certain physical and/or cognitive impairments, including glaucoma, macular degeneration, early onset of dementia, and other chronic to acute conditions, such as diabetes, high blood pressure, and arthritis, which could not be cured, but required daily management. These impairments created a loss of roles, as well as the capability to do what elderly family members were previously able to accomplish. Loss
of health and mobility as well as limited financial resources affected an elderly participant’s family roles and relationships, which is evident from the excerpt below:

I’m on wheelchair and oxygen. My ankle is swollen; I used to walk, but I have arthritis now. I’m on a lot of pills for diabetes and high blood pressure, you know, the water pills, lasix, that keeps me going. I’d be sleeping all the time with all of these drugs. I have twin brothers, but they live in Texas, and I have a sister in Oklahoma. They call me sometimes, but I haven’t seen them in a real long time. It’s just too far, and because of the economy, you know, nobody wants to fly. It’s scary. They want to check your bags, and you can’t carry nothing. I don’t fly now. I’m too scared. I can’t hardly visit anybody, because nobody wants to be bothered by a wheelchair, not even my daughter. She says I might have a fit, because she has a long flight of stairs—she lives in a town home. She has lots of stairs, and I sure can’t walk up those steps, because I’m in a wheelchair. I’ve only been there one time, but I wasn’t on a wheelchair then. I could walk, but now I can’t stand up for too long.

Vision loss for two of the elderly participants was associated with losing the ability to engage in leisurely activities and other constructive pursuits, such as driving, shopping, watching television, reading, socializing, and volunteering. For 1 study participant, this was reported to have increased perceptions of depression, frustration, embarrassment, and extreme dependency. This researcher learned about such perceptions and experiences from a caregiving daughter, which is illustrated below, instead of discovering them from the interview with her elderly mom, who was suffering from vision loss because of advanced macular degeneration:

My mom is extremely uncomfortable, embarrassed at the fact that when she comes up to somebody she cannot recognize them, even as close as you and I are together, they are just a blur to her. And so it embarrasses her if somebody comes up to her that she knows, and she has no idea who they are, and it’s got worse over the years.

An elderly resident who had lost his pet dog because of his physical constraints, shared, “My dog, Gem, being gone has been a real blow for me. My daughter has him,
because I can no longer walk him. He belongs to her now.” Another elderly resident, who associated a loss of social roles and connections with losing her ability to drive, reflected in her comment,

I have lost touch with so many people I used to know. My church is too far for the transportation service here. It’s an 8 mile radius and my church is a few hundred yards too far, yards. I can’t visit with others as I can’t drive anymore.

Some elderly participants in this study perceived their feelings of loss and dependency as relative to that of other individuals. When reminiscing about their past, or discussing their present and future, elderly care-recipients’ perceptions about their needs were influenced by the circumstances of other people who were less fortunate than they were. An elderly resident put it this way, “The quality of life is fairly good here. I think we’re pretty lucky to be here actually...there are a lot of people who would like to be here, but cannot do that.” Such comparisons can help elderly residents employ coping mechanisms in order to deal with illness and dependency.

**Inability to identify meaningful contributions.** Most of the responses that were elicited from elderly participants pointed not only to perceptions of loss and dependency but also to a limited identification of meaningful contributions and roles. This researcher observed that some older adults did not want to dwell on their experiences with loss and dependency, because they felt powerless to do anything about it. This was obvious from statements, such as, “What can you do about it” and “It is what it is.”

Most elderly residents perceived their role in an instrumental and a functional context, and when asked about their roles, a couple of participants made the following statements, respectively: “I don’t cook or clean…they help me with my laundry…I don’t
have to do any of those things, as they all get done for me,”, and “I don’t have to do much in here.” Physical impairments and limitations, such as loss of vision, memory loss, and loss of transportation, were associated with increasing dependence that contributed to a loss of roles. Elderly participants as well as their family caregivers found this a difficult subject to comment on. A caregiving daughter commented on her mother’s as well as her own perception of her mother’s role and position in their family, in this way:

My mom, she just doesn’t see her role. She just thinks that she is of not much use, but she doesn’t realize how useful she is...She’s not out of the picture, you know. Her being here with me is enough. I can visit her here in person and that I don’t have to go visit her somewhere in a cemetery is enough for me.

However, this caregiving daughter’s mother responded,

There’s not much that I can think of, that I do. My daughter has to fill my pills, she does my insulin, drives me to my doctor’s appointments, she does everything. I feel like I’m a burden on her—this feeling is there and it is true.

Interestingly, some of the other family caregivers also concurred with such notions and felt that their care-receiving relatives were limited in their role and function but were, symbolically, very much a part of their households. A caregiving daughter described her elderly mother’s involvement:

Generally, we bring Mom to home for holidays and visits. She isn’t comfortable with being around the grandkids very long. She doesn’t join in, in the cooking. So I would say that her role in our family is kind of limited right now. I think it is because of her age, and I think that she has limitations now.

A caregiving son described his perception of his elderly parents’ limited involvement in these words:

My parents are involved in our lives, when we go and visit them. They are restricted in their ability to move around. There’s really not many opportunities for them to come visit us or anything like that, and so it’s up to us to really be in
communication with them and go and visit them to be involved with them right now.

Health and physical constraints were also perceived to determine elderly family members’ psychological and social well-being and involvement with family members, as explained by another caregiving daughter:

My mom has been very depressed over the years because so many things were taken away from her. Because of her loss of vision, my mom can’t recognize people; she has become very reserved socially. She doesn’t really have a social network except for me, and that’s just gotten worse and worse. I am pretty much her sole outlet. Life hasn’t been fun for my mom for a long time, because it’s been 10 years since she’s been able to read, and she was a voracious reader. so all she can do is listen to her books on tape, and that gets old—she can’t go to a library. I try not to go into a book store with her; its too painful for her. She used to be a bridge player herself, but then her eyes went bad, and that went along with it. Watching television, driving, socializing, being independent, being able to shop by her self—going shopping together was always our enjoyed outings—but as she has become weaker, she can’t even do that…so all these things that she enjoyed have been taken away from her.

Caregiving Participants’ Experiences and Perceptions

In this part of the findings, family caregivers’ involvement in caring for their elderly relatives in assisted living is reported. This researcher included both positive and stressful exchanges between family caregivers and their elderly care-receivers, because caregiving participants perceived both losses and gains in their relationships. Based on interviews with the eight caregiving participants, the following themes have been identified that illustrate the caregiver experience: (a) Moving from a parallel relationship to a braided experience, (b) intersecting caregiving roles and relationships in family systems, and (c) caregiver perceptions regarding reversed, over-extended, and over-loaded roles.
Theme 4: Moving From a Parallel Relationship to a Braided Experience. The first theme, moving from a parallel relationship to a braided experience, describes the changing relationship caregivers experienced as their elderly relatives continued to age. Parallel relationships referred to when the caregiver adults related to their parents on a more equal basis, whereas braided relationships describe how their relationships become more enmeshed as elderly relatives need more caregiving. Changes in family caregivers’ efforts to assist, interact, and intervene on behalf of their aging parents, as well as their responsibility for maintaining intergenerational family engagement are presented here. This theme has three sub-themes, which are outlined in Table 8.

Table 8

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<th>Theme 4 and Sub-Themes</th>
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<tr>
<td><strong>Moving From a Parallel Relationship to a Braided Experience</strong></td>
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<td>1. Being in the middle</td>
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<tr>
<td>2. Feeling responsibility towards elderly care-receivers as their dependence on family members increases</td>
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<tr>
<td>3. Arranging and maintaining intergenerational family involvement</td>
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<tr>
<td>• Being the bridge</td>
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<tr>
<td>• Balancing the need to maintain intergenerational participation versus independence</td>
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A caregiving daughter described her involvement with her aging parents as having become more braided, instead of being parallel in this way:

When my parents were in their house, I would pop in and out, talk to my mom a couple times a week. Periodically they would invite us over for cocktails. We would get together for holidays and special occasions. But my dad was able to get my mom to where she needed to go. They did their own grocery shopping and so forth and so on. But they were capable of taking care of themselves, because they
were independent; they didn’t rely on me as heavily as they do now. In terms of being the taxi driver, being the go between. Earlier they didn’t depend on me emotionally as much as they do now. I think they both try not to; they try not to put things on me, but they do. We had our lives; they were parallel—there were interconnections. I would see them generally once a week and not more. But all that has changed now. Now it so braided. If there’s any place they need to go—my dad’s not comfortable taking taxis. If there’s any place they need to go, to a doctor’s appointment or to whatever, I’m it. I am the taxi driver.

This participant regarded her relationship with her elderly parents as becoming extremely complex and inter-linked. The changing nature of this relationship between a daughter and her parents, one from leading independent lives to intertwined lives, was repeated in a number of ways by all the caregivers interviewed, as illustrated in the following sub-themes.

**Being in the middle.** A part of the braided experience was to be thrust in the middle of multiple relationships with aging parents, other professionals, and the staff and management of an assisted living facility. Mediating between parents was also identified as a caregiving role by some adult children who were providing care to both their parents in an assisted living setting. A caregiving daughter explained her involvement with her 90-year-old father and her step-mother in these words:

> My step-mom, Jan, has severe Alzheimer’s—she stays downstairs in the reminiscence unit. My dad yelled at her tonight. He thinks if he yells at her bad enough, she’ll eat. She won’t eat. It just makes her shut down faster; but he thinks he can get her better, and I can’t take that away from him. I had to go bring her some Ensure, because Jan’s not eating anything, and my dad said, “I like that as well, where’s mine?” So I had to go out again to bring him some—but he doesn’t like chocolate. I brought her the dark chocolate, and he got the white chocolate flavor. He wants strawberries if I get her strawberries. It’s almost like he’s jealous. If I go down at dinner to see her, he’s like I would have gone.

Caregiving family members are often the go-between in residential long-term care facilities and are increasingly involved in mediating between conflicting relationships and
negotiating health care on behalf of their elderly relatives. Another example was provided
by a caregiving daughter, who described her over-extended experience of negotiating
long-term care and health care on behalf of her elderly parents and its impact on her:

I and my parents go to the same medical internist. So we all know each other,
which for a long time has been very convenient, because my mother’s doctor, Dr.
Perry, is willing to talk to me about my mom’s situation. Although, in the past
few months, our relationship has become strained. I feel like I am being put in the
middle very frequently between the assisted living facility and my parents, and
the facility and Dr. Perry, and Dr. Perry and my parents. I have become the go
between, the translator. I have the medical power of attorney, so at one point, Dr.
Perry said, “If you don’t think that you can handle having the power of attorney,
then you need to give it over to somebody else.” This is my doctor scolding me
practically. The relationship between me and Dr. Perry has been strained to the
point where I am still considering going to another doctor, but I’ll still have to
deal with Dr. Perry, because I have to be the one who will take my mom to her
doctor’s appointments. So I am inextricably bound in all of this.

As both of the caregiving daughters expressed above, past relationships and roles
change in dramatic ways. Some of the interviewed family caregivers regarded their
relationships with their aging parents as being extremely involved and inter-connected.
Such changes, including being in the middle, were described as stressful experiences by
some caregiving participants. This researcher observed that some of the caregiving
participants who were assisting both their elderly parents reported higher levels of stress
than other family caregivers who were providing care to a single parent. For one
daughter, it was like not knowing what to expect. “It’s like everyday you wake up, and
you go, “What’s it going to be like today?” So every year, it’s kind of like—no it’s not
every year, we’re going into months—every month, it seems things change.” Another
caregiving daughter who was caring for both of her parents stated,

I am being pulled in all these directions by all these people. My parents are
perfectly happy having me in this situation, because it means they see me more
frequently. But this has really increased my stress. So, it is maybe the most difficult part of this.

Being placed in between the familial, the assisted living, and the health care system can account for a particularly braided experience. This constitutes a new role for caregivers and can change the nature and quality of several relationships that need to be re-negotiated and maintained during the caring process.

**Feeling responsibility towards elderly care-receivers’ as their dependence on family members increases.** Another component of the braided experience was identified to be more dependence on family, as outside relationships become more limited. A caregiving daughter explained in this way:

I think now Mom has to depend on her family more, both physically and emotionally. We have to make sure that she’s getting her medicine, food, exercise. I’m her caregiver as far as getting her to her doctor’s appointments, buying her groceries and snacks—it’s a lot of responsibility. All her friends are her age and have their own health issues; and so it falls on us to look after her. Some family caregivers also tried to find ways to help an elderly parent or parents to participate and feel more involved in their families. Another caregiving daughter felt responsible for providing her aging father with family support, as she pointed out,

I have to try to keep them all together, because if I don’t, everybody is going to go in different directions. I try to make it possible for all of them to visit with dad and stay involved as much as I can.

Yet another caregiving daughter described her and her elderly mother’s desire for family as follows:

Family is a big thing for my mom. She always thinks that everybody comes to her. She never would pick up the phone to call you, but you call her. So I think her seeing us being involved makes her comfortable and happy… She’s very open with the kids, with all of us. There isn’t one thing she wouldn’t discuss with us. I think, she realizes her and my role in the family. I think she appreciates it. She’s accepting of that—what we have done is, we have involved my husband’s mother,
because she is also alone. And so when we have holidays, we all come together. So it gives mom someone else to visit with.

**Arranging and maintaining intergenerational family involvement.** The final component of the new braided experience was the role family caregivers assume in thinking and worrying about, as well as arranging and planning for family involvement across the different generations. Some caregiving participants, mostly adult children, expressed the need to maintain intergenerational ties by involving their children in supporting their aging parents, because it was perceived as their way of caring and giving back to their elderly parents. A caregiving participant emphasized, “We need to prepare our children and raise them well. They should be taught to respect their grandparents. We wouldn’t be here if it weren’t for them.”

Another caregiving daughter referred to health concerns for elderly residents, within the regulatory and institutionalized structure of assisted living settings, that can prevent families from facilitating more intergenerational involvement by explaining,

It’s hard…especially when, like right now, with the flu bugs and everything else going on, you can’t bring the younger great-grandkids in here without somebody tomorrow waking up and feeling bad, and I can’t do that to these people here.

**Being the bridge.** Some caregiving participants wished that their children and grandchildren would be more involved in visiting and spending time with their elderly grandparents, because it was identified as an essential component to further elderly residents’ social engagement in institutional and communal settings. A caregiving daughter noted that her elderly parents desired to regularly see and visit with their college-going grandchildren more than they wanted to express:
My parents would like to see my children who are in college more often than they let on, especially now, as they live here. I try to make that happen whenever possible. It gives them something to look forward to.

Another caregiving daughter shared that one of her sons did not like to visit with her elderly mother at the assisted living facility: “My younger one comes to visit more often; he’s more understanding. My older son feels more like, even though it’s an assisted living home, he feels as though it’s more like a nursing home thing.” She went on to explain how her older son does not understand the changing role his grandmother may experience, even though she is still the same person; and therefore she finds herself trying to potentially help her son understand his grandmother’s experience:

He doesn’t like to see people just sitting around watching T.V, which some of the residents do. He just doesn’t understand my mom’s part in this—the fact that she is still a smart person, she can still speak, she is still able to get around and meet people and do things.

Yet another caregiving daughter expressed how her children and grandchildren did not have the same values about taking care of elders, and also talked about her perception of how different generations in her multigenerational household perceived their responsibilities towards elderly family members:

We’re from the generation that whatever Dad said was it, even if it wasn’t it. I don’t know where we’ve messed up with our kids. My son has come, not my oldest son, he’s not come here. My daughter came here once—they are the generation that has to work. I am the bridge between their generation and my parents—my grandkids generation, it’s all about me. I’m not quite sure what’s going to happen to me, if it’s not for my daughter or my sons. It’s not going to be my grandkids, because if it doesn’t fit into their schedule—it’s very scary. That’s just not there, compassion. When Dad calls, sometimes they say how many times has it been today. Who cares? He knows I’m here; he’s satisfied.

**Balancing the need to maintain intergenerational participation versus independence.** According to a caregiving daughter, familial and intergenerational
involvement becomes critical to elderly residents’ psychological well-being, because it can take the focus off their physical challenges and health conditions and direct it towards their families and communities. She responded,

I think that elderly people have it a lot worse now or in our culture than before—my parents, who are the people that they are with. They are with people who are waiting to die, otherwise they wouldn’t be there.

This caregiving participant also emphasized the need for more multigenerational settings that could contribute to elderly relatives’ family involvement and well-being:

Even with the limitations that Mom has, being unable to see, the hearing getting worse and worse. If she were in a house with kids, then life would be going on around her rather than dying going on around her.

Moreover, this participant explained,

In terms of what would be psychologically best for the elderly and maybe for everybody else too would be for everybody to be together in a single household. The problem is that our culture doesn’t support that, and we are not conditioned to even consider the idea anymore. We as a culture prize independence. My son is going off to college, and I am very much looking forward to having one less kid in the house. I am going to miss my kids, especially my daughter, but I don’t like the idea of them going to college and then coming back to live with me again. I want them to have their own families. So what I am saying is the ideal than what I am interested in seeing in my own life. So it’s a little bit hypocritical on my own part.

This finding points to the paradox that many caregiving families face in wanting to involve elderly members in family exchanges and activities, but simultaneously maintain their sense of individual and familial independence and boundaries. Familial and intergenerational ties, therefore, provide a sense of continuity, heritage, and reciprocity for younger and older family members.

**Theme 5: Intersecting caregiving roles and relationships in family systems.**

Intersecting caregiving roles and relationships that help to distribute responsibilities
across family members were identified as the second theme by family caregivers. In the following themes and sub-themes, caregiving participants described the multiple new roles they assumed to negotiate relationships within the family systems. These roles included how they related to their aging parents as individuals, as a couple, and as siblings, and how they negotiated outside relationships. As these caregivers told their stories, it was obvious that managing these new “braided” relationships was predominantly stressful and time-consuming. Factors that impact such intersecting caregiving roles and relationships, which were identified by the participants, are discussed below (see Table 9).

Table 9

*Theme 5 and Sub- Themes*

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<thead>
<tr>
<th>Intersecting Caregiving Roles and Relationships in Family Systems</th>
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<td>• Consensus among siblings</td>
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<td>• Conflicting roles and relationship with a sibling’s spouse</td>
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<td>2. Association between family caregivers’ physical proximity to elderly care-receivers and their mutual involvement</td>
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<td>3. “It’s a male thing” - Generational and gender influences on caregiving roles</td>
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*Sibling involvement.* Six of the eight pairs interviewed in this study represented family types that had more than one adult child who shared responsibilities for meeting the needs of their aging parents. Sibling involvement varied in different families from being non-existent to being active. An African-American caregiving daughter did not expect much from her adult brother in caring for their mother and therefore identified herself as her elderly mother’s primary caregiver in these words:
I talk to my mom every night, we’re real close. I visit her about twice in a week. I get her what she needs, groceries and stuff—I do her laundry, I put her clothes up. My brother lives in Colorado, but he hardly visits my mom. He’s only been here but one time. He likes to borrow money from me and her, and I tell him I don’t have no money to give—you can’t ask me for no money, because I don’t have it. I work as a checker in King Sooper’s, you know.

In this study, more daughters, who lived in close proximity to their mother or father or both their parents identified themselves as the primary caregiver and had taken on the role of frequently checking in with other siblings and family members, and in some cases, become the go-between. This researcher noted that, typically, most of the primary caregiving daughters expected more support from other siblings. Caregiving daughters were observed to take the lead role in negotiating and allocating care duties among family members, which required frequent interaction and involvement with other siblings and family members. Yet, in another study participant’s family, multiple siblings were involved in regularly caring for their aging mother. A primary caregiving daughter reported her expectation and perception of her family’s involvement with her elderly mom in these words:

Honestly, I don’t give them a choice, and so here is what I say, “There are 4 weeks out of a month; that means you have to come down once a month and be with Mom.” Personally, I would expect a lot more. For instance, my husband’s sister, my sister-in-law, she lives in Denver, and she comes down every Saturday. She only stays 3 hours, but she comes and does that. I expect that out of my siblings. My brother feels strongly about all of this, that you know I take care of Mom and that we need to see her and make her involved, and that type of stuff. But his main thing is not being the caregiver—he lives in Denver. But my brother is an accountant, so he does all her taxes. He helps me with all the financials we need, and we go over Mom’s finances.

Consensus among siblings. This researcher found that another major factor in facilitating care for elderly parents was not only the nature and quality of the
relationships between siblings, but also the extent to which siblings tended to agree or disagree with each other and react to their elderly parents’ long-term care. The findings suggested that there were pros and cons to sibling involvement in caring for their elderly parents. This study found that sibling relationships were perceived as being cohesive and harmonious by some, whereas that was not so in other cases. Caregiving children reacted differently to certain situations and care responsibilities. Different expectations of parental care resulted in conflicts and disagreements among more than one of the caregiving children. A primary caregiving daughter shared this sentiment by stating, “The relationship between siblings can affect the caring process, and I think, sometimes relationships might be easier to maintain from a distance.”

A caregiving participant, who was primarily involved in assisting her widowed mother, also reported perceptions of how the involvement of one of her siblings affected relationships between them and strained her sibling and her mother’s relationship. The participant’s over-protective sister seemed to have over-stepped her boundaries by exerting more control on how their mother used and reported her finances, as is illustrated below:

My other sister—and I don’t know if my mom mentioned this—but she and my mom are estranged. They had a falling out over money. My sister was kind of handling, like sending all the money for my mom’s taxes. But my mom felt like my sister was dictating more like my dad was, and I think my mom never felt like she could do whatever she wanted to with her money, which she can, you know. It’s her money, and I had to explain this to my sister. It is not that they don’t speak; they just don’t speak on a regular basis.
Coordinating long-term care and providing assistance to elderly parents required some siblings to closely collaborate and regularly interact with one another. A caregiving son regarded his sister’s involvement in this way,

She’s very involved with staying in touch with my brother and I, staying on top of things, and following up on how things are going with my parents. So I’ll say that my sister is quite involved. It takes more effort, but she takes that effort.

This may help to strengthen relationships between siblings, or it may present challenges, depending on past patterns of interaction and involvement. Another caregiving daughter concurred by sharing,

I have a lot better than some other people do, because my two brothers and I, we’re pretty cohesive in how we react with our parents. We form a consensus over the phone before we do anything. I am very lucky in that not only do they support me 100%, but all three of us, we’re on the same page. We talk frequently—we’re all very close. But then, there are other people that I know who have conflicts with their siblings even at a distance.

Conflicting roles and relationships with a sibling’s spouse. Findings from this study suggested that care provision across siblings was determined not only by their personal qualifications, but also by their mutual relationships with one another and their spouses. One of the factors that had an impact on sibling involvement, as identified by some caregiving participants, was the sense of responsibility and filial obligation perceived by each of their sibling’s spouses, which affected caregiving roles and relationships. Depending upon the nature and quality of the relationships, elderly care-receivers’ relationship with their married adult children’s spouses also had an impact on their involvement in their adult children’s nuclear families. Family involvement among some siblings was perceived to be affected by their spouse’s willingness and attitudes towards filial duty, as is expressed below by one caregiving daughter:
Okay, so with my brother, Tom, we’re lucky if he comes and visits once a year… So I’m the youngest. I have two sisters, then a brother, and then me. You know, I did as much as I could from being here and my mom being in California. My brother was an 1 ½ hours away, and then there are three of us girls, and none of us lived around. But we probably did more than he did, living right there. I think his wife has control issues. And he always had a very close relationship with my mom, you know, not so much with my dad. But I just think for him it was peace at all cost and the cost was his family and still is his family, which—it’s frustrating when you’re 3 states away and he’s an hour and a half away, and he can’t go. Like when my dad had surgery one time. He was like, “Oh, I should go.” And I told my brother, “You need to get down there, now.” So anyway, I told my mom about five years ago—they had to come down and live here since we were the ones that always went out and saw them and everything.

Relationship dynamics can therefore present a potential conflict in integrating several roles, as is evident from the above excerpt. Tom’s roles as a son and as a brother were in conflict with his role as a husband. Elderly family members’ relationship with some of their adult children’s spouses also influenced their mutual involvement. The following statement presents a primary caregiving daughter’s perception of her younger sister’s relationship with their elderly mother:

I think what happened is my sister moved away and went to college—started getting her independence, fell in love, married a guy, and the guy is someone my mom doesn’t like. So I think that my sister of course sides with her husband and builds her family in that direction. And so it kind of puts a little bit of an edge to the relationship.

*Association between family caregivers’ physical proximity to elderly care-receivers and their mutual involvement.* Family members living in close residential proximity to their elderly relatives in assisted living facilities demonstrated an increased level of family involvement on a day-to-day basis. Physical proximity resulted in frequent contact and subsequently an increase in both caregiving responsibilities and stress for some family members, whereas for others, it contributed to more emotional
closeness between the elders and their family caregivers. This researcher found that in some cases, primary family caregivers who were physically located in close proximity to their elderly relatives developed a strong commitment to care over a period of time, and experienced a positive change in their relationship with their elderly relative, as illustrated in the following excerpt from an interview with a primary caregiving daughter:

My mom and I, we’d never been extremely close. She was very close with my little sister, and Mom and I live in the same vicinity, and we talked all the time. But we never had that really, really close relationship that my sister had with her. It seems that that has changed quite a bit, because after Mom came to this facility, she became more dependent on whoever is here, whoever is closest to her, because she needs that help. So I think that relationship changed. I was so worried about her when she had that stroke. I had to sit down with her and discuss her power of attorney, her choices for funeral, her choices for DNR. Our closeness really grew during that time. She and I are complete opposites of each other. It was my sister and my mom together. Now my sister has kind of drawn away, you know, with her life, and I think that I have become the caretaker.

This researcher learned from the perceptions of the interviewed family caregivers that siblings who lived in other states and could only visit a couple of times, or once a year, felt guilty for not being able to visit more often to relieve their primary caregiving siblings of their day-to-day caregiving responsibilities and tasks. One study participant reflected on how guilt had affected her communication with her siblings. This primary caregiving daughter described her experience in these words:

This is something that has definitely been the hardest thing that I have ever had to do. It’s hard—if I was away and my sisters were doing what I’m doing, I couldn’t have handled it. I would have wanted to be here, and I know that that’s the guilt thing that they’re going through. But then, they don’t want to talk to me a lot, because they feel guilty. They want to help—it’s a guilt thing with them, and I don’t know how to tell them that this is my choice to be here, and I only call you or when you call me, we discuss what’s going on with Dad and how to take care of it. They become my sounding board—they are there to listen. But then, on the other hand, that makes them feel bad that they’re not here to give me a break. It’s trying to tell them what’s going on, but at the same time I don’t want them to feel
guilty. And sometimes I don’t really know what’s going on, and they are like, “Why can’t you find somebody who can tell you what’s going on.”

Siblings adopted different roles, because those siblings living at a distance seemed to participate in joint decision-making and visit more in the event of a medical or health-related crisis in their elderly parent’s life. Primary caregiving daughters were found to be actively involved in not only providing the bulk of care, but also following up with their siblings and involving them in the long-term care process. Primary caregiving participants’ expectations of assistance and involvement depended on residential proximity and experiences of supportive exchanges and interaction with their elderly parents and other family members, including their siblings.

“It’s a male thing”- generational and gender influences on caregiving roles.

Generational and gender influences as evidenced in family life were also identified as parameters for understanding family involvement between elderly care-receivers and their family caregivers. In such situations, caregiving family members had to learn to adjust their communication patterns and expectations of changing intergenerational ties and relationships with their aging parent(s), as well as their siblings.

According to a primary caregiving daughter, generational and gender differences were perceived as factors in receiving and inviting care and support in her family, along with negotiating her father’s welfare with her brother:

When dad calls and he’s yelling—he needs some help, and he wants me to take care of it. And I take care of it, but I took care of it wrong, whereas my brother can do no wrong—he was a late in life child—because I’ll say to him, “I think Dad really can’t do that,” and he’ll say, “Yes he can.”
In addition, this caregiving participant described her experience of generational and gender-based differences in her family in these words:

It’s a male thing. Dad doesn’t yell at my husband, John, when he drives. He doesn’t yell when my brother drives. It’s just us girls. The other day, I was driving him—Dad was sitting beside me—so the light turned green. He’s yelling at me to go, and I said, “Dad, as soon as the other cars in front of us do, I can go.” “Well, make them go!” “I can’t really, Dad.” or “Why don’t you turn there?” or “You’re going too fast.” He’s in that generation, where, yes, women and men have different roles and positions—he’s always been like that. My mother worked, but she only did it because she wanted to. That wasn’t true. They needed to make ends meet, but that saved him from “I can’t support my family,” but he won’t tell anyone that—he’s always known that. So it’s definitely a male thing.

As indicated above, gender bias persisted in this elderly family member’s relationships with his caregiving children. Generational and gender-based values prevented him from informing or asking other family members for help, in order to be able to exert and maintain a sense of control to some extent. Another elderly male care-receiver reflected, “It’s more difficult for the men. Men have never embraced this way of living with others. In our generation, older women have not been working as long as the younger women work now.”

This researcher found that adult sons tended to be more involved in terms of assisting elderly parents in managing their finances and taxes, irrespective of their residential proximity. In some cases, caregiving sons had the financial power of attorney to make financial decisions and manage monthly expenses for caregiving needs on behalf of their elderly parent(s). A caregiving daughter pointed to this finding in her statement:

I have the medical power of attorney. I am Johnny on the spot here, because I live here. But my elder brother in Sacramento has the financial power of attorney. He takes care of all the bills, taxes, investments, everything. I could never have done all of that.
A caregiving son also spoke from the perspective of elderly male residents and emphasized the role of family members, as mentioned below:

Men are much more reticent to let somebody get into filling out their personal information. The family needs to stay in close contact, because a lot of these people have lost important documents to the move—lost their ability to keep their own financial records straight, to write checks, to keep check books, tax work—all of the things that they used to do.

*Negotiating instrumental assistance and quality of life issues.* Some family caregivers may not realize the overall ramifications of their roles. Family members typically undertook specific roles that required their time, energy, and finances. The family caregiving participants in this study had to adapt themselves to meeting the changing physical, cognitive, and behavioral needs of their elderly relatives. In some cases, because of elderly residents’ increasing emotional dependency on family caregivers, their caregiving adult children had to ascertain ways to emotionally and physically support and protect their elderly parent(s). In this next statement, a caregiving daughter talked about how she and her brother had to adapt to protecting their father, and also safeguarding their own interests by withholding information from him at times:

So I have to always be close. If Dad calls and I don’t answer, he gets upset, because I am always supposed to be home. I try not to go out that much. And when we do go, when my brother and I go out of town, we can’t tell Dad, because bad things happen. He either has to go to the hospital, he gets sick, and something bad happens. So when my brother went on a cruise, Dad didn’t know, and he did perfect.

In families with multiple siblings, some caregiving daughters who lived in close residential proximity to their elderly parent(s), assumed a primary supportive function, as mentioned earlier, with other siblings being involved in a supplementary role. Helping elderly family members fill out forms and provide them with resources and important
information was part of the caregiving role. A caregiving daughter also felt relieved to know that her parents were in a safe environment and that she did not need to constantly worry about them:

It’s easier for me now, because when they were living in their home, I would call and think—I would dread, I’d be worried about them. I know she’s safe here. I know she’s taken care of, she’s got food, she’s got us, and that’s huge.

Another caregiving daughter providing assistance to her mother, who lived in a smaller assisted living facility, was also involved in supervising and assessing some everyday quality-of-life issues. In the following interview excerpt, this caregiving participant explained how she was involved in negotiating her elderly mother’s quality of life and draws attention to some challenging basic needs within smaller assisted living facilities that pertain to staff support, exercise, and nutrition:

I’ve shared with the staff here before. I wish that the facility had some type of an exercise program. I worry about Mom’s muscles. Even if they had a little walking club that went around the block, but they are limited on help here. That’s the one thing I don’t like—they are really limited; they all have their duties, and there really isn’t someone to be looking after their little needs, like if somebody rings a bell or someone needs help with the bathroom. And sometimes, it’s just the little social contact of dropping in and saying “Hi, how are things going?” and that type of thing. But, I think the staff here has to work hard, because they are limited. The other thing that I really have a problem with is the nutrition, is because I think they get too many frozen foods, too many pre-cooked, high sodium foods. They buy foods that are already prepared and heat them. Lot of times, it’s too hard—they can’t chew it, they can’t eat it. I just wished that they had someone who could dedicate a little more cooking time.

This researcher observed that caregiving daughters were also more involved in providing reassurance, emotional support, and instrumental assistance, with respect to transportation, companionship, grocery, and personal shopping. More caregiving
daughters lived in close proximity to their elderly family members and provided regular and frequent support.

Another major role identified in this study was that of negotiating medical care for elderly parent(s). One caregiving daughter was frustrated about having encountered ageist attitudes from some of the health care personnel towards her father and described a difficult experience in these words:

At times I have not been able to find a doctor for my dad who cared enough. When, once, my dad was in excruciating pain, the hospital didn’t want him—he’s a DNR—but he was in pain. Who in their right mind would send someone in pain away, just because he’s 90—that’s not right. He still has a mind. It’s such a scary thought: …Because he’s old, so let’s just put him in a drawer and let him go. When he had his stroke, he had to go to the bathroom, and they said…“Bring him a bedpan.” Well, that’s not my dad. I mean he could walk and he didn’t realize that something was wrong, so he wanted to go to the bathroom. All of a sudden all these people kept going into the bathroom and coming out laughing. That’s my dad. He had a camera in there. It was in his walker. He was taking pictures, and they were making fun, and they didn’t see anything wrong with it.

The findings suggested that such ageist attitudes, which promote infantilization and discrimination against older individuals in need of health care services, add to the experiences of dependency and loss among care-receivers, which intensify perceptions of frustration, stress, and guilt among family caregivers. It therefore becomes essential to help older adults and their family members of all generations negotiate empowering images of aging and adopt a new outlook on rediscovering and re-conceptualizing care-receiver roles and relationships that extend to other elders and residents, especially in residential long-term care settings, such as assisted living.

**Theme 6: Caregiver Perceptions of Stress and Burden.** This study showed that the many expectations, pressures, and demands that are associated with family caregiving
are complex in nature, which creates the potential for conflicting situations and for increasing caregivers’ level of stress and guilt. Table 10 identifies caregiver perceptions regarding balancing multiple responsibilities, while caring for elderly family members, along with negotiating roles and relationships between elderly parents, siblings, and other family members.

Table 10

*Theme 6 and Sub-Themes*

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<tr>
<th>Caregiver Perceptions of Stress and Burden</th>
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<tr>
<td>1. Assuming a supervisory/parental role</td>
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<td>• Efforts to assist without crossing the line</td>
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<td>• Letting go</td>
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<td>2. “I am my dad’s lifeline”</td>
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<td>3. Impact of elderly couples’ mutual relationships</td>
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<td>5. Role overload – Juggling multiple roles and relationships</td>
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*Assuming a supervisory/parental role.* Family members experienced mixed emotions that ranged from being satisfied to being overwhelmed, along with feelings of guilt and frustration. In this sample, family caregiver experiences of increased physical and emotional dependency among aging parent(s) were associated with perceptions of a supervisory/parental role. Of the 8 caregiving participants, four caregiving daughters identified perceptions of assuming more of an advisory role in their relationship with their elderly parent(s). One of these four caregiving daughters stated her and her elderly mother’s perception of reversing roles in the following statement:

Before, Mom was very strong, very tough, very independent, and now she says, “I have become the daughter, and you’ve become the mom.” She teases, but you know its really the truth. It is really the truth—I have to look out for her.
Perceptions of a reversal in roles and responsibilities were associated with caregiving tasks that required constant monitoring and interaction to ensure elderly relatives’ welfare and satisfaction. A caregiving daughter related her experience by sharing,

It’s almost like you become the parent, for lack of a better word, and they become, well, not the child, but you know, you’re the caretaker, which I guess in the beginning that was real difficult for me, just because they did always take care of us; and now that’s what it’s evolved to.

Another caregiving daughter, who was frustrated at both of her parents’ lack of cooperation in receiving and maintaining their care, stated,

My perception of my parents’ role is that they have become the children. It’s like having toddlers again. You have to take them everywhere; you have to tell them what to do. They throw tantrums; they are obstinate. For example, I had finally gotten my mom set up for physical therapy, which I thought she really wanted, because she has a lot of pain in her left leg. Took her to that for the first time last week, and she said, “It’s too much work—I don’t want to go back. I was like, “I can’t make you or force you to go,” and she said, “No, you can’t.” But it would do her so much good if she would go. It’s hard to see your parents go from not necessarily being in a support role, but to the point where you have to tell them what to do. It’s very much like a role-reversal.

These caregiving participants, who over a period of time felt primarily responsible for managing their elderly parent(s)’ affairs, behavior patterns, and spousal relationships, as well as their relationships with others in assisted living, felt that they saw their parents more than they would have liked to. One of the caregiving daughters added,

It’s kind of like I am being the parent now who is being played by a child. What does he want me to do? What does he want me to say? And since the stroke, I am seeing more of my father than I really care to see, if you know what I mean.

Efforts to assist without crossing the line. Caregiving participants identified some other sources of frustration and anxiety, which became evident only after their elderly
parent’s placement in an assisted living facility. This researcher observed that family
caregivers also felt conflicted over their desire to help without crossing over what they
considered were boundaries in their relationship with their elderly relatives. For example,
a caregiving daughter mentioned, “With Dad, I just want to clean his room so bad. But he
knows where all his clutter is, so I can’t just go in and clean. There has to be a line that I
can’t cross yet.”

Another 64-year-old caregiving daughter, providing care to her 90-year-old
father, described her struggle to balance between her efforts to protect her dad, along with
continuing to help him to maintain autonomy and control, which included decision-
making on a daily basis in regard to his affairs and care needs. She communicated this
dilemma in these words:

It’s been really hard, because he’s my dad and I know that I’m having to change
the role, because I have to tell him that he can’t do something. But we also don’t
want to take something out of his hands, because he thinks he can do things the
right way.

In the following excerpt, this same caregiving participant went on to say that her care-
receiving father had also engaged in manipulative behavior to either test her or to gain
more attention from caregiving family members:

Sometimes, he’s just trying to see if I really mean no. I noticed, last month or so, he
tells lies, not bad, or lies to hurt. It’s just, my brother’s doing this, or that these
people don’t do this, so that I’d have to call and check. But when I said, “Dad
that’s not true.” “Oh, you finally caught on. I can’t get away with anything,” and
that’s another thing that I will have to get used to. Instead of going after who he
says I need to go after, I need to get into deeper as to why he’s doing this. It’s an
eye opener.
Yet another caregiving daughter added to this finding by mentioning,

Sometimes Mom will say something that she wants to do. You have to put it a
different way with her. I’m like, “You can’t do that Mom,” and after a while she
realizes and says, “Oh yeah, you’re right, I can’t do that.” It’s kind of like I’m
being put to the test.
Hence, primary caregiving daughters indicated that their involvement in caring
for their aging parent or parents was experienced as a changing or transformative and
disorienting process that required them to alter their communication and negotiating
patterns, because nobody or nothing had prepared them for dealing with elderly parents
who at times behaved like children. A caregiving daughter emphatically shared, “There
should be some class in school that prepares young men and women, that some day this
may be you either as a caretaker or as someone in need of care.”

Letting go. Elderly care-receiving residents’ attitude towards letting go, and
approaching their health challenges and limitations, and managing long-term care were
also perceived as factors in alleviating or exacerbating perceptions of stress, burden, and
guilt among the caregiving participants of this study. One caregiving daughter related,
“As my mom gets older, you see things change—the toughness, the stubbornness. She
has to start letting go of some of that, and she has.” As a result, this caregiver felt less
stressed because her mother was more cooperative and accepting of a change in her
situation, as opposed to other elderly residents who did not share the same attitude.
Another caregiving daughter associated her sense of helplessness and stress with her
mom’s experience, in this way,

Mom’s eyesight right now is just awful—she is legally blind. She was furious
when they said, “You’re not able to administer your own medication anymore; we
have to take that over.” She said she felt like she was being treated like a child,
but there’s no choice—she has to let go and there’s nothing I can do about it.
Perceptions of guilt were associated with not only helping elderly parent(s) let go, but also being able to release the parent or parents to be cared for by a care facility. This researcher noted that caregiving daughters, who provided care to both their parents, reported higher levels of stress and guilt. One of them expressed it this way:

There isn’t a miracle out there that tells me you can do it better. I wish in my heart that I can let go to let them be here. My dad, he never wanted to go to a facility, until he came here. But this was like, don’t ever let them do that to me.

Hence, this study revealed that having to intervene, interact, and negotiate on behalf of emotionally and physically dependent elderly parents can put a considerable physical and mental strain on family caregivers. Another caregiving daughter who was overwhelmed by her caregiving responsibilities stated,

I want somebody to take over for me. I have 6 kids and 12 grand babies, and they want me...so I need to go away for a while, because I’m just on a thread. I don’t want to ever think that I didn’t do something for my dad, because I thought I was too tired.

**Impact of elderly couples’ mutual relationships.** A caregiving daughter viewed her parents’ dependence on each another and herself as a key factor that prevented them from developing other emotional connections that would help to extend their social network within their facility. Caregiving participants’ stress level increased as they worried about their elderly parents’ mental and emotional well-being, as well as their social adjustment. This caregiving daughter also felt extremely caught in between her parents, because they did not want to or maybe felt they could not reach out to others except their caregiving children. She voiced her frustration as illustrated in the following excerpt:
My parents really don’t like it here, and my dad has said more than once that this was the worst decision that he had made. My dad has become more reclusive, grasping. So if Mom were alone, she might actually be able to develop friendships and relationships with the other ladies at the facility. But my dad gets antsy, agitated if she is away from him for any length of time. My dad wants her close, and so she wants to accommodate him—it’s like a devil’s circle. I think, horrible as it sounds, when my dad dies, I think my mom may be actually happier there, because she won’t be chained to him. One of the things my mom says is, she doesn’t know how much time she has left with my dad, as he has cancer. She wants to make it pleasant, so she is going to indulge him; she is not going to fight for what is right for her, because she doesn’t want conflict.

“I am my dad’s lifeline.” In this study, most caregiving participants experienced being a vital emotional support or link for their parents. Some family caregivers felt torn between the need to be physically available and present, and a desire to occasionally feel relieved of constantly assisting their elderly parents. A caregiving daughter explained in these words,

I have not been away for about a year now, and I am up to the point where I need to go away for a little while to regroup…my sister from Oklahoma is coming, and she’s going to take over for me for a little bit. But we can’t tell Dad that I will be leaving, because if I’m gone, he gets very upset.

It was found that as elderly care-receivers advanced in age, their level of emotional dependency on their primary caregiving children also increased, which led to more perceptions of caregiver stress and burden. The range of emotions as experienced by caregiving family members are so complex, as is evident from the following excerpt from an interview with a primary caregiving daughter who was closely involved in assisting her institutionalized 90-year-old father, along with her step-mother who was suffering from severe Alzheimer’s disease:

Dad’s always relied on me. Once he had called me 15 times, and I had gone to the grocery store; but he settles down when he knows I’m there. He has a problem
when I’m not. Then he worries—when you’re 90, you have to have the lifeline of somebody. Right now, I am my dad’s lifeline. I haven’t figured it all out. With my step-mom, Jan, when we go see her, not everybody can leave all at once; we have to do stages of leaving, and the last person is sitting in there saying, “Wasn’t that fun. Did you have a nice time visiting with everyone?” And she goes, “I didn’t see anyone today—that’s how short her memory span is...so I really don’t see her as much as I would really like to. I feel even worse for leaving her. I call to see if she’s doing okay—if she needs anything—because I just seem to upset her when I leave.

**Over-extension of specific caregiving roles.** Although, caregiving participants of this study were most willing to provide care and support and be available to their elderly parent(s), the over-extension of a specific role or roles led to perceptions of strain, resentment, and guilt. A caregiving daughter’s primary role to provide transportation to her elderly parents in getting them to their doctor’s appointments and shopping, and so on, in conjunction with listening to complaints, was extremely frustrating and stressful, as demonstrated in the following excerpt:

> If they would rely on others for transportation for doctors’ visits, that would be a huge relief on me. They don’t like the Silver Key. They don’t like taking taxis—my dad finds it inconvenient. My dad is not inclined to pay anyone for transportation, and they have plenty of funds. I have to listen to their complaints. I feel guilty for not wanting to be here more often, which stresses me out, but it’s like my life is not my own anymore.

Thus, the findings suggested that generational beliefs regarding employment-related and family responsibilities of women impact gender-based expectations and roles in families, which can also lead to the over-extension of specific roles. In this study, mainly caregiving daughters identified themselves as primary caretakers of their elderly parent(s). An older caregiving daughter in a large family assumed the role of a kin-keeper, who was responsible for maintaining family functions for her aging father by
regularly hosting holiday dinners and events in order to bring her entire family together on special occasions. The pressure of having to create opportunities to engage family members to strengthen family ties across multiple segments of generations added to the caregiving burden of this caregiving participant, as is evident from the excerpt below:

Before my mom died, she made me promise to keep the family together, which is what I’m doing—I’m trying. I’m doing the best I can right now. And this is my husband’s biggest thing with me too—I have to have all of the dinners for my family. But Dad is my family, I keep thinking, and this is horrible, that if anything was to happen to my dad, I would like to do something on holidays. I hear of people who go on trips for holidays. I hear of people who don’t have to cook a week before. I would also love to be able to go places. I don’t know if I could even do that if something was to happen to my dad. We’re retired but I can’t leave Dad.

Role overload - juggling multiple roles and relationships. In this study, many family members, especially the caregiving women who cared for both or even one of their parents, were also responsible for providing care to their mother- or father-in-law and, as a result, were over-burdened and stressed out. A caregiving daughter explained by sharing,

I can’t take care of both of them at home—I can’t. I did it with my in-laws, but I can’t do it again. It’s 24/7, all the time; and then you have people coming into your home to inspect things to make sure you’ve got drawers that won’t open and stuff like that.

Middle-aged caregivers are being increasingly caught between their children who are struggling to grow and elderly parents who are struggling to age with dignity. Additional responsibilities and obligations towards other family members and prior commitments can result in a role overload for some family caregivers. A 64-year-old caregiving daughter described her experience as follows:
It is very stressful now, because when my family needs me and Dad needs me, I have to pick my dad. Sometimes it hurts them, but when they see, when they are around him, they understand. I try to tell them that if this is ever me, what would you do? I know what they’re saying, but when I do have the time, I’m there for them.

Competing role demands, such as other caregiving roles in a family that can add to caregiver stress and a role overload, were perceived to affect some family caregivers’ relationships with their elderly parents. Caregiving stress contributed to perceptions of frustration, guilt, and coping strategies. The following excerpt from an interview with a caregiving daughter illustrates the impact of such subjective factors on her other roles and relationships:

When I’m at home, the way I seem to deal with stress is, I don’t do anything. I sit and crochet or I play on my phone. But that means that things around the home, like laundry, like dinners, aren’t being taken care of. It’s worse than it used to be, and so I feel guilty about that, and it piles up. My husband is primarily affected by his concern for me. He would get angry on my behalf, which would just make me defensive. I finally managed to get him to understand that while I need to express my frustration, his ratcheting up and getting angry with my parents doesn’t help me; it only makes it worse on me.

Valuing communication. Communication was identified as being central to alleviating caregiving family member’s stress and frustration. A caregiving daughter, in her interview, perceived this situation as follows:

Mom’s at the point now where she feels badly, because she doesn’t like to take up my time, which again, I really don’t mind, and I am happy to do it. But the biggest thing that annoys me is that she’s being too nice. And because she doesn’t want to bother me, she doesn’t tell me things right away, which then turn into a crisis.

In addition, this study found that after an extended period of time, family caregivers may also feel frustrated if they keep investing in relationships with their elderly relatives without seeming to receive any meaningful exchanges and positive
feedback from them. This was evident from interviewing a couple of primary caregiving daughters who, in spite of their willingness and a strong commitment to care for their elderly parents, wanted to feel validated in their caregiving efforts. One of the participants mentioned, “I persuaded my mom to move to come and live by me. When she said that she couldn’t have stayed there, I felt validated that, yeah, this was the right decision—that’s important to me.” As a structural barrier to being more involved, another caregiving daughter identified a dearth of meaningful conversational material and limited reciprocal communication between her and her elderly parents. She described such perceptions in these words:

Something that I feel sad about in my relationship with my parents is that I really have to search hard for things to talk about. My dad is very willing to talk about his frustrations with Dr. Perry, but it’s very hard to come up with conversation material. Even for my mom, it never used to be that difficult before. I want to spend time with them, but what can I talk about. The problem is that I cannot get my dad, in particular, to focus outside of himself—his apartment. He doesn’t pay attention to the news, so it’s hard to discuss the news with him. He reads the paper, but not really. He used to tell me about the books he was reading but not anymore. This narrowing of focus is a common thing, and I don’t know if there is anything to break through that. It’s got to be an effort on both sides. You can either reach out to others…or you can just go into your room and hibernate, which is what my parents do.

Moreover, another caregiving daughter reported that a disapproving attitude towards allowing family caregivers to express their frustration and confusion only added to their perceptions of stress and guilt. She continued to explain,

For caregivers, like myself, it is a family responsibility and obligation to take care of our elderly parents, and we are very uncomfortable about expressing resentment because we are not supposed to complain…we are just not conditioned to express negative feelings.
This finding points to the importance of allowing both caregiving and care-receiving family members to confront and openly communicate their frustrations and perceptions of dependency, loss, and passivity.

**Composite Textural and Structural Descriptions of Family Involvement as Experienced by Care-Receiving Residents and Their Family Caregivers**

A composite analysis of the textural descriptions that highlight what experiences were shared by participants, as well as the structural descriptions that account for the underlying dynamics of how the experiences were shaped (Moustakas, 1994), are presented in this section. This is followed by the essence and meanings of the participants’ experience as a whole. Essence has been defined as “an integration of the composite textural and composite structural descriptions, providing a synthesis of the meanings and essences of the experience” (Moustakas, 1994, p. 144). Hence, in conclusion to this chapter, the essence of the phenomenon of family involvement as experienced by the care-receiving residents in assisted living facilities and their family caregivers is described.

**Composite textural description. Caregiving experience of elderly residents.** In each of the eight family systems, comprised of an elderly care-receiving and a caregiving member, recruited for this study, family involvement was considered to be highly important and mutual. This is in contrast to viewing elderly care-receivers as merely helpless and dependent relatives in their roles and relationships with other family members. According to an elderly care-receiver,
Family members should not just put their parents here and forget about them and think that the facility will take care of them. But the families need to continue to participate and also involve Mom and Dad in their affairs.

The perspective of this study participant was similar to others who considered family participation and involvement as being imperative to both the care-receivers and their caregiving family members’ well-being and adjustment to institutionalized long-term care.

In this study, based on participants’ responses, care-receiving elders were also regarded as caregivers. Of the eight elderly residents, the 3 participants who were married preferred to live with their spouses and primarily rely on each other for socio-emotional support and personal care for as long as possible, in spite of living in an assisted living care facility. It seemed logical and natural for married elderly participants to take on these roles. Finally, intergenerational relationships and contributions of elderly participants, including their roles as parents and grandparents, were evident through both their functional and symbolic involvement. These relationships were facilitated by close physical proximity.

Elderly residents’ experience with care-receiving. Care-receiving participants were observed to respond, both positively and negatively, to age-related and life changes. Often elderly care-receivers had to overcome denial to recognize the need for institutionalized care and the need to adapt to the physical and environmental aspects of their assisted living facility. Elderly participants shared that they did not want to become a burden on their family members and maintained the need for being self-reliant to the extent possible, despite being in an assisted living care setting. Transportation to meet...
residents’ social and spiritual needs was identified as a major need within the assisted living system. Most care-receivers were more comfortable with relying on caregiving family members who lived in close residential proximity to them. Some elderly residents identified challenges to establishing new relationships with other residents in their facility, including discriminatory attitudes against elderly residents suffering from physical and/or mental impairments.

**Care-receivers’ experience of aging and loss.** Coming to terms with a sense of loss was identified as a major component of the aging process. Elderly residents’ experiences of aging and loss were attributed to declining physical and mental health, as well as a subsequent move to an assisted living care facility. The loss of home, car, and personal belongings, and the loss of roles, in conjunction with the loss of vision and mobility, influenced most elderly participants’ sense of empowerment and their ability to identify meaningful contributions and roles. Some caregiving participants also reported that they observed their elderly parent(s)’ self-involvement with their health status and physical condition, a narrowing of focus, and limited transportation and communication as factors that exacerbated perceptions of loss and dependency among care-receivers. All of these age-related changes hindered mutual involvement between elderly care-receivers and their family caregivers.

**Caregiver perceptions of their relationships and roles.** Based on the participants’ responses, family caregivers, who were providing care to their parents in an assisted living setting described their mutual relationships as being more braided and enmeshed. Caregiving family members who lived in close physical proximity to their care-receivers
were more emotionally and instrumentally involved with their elderly relatives and often experienced multiple roles and relationships with their aging parents, siblings and their families, other health professionals, and the assisted living staff and management.

Caregiving participants frequently had to interact and associate with their elderly parent(s), or on behalf of them, and therefore had to adapt to being more communicative and collaborative with others who were also involved in the caring process.

Family caregivers also preferred to help their elderly parent(s) transition to an assisted living in order to not only ensure the provision of ongoing care and supervision, but also help them find an extended support network. Caregiving participants who had children and even grandchildren felt responsible for maintaining and facilitating intergenerational involvement in their families by bridging the gap between their elderly parents and their own children and assuming a kin-keeping role. Hence, most adult children had to determine how to meet the changing physical, mental, and socio-emotional needs of their elderly parent(s).

*Experiencing caregiving stress and burden.* Some caregiving participants shared their perceptions of stress and frustration, as a result of their continual involvement with aging relatives residing in a long-term care setting. A caregiving participant reflected, “I think that assisted living homes do the best they can. I don’t know if there is any other way we can manage in our society. So they are probably the best we can do.” Most family caregivers shared that they had not known what to expect, because their set processes of communication and negotiation with their elderly parent(s) were now in a
constant state of flux as a result of progressing age-related disabilities and cognitive impairments.

Caregiving adult children also described experiences of role reversal, role strain, and role overload, all of which were associated with constant monitoring and more frequent caregiving tasks, in conjunction with managing additional family responsibilities and relationships. Incurred costs with respect to emotional and mental strain, as well as the time and energy spent on additional and atypical caregiving responsibilities, were identified as contributing to caregiving pressure.

**Composite structural description.** The three structural themes that emerged from this study’s findings are discussed below. These themes explain how the experiences reported by both care-receiving and caregiving participants were evoked and created.

*Coping efforts and attitudes that characterize the aging, the care-receiving, and the caregiving processes.* As illustrated in this study, the aging process is characterized by considerable and complex physical, emotional, psychosocial, and environmental adjustments. As a result, often, many elderly persons have to live in long-term care facilities where care and monitoring are provided on a continual basis. In this study, even though elderly care-receivers were receiving long-term care assistance within an assisted living system, most caregiving participants’ emotional and instrumental involvement with their elderly family members increased over a period of time.

As was evident from this study’s findings, the experiences of care-receiving and caregiving were not only determined by care-receivers and their family caregivers’
affectional ties, but also by their personal reactions, coping abilities, and attitudes associated with aging. Elderly participants’ ways of coping with loss, and their attitude towards aging and care-receiving affected their sense of self and their relationships with family members, other residents, and the staff personnel within their assisted living facilities. This researcher noted that a few elderly residents hesitated and even avoided talking about their experiences of loss with respect to roles and relationships, their home, and health, as well as other problematic familial circumstances.

Some study participants reacted to developmental and life changes more optimistically than other participants who were not prepared for losing their home, or encountering physical constraints related to vision and mobility. Both the care-receiving and the caregiving participants had to engage in letting go of what used to be, in order to accept and adapt to their current circumstances and roles. Age-related adaptations and health challenges necessitated decision making through careful reflection and open communication, which was an emotionally difficult process for all elderly participants and their family caregivers.

*Enduring and changing roles and relationships in family systems as a result of aging family members’ need for long-term care assistance.* Family roles and relationships were perceived to be rewarding and gratifying as well as stressful for the participants of this study. Elderly participants and their caregiving family members experienced a change in their mutual relationships as well as their relationships with other family members. Family systems had to acclimatize to a reformulated role in the caring process. Health problems and physical constraints were accompanied by
subsequent role changes that shifted the dynamics of family involvement among and between elderly parents, their adult children, and grandchildren, as well as other family members. When mobility, transportation, food preparation, and the ability to clean and do one’s own laundry became a challenge, elderly participants had to acknowledge and come to terms with their own limitations and their changing roles and relationships.

Caregiving family members provided emotional and instrumental support, which was based on their mutual relationships, affection, and a sense of responsibility. An increased level of involvement resulted in frequent contact and an increase in caregiving responsibilities, which resulted in bringing some pairs of family caregivers and their care-receiving relatives emotionally and physically closer to one another. Elderly residents’ attitudes and willingness to adapt to health-related and life changes also contributed to a change in their roles and relationships with other caregiving family members. Those with a positive and accepting attitude towards adjusting to life in an assisted living facility were committed to rediscovering new roles and interests, along with maintaining their extended family networks and other commitments. However, elderly residents who found it difficult to adapt to new changes often became more isolated and dependent on their family caregivers. Inability to assimilate and adjust to living in an assisted living facility therefore affected some elderly residents and their family caregivers’ relationships negatively.

The paradox of institutional long-term care: Creating relief as well as stress for both elderly care-receivers and their caregivers in family systems. The processes of care-receiving and caregiving, comprising various roles, relationships, and decision
making, often seemed like a trade-off. Family caregivers regarded assisted living care as a necessary option that relieved them of being constantly worried for their aging parent(s)’ health and safety, but resulted in other sources of anxiety and perceptions of stress and guilt. Caregiving participants had to negotiate and mediate between relationships with other siblings and their spouses, along with the assisted living staff and management. In addition, they acted to keep their families and children involved with their elderly parent(s) to the extent possible. In some cases, spousal ties, relationships, and responsibilities were also observed to inhibit elderly spouses from extending their social network within an assisted living context.

Care-receiving and caregiving participants had to ascertain ways to interact and deal with the changes and losses in their families in order to be able to move forward. Living in an assisted living setting was perceived as a huge adjustment for many elderly care-receivers, who had to adjust to relying on their adult children and extended family members. This process involved a re-negotiation of family boundaries and expectations. Some elderly participants stated not wanting to overstep boundaries and expected the same from their family caregivers and other family members.

**The Essence of the Phenomenon of Family Involvement**

An 85-year-old father, who had always been the patriarch of his family, could no longer drive or walk his dog, because he was suffering from prostate cancer and was living in an assisted living facility with his wife, who could not read, or watch television, or even shop because of macular degeneration, which had rendered her legally blind. An 82-year-old wife was limited in her physical mobility and ability to care for herself,
because she had Parkinson’s disease that had also affected her speech, which was reduced to barely a whisper. She and her 84-year-old husband, who had glaucoma, were therefore living in an assisted living facility together. A 90-year-old husband, who was suffering from short-span memory loss, was also concerned about his wife who was suffering from Alzheimer’s disease, which made it necessary for both of them to accept help from not only their family members and friends, but also other formal long-term care sources.

These were just some scenarios from this phenomenological study’s sample that represented the experience of what many elderly persons and their caregiving families are facing on a daily basis. The findings suggested that many family systems that include family members who are in a primary caregiving role are not prepared to assume the wide range of tasks that encompass specialized and skilled care provision for complex physical and psychological challenges associated with aging, especially because this is an ongoing and a very demanding process. Hence the need for both family caregiving and formal care, including facilities that provide residential long-term care such as assisted living, is escalating at a significant rate.

In this study, care-receiving and caregiving participants experienced family involvement as a dynamic process, characterized by personal value systems and reactions, such as relief and stress as well as changing roles and relationships. Most elderly participants continued to stay involved in their families to the extent possible, but viewed their role as being limited because of health challenges. The processes of aging, care-receiving, and caregiving encompassed several inevitable adjustments and
experiences that led to the re-negotiation of responsibilities, expectations, boundaries, and communication patterns in the family systems that participated in this study.

In conclusion, based on responses from this study’s participants, family members continued to demonstrate a strong commitment to staying involved with and on behalf of their aging family members, despite experiencing a variety of emotions that ranged from feeling validated and affection to frustration, stress, and guilt, all of which can be part of the caring process. Given this phenomenon, both care-receiving and caregiving members’ needs and experiences of their roles and relationships at different stages related to their transition and adjustment to institutionalized long-term care needs continued attention, because it is a reality that continues to impact a growing number of elderly care-receivers and their caregiving families.
Chapter 5: Discussion

Uprooted from her home with the chrysanthemum garden this weaver of words and ways had buffed lives and silver with equal grace in the richness of her days. Her children were achieving; we listened; she had followed our small accomplishments.

From the supper tray she tasted the institution soup, tested the applesauce, ignored the peanut butter sandwich. “They feed me too much”, she whispered, looking weary. “You do not sleep well?” “No…not with the talking.” Certified care was a shawl that covered but did not fit.

(Fortner, 1986, p. 118).

This qualitative, phenomenological study elicited discursive accounts of how elderly residents experienced familial involvement while living in an assisted living facility, which is, more often than not, associated with a lifestyle that implies connotations of being isolated and sheltered. An elderly care-receiver’s family involvement cannot be explored in isolation, which is why this study maintained a focus beyond the circumstances and experiences of elderly residents in assisted living, by also taking into account their caregiving family members’ perceptions of their involvement.

Based on this study’s findings, involvement in family systems was both continuous, as well as dynamic in response to the numerous changes that were associated with aging, such as long-term disability, widowhood, and declining health, which resulted in the need for assisted living care. This researcher discovered that this study’s sample did not represent a typical case, but that there were some dominant and common
themes that became apparent from care-receiving elders and their caregiving relatives’ experiences, which characterized and influenced their family involvement.

Three structural themes that emerged were, (1) Coping efforts and attitudes that characterize the aging, care-receiving, and caregiving processes; (2) Enduring and changing roles and relationships in family systems; and (3) The paradox of institutional long-term care, as it created both relief and stress for elderly care-receivers’ and their caregivers in family systems. In this chapter, these three themes will be examined in their relation to existing research, and to the systems/ecological framework, followed by a discussion about implications for theory, policy, and social work research and practice.

**Coping Efforts and Attitudes that Characterize the Aging, Care-receiving and Caregiving Processes**

The aging process provides the context for this study. As outlined in chapter 2, the life-course theory regards aging as a developmental stage, which is normally associated with a set of social tasks, expectations, and concerns related to transitions or role changes (Quadagno, 2005). Life experiences that result from changing life-stages that comprise certain roles and relationships, contribute to molding every individual in a unique way. The care-receiving and the caregiving processes evoked many personal reactions among the study participants regarding the way they coped, and their attitudes, which comprised the first structural theme of this study. Also, care-receiving participants’ experiences with caregiving, care-receiving, and loss, as well as caregiving participants’ experiences with increasing involvement and negotiation on behalf of their elderly relative(s), created changes in attitude and disposition for those involved. While each interviewed dyad had
some common, as well as unique experiences of care-receiving and caregiving, these experiences were determined by the individual’s reactions and values associated with aging.

This finding was congruent with literature. Aging related research has found that attitudes, such as those towards institutionalized care, physical and cognitive disabilities, or internalized ageism, all have an impact on supportive familial exchanges (Price, 2005). Some caregiving participants in this study reported that denial and an inability to accept the need for long-term care assistance among elderly care-receivers’ influenced their interaction and involvement with their elderly relatives. One value that most of the elderly participants considered important was to have control over their lifestyle, finances, and care choices, such as being able to shower, dress, and administer their own medications. This finding has also been affirmed by social psychology and legal developments concerning institutionalized elderly residents, which have established that a sense of self-efficacy, and the ability to maintain autonomy and control are the most basic components of well-being among elders (Zarit & Braungart, 2007). Feelings of efficacy have been associated with empowerment, and the ability to cope when confronted with powerlessness and stressful situations (Keith, Wacker, & Collins, 2009). Research in this area has established that care-receiving residents, who were unable to choose for themselves, and who felt that their privacy and their personal space was threatened, found it most difficult to adjust to residential long-term care (Shippee, 2009). This value of self-determination among elderly participants likely plays a role in the care-receiving and caregiving processes.
Another attitude that can influence care-receiver and caregiver relationship and roles is ageism. Negative ageist attitudes towards physically and/or cognitively disabled older adults have been extensively addressed in gerontological research literature (Kite, Stockdale, Whitley, & Johnson, 2005), as opposed to elderly people’s perceptions and experiences, which have been inadequately examined. In this study, some elderly participants’ negative attitude towards their cognitive and physical health compromised their desire and ability to engage in reciprocal exchanges with their family members, and other residents in an institutional care setting. This is congruent with research literature, which suggests that elderly residents embarrassed by their physical limitations, were more likely to become socially reclusive and isolated from others (Park, 2009). Further research has indicated that elderly residents' who expressed negative attitudes towards aging, as well as other functionally and cognitively disabled elders in residential care settings, experienced more difficulties in coping with their own aging and feared this process (Iecovich & Lev-Ran, 2006). This study, also, discovered that care-receiving participants’, who found it difficult to adjust to living in an assisted living facility, became more emotionally dependent on their family caregivers, who in turn felt considerably over-burdened and guilty.

As is common knowledge, the availability of a family support network is critical to elderly care-receiving residents’ satisfaction and adjustment to an assisted living facility (Brechin as cited in Tanner & Harris, 2008; Nolan, Grant, & Keady, 1996). Research has also indicated that perceptions of filial love, closeness, and mutual affection in relationships contribute to the psycho-social and emotional well-being among elderly
residents (Merz, Schuengel, & Schulze, 2009). However, in this study, despite the availability of kin, family support, and finances to afford assisted living care, some disabled elderly participants, who felt disempowered and unable to change their circumstances, struggled to adapt to living in a regulatory environment with other elders. This study found that elderly participants’ reactions and values regarding their aging process, their sense of empowerment, and their need for institutionalized long-term care, had an impact on their family involvement, beyond the accessibility and affordability of residential care options, such as assisted living.

Also, levels of disability and illnesses among some elderly study participants were found to produce a loss of interest, and a loss of influence, especially with grandchildren, which negatively affected elderly residents and their family caregivers’ experiences of involvement. This is important to note, because research has suggested that typically, grandparents who perceive their relationships with their grandchildren as being fulfilling and active, maintain a more positive attitude (Williams & Guendouzi, 2005). In some cases in this study, the lack of intergenerational support and exchange, which tended to be symbolic and meaningful for elderly family members’ had an impact on their perceptions of family involvement.

Research has established that developing familial ties, inter-generational support, and engagement not only in families but in care communities is becoming increasingly popular in attempting to foster interdependence between older and younger generations. (Kaplan, Liu, & Hannon, 2006). However, very few research studies on residential-based care have emphasized the important role of family members, including grandchildren,
who are closely involved in providing ongoing socio-emotional support and instrumental assistance to their elderly relatives (Gaugler & Kane, 2007).

**Enduring and Changing Roles and Relationships in Family Systems**

Family systems are generally characterized by caring relationships, which develop out of personal knowledge, attitudes, and affection. Role theory, which was briefly described in chapter 2, has emphasized on defining an individual’s roles in relationship to another person or social institution (McInnis-Dittrich, 2002). Role theory is applicable to this study, which focused on exploring elderly care-receivers’ and their respective family caregivers’ roles, which are understood in terms of their mutual relationships, as well as their relationship with the assisted living facility. This study found that such roles and relationships were often subject to changes, which represented the second structural theme of enduring and changing roles and relationships in family systems, even as elderly participants in assisted living tried to adapt to their aging process.

Literature on family as the principal source of care and support for its dependent aged members has been widely documented (Park, 2009; Tanner & Harris, 2008). After elderly spouses, adult children largely constitute the next preferred group of potential family caregivers (Davey & Szinovacz, 2008), as was evident in this research study. Care-receiving participants’ of this study, who were married and living together in an assisted living facility, were primarily involved in negotiating and providing care and socio-emotional support. Families are a system of roles and relationships that evolve, and are learned and carried out depending on family members’ developmental stages, their
abilities, personal characteristics, and social and emotional needs, which keep changing over time (Anderson, Carter, & Lowe, 1999).

Both care-receiving participants and their caregiving family members reported that they had to learn to adjust to their changing roles and relationships. This finding was congruent with research literature, which has maintained that older adults have to not only adapt to status loss and physical limitations, but also to establishing new patterns of interaction and integration, and redefining the restrictions they experience, especially in an assisted living care setting (Sterns & Kahana, 2007). This was also described as being true for the caregiving participants of this study, who became increasingly involved in trying to arrange and coordinate involvement between their elderly relative(s) and other family members, as well as negotiate with health care professionals and assisted living staff regarding issues pertaining to the quality of care received by their elderly loved ones.

Some other researchers have also indicated that contributions or exchanges between care-receivers and family caregivers become imbalanced during certain periods in time (Wacker & Roberto, 2008). A recent study maintained that intergenerational support patterns varied, depending upon the different developmental phases in a life span, and the subsequent shifts in the amount of emotional and instrumental assistance exchanged between care-receivers and their family caregivers (Merz, Schuengel, & Schulze, 2009). Lately, a few researchers have also drawn attention to different aspects of family care and to reciprocal influences in care dyads, which comprise an elderly care-receiver and a caregiving family member (Sebern & Whitlatch, 2007; Whitlatch, Judge,
Zarit, & Femia, 2006). However, more qualitative studies that take a dyadic approach to changing care-receiver and caregiver roles and relationships, and the ensuing challenges with respect to self-efficacy, and autonomy, need to be developed.

Research literature has predominantly focused on assessing the frequency, quality, and sources of informal support to elderly care-receivers (Merz, Schuengel, & Schulze, 2009). This study found that within family systems with several potential caregivers, those with residential proximity to their elderly relatives were most involved. Family dynamics, which included gender differentials, and support from siblings and other family members, also influenced the family’s roles and relationships. Some researchers have suggested that adult children who live at a distance from their elderly parent(s) may express weaker filial responsibilities than those living closer (Finley as cited in Silverstein, Conroy, & Gans, 2008), but such an assessment may vary from family to family.

Research in this area has, also, suggested that adult daughters provide more support than adult sons, and that family size and gender composition impact the coordination of care across siblings (Silverstein, Convoy, & Gans, 2008). This was congruent with findings from this study, which revealed that caregiving tasks that were more continuous in nature, such as managing elderly care-receivers’ bank accounts, negotiating doctors’ visits, grocery shopping, and transportation that needed to be frequently and regularly performed, were typically, assumed by a primary caregiving daughter, who was living in close residential proximity. Other responsibilities such as
maintaining financial records and tax documents that were not as continuous were performed by other siblings, living at a distance, or in another state.

Because of increasing health care improvements and longer life-spans, the onset of age-related disabilities is being deferred until later in life, which has also caused many family members to assume the role of a caregiver at a later age, when they may also be vulnerable physically, emotionally, or financially (Hansson & Carpenter, 1994). Based on findings from this study, it was noted that some adult children who were middle-aged, and even 60 plus, were providing care and support to their elderly parent(s) in their late 80s and 90s. Assessment of relationships and roles in late life becomes more complex, because even as elderly care-receivers are changing developmentally and psychologically, their caregiving family members are also growing older. Age-related changes, therefore, determine the quality of mutually supportive relationships within care-receiving and caregiving family systems.

Within caregiving literature, an overarching emphasis on care provision to elderly residents with Alzheimer’s and dementia, with respect to issues concerning autonomy, and caregiver burden, has in turn contributed to an under-representation of care-receiver experiences related to their family life and involvement (Hoff & Tesch-Romer, 2007; Zarit & Braungart, 2007). Care-receiving participants in this study maintained their need to be self-reliant inspite of living in an assisted living environment. Elderly participants who were living with their spouses in an assisted living preferred to primarily rely on each other for support and personal care. Prior research in this area has also documented that primary spousal caregivers’ mutual efforts to provide care are less likely to be
supplemented by adult children and other family members (Stoller & Miklowski, 2008). Older married couples have been found to assist each other with a broader range of tasks and activities of daily living, such as providing companionship, communication, supervision, and mental stimulation (Stoller & Miklowski, 2008).

However, some care-receiving participants described their role and relationships as being limited, because of their physical constraints and health challenges. Cognitive and visual impairments affected some participants’ ability to drive, and to remember things. Hence, ongoing support from family and friends becomes extremely important for preserving elderly relatives’ sense of autonomy and well-being (King & Johnson, 2002). Other empowerment-oriented approaches are also extremely helpful, because empirical research has established that when engaging in one-on-one care provision and assistance to others, older adults’ sense of self, sense of well-being, and satisfaction with life and personal relationships increases (Cox, 2005).

The Paradox of Institutional Long-term Care

Personal and social exchanges on behalf of elderly family members, and between care-receiving residents and their respective family caregivers may lead to both relief and stress in family systems. In this study, the experience of providing and receiving family-based care in assisted living was reported as being, both positive, as well as extremely stressful. This paradox emerged as the third structural theme of this study, which is reflected in a few research studies that describe aging and coping as very individualized processes, that depend on environmental and personal lifestyle factors, and resources, and consequently impact care-receivers and caregivers in different ways (Price, 2005; Lyons,
Zarit, Sayer, & Whitlatch, 2002). Family roles and relationships can either have positive or stressful long-lasting influences, or involve a bit of both of these extremes for most people.

Past experiences, events, and lasting perceptions highly influence family caregivers’ willingness to support and care for their elderly relatives and vice versa. Research literature has also indicated that quality of relationships between care-receivers and their family caregivers has more of an impact on elderly parent(s) sense of well-being than mere quantity of support (Merz, Schuengel, & Schulze, 2009). The nature and quality of family involvement among family members is also determined by past patterns of reciprocal roles and relationships over a life-course (Ball et al., 2005).

Interestingly, in this study, elderly care-receivers were more likely to report perceptions of congruence in their familial involvement, whereas caregiving participants were more open in identifying perceptions of conflict and stress, associated to their overall involvement. Previous research in this area has suggested that caregiving family members, who may be extremely burdened and frustrated, were slightly more likely to perceive their care-receiving relatives as being increasingly dependent (Lyons, Zarit, Sayer, & Whitlatch, 2002). Elderly residents’ appraisal of their experiences was critical to this study. Some care-receiving participants also reported perceptions of their dependence and frustration, as a result of their experiences of loss and aging.

Caregiving participants in this study described perceptions of role reversal, role strain, and role overload, which increased their sense of burden. Research literature has established that caregiving and care-receiving family members may become frustrated,
and experience stress when they are undergoing a loss of resources, freedom, privacy, mobility, energy, and time (Greene, 2008). This study noted that some caregiving participants had to frequently interact with their siblings on behalf of their elderly parent(s), which depending upon their past relationships could either have a positive or a negative effect. Other researchers have estimated that siblings in larger families tend to provide less support per capita than those in smaller families (Wolf, Freedman, & Soldo as cited in Silverstein, Conroy, & Gans, 2008). However, in some cases, caregiving adult children, who participated in this study, willingly provided assistance to their elderly parent(s), despite feeling frustrated and stressed, at times, by their elderly parent(s) attitude and increasing emotional dependence.

Perceptions of stress and guilt mainly result from over-extending and mounting caregiving tasks and responsibilities. Having to fulfill several co-existing roles may also become the source of internal and externally imposed conflict (Bumagin & Hrn, 2001). This was congruent with the experiences of some caregiving participants, who had to balance between the needs of their younger or teenaged children and the long-term care needs of their elderly parents. Therefore, researchers have suggested that greater coordination and allocation of care responsibilities have to be negotiated in families with middle-aged children, who have grown-up children of their own, as the different care needs of elderly parents and parents-in-law increase (Davey & Szinovacz, 2008).

Some care-receiving, as well as caregiving participants also experienced a sense of relief, because of receiving ongoing formal assistance within an assisted living care facility. Assisted living care relieved some married residents of providing constant
monitoring, and personal assistance to their elderly spouses on a daily basis. Positive experiences of family involvement have been linked to increased positive affect, higher self-esteem, and improved caregiver well-being, and coping efforts during distressing and stressful periods (Tugade & Fredrickson, 2004). Also, stronger attachment between elderly care-receivers and their caregiving adult children has been associated with less caregiving burden, whereas strong feelings of filial obligation were related to high caregiving burden (Cicirelli as cited in Merz, Schuengel, & Schulze, 2009). Family caregivers, who were more enthusiastic about their caregiving roles, experienced more satisfaction and less depression and strain (Greene, 2008).

This study, therefore, established that care-receiving, and caregiving participants, while being involved with each other, and with other family members, reported perceptions of relief, as well as stress. Very few researchers have emphasized the importance of examining positive aspects of family caregiving, which include family members’ appraisals of caregiving as being enjoyable, meaningful, competent, and rewarding, in conjunction with studying the stressful experiences of caregiving (Robertson, Zarit, Duncan, Rovine, & Femia, 2007). Hence, even as the negative aspects of caregiving practices are frequently identified in numerous research studies, more researchers should emphasize the importance of exploring the qualitative aspects of familial relationships and involvement between care-receivers and their family caregivers, such as closeness, solidarity, and loyalty (Connidis, 2001).
Applying a Systems/Ecological Framework to Examine Family Involvement in Assisted Living

The impact of elderly care-receivers’ and their family caregivers’ experiences and personal reactions regarding the aging process and institutionalization, along with the changing nature of their roles and relationships upon their mutual involvement and family systems is discussed in this section. Importantly, relationships were made to the role of the assisted living care network in this process. In this chapter, findings from the participant’s responses were discussed in relation to the overarching systems/ecological framework guiding this study, which was described in detail in chapter 1.

The systems/ecological framework provides an approach to comprehensively understand the nature of developing relationships within and between systems, as well as the mutual impact of continuous interaction between individuals and their environment. Systems theory has been used to examine the structure and organization of how people interact and react to any stressful situations, especially in families that are characterized by a unique set of relationships and roles (Greene, 2008). Elderly care-receivers and their family caregivers need to be understood in their relationship to each other, and to other social systems.

The incorporation of an ecological approach is also highly relevant to systems theory’s focus on increasing adaptation between people and their environment (Healy, 2005). It is an extension of the systems perspective as it adds to the transactional processes within and among systems, by focusing on the roles and relationships between organisms, or social systems, and their environments (Kemp, Whittaker, & Tracy, 1997).
Moreover, the ecological perspective offers not only an understanding of the relationships between individuals and their various environments, but also gives importance to human diversity, action, self-management, and identity (Payne, 2005). From this perspective, scholarship in person-context relational approaches has evolved, which chiefly includes the work and contributions of Urie Bronfenbrenner in areas of human ecology and development (Bronfenbrenner, 1986). The following section discusses the three major findings from this study, which include the contradictory, paradoxical care-receiver and caregiver experiences of relief and stress, in relation to the phenomenon of continuity and change, which are central to Bronfenbrenner’s human ecological theory (Bronfenbrenner, 2001).

**Continuity, change, and contradictory care-receiver and caregiver experiences.** Bronfenbrenner viewed individuals and their families as being embedded within encircled networks, referred to as microsystems, mesosystems, exosystems, and macrosystems, which were presented in chapter 1. A microsystem was defined as a face-to-face setting, which comprised a pattern of activities, roles, and relationships that invited, allowed, or inhibited progressive engagement, and also included the formulation of intentions and goals (Bronfenbrenner, 1977). In his work, Bronfenbrenner drew attention to the processes of continuity and change in the biopsychosocial characteristics and experiences of people, both as individuals and as groups (Bronfenbrenner, 2001).

Bronfenbrenner emphasized the biopsychosocial characteristics of an individual, which include the bio-ecological resources of disposition, ability, experience, knowledge, and skill, because of their continuous impact on human beings (Bronfenbrenner &
Morris, 1998). Both care-receivers and their family caregivers, who are the focus of this study, are nested within Microsystems, which are particular settings with physical, social, and cultural features that allow for an individual’s continuous interactions with other people, and their immediate environment. Such continuous reciprocal exchanges are not only essential for determining the nature and extent of involvement and development among people, but are central to the creation of elderly care-receivers’ and their family caregivers’ attitudes and coping efforts, as is depicted in Figure 2. Personal characteristics of a person function as both an “indirect producer” and “a product”, which implies the qualities of an individual that emerge with time, because of such continuous reciprocal exchanges between an actively evolving human being and other individuals and activities in an immediate face-to-face setting (Bronfenbrenner & Morris, 1998; p. 996).

Elderly participants of this study experienced a loss of their homes and their personal belongings, which over the years, was linked to numerous memories. Residents’ attitude towards their changing health and social circumstances, as well as their acceptance of changing roles and relationships with family members was critical to this study. Caregiving participants reported being more relieved when their care-receiving relatives demonstrated a resilient and an accepting attitude towards their need for long-term care. This subsequently kept them from constantly worrying about their elderly family member’s whereabouts, safety, and their emotional and physical health.

A positive attitude towards participating in assisted living activities, resources, and community events, and towards rediscovering hobbies, and other recreational and
leisure interests, increasingly determined elderly residents’ adaptation to institutionalized settings. Care-receiving participants’ willingness to maintain an extended support network, comprising of neighbors and long-lasting friendships from work, support groups, churches, and other organizations was critical to their social development, engagement, and adaptation, which in turn, also enhanced their family involvement.

As was evident from this study’s findings, even as elderly care-receivers experienced a process of developmental changes, their caregiving family members were also aging, and encountering change, with respect to changing responsibilities, needs, roles, and relationships, which created stressful circumstances for some caregiving participants. As illustrated in Figure 2, the changing nature of family involvement, the level of involvement within an assisted living facility, and the availability or the lack of access to a supportive social network were identified as some key areas which created both relief and stress for study participants.
Figure 2. The processes of continuity, change, and contradictory care-receiver and caregiver experiences characterizing family involvement within assisted living

Note: CRs=Carereceivers; CGs=Caregivers

Importantly, the availability of family support to care-receiving and caregiving participants, the physical proximity between care-receivers and their respective caregivers, and relationships with assisted living staff and other residents were other determinants. For example, sustaining relationships with other residents within assisted living was a stressful experience for some care-receiving participants of this study. Hence, promoting meaningful pursuits and participation within assisted living facilities
can help to alleviate care-receiver perceptions of dependency, and reduce caregiver stress and guilt.

Understanding the relationship between informal and formal caregiving settings and resulting adjustments is critical to examining a change in expectations and roles. A shift in care-receiver and caregiver needs, attitudes, and verbal or non-verbal behaviors also affects their mutual involvement, which may either create satisfaction or stress for care-receivers, caregivers, and other family members. Such continuously, changing interactions, and their impact determined the third major finding of this study, resulting in contradictory or paradoxical experiences of both relief and stress within care-receiving and caregiving family systems.

Elderly care-receivers’ needs for care may result from physical, functional, and mental impairments, as well as psycho-social and environmental factors. Ecological interventions can help modify any environmental pressures, as well as care-receiving residents and their family caregivers’ ability to deal with stressful situations. The systems/ecological framework can, therefore, help to identify those supports that may improve elderly care-receivers’ functioning, which consequently helps to maintain their psychological well-being and satisfy their behavioral needs (Cox, 2005).

**Assisted living facility’s role and influences.** While caring for elderly care-receivers within an assisted living setting, both the familial caregiving system and the formal caregiving system need to intersect and interact with each other. Even though assisted living staff personnel were not interviewed directly, the environmental and social impact of living within a regulatory system upon care-receiver and caregiver roles and
relationships emerged as an important aspect of this study. The nature of family involvement within an institutionalized context cannot be examined, without discussing the assisted living facility’s role and influence on care-receiving and caregiving processes.

Elderly residents, their family caregivers, and the staff within an assisted living care system share roles and interrelationships among each other, while maintaining contacts, as well as other roles and relationships outside of the assisted living system. A systems approach provides useful concepts that can help analyze how roles are defined and may overlap, and how close or distant the relationships between family caregivers, care-receivers, and formal care providers actually are, within and between family systems and assisted living care systems.

In an earlier study, Atherton (1989) applied concepts from the systems framework to residential care for the elderly, suggesting that the systems perspective is concerned with how the care-receiving residents relate to their family members and each other within social situations. Atherton’s focus was on communication among residents, both as a way of explaining how problems are generated, and as a way of intervening (Payne, 2005). Thus, attention to the critical concepts within a systems approach is essential to an understanding of how the assisted living care system can cooperate and network with the family system in providing the best care and assistance possible for the elderly residents.

The ecological framework on the other hand, regards people as the product of their social and physical worlds, which provide them with the resources and roles that make and define them. Roles are a set of expectations and responsibilities that result from
people’s relationships and position in the family and society. The roles and interactions between family caregivers, their care-receiving relatives, and the staff/administration within an assisted living system of care can be described as being highly connected or disengaged, cooperative or competitive, and protracted or intermittent (Caron as cited in Hargrave & Hanna, 1997). Social and environmental pressures can either alleviate or aggravate conflicts and relationship adjustments. A combination of both systems and ecological concepts can, therefore, provide useful insights that can help improve the aging and the caregiving process.

Human systems comprise several forms, which include individuals, families, communities, organizations, and institutionalized care facilities like assisted living. Such systems are in constant interaction and collaboration with each other. The systems/ecological framework is particularly relevant to the partnerships that exist between the assisted living system of care, the care-receiving residents in assisted living, and their caregiving family systems. This can be referred to as the care triangle, which while facilitating the involvement of care-receivers and their family caregivers, also ascribes a greater role to professional caregivers in the care process (Nolan, Grant, & Keady, 1996). This researcher has made an attempt to depict the partnership that develops between these three role-driven focal systems in Figure 3.
Figure 3. Care Triangle. Depiction of the partnerships that develop between the assisted living system, the care-receiving residents in assisted living, and their caregiving family systems.

Note: CRs = Care-receivers, CGs = Caregivers.

The systems/ecological framework emphasize the elements of wholeness, and the interdependency of parts (White & Klein, 2002). Assisted living as a larger system is made up of unique subsystems, having their own structure and issues, which are organized around professional groupings like the social services staff, nursing staff, and the administrative staff (Golant, 2008). This framework recognizes the exchanges
between the subsystems by examining the regularity, predictability, and the quality of the patterns of interaction (Hargrave & Hanna, 1997).

Strongly organized families in an assisted living can also form a separate coherent subsystem, interacting with other subsystems within the ecosystem. However, when a family system of caring for elderly family members and a professional system of care overlap, there exists the potential for conflict in such situations, which needs to be identified and addressed for meaningful partnerships to develop.

Kahana, Kahana, Johnson, Hammond, and Kercher (1994) suggest that caregiving occurs within a complex social ecology, emphasizing that more attention needs to be focused on both the personal caregiving context and the social caregiving context. Also, it is crucial to examine how a family can continue functioning as a close-knit family network, sustaining relationships and mutual interdependency through roles and contributions despite the institutionalization of elderly family member(s).

Another factor, as identified by some participants of this study, involved an elderly family member’s relocation from their home-town and state to an assisted living facility in a different city and state, in order to be in close residential and physical proximity to a caregiving family member, typically an adult child and their family. This geographical and residential transition generates a double effect that can be assessed within a systems/ecological framework, because it relates to a change in the external and internal environments that many elderly couples or an elderly parent are suddenly thrust in to cope with on a daily basis.
Hence, a systems/ecological framework not only provides a context for hierarchically organizing and accessing interpersonal relationships in old age, but also draws attention to how environmental and internal factors and characteristics, influence family involvement, especially in an assisted living setting. A combination of systems and ecological perspectives can help to identify ways to maintain a balance between environmental pressures and individual capacities by identifying interventions that can maximize optimal functioning, which can only occur when elderly care-receivers’ and their family caregivers’ behavioral and psycho-social needs are met (Cox, 2005).

**Implications for Gerontological Research and Education**

Early gerontological research assumed a very negative focus on aging, which was largely defined as a biomedical problem. Accordingly, research studies were mostly focused on pathologies and stress related to physical and mental limitations of elders living in nursing home settings (Whitlatch, Schur, Noelker, Ejaz, & Looman, 2001). With respect to family caregiving and care-receiving in the long-term care system, there is a clear need for research efforts that focus on how caregivers, care-receivers, and staff personnel interact and fulfill their roles, particularly within the context of less institutionalized environments, such as assisted living facilities. Limited research in these settings on caregiver response is available but additional research is needed. Exploring how family roles and relationships are maintained and facilitated within institutional long-term care constitutes an imperative research agenda with significant implications.

Researchers have consistently focused on family caregiving, with stress and burden being the primary features of most caregiving models and studies (Brodie &
Research on care-receivers has revealed that physical, psychological, environmental, and functional dimensions greatly affect institutionalized elderly individuals’ quality of life (Andrews, 1986; Arnold, 1991; Kane, 2001). Transitioning to a long-term care facility requires major adjustments and management of specific internal and external environmental demands (Greene, 2008). As was evident from this study’s findings, both care-receiving and caregiving participants’ experiences reflected on this struggle for letting go, as well as maintaining and valuing autonomy within an institutionalized care environment.

Personal autonomy and control in long-term care decision making has important implications for care-receivers, their respective family caregivers, and also long-term care providers. Research has documented the important link between exercising autonomy and maintaining prolonged physical and cognitive functioning (Zarit & Braungart, 2007), which becomes even more pronounced in institutionalized settings. Available findings have indicated that opportunities to participate in and exercise control over decisions have led to improved adaptation and socio-emotional and psychological well-being (Greene, 2008). Hence, more comprehensive and three-dimensional research studies that focus on autonomy and control and explore such processes and changes among care-receiving residents and within their respective caregiving family systems, along with their reciprocal exchanges with the assisted living system are essential.

The complexity of adjustment to assisted living, the reorganizing and redefining of family roles with respect to environmental changes, and negotiating relationships with
the assisted living staff, health personnel, and other residents emerged as challenges for the care-receiving and the caregiving respondents of this study. Very limited research has focused on the quality of life in assisted living and the quality of assisted living staff, which can impact both care-receivers and family caregivers (Gaugler & Kane, 2007; Stone, 2008). Hence, in-depth research on the types of partnerships that are created between assisted living staff, elderly residents, and family caregivers needs to be rigorously developed and implemented. Additionally, intervention research, which includes pilot programs that assist family members, assisted living staff, and care-receivers, as they transition and adapt to residential long-term care are vital to quality of life and quality of service.

Assisted living is a bridge to fill the gap between home care and nursing home care within the continuum of long-term care. The specific nature of this gap with respect to when nursing home care is required has been expanding over the past decades to incorporate assisted living’s inclusion of more dementia care (MetLife, 2008). Findings from this study, therefore, indicated that discriminatory practices against elders suffering from cognitive and other disabilities within assisted living facilities, impacts care-receiver and caregiver roles and relationships. More research that draws attention to this discrimination and provides solutions to this dilemma must be increasingly funded and conducted.

Many care-receiving and caregiving participants in this study perceived their roles as being reversed. However, it is essential to help family caregivers and care-receivers clearly understand and express this changing nature of their roles. For example, many
gerontologists have noted that the concept of “role reversal” can lead to infantilization of older adults. Therefore, more research is needed on understanding such role changes in family systems. A sustained focus on supporting caregivers and empowering elderly residents in long-term care facilities is absolutely critical to dealing with feelings of guilt and burden experienced by most care-receivers and their caregiving family members.

Recently, a number of gerontologists have also assumed a positive stance, urging a reintroduction of social concerns related to caregiver well-being, and an emphasis on autonomy, personal efficacy, and empowerment of elderly residents (Cox, Green, Seo, Inaba, & Quillen, 2006). More studies of resilience among older adults, who have successfully adapted to the long-term care environment, that examine their sense of continuity, competence, and their inherent ability to bounce back in life, are essential to support this trend (Park, 2009). A focus on resilience has been “associated with effective problem solving, emotional coping, personal competence, and acceptance of self and life” (Garity as cited in Greene, 2008, p. 150). Emphasizing resilience can draw attention to how family members interact and relate to each other in coping with change and stress, and can help to uncover how they make sense of a difficult situation and grow from it.

Furthermore, even as the American society is becoming more multicultural, a research focus on diverse ethnic populations has included some available studies that have only focused on the psychological and physical health of caregivers (Pinquart & Sorensen, 2003). However, critical issues of quality and accessibility to long-term care, cultural and gender-based differences, and care preferences of minority elders and their families, and their impact on caregiving practices and patterns have largely remained
unexplored (Hernandez & Newcomer, 2007). This is relevant to our discussion, because most elderly African-Americans, Mexican Americans, and Asian Americans who are 65 years and over, prefer to give and receive care in their homes and are more likely to rely on their relatives and friends over other alternatives (Herrera, Lee, Palos, & Torres-Vigil, 2008). More in-depth research on family caregiving roles and patterns among minority groups underline the need for culturally competent long-term care services. Hence, individual preferences for services, family relationships and roles, and other interactions need to be understood within the context of their ethnic and racial background.

Most minority elders receive lower quality health care than White elders, who are reported to have better access to new procedures and other specialized care services. White elders are more likely to be able to afford living in larger and newly modeled assisted living facilities, when compared to African-American, Hispanic, and other minority elders, who have typically used smaller board and care homes (William, Desai, Rurka, & Mutran, 2008). According to some researchers, health and functional disparities among racial and ethnic elderly groups have depended upon variations in socioeconomic resources, access to health care treatment, region of birth within the United States, and also the country of origin for recent immigrants. Such disparities need to be addressed and reduced (Borrell, 2008; Crimmins, Hayward, & Seeman, 2004).

So far, caregiving research has focused on understanding caregiving efforts and their implications for gerontological social work practice, caregiver roles, and gender-based inequities due to caregiving responsibilities that fall disproportionately on women, as well as developing structured interventions to help caregivers (Berg-Weger & Tebb,
2004; Feinberg & Newman, 2004; Wallhagen & Yamamoto-Mitani, 2006). Most of this research has, however, been conducted within nursing homes instead of assisted living facilities (Carpenter, 2002; Stone & Clements, 2009). The areas of research suggested above are critical to social work intervention, development, and social work education. A medical model of intervention in aging research is to some extent related to a limited focus on self-efficacy based behaviors and opportunities, strengths, and multi-cultural understanding. Additional research is, therefore, required to develop and provide culturally-sensitive care to institutionalized elders within assisted living facilities.

**Implications for Social Work Practice**

As a growing proportion of the American population survives into old age, an explosion in demand for long-term care options, such as assisted living seems inevitable, resulting in major implications for social work and health care practitioners. Gradual or sudden age-related, physical and cognitive impairments bring about a significant change or a set of individual, familial, and environmental transitions in an older person’s life. Functional changes, such as, becoming wheelchair dependent, may necessitate changes in living arrangements for most elders. Hence, an increasing number of elderly care-receivers and their families need proper guidance in locating a residential long-term care facility that will provide formal, yet personalized care. Social workers have the important role of providing guidance, support, and advocacy, and can mediate between elderly residents, their family caregivers, and the institutional caregiving system. Physical or
social transitions need to, therefore, be understood as processes rather than a point in an elderly resident’s life, which are influenced by the long-term aspects of living with chronic conditions or a disability (Institute of Medicine, 2007).

Sudden life changes that may be brought on by the death of a spouse or an illness may cause older adults to lose confidence and become vulnerable. Well balanced communication, which is based on clear and positive expectations, flexibility, and emotional commitment are critical to elderly care-receiver and family caregiver relationships and experiences of caregiving (Merz, Schuengel, & Schulze, 2009). In this study, physical disabilities including the loss of vision, and mobility restricted some elderly participants’ will to assert self-efficacy, or even communicate their preferences in an assisted living context, which also influenced caregiver experiences of family involvement. Social workers can empower and engage elderly residents to communicate their expectations and to realize their role and potential strengths within their families and assisted living facilities, which is critical to elderly residents’ overall well-being, and to their mutual involvement with their caregiving family members. However, it is important to note that processes that contribute to partnering and empowering elderly residents need to be negotiated with them on their own terms, instead of being controlled or forced (Tanner & Harris, 2008).

Moreover, a renewed effort to confront negative cultural attitudes towards care-receiving residents and caregiving family members that are reflected in poor standards of practice is equally important (Iecovich & Lev-Ran, 2006). Hence, social workers can help elderly family members’, their respective family systems, and the assisted living
system, to identify elderly residents’ strengths and roles, recognize their personal and social worth, and create opportunities for their further involvement in their families and communities, which can contribute to relieving caregiving family members’ experiences of stress and burden.

Some study participants perceived care receivers’ role as being very limited. Physical and cognitive limitations also had an impact on elderly residents’ willingness to build new relationships with other residents and assisted living staff members. This finding suggests that it is highly important to be sensitive to elderly residents’ physical and cognitive impairments by confronting biases and negative stereotypes, facilitating social exchanges, and including a social skills training agenda in assisted living facilities. Social workers can help caregiving family members and staff personnel to support elderly residents in assisted living facilities, to maintain their lifestyles in as similar a pattern as possible, because it can lead to improved adaptation and social functioning, and promote better family functioning.

A majority of the caregiving participants in this study were women. Traditionally, even as families in the United States have been held responsible for their elderly relatives, the women in these families are considered the primary caregivers for the elderly. Increasing demands on women in terms of family, employment, and other social responsibilities, when coupled with caregiving, affect their ability to provide care and isolate many women from meaningful activities and rewards. Hence, many caregiving women experience emotional, physical, and financial costs, which only add to their feelings of guilt and self-doubt. In response, social work practice can help to develop and
advocate for more inclusive, load-sharing, and participatory long-term care models, which will help to enhance women’s economic roles in order to ensure their full familial, social, and political participation.

Social work practice also includes advocacy for family systems that are collaborating with the institutional long-term care system, by raising issues resulting from bureaucratic regulations and institutional protocol (Levine & Kuerbis, 2002; Malench, 2004). As evident from this study’s findings, adult caregiving children are involved in managing care, as well as their elderly parents’ bank accounts and complicated investments, and maintaining medical and financial records, in order to help their elderly family members understand the future ramifications of their financial assets. The complexity of these challenges was illustrated by the experiences of families in this study. Meeting these challenges is a huge undertaking for many adult children who are shouldering other family responsibilities, but have to simultaneously keep up with the cumbersome task of constantly monitoring the paperwork required for Social Security, Medicare, and Medicaid policies, because of its changing language and revisions.

Hence, social workers can ensure that by including elderly members in detailed and open family conversations, family systems can carefully plan for future options and continue to move ahead in the caring process. Social workers also need to understand the personalities and the history of relationships and interactions between family members, before taking a service-focused approach to care-receiving and caregiving (Bumagin & Hirn, 2001). Social work practice can, therefore, help to identify a wide range of factors that impact elderly residents’ quality of life, as well as their family’s involvement in their
care within the assisted living system, and serve as a basis for more effective advocacy related to changing any situations or exchanges that may cause conflict. Finally, even as the various responsibilities of social workers have been identified in this section, the role of gerontological social work practice within residential long-term care facilities, such as assisted living needs to be clearly defined and developed, because it differs from state to state.

**Implications for Policy**

Policy development and implementation, as it relates to options in both health care and housing for the elderly is a significant concern in this country. For example, as a result of the complicated structures and funding mechanisms provided by the Medicare and Medicaid programs, the current institutional long-term care system confounds most care-receivers and their family members with a fragmented array of health, social service, and financial entitlement programs that fall short of meeting critical needs (Estes, 2001, Jurkowski, 2008). In a few cases, study participants who were interviewed, raised concerns regarding policy issues that were specifically related to assisted living facilities. The facilities that were recruited in this study were primarily private pay assisted living facilities, with 2 facilities that housed elders, who were on Medicaid. 5 participants in this study, which included both care-receiving elders and their respective caregivers, drew attention to the challenges related to making assisted living more affordable. These challenges included financial planning to help elderly relatives to continue to afford living within assisted living facilities, which becomes increasingly difficult in light of growing out-of-pocket costs that are needed to pay for housing and services within
assisted living. For example, one elderly participant had shared how a long-term care continuum had encouraged him and his disabled wife to buy an independent living cottage and had promised to buy back the cottage from them, once they began to require more assistance and needed to transition to assisted living. However, even after moving to the assisted living facility, this participant was considerably stressed because the long-term care continuum had refused to buy back their cottage, because of the current economic conditions. Instead, he was responsible for selling the cottage on his own to continue to financially provide for long-term care services within assisted living. Hence, frail older persons may become especially vulnerable as they transition within the long-term care continuum. Furthermore, ethical institutional long-term care practices and standards are essential to alleviating perceptions of considerable financial strain and dependency.

Transitioning to a long-term care facility is a turbulent period for not just the elderly family members, but also their caregiving family members. Stringent regulations and a lack of coordination among care providers can subject older adults to the loss of needed services, duplication, conflicting treatments, and increased stress (Parry et al. as referred to in Institute of Medicine, 2008). A strong sense of isolation, discontinuity, and role loss, along with feelings of uselessness and boredom among care-receiving residents urgently need to be addressed, because they obstruct aging in place, which affects family interactions and participation (Frank, 2002).

More specifically, cultural values are increasingly being embraced as part of a cultural change movement within residential long-term care facilities, which include
policies for creating a respectful, supportive, and pleasant long-term care environment; sensitive care provision; quality interventions; reciprocal interactions with the broader community; and an ethical and participatory decision-making process for older residents and their family caregivers (Fahey, 2003). Both care-receiving and caregiving participants in this study reiterated the importance of maintaining autonomy and safety, along with creating a respectful and an empowering environment, even as elderly family members lived within assisted living facilities. Hence, social work policy experts and lobbyists can be invaluable to this process. Moreover, advocates need to be actively involved with key advocacy organizations such as American Association of Retired Persons, the National Association of Homes and Services for the Aging, and the National Institute for Nursing Home Advocacy, and with the cultural change movement at work in many states, which specifically addresses issues related to assisted living on federal, state, and service delivery systems levels.

Finally, as formal care is becoming increasingly expensive, an over-reliance on institutional long-term care options increases public expenditure, and the demand for developing innovative programs and resources to help and support the caregiving and care-receiving family members of our society (Caron & Bowers, 2003). Hence, supporting family caregivers and their elderly relatives needs to become a national priority. Policy advocacy that supports family involvement; client efficacy; and care-receiver, caregiver, and staff exchanges must be increased at all policy levels.
Maintaining a clear focus on understanding the nature and scope of the care-receiving and the caregiving processes, within the long-term care context has important implications for organizing the delivery of needed services, and reimbursement benefits.

**Limitations of this Study**

In this study extensive and detailed information was gathered from a relatively small number of participants, as is typical of a qualitative study. One of the drawbacks to this study was the inability of the researcher to acquire a more diverse study sample. Elderly residents and only their primary caregivers were included in this study. Perspectives on family involvement of caregivers and elderly residents in other institutionalized care settings, such as nursing homes, could not be examined in this study.

A relatively small sample that lacks diverse perspectives and experiences limits the findings of this study. The primary setting for this study is Colorado Springs, which also limits the sample and its potential diversity. Since each participant’s experience is very subjective and dependent on their circumstances, family history, and background, this study was not able to capture how the participants’ differed from those who chose not to participate in this study. However, despite an attempt to select study participants from different kinds of assisted living facilities in terms of their location and size, this study was limited in its size and diversity.

This study interviewed elderly residents within the assisted living system, who were privately paying for assisted living care and services. However, this study did not include or reflect on the experiences of those care-receivers who have had to move out of
assisted living facilities, because they could no longer afford to live there, or even discuss
the experiences of the many elders who are unable to access quality residential care.

This researcher had to go through the assisted living managers and supervisors to
recruit participants for this study. Some assisted living facilities had to acquire
permission from their executive board or owners. Other assisted living facilities
stipulated that permission needed to be sought from family members before this
researcher could interview any elderly resident. Elderly residents should have the right to
make their own informed decision about participating in research studies, or any other
activities. The researcher should be able to directly contact the elderly residents to invite
them to participate in the study.

Finally, this researcher recognizes the importance of examining multiple
perspectives that represent other significant relationships in a family. This study did not
take into consideration the experiences of multiple family members or caregivers, such as
other adult children who were living at a distance or in another state. Hence, it is
important to understand family involvement by exploring the differing perceptions of
multiple members’ roles and relationships in their families.

Conclusion

Family roles and relationships are persistent, and are rooted in family traditions
and norms. Elderly family members are an important link to our collective past and have
immensely contributed to the well-being of their families and communities. As evident
from this study, even as a growing number and proportion of older adults advance in age,
and their needs for care and assistance increase, American family systems, in spite of
demonstrating a strong commitment and willingness to be involved are under considerable pressure, in terms of their capabilities and resources to support and provide for elderly family members.

However, due to a growing demand for public and private assistance, and federal- and state-level programs and services for older adults, expectations governing the role of family members have changed in the recent decades (Conner, 2000). In this context, assisted living facilities continue to carve their way into this continuum, with connections to both health and housing policy (Golant, 2006). Roles and relationships that are established within an assisted living system have a profound impact upon the quality of life of the care-receiving residents and their families. This study established that within the assisted living context of care, family caregiving relationships and roles pertaining to personal and instrumental care change and create both relief and stress, but continue to be very apparent and essential, and need to be explored in relation to elderly care-receiving residents’ roles, relationships, perspectives, and experiences.
References


Appendix A

Care-receiver Informed Consent Form

Family Involvement Within Assisted Living: Caregivers and Care-Recipients’ Roles and Relationships

You are invited to participate in this qualitative research study. The purpose of this study is to investigate your experiences and perspectives regarding your family involvement, as you live in an assisted living facility. This study is being conducted to fulfill the requirements of a doctoral degree in social work from the University of Denver. The study is conducted by Rachel V. Solomon, MSW, who can be reached at 719-360-0468/rsolomon@du.edu. This research project is supervised by Dr. Jean East, Associate Professor, Graduate School of Social Work, University of Denver, Denver, CO 80208. The supervisor can be reached at 303-871-2870/jeast@du.edu.

Participation in this study should take about sixty to ninety minutes of your time. Participation will involve face-to-face interview sessions, which will be held at a time and place of your convenience. Your participation is strictly voluntary. The risks associated with this project are minimal. If, however, you experience discomfort you may discontinue the interview at any time. We respect your right to choose not to answer any questions that may make you feel uncomfortable. Refusal to participate or withdrawal from participation will involve no penalty or loss of benefits to which you are otherwise entitled.

Your interview responses will be audio-taped and then transcribed. The transcribed responses will be identified by a code number only and will be kept separate from information that could identify you. This is done to protect the confidentiality of your responses. Only the researcher will have access to your individual data and any reports generated as a result of this study will use only group averages and paraphrased wording. All of the information collected from you, including the audio recordings and the transcribed data will be kept in a locked file cabinet. However, should any information contained in this study be the subject of a court order or lawful subpoena, the University of Denver might not be able to avoid compliance with the order or subpoena. Although no questions in this interview address it, we are required by law to tell you that if information is revealed concerning suicide, homicide, or child abuse and neglect, it is required by law that this be reported to the proper authorities.

There are benefits to participating in this study. Results of the study will be used to educate other families and the assisted living systems about the issues concerning family involvement, as well as to suggest some ways to improve and increase the level of family involvement within the regulatory and administrative structure of assisted living environments.
If you have any concerns or complaints about how you were treated during the interview, please contact Susan Sadler, Chair, Institutional Review Board for the Protection of Human Subjects, at 303-871-3454, or Sylk Sotto-Santiago, Office of Research and Sponsored Programs at 303-871-4052 or write to either at the University of Denver, Office of Research and Sponsored Programs, 2199 S. University Blvd., Denver, CO 80208-4820.

Please return the consent form to me after you have completed it. You may keep this page for your records. Please sign the next page if you understand and agree to the above. If you do not understand any part of the above statement, please ask the researcher any questions you have.

I have read and understood the foregoing descriptions of this research project. I have asked for and received a satisfactory explanation of any language that I did not fully understand.

I agree to participate in this study, and I understand that I may withdraw my consent at any time. I have received a copy of this consent form.

Signature _____________________ Date __________________

(If appropriate, the following must be added.)

___ I agree to be audiotaped.

___ I do not agree to be audiotaped.

Signature _____________________ Date __________________
CARE-RECEIVER SOCIODEMOGRAPHIC INFORMATION

_________ Male

_________ Female

_________ Age

Is your race or ethnicity

_________ Caucasian

_________ African-American

_________ Hispanic American

_________ Native American Indian

_________ Other

Are you currently

_________ Married

_________ Divorced

_________ Separated

_________ Widowed

_________ Never been married

How long have you lived in this assisted living facility?

_________ Years  _________ Months

If you would like to know the results of this research study, please write your mailing address or your email address below.
Appendix B

Caregiver Informed Consent Form

Family Involvement Within Assisted Living: Caregivers and Care-receivers’ Roles and Relationships

You are invited to participate in this qualitative research study. The purpose of this study is to investigate your experiences and perspectives regarding your family involvement with your elderly relative who is residing in an assisted living facility. This study is being conducted to fulfill the requirements of a doctoral degree in social work from the University of Denver. The study is conducted by Rachel V. Solomon, MSW, who can be reached at 719-360-0468/ rsolomon@du.edu. This research project is supervised by Dr. Jean East, Associate Professor, Graduate School of Social Work, University of Denver, Denver, CO 80208. The supervisor can be reached at 303-871-2870/jeast@du.edu.

Participation in this study should take about sixty to ninety minutes of your time. Participation will involve face-to-face interview sessions, which will be held at a time and place of your convenience. Your participation is strictly voluntary. The risks associated with this project are minimal. If, however, you experience discomfort you may discontinue the interview at any time. We respect your right to choose not to answer any questions that may make you feel uncomfortable. Refusal to participate or withdrawal from participation will involve no penalty or loss of benefits to which you are otherwise entitled.

Your interview responses will be audio-taped and then transcribed. The transcribed responses will be identified by a code number only and will be kept separate from information that could identify you. This is done to protect the confidentiality of your responses. Only the researcher will have access to your individual data and any reports generated as a result of this study will use only group averages and paraphrased wording. All of the information collected from you, including the audio recordings and the transcribed data will be kept in a locked file cabinet. However, should any information contained in this study be the subject of a court order or lawful subpoena, the University of Denver might not be able to avoid compliance with the order or subpoena. Although no questions in this interview address it, we are required by law to tell you that if information is revealed concerning suicide, homicide, or child abuse and neglect, it is required by law that this be reported to the proper authorities.

There are benefits to participating in this study. Results of the study will be used to educate other families and the assisted living systems about the issues concerning family involvement, as well as to suggest some ways to improve and increase the level of family involvement within the regulatory and administrative structure of assisted living environments.
If you have any concerns or complaints about how you were treated during the interview, please contact Susan Sadler, Chair, Institutional Review Board for the Protection of Human Subjects, at 303-871-3454, or Sylk Sotto-Santiago, Office of Research and Sponsored Programs at 303-871-4052 or write to either at the University of Denver, Office of Research and Sponsored Programs, 2199 S. University Blvd., Denver, CO 80208-4820.

Please return the consent form to me after you have completed it. You may keep this page for your records. Please sign the next page if you understand and agree to the above. If you do not understand any part of the above statement, please ask the researcher any questions you have.

I have read and understood the foregoing descriptions of this research project. I have asked for and received a satisfactory explanation of any language that I did not fully understand.

I agree to participate in this study, and I understand that I may withdraw my consent at any time. I have received a copy of this consent form.

Signature _____________________ Date _____________________

(If appropriate, the following must be added.)

___ I agree to be audiotaped.

___ I do not agree to be audiotaped.

Signature _____________________ Date _____________________
CAREGIVER SOCIODEMOGRAPHIC INFORMATION

_______ Male
_______ Female
_______ Age

Is your race or ethnicity
_______ Caucasian
_______ African-American
_______ Hispanic American
_______ Native American Indian
_______ Other

Are you currently
_______ Married
_______ Divorced
_______ Separated
_______ Widowed
_______ Never been married

What is the nature of your relationship with your elderly relative?

____________________________________

If you would like to know the results of this research study, please write your mailing address or your email address below.
Appendix C

In this study, a phenomenological approach helped to derive comprehensive individual descriptions that provided the essence of elderly residents’ lived experiences, as well as their family caregivers’ experiences. A major assumption of this qualitative study was that most family members continued to willingly stay involved in caring and supporting for their institutionalized elderly relatives. Another assumption of this study was that being able to afford care within an assisted living facility is highly expensive, because it is mostly private pay. Yet another assumption was that care-receiving elders contribute to their families in many ways through their involvement, in terms of their relationships and roles. There is a dearth of qualitative research studies that have represented care-receiving residents’ understandings and perspectives, along with their primary family caregivers’ experiences. The researcher assumed that elderly care-receivers are engaged in several familial and social roles, which is central to their experiences of family involvement.
Appendix D

Care-receiving Resident Interview Guide

1) Introduce the study
2) How did you come to be living here?
3) Do you like living here?
4) What is it that you like or dislike about living here?
5) Tell me about your family members and your relationship with them?
6) Tell me specifically how your family members are involved in your life now that you are living here?
7) How has your role in family changed now that you are living here?
8) How has the assisted living staff and administration detracted from or supported your roles and relationships within your family and within the assisted living facility?
9) How can the assisted living staff and administration facilitate more involvement between you and your caregiving family members?

Key Focus Areas of Interview

1) Elderly residents’ Perception of their Family Involvement

- Family Relationships
  - Nature of relationships
  - Quality of relationships
- Role Fulfillment within your Family
  - Types of role fulfillment
  - Frequency of role fulfillment
- Obstacles to Attaining Active Family Involvement
  - Assisted Living Policies & Regulations
  - Assisted Living Staff Attitudes’ & Behaviors
  - Assisted Living Environment
  - Sense of Community & Belongingness
- Strategies to Overcome Barriers and Promote Family Involvement

2) Elderly residents’ perception of their Primary Family Caregiver(s) Involvement

- Primary Caregiver’s level of Involvement
- Support from other family members’
- Assisted Living Support programs to assist caregivers’
- Policies that restrict more caregiver involvement
- Suggestions to help improve and enhance family involvement
Appendix E

Family Caregiver Interview Guide

1. Does your elderly relative like living in an assisted living facility?
2. How has your elderly relative’s residence in assisted living had an impact on your involvement in their care process?
3. How has living in an assisted living facility had an impact on your elderly relative’s level of family involvement?
4. How has caring for your elderly relative(s) in assisted living affected your mutual involvement, as well as your involvement with other family members, with respect to family relationships and role fulfillment?
5. How has the assisted living staff and administration detracted from or supported your involvement with your elderly family member(s)?
6. How can the assisted living staff and administration facilitate more involvement between your elderly relative(s) and you, as well as other members of your family network?

Key Focus Areas of Interview

1) Primary family caregiver’s perception of their family involvement

- Family Relationships
  - Nature of the relationship
  - Quality of the relationship
- Role Fulfillment
  - Type
  - Frequency
- Obstacles to Attaining Active Family Involvement
  - Assisted Living Policies & Regulations
  - Assisted Living Staff Attitudes’ & Behaviors
  - Assisted Living Environment
  - Sense of Participation
- Strategies to Overcome Barriers and Promote Family Involvement

2) Primary caregiver’s perception of their elderly relative’s family involvement

- Elderly relative’s level of Involvement
- Sense of Freedom & Flexibility to stay involved
- Assisted living Policies that restrict more care-receiver involvement
- Suggestions to help improve and enhance family involvement