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Changing Places: Adult Children and the Transition of Aging Parents

Sarah Martin Gilbert

A dissertation submitted to the faculty of the Medical University of South Carolina in partial fulfillment of the requirements for the degree of Doctor of Philosophy in the College of Nursing

October 21, 2014

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## Acknowledgements

This journey and its ultimate reward would not have been possible without the love, support, kindness, and mentoring of my committee. Drs. Elaine Amella and Barbara Edlund have been my advisors, my colleagues, and my friends. They have demonstrated to me what excellence and passion in nursing and teaching can and should be. Dr. Lynne Nemeth has been my light and muse on this first journey through qualitative research and encouraged me to “see” what my participants were telling me. I am grateful for her patience and her wisdom. Finally, Dr. Virginia “Ginger” Burggraf who has sometimes quietly and sometimes vociferously pushed me to be a better nurse, student, teacher, wife and mother, I have learned so much from you and vow to continue to write, research, teach, and advocate to advance the care of the older adult.

To my husband, Thad, my son Sam, and my sister Caroline (Sissy), your ever present encouragement and praise elevated me through this program. I am thankful for your presence in my life and the unconditional love you have given.

To the rest of my family and friends, thank you for your forgiveness for birthdays missed, cards and phone calls not returned, and for letting me know you were there for me. I am truly blessed to be so loved.

Finally, in memory of my mother, Vivian and my father, Sam. You instilled in me a love and passion for learning, for laughing, and for caring and kindness toward others. I was humbled by your bravery and courage in your final days. Thank you for allowing me the honor of being your nurse and caring for you the way you cared for me...with Everlasting Love.

## **Changing Places: Adult Children and the Transition of Aging Parents**

### **Abstract**

**Purpose:** This dissertation analyzed measurement of relocation transition in older adults, assessed research for the manner in which older adults make the decision to move, and the adult child's role in the transition of their aging parents.

**Design:** Using Hawker, Payne, Kerr, Hardey, & Powell's (2002) mixed research review method, two integrative reviews were conducted. The first examined how relocation transition is measured in the literature while the second applied the Theory of Planned Behavior (Ajzen, 1985) to determine the behavioral beliefs, subjective norms, and perceived behavioral control of older adults as they contemplate a relocation from independent living to supervised housing. Finally, qualitative semi-structured telephone interviews were conducted using questions framed by Symbolic Interaction Theory (Blumer, 1969).

**Conclusion:** Measurement of relocation transition in older adults was defined by three distinct stages: Planning the Move, Physical Move, and Adaptation. Older adults' whose behavioral beliefs about relocation were optimistic and hopeful and who participated in the relocation decision-making process experienced more positive transitions during relocation. Additionally, family members, especially adult children, provided the older adult with assistance and advice throughout the process. However, little is known about how the relocation transition experience impacts the adult child. Qualitative interviews with adult children revealed two themes: Changing Places and Everlasting Love.

**Clinical Relevance:** Adult children often accompany their aging parent(s) to health care providers, acute and skilled nursing care facilities. Collaboration and communication with the

adult child and older adult allows for patient-centered goal setting and dialogue about the living environment and safety of the aging parent(s). Health care providers' recognition of and respect for the adult child's role as caregiver not only fosters better communication and outcomes for the older adult but also may contribute to improved health and well being of the caregiver.

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## **Introduction to Dissertation: Changing Places: Adult Children and the Transition of Aging Parents**

The global population of older adults is rising dramatically. Not only have advances in health care, improved nutrition and housing, and public health initiatives improved life expectancy worldwide but also decreases in fertility rates and infant mortality over the last 60 years have resulted in large numbers of people living well into old age (Correia et al., 2012; Crimmins, Preston, & Cohen, 2011; United Nations Population Fund & HelpAge International, 2012). However, living longer has its challenges such as decreased function, impaired cognition and chronic conditions. According to the World Health Organization, the four most prevalent chronic illnesses worldwide are cardiovascular disease, cancers, chronic respiratory disease, and diabetes (World Health Organization, 2014). These data are also relevant to the United States and with the inclusion of Alzheimer's Disease, these chronic diseases are the leading causes of death in adults over the age of 65 (Centers for Disease Control and Prevention, 2013). Increased longevity also means that older adults are living with the consequences of chronic disease. Diminished mobility, cognitive declines, loss of vision or hearing, and physical effects of medications or disease processes place the older adult at risk for losing their independence and having to rely on family to support their day-to-day needs.

The ravages of chronic illness and their concomitant physical and cognitive declines impact the older adult's ability to live independently and consequently, their need for assistance becomes more acute and often leads to the need to relocate. Some older adults relocate to a higher level of care such as a retirement community, supervised housing, assisted living, or nursing home (Bekhet, Zauszniewski, & Nakhla, 2009; Carpenter et al., 2007; E. Walker &

McNamara, 2013). Many others elect to remain in their homes with environmental adaptations and/or in-home care (Carpenter et al., 2007; Gitlin, Szanton, & Hodgson, 2013; Tang & Pickard, 2008).

At the forefront of maintaining the older adults' independence and quality of life are the unsung heroes of caregiving: adult children. Adult children become involved in the older adult's care when functional and cognitive declines precipitate increased participation in the oversight and supervision of the parent's life. Instrumental activities of daily living such as, paying bills, grocery shopping, meal preparation, driving, and medication management are often assumed by the adult child and, as function and cognition diminish, personal care or activities of daily living are assumed by the adult child caregiver (Cagle & Munn, 2012; Feinberg, Reinhard, Houser, & Choula, 2011; Hagan, 2013; Khalaila & Litwin, 2011; Schultz & Sherwood, 2008).

### **Significance of the Problem**

Although many older adults can and do live independently with or without a spouse, many require the assistance of others. In 2013, 57% of noninstitutionalized older adult couples lived independently and 28% of single or widowed older adults lived alone (Administration on Aging, 2013). While only 3.5% of older adults lived in supportive housing such as nursing homes, institutionalization increases with age (Administration on Aging, 2013). Reasons for relocation are numerous and encompass the physical, cognitive, and emotional needs of the older adult (Bekhet et al., 2009; Granbom, Lofquist, Horstmann, Haak, & Iwarsson, 2014; Jungers, 2010; Krout, Moen, Holmes, Oggins, & Bowen, 2002; E. Walker & McNamara, 2013).

According to the Congressional Budget Office, 82% of older adults with functional and/or cognitive limitations reside in the community with support provided predominantly by informal caregivers (Hagan, 2013). Most caregivers are female (66%) and if employed, are likely

to be African-American (21%) or Hispanic (20%). A typical caregiver in the United States is female, 49 years old, employed, and devotes 20 hours per week tending to her mother (Shell, 2014). Aging parents or parents-in-law are the most common care recipients (72%) and were still residing in their own homes (51%) or with the caregiver (29%) (Shell, 2014). Adult children caregivers assist with Instrumental Activities of Daily Living (IADLs) such as transportation, medication administration, shopping, finances, housekeeping, laundry, and meal preparation in addition to more personal Activities of Daily Living (ADLs) such as bathing, dressing, feeding, transferring, and toileting (Feinberg et al., 2011; Mathew Greenwald & Associates, 2009). These responsibilities can take an emotional and physical toll on the caregiver leading to a decline in physical health, decreased socialization, and higher prevalence of depression and perceived stress (Cagle & Munn, 2012; Feinberg et al., 2011; Khalaila & Litwin, 2011; Schultz & Sherwood, 2008).

Some adult children must provide caregiving support from a distance due to employment and family obligations. Long-distance caregivers (LDC) assist with financial management and support, coordinate care for a distant parent, and plan for future care needs (Bevan, Vreeburg, Verdugo, & Sparks, 2012; Cagle & Munn, 2012). Geographical distance between the child and parent can be mitigated by relocation of the parent to live with the adult child or reside nearby (Hays, 2002). Some families make relocation decisions cooperatively, deciding what is best for the family unit. This could result in either the older adult or the adult child relocating so that care needs can be addressed (Zhang, Engelman, & Agree, 2012).

The economic impact of caregiving is alarming. In 2011, the estimated value of unpaid family caregiving in the United States for individuals 65 years and older was \$234 billion (Hagan, 2013). Thirty-two percent of adult children have provided financial assistance to their

aging parents to pay for household goods, food, transportation, medications, and medical co-pays at an annual out-of-pocket cost of \$5,531 per year (Evercare, 2007). Adult children with incomes of \$50,000 or less were more likely to subsidize an aging parent's living expenses (44%) than those with higher earnings (23%) (Parker & Patten, 2013).

Not only is caregiving for an aging parent costly for the adult child but it is also costly for employers. Working caregivers were more likely to have increased stress, greater health risk behaviors, and more absenteeism which cost employers \$13.4 billion annually (Met Life Mature Market Institute, National Alliance for Caregiving, & Aging, 2010). Additionally, adult sons and daughters can expect to lose an average of \$303,880 in wages, pensions, and Social Security benefits due to withdrawal from the work force because of caregiving responsibilities (MetLife Mature Market Institute, 2011).

### **Knowledge Gaps**

Research on adult children who participate in the relocation transition process with their parent(s) is scant. Many studies focus on the burdens of caregiving, the process of relocation, level of assistance provided to the parent, or caregiving from a distance (Bevan et al., 2012; Cagle & Munn, 2012; Dhar, 2012; England & Tripp-Reimer, 2003; Katz, Gur-Yaish, & Lowenstein, 2010; Pereira & Bothelo, 2011; Rodgers, 1997). Additionally, there is little evidence in the literature that chronicles the witnessed progression of cognitive and functional decline through the eyes of the adult child. These cues provide a window into the future care needs of the older adult. Early recognition of the loss of skills that could impinge on the older adult's ability to live independently would allow the adult child time to research and discuss treatment and living options with health care professionals and begin relocation discussions with the parent(s).

While some older adults recognize their declining health and abilities and elect to relocate to a dependent care environment, others are forced to move due to an emergent event, such as a serious fall, stroke, prolonged hospitalization or skilled nursing stay (Fraher & Coffey, 2011; Johnson, Popejoy, & Radina, 2010; Leggett, Davies, Hiskey, & Erskine, 2011; Saunders & Heliker, 2008; Sviden, Wikstrom, & Hjortsjo-Norberg, 2002; C. Walker, Curry, & Hogstel, 2007). Inability of the older adult to participate in decisions surrounding a change in living environment can produce negative transition responses which are manifested by increased depressive symptoms, decreased social interactions, and poor adaptation (Bekhet et al., 2009; Fraher & Coffey, 2011; Saunders & Heliker, 2008; Shippee, 2009; Sviden et al., 2002; C. Walker et al., 2007; Wilson, 1997).

### **Theoretical Framework**

Symbolic Interaction is a person-centered framework that seeks to rationalize how humans interact with and react to the world around them. Herbert Blumer (1900-1986) is recognized for transforming the work of George Mead (1863-1931) into a social theory that focuses on the individual's abilities to interpret their interactions, assign meaning to those interactions and modify behaviors based on personal interpretations and meanings (Blumer, 1969; Crooks, 2001; Snow, 2001).

Three assumptions create the foundation of Symbolic Interaction Theory. First, humans react to "things" based on the meaning those "things" have for them. The human's experience and interface with the environment, organizations, other humans, and the moral principles that guide behavior help to establish individual's perceptions and beliefs about the world (Blumer, 1969, 1986). Blumer (1986) writes that the meaning of "things" is often overshadowed when researchers and theorists dismiss the individual's right to possess the ingenuity to interpret

meaning and act accordingly. Ascribed meaning is the result of an inductive process where the individual assimilates all the information received each day and determines how to act or react in the future (Blumer, 1969, 1986). In simpler terms, the meaning of “things” is what the individual says it is and not the result of other influences.

The second assumption is that meaning is derived from social interaction with others. The actions, reactions, beliefs, and opinions of family, friends, acquaintances, and professionals shape the meaning of “things” for the individual (Benzies & Allen, 2001; Blumer, 1969, 1986). It is through this social dialogue and interface that the individual develops social fluency and social agency or the ability to form cooperative relationships and to make independent decisions.

The third assumption is a dual process of evaluation and action. The initial phase involves self-reflection and assessment of the “things” that have meaning. The individual reconsiders, reconstructs, and reformulates meaning. In the second phase the individual applies these new meanings to situations and adjusts behavior accordingly (Blumer, 1969, 1986). The individual’s decision to maintain or change behavior is, according to Blumer (1986), made independently within the cultural constraints and mores.

SI is a dynamic theory in which the individual assimilates information from the world at large, assigns meaning to that information, and adjusts behavior based on the meaning it has for that individual. In this dissertation, the adult child observes behaviors and function (“things”) of an aging parent and assigns meaning. In the early stages of decline, the adult child may dismiss or overlook signs that portend future functional or cognitive disability. As the cognitive behaviors and physical function produce more pronounced symptoms (“things”), the adult child may relate the changes to others or begin to gather information about care options. The meaning of “things” changes again and again as the declines escalate. At some point in time, when a

critical event occurs which endangers the older adult's safety and security, the adult child will reassess, reevaluate, and reconstruct the meaning of "things" and adapt their behavior in caring for the aging parent.

## **Manuscripts**

In this dissertation, the relocation and transition experiences of older adults are explored through two integrative review manuscripts, *Relocation Transition in Older Adults* (Chapter 1) and *Making the Move* (Chapter 2). The third manuscript, *Changing Places: Adult Children and the Transition of Aging Parents* (Chapter 3) explores the experiences of adult children as they transition their aging parent(s) from independent living to supervised care.

In *Relocation Transition in Older Adults* (Chapter 1) a mixed research integrative review was performed to determine how relocation transition in the older adult is measured in the literature. Seventeen articles were retained for evaluation and examined. Three themes emerged that symbolize the focus of the studies: Planning the Move, Physical Move, and Adaptation. While the articles provide various avenues for measurement, none produced a reliable and valid instrument to adequately determine the totality of a physical, psychological, and emotional assessment of relocation transition in older adults.

In *Making the Move* (Chapter 2) relocation transition was examined using the Theory of Planned Behavior to identify key elements of this process for older adults. Sixteen articles were retained for review using a mixed research integrative review method developed by Hawker, Payne, Kerr, Hardey, and Powell (2002). Results indicated that positive behavioral beliefs and participation in decision-making enhance good transitions when relocation is anticipated. Additionally, older adults consult family, especially adult children, to provide support and guidance during a transition to a new living environment.

*Changing Places: Adult Children and the Transition of Aging Parents* (Chapter 3)

chronicles the process of adult children as they become involved in the caregiving of aging parent(s). A qualitative grounded theory approach was used to conduct semi-structured telephone interviews with adult children (n = 16) using questions developed from Symbolic Interaction Theory. Questions were designed to follow the pattern of increased frailty of the parent(s) and escalating involvement of the adult child. Two major themes were revealed from the data: Changing Places and Everlasting Love. Adult children began to assume caregiving responsibilities when the older adult began to suffer cognitive and/or functional declines that compromised safety and well-being. Love and respect for the aging parent was evident in the adult child's stories and provided emotional support during the caregiving experience.



Measurement of Relocation Transition: A Mixed Research Integrative Review

*This manuscript will be submitted to Gerontological Nursing Research*

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## **Abstract**

The purpose of this mixed integrative review is to determine how relocation transitions of older adults are measured in the literature. PubMed, CINAHL, and PsycInfo databases were queried using the key words *relocation*, *transitions*, and *older adults*. From a search of 396 articles, 17 articles were retained for this assessment. Five quantitative studies measured relocation from the older adult's perspective while two used mixed methods to determine older adults' vulnerability to relocation and decision making in the relocation process. The remaining studies, qualitative in design, revealed autonomy, decision-making, social support, and physical health declines as persistent themes in older adults' relocation transition experiences. Using Hawker's method of mixed integrative review, three overarching stages of transition could be identified and measured: Planning the Move, Physical Move, and Adaptation. These stages may present multiple opportunities for nurses to collaborate with older adults and their families as they negotiate the relocation process.

*Keywords: relocation, transition, older adults, integrative review, mixed research*

## **Introduction**

Becoming “old” in America in the 21<sup>st</sup> century presents challenges to society, government, and families. Most of all, however, becoming “old” challenges the aging adult, in adapting to changes in physical functioning, control of chronic illnesses, and perhaps face the daunting challenge of a transition to a less independent living arrangement. Transitions occur when there is a change or move from one place to another or from one condition or state to another (Meleis, 2010). Relocation prompts a transition for the older adult and can be initiated by a change in health status, death of a spouse, decrease in financial resources, or the desire to be near family. In and of themselves, these changes are stressful and anxiety ridden, but a move to a different environment creates more disequilibrium and chaos for an older adult than it does for others (Carpenter et al., 2007; Rossen, 2007).

In 2013, 85% of adults age 65 and older lived independently, some with spouses and some alone. In that same year, 3.5% of older adults resided in senior housing and required assistance with at least one activity of daily living. The percentage of older Americans who enter a facility with supportive services increases with advancing age (Administration on Aging, 2013). Relocation is often an inevitable process, which older adults and their families must endure. While the national rate of late-life relocation has been reported at 5%-39%, Sergeant, Ekerdt, and Chapin (2008) methodically examined that same research and found wide variation in the way the declared statistics were derived. Inconsistent operational definitions for key variables such as housing type (single family, congregate, long term care, assisted living) and study design issues (longitudinal vs. cross-sectional) contribute to the wide variance in late-life relocation estimates. Some of the studies utilized different geographic scales to measure a move. Geographic scales describe the characteristics of the region associated with the move, such as

private residence, census/zip code zones, or states. The authors concluded that more research is needed with greater attention to study design and specification of the “geographic unit” (Sergeant et al., 2008, p. 597) used to measure late-life relocation.

The purpose of this integrative review is to determine how older adults’ relocation transitions are measured in the literature. The theoretical definition of ‘relocation transition’ is: an alteration in living situation that encompasses planning the move, the physical relocation, and adaptation to new surroundings (Remer & Buckwalter, 1990, as cited in Rossen & Knafl, 2007).

### **Risk Factors and Relocation**

Despite limited availability of statistics on relocations among older adult populations, the implications of relocation are a concern for health care workers and families. In a quantitative study (n= 324) conducted in a naturally occurring retirement community (NORC), researchers defined *anticipatory relocation* as the thinking, planning, and worrying that precedes relocation. Using the results of this study, the researchers were able to determine the profile of a resident who was most likely to need to move to a higher level of care. The most likely candidate for relocation was an unmarried female living alone in an apartment and unsure of her financial security. Results showed that 26% of the residents believed they would need to relocate in the next few years due to poor health and diminished finances. Other issues, which the residents said would contribute to relocation, were decreased mobility, maintenance of the home, and diminished support systems (Carpenter et al., 2007). Tang and Pickard (2008) used secondary data from a previous study of community dwelling older adults (n=4501) who participated in a telephone survey on utilization of home and community based services for aging-in-place. The more services the respondents used (adult day centers, senior centers, housekeepers, visiting nurses, and personal aides), the higher the perceived need to relocate to a higher level of care.

Vulnerable older adults (i.e., those with financial instability and low educational attainment) were not as adept in acknowledging the need for services or relocation as their functional status declined. It is evident that many independent older adults believe they will need to move in the future; however, their awareness and utilization of community services may be suboptimal. Tang and Pickard (2008) report that community-dwelling older adults (N=4611) were overwhelmingly unaware of services and support systems, which would enable them to remain in their homes. The most prevalent reasons older adults relocate are declining health status, financial issues, decreased ability to maintain their homes, and functional decline (Bekhet, Zauszniewski, & Nakhla, 2009; Carpenter et al., 2007; E. Walker & McNamara, 2013). However, many issues surrounding relocation could be mitigated by improving awareness of available in-home or community-based services, such as adult day centers (Carpenter et al., 2007; Gitlin, Szanton, & Hodgson, 2013; Tang & Pickard, 2008).

Pope and Kang (2010) examined proactive and reactive reasons for relocation in older adults (n=1311). Proactive coping involves preparing and planning for future calamities by developing strategies to attenuate the impact of catastrophic events. In contrast, reactive coping consists of attempting to mitigate the effect of stressful situations as they occur. Proactive reasons for relocation were to move in with or near adult children or other family, downsizes to a smaller house, move to a retirement community, find a safer community, and move to a warmer climate. Reactive reasons included declining health of the older adult or spouse, death of a spouse, or transfer to a nursing home (Pope & Kang, 2010). These findings are substantiated in other research (Bekhet et al., 2009; Crisp, Windsor, Anstey, & Butterworth, 2013; Fraher & Coffey, 2011).

However, some older adults have no choice in their relocation to an assisted living facility or nursing home due to health, functional, and cognitive declines. The risk factors for relocation following a hospitalization are old age, being female, poverty, health problems, poor health behaviors, limited physical function, decreased hearing and/or visual acuity, and inadequate social support (Hertz, Koren, Rossetti, & Robertson, 2008). Current housing type is also a risk factor for relocation. Older adults who reside by themselves, are located in a rural community, rent an apartment or house, and who cannot access support services may face relocation to less independent housing after discharge from the hospital or skilled nursing facility (Hertz et al., 2008). Thus, it is important to determine how to measure effectively the need and process for relocation as well as the impact of the transition on the older adult.

### **Design and Method**

To obtain data for this integrative review, database searches were conducted using *transitions*, *relocation*, and *older adults* as key words in the title and/or abstract of the manuscript. CINAHL, PubMed, PsychInfo, and ERIC databases were searched for the years 1994 through 2014, with a return of 404 manuscripts. The search interval was selected to include the growth and expansion of assisted living facilities which offer an alternative living environment to long term care homes (Wilson, 2007). Excluded from this review were dissertations, non-research based articles, books, and manuscripts that focused on physiological or biological transitions. When duplicates were removed, a total of 43 articles were reviewed for inclusion. Articles were reviewed again for relevancy of research on relocation transitions; specifically, they were included if they addressed the following issues: preparing or planning to move, reasons for relocation, the relocation experience, and the adaptation or adjustment to a new environment. As a result, seventeen articles were retained for this review.

Articles were critically appraised using a review style developed by Hawker, Payne, Kerr, Hardey, and Powell (2002). This process allows for the inclusion of both qualitative and quantitative studies in systematic or integrative reviews (Kehinde, 2009). Sandelowski, Voils, and Barroso (2006) maintain that mixed research synthesis enables critical literature reviews to sample all relevant literature including qualitative and mixed methods studies. Meshing the three methodologies provides a comprehensive evaluation of the scientific research and informs the scientific community.

The Hawker et al. (2002) appraisal method utilizes a three-step approach to integrative reviews. The initial step is to assess the relevance of the retrieved articles for research question applicability, type of setting and researcher credentials, data sources, and study methodology. The second step is “data extraction” (Hawker et al., 2002, p. 1290) in which essential components of each study are reviewed for concurrence with the review’s research questions. The final step of the process is rating each retained study for “methodological rigor” (Hawker et al., 2002). The instrument for this stage of the review critically appraises the quality of the research articles to include abstract and title, introduction and aims, method and data, sampling, data analysis, ethics and bias, results, transferability/generalizability, implications and usefulness.

## **Results**

### **Synthesis of the Literature**

Seventeen articles were retained for this integrative review. Ten were qualitative, 5 were quantitative, and 2 were mixed methods. Three main categories emerged from the research articles: Planning the Move, Physical Move, and Adaptation (Table 1). Planning the Move involves placement decisions or processes, discovering the need to move, and the decision-

making or control the older adult has on the relocation process. The Physical Move includes the older adult's perception of the move and the physical act of packing belongings. Adaptation encompasses the relocation process as viewed by the older adult, transitions and social connections that facilitate a favorable relocation transition, and adaptation to a new living environment. Assessment categories from Hawker et al. (2002) were used to organize findings.

**Abstract/title.** All studies presented an appropriate title and a clear and concise abstract.

**Introduction/aims.** Introduction and aims were relevant in all studies except for Anderson and Tom (2005). The introduction for this study was brief and lacked relevant literature to support the aims.

**Method/data.** Appropriate methodology was used in all studies to extract the proposed data. The methodologies also were convergent with the research questions. Nine studies were qualitative, 5 were quantitative and two were mixed methods.

**Sampling.** Sampling was clearly defined in all studies as was the study setting.

**Data Analysis.** Analysis of the data was explicated in most studies to include psychometric testing and qualitative content examination. Carpenter et al. (2007), and Anderson and Tom (2005) had scant psychometric data while Weeks, Keefe, and Macdonald (2012) administered an adapted survey instrument but reported no validity and reliability statistics.

**Ethics/bias.** Ethical considerations were clearly stated in only 4 studies (Dupuis-Blanchard, Neufeld, & Strang, 2009; Rossen & Knafl, 2003; Shippee, 2009; E. Walker & McNamara, 2013). Five studies were secondary or retrospective analyses of earlier or larger studies and the reader was referred to the original studies for more information (Bekhet & Zauszniewski, 2014; Johnson, Popejoy, & Radina, 2010; Kampfe, 2002; Krout, Moen, Holmes, Oggins, & Bowen, 2002; Rossen & Gruber, 2007). It can be assumed that human subjects



protections were presented in articles from the parent study. Ethical standards were missing from the remaining studies and could be the result of editing prior to publication.

**Results.** All studies presented results that were descriptive of the findings and reflected the particular methodology. Qualitative studies included salient quotations to emphasize the richness of the data while quantitative studies provided tables and figures to support the findings.

**Transferability/Generalizability.** Settings, participants, and methods were clearly reported in all studies. Qualitative studies, while not generalizable, possessed thorough descriptions of significant findings.

**Implications/usefulness.** Only one study did not provide any discernable implications and usefulness (Anderson & Tom, 2005). All other studies suggested avenues for future research or utilization of study results to assist older adults in the relocation process.

**Synthesis Summary.** This section will summarize the findings of the integrative review by examining how the studies measure relocation transition in the older adult (See Table 1). The reviewed articles focused on different aspects of the relocation experience: *Planning the Move*, *Physical Move*, and *Adaptation*. Subcategories for each of these themes are discussed below.

#### *Planning the Move*

The process of how a move occurs can be divided into three parts: *placement decisions/processes*, *need to move*, and *decision-making/control*. The relationship between the three is not discrete and can occur in any order or simultaneously.

#### *Placement decisions/processes*

Anderson and Tom (2005) implemented the Geriatric Functional Rating Scale (GFRS) to determine if this instrument could predict the functional decline of older adults in a continuing care retirement community. The article did not report any psychometric properties on this

instrument so it is difficult to determine its validity and reliability as a screening tool for placement decisions. Two qualitative articles described decision-making in their respective populations (Johnson, Schwiebert, & Rosenmann, 1994; Young, 1998). Both studies revealed the reasons the participants moved (poor health, lack of transportation, loneliness, and absence of reliable caregivers) and discussed the repercussions of the move (loss of privacy and independence, increased socialization).

#### *Need to move*

Two qualitative studies expressed the push to move, usually due to declining health status of the participant (Kemp, 2008; Young, 1998). Kemp (2008) interviewed married couples that had relocated to assisted living and found that while one spouse had functional or cognitive issues that prompted a move, the couple moved so they could remain together. Quantitatively, Weeks et al. (2012) adapted a Canadian survey to determine the “push” and “pull” factors of relocation. The revised survey was piloted prior to being mailed to older adults. The results attested to predictors of relocation such as age, gender, driving, income, lack of home maintenance support). Another quantitative study included questions about relocation within a questionnaire and was completed during face-to face interviews (Krout et al., 2002). Krout et al. (2002) reported the psychometric tests but did not include the actual scores. Carpenter et al. (2007) used mixed methodology to measure older adults’ perceptions about aging in place or relocation. Multiple instruments were used to quantify functional and health status, social resources and cognition while the qualitative component was a face-to-face questionnaire developed by the researchers. Inter-rater reliability was assessed during coding of the qualitative data but psychometric properties were not provided for the quantitative instruments.

### *Decision-making*

The studies in this category detail the process of decision-making and relocation. Young's (1998) qualitative study chronicled the entire process of a relocation from the decision to move to packing and making the move. The decisional process revealed some older adults instigated the relocation while others relied on others to gather information and assist in the selection of a facility. E. Walker and McNamara (2013) used qualitative interviews to describe the older adult's desire to move before an emergent event forced relocation. Rossen and Gruber (2007) provided the psychometric testing of the Relocation Self-Efficacy Scale, which measures the older adult's ability and readiness to move. The article provided detailed testing of the instrument from initial question development through factor analysis. One mixed-methods study utilized multiple instruments to measure function, physical ability, and sense of coherence. Qualitative interviews focused on the decision to move and if those decisions were made independently or with assistance from others (Johnson et al., 2010).

### *Physical Move*

Two studies examined the *physical move*, which occurs once the decision to relocate has been made. *Perceptions* were the focus of Kampfe's (2002) qualitative study. Most participants felt they had power and input into the decision-making process but still experienced emotional strain and disruption in their lives as a result of the relocation. Participants also emphasized that they were ambivalent about the move, ie, that it was neither good nor bad. *Packing up* another component of the *Physical Move*. Participants in Young's (1998) study voiced that the physical move (packing, sorting, and unpacking) was the least stressful element of the relocation.

## *Adaptation*

Adaptation begins once the older adult begins to settle into their new living environment. *Relocation experiences* were documented in two qualitative studies. Jungers (2010) interviews with older adults revealed themes related to health challenges that prompted the move and hoping to not be a burden to others. Specific to the relocation were loss of independence and feelings of isolation and disengagement. Young's (1998) participants reflected on adapting to their new living space, learning the rules and timetables, and attempting to connect with new friends. *Transitions/social connections* were the topic of two qualitative studies. Participants in Shippee's (2009) study were disheartened at their own frailty, which inhibited attending group events. Additionally, older adults in this study voiced concern over the decrease in their social interactions and the quality of those interactions after relocation. Dupuis-Blanchard et al. (2009) qualitatively studied newly relocated older adults who established social relationships after relocating to a facility. Three motives emerged for creating new friends: safety, casual conversation, and compassion. *Transitions/adaptations* depicts the manner in which older adults acclimate to their new surroundings. Rossen and Knafl (2003) developed three relocation transition styles from their interviews with older adult women. Partial or minimal integration into the new living environment places the older adult at risk for poor transition and adaptation while full integration signals healthy and positive transition. E. Walker and McNamara (2013) found that older adults who were involved in the decision-making and information gathering in addition to proactively choosing to relocate experienced more positive and successful transition into a new living environment. Young (1998) concluded that positive transitions occur once the older adult reconciles the past accepts a 'new' normal. Two quantitative studies explore adaptation to relocation. Bekhet and Zauszniewski (2014) compared American and Egyptian

older adults and their adaptation to relocation. This study used various instruments to provide quantitative measures of adjustment as did Smider, Essex, and Ryff (1996).

### **Limitations**

This review encompassed published articles from 1994-2014. The growth of the assisted living and senior living communities during this time period offered an interim living environment that provided supervision of the older adults' health status. Publications released prior to 1994 may have provided a different historical perspective on relocation of older adults as there were fewer options for supervised housing.

### **Discussion**

This review attempted to critically appraise relevant research literature on relocation transition in older adults. Seventeen studies were evaluated first, for the overall presentation of the research and the inclusion of details significant enough to replicate or generalize, and second, to classify the research into distinctive relocation transition themes. These themes capture the diversity of the relocation experience for older adults and highlight the extensive nature of a relocation transition.

All of the articles adequately reported their findings except many did not include human subjects protection language (Anderson & Tom, 2005; Bekhet & Zauszniewski, 2014; Carpenter et al., 2007; Johnson et al., 2010; Johnson et al., 1994; Jungers, 2010; Kampfe, 2002; Krout et al., 2002; Rossen & Gruber, 2007; Weeks et al., 2012; Young, 1998). However, many of these studies were secondary analyses of earlier research and human subjects protections were reported in earlier published reports.

Some of the quantitative studies described psychometric properties of the instruments used in the research (Bekhet & Zauszniewski, 2014; Rossen & Gruber, 2007). However, other

studies only partially reported psychometric testing (Anderson & Tom, 2005; Carpenter et al., 2007). The importance of this data cannot be overstated. Without appropriate measurement and reporting of validity and reliability, replication of the research could be hindered.

Most quantitative studies in this review used an assortment of instruments that were adapted to capture the needed data without benefit of reliability and validity testing. Determination of function, both cognitive and physical can be measured with valid and reliable instruments. The Katz Index of Independence in Activities of Daily Living (Katz, Ford, Moskowitz, Jackson, & Jaffe, 1963), Lawton Instrumental Activities of Daily Living (Lawton & Brody, 1969), the Mini-Cog (Borson, Scanlan, Chen, & Ganguli, 2003) and the Geriatric Depression Scale (Yesavage et al., 1983) have more than 30 years of data to support their use as complimentary evidence-based assessments of the ability of the older adult to live independently.

Qualitative studies explicated the experiences of the older adult as they negotiate the task of a relocation from inception to conclusion. Decision-making, autonomy, social support, and declining physical function were consistent themes across studies and describe the multiple layers of relocation transition from the older adult's perspective. Some researchers have followed their qualitative inquiry on this topic with the development of instruments to measure relocation transition (Bekhet, Fouad, & Zauszniewski, 2010; Bekhet & Zauszniewski, 2014; Bekhet et al., 2009; Bekhet, Zauszniewski, & Nakhla, 2011; Bekhet, Zauszniewski, & Wykle, 2008; Rossen, 2007; Rossen & Gruber, 2007; Rossen & Knafl, 2003, 2007).

Qualitative studies examined the transition processes that occur for older adults who relocate. More qualitative than quantitative manuscripts were obtained for this review and indicate the need for more theory development on the relocation transition experience of older adults. Multiple theories, such as Meleis' Transition Theory (Meleis, 2010), Theory of Planned

Behavior (Ajzen, 1985), and Bandura's Self-Efficacy Theory (Bandura, 1993) allow the inclusion of the older adults' perceptions, thoughts, and support systems necessary for a successful transition or aid in the creation of guidelines to address poor transitions.

Relocation transition has been and continues to be studied and advances have been made in the development of instruments to measure the older adults' processes, however these experiences, which involve both physical and psychological implications, should not be viewed in isolation. Physical and functional declines propel the older adult to consider relocation but that relocation comes at a cost to their emotional and psychological health (Bekhet et al., 2009; Krout et al., 2002; C. Walker, Curry, & Hogstel, 2007; E. Walker & McNamara, 2013; Weeks et al., 2012).

### **Conclusions and Implications**

Determination of the older adult's ability to negotiate a move to a congregate living situation is essential to provide needed support systems in an effort to mitigate the negative impact of relocation. Additionally, each move to a higher level of care presents its own struggles for the older adult. While articles retrieved for this review highlighted the relocation transition process, the moves occurred in multiple venues (continuing care retirement community, nursing home, assisted living, independent living). Future research into the specific skills necessary to relocate through each level of care may reveal different transition interventions are needed for each relocation.

In most cases, older adults rely on family members, specifically adult children to assist them in the process of relocation but their multilayered involvement is often overlooked and their participation combined with other "family caregivers" or "informal caregivers". Research, which

would identify key persons and their role in supporting the older adult, would benefit health care providers who are often consulted in a move to more supervised housing.

Consistency in operationalizing the components of relocation would assist researchers by providing standards of measurement that clearly assess the older adult's physical and emotional function, depressive symptoms, and motivation to move. Factors that contribute to relocation should also be considered for study by using evidence-based instruments to determine what skills the older adult needs to remain independent. The majority of studies in this review used measurement instruments that were time consuming to administer and lacked the validity and reliability required for replication. While the quantitative studies measured various aspects of relocation, only the Relocation Self-Efficacy Scale (Rossen & Gruber, 2007) offers a simple and concise instrument to measure readiness to relocate from the older adult's point of view.

Qualitative studies could be used to inform researchers on the older adult's perspective on moving and further understanding of the emotional and psychological ramifications of transitioning to a higher level of care. Additionally, qualitative inquiry provides the "face" of a relocation transition, which encompasses the concerns, regrets, apprehensions, and joys of entering a new living situation and a new phase in life. The positive and negative impact of relocation should be explored and programs developed to assist health care providers, staff, and marketing departments recognize the fragility of an older adult who is transitioning from one housing environment to another.

Relocation transition is a complex and stressful experience in an older adult's life and should be examined in a manner that will yield productive answers and foster a greater awareness of the issues that surround a transition to another environment. As the number of older



adults rapidly expands, relocating to supervised housing will require that transitions become our focus instead of our oversight.

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Table 1  
*Review summary*

| Planning the Move  | Physical Move  | Adaptation  |
|--|--|---|
| <ul style="list-style-type: none"> <li>• Placement decisions/process (Johnson, R., et.al, 1994, Young, H., 1998, Anderson, B., 2005, Jungers, 2010)</li> <li>• Need to move (Kemp, C. 2008, Young, H., 1998, Krout, J., 2002, Carpenter, B. 2007, Weeks, L., 2014)</li> <li>• Decision-making/control (Johnson, R., et. al. 2010, Young, H., 1998, Rossen, E., &amp; Gruber, K., 2007, Walker, E. &amp; McNamara, B. 2013 )</li> </ul> | <ul style="list-style-type: none"> <li>• Perceptions of the move (Kampfe, C., 2002)</li> <li>• Packing up (Young, H., 1998)</li> </ul> | <ul style="list-style-type: none"> <li>• Relocation experience (Jungers, C. 2010, Young, H., 1998, Smider, N., et.al., 1996)</li> <li>• Transitions/Social connections (Shippee, T. 2009, Dupuis-Blanchard, et. al 2009, Walker &amp; McNamara, 2013)</li> <li>• Transitions/adaptations (Rossen, E. &amp; Knafl, K., 2003, Young, H., 1998, Walker, E. &amp; McNamara, B. 2013, Bekhet, A., 2014)</li> </ul> |

Table 2

*Reviewed studies by theme and study strength*

|  | Author   | Aim/Purpose  | Sample  | Method  | Key findings/Themes  |
|--|--|--|---|---|--|
| Planning the move: placement decisions/process | Johnson, R.,<br>Schwiebert, V.,<br>Rosenmann, P.<br>(1994) | To identify factors influencing placement of older adults in nursing homes;<br><br>To delineate the process by which this decision occurred. | Cognitively intact older adults (n=18), >60 years         | Qualitative descriptive.  | Factors Influencing placement: health issues, caregiver issues, fear of living alone; placement decision makers: "powerful other"/self; advice to others making placement decisions. |
|  | Young, H.<br>(1998)  | To describe the experience of moving to congregate housing   | Qualitative Purposive and convenience: new residents n=21 | Face validity of interview questions using expert professionals; content validity of emerging themes/ categories using two participants and two experts; raw data/conceptual categories reviewed/sorted by two experts; final themes/ categories presented to participants. | Themes: Feeling at Home; Nesting; Working out Logistics; Fitting In; Reconciling with Life Changes   |

Table 2 continued

|  | Author                 | Aim/Purpose  | Sample                                 | Method   | Key findings/Themes   |
|--|------------------------|--|--|--|---|
| Planning the move: placement decisions/process | Jungers, C. (2010)     | How do older adults experience a late-life transition when they move from their home into an ALF?                              | Older adults (n= 14)                   | Qualitative Phenomenology; semi-structured interview | Eight themes: Experiences with health challenges, desire not to be a burden, loss of independence and autonomy, loneliness and disconnectedness, experiences related to stereotypes about aging and older adulthood, relatedness as a support, experiences of decision making and personal choice, experiences of positive aging. |
|  | Anderson, B. J. (2005) | To demonstrate Geriatric Functional Rating Scale (GFRS) can be used to predict resident's future level of care in CCRC setting | Independent living residents (n = 290) | Quantitative   | GFRS predicted increased care needs   |
| Planning the move: need to move                | Young, H. (1998)       | (See above)  |  |  |   |
|  | Jungers, C. (2010)     | (See above)  |  |  |   |



Table 2 continued

|                                 | Author                         | Aim/Purpose  | Sample  | Method  | Key findings/Themes   |
|---------------------------------|--------------------------------|--|---|---|---|
| Planning the move: need to move | Carpenter, B. D.et. al. (2007) | To identify predictive characteristics associated with vulnerability to relocation   | Older adults (n = 324) recruited from an naturally occurring retirement community | Mixed methods   | <p>Participants were most worried about moving due to ill health or financial issues; worried participants reported more chronic illnesses, lack of social engagement and family support</p> <p>Authors offer suggestions for services to allow residents to age in place</p> |
|                                 | Kemp, C. L. (2008)             | What pathways lead couples to reside together in ALFs? How does the context of marriage influence couples' everyday lives? | Participant couples: n= 20; age range: 66-94                                      | Qualitative: exploratory; semi-structured interviews; secondary data analysis | <p>Transition to AL precipitated by health event experienced by one/ both spouses.</p> <p>Pathway to ALF was couples' desire to remain together.</p>  |
|                                 | Krout, J., et. al. (2002)      | To present an analysis of motivation for moving reported by sample of older adults   | Older adults (n = 91);  | Quantitative  | Health concerns, services provided, future needs  |

Table 2 continued

|  | Author                          | Aim/Purpose   | Sample  | Method                                  | Key findings/Themes   |
|--|---------------------------------|---|---|---|---|
| Planning the move: decision making/control | Young, H. (1998)                | To present an analysis of motivation for moving reported by sample of older adults  |   |   |   |
|  | Walker E. & McNamara, B. (2013) | To identify key factors over different stages of relocation; to determine the range of strategies employed by older adults in relocating and maintaining a sense of home; to explore the scope for preventative occupational therapy in promoting health and well-being | Purposive/snowball sample; Australian older adults (n=16) | Qualitative; semi-structured interviews | Two main findings: successful transitions were made by researching and gathering information prior to the move and maintaining the ability to exercise agency across the relocation process |
|  | Johnson, R., et. al. (2010)     | To identify extent of older adults' participation in relocation decision making; to identify extent of SOC (sense of coherence), function, physical ability as related to decision making.  | Random selection of nursing home residents (n = 16)       | Mixed methods                           | Two types of decision-making: 'I made the decision'/'they put me here'<br><br>African-Americans less likely to participate in decisions of placement.                                       |

Table 2 continued

|  | Author                         | Aim/Purpose   | Sample   | Method                        | Key findings/Themes  |
|--|--------------------------------|---|--|-------------------------------|--|
| Planning the move: decision making/control | Rossen, E. & Gruber, K. (2007) | To develop and test an instrument measuring older adult's self-efficacy to relocate to independent living communities (ILC)   | Older adults (n = 166); ≥ 65 years                                   | Quantitative                  | Psychometric testing of the Relocation Self-Efficacy Scale (RSES)  |
| Physical move: perceptions of the move     | Kampfe, C. (2002)              | To what degree do older people perceive their residential relocations from one level of independence to another level of independence to be significant, controllable, stressful, disruptive or positive? | Qualitative Structured interviews conducted as part of larger study. | No qualitative rigor reported | Perceptions:<br>Significance: most participants did not feel their move was significant.<br>Personal control: Most participants felt they had control over the decision to move.<br>Stressfulness and disruption: About half of participants perceived move to be stressful and disruptive.<br>Quality of Residential Relocation: most participants were ambivalent about quality of new living situation. |

Table 2 continued

|   | Author                         | Aim/Purpose  | Sample                                  | Method                                   | Key findings/Theme   |
|---|--------------------------------|--|---|--|--|
| Physical move:<br>packing up            | Young, H.<br>(1998)            | To describe the<br>experience of moving<br>to congregate housing   | Older adults-new<br>residents (n = 21)  | Qualitative Purposive and<br>convenience | Themes: Feeling at Home;<br>Nesting; Working out<br>Logistics; Fitting In;<br>Reconciling with Life<br>Changes   |
| Adaptation:<br>relocation<br>experience | Smider, N.,<br>et. al., (1996) | To investigate the<br>interactive influences<br>of psychological factors<br>and contextual factors<br>on short-term<br>adaptation to<br>community relocation | Older adults<br>(n = 102), >55<br>years | Quantitative                             | Person-context interactions<br>involving psychological<br>resources are important in<br>understanding the early<br>emotional responses to<br>relocation; specific<br>resources work<br>interactively with particular<br>situational stresses or<br>opportunities; positive<br>contextual characteristics<br>may be especially<br>important to the short-<br>term adaptation of those<br>with lower resources prior<br>to the transitional life<br>event. |

Table 2 continued

|  | Author                | Aim/Purpose   | Sample   | Method   | Key findings/Theme  |
|--|-----------------------|---|--|--|---|
| Adaptation: relocation experience          | Jungers, C. (2010)    | How do older adults experience a late-life transition when they move from their home into an ALF?   | Older adults (n= 14)                                     | Qualitative Phenomenology; semi-structured interview | Eight themes: Experiences with health challenges, desire not to be a burden, loss of independence and autonomy, loneliness and disconnectedness, experiences related to stereotypes about aging and older adulthood, relatedness as a support, experiences of decision making and personal choice, experiences of positive aging. |
| Adaptation: transitions/social connections | Young, H. (1998)      | See above   |  |  |   |
|  | Shippee, T. S. (2009) | To investigate how residents perceive transitions across levels of care; to investigate how residents manage social relations while moving within the CCRC. | Older adults in assisted living; researcher was embedded | Qualitative  | Three themes: autonomy, fatalism, social disengagement.   |

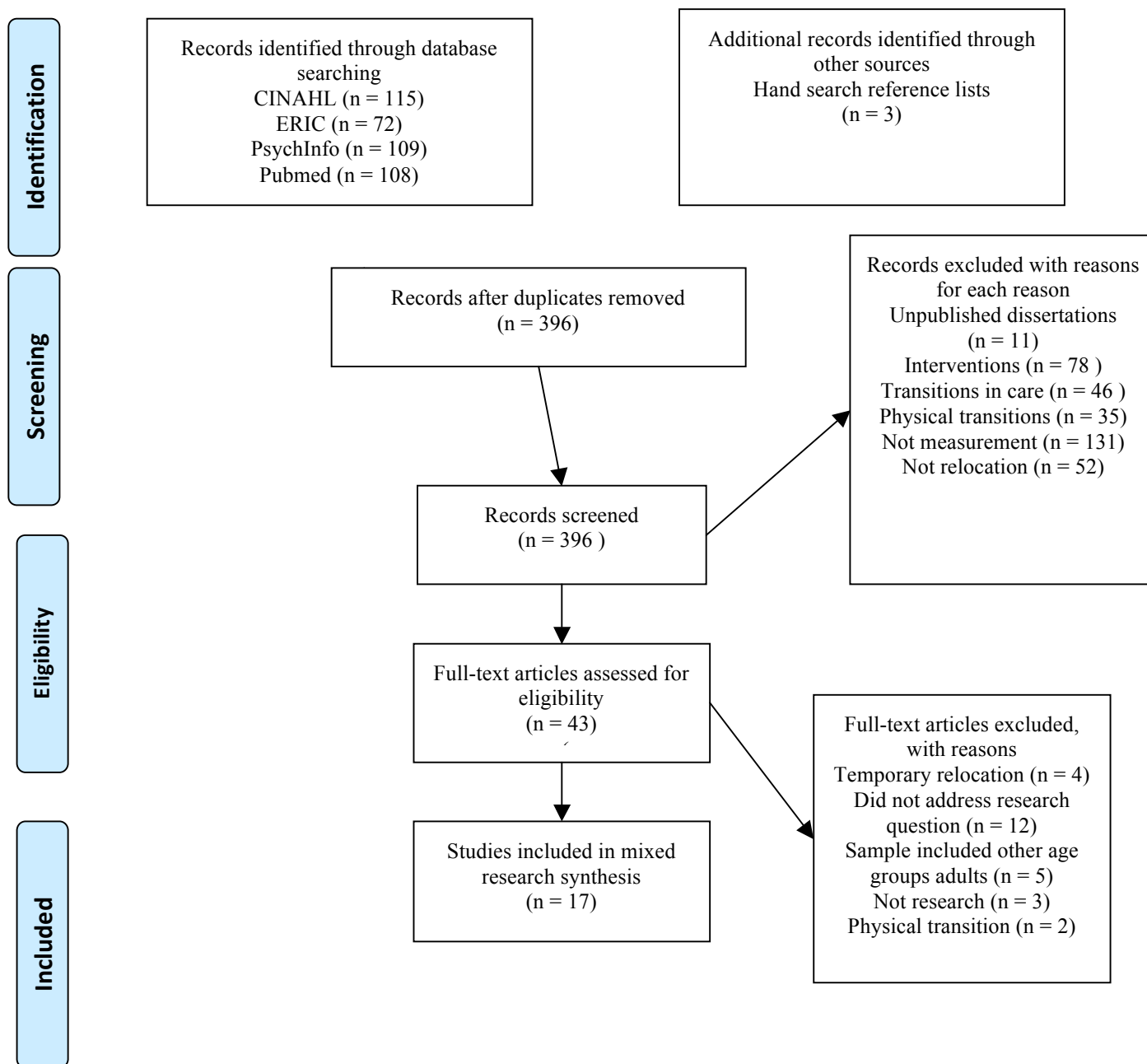
Table 2 continued

|  | Author                                    | Aim/Purpose   | Sample  | Method   | Key findings/Theme   |
|--|---|---|---|--|--|
| Adaptation:<br>transitions/<br>adaptations | Rossen, E.K. &<br>Knafl, K. A.<br>(2003). | 1) Develop a<br>conceptualization of<br>early relocation<br>transition experienced<br>by older women<br>relocated from family<br>home to congregate<br>living.<br><br>2) Identify factors<br>related to unhealthy<br>outcomes.  | Older women<br>(n = 31)   | Qualitative<br>Longitudinal, naturalistic<br>inquiry | Three transition styles: full,<br>partial, and minimal. Less<br>than half experienced full<br>integration of relocation<br>transition. Over half had<br>partial or minimal<br>integration of relocation<br>transition. |
|  | Walker, E., &<br>McNamara, B.<br>(2013)   | To identify key factors<br>over different stages of<br>relocation; to<br>determine the range of<br>strategies employed by<br>older adults in<br>relocating and<br>maintaining a sense of<br>home; to explore the<br>scope for preventative<br>occupational therapy<br>in promoting health<br>and well-being | Purposive/<br>snowball sample;<br>Australian older<br>adults (n=16) | Qualitative; semi-<br>structured interviews          | Two main findings:<br>successful transitions were<br>made by researching and<br>gathering information prior<br>to the move and<br>maintaining the ability to<br>exercise agency across the<br>relocation process       |

Table 2 continued

|                                      | Author                               | Aim/Purpose  | Sample  | Method   | Key findings/Theme  |
|--------------------------------------|--------------------------------------|--|---|--|---|
| Adaptation: transitions/ adaptations | Young, H. (1998)                     | To describe the experience of moving to congregate housing   | Qualitative Purposive and convenience: new residents n=21 | Face validity of interview questions using expert professionals; content validity of emerging themes/ categories using two participants and two experts; raw data/ conceptual categories reviewed/sorted by two experts; final themes/ categories presented to participants. | Themes: Feeling at Home; Nesting; Working out Logistics; Fitting In; Reconciling with Life Changes                |
|                                      | Bekhet, A. & Zauszniewski, J. (2014) | Compare relocation adjustment between relocated American and Egyptian older adults to determine whether one group adjusted more successfully than the other: determine the factors that affect the successful adjustment of relocated older adults and the relationships among these factors; Provide recommendations regarding interventions to help re-located older adults in both cultures adjust to their new surroundings. | Older adults (n = 198) American and Egyptian              | Secondary analysis of two cross-sectional descriptive studies  | American older adults have better adjustment to relocation than Egyptian older adults due to cultural differences |

Figure 1. Literature Review Flow Diagram (based on PRISMA)





Making the Move: A Mixed Research Integrative Review

*This manuscript will be submitted to Journal of Applied Gerontology*

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## **Abstract**

The purpose of this mixed research integrative review is to determine factors that facilitate positive relocation transitions for older adults who are considering a move from independent living to supervised housing, such as assisted living, using the Theory of Planned Behavior as a conceptual guide. PubMed, CINAHL, and PsychInfo databases were queried using key words: relocation, transition, older adults, and, elderly and time limited from 1992-2014. Sixteen articles were retained for review. The majority of articles, qualitative in design, reveal positive relocation transitions can be achieved when the older adults' behavioral beliefs toward relocation are positive and hopeful. Additionally, the older adult's input into the decisions surrounding the move is also essential for positive relocation transitions. Finally, the influence of family, especially adult children, provides the older adult with support and guidance throughout the process. However, little is known about how the relocation transition experience impacts the adult child.

*Key words: relocation, transition, relocation, older adults, elderly, Theory of Planned Behavior, integrative review, adult children, supervised housing*

## **Introduction**

The aging demographic is exploding. Globally, the number of people aged 60 and over will triple from 605 million in 2000 to 2 billion in 2050 (World Health Organization, 2012). The number of older Americans, age 65 and over will double from 2000-2040, and by 2040; older adults will comprise 21% of the U.S. population (Administration on Aging, 2013). This aging explosion presents challenges to society, governments, and families, however the greatest challenge will be for the older adult who must adapt to changes in physical functioning, the struggle to control chronic illnesses, and perhaps face the daunting challenge of a relocation and transition to a less independent living arrangement. Defined by Meleis (2010) transition is a change or move from one place to another or from one condition or state to another, transition affects older individuals in many ways. In particular, relocation is a common transition for older adults and can be initiated by a change in health status, death of a spouse, decrease in financial resources, or the desire to be near family.

For people of any age, these changes are not only stressful and anxiety ridden, but also a move to a different environment creates disequilibrium and chaos for an older adult when compared to younger counterparts (Carpenter et al., 2007; Fraher & Coffey, 2011; Rossen, 2007; Sergeant & Ekerdt, 2008). However, many older adults are relocating to a more supportive living environment for multiple reasons, yet *how* they are able to achieve a positive transition into supervised housing is the focus of this integrative review. It will summarize, synthesize, and appraise research findings about older adults relocating from independent living to supervised housing using the Theory of Planned Behavior (Ajzen, 1991; Huang, 2012). The aims that will be addressed in this review are: (a) to determine the behavioral beliefs of older adults who are relocating from independent living to supervised housing; (b) to determine the older adult's level

of perceived control of the relocation; and (c) to determine the influence of subjective norms on the older adult's relocation.

### **Background**

The U.S. Census Bureau reported that, from 2005-2010, 15.2% of adults age 65-74 and 11.9% of adults age 75 and older relocated (Ihrke & Faber, 2012) and moved within the same county of residence (8.5% and 7.1%, respectively) (Ihrke & Faber, 2012). In 2013, 85% of adults age 65 and older lived independently, some with spouses and some alone. That same year, 2.7% of older adults resided in senior housing and required assistance with at least one activity of daily living (Administration on Aging, 2013). It is noted that the percentage of older Americans who enter a facility with 24-hour supervision increases with advancing age (Administration on Aging, 2013).

Relocation is often a necessary process that older adults and their families often face as functional and cognitive declines necessitate environmental adaptations. Older adults who live alone or with family often lack adaptive amenities to compensate for functional declines (grab bars, safety rails, and emergency call system) while older adults living in communities designed for seniors were able to “age in place” for longer periods of time due to structural adaptations such as wheelchair access and safety bars (Choi, 2004; Gitlin, Szanton, & Hodgson, 2013). Older adults are often compelled to move closer to adult children caregivers as the health of self or spouse deteriorates or merge into multigenerational households as do many African-American elders (Hays, 2002; V. Lee, Simpson, & Froggatt, 2013). Therefore, the purpose of this integrative review is to determine the factors that facilitate positive transitions for older adults relocating from independent living to supervised housing.

Relocation has many implications for health care workers and families. Tang and Pickard (2008) used secondary data from a previous study of community dwelling older adults and found that, the more services the respondents used (adult day centers, senior centers, housekeepers, visiting nurses, and personal aides), the higher the perceived need to relocate to a higher level of care (Tang & Pickard, 2008). Vulnerable older adults (i.e., those with financial instability and low educational attainment) were not as adept in acknowledging the need for services or relocation as their functional status declined. Many independent older adults believe they will need to move in the future; however, their awareness and utilization of community services may be suboptimal (Tang & Pickard, 2008). Many relocation issues may be mitigated by improving awareness of available in-home or community-based services, such as adult day centers (Fraher & Coffey, 2011; Tang & Pickard, 2008).

For many older adults and their families, the solution to increasing care needs is a relocation to senior housing. There are many iterations of supportive housing such as, assisted living, senior apartments, continuing care retirement communities, and naturally occurring retirement communities. Most all of these options provide security and maintenance free living, however, not all provide 24 hour nursing supervision. Assisted living facilities are regulated by each state and as such, have widely variable staffing requirements and services but do provide room and board, assistance with activities of daily living, activities, and basic nursing care (O'Shaughnessy, 2013). Currently, 735,000 older adults reside in assisted living facilities where the average length of stay is 22 months (National Center for Assisted Living, 2014).

Bekhet, Zauszniewski, and Nakhla (2009) interviewed older adults who had relocated to senior housing (independent and assisted living). The results revealed multiple reasons for seeking a more supportive living environment. 'Pushing' factors toward relocation were

declining function, shedding home ownership responsibilities, lack of assistance, loneliness, and moving closer to family. 'Pulling' factors reflected the older adults' need for secure housing, reconnecting with friends, and familiarity with the senior living community. Some of the data revealed 'overlapping' factors, which were a combination of the 'pushing' factors (needing to move) and the 'pulling' factors (wanting to move). These findings have been substantiated in other research (Saunders & Heliker, 2008; Sergeant & Ekerdt, 2008; E. Walker & McNamara, 2013).

An acute care hospital stay and subsequent rehabilitation can significantly diminish the older adult's functional status requiring a change in living arrangements (D'Ambruso & Cadogen, 2012). Risk factors for relocation following a hospitalization are old age, being female, poverty, health problems, poor health behaviors, limited physical function, decreased hearing and/or visual acuity, and inadequate social support (Hertz, Koren, Rossetti, & Robertson, 2008). Older adults who reside by themselves, are located in a rural community, rent an apartment or house, and who cannot access support services may face relocation to a higher level of care after a hospital discharge (Carpenter et al., 2007; Hertz et al., 2008).

For older couples, the reasons for relocation may include some of the issues previously mentioned (downsizing the family home, relocating nearer adult children, safety, etc.) but the timing of the move may be determined by the increasing frailty or declining health of one (Bekhet et al., 2009) spouse (Fraher & Coffey, 2011; C. Walker, Curry, & Hogstel, 2007). Additionally, lack of consistent, reliable caregiving help in the home, both formal and/or informal, often prompts a move to a different living situation (Fraher & Coffey, 2011).

## Theoretical Framework and Definitions

The Theory of Planned Behavior (TPB) is an expansion of the Theory of Reasoned Action (TRA). The assumption of TRA is that intention to adopt a behavior is influenced by attitudes about performing the behavior (behavioral beliefs) and the value that important others (referents) place on the behavior (subjective norms) (Ajzen, 1991).

Behavioral beliefs are the perceptions that an individual develops concerning a specific behavior and are the antecedent to either positive or negative attitudes about that behavior while subjective norms are the opinions and beliefs that are communicated from others and the incentive to adopt those opinions about the behavior (Ajzen, 1985). Perceived behavioral control was added to TRA to allow for the assumption that behavior is volitionally controlled and as such, is impacted by external factors that help or hinder performance of the behavior (Ajzen, 1985).

The following operational definitions were developed to simplify and standardize terms in this review. *Independent living* is defined as older adults living alone in their own home or apartment with minimal assistance from paid and/or unpaid caregivers while *supervised housing* is defined as older adults living in a congregate environment with 24-hour supervision.

Supervised housing is also described in the literature as congregate housing, assisted living, care homes, nursing homes, long term care, sheltered housing, and residential care (Ellis, 2010; Hong & Chen, 2009; V. Lee et al., 2013; Rossen, 2007; Sviden, Wikstrom, & Hjortsjo-Norberg, 2002).

Additionally, theoretical definitions are used to explicate the application of Theory of Planned Behavior concepts (Ajzen, 1985, 1991). *Behavioral beliefs* are defined as the beliefs, perceptions, and experiences that the older adult considers when contemplating a move to a more supervised care environment. These beliefs entail reasons for the relocation, the impending

move, and the decision-making process. *Perceived control* describes the level of perceived control the older adult has in decisions related to relocation. Perceived control manifests through the choices pertaining to relocation, reasons for relocation, and adjustment to a new living environment. Finally, *subjective norms* are the influence and opinions of others (family, health care providers, and friends) on the relocation decision and transition to supervised housing.

The Theory of Planned Behavior has been widely used to understand behavioral intention to perform health behaviors and can be applied to both quantitative and qualitative inquiry (Huang, 2012; Montano & Kasprzyk, 2008). Behavioral and control beliefs in addition to subjective norms, are identified through focus groups or interviews and enable the development of measurement instruments to quantify the beliefs most likely to encourage the health behavior of interest (Montano & Kasprzyk, 2008).

### **Method**

Articles were retrieved and assessed using a review style developed by Hawker, Payne, Kerr, Hardey, and Powell (2002) (see Table 1 for criteria). This style has been utilized to evaluate qualitative and quantitative studies for systematic or integrative reviews (Kehinde, 2009). The Hawker, et al.(2002) method, also known as mixed research synthesis, allows for inclusion of research that measures concepts not well documented in traditional, clinically based reviews (Sandelowski, Voils, & Barroso, 2006).

Hawker et al. (2002) advocates using a three stage method for examining retrieved articles: Stage 1-assess for relevance; Stage 2-data extraction; Stage 3-grade for methodological rigor. Stage 1 involves reviewing the articles resulting from the literature search. Articles are either accepted or rejected. Criteria for acceptance included applicability to the research question(s), appropriateness of the study particulars (sample, setting, researchers), origination of



the data (professional or layman), and study methodology (Hawker et al., 2002). Stage 2 consisted of extrapolation of key data points about the studies to include design, sample, setting, research aim/hypotheses/questions, method and analysis, results, and conclusions. This step allows the reviewer to organize the major points of each study and further correlate the article with the review aims. Stage 3 entails evaluation of the articles using a 4 category scoring mechanism based on specific criteria for components of the study. Ratings ranged from 1 (very poor) to 4 (good) and included the following study sections: abstract/title, introduction/aims, method/data, sampling, data analysis, ethics/bias, results, transferability/generalizability, implications/usefulness (Hawker et al., 2002).

Database searches were conducted using *relocation, transition, older adults, and elderly* as key words in the title and/or abstract of the manuscript. CINAHL, PubMed, and PsychInfo databases were searched for the years 1992 through 2014, with a return of 907 manuscripts. The search period was determined by the historical development and expansion of assisted living facilities in the United States (K. Wilson, 2007). Excluded from this review were dissertations, non-research based articles, books, and manuscripts that focused on physiological or biological transitions, and older adults with dementia. Once duplicates were removed and relevance assured, a total of 39 articles were reviewed for inclusion. Articles were reassessed for relevance of research on relocation transitions. Specifically, articles were included that addressed the following issues: behavioral beliefs about relocating to a higher level of care, perceived control over the decisional process, and the effect of the opinions of others (subjective norms). Reference lists were hand searched for those articles frequently cited in retained publications.

## Results

### Synthesis of the Literature

Sixteen articles were retained for this review: twelve were qualitative studies, three were mixed methods, and one was a quantitative design. Categories from Hawker (Hawker et al., 2002) are used to organized the findings. (See Table 1 for criteria).

**Abstract/Title.** All abstracts contained complete yet concise information about the research, and all titles reflected the content contained in the publication.

**Introduction/Aims.** All articles except Fraher and Coffey (2011) clearly provided an introduction to the problem and addressed the specific aims of the reported research.

**Method/Data.** All studies except C. Walker et al. (2007) used an appropriate methodology and data collection techniques. Using both quantitative and qualitative methodology to support the research aims might have strengthened Walker's examination of various dimensions of the relocation process.

**Sampling.** All articles had age-appropriate sampling from environments that addressed the transition experience. Most studies used convenience, opportunistic, or purposive sampling. One mixed methods study (Johnson, Popejoy, & Radina, 2010) used a random sample of participants from a larger study.

**Data analysis.** Descriptions of data analysis were clear and understandable in all but three studies (Armer, 1993; Fraher & Coffey, 2011; Wilson, 1997). Wilson (1997) and Armer (1993) used a plethora of instruments and reported psychometric properties for all; however, no description of the statistical analysis performed on the results from the instruments was presented. (Fraher & Coffey, 2011) did not describe their method for data analysis in their

qualitative study. Wilson (1997) discussed data analysis, but utilization of respondent verification of themes or triangulation was not included.

**Ethics/Bias.** Most reviewed studies reported institutional/university review board approvals, and some also reported approvals from facilities in which the studies were conducted. The majority of articles, qualitative in design, did not thoroughly address human subject protections or privacy issues. For example, Armer (1993), Lee (1997, 1999) and Leggett, Davies, Hiskey, and Erskine (2011) did not describe the venues in which their interviews occurred, nor did they discuss how privacy was maintained for the participant. Johnson, Schwiebert, and Rosenmann (1994) did not report any human subject protections.

**Results.** Findings for all studies but Armer (1993) clearly describe the outcomes with adequate supportive data and logical progression. Armer's results section is very brief, lacks depth, and is primarily dominated by descriptive statistics and qualitative results. This brevity was surprising, especially considering the number of quantitative instruments (7) described and utilized.

**Transferability/generalizability.** All studies report enough information for replication for further research. Since the majority of studies are qualitative, generalizability is not possible. However, reports of this research seek to describe behaviors, attitudes, and perceptions rather than quantify the process of transition experiences.

**Implications/Usefulness.** All studies offer suggestions for further research and processes for assisting older adults through a transition experience. Saunders and Heliker (2008) advocate the establishment of an interdisciplinary team to assist new residents, families, and staff during the relocation transition process. Wilson (1997) suggests a resident volunteer who would orient the older adult to his or her new home.

## Synthesis Summary

This section will summarize the results of the integrative review using the Theory of Planned Behavior concepts: behavioral beliefs, perceived control, and subjective norms. Articles were grouped into themed categories and explanations of how the definitions were addressed are included.

**Behavioral beliefs** are thoughts, perceptions, and idealizations of future actions or activities. For the older adult, perceptions about relocating to a supervised housing can influence the behaviors necessary to attain positive outcomes. In this research review, those attitudes can be classified into five categories: *perceptions of relocation, reasons for relocation, adjusting to relocation, decision-making, and “wild card”*.

Qualitative studies dominate the evaluation of older adults' perceptions of relocation from independent living to supervised housing. Lee (1997) interviewed independent living elderly Chinese about their beliefs on residential care homes. Perceptions were mostly negative and described long term care as “a dumping ground” and “a place to die” (Lee, 1997, p. 605). The quality of care in congregate housing was also a concern for these older adults who felt that attentiveness of staff might not be adequate. Shippee's (2009) participants, who resided in a continuing care retirement community, viewed a move to a higher level of care as a disintegration of their established role as a healthy older adult, thereby disrupting friendships and social networks. Some older adults viewed relocation as a positive endeavor describing familiarity with the facility, social connections with current residents, closer proximity to adult children or other relatives, and, for those living alone, a means of combating loneliness (Armer, 1993; Bekhet et al., 2009; Fraher & Coffey, 2011; Johnson et al., 1994; Lee, 1997, 1999; Leggett et al., 2011). Reasons for relocating to a higher level of care included physical and functional

issues and psychosocial factors. The most common motivations were declines of the older adult's or a spouse's health and function (Bekhet et al., 2009; Fraher & Coffey, 2011; Johnson et al., 1994; Lee, 1997; Leggett et al., 2011; Saunders & Heliker, 2008; Sviden et al., 2002; C. Walker et al., 2007; E. Walker & McNamara, 2013). Relinquishing home ownership and responsibilities, especially housekeeping duties for women, was another factor in relocating (Bekhet et al., 2009; Lee, 1999; Leggett et al., 2011). Inconsistencies in family support and in-home assistance as well as unwillingness to move in with family were additional reasons for older adults to relocate (Bekhet et al., 2009; Johnson et al., 1994; Lee, 1997; Leggett et al., 2011). Interviews with African-American and European-American older adults revealed that indigent elderly may not be aware of or able to afford community-based care. Therefore, they had to move to a higher level of care sooner than their wealthier counterparts (Johnson, Popejoy, & Radina, 2010). Several studies reported that fear of becoming a burden to families was a motivator for older adults who proactively relocated to a higher level of care (Leggett et al., 2011; Saunders & Heliker, 2008; Sviden et al., 2002). Adapting to a new living environment was reported in multiple studies and highlighted the differences in the belief systems held by older adults to navigate a new living situation. Some new residents experienced fear, anxiety, despondency, frustration, helplessness, anger, and stress (Fraher & Coffey, 2011; Lee, 1999; Leggett et al., 2011; Saunders & Heliker, 2008; Sviden et al., 2002; Wilson, 1997). These feelings subsided over time, but for those in whom the move was precipitous and unplanned, the adjustment period was longer (Saunders & Heliker, 2008; Sviden et al., 2002; Wilson, 1997). However, an equal number of responses described relief of household duties, meeting new friends, improved safety, and increased socialization in addition to having continuous nursing supervision as benefits of relocating (Fraher & Coffey, 2011; Lee, 1999; Saunders & Heliker, 2008; Sviden et al., 2002; Wilson,

1997). Decision-making throughout the relocation process involved the choice of when and where to move and also the loss of freedom to make decisions in a congregate living situation. Relocation decisions were usually made by the older adult, sometimes independently and sometimes with the assistance of family or health care providers (Fraher & Coffey, 2011; Johnson et al., 2010; Johnson et al., 1994; Saunders & Heliker, 2008; Sviden et al., 2002; C. Walker et al., 2007). In one study, residents of a continuing care retirement community expressed dismay that the decision to transition to a higher level of care would be made by a committee (resident director, nurse, facility administrator) after evaluation of the older adult's functional abilities (Shippee, 2009). The rules, regulations, and absence of privacy at the new facility, lack of communication challenged autonomy from staff, family and health care providers, and disruption of the older adult's usual routines (Fraher & Coffey, 2011; Lee, 1997, 1999; Shippee, 2009; Wilson, 1997). One study, "wild card", defied classification within the parameters of the beliefs of older adults toward relocation. C. Walker et al. (2007) attempted to validate the physical and emotional toll (Relocation Stress Syndrome) experienced by elders transitioning from independent living to a supervised living situation. All the participants in this study expressed steadfastness and strength in the belief that moving was the best option for them and their families; this is not consistent with findings in the other studies.

**Perceived control** or the amount and quality of control the older adult has in the relocation decision-making process is directly related to positive outcomes and adjustment to a new living environment. The articles assessed for this section were classified into three categories: *reasons for relocation, decision-making, and adjustment to relocation.*

Older adults cited their own or a partner's health and safety issues as the primary *reason to relocate* to supervised housing, and a decision they made either independently or with

assistance from family or health care providers (Bekhet et al., 2009; Fraher & Coffey, 2011; Johnson et al., 2010; Johnson et al., 1994; Leggett et al., 2011; Saunders & Heliker, 2008; C. Walker et al., 2007; E. Walker & McNamara, 2013; Wilson, 1997). Other factors that contributed to a move were the desire to be closer to adult children, the desire for socialization, and elimination of household responsibilities. When the impetus to move was proactive or before an emergent event, older adults had more latitude in the decision-making process (Bekhet et al., 2009; Johnson et al., 1994; C. Walker et al., 2007; E. Walker & McNamara, 2013). Armer (1993) found that when a choice in relocation *decision-making* was perceived, the older adult experienced more positive transitions during the transition. This finding was supported by Bekhet, Fouad, and Zauszniewski (2010), Leggett et al. (2011), and E. Walker and McNamara (2013). In contrast, elders who were unable or not allowed to have input into relocation decisions experienced prolonged adjustment periods, dissatisfaction with the facility and staff, and hesitancy to participate in the social activities of the community (Johnson et al., 2010; Shippee, 2009; Sviden et al., 2002; Wilson, 1997). Participants in a continuing care retirement community who were assessed for self-care abilities by staff resented that they had no control over when the move would be deemed imminent (Shippee, 2009). Wilson (1997) found that the majority of unplanned moves were a consequence of escalating functional decline and acute care hospitalization, resulting in a lack of decisional participation in relocating and a prolonged period of grief, anger, and regret.

Adjustment to relocation was a recurrent theme, particularly with loss of privacy, rules and regulations, and as well as coping with the loss of independence (Armer, 1993; Lee, 1999; Saunders & Heliker, 2008; Sviden et al., 2002; Wilson, 1997). At the same time, some older adults expressed a renewed sense of safety, consistent care and increased social interactions as a

positive outcome to relocation (Fraher & Coffey, 2011; Lee, 1999; V. Lee et al., 2013; Saunders & Heliker, 2008; Sviden et al., 2002; E. Walker & McNamara, 2013). Bekhet et al. (2010) found that adjustment to relocation occurred more quickly if the older adult had participated in the decision to relocate. This finding was supported by Armer (1993) and Leggett et al. (2011). V. Lee et al. (2013) interviewed British older adults and found that adjustment to relocation was not ‘time bound’ but fluid and comprised of ‘plots’ reflecting ‘control’, ‘power’, ‘identity’ and ‘uncertainty’ (V. Lee et al., 2013, p. 48). Chinese elders’ acclimation to congregate living was mediated by cultural influences which enabled them to assume a new way of life and become one with their environment (Lee, 1999).

**Subjective norms** are the influences of “others” in changing perceptions and actions of behavioral change. Also termed “referents”, the approval, assistance and guidance of these individuals was instrumental in assisting the older adult in the transition to supervised housing.

Family members were most often reported as assisting the older adult in the decision to relocate (Armer, 1993; Fraher & Coffey, 2011; Johnson et al., 1994; Leggett et al., 2011; Shippee, 2009). This varied from adult children, to extended family, or spouses. Health care providers, including nurses, social workers, and physicians, provided either support for the older adult’s decision to move or influenced them to pursue a higher level of care must be attained (Johnson et al., 2010; Johnson et al., 1994; Sviden et al., 2002). Relationship of the caregiver to the older adult was only revealed in qualitative narrative excerpts, limiting the ability to discern the type of caregiving affiliation.

### **Limitations**

This review was time limited to literature published from 1992-2014. Other publications released prior to 1992 may have provided a different historical perspective on relocation of older



adults as they would focus on a different generational cohort. Additionally, studies that involved the relocation of older adults with dementia were excluded. While this phenomenon is widely researched, it would be difficult to fully explicate the impact of perceived control, behavioral beliefs, or subjective norms in older adults whose communication and recall may be impaired. Some of the studies were multi-cultural (African-American, Egyptian, Chinese, Scandinavian); however, only one addressed the issue of relocation experiences for low-income older adults (Johnson et al., 2010).

### **Discussion**

Using Hawker's (2002) process for examining the strength of the selected articles, six studies emerged that were inclusive of all the measurement criteria (Bekhet et al., 2010; Bekhet et al., 2009; Johnson et al., 2010; Saunders & Heliker, 2008; Shippee, 2009; Sviden et al., 2002). The abstracts and introductions impart to the reader a thorough synopsis of the study and a summary of supportive literature on the selected topic. The articles provide rich, detailed reporting of their methodology, sampling, data analysis, ethics, results, transferability, and implications. While the remaining articles (Armer, 1993; Fraher & Coffey, 2011; Johnson et al., 1994; Lee, 1997, 1999; Leggett et al., 2011; C. Walker et al., 2007; Wilson, 1997) add to the general knowledge of relocation transition in older adults, a more comprehensive description of the introduction, method, data analysis, ethics, and results would have supplied the reader with an enhanced understanding of this important research.

Supporting the Theory of Planned Behavior, behavioral beliefs and perceived control are well documented in the articles reviewed. Studies reflect the duality of the older persons' beliefs and perceptions of control over their destiny. For some, transition into a new living environment was welcomed because it decreased the burden of home ownership, provided a safer and more

secure living situation, and afforded continuous supervision and nursing care. Other older adults, especially those whose relocation was forced or unexpected, suffered from emotional distress, loss of self-worth, and inability to integrate into the new community. For them, the move did not provide the same level of acceptance or positive outcomes. The majority of participants, whether willing or unwilling movers, experienced some amount of sadness and grief over the loss of independence, but most were eventually able to accept their physical declines and increased care needs. An interesting finding indicated that some older adults had difficulty “looking” at their own futures embodied by fellow residents who were more infirm and needy (Fraher & Coffey, 2011; Lee, 1999; Shippee, 2009; Sviden et al., 2002). This realization occurred sometime after admission and limited socialization and participation in activities. Manifestations of both positive and negative transitions to a higher level of care are described in these studies and reflect an increased awareness of the power and magnitude of behavioral beliefs and perceived control on positive transitional experiences.

Those who assist the older adult in the relocation decision process (referents) are viewed in the studies as one entity. Some of the qualitative narrative identifies a specific relationship (daughter, niece) or profession (physician, social worker) but most referents are termed “family”. Although the literature presented here heralds and supports the role of family, the term is a misnomer. Family caregivers can be family, friends, partners, and neighbors, but the most common caregiver is a 49 year old female caring for her widowed mother (Mathew Greenwald & Associates, 2009). Filial caregivers are the adult children of older adults who assume the caregiver role for one or more parents while caring for dependent children and maintaining full time employment. Sandberg, Lundh, and Nolan (2002) examined the role of the adult child in the transition of one parent to a higher level of care while still supporting the “healthier” parent. The

degree of involvement of the adult child was determined by the needs of the remaining parent. The adult child influenced the decision to move the sicker parent and remained an active participant in caregiving for both parents. Additionally, the adult child assumed the burden of guilt associated with the placement decision. After relocation, the adult child's caregiving role is revised to incorporate maintaining contact with life outside the care facility and monitoring care received by paid staff (Davies & Nolan, 2006). Future research should explore the role of the family caregiver by clearly defining the relationship to the older adult and the depth of their involvement in the caregiving and relocation processes.

Another area of research should focus on how the Baby Boomers are planning for their long term care needs, many of whom are caring for aging parents. Robison, Shugrue, Fortinsky, and Gruman (2013) surveyed randomly selected Baby Boomers to determine their engagement in long-term care planning. Although 60.1% of the respondents felt they would require assistance as they aged, 77.4% of Baby Boomers had no plans for financing future care needs or did not know how they would pay for care as they aged (Robison et al., 2013). This is particularly disturbing in that this cohort will significantly swell the aging population and tax an already fragile system of social supports for older adults.

### **Conclusion**

The majority of studies for this integrative review are qualitative, and the few that are quantitative used a multitude of instruments to determine the elements of a relocation transition for older adults. It is interesting that all of the studies essentially arrive at the same conclusion: positive relocation transitions are based on the older adults' belief that a move is necessary and that there must be some level of choice and control over the decisions made prior to the relocation. This finding reflects the tenets of the Theory of Planned Behavior in that older adults

believe they will need to relocate and when possible, should have control over the decisions surrounding relocation. While some older adults make these decisions independently, many rely on others to assist in the process of making a move.

How then, do health care professionals facilitate these two vital components so that older adults can transition to supervised care with minimal emotional turmoil? The answers, gleaned from the research evaluated here, are to explore the older adult's preferences for supervised housing and to encourage proactive decision-making about alternate housing options. Open, consistent, and honest conversations with older adults and their families are essential to avoid the poor outcomes that result from an emergent relocation. Other avenues of research should focus on methods to mitigate or alleviate the major issues expressed by the participants, such as lack of privacy, inflexible rules and regulations, and suppression of autonomy.

Many of the participants in these studies relied on others, particularly family, to assist in the decision-making process. However, what is unclear is the physical and psychological toll these decisions exact on the caregiver. What are the factors that facilitate a positive relocation transition for the caregiver, specifically the adult child? What are the barriers for the adult child in orchestrating the relocation process? What are the adult child's feelings and emotions about the transition of a parent from independent living to supervised housing? Future research into the experiences of adult children as they assume responsibility for the well-being of an aging parent would illuminate the trajectory of increasing frailty and dependence inherent in a move to a higher level of care.

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Table 1 *Reviewed Studies*

| Author  | Aim/Purpose  | Sample  | Method   | Key Findings/Themes   |
|---|--|---|--|---|
| Bekhet, A., Zauszniewski, J., & Nakhla, W. (2009) | To understand the reasons why elders move to retirement communities and what living in retirement communities is like from the perspective of relocated elders   | Cognitively intact, relocated elders (n=104) from a parent study  | Qualitative interviews   | Pushing factors; Pulling factors; Overlapping factors   |
| Lee, V., Simpson, J., Froggatt, K. (2013)         | To explore qualitatively older people's experiences after an initial adjustment phase in order to illuminate ongoing processes of transition and related psychological factors; to explore how transitions were internalized and reflected upon within residents' life stories | Purposive sample; British older adults (n=8)  | Qualitative; interviews  | Transition may be influenced by key plots of 'uncertainty', 'identity' and 'power/control', which are interwoven within individual's daily and more long-term existence.                    |
| Walker, E., & McNamara, B. (2013)                 | To identify key factors over different stages of relocation; to determine the range of strategies employed by older adults in relocating and maintaining a sense of home; to explore the scope for preventative occupational therapy in promoting health and well-being        | Purposive/snowball sample; Australian older adults (n=16)   | Qualitative; semi-structured interviews  | Two main findings: successful transitions were made by researching and gathering information prior to the move and maintaining the ability to exercise agency across the relocation process |
| Johnson, R., Schwiebert, V., Rosenmann, P. (1994) | To identify factors influencing placement of older adults in nursing homes; to delineate the process by which this decision occurred   | Cognitively intact older adults (n= 18), >60 years, at least one year in nursing home, English speaking | Qualitative descriptive design; semi-structured one hour interviews using open ended questions | Factors Influencing placement: health issues, caregiver issues, fear of living alone; placement decision makers: "powerful other"/self; advice to others making placement decisions         |

Table 1 continued

| Author                            | Aim/Purpose  | Sample  | Method  | Key Findings/Themes   |
|-----------------------------------|--|---|---|---|
| Lee, D. (1997)                    | To explore and investigate Chinese elder people's perceptions of residential care placement  | Convenience sample (n=20); older adults >60 years from adult day centers  | Quasi-qualitative; semi-structured taped interviews                             | Likelihood of residential care placement: Most (40%) believed a move would be necessary<br><br>Beliefs about residential care: Positive and negative perceptions<br><br>Knowledge/experience of residential care homes: most information garnered from friends/acquaintances or volunteering in a care center |
| Lee, D. (1999)                    | To achieve understanding of how Chinese elders in Hong Kong experience the changes associated with admission to residential care homes | Purposive sampling; older adults (n=10) newly admitted to residential care homes; no hearing or speech deficits     | Descriptive qualitative; audio-taped interviews within one week of admission    | Positive and negative feelings about the move; Chinese culture encourages modifying expectations and adaptation; Communal living; Establishing new relationships  |
| Saunders, J. & Heliker, D. (2008) | To explore the expectations and experiences of 5 newly admitted residents of an assisted living facility (ALF) over a 6-month period   | Convenience sample; older adults (n=5), Mini-Mental Status Exam score >24, English speaking, ability to communicate | Quasi-qualitative using semi-structured interview questions over 6 month period | Deciding to move; Becoming dependent; Remembering what was and yearning for the past; Creating a new community  |
| Shippee, T. (2009)                | To investigate how residents perceive transitions across levels of care and how residents manage social relations while moving within  | Purposive sample (n=35)   | Qualitative: observation and interviews   | Autonomy; Threats to privacy/personal space; Fatalism; Social   |

Table 1 continued

| Author   | Aim/Purpose  | Sample   | Method  | Key Findings/Themes   |
|--|--|--|---|---|
| Sviden, G.,<br>Wikstrom, B.,<br>Hjortsjo-Norberg,<br>M. (2002) | To describe the qualitatively different ways in which the participants said they experienced relocating to sheltered housing and adjusting to new living arrangements  | Swedish older adults (n=59) who resided in sheltered housing at least one year   | Qualitative, exploratory, phenomenological approach; semi-structured interviews                                       | Reasons for moving to sheltered housing; Experiences related to reception at the sheltered housing; Adjustment to living in sheltered housing   |
| Walker, C. ,<br>Curry, L., &<br>Hogstel, M.<br>(2007)          | To verify the nature and kind of distress associated with relocation stress syndrome (RSS); to validate diagnostic criteria for RSS among older adults residing in nursing homes and assisted living facilities; to determine whether RSS manifests differently among residents of one kind of facility versus another | Convenience sample (n=16); nursing home (n=8)and assisted living (n=8) residents; >65 years, no greater than mild cognitive impairment | Qualitative; structured interviews  | Moving from independent residence to LTC; Relocation differences between AL and LTC placement; Stressful relocation?  |
| Wilson, S. (1997)  | To identify variance in the initial responses of older adults whose move into a nursing home is expected to be a permanent move and is either planned or unplanned   | Older adults (n=15) who had recently relocated   | Exploratory, descriptive, qualitative interviews  | Overwhelmed phase; Adjustment phase; Initial acceptance phase   |
| Armer, J.(1993)  | To examine the relationship of perceived choice, perceived social support, cognitive appraisal, coping strategies, self-related health with adjustment to relocation of community based rural elderly  | Older adult residents (n=50)   | Mixed methods: Cross-sectional, descriptive-correlational; semi-structured interviews; Questionnaire with instruments | Instrument scores correlated significantly with perceived choice in relocation and current environment, social support (family/neighbors), predictability, threat appraisal, challenge appraisal.<br>Qualitative themes: Most reported positive feelings toward relocation; Perceived choice in relocation/ environment improved adjustment |

Table 1 continued

| Author  | Aim/Purpose  | Sample   | Method   | Key Findings/Themes  |
|---|--|--|--|--|
| Johnson, R., Popejoy, L., Radina, E. (2010)               | To identify extent of older adults' participation in relocation decision making and extent of SOC (sense of coherence), function, physical ability as related to decision making.  | Random selection of nursing home residents (n = 16)  | Mixed methods: qualitative interviews and four instruments:                                | Qualitative: Two themes: "They put me here" & "I made the decision."<br><br>Quantitative: Significance was not attained  |
| Leggett, S., Davies, S., Hiskey, S., & Erskine, J. (2011) | To explore the application of the Time, Environment, Motivation, Personality, and Outcome (TEMPO) model and establish whether an increase in frequency of prefactuals/counterfactuals might emerge as people move along the TEMPO timeline | Opportunistic sampling (n=66) divided into two groups: Age 18-64 (n=33) and age >65 (n=33)     | Mixed methods; cross-sectional; Interviews using two fictitious scenarios about relocation | Qualitative-multiple themes focused on pre-planning for a move due to poor health<br><br>Quantitative-Older adults tended to view scenarios as opportunities to plan ahead   |
| Bekhet, A., Fouad, R., & Zauszniewski, J. (2010)          | To determine whether the effects of risk factors (relocation) on elders' resilience (adjustment) are influenced by protective factors such as positive cognitions  | Convenience sample of Egyptian older adults (n=94) who had relocated to retirement communities | Cross-sectional; quantitative; three instruments   | Mediation: Relocation controllability had a direct negative effect on relocation adjustment ( $B = -.36, p < .001$ )<br>Relocation controllability had a direct negative effect on positive cognitions ( $B = -.41, p < .001$ )<br><br>Effect of relocation controllability and positive cognitions on relocation adjustment ( $B = -.20, p < .05$ ) |

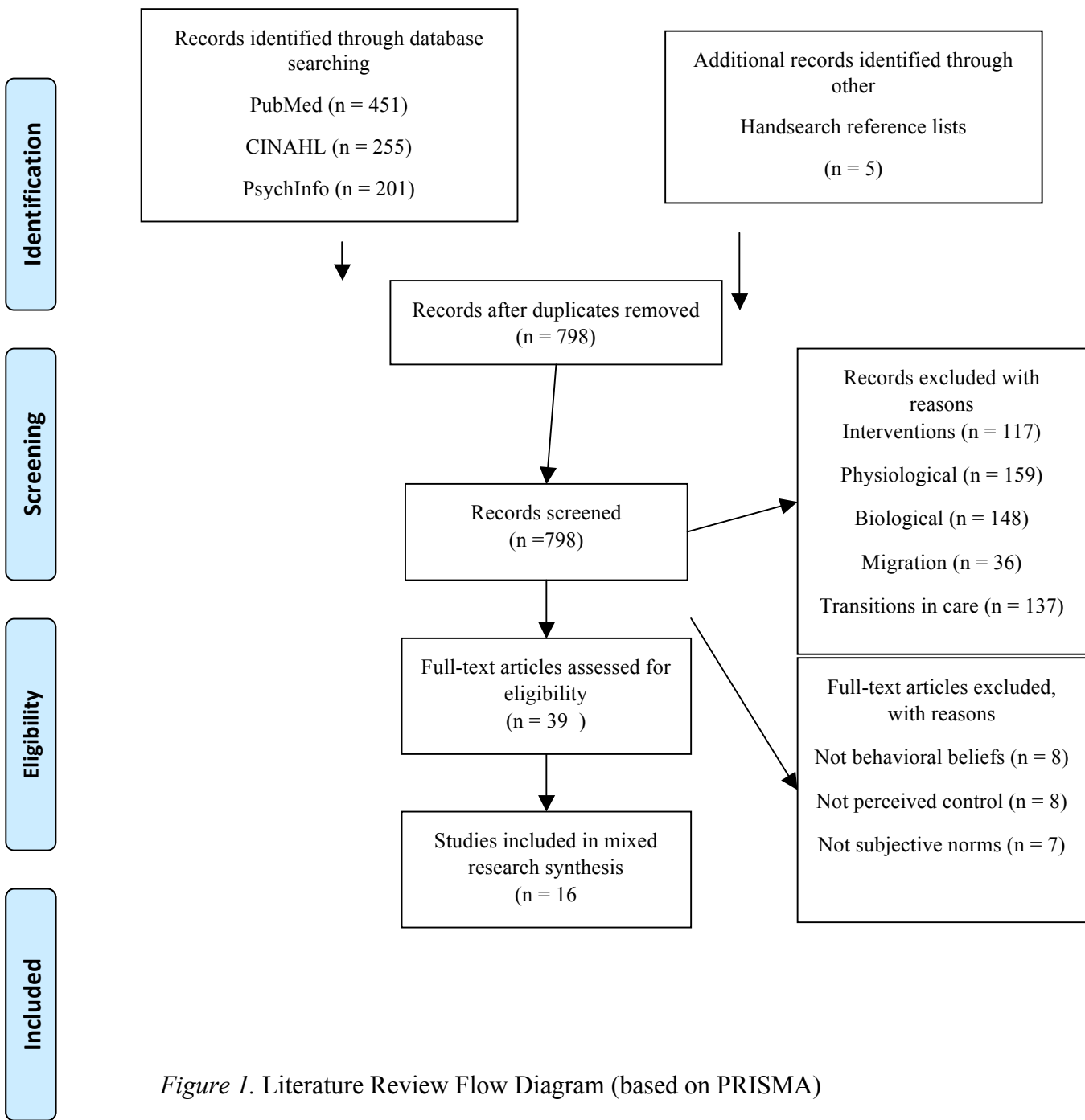


Figure 1. Literature Review Flow Diagram (based on PRISMA)

Changing Places: Adult Children and the Transition of Aging Parents

*This manuscript will be submitted to The Gerontologist*

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## Abstract

**Purpose of the study:** This study explore the experiences of adult children as they transition their functionally and/or cognitively declining aging parents from independent living to supervised housing.

**Design and Methods:** A qualitative grounded theory approach was used to chronicle the experiences of adult children as their caregiving responsibilities intensified and the parents' health declined. Purposive sampling was used to enlist adult children (n=16) from three assisted living facilities and a small university in the southern United States. Semi-structured telephone interviews were conducted using questions developed from Symbolic Interaction Theory (SI) and designed to follow a pattern of increased frailty of the parent(s) and escalating involvement of the adult child.

**Results:** Two major themes emerged from the data: Changing Places and Everlasting Love. Adult children began to intervene when cognitive or physical declines compromised the safety and well-being of the older adult. As disabilities intensified, adult children relied on siblings, friends, social services and health care providers to assist in planning and implementing caregiving responsibilities. Deep respect and abiding love of the aging parent(s) sustained the adult child throughout the caregiving experience.

**Implications:** Research on caregiving should define "family caregiver" to delineate between adult children and other caregivers. Further research should also focus investigations on programming that could assist the adult child in their caregiving responsibilities such as affordable in-home care, adult day services, and financial planning.

*Key words: older adults, adult children, caregiving, grounded theory, qualitative research, Symbolic Interaction Theory*



## Changing Places: Adult Children and the Transition of Aging Parents

As the population of older adults grows, so too will the population of informal caregivers. According to the Congressional Budget Office, 82% of older adults with functional and/or cognitive limitations reside in the community with support provided predominantly by informal caregivers (Hagan, 2013). Most caregivers are female (66%) and if employed, are likely to be African-American (21%) or Hispanic (20%). A typical caregiver in the United States is female, 49 years old, employed, and devotes 20 hours per week tending to her mother (Hagan, 2013). Aging parents or parents-in-law are the most common care recipients (72%) and were still residing in their own homes (51%) or with the caregiver (29%) (Shell, 2014).

Adult children caregivers assist with Instrumental Activities of Daily Living (IADLs) such as transportation, medication administration, shopping, finances, housekeeping, laundry, and meal preparation in addition to more personal Activities of Daily Living (ADLs) such as bathing, dressing, feeding, transferring, and toileting (Feinberg, Reinhard, Houser, & Choula, 2011; Mathew Greenwald & Associates, 2009). These responsibilities can take an emotional and physical toll on the caregiver leading to a decline in physical health, decreased socialization, and higher prevalence of depression and perceived stress (Cagle & Munn, 2012; Feinberg et al., 2011; Khalaila & Litwin, 2011; Schultz & Sherwood, 2008).

Caregiving for an aging parent impacts the financial stability of an adult child, many of whom are preparing for its own retirement. Sixty-eight percent of employed adult children caregivers adjusted works schedules, left the workplace early or arrived late, retired early, declined a promotion, or took a leave of absence (Shell, 2014). Workers who leave jobs to fulfill caregiving responsibilities for an aging parent can, over their lifetime, expect to lose an average of \$304,000 in income and benefits (Feinberg & Choula, 2012).

Respondents to a telephone survey report using their own money to purchase household goods, medication and health care co-payments, food, and transportation for their aging parents (Evercare, 2007). Estimates of yearly expenditures of \$5531 had a negative impact on the adult child's disposable income, delaying home maintenance, depleting savings, and reducing available funds for their own health care (Evercare, 2007).

Eventually, the older adult's care needs will outpace the ability of the adult child to provide that care. There is a dearth of research on the particular phase of the caregiving experience that centers on the adult child and how they "know" when relocation preparations should commence. How does the adult child process the functional or cognitive decline of an aging parent? At what point do the declines become evident? And when does planning for relocation to supervised housing begin? Therefore, the purpose of this study was to answer the following questions:

1. What are the experiences of adult children when transitioning their functionally declining parent(s) from independent living to supervised housing?
2. What are the experiences of adult children when transitioning their cognitively declining parent(s) from independent living to supervised housing?

## **Method**

A qualitative grounded theory design was employed, using semi-structured interviews framed by Symbolic Interaction Theory (SI) (Blumer, 1969). Qualitative inquiry allows for the exploration of the world through the participants' eyes, specifically to give voice to the participants' reality and develop understanding of that reality (Petty, Thomson, & Stew, 2012). SI enables the researcher to appreciate the human process of constructing a world view through experiences, perceptions, and interpretations of events and interactions thereby framing individual behaviors (Blumer, 1969). In this study, SI was utilized to give voice to the adult

child's experiences with the declining health of an aging parent. Through recognition of problems, implementation of support to the parent, and escalation of that support as needs arose rich descriptions of the adult child's journey through caregiving were provided.

### **Setting and Participants**

Purposive sampling was used to recruit adult children who contacted three assisted living facilities in the southern US. Sampling was widened to include a health sciences college within a small state-supported university in the same geographic region due to low response rates from the facilities. Participants were invited to volunteer for an interview if they were caring for an older adult parent.

### **Data Collection**

Following approval of research protocol and amendments from the principal investigator's Institutional Review Board, the assisted living facilities distributed a letter to potential participants, explaining the nature of the study. This recruitment method yielded no participants, thus an email was distributed to the faculty and staff of the health sciences college. Participants contacted the principal investigator (PI) who followed up with the participant by telephone or email.

If inclusion criteria were met, an interview time was scheduled and participants received a Statement of Research describing the study and human subject protections. The Statement of Research was used in lieu of a signed Informed Consent as interviews were conducted over the telephone. A signed Informed Consent document would have been the only identifier linking the participant to the study.

At the beginning of each interview, the PI confirmed that participants read and understood the Statement of Research. Additionally, the PI asked if the participant had any

questions about the interview process. Participants were assigned a pseudonym, which was used during the interviews and during transcription. Interviews were conducted in a private office with the door closed, and were audio-recorded then immediately sent to a secure transcription service. Transcripts were saved on a password-protected, secure server. The PI regarding the interviews, which contained only the participant's pseudonym, wrote reflexive and process memos. A series of demographic questions included age, gender, race/ethnicity, number of living siblings, rural/urban setting, the number of years of caregiving, employment status, and types of caregiving provided. Interview questions walked the adult child through the beginning stages of their parents' decline to the recognition that the parent could no longer live independently. During each interview, key elements of the conversation and any nonverbal expressions of the participants were documented using memo writing. Transcripts were sent to the adult child for verification and editing of content (Mero-Jaffe, 2011). It was important for the participants to review transcripts to ensure that the substance of their interview was maintained, to clarify content, and to provide the opportunity for reflection on the questions.

### **Data Analysis**

Transcripts were uploaded into Atlas.ti ® data management system for analysis by the PI. Line-by-line coding of thematic content was conducted on the initial reading of each transcript. As themes emerged, selected descriptive quotes were noted in Atlas.ti ®. Subsequent readings of the transcripts with comparisons to memo-writing notes elicited sub-themes (Charmaz, 2006). Interview questions were developed to simulate the aging parents' chronological decline in health and to illuminate the adult child's process of providing increased assistance to the aging parent. The first interview question, "Tell me about what and when you first noticed that your mother/father was having problems" was followed by probes such as: "Describe those problems;

memory problems; functional problems; what went through your mind at the time; how did you handle those problems”. The responses to these questions supplied the foundation for the major themes as the participants described how they processed the issues of caregiving for an aging parent. For example, responses to the first interview question elicited multiple data on physical and cognitive decline of the older adult but also on the IADLs that the adult child assumed. The IADLs are tasks that the aging parent could not perform, therefore the adult child “changed places” when they began performing those tasks. Once the main themes were noted and descriptive quotes were selected, transcripts were reviewed again to discern subthemes. Quotes were selected to represent the subthemes and diagrams were developed to illustrate relationship between themes and subthemes. An example of this would be the final question of the interview: “If you have the opportunity, what advice would you give to others who are going through the same process?” The responses were, at times, straightforward with the participant describing practical information for others. Member checking was accomplished through returning a list of themes with accompanying quotes to three participants. The PI discussed the themes and salient quotes with a senior qualitative mentor to verify and finalize the themes and subthemes. An immersion and crystallization process in which both researchers asked questions and probed findings to refine the terminology of themes enabled this process. (Borkan, 1999)

## **Results**

### **Participants**

Sixteen participants were interviewed for this study (Table 1). Two were age 41-50, 7 were age 51-60, and 7 were age 61-70. The majority were female (n=13) and all were White. Most lived in rural environments (n=14) and were employed full-time (n=9). Four participants were retired and 3 worked part-time. Thirteen adult children had 0-3 siblings while 3 reported 4-

6 or more brothers and sisters. Fourteen adult children had been caregiving for their aging parent for 0-10 years and 2 had been caregivers for 10 or more years. The average number of hours adult children were involved in caregiving was dependent on their parents' housing circumstances. Long distance caregivers pooled their caregiving time with one participant spending one 72-hour weekend every 3-4 months and another spending a week or more with aging parents. Weekly averages of caregiving hours also varied if the parent had assistance in the home or resided in supervised housing. Three participants stated they provided caregiving 0-10 hours, 11-20 hours, and 21-30 hours, respectively. Five adult children averaged 30+ caregiving hours per week, especially if older adult resided with the child. (Table 1).

The predominant assistance provided to the older adult were Independent Activities of Daily Living (Lawton & Brody, 1969). Fourteen participants provided the primary means of transportation for the older adult while 15 completed the shopping. The adult child either maintained housekeeping or a cleaning service was engaged for 13 participants. Ten adult children prepared one or two meals per day for the parent. Financial assistance (bill-paying) was performed by 11 participants while 9 prepared weekly medications or ensured the older adult was taking the medications appropriately. (Table 2)

Fewer adult children helped their aging parents with ADLs. Performing these tasks occurred more often if the older adult resided with the adult child or the adult child provided care over a long period of time (weekends, overnight). Five participants assisted with dressing and 4 helped with bathing. Three adult children helped their parent with toileting and transferring, respectively. Only 2 older adults required assistance with feeding, mostly cutting food.

## Themes

Once themes were determined and quotations selected, three participants were selected to validate that the themes corresponded to their perception of the interviews. All three adult children communicated their acceptance of the themes. Member checking allows for the validation of themes by participants (Charmaz, 2006).

Two major themes were revealed during the data analysis: Changing Places and Everlasting Love. (Figure 1) (Figure 2) *Changing Places* describes the process the adult child used to address problems caused by diminished functional or cognitive abilities. The adult child assumes roles, or changes places with the aging parent by performing Instrumental Activities of Daily Living (Lawton & Brody, 1969) such as, paying bills, shopping, preparing meals, and setting up medications and later in the process, assisting with Activities of Daily Living (Katz, Ford, Moskowitz, Jackson, & Jaffe, 1963). Six subthemes were discovered related to *Changing Places* (Figure 1). *Memory Failure* and *Functional Failure* were the cause of the adult child 'changing places' and pushed the adult child to intervene. *Patching the Holes* was associated with the main theme and describes the responsibilities the adult child fulfilled for the aging parent. Another group of subthemes illuminate the task of arranging *Help from Others*. *Family Discord* illustrates the friction between the adult child and the aging parent, siblings, and spouses, and *Money Matters* explains the financial concerns of the caregiving experience. The second major theme, *Everlasting Love*, illustrates the adult child's desire to honor their parents with abiding respect and dignity. Two related subthemes were identified: *Words of Wisdom* in which the adult child proposes recommendations for others and contemplative statements of the adult child's experiences titled *Regret*.

## Changing Places

The theme *Changing Places* revealed the beginning of the adult child's transition into a caregiver for an aging parent. It was evident that the adult children recognized that the older adult needed assistance but also ensured that the aging parent participated in the decision-making process.

“She was ready to make the move. She initiated it, and said she was ready. But I was the one a little hesitant at first.”-Anne

“It was his desire to stay in his house as long as he could, but he decided that just; because, of his age, his safety, he didn't want to be by himself.”-Jenny

“I took a job where she lived so that we might come up on Sunday evening and I would work three days a week to where we could both stay in her home.”-Bonnie

Two sub-themes were identified as causative factors in the adult child assuming caregiving responsibilities for the older adult. *Physical failure* had several manifestations but repeated falls or weakness that could cause a fall were a concern to the adult children. Safety became the primary objective for both the adult child and the older adult, often providing the impetus for relocation.

“Within the last year, about four to five falls, associated with her blood sugar dropping.”-

Anne

“She seemed unstable on her feet...peripheral neuropathy...the instability of her feet became one of our main concerns just in terms of mobility and, again, worrying that she would fall.”-Claire

“He started having chest pain, I believe maybe shortness of breath or maybe getting tired.”-Jenny



*Memory failure* presented more challenges to the adult child because the parent was often unaware that there was a problem. The cognitive changes arrived slowly and sometimes went unnoticed until there was an incident.

“I started hearing about her getting late payment notices, and that is very much not like her”-  
Craig

“There was a fire in the kitchen and my mother was at a loss as to what to do”-Claire

“She was having episodes where she wouldn’t recognize my father”-Craig

*Patching the Holes* was noted once the realization of the aging parents’ diminishing abilities occurred and was the result of the changing roles within the family dynamics. The adult child provided transportation, meals, financial management, preparing medication, shopping, and housekeeping.

“I’ll fill up his medicines for the week. I’ll take his meals and I’ll help him pay his bills and help him with whatever he needs”-Jenny

“I would get up early in the morning and prepare her breakfast and leave it for her and her lunch in the refrigerator”-Bonnie

“I’m dealing with the financial part”.-Craig

Some families made adjustments to the home environment to allow the older adult to remain independent as long as possible. Removing carpet, installing handheld showers, grab bars, ramps, and comfort height toilets added another layer of safety and convenience for the older adult. Others reported that they obtained medical alert bracelets and door alarms in addition to disconnecting the stove to protect older adults with cognitive decline. The adult child monitored the parents’ well-being implemented safety and supports as the parent’s cognitive decline worsened.

“You see the need and you fill it”-Diane

During the adult child’s transition as a caregiver to aging parents, they seek the advice, counsel, and support of others. *Help from Others* reflects the manner in which adult children accessed resources. Many depended on siblings to share caregiving responsibilities while others relied on neighbors or faith communities. Some adult children contacted their local Agency on Aging or Social Services to inquire into local resources such as, Meals on Wheels, adult day centers, congregate meal sites, and personal care aides. Health care providers provided medical supervision and advice for some participants. Internet resources were used by some of the adult children to search for information and to communicate with other family members.

“I called the Agency on Aging and that’s how I got her involved in the senior citizen program”-  
Ferne

“My siblings and I took turns, but then we finally got the caregivers signed up and they started the first week”-Ginger

“The Internet was a huge resource for us, just in terms of communication”-Kathy

At times, even *Help from Others* created difficulties for the adult child. Depending on the older adults’ financial resources, adult children either struggled to pay for in-home care or had to judiciously manage finances to ensure that care would be available as long as necessary. *Money Matters* highlights the complications that arose due to an abundance or scarcity of resources.

“Otherwise we would have had to take her out of the house and put her into a nursing home and then after the money to keep her there ran out, they’d kick her out anyway so why bother”.-

Diane

“They saved money over time and have a fair amount of money to rely on now.”-Jenny

“My parents were so old and sick, they outlived their money a long time ago. They weren’t eligible of Medicaid when I first started taking care of them.”-Lottie

There were difficulties on a more personal level as well with expressions of frustration and resentment toward siblings and the aging parent and concerns about the fallout in their own personal relationships. *Family Discord* reflects the unintended consequences of caring for aging parents.

“There’s been resentment and my husband feels like he gave up a lot of his life”-Mary

“Sometimes I would lose my temper with her, which doesn’t help anything, but I just couldn’t help it.”-Ginger

“Basically I was pissed off because you’re [brother] leaving me to take care of mom even though he’s [brother] sick and died of pancreatic cancer. There wasn’t much I could do about it. I was angry because he wasn’t there to be supportive”.-Ferne

### **Everlasting Love**

Despite the struggles and exasperation many adult children experienced, one theme surfaced throughout the interviews: *Everlasting Love*. Even though adult child’s primary concern was safety of the aging parent, the overwhelming goal was to include the older adult in the decision-making to maintain dignity and quality of life.

“I was kind of at peace once I knew this is what would make her happy.”-Anne

“I admire her desire to keep her independence and her abilities with everything she’s got in her as long as possible.”-Mary

“You look at her and it’s your mamma’s little body, but the mamma I knew and loved has been gone a long time.” Lottie

“We’ve tried to keep her in the loop as much as possible.”-Bonnie

The adult children in this study were more than willing to share their *Words of Wisdom* with others. Gleaned from their experiences and influenced by their love and respect for their parent(s), the advice they rendered impacted both care of the older adult and preparing for their own aging.

“I would’ve intervened sooner...they were absolutely emphatic that they could take care of themselves and take care of each other and didn’t want help or intervention.”-Claire

“Do talk to people, do talk to your friends, your family, your counselor, your pastor, seek help. Don’t try to do it all yourself.”-Claire

“Maintaining a sense of humor.”-Kathy

“Our theme is one day at a time.”-Kathy

Reflecting on what advice they would offer others, the adult children in this study also contemplated what could have been. *Regret* reveals the adult child’s missed opportunities and hope or fear of their future aging.

“My prayer, my daily prayer is that I don’t leave a mess behind me.”-Ida

“...during the last weeks of her life, if I knew they had been her last weeks, I would have stayed overnight in the room with her.”-Ida

“[It] worries me that Alzheimer’s could be something in my genetics.”- Kathy

“I’d like to be more like her, but I’m not.”-Mary

“I think time was a wave that just washed over my parents. They thought they were one place, and time just washed right over them. They weren’t prepared for it.”-Craig

## **Discussion**

This qualitative study identified the experiences of adult children who were contemplating relocation for their functionally or cognitively declining older parent. We found that within the

processes of caregiving and its inherent escalation, relocation is sometimes not a viable option due to finances or the preferences of the adult child and the parent.

Adult children whose parents exhibited functional decline were often able to intervene earlier due to observable and quantifiable indicators such as falls, hypoglycemia, and atrial fibrillation with weakness, cardiovascular issues (chest pain, shortness of breath, fatigue), macular degeneration, and hypertension. For the children and parents, safety became a key motivator for change. This finding is supported by numerous studies on older adults that indicated safety is a primary reason for relocating (Bekhet, Zauszniewski, & Nakhla, 2009; Fraher & Coffey, 2011; Johnson, Popejoy, & Radina, 2010; Leggett, Davies, Hiskey, & Erskine, 2011; Stoeckel & Porell, 2010; Walker, Curry, & Hogstel, 2007). At times, adjustments were made in the aging parents' home with the addition of assistive supports (ramps, comfort height toilets, grab bars) and subscriptions to medical alert systems. Aging in place modifications have been reported in other research on relocation in older adults (Choi, 2004; Gitlin, Szanton, & Hodgson, 2013; Hwang, Cummings, Sixsmith, & Sixsmith, 2011). Additionally, the adult child increased visits to the older adult until such time that the aging parent either chose to relocate to supervised housing or increased supervision in the older adult's home through formal or informal caregivers. If a relocation was chosen, the adult child assisted in information gathering, financial management, the physical move, and packing and selling the parents' home. Older adults who elected to remain in the home experienced more decline with the adult child assuming more responsibilities to include medication and financial management, transportation, housekeeping, meal preparation, and organizing and participating in health care visits. Other reports have documented these needs as well (Blomgren, Breeze, Koskinen, & Martikanine, 2012; Gould & Mitty, 2010; Metlay et al., 2005; Pope, Kolomer, & Glass, 2012). Turner, Hochschild, Burnett,

Zulfiqar, and Dyer (2012) found that older adults who were non-adherent with medications also had physical declines and comorbid conditions, which placed the older adult at risk for under- or over-dosing on, prescribed medications.

Older adults with cognitive deficits were often able to mask their difficulties until the adult child is alerted through unpaid bills or discrepancies in the older adults' verbal statements. Accumulation of incidents confirms the adult child's suspicions and safety precautions are implemented such as door alarms and 24-hour formal/informal caregivers. Types of care rendered by the adult child included financial management, meal preparation, medication preparation, transportation, and housekeeping. The adult child was also responsible for communication with health care providers. The majority of older adults with cognitive declines in our study were cared for in their own homes with the adult child providing most of that care. As cognitive decline progressed, the adult child increased supervision and caregiving duties; some even moved to be nearer to the aging parent. Statistical reports verify that older adults with decreased abilities due to cognitive or functional declines are cared for in the home until the care needs become too complex for the caregiver to manage (Shell, 2014).

While aging parents with cognitive decline were less afflicted with functional issues, some older adult parents with functional declines experienced differing levels of cognitive decline. This was most often manifested in missed medications, forgotten meals, lack of personal hygiene, and unpaid bills (Gould & Mitty, 2010; Tomita et al., 2010). This created difficulties for the adult child as it complicated safety precautions for the parent living in their own home. Tomita et al. (2010) study across three countries (India, Taiwan, United States) comparing caregiving for older adults with dementia findings suggest that there are little differences in the roles of the adult child caregivers between countries but all caregivers expressed the need for

support in the form of adult day centers, respite, support groups, and easily obtained, yet current information via the internet

The lack of services for older adults who wish to remain in their homes or desire to relocate to supervised housing but have too many assets to qualify for those services due to Medicaid spend-down requirements was a somber finding in the interviews. Adult children or the older adults were often not able to afford to pay out-of-pocket fees for formal caregivers (Watari et al., 2006). Transportation, housekeeping, meal preparation, and medication management were responsibilities most often assumed by adult children and yet, could be managed by programming through local Agency on Aging or Social Services. Most all communities have these services but the level of programming varies from state to state. Some adult children in our study found themselves struggling to keep their parents afloat financially and looking to their own long term care needs. Robison, Shugrue, Fortinsky, and Gruman (2013) report that Baby Boomers, many of whom are caregiving for aging parents, have not planned for future care needs. Indeed, 66% of Baby Boomers expected to need long term support even though 31% had no idea how they would pay for it (Robison et al., 2013).

An unexpected finding in our study is that while all the participants spoke of the caregiving responsibilities they carried and the difficulty in managing work, family, and caring for an aging parent, the word “stress” was never mentioned. The literature abounds with caregiver stress related research and this population is particularly vulnerable to adverse health events and depressive symptoms (Fraher & Coffey, 2011; Johnson et al., 2010; Leggett et al., 2011; Papastavrou, Charalambous, Tsangari, & Karayiannis, 2012; Shippee, 2009) however, a meta-analysis of spousal and adult child caregiving found that while adult children reported

experiencing caregiver stress, they also found that ‘giving’ care was rewarding (Pinquart & Sorensen, 2011)

Although this study focused on the experiences of the adult child as they transitioned their aging parent into supervised housing, what was revealed through the interviews was the love and respect for the aging parent. While not unexpected or surprising, these statements were poignant and moving and reflected the irony of the adult child’s situation. Adult children learned grace and dignity, patience and humility, emotional pain and grief. They were humbled by their parents’ tenacity and drive for independence and struggled to ensure that, above all else, their parents were respected. Dhar (2012), in her research on parental caregiving from the Indian perspective, stated that adult children gain ‘eternal satisfaction’ in caring for their aging parent. Adult children also begin this journey, not because they are repaying a caregiving debt but because they want to demonstrate their love and support for the aging parent (Dhar, 2012; Funk, 2012; Pope et al., 2012; Ziemba & Lynch-Sauer, 2005).

### **Limitations**

One limitation of this study was lack of ethnic and racial diversity due to the demographic footprint of the researcher’s location. Replication of the research in an urban environment may yield better representation of all groups of caregivers. Additionally, this study used a convenience sample from a southeastern rural college setting. Results may be different in another geographical location. The sample size is small (n=16) however, qualitative inquiry is not meant to be generalized but to generate hypotheses for future study.

### **Conclusions and Implications**

This study revealed the processes of adult children as they assume and advance their care of aging parents. They adopt the roles of financial manager, chauffeur, housekeeper, and nurse



and do so without looking back. They are planners, investigators, advocates, cooks, and companions. They have, in fact, changed places with the parent. But what was also uncovered in their stories were the struggles and joys they encountered along the way.

For low-income older adults and the adult children who endeavor to meet their needs, the social service system is complex, frustrating, and requires hours of work to gather information, complete forms, and monitor the progress of applications for services. Adult children must use their own funds to support their aging parents or sell off family property in a timely manner. Research should focus on successful programs and provide translational assistance for application in more communities.

In many research studies, adult children are often combined with other unpaid or family caregivers as “informal caregivers”. This population is unique in its challenges of employment, family responsibilities, and caring for an aging parent whose needs increase over time. More research is needed to explore the distinctive challenges of adult children caregivers to develop interventions and programs to alleviate some of their caregiving burden (Sundar, Fox, & Phillips, 2014) .

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Table 1  
*Demographics*

| Variable                      |    |
|-------------------------------|----|
| Age Range (Years)             |    |
| 41 – 50                       | 2  |
| 51 – 60                       | 7  |
| 61 – 70                       | 7  |
| Gender                        |    |
| Male                          | 3  |
| Female                        | 13 |
| Ethnicity / Race              |    |
| White                         | 16 |
| Employment                    |    |
| Full-time                     | 9  |
| Part-time                     | 3  |
| Retired                       | 4  |
| Setting                       |    |
| Rural                         | 14 |
| Urban                         | 2  |
| Siblings                      |    |
| 0 – 1                         | 7  |
| 2 – 3                         | 6  |
| 4 – 5                         | 2  |
| 6+                            | 1  |
| Years Caregiving              |    |
| 0 – 5                         | 7  |
| 6 – 10                        | 7  |
| 11 – 15                       | 1  |
| 16+                           | 1  |
| Average hours/week caregiving |    |
| 0 – 10                        | 3  |
| 11 – 20                       | 3  |
| 30+                           | 5  |
| 72 hour weekends              | 1  |
| Weeklong visits               | 1  |

Table 2  
*Types of Assistance Provided*

| Independent Activities of Daily Living | # of Adult Children |
|--|---------------------|
| Transportation                         | 14                  |
| Bill-paying                            | 11                  |
| Housekeeping                           | 13                  |
| Meal preparation                       | 10                  |
| Shopping                               | 15                  |
| Setting up medications                 | 9                   |
| Activities of Daily Living             | # of Adult Children |
| Feeding                                | 2                   |
| Bathing                                | 4                   |
| Dressing                               | 5                   |
| Assisting with toileting               | 3                   |
| Assisting with transfers               | 3                   |



Figure 1 Changing Places

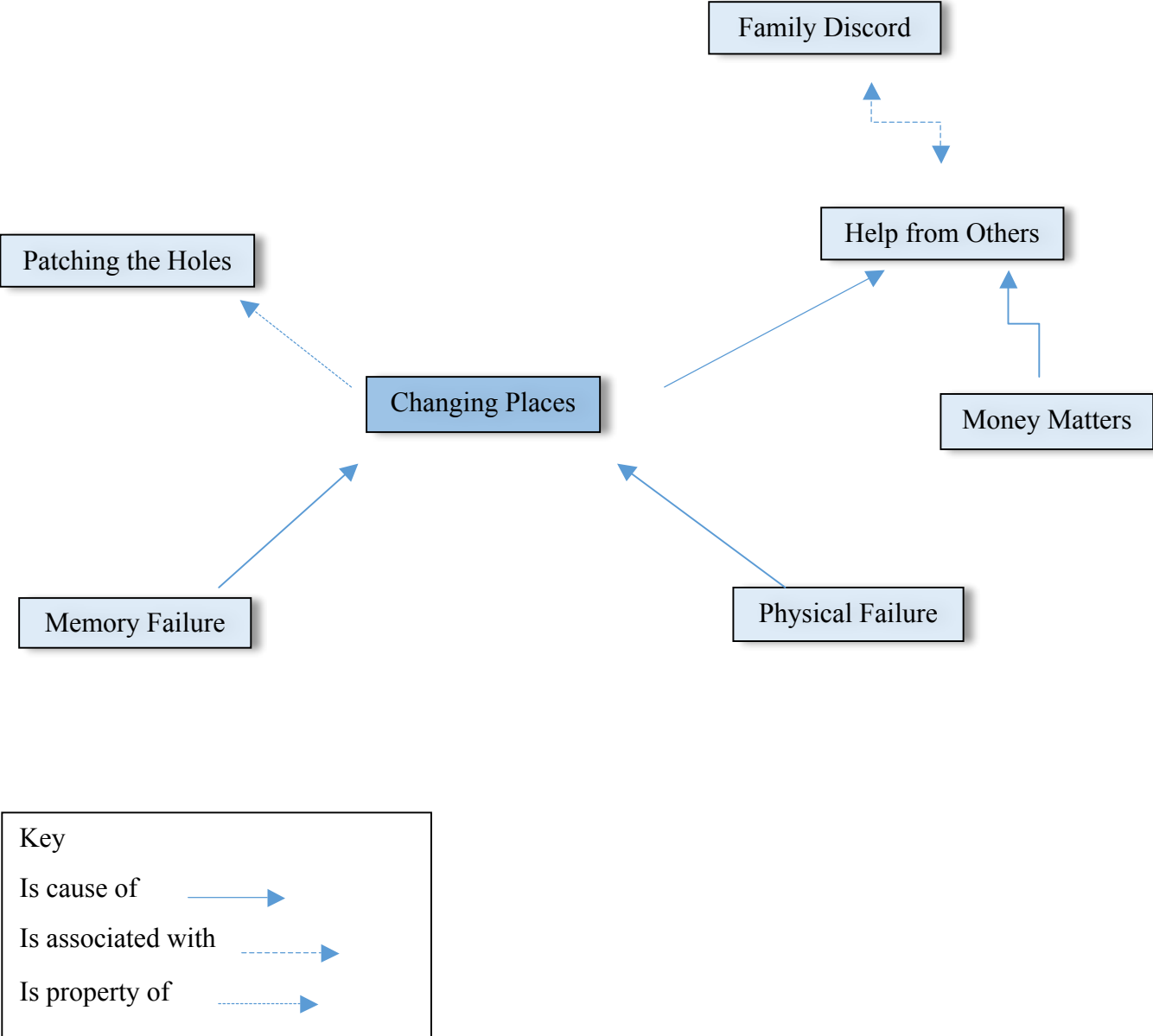


Figure 1. Changing Places: Themes and Subthemes

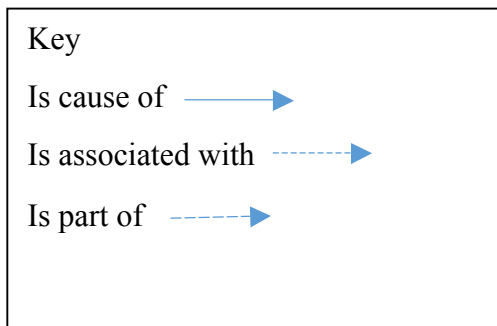
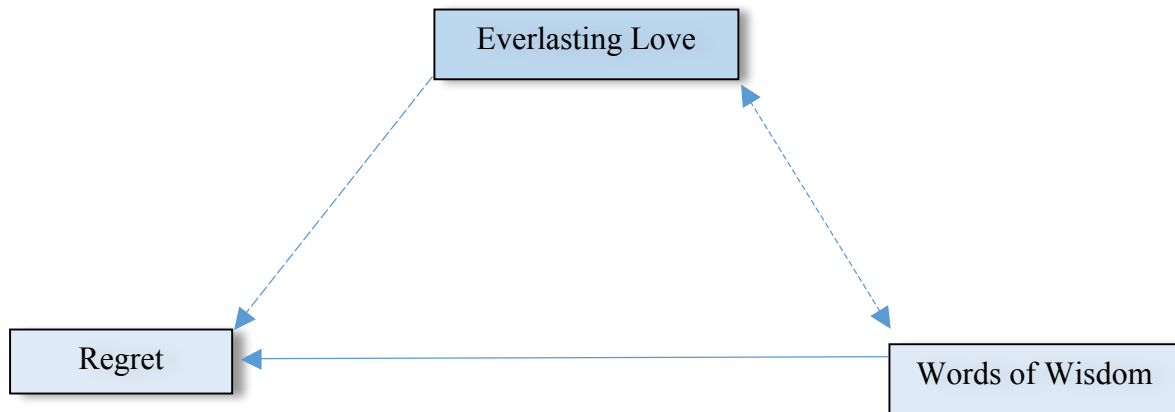


Figure 2. Everlasting Love: Themes and Subthemes

## Summary and Conclusions

Relocation transition in the older adult is a complex series of physical and cognitive declines, perceptions, behavioral beliefs, and subjective norms. The ultimate fulcrum in this process is the support and guidance of the adult child. The three manuscripts in this dissertation document the older adult's relocation transition and the impact of the adult child on the process of a move to a supervised living environment.

The first manuscript, *Relocation Transition and the Older Adult*, was a mixed methods integrative review that examined how relocation transition is measured in the literature. The reviewed studies were placed into categories based on the focus of the study. Three distinct themes emerged: Planning the Move, Physical Move, and Adaptation. The majority of articles, qualitative in design, explored relocation transitions from the perspective of the older adult through decision-making, social support, autonomy, and physical declines. Quantitative and mixed-methods studies used multiple instruments, adapted instruments or created instruments to measure vulnerability for relocation, decision-making, and readiness to move in older adults. This integrative review found that measurement of relocation transition involves not only measurement of functional limitations but also the older adults' psychological and emotional willingness and readiness to move. Use of valid and reliable instruments to quantify the need to move or readiness to move would improve assessment of relocation transition in this population.

The second manuscript, *Making the Move*, used a mixed research review process to assess relocation transition in older adults by applying the Theory of Planned Behavior concepts (Ajzen, 1985). Behavioral beliefs or the perceptions an individual develops about a specific behavior and can result in either positive or negative attitudes toward that behavior. Referents or significant others impart their opinions and perceptions which can influence the individual's

intention to perform the behavior (subjective norms) (Ajzen, 1985). Perceived control is the individual's perception that they have volitional control of their choices but are likewise influenced by their own beliefs and the opinions of others (Ajzen, 1985). In this review, behavioral beliefs and perceived control are well documented in the literature. For some older adults, relocation offered welcome relief from home maintenance, loneliness, and provided a safe, secure, supervised living environment. Other older adults whose relocation was emergent or occurred without their input, experienced emotional distress, loss of self-worth, and difficulty integrating into a new social environment. The significant others who assist the older adult in the relocation experience are identified as one entity: family caregivers. This inclusive moniker diminishes the different contributions of the individual family member. Adult children assist the older adult through the relocation process by gathering information, visiting the facilities, packing belongings, and providing support after the move (Armer, 1993; Fraher & Coffey, 2011; Johnson, Schwiebert, & Rosenmann, 1994; Leggett, Davies, Hiskey, & Erskine, 2011; Shippee, 2009).

The third manuscript of this dissertation, *Changing Places: Adult Children and the Transition of Aging Parents* used a qualitative grounded theory approach to conduct telephone interviews with adult children caregivers. Questions were developed using Symbolic Interaction Theory and designed to chronicle adult child's experiences as they begin their caregiving responsibilities (Blumer, 1969). The purpose of the research was to discover the experiences of adult children as they transition their functionally and/or cognitively declining parents from independent housing to supervised housing.

Two major themes emerged from the data: *Changing Places* and *Everlasting Love*. *Changing Places* describes the process the adult child used to address problems caused by

diminished functional or cognitive abilities. The adult child assumes roles, or changes places with the aging parent by performing Instrumental Activities of Daily Living (Lawton & Brody, 1969) such as, paying bills, shopping, preparing meals, and setting up medications and later in the process, assisting with Activities of Daily Living (Katz, Ford, Moskowitz, Jackson, & Jaffe, 1963). Six subthemes were discovered related to *Changing Places* (Figure 1). *Memory Failure* and *Functional Failure* were the cause of the adult child 'changing places' and pushed the adult child to intervene. *Patching the Holes* was associated with the main theme and describes the responsibilities the adult child fulfilled for the aging parent. Another group of subthemes illuminate the task of arranging *Help from Others*. *Family Discord* illustrates the friction between the adult child and the aging parent, siblings, and spouses, and *Money Matters* explains the financial concerns of the caregiving experience.

The second major theme, *Everlasting Love*, illustrates the adult child's desire to honor their parents with abiding respect and dignity. Two related subthemes were identified: *Words of Wisdom* in which the adult child proposes recommendations for others and contemplative statements of the adult child's experiences titled *Regret*.

The results of the data analysis supported the research questions, Adult child begin caregiving when Instrumental Activities of Daily Living (IADLs) are not performed by the aging parent (Lawton & Brody, 1969). As functional and cognitive declines escalate, the adult child increases support and supervision of the older adult. Another unexpected but unsurprising finding was the deep and abiding love and respect the adult child demonstrates for the aging parent.

There are limitations for all three of these studies. Both integrative reviews were time limited and might have missed research occurring prior to the starting year. Acquisition and

assessment of articles could yield different studies for inclusion due to this author's interpretation of the theoretical framework (Manuscript 2) and measurement instrument criteria (Manuscript 1). Manuscript 3 participants reflected the ethnic and racial composition of the Principle Researcher's geographic region. Replication of this study with diverse populations might reveal different caregiving experiences. Although the sample size in Manuscript 3 is small (n = 16), qualitative inquiry is not meant to be generalized but to generate hypotheses for future study.

### **Implications for Future Research**

Avenues for future research should include adult child specific inquiry to capture the unique challenges of caregiving for an aging parent. Another area of inquiry should focus on the Baby Boomers and their attitudes toward long-term care planning and perceptions of relocation to supervised housing.

Research should also focus on development of affordable, high quality programs to support the adult child's caregiving responsibilities, especially services that could be provided in the home. Additionally, health care providers should query the adult child with the older adult and alone, to determine possible care deficiencies and needs.

## **Contributions to Science and Nursing**

This dissertation isolates two particular client populations that require and deserve care. Older adults have reaped the benefits of health care advances, abundant resources, and improved living conditions. But living long does not always equate with living well. With advanced age, infirmity is almost a given. Older adults interface with the health care system more than any other age group (Centers for Disease Control and Prevention, 2013). Adult children caregivers often accompany their aging parents to physician visits; attend to them in the hospital, and research community programs to support the older adult. Nurses have the ability to promote the health and well being of the older adult, preserve dignity and assist and comfort the adult child caregiver. Attendance to the needs of the older adult is the primary focus of the adult child and nurses can advocate to meet those needs.

Relocation transition can be a difficult transition that can be mitigated by the intervention of nurses in the transition process. Progressive discussion about care needs and the older adult's cognitive and functional status should be initiated by the nurse and revisited over time. Involving the adult child in the dialog ensures continuity of care and communication. Encouraging the adult child to include the older adult in the planning, packing, and moving into supervised housing ensures that the decision to relocate will foster positive transitions.

Lastly, nurses should be responsive to the adult child by collaborating on care needs, discharge goals, rehabilitation plans, environmental modifications, and medication regimens. It would also be important for the nurse to monitor the adult child for signs of the undue burdens of caregiving and assist in finding resources to support care needs of the aging parent.

APPENDIX A



**Institutional Review Board for Human Research (IRB)  
Office of Research Integrity (ORI)  
Medical University of South Carolina**

**Harborview Office Tower  
19 Hagood Ave., Suite 601, MSC857  
Charleston, SC 29425-8570  
Federal Wide Assurance # 1888**

**APPROVAL:**

This is to certify that the research proposal **Pro00028687** entitled:  
**Changing Places: Adult Children and the Relocation of Aging Parents**

and submitted by: **Sarah Gilbert**  
Department: **Medical University of South Carolina**

For consideration has been reviewed by **IRB-I - Medical University of South Carolina** and approved with respect to the study of human subjects as adequately protecting the rights and welfare of the individuals involved, employing adequately methods of securing informed consent from these individuals and not involving undue risk in the light of potential benefits to be derived therefrom. Additionally, the Institutional Review Board for Human Research (IRB) recommends approval of the investigator's request for Waiver of Signed Consent in accordance with 45 CFR 46.117(c)(1),(2) because the only record linking the subject and the research would be the consent document and the principal risk would be potential harm resulting from a breach of confidentiality and/or because the research presents no more than minimal risk and involves no procedures for which written consent is normally required outside of the research context. No IRB member who has a conflicting interest was involved in the review or approval of this study, except to provide information as requested by the IRB.

Original Approval Date: **10/23/2013**  
Approval Expiration: **10/22/2014**

Type: **Expedited**

Chairman, **IRB-I - Medical University of South Carolina**  
**Susan Newman\***

**Statement of Principal Investigator:**

As previously signed and certified, I understand that approval of this research involving human subjects is contingent upon my agreement:

1. To report to the Institutional Review Board for Human Research (IRB) any adverse events or research related injuries which might occur in relation to the human research. I have read and will comply with IRB reporting requirements for adverse events.
2. To submit in writing for prior IRB approval any alterations to the plan of human research.
3. To submit timely continuing review reports of this research as requested by the IRB.



4. To maintain copies of all pertinent information related to the research activities in this project, including copies of informed consent agreements obtained from all participants.
5. To notify the IRB immediately upon the termination of this project, and/or the departure of the principal investigator from this Institution and the project.

*\* **Electronic Signature:** This document has been electronically signed by the IRB Chairman through the HSSC eIRB Submission System authorizing IRB approval for this study as described in this letter.*

APPENDIX B

12/20/13

IAA Gilbert MUSC 12.20.13.pdf

Version Date: 03/31/2011

Sample text for an Institution with a Federalwide Assurance (FWA) to rely on the IRB/IEC of another institution (institutions may use this sample as a guide to develop their own agreement).

**Institutional Review Board (IRB) Authorization Agreement**

Name of Institution or Organization Providing IRB Review (Institution/Organization A):

Medical University of South Carolina

IRB Registration #: IRB00000027 Federalwide Assurance (FWA) #, if any: FWA00001888

Name of Institution Relying on the Designated IRB (Institution B):

Radford University

FWA #: FWA00004850

The Officials signing below agree that Radford University may rely on the designated IRB for review and continuing oversight of its human subjects research described below: (check one)

This agreement applies to all human subjects research covered by Institution B's FWA.

This agreement is limited to the following specific protocol(s):

Name of Research Project: Changing Places: Adult Children and Relocation of Aging Parents

Name of Principal Investigator: Sara Gilbert

Sponsor or Funding Agency: \_\_\_\_\_ Award Number, if any: \_\_\_\_\_

Other (describe): \_\_\_\_\_

The review performed by the designated IRB will meet the human subject protection requirements of Institution B's OHRP-approved FWA. The IRB at Institution/Organization A will follow written procedures for reporting its findings and actions to appropriate officials at Institution B. Relevant minutes of IRB meetings will be made available to Institution B upon request. Institution B remains responsible for ensuring compliance with the IRB's determinations and with the Terms of its OHRP-approved FWA. This document must be kept on file by both parties and provided to OHRP upon request.

Signature of Signatory Official (Institution/Organization A):

Date: \_\_\_\_\_

Print Full Name: \_\_\_\_\_

Institutional Title: \_\_\_\_\_

NOTE: The IRB of Institution A may need to be designated on the OHRP-approved FWA for Institution B

Signature of Signatory Official (Institution B):

Date: 12/19/13

Print Full Name: Dennis O. Grady

Institutional Title: Dean, Graduate College

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