

5-2013

# Adapting to Change: "Provider Perspectives on the Transition to Long Term Care"

Paige Elise Sorenson  
*St. Catherine University*

---

## Recommended Citation

Sorenson, Paige Elise, "Adapting to Change: "Provider Perspectives on the Transition to Long Term Care"" (2013). *Master of Social Work Clinical Research Papers*. Paper 260.  
[http://sophia.stkate.edu/msw\\_papers/260](http://sophia.stkate.edu/msw_papers/260)

This Clinical research paper is brought to you for free and open access by the School of Social Work at SOPHIA. It has been accepted for inclusion in Master of Social Work Clinical Research Papers by an authorized administrator of SOPHIA. For more information, please contact [ejasch@stkate.edu](mailto:ejasch@stkate.edu).

Adapting to change:

"Provider perspectives on the transition to long term care"

by

Paige Elise Sorenson, B.A.

MSW Clinical Research Paper

Presented to the Faculty of the School of Social Work

St. Catherine University and the University of St. Thomas-St. Paul, Minnesota

In partial fulfillment of the requirements for the degree of Master of Social Work

Committee members:

Colin Hollidge, Ph.D., LICSW (Chair)

Susan Bollinger-Brown, MSSW, LICSW

Marjorie Spagl, MA, LSW

The Clinical Research Project is a graduation requirement for MSW students at St. Catherine University/ University of St. Thomas School of Social Work in St. Paul, Minnesota and is conducted within a nine-month time frame to conceptualize a research problem, formulate a research design that is approved by a research committee and the university Institutional Review Board, implement the project, and publicly present the findings of the study. This project is neither a Master's thesis nor a dissertation.

### **Abstract**

This study investigated the transition from independent living to long-term care settings from the perspective of social workers currently in the field. This study was carried out using qualitative interviews with semi-structured questions. The sample was made up of five participants. The primary purpose of this study was to gain a better understanding of the transitional process from independent living to long-term care from the perspective of social workers who are professionally-involved in this process. The secondary purpose of this study was to understand the dynamic issues faced by long-term care social workers and to better understand how their unique experience drives their own insight. The results of the study yielded three distinct themes. Theme one: reassurance, education, and insight on behalf of families. Theme two: admissions and screening. Theme three: administrative strain.

### **Acknowledgements**

Thank you to my Committee chair, Dr. Colin Hollidge, for all of your assistance and support and for helping me maintain a sense of control throughout this process. Your combined expertise and flexibility did not go unnoticed. In addition, I would like to thank my Committee members, Susan Ballinger-Brown and Marjorie Spagl, who provided me with wonderful insight and feedback regarding my project. Most of all, thank you to all my family members and friends for your continual support over the past two years.

## Table of contents

Abstract.....	p. ii
Acknowledgements.....	p. iii
List of tables.....	p. iv
Introduction.....	p.1
Literature review.....	p.3
Conceptual framework.....	p.19
Methodology.....	p.20
Findings.....	p.24
Discussion.....	p.28
Implications for policy and practice.....	p.32
References.....	p.33
Appendix A: Semi-structured interview questions.....	p.38
Appendix B: Consent form.....	p.39
Appendix C: Debriefing form.....	p.41

**List of tables**

Table 1: Participant demographics.....	p.21
Table 2: Theme of reassurance, education, and insight.....	p.25
Table 3: Theme of admissions and screening.....	p.27
Table 4: Theme of administrative strain.....	p.28

## Introduction

The idea for the current research study stemmed out of a former interest in the overall referral process in medical settings-i.e. how individuals arrive at a "care destination." While understanding the fundamentals of the referral process is important, it is equally-important to know how the process affects individuals and families. The current research study will focus on the experience of moving a geriatric family member from independent living to a long-term care setting from the perspective of familial caregivers who were closely-involved in that transitional decision-making process.

Today, one in eight Americans is 65 or older-and the average life expectancy is only expected to increase with time (Feinberg, 2012). From this population segment, there are approximately 1.5 million geriatric-aged adults who live in long-term care facilities, and almost one million older adults who reside in assisted living facilities (Shippee, 2009). In Minnesota, long-term care facilities comprise a \$2 billion a year industry ("Nursing home facts," 2012). It is essential to comprehend the scope of experiences that have and will continue to accompany an aging society. This scope includes professionals in the healthcare systems, for the aging individuals themselves, and for family members and friends. Studying the qualitative experience of the families who complete the process of moving a family member from independent living to long-term care settings may yield useful results for researchers, policymakers, and most importantly, the individuals who rely on this system of care.

Relocation from independent living to long-term care settings can occur for a number of reasons: medical, mental health, or interpersonal. The current study defines "long-term care settings" as facilities where individuals live in close proximity to professional healthcare providers for round the clock care. Settings such as these provide coordinated, routinized,

closely-monitored services 24 hours a day, 365 days a year, typically over an extended period of time. "Long-term care" settings are most often referred to as "nursing homes" or sometimes "assisted living facilities." "Independent living" is therefore used to describe the act of an individual living in a non-medical residential property, regardless of whether they receive formal or informal support from caregivers.

A review of the available literature on the topics of aging, long-term care settings, and geriatric decision-making found that families' experiences with moving a geriatric relative from independent living to long-term care vary greatly. The long-term care setting, knowledge of its staff, and comfort level of the family also have the potential to affect the families' feelings toward the overall transitional experience. At this time, there is no uniform protocol for transitioning individuals and families from independent living to long-term care settings; the only requirement involved is the approval of a medical doctor. There are many inadequacies in how this system is structured. However, long-term care remains an essential option for individuals. Therefore, further research on this experience is needed in order to more adequately prepare individuals and families for such difficult decisions and transitions. Facilitating a long-term care arrangement requires attention to medical, psychological, social, and financial needs and many families may find themselves unprepared to do so. Further research is also needed to find methods of making the intake process more manageable for both the families and the professionals involved.

The research question for this study is: "What is the experience of moving an aging elder from independent living to a long-term care setting from the perspective of a familial caregiver?" A review of the literature, the methodology utilized, the major findings, and a discussion of this current study's findings can be found in the following sections.



## **Literature review**

### **Introduction**

This literature review encompasses the topic of aging and its related implications within American culture. It focuses on the large issue of care giving and what it means to take care of an elder in today's world, with special emphasis on the sandwich generation, which is later discussed in detail. This literature review also highlights current trends in aging resources and policy implementations addresses means of forward progression in these areas.

### **Background**

In recent years, there has been increasing attention to the fact that older adults comprise the most rapidly-growing segment of the population in the western hemisphere (Flynn Reuss, Dupuis, & Whitfield, 2008). Policymakers, professionals, and individual citizens have been well-aware of aging-related trends for decades. The Gerontologist, an aging-specific research journal, first began publication in 1961, and an influx of gerontologically-related research emerged in the mid-late 1980s in a variety of other primary research sources (Rubin & Shuttlesworth, 1983; Hatch & Franken, 1984; Bowers, 1988; Schwartz & Vogel, 1990; The Gerontologist, 2008). As a result, most individuals are aware of the obvious economic and financial implications of an aging society coupled with the current strain on global resources. People are deeply concerned about how future generations will respond to the issues that accompany our aging society, given the information we already know. The vast cultural shift in demographic profiles has become more pronounced in the last decade and it seems our society is unprepared to deal with the ramifications of that change.

Over the years, extraneous factors have emerged and added to the difficulty of effectively handling the ripple effects of a rapidly-aging society. One such factor is how the number of

individuals who reside in long-term care settings has declined over time in response to the growing costs of such care in addition to changing cultural attitudes, values, and tastes. It is now viewed as common knowledge that the older prefer to remain in their homes as long as possible. In fact, these changing tastes coupled with state initiatives to cut costs by reducing long-term care admissions have decreased the size of the long-term care industry by 37% since the late 1980s ("Nursing home facts," 2012). Throughout the 1980s and 1990s, there was a purposeful effort to decrease long-term care admissions to cut the overall cost to the state of Minnesota ("Nursing home facts," 2012). Such measures made it necessary to develop innovative ways of caring for an aging society.

In American culture, transitioning from independent living to primary has traditionally been seen as a significant experience for individuals and families. For those individuals and families who may or may not want to choose to utilize long-term care facilities, the initial move can be seen as a stigmatizing and a life-changing experience. Therefore, maintaining the autonomy of an aging society should be a high priority issue amongst public health officials (Perrig-Chiello & Hutchingson, 2010).

### **Aging in place**

"Aging in place" is simply a phrase used to describe individuals' ability to continue comfortably living in their homes throughout their older years until their eventual death. In much of the world, there has been a long-standing societal ideal of "aging in place" (Engelhardt & Greenhalgh-Stanley, 2010). Surveys and empirical research have demonstrated "aging in place" to be the new American preference. Albeit, "aging in place" has a hint of morbidity. It has emerged as a momentous cultural ideal that is likely to continue. In formal literature, the home is often described as "a crucial site in the construction and maintenance of identity in later life,"

which serves to support the anecdotal reports of this ideal (Kontos, 2000). Historically-speaking, individuals spend their lives working, amassing valuables, preserving a home—and attributing substantial meaning to these domains. It should come as little surprise that individuals would want to maintain that standard of meaning and worth through "aging in place."

Maintaining comfort, dignity, integrity, and peace of mind are several implied benefits derived from residing independently in one's own home. It allows the maintenance of control. Previous research has highlighted several concrete and explicit benefits to elders living independently. In their qualitative research focusing on the daily living experience of older individuals with dementia, Brittain, et. al. found that older adults tend to function most effectively in a familiar environment (Brittain, Comer, Robinson, & Bond, 2010). Their research focused on how older adults navigate a world of technology and found that anxiety derived from both the individual and family members, has made a significant impact on how older adults perceive and function in their environment (Brittain, et. al., 2010). This information raises the question as to whether the move from independent living or living in one's own home to a long-term care facility would be a factor that contributes to a faster cognitive decline among older individuals.

### **The formal care giving industry**

Care giving is not only a family issue, but a community issue as well. The cultural preference of aging in place is a necessary consideration for today's formal care giving industry. Elder care giving makes up a substantial component of today's overall health care industry, and it encompasses professionals with various levels of experience, including: nurses, occupational therapists, physical therapists, home health aides, social workers, and homemaking services (Sims-Gould & Martin-Matthews, 2010).

In particular, home health care has bolstered the ability for older adults to "age in place" even if they are in poor physical health (Engelhardt & Greenhalgh-Stanley, 2010). Home health care is an elder care option that meets individuals at their current level of need and reinforces their ability to self-determine. This has made home health care popular amongst families who can afford it and for elders who have an appropriate level of need for the safety net it provides. In America, annual home health care expenditures are approximately \$57.6 billion ("Basic statistics," 2008). Home health care services are relatively expensive, are not for every level of need, and do not necessarily ensure the safety of the older family member in question. Many families work closely with the formal care giving industry to manage their aging elder's care. However, instead of working cooperatively, some families take on exclusive responsibility through their own style of informal care giving (Sims-Gould & Martin-Matthews, 2010).

### **The informal care giving industry**

Informal care giving services most often involve: providing direct personal care, doing household chores, meal preparation, shopping, financial oversight, providing companionship, coordinating medical care, and arranging or supervising other daily activities (Silverstein & Giarrusso, 2010). Pinquart and Sorensen's (2011) meta-analysis of 168 empirical studies on the topic of elder care giving has illustrated that adult children most often consider maintaining their parent's autonomy and lifestyle as one of their integral life course responsibilities in an extrinsic sense. On the contrary, Funk (2010) used 28 semi-structured qualitative interviews on the care giving experience and found that some individuals loathe the responsibility in regard to care giving, others clung to that responsibility, and some differentiated between "responsibility to" and "responsibility for." Nonetheless, a significant amount of older care giving occurs informally with the assistance of family members and friends.

Informal care giving can be intrusive for all involved parties. As it stands, family members and friends provide 92% of the care required by aging adults in Minnesota, and adult children take on approximately 41.3% of that responsibility (Knatterud, 2011; Pinquart & Sorensen, 2011). The demand for care coupled with the dual-relationships often experienced by caregivers can make boundary-setting and limiting the scope of involvement a complex task (Funk, 2010). Several consequences of informal care giving include higher instances of stress, depressive symptoms, anxiety, and use of psychotropic medications (De Koker, 2010; Schulz, O'Brien, Bookwala, & Fleissner, 1995). However, in their qualitative study which examined burden among dementia caregivers, Schulz and colleagues found that consequences of care giving are moderated by factors such as: coping strategy, personality attributes, quality of interpersonal relationship, and the resources available for both social and fiscal support (Schulz, et. al., 1995). In addition, extraneous societal influences and geographic location can also have an effect (Stone & Clements, 2009).

Family members often see themselves as "care managers" due to the extent of their responsibilities (Brown, Potter, & Foster, 1990). In fact, familial caregivers have been described by researchers as "hidden patients" due to the multitude of effects that care giving has on their lives (Sims-Gould & Martin-Matthews, 2010). Sims-Gould and Martin-Matthews focused particularly on the effects of care giving for those who coordinate home health care services for an aging parent (sample size= 52) and found that there are often ill-defined boundaries between those entities. It was identified that the care giver burden and responsibility does not go away during the time that home health care services are utilized-that it is still a joint partnership that requires their attention (Sims-Gould & Martin-Matthews, 2010). This can be problematic in a number of different respects.

Caregivers are also believed to have higher instances of heart disease, diabetes, and depression than non-caregivers (Knatterud, 2011). It is believed that caregivers experience these symptoms as a result of the numerous adjustments and strain that is initiated through adopting informal care giving responsibilities (Given, et. al., 1999). The (1999) qualitative research study conducted by Given and colleagues focused on the experience of familial caregivers who accrue responsibility for their loved ones care following hospital discharge. Their results indicated that new care giving responsibilities were positively correlated with instances of caregiver depression, independent of the care recipient-care provider relationship (Given, et. al., 1999). Even trained social service and health professionals are not immune to this. Many anecdotal reports indicate that they also have difficulty employing healthy coping strategies when they gain responsibility for informal care giving. However, as aforementioned, many factors have significant effects on the overall experience.

### **The experience of informal caregivers**

The qualitative experience of informal caregivers has been found to vary greatly depending on population and circumstance. In the early 1990s it was identified that middle-aged, employed women were the most affected by care giving responsibilities (Stone & Farley-Short, 1990). Recent research has highlighted that— nationally-the average caregiver to an aging parent is a female, aged 46, who works outside the home and earns an average yearly income of \$35,000 (Family Caregiver Alliance, 2003). The average caregiver in Minnesota is a 46 year-old female who has at least one child and participates in the workforce; she provides an average of 20 hours of care per week to a geriatric female, average age 77 ("What will keep," 2009; National Alliance for Caregiving & AARP, 2009). Indeed, women caregivers have been known to be most likely to provide direct care giving, while male caregivers are most likely to take on

financial responsibility for their aging elder (Sandberg, Lundh, & Nolan, 2002). Women are also said to experience a higher level of "caregiver burden" than male caregivers, which is positively correlated with the number of hours they spend providing personal assistance through direct care (Silverstein & Giarrusso, 2010). Conversely, not all caregivers have the same experience.

Stephens, Franks, and Atienza (1994) demonstrated that caregivers can derive benefit from occupying multiple roles-although their degree of involvement with their various roles is likely what moderates this benefit. In the nearly 20 years since then, researchers have found that care giver's expectations of "normal" aging also play into this scenario. Situations where an elder underwent a rapid cognitive decline were not viewed as positively as were situations of slow, progressive aging and cognitive changes (Hagerty-Lingler, Nightingale, Erlen, Kane, Reynolds, Schulz, & DeKosky, 2006). Positive effects of care giving can also include the following: satisfaction and pride in the care giving role, sense of mastery and purpose, feelings of reciprocity, perceived personal growth, and strengthening of the relationship with the care recipient (Smale, Dupuis, & Epp, 2004).

Some caregivers report experiencing a sense of intrinsic reward as a result of their services, while others report feelings of entrapment due to the immense responsibility they have acquired (Silverstein & Giarrusso, 2010; Birkeland & Natvig, 2009). In their (2009) research, Stone and Clements gathered data from 26 surveys, which addressed the issue of care giver burden both before and after care givers had placed a loved one in a long-term care facility. It was discovered through the utilization of The Montgomery-Borgatta Caregiver Burden Scale that care giver perceptions of responsibilities and subsequent stress were high enough to warrant individual counseling or supportive group therapy—even following long-term care placement

(Stone & Clements, 2009). This finding indicates the significance of the subjective feelings associated with care giving.

The subjective feeling of ambivalence is a major theme that has emerged from the research in the area of caregiver well-being (Silverstein & Giarrusso, 2010; Chapman & Ingersoll-Dayton, 1994; Flynn Reuss, et. al., 2008; Soderberg, Stahl, & Emilsson, 2012). In particular, in the (2012) qualitative research study conducted by Soderberg, Stahl, and Emilsson, it was found that rationality and emotionality are often in conflict for families who provide elder care. Through the use of 17 qualitative semi-structured interviews, it was demonstrated that the individuals interviewed simultaneously strove for continuity (aging in place) and change (moving to a long-term care setting), both of which are easier in some respects and more difficult in others (Soderberg, Stahl, & Emilsson, 2012).

The notions of role-reversal and parental dependence certainly create ambivalence and further-complicate the care giving scenario. Qualitative research in the area of caregiver support has found that adult children who provide extensive care and support to aging parents were more likely to experience ambivalence in comparison to those providing care for aging parents with mild to moderate levels of need (Fingerman, Chen, Hay, Cichy, & Lefkowitz, 2006). These researchers report that caregiver ambivalence was negatively correlated with psychological well-being (Fingerman, et. al., 2006). This finding may be even more pertinent for the next population discussed.

### **Sandwich generation caregivers**

For years, it has been a well-documented trend that couples are postponing the process of marriage and starting a family later in life-often waiting to have children until they are in their 30s or 40s. This has made these individuals more susceptible to later involvement in multiple



care giving roles. It is estimated that approximately 9-13% of individuals aged 30-60 fall into this distinct category, which has been dubbed the "sandwich generation" in popular media as well as formal research (Hammer & Neal, 2008). The following assertion captures the difficulty faced by the sandwich-generation:

"Whether in another state or in the spare room upstairs, dependent elders are combining with children and work responsibilities to overwhelm the sandwich generation. The irony is that the very traits that threaten to take this generation out of the workforce— responsibility, loyalty, self-worth— are the same ones making them valuable workers" (Durity, 1991).

That assertion from 20 years ago accurately reflects today's notion that work and family should not intersect. Certainly, many employers presume that involvement of familial affairs in the workplace is unprofessional, unproductive, and has grounds for implication (Durity, 1991). Accordingly, the average yearly loss in productivity for each sandwich generation employee is said to be approximately \$2,000, which is significant because around 60% of all caregivers to aging adults in Minnesota are currently employed, which some may say is a low estimate (Knatterud, 2011). Nationally, there is a loss of about \$33.6 billion per year in productivity costs from care giving employees, with approximately \$25 billion of that cost derived from employee absenteeism (Feinberg, 2012). There are also many direct employee costs.

In a national survey conducted in 2012 by the Employees Benefit Research Institute, one in five of the retirees surveyed indicated that they retired earlier than planned due to care giving responsibilities (Hellman, Copeland, & Can Derhei, 2012). In addition, nearly 70% of current caregivers reported making work accommodations due to care giving responsibilities—meaning that there are tremendous policy implications for caregivers in the workforce (Hellman, et. al.,

2012). There are many more employment-related consequences for employees who are sandwich-generation caregivers. Due to the reduced work hours that can accompany care giving, employees often make compromises in terms of monetary earnings, Social Security benefits, career mobility, health insurance, retirement savings, and job security (Feinberg, Reinhard, Houser, & Choula, 2011). A reduction in the time committed to employment can significantly impact options for career mobility. However, there is hope: employment settings who have been willing to integrate elder care programs into employment benefit packages have witnessed increased employee retention and productivity via healthy employees who are able to regulate their stress (Wagner, Lindemer, Yokum, & DeFreest, 2012). This has considerable implication for sandwich-generation caregivers, as they make up the majority of today's workforce.

It has been said that stress and conflict that arises from care giving responsibilities is arguably the highest amongst individuals who fit the sandwich generation profile. When the implications of care giving are taken into account, it becomes clear that our American system of capitalistic productivity offers little support for employees with familial needs (Chapman, Ingersoll-Dayton, & Neal, 1994). However, anecdotal reports identify that employers who are in the care giving industry are frequently more attuned and responsive when an employee needs to fulfill a care giving role in their personal lives.

According to Birkeland and Natvig, research studies have demonstrated that there is a trend of resigned and passive acceptance amongst sandwich-generation caregivers-as many of them surveyed through various measures report feeling as though they "have to" care for their older family member (Birkeland & Natvig, 2009). Therefore, a majority of these caregivers viewed their new care giving role as somehow violating the parental independence (Funk, 2010). They may try to avoid transitioning into this new role by minimizing the level of need a geriatric

parent may have (Lunde, 2011). However, denial does not solve problems. Denial prolongs the amount of time a geriatric individual goes without proper care, negatively impacts their quality of life, and can cause significant familial strain if certain family members are in denial whilst others are not (Lunde, 2011).

### **Independent living to long-term care**

The transition from independent living to long-term care settings has been described as one of the most stressful, traumatic, and challenging periods experienced by aging adults and their families (Nolan & Dellasega, 2000). This move or transition occurs when the demands of informal care giving—or even formal care giving—exceed the available resources and caregivers' individual ability to effectively handle the circumstances (Flynn Reuss, et. a., 2008). Due to the cultural change in preferences that initiated in the 1980s, Americans sometimes view their elder's eventual need to reside in long-term care settings as a "functional failure" within their family (Stone & Clements, 2009). Anecdotal reports from individuals in this position maintain that negative feelings can run even deeper when an aging adult is moved into a long-term care facility for memory care issues rather than physical issues because it is seen as something that a family "should" be able to manage.

Many caregivers have a tendency to harbor guilt feelings around moving their older parent to a long-term care setting. Families have the tendency to subjectively experience guilt as a result of the stigma surrounding institutionalization and perceived expectations around familial responsibility (Flynn Reuss, et. al., 2008). Families and caregivers have had a tendency to subjectively experience guilt as a result of the stigma surrounding institutionalization and perceived expectations around familial responsibility (Flynn Reuss, et. al., 2008). Many families highlight concerns regarding the standards of care for those institutionalized in long-term care

settings (Flynn Reuss, et. al., 2008). Indeed, there are substantial differences between independent living and long-term care, with the latter often seen as the antithesis of what Americans stand for—freedom and autonomy.

Qualitative research by Shippee (2009) identified that, older individuals often report a perceived loss of autonomy once faced with such a move. Shippee also highlighted that older individuals experience difficulty adjusting to the rules that accompany living in their new space, violation of their privacy and personal space, disengagement in social activities, and fatalistic thinking (Shippee, 2009). All of this can be derived from the perception of having been "pushed" into long-term care (Shippee, 2009). Shippee's expansive research methodology included 23 months of live-in observation of residents who lived independently, in assisted living, and in nursing care (all of which was located on the same compound). There were 35 participants in total, all of whom completed an in-depth interview with the researcher. Because these transitions can be so difficult on the individual, family members may have successive difficulty in following through with facilitating that transition. This often holds true even though the benefit of moving to long-term care may mean increased quality of life and less direct caregiver burden.

The lifetime prevalence of long-term care utilization is estimated to be approximately 30% amongst individuals aged 65 and older, which means that a sizeable portion of Americans undergo at least a portion if not all of the qualitative challenges aforementioned (Flynn Reuss, et. al., 2008). Of those in long-term care facilities, approximately half of individuals currently residing in them have a diagnosis of dementia or a related cognitive disorder (Kasper, 2005). This suggests that the process of relocation to long-term care will continue to have widespread influence as American society continues to age and large proportion of caregivers find themselves occupying the role of decision-maker for their aging adult (Stone & Clements, 2009).

Relocation from independent living is a virtually-inevitable process, and the shift in cultural demographics have placed families in a position of involvement decision-making for their elder (Soderberg, et. al., 2012.) The following statement describes the complexity and nuance involved in this common situation:

"The combination of the family members' respect for their older relative's self-determination and integrity, the idea of best care possible and their own personal life situation, generates a seemingly impossible equation, and there might be reasons to ask if family members are forced into developing a hidden agenda, advocating relocation surreptitiously" (Soderberg, et. al., 2012).

Indeed, compromise on behalf of individuals and families is a huge component of eldercare in today's world and oftentimes, it can be said that the difference between self-determination and persuasion is quite subtle (Soderberg, et. al., 2012). There is a huge degree of difficulty associated with simultaneously advocating for the needs of an aging adult, supporting their self-determination, and refraining from allowing their own preferences from influencing the decision-making process. Many caregivers report resigning from their positions—Or rearranging their work schedules in the name of care giving (Stone & Clements, 2009). Caregivers who have a sense of extrinsically-based reciprocity rather than internally-based reciprocity may experience more temptation to jump to a decision or solution that most benefits them (Stone & Clements, 2009). This can have sizeable consequences on a systemic level.

### **Significance of this research**

The transition from independent living to long-term care is one of significance for both older adults and their families. Individuals—even practitioners—oftentimes find themselves wondering what will happen to their loved ones as they grow older and if they will be able to

continue living an optimal quality of life. In the coming years, it will be vital for all individuals to learn ways to counterbalance the many negative effects that are currently associated with transitioning to long-term care settings.

Negative transitionally-based effects include alterations in psychological health, decline in physical health, disruption of interpersonal relationships, discontinuation of hobbies and leisure activities, and financial strain (Flynn Reuss et. al., 2008). As aforementioned, Stone and Clements' cross-sectional research examined care giver burden within family members who were powers of attorney for their aging relative to determine if or how it affects their subjective well-being. The results suggested that the stressfulness and the infringing sensation associated with care giving continue even after the relocation to long-term care has occurred (Stone & Clements, 2009). Clearly this is an issue worthy of evaluation by future researchers— when does care giver burden dissipate, and does it ever?

In their qualitative research study entitled: "Understanding the experience of moving a loved one to a long-term care facility," Reuss, Dupuis, and Whitfield (2008) demonstrated the value of adequately preparing families to facilitate the move to long-term care. Through this research utilizing twenty-one semi-structured interviews, these researchers found that families felt pressured into making quick decisions, having inadequate time to prepare for the move and become familiarized with the long-term care facility, and having an overall lack of information— which increased general confusion and frustration (Flynn Reuss, et. al., 2008). Their results uncovered four major factors that families perceive in aiding in "successful" transitions to long-term care settings. They are as follows: (1) anticipation— using rational thought and strategic planning, (2) participation— of all parties, (3) explanation— of alternative care options and feelings involved with each, and (4) information— enough to make informed decisions (Flynn

Reuss, et. al., 2008). Families anecdotally report experiencing some denial in regards to their aging family member's functional capacity. However, the very essence of denial is that it is difficult for individuals to endorse and therefore difficult for researchers to measure.

### **Need for further research**

The transitional process from independent living to long-term care settings usually involves multiple stages, so it is a necessity for health and human service professionals to refine and adapt this process. It requires further tailoring to meet specific family needs and be adaptable across varying situational contexts. The trends of smaller households, highly mobile families, and an ever-aging society have prompted the need for more formal services. Fewer families are expected to have members who are able to step into the role of "caregiver" in the coming years ("Nursing home facts," 2012). There is an advancing need for social workers to be trained in gerontology and to be capable of utilizing a distinct approach for each caregiver and set of circumstances that they are presented with— because not all present the same (Stone & Clements, 2009; Pinquart & Sorensen, 2011). In a study by Kelsey, Laditka, and Laditka (2010), it was identified that the support needs during this transitional time vary based on who occupies the caregiver role— whether that person is a spouse, an adult child, or another individual altogether.

Typically, a move into a long-term care facility involves a variety of health and human service professionals and organizations (Flynn Reuss, et. al., 2008). The success of their collaborative efforts affects the qualitative experience for residents and their families. Timely research through the Minnesota Department of Human Services led to recommendations that caregivers be formally included in the treatment planning for aging adults (Knatterud, 2011). Another initiative-Aging 2030-is a collaboration between Minnesota's Department of Human Services, Minnesota Department of Health, and Minnesota Board on Aging. The purpose of the

project is to prepare Minnesota for the permanent demographic changes that will occur with the baby boomers coming of age. By 2031, it is estimated that one in four Minnesotans will be over the age of 65 (Aging 2030, 2011). Aging 2030 has five focal areas: "redefining work and retirement," "supporting caregivers of all ages," "fostering communities for a lifetime," "improving health and long-term care," and "maximizing the use of technology" (Aging 2030, 2011). Initiatives as such seem to indicate that the state of Minnesota appears to be taking a progressive approach—our actions may be exemplified by other states in the coming years as they do their part in preparing for this crucial issue.

The past decade has yielded many improvements in regard to gerontological issues. These have namely been in the development of caregiver support programs, respite services, and in the increasing numbers of gerontological-focused health professionals (Kasper, Pezzin, & Rice, 2010). Long-term care consultation (LTCC), available in each county in Minnesota, is another significant improvement in informative resources, which currently is operated with the aid of county social workers and public nurses. They are responsible for visiting families, educating them about program options, conducting long-term care pre-admission screenings, and supporting individuals and families through the transitional process to long-term care ("Nursing home facts," 2012). However, many in the health and human service professions are aware that such county programs are incredibly backed up due to high demand. There continues to be room for improvement.

In the formal research literature, there seems to be a plethora of information about successfully transitioning aging adults out of the hospital or skilled nursing facility and back into their home communities (Nishita, Wilber, Matsumoto & Schnelle, 2008). However, it is difficult to locate studies that provided "nationally-representative" information on informal caregivers—



or even general information on the natural transition from independent living to long-term care (Wolff & Casper, 2006). Even a smaller amount of studies have focused on this significant transition from the perspective of close familial caregivers (Soderberg, et. al., 2012). In addition, many studies have utilized convenience or snowball sampling in their methodology, which has provided an information base with a limited scope. Despite Minnesota often being referred to as one of the better-prepared states, there is still a need to understand how families in Minnesota handle the ambivalence that has been linked with care giving responsibilities.

### **Conceptual framework**

Systems theory is the major theory driving this research project. Systems theory has a broad focus on understanding how individuals function in their environment and was chosen for that very reason. Systems theory recognizes that interaction occurs between large systems, sub-systems, and the individuals within them. This is why systems theory suits this research study, which specifically examines the interactions between individuals, their familial care givers, and long-term care settings. Systems theory maintains that systems and sub-systems are dynamic, and that change in one entity is bound to effect change in the other entities. This research study will focus on how familial care givers respond to changes in their care recipient's needs and how they work with health care facilities to affect change. The results generated from this research will describe the qualitative nature of such interactions.

It is projected that the results will also be effective in forming a conceptualization of how each participant functions within their system and sub systems with regard to the research topic: transitioning a geriatric family member from independent living to a long-term care setting. A benefit of this kind of qualitative research is that the results will tell a great deal about how varying situational contexts influence the subsequent feelings and behavior of participants. It is

presumed that sub-systems within each participant's life will influence their perception and reaction to the aforementioned research topic. Finally, this research study will operate from the notion that each participant's system is their family, and that their sub-systems can include things such as employment, geographic location, and monetary capabilities, among a variety of other variables.

An explicit goal of the research study was to gauge how participants view their care giving role. Another explicit goal was to learn something about each participant's outlook on the process of transitioning a geriatric family member from independent living to a long-term care setting. A latent goal of the research study was to see how sub-systems influence that transition, and which sub-systems hold the most leverage for participants. Another objective is to understand how familial care givers think and reason about their own actions during the transition process. A final objective is to determine if there are differences in the ways that respective familial care givers interpret their older family member's decision-making rationale during that process. This was accomplished through the use of semi-structured interviews designed with systems theory in mind. The interview questions are styled in a way that yield a depth and breadth of information regarding the system and sub-systems in each participant's life and the ways in which interaction occurs.

## **Methodology**

### **Introduction**

This exploratory research study focused on investigating the qualitative experience of long term care social workers and the environmental and interpersonal factors that influence their role functions. The research question for this current study focuses on: what is the social work perspective on transitioning from independent living to long term care? Questions relating to

participants' knowledge, experiences, and feelings as related to this topic were used to formulate this perspective.

### **Sample**

The non-probability sample used was a mixture of both availability and snowball. Five participants took part in the study (Table 1). Inclusion criteria for the study include being a licensed social worker currently practicing in a long term care setting.

The current study defines long-term care settings as: facilities where individuals live in close proximity to professional healthcare providers, where coordinated, routinized, closely-monitored services are provided 24 hours a day, 365 days a year, typically over an extended period of time. The current study defines independent living as the act of an individual living in a non-medical residential property, regardless of whether they receive formal or informal support from caregivers.

**Table 1.** Participant demographics

<b>Gender</b>	<b>Degree</b>	<b>Experience</b>	<b>Beds in facility</b>
Female	LGSW	20+ years	48
Female	LICSW	20+ years	163
Female	LICSW	14+ years	64
Female	LGSW	8+ years	105
Female	LGSW	6+ years	92

### **Procedure**

Data collection began following IRB approval. The sample was obtained through long term care facilities in the Minneapolis-St. Paul community and surrounding metro area. The

facilities utilized for this research study were derived from a publicly-accessible list from the Minnesota Department of Human Services website. There were five facilities represented in total. The researcher of the current study made initial contact via telephone with each respective long-term care social work office (visible on the accessible list) to assess whether they would grant access to interview their social work staff and to answer any preliminary questions they may have had regarding the study.

Five social workers spoke with the researcher and indicated interest via phone. The researcher then worked with these potential participants to determine a date and time to schedule each interview, and spent additional time detailing what the study would entail. This explanation included facets such as the types of questions to be asked, approximate time commitment, and the primary researcher's information such as program represented and contact information. Those who may have needed permission from their supervisor or administrator were encouraged to do so prior to scheduling an interview.

Each interview took place in an office setting or conference room located on each respective facility. Caution was taken to conduct interviews in as quiet and private a setting as possible. At the beginning of each respective interview, the researcher briefed each participant on the study characteristics, fully reviewed the consent form with them (Appendix B), and obtained their signature on the consent form. Each interview was audio-recorded. Following each interview, the researcher offered a verbal debriefing to each participant. Each participant was also provided with a debriefing form (Appendix C).

### **Data Collection**

Data was collected for use in the current study by way of semi-structured interviews. The questionnaire for the interviews was developed from a review of the formal literature on the

topic. The themes of the interview centered on the variables that impact the transition from independent living to long-term care, as well as on the demographic characteristics of participants. There were ten semi-structured questions in total.

### **Protection of participants**

This research study gained approval through the University of St. Thomas Institutional Review Board (IRB) prior to its implementation. A consent form (Appendix B) was prepared for the purposes of this study according to the guidelines on the University of St. Thomas IRB website. The consent form described the following in detail: the background and purpose of the study, the study's procedure, the benefits or risks of participation, the compensation for participation, confidentiality, and the voluntary nature of the study. It also provided the contact information of the researcher, the research methods chair, and the University of St. Thomas IRB. Prior to each respective interview, the consent form was discussed in detail and signed by both the researcher and the respective participant. All individuals who met with the researcher followed-through with participation in the study. They were informed that their decision to participate or not participate would be kept completely confidential. They were reminded that their decisions regarding participation would not impact their relationship with their long-term care facility or the University of St. Thomas or St. Catherine University in any manner.

### **Data analysis**

For the purposes of the current research study, a descriptive phenomenological approach was taken with regard to data analysis. This allowed manifest content and themes to be the primary focus. Each respective interview was audio-recorded, reviewed, and transcribed by the researcher (Appendix D). The interview transcription was then examined by the researcher for

the purpose of coding the data. For the purposes of the current study, codes were defined as words, phrases, topics, or paragraphs that lead the researcher to a particular topic area.

After a list of initial codes was compiled by the researcher, the data was reexamined for larger themes as well as sub-themes. Following data collection, all interview materials were immediately stored in a lock-box in the researcher's home. The researcher was the only person with access to the data, which maintained the confidentiality of all participants. In addition, no identifying information was attached to each respective set of notes from each qualitative interview; rather, any identifying information (contact information) was kept on a separate document. All data will be destroyed (shredded) following a public presentation on May 20, 2013.

## **Findings**

### **Manifest content**

Three (60%) participants did not have an opinion on long term care prior to becoming professionally-involved. However, at the time of the interviews, participants displayed a willingness to candidly discuss the challenges related to being a long term care social worker. The positive or supportive aspects of their work were emphasized to a lesser degree.

Despite the variety amongst participants (Table 1), there were many commonalities in the ways they responded to the interview questions. The participants' language centered on words such as: process, communication, expectations, resources, trust, and acceptance, which were repeated throughout each participant's respective interview. A common thread throughout the interview transcriptions was the notion of expectations.

As one participant stated: "Social workers just like everybody else who works in long term care are impacted by the financial changes— the decreased funding for facilities-and how

that impacts the quality of care and people's perception of what's provided. And, expectations as I said, I think are higher than they ever were." The three sub themes relating to expectations were: reassurance, education, and insight, admissions and screening, and administrative strain. In essence, these participants viewed their role as the liaison between families, residents, and administration as strained due to inadequacies in being able to address increasing intensities of families and caseloads with limited budgets and time.

**Theme 1: Reassurance, education, and insight**

The first major theme that emerged from the data related to reassurance, education, and insight of families. Several participants attributed difficulties in this area to dysfunctional family dynamics and non-traditional caseloads. All participants mentioned this theme in some capacity, including the enormous responsibility involved with reassuring families throughout the admissions process and family's lack of knowledge of what to realistically-expect in terms of the older adults adjustment or to characteristics of the facility itself. Participants also spoke to families' lack of insight into medical and mental health issues. As one participant stated, "It's like an onion. They need to hear that stuff several times before it's really sinking in and they're getting it." Four participants (80%) cited this theme as the single most challenging component of the admissions process. Below are some participant statements regarding this theme (Table 2).

**Table 2:** Participant statements suggesting a theme of reassurance, education, and insight.

	<b>Participant Statements</b>
<b>Theme 1: Reassurance, education,</b>	<i>"They're worried about consistency among staff, they're worried about <b>if</b> their loved one is going to fall between the cracks, they're worried about roommates <b>if</b> there 's a roommate situation and how that's going to affect their parent. They're worried about the parent's mental health even for those that don't have a history of depression. "</i>

<p><b>and insight-treading lightly and putting things in perspective.</b></p>	<p><i>"And you've got people that are really coping and supportive and want to look at support and other people who are really pretty unrealistic in what their parents functioning is which then creates conflict whenever you're trying to put behavior into perspective. .."</i></p>
	<p><i>"I think sometimes if they had that caregiver role for their loved-one prior it's hard to adjust or adapt to having a loved-one in a nursing home because certainly its 24-hour care but that doesn't mean that you have somebody by your side 24/7. .."</i></p>

## **Theme 2: Admissions and screening**

The second major theme that emerged from the data related to admissions and screening. Admissions and screening involve the residents, families, referral sources, and long term care administration and staff. Admissions were a topic that participants most often spoke at length about. Four participants (80%) said that the number one thing they would do to reform the admissions process would be to spend more time with residents and families up-front-to learn something personal about their story.

One participant cited poor rapport with hospitals and discharge planners as the primary reason why information is often limited prior to admission. Another participant stated that simply being proactive and having those difficult conversations before concerns are exacerbated by crises can lead to smoother transitions all around. As one participant states, "We just have to figure out how to adjust our day and our workloads, so I think if families and customers would let us know what's important to them and ask questions about whether we can accommodate it and how we can accommodate it, it prepares them better— it establishes more realistic expectations." Next are some additional participant statements regarding this issue (Table 3).



**Table 3:** Participant statements suggesting a theme of admissions and screening.

	<b>Participant Statements</b>
<p><b>Theme 2: Admissions and screening-keeping transitions cohesive.</b></p>	<p><i>"Nobody has hours to spend with the individual. And I think that's a huge deficit. It's a luxury, none of us have that opportunity anymore the way I think we should Or if I take the time to do that, it's at the expense of something else or someone else."</i></p>
	<p><i>"I think— this would never happen— but if our admissions department was able to go and meet with the patients and screen them really good. We just don't have the time or resources to drive to all the patients. Some patients look really good on paper and they come here and it's a disaster because either they have behaviors or we find out all this background"</i></p>
	<p><i>"Sometimes they can also have tremendous, excessive needs ...That can be challenging when-dependending on when the admission occurs-it might just happen at a time when the social worker isn't really free to be present."</i></p>

### **Theme 3: Administrative strain**

The third major theme that emerged from the data related to administrative strain and the participants' perceived ability to simultaneously meet the demands of both administrators and family systems. Surprisingly, even though this sub-category was not directly assessed in the interview questions, 4 (80%) participants wove it into the conversation at some point during each of their respective interviews. Social workers who initiated this topic often spoke at length about it. It was evident that this is a concern that is at the forefront of their work with patients, families, and larger systems. Following are some participant statements regarding this issue (Table 4).

**Table 4:** Participant statements suggesting a theme of administrative strain.

	<b>Participant Statements</b>
<p><b>Theme 3: Administrative strain--occupying the liaison role.</b></p>	<p><i>"Their mindset is finances; we see things from the patients' perspective. And we're the social worker but our managers are saying this and administration is saying this and we have to find that balance."</i></p>
	<p><i>"...you don't want to have too many medical assistance because it doesn't pay enough to keep everything going. So you know the administrator and the business office kind of keep their pulse on case mix so that it's somewhat profitable."</i></p>
	<p><i>"Right now we are talking about private room charges— when they should be increased and who should pay— it's a mess. And as a social worker you're like ethically I can't charge one patient and not charge another if they're here for the same reasons. But then business-wise they're saying we need to get as much money as we can."</i></p>

## Discussion

### Theme 1: Reassurance, education, and insight

The first major theme that emerged from the data related to reassurance, education, and insight of families, which is something that all participants discussed in detail. Attending to family dynamics has been identified as one of the top three ways in which health care professionals are involved in the transition process, which is consistent with the research of this study (Couture, Ducharme, & Lamontagne, 2012). Levine and colleagues state: "Especially in busy institutional settings, families are sometime perceived as troublesome, interfering with proper care, fighting among themselves, challenging physicians' or nurses' authority, and

generally behaving badly" (2010). One particular participant spoke at length about how difficult it is to manage families who are in conflict.

In a literature review on conflict management in long-term care settings, Allen and colleagues identified that family-initiated conflict is most often rendered when there is dissimilarity between the family's "unrealistic" perception of care and what the facility is able to provide (Allen, Nelson, Netting, & Cox, 2007). All participants of this research study mentioned the notion of "expectations." The manner in which some participants discussed the challenges associated with meeting growing expectations on behalf of residents and families reflects the cultural shift away from seeing residents as "institutional bodies" (Wiersma & Dupuis, 2010). This shift has so far been manifested in the re-structuring of the daily schedule in a way that reflects individual resident needs rather than strictly staff preferences.

Several participants brought up the topic of "letting go." One pertinent reason why it is often difficult for familial caregivers to transfer the caregiving responsibility to the long-term care facility is because they have oftentimes been the single witness to the entire trajectory of care for the individual (Levine, et. al., 2010). One participant stated that she would estimate that—of all the families she interacts with—only 5-10% of them have an accurate understanding of long-term care. Social workers can make a difference in the successfulness of the admissions process by reassuring families that they made an equitable choice and by transferring their education and insight as to what constitutes long-term care onto those families.

## **Theme 2: Admissions and screening**

The long-term care facility is in many ways the ultimate institution—important, well-established, a place of confinement and limited options, and governed by larger powers. Moving into a long-term care facility should ideally be a deliberate, conscious, and timely act—but it

rarely happens that way. "Much of the advice given to family caregivers about what to consider when choosing a nursing home comes too late; that initial choice is likely to be made by a hospital discharge planner, often with little notice" (Levine, et. al., 2010). Therefore, the second major theme that emerged from the data related to admissions and screening, which was a topic all participants spoke at length about. They had many qualms. Eighty percent of participants said that they had a desire to devote more time up front to getting residents acclimated to the environment and learning the full picture on their story.

A meta-analysis by Sury, Burns, and Brodaty found that successful transitions into long-term care are facilitated when the individual of attention is dealt-with through a person-centered approach (2013). A person-centered approach would include things such as comprehensive orientation procedures when first moving into a facility and a "buddy system for new arrivals" – things that just do not happen today (Sury, et. al., 2003). In a quantitative research study utilizing nationally-representative data of current long-term care social service directors, it was identified that "having enough time to identify and meet resident psychosocial needs" was the single largest contributing factor to whether participants reported "thriving at work" than those who did not (Liu & Bem-Klug, 2013). Meeting the needs of families is a component of meeting the psychosocial needs of residents; therefore, this is a theme with perhaps more widespread implications than traditionally-identified.

### **Theme 3: Administrative strain**

Too-often, there are flaws in the organization of long-term care facilities that lead to inevitable value incongruences. As Rockwell's qualitative research study identifies, there is tension between the business-orientated administration and the person-centered service delivery team (2012). Therefore, the third major theme that emerged from the data related to

administrative strain and the participants' perceived ability to simultaneously meet the demands of both administrators and family systems. Neuman states: "Social workers often stand alone in the middle of heated ethical controversies about providing intimate care within a very rigid health-business model (2000). This interaction between models has real implications for quality of care, affordability, satisfaction, and a host of other issues. Clearly, this topic was on participants' minds, as 80% of them initiated this topic which was not represented among the semi-structured questions.

### **Limitations**

Perhaps the limitations of this study yielded the most profound information in regard to the topic at hand. The initial goal of this research was to interview the primary caregivers for individuals who had recently completed the move from independent living to long-term care facilities, with the goal of understanding the ways in which the current system (or lack thereof) could be streamlined to better-suit families and their needs. However, in the beginning stages of executing the methodology of this study, it became clear that the study had too many disincentives for participants and facilitators and may therefore be ineffective. One such deterrent to effectiveness was long-term care facilities' unresponsiveness to the study; out of the 30-plus phone calls that were made, far less than half were answered. Of the social service departments who did return those phone calls, many individuals raised concerns regarding their ability to facilitate the connection between the primary researcher and respective families-even with regard to the ethical and logistical considerations that were set up by the primary researcher prior to the proposal's submission to the University of St. Thomas Institutional Review Board. Therefore, it was determined that the participants would be long-term care social workers.

Only five long-term care social workers were able to participate in this study. Notably, those who agreed to participate were inevitably employed with smaller facilities (most of which were located in Ramsey County)-presumably because those were the facilities with more adequate funding and therefore time to respond to the phone calls and agree to donate 30 minutes of their time. Therefore, there was not the variation in participants or facilities that was originally sought-out.

### **Implications for policy and practice**

In 1987, the Nursing Home Reform Act was passed, which increased national recognition that there is a link between quality of care and quality of life among residents (Liu & Bern-Klug, 2013). Since then, long-term care facilities have become more regulated. The quality of care and efficiency of facilities has improved, but there is still work to be done. Levine and colleagues identified four major areas for policymakers to consider when addressing long-term care reform: information for families, training for families, program development, and financing (2010).

Many times, the choice of a long-term care facility is not much of a choice at all, as beds are in short-supply and families often feel pressure to make moves quickly (Levine, et.al., 2010). Policymakers and professionals alike should be held accountable for improving the facilitation of these difficult transitions. However, Wiersma and colleagues identified that there is a deficit in the quantity and quality of research literature that details the process of individual adjustment into a long-term care setting, as well as how staff (i.e. social workers) facilitate that process (Wiersma & Dupuis, 2010). Additional research is warranted.

## References

- Aging 2030: Preparing Minnesota for the age wave and beyond. May 2011 conference.  
*Minnesota Department of Human Services*.Dhs-5059c-eng.
- Allen, P.D., Nelson, H.W., Netting, F.E., & Cox, D.M. (2007). Navigating conflict: A model for nursing home social workers. *Health and Social Work, 32* (3), 231-234.
- Birkeland, A., & Natvig, G.K. (2009). Coping with ageing and failing health: A qualitative study among older living alone. *International Journal of Nursing Practice, 15*, 257-264.
- Brittain, K., Comer, L., Robinson, L., & Bond, J. (2010). Ageing in place and technologies of place: The lived experience of people with dementia in changing social, physical and technological environments. *Sociology of health & illness, 32*(2), 272-287.
- Bowers, B.J. (1988). Family perceptions of care in a nursing home. *The Gerontologist, 28*, 361-368.
- Brown, L.J., Potter, J.F., & Foster, B.G. (1990). Caregiver burden should be evaluated during geriatric assessment. *Journal of the American Geriatric Society, 38*, 455-460.
- Chapman, N.J., Ingersoll-Dayton, B., & Neal, M.B. (1994). Balancing the multiple roles of work and care giving for children, adults, and elders. In G.P. Keita & J.J. Burrell, Jr. (Eds.), *Job stress in a changing workforce* (283-300). Washington, DC: American Psychological Association.
- Couture, M., Ducharme, F., & Lamontagne, J. (2012). The role of health care professionals in the decision-making process of family caregivers regarding placement of a cognitively impaired older relative. *Home Health Care Management and Practice, 24* (6), 283-291.
- De Koker, B. (2010). Perceived care giver burden of spouses and children in Flanders: who's feeling more burdened and why? In G. Doblhammer & R. Scholz (Eds.), *Ageing, care need and quality of life*. Wiesbaden: VS research.
- Durity, A. (1991). The sandwich generation feels the squeeze. *Management Review, 80* (12), 38-41.
- Engelhardt, G.V., & Greenhalgh-Stanley, N. (2010). Home health care and the housing and living arrangements of the older. *Journal of Urban Economics, 67*, 226-238.
- Family Caregiver Alliance (2003). Women and caregiving: Facts and figures. Retrieved from: [http://www.caregiver.org/caregiver/jsp/content\\_node.jsp?nodeid=892](http://www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=892).
- Feinberg, L. (2012, November). Family caregiving and the workplace: The problem and solutions. *AARP Public Policy Institute*: Washington, D.C.

- Feinberg, L., Reinhard, S.C., Houser, A., and Choula, R. (2011, June). Valuing the invaluable: 2011 update, the growing contributions and costs of family caregiving. *AARP Publish Policy Institute on the Issues: Washington, D.C.*
- Fingerman, K.L., Chen, P.C., Hay, E. L., Cichy, K.E., & Lefkowitz, E. S. (2006). Ambivalent reactions in the parent and offspring relationship. *Journal of Gerontology: Psychological Sciences, 61B*, 152-160.
- Flynn Reuss, G., Dupuis, S.L., & Whitfield, K. (2008). Understanding the experience of moving a loved one to a long-term care facility. *Journal of Gerontological Social Work, 46 (1)*, 17-4
- Funk, L.M. (2010). Prioritizing parental autonomy: Adult children's accounts of feeling responsible and supporting aging parents. *Journal of Aging Studies, 24*, 57-64.
- Given, C.W., Given, B.A., Stommel, M., Azzouz, F. (1999). The impact of new demands for assistance on caregiver depression-tests using an inception cohort. *Gerontologist, 39 (1)*, 76-84.
- Hagerty-Lingler, J., Nightingale, M.C., Eden, J.A., Kane, A.L., Reynolds, C.F. III, Schulz, R., & DeKosky, S. T. (2006) Making sense of mild cognitive impairment: A qualitative exploration of the patient's experience. *The Gerontological Society of America, 46 (6)*, 791-800.
- Hammer, L.B., & Neal, M.B. (2008). Working sandwiched-generation caregivers: Prevalence, characteristics, and outcomes. *The Psychologist-Manager Journal, 11*, 93-112.
- Hatch, R.E., & Franklin, M.L. (1984). Concerns of children with parents in nursing homes. *Journal of Gerontological Social Work, 3*, 19-30.
- Hellman, R., Copeland, C., & Can Derhei, J. (2012). The 2012 retirement confidence survey: Job insecurity, debt weigh on retirement confidence, savings. *Issue Brief Number 369, Employees Benefit Research Institute: Washington, DC.*
- (2005). *Who stays and who goes home: Using national data on nursing home discharges and long-stay residents to draw implications for nursing home transition programs.* (Master's thesis, Johns Hopkins University).
- Kasper, J.D., Pezzin, L.E., & Rice, J.B. (2010). Stability and changes in living arrangements: Relationship to nursing home admission and timing of placement. *Journal of Gerontology: Social Sciences, 65 (6)*, 783-791.
- Kelsey S.G., Laditka, S.B., & Laditka, J.N. (2010). Caregiver perspectives on transitions to assisted living and memory care. *American Journal of Alzheimer's Disease and Other Dementias, 25 (3)*, 255-264.



- Knatterud, L. Minnesota Department of Human Services, (2011). *Caregiver role in quality of care*.
- Kontos, P.C. (2000). Resisting institutionalization: Constructing old age and negotiating home. In J.F. Gubrium & J.A. Holstein (Eds.), *Aging and everyday life* (pp. 255-272). Oxford: Blackwell.
- Levine, C., Halper, D., Peist, A., & Gould, A.A. (2010). Bridging troubled waters: Family caregivers, transitions, and long-term care. *Health Affairs*, 29 (1), 116-124.
- Liu, J., & Bem-Klug, M. (2013). Nursing home social services directors who report thriving at work. *Journal of Gerontological Social Work*, 56, 127-145.
- Lunde, A. (2011). Denial challenges families in Alzheimer's care giving. Retrieved from website: <http://www.mayoclinic.com/health/alzheimers-denial/MYO1922>.
- Minnesota Department of Human Services, (2012). *Nursing home facts*. Retrieved from website: [http://www.dhs.state.mn.us/main/idcplg?IdcService=GET\\_DYNAMIC\\_CONVERSION&RevisionSelectionMethod=LatestReleased&dDocName=id\\_005399](http://www.dhs.state.mn.us/main/idcplg?IdcService=GET_DYNAMIC_CONVERSION&RevisionSelectionMethod=LatestReleased&dDocName=id_005399).
- Minnesota Department of Human Services, Minnesota Board of Aging & Minnesota Department of Health. (2009). *What will keep family caregivers caring: Policy alternatives for Minnesota*. St. Paul.
- National Alliance for Caregiving (NAC), & AARP. (2009, November). *Caregiving in the U.S. MetLife Foundation*: Bethesda, MD.
- Neuman, K. (2000). Understanding organizational reengineering in health care: Strategies for social work's survival. *Social Work in Health Care*, 31 (1), 19-33.
- Nishita, C.M., Wilber, K.H., Matsumoto, S., & Schnelle, J.F. (2008). Transitioning residents from nursing facilities to community living: Who wants to leave? *Journal of the American Geriatrics Society*, 56 (1), 1-7.
- Nolan, M., & Dellasega, C. (2000). 'I really feel I've let him down:' Supporting family carers during long-term care placement for elders. *Journal of Advanced Nursing*, 31, 759-767.
- Perrig-Chiello, P., & Hutchison, S. (2010). Family caregivers of older persons: A differential perspective on stressors, resources, and well-being. *GeroPsych*, 23 (4), 195-206.
- Pinquart, M., & Sorensen, S. (2011). Spouses, adult children, and children-in-law as caregivers of older adults: A meta-analytic comparison. *Psychology and Aging*, 26 (1), 1-14.
- Rockwell, J. From person-centered to relational care: Expanding the focus in residential care facilities. *Journal of Gerontological Social Work*, 55, 223-248.

- Rubin, A., & Shuttlesworth, G.E. (1983). Engaging families as support resources in nursing home care: Ambiguity in the subdivision of tasks. *The Gerontologist*, 23 (6), 632-636.
- Sandberg, J., Lundh, U., & Nolan, M. (2002). Moving into a care home: The role of adult children in the placement process. *International Journal of Nursing Studies*, 39, 353-362.
- Schulz, A., O'Brien, A.T., Bookwala, J.M., & Fleissner, K. (1995). Psychiatric and physical morbidity effects of dementia care giving. *The Gerontologist*, 35, 771-791.
- Schwartz, A.N., & Vogel, M.E. (1990). Nursing home staff and residents' families role expectations. *The Gerontologist*, 30, 49-53.
- Shippee, T. P. (2009). But I am not moving: Residents' perspectives on transitions within a continuing care retirement community. *The Gerontologist*, 49 (3), 418-427.
- Silverstein, M., & Giarrusso, R. (2010). Aging and family life: A decade review. *Journal of Marriage and Family*, 72, 1039-1058.
- Sims-Gould, J., & Martin-Matthews, A. (2010). We share the care: Family caregivers' experiences of their older relative receiving home support services. *Health and Social Care in the Community*, 18 (4), 415-423.
- Smale, B., Dupuis, S., & Epp, T. (2004). *Caregivers of persons with dementia: roles, experiences, supports, and coping*. Unpublished manuscript, Murray Alzheimer Research and Education Program, University of Waterloo.
- Soderberg, M., Stahl, A., & Emilsson, U.M. (2012). Family members' strategies when their older relatives consider relocation to a residential home—Adapting, representing and avoiding. *Journal of Aging Studies*, 26, 495-503.
- Stephens, M.A.P., Franks, M.M., & Atienza, A.A. (1997). Where two roles intersect: Spillover between parent care and employment. *Psychology and Aging*, 12, 30-37.
- Stone, L.J., & Clements, J.A. (2009). The effects of nursing home placement on the perceived levels of caregiver burden. *Journal of Gerontological Social Work*, 52, 193-214.
- Sury, L., Burns, K., & Brodaty, H. (2013). Moving in: Adjustment of people living with dementia going into a nursing home and their families. *International Psychogeriatrics*, 1-10.
- The Gerontologist. (2008). *About the journal*. Retrieved from [http://www.geron.org/Publications/The\\_Gerontologist](http://www.geron.org/Publications/The_Gerontologist).
- The National Association for Home Care & Hospice, (2008). *Basic statistics of home care*. Washington D.C.

- Stone, R.I., & Farley Short, P. (1990). The competing demands of employment and informal care giving to disabled elders. *Medical Care*, 28 (6), 513-526.
- Wagner, D.L., Lindemer, A., Yokum, K.N., & DeFreest, M. (2012, March). Best practices in workplace eldercare. *National Alliance for Caregiving*: Bethesda, MD.
- Wiersma, E., & Dupuis, S.L. (2010). Becoming institutional bodies: Socialization into a long-term care home. *Journal of Aging Studies*, 24, 278-291.
- Wolff, J., & Kasper, J. (2006). Caregivers of frail elders: Updating a national profile. *The Gerontologist*, 46 (3), 344-356.

### Appendix A: Semi-structured interview questions

1. Please describe your current role.
2. Please describe your experience in the field of social work.
3. What was your viewpoint on long-term care facilities before and after working in one?
4. When family is involved, what are some of the most common concerns you hear in regards to moving from independent living to long-term care?
5. Among the clients/families you work with, what most often prompts the relocation from independent living to long-term care?
6. What is difficult or challenging for you as the social worker throughout the relocation/transition?
  - a. What do you suspect families find most difficult or challenging?
7. What is supportive or helpful for you as the social worker throughout the relocation/transition?
  - a. What do you suspect families find most supportive or helpful?
8. If you could reform the admission process, would you?
  - a. If so, what would you change and what would you keep the same?
9. Do you have any recommendations for families moving an individual into a long-term care facility?
10. What do you think are the biggest challenges facing long-term care social workers today?

## **Appendix B: Consent form**

"Adapting to change: The qualitative experience of transitioning from independent living to a long-term care setting from the social work perspective"

IRB log # 406993-1

### **Introduction**

I am conducting a study about the qualitative experience of transitioning from independent living to long-term care. I invite you to participate in my research study and contribute to the knowledge base on the topic. You are eligible for participation based on your role as a social worker in a long-term care setting. Please take a moment to read this form and ask any questions you may have prior to agreeing to participate in the study and share your information.

I, Paige Sorenson, am the primary researcher involved in the current study. This research is being conducted as a requirement for graduation from the University of St. Thomas/St. Catherine University dual Masters' of Clinical Social Work program. My clinical research committee chair is Dr. Colin Hollidge.

### **Background**

The purpose of this study is to gain a better understanding of the qualitative experience of transitioning from independent living to long-term care. With the growing numbers of older Americans, this is a topic that is expected to receive substantial attention in the coming years. Previous research has demonstrated that health professionals are addressing this topic in a wide variety of ways. The goal of this study is to better understand the qualitative nature of social work in long-term care settings and set forth some goals for the future.

### **Procedure**

If you agree to be in this study, you will be asked to meet with the primary researcher for one interview. At this meeting, you will be asked to describe your personal experience with the research questions that are presented to you. There is no "right" or "wrong" answer. Everything from the meeting will be audio-taped, and this meeting is expected to require approximately 30 minutes of your time. Following the meeting, I will compile the information that was discussed, and the audio tape will be deleted. The information obtained during the interview will be used for my clinical research project-but no personally-identifying information will be linked to any of your responses. You will be given a copy of this consent form for your records.

### **Benefits or risks**

There are some minor risks associated with your participation in this qualitative research. Although this will vary based on your level of comfort with discussing this topic, it is possible that the questions you will be asked to elaborate on could evoke a stressful response. Therefore, it is asked that you use your own discretion when answering questions.

### **Compensation**

Participation in this research study is voluntary, and therefore non-compensated.

**Confidentiality**

Only the primary research will have access to the audio tape from this study, as well as any personal or identifying information. Notes from the interview may be examined by my research advisor, but these will not include any identifying information. Your contributions will be included in my for-credit clinical research presentation, which is a requirement for graduation from the University of St. Thomas/ St. Catherine University dual Masters' of Social Work program.

**Participation**

Your participation in this qualitative research study is completely voluntary. Your decision whether or not to participate will in no way affect your current or future relations with the primary researcher or the University of St. Thomas/ St. Catherine University. If you decide to participate, you are welcome to skip any interview questions that you feel uncomfortable or unprepared to answer during the interview. You may request to stop the interview and withdraw from this research study at any time, and for any reason. Should you choose to withdraw after the interview has been conducted, please contact the primary researcher immediately following your decision.

**Contact Information**

You may ask any questions you have now. If you have questions, comments, or concerns at a later time, you can contact any of the following:

**Primary Researcher**

Paige Sorenson  
218-684-5264  
sore7246@stthomas.edu

**Research Chair**

Dr. Colin Hollidge  
651-962-5818  
cfhollidge@stthomas.edu

**University Authorities**

University of St. Thomas IRB  
651-962-5341  
IRB@stthomas.edu

**Statement of Consent**

I have read the information in this consent form. My questions have been adequately answered, and I understand this consent form as well as what the primary researcher is asking of me. I certify that I am at least 18 years old and therefore consent to participate in the research study.

Signature of Participant \_\_\_\_\_ Date \_\_\_\_\_

Printed Name of Participant \_\_\_\_\_

Signature of Primary Researcher \_\_\_\_\_

Date \_\_\_\_\_

## Appendix C: Debriefing form

Thank you for participating in this research study!

*"Adapting to change: The qualitative experience of transitioning from independent living to a long-term care setting from the social work perspective."*

### Purpose

The primary purpose of this study was to gain a better understanding of the transitional process from independent living to long-term care from the social work perspective. The secondary purpose of this study was to understand the unique issues faced by long-term care social workers. I recognize that the experience of care giving can vary greatly from one individual to another, one family to another, and one facility to another, but that care giving can oftentimes be a stressful, challenging experience for everyone involved. Thank you for putting in your time and supporting my research!

### Further questions

If you would like to learn about the results of this research study or would like to acquire some formal literature on the topic, please feel free to contact me.

Thank you,

Paige Sorenson (218)

684-5264

sore7246@stthomas.edu

University of St. Thomas/ St. Catherine University