

THE AGING MARKET: TRANSITIONS FROM  
UNASSISTED TO ASSISTED LIVING

By

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## ABSTRACT

The field of gerontology is rapidly growing and shedding new light on previously hidden issues within old age. One of these issues that has seen increased attention over the past few decades has been on the quality of assisted living. Transitioning from unassisted to assisted living is a debacle many will face in the United States as they age and soon become incapable of living on their own. What comes during this transition into assisted living is a mix of emotionally draining and confusing processes that put undue burden on family members and their loved ones. Through literature review and primary data collection it is clear that there are gaps of knowledge, structure, and service during this transitional period. This paper aims to illuminate these problems with the goal of informing others so individuals and corporations alike are more prepared when making a transition like this.

## Introduction

I've got good news and bad news. The good news is that life expectancy in the US has been on the rise for a considerable amount of time now (Hanowell, 2016). This means that children born today will, on average, live longer than any other age cohort that has come before them. Old age is a relatively new phenomenon and one that has seen increased research and study over the last few decades as gerontological work has exploded. So what's the bad news? Well unfortunately, today's systems that were built in the early 1900's to deal with the elderly cannot support this large influx of our aging population today. As a result, more and more people are turning towards formal support systems to manage their care into old

age.

The biggest issue with this longevity and the need for supports lies in the disconnect that exists between formal support facilities and those searching for these facilities. Individuals don't trust large corporations to take care of their elders, facilities provide information that is difficult to decipher for specific circumstances, and the level of personalized care that many desire is out of reach either monetarily or structurally in these living environments. This paper takes aim, specifically, at the assisted living industry.

Merriam-Webster defines assisted living as "a system of housing and limited care that is designed for senior citizens who need some assistance with daily activities but do not require care in a nursing home" (2018). Help can be administered for daily living tasks such as bathing and eating or for tasks as simple as reminding someone to take their pills on a regular basis. The emergence of assisted living facilities (ALFs) stemmed from the formal nursing home community, which provides more extensive care options. What business leaders and care professionals saw was an unmet market of elderly people who couldn't live on their own but still functioned relatively well in many of their daily activities. The hybrid child born out of this intersection of supports and independent living is what we know today as the Assisted Living Industry.

In addition to this discussion on ALFs, it is important to understand the specific demographic we are discussing that is affected by and experience this transition. For the purpose of this discussion, elderly individuals are those over the age of 60 who are facing impending health issues, financial issues associated with

aging, and portray several of the defining value-based characteristics of aging, which include: security, comfort, respect, and the ability to maintain control. These four values influence many of the daily decisions an elderly person makes and will be important to reference when talking about the many obstacles an elderly person encounters throughout the transition process. The other major player involved in this process is the elder's family. In most cases, informal support systems such as family members are used before transitioning into formal assisted living (Dellmann-Jenkins, 2000). As a result, these family members often play integral roles in moving their loved ones into ALFs and can therefore provide a unique perspective into the struggles that are present for both the elder and themselves.

Characterized by a lack of oversight and widely varying standards, ALFs have been able to operate under conditions that mimic the Wild West. Their lack of uniform structure makes selecting a facility and completing a successful transition into that facility a major challenge for many elderly who embark on this journey. Through primary and secondary data analysis it is clear that there are mismanaged steps in the transition process of an elderly person from unassisted to assisted living.

What we know today on this topic comes from the point of view of the elder making this transition. For research, there are a number of independent resources available for individuals going through this transition but they lack standardization. Info from the AARP, anecdotal online forums, and personal Internet research are some of the most common ways elders and their families conduct research to aid in this transition (Kane, 2007). However, these sources can provide circumstantial

advice at best due to the specificity of each individual's transition. There have been several attempts to improve the ALF industry through government regulation and additional oversight programs but these measures have failed to live up to their noble aspirations (Konetzka, 2013). What is still unclear are a multitude of other issues that elders and their families might experience, as well as how difficult or frequently these issues might arise.

The specific research question this paper seeks to address is: What key pain points exist for both elders and their families as they make a transition from unassisted to assisted living? Answering the research question will require a deep analysis of current literature available for review in addition to analysis of primary research that was conducted to supplement literature findings. These two bodies of research will combine to answer where current unmet needs exist in the transition process and what types of needs, or gaps, elders and their families find most crucial to their situation. The findings from both the literature review and primary research will then be combined in the Discussion and Implications section where application of these findings will be discussed. Finally, a review of these key findings and future endeavors will be discussed at the end of this paper to wrap up the topic as a whole.

## Literature Review

The overarching goal of this paper is to explore the major pain points that families and the elderly endure throughout the transition process to an ALF. While

this is an evolving issue and one that will demand more research moving forward as the population ages, there are a number of sources that can answer this question to some extent today. To better answer this question, it's important to look at the two main spheres that these major issues are broken into. Koenig described the logistical and the emotional sphere as two of the main categories with which transitional pain points can be broken into (2014). Evaluating these pain points through the lens of these two spheres will allow for a more detailed and distinguished discussion to occur on each topic.

The two primary parties involved in this transition process are the elder themselves and the elder's family. Both group's perspectives are important to this discussion because they each experience a variety of issues throughout the transition. The elder holds a unique first person encounter, while family members, who often act as a primary caregivers before a move to an ALF (Dellmann-Jenkins, 2000), provide keen insights on additional issues the elder experiences or that they experience themselves. The literature up until this point has focused primarily on the elder, which is where the majority of these insights from the literature will come from.

As described in the study conducted by Koenig, participants described the logistical elements of the transition process as the steps involved with a physical movement to a facility (2014). Within this physical movement we can find issues relating to the geographic proximity of the facility, the cost of the facilities in question, and the process of searching for information related to finding a suitable home for the elder.

## **Logistical Sphere**

### **Facility Information Search + Cost**

Once it has been decided that a move to an ALF needs to occur, the elder and their family typically move into the next phase of searching for viable options. This search, in today's world, happens online for many people and has become a major point of frustration for those struggling to compare various home options and cost structures. As of now, there isn't a one-stop shop to search and compare ALFs in any given area. The lack of a uniform and comprehensive source leaves many guessing what options are best for their elder and how much they'll be left paying in this new facility. In many cases, forums are an elder's best option for finding useful data concerning a specific facility leaving only anecdotal data to base decisions off of.

The information search stage is important in the transition process because there are many variables to account for when choosing a home. The lack of uniform regulation within the assisted living industry make it a daunting task to sort out all the options that meet a bare minimum set of criteria. Above all else, families want to ensure that what the facility promises is what they'll actually deliver on. Instances of mistreatment can be common within assisted living where there is an imbalance of power between the employees of the facility and residents. The size of the facility, the amount of training employees are exposed to, whether it is for-profit or not for profit, and even the location of the facility relative to large cities all play roles in the rate of mistreatment (Phillips, 2011). Properly vetting a facility before making a



final commitment is crucial to prevent instances of mistreatment later down the road.

A Google search for assisted living facilities will produce results that vary from full time care institutions, to memory care facilities, and everything in between. With a lack of standardization, it's difficult to pinpoint the exact service offerings each ALF will offer. One of the more important ways an ALF is run that affects resident behavior and levels of happiness involves how the facility is staffed. In facilities where there were higher numbers of staff and lower turnover of nurses, residents were found to be better cared for and functioning at a higher level (Harrington, 2000). Individuals who suffer from additional impairments such as dementia, arthritis, and urinary complications might require more personalized offerings in order to achieve a quality standard of living.

Aside from the various options a facility might offer, it's cost structure in terms of how residents are billed is a second major factor that must be considered in the facility search process. Two surveys that were completed with uniform sample sizes yielded varying levels of costs for assisted living throughout the United States. The two surveys concluded costs ranging from \$2,500 a month (UMH, 2017) to \$7,000 a month (Genworth, 2017). This variation speaks to the discrepancy in facility pricing that makes it even more difficult for elders and their families to simplify choices. The lack of accurate research tools and transparent cost structures cause elders to find discomfort and difficulty in the early stages of the transition process.

### Location Attachment

There are many factors that come into play when evaluating location preferences for an elder's ALF. A combination of logistical ease and the elder's level of comfort are paramount in this decision, but there are several other variables that cloud judgment during this time. A simple way to choose an ALF is to look in the immediate area of where the elder currently lives. According to the AARP, 40% of adults 85 and older live alone at home (Abrahms, 2014). This is a direct reflection of the high level of comfort and familiarity elder's experience as they age in a single place. Staying within the immediate area would allow for elders to remain in their current town thus minimizing the amount of drastic change that occurs during a transition. Not only would this be important for the elder themselves, but be less of a logistical headache for the family members who are assisting their elder in this move. Moving down the street to an ALF compared to another state minimizes the physical travel to the new location, the difficulty in moving personal items, and the availability of family in the immediate area. According to a study reported in the New York Times, the average American lives only 18 miles away from one or both of their parents (Miller, 2015). Moving to an ALF close to their current residence could prove best for both the elder and their family. However, there is strong data to support otherwise.

According to the findings discovered through Cutchin in a questionnaire they distributed throughout the US, "The direct relationship to becoming at home in a residence is negative, signifying that the greater attachment to town or community, the less likely one is to become at home in assisted living (2003). In this instance,

the move to an ALF would be closer to resembling the move to a hotel. The elder would not fully adopt the hotel as their new home just as they would not adopt the ALF as their new home if it were in close proximity to where they previously lived. One reason for this resistance to adopt could be that the elder is battling, psychologically, their two lifestyles: the one they had before entering the ALF and their new, current lifestyle inside the facility. This mental battle might prevent them from ever moving on and fully accepting this new reality.

Cutchin's alternative to searching for facilities in close proximity is to look for ALFs that are out of the immediate realm of the elder's current living situation. Moving further away through this transition would allow for a 'clean break' to occur. Moving far enough away from their current home would create an adapt-to-survive mentality with fewer structural supports in place they are able to lean on when they feel resistant to change (2003). While moving further away might be the healthiest option long term, there are a number of logistical considerations that need to be discussed. Moving further away means that family members are less available in case of emergencies and routine visits. Additionally, a further move means a more complicated moving process, which can contribute to more stress on the elder's family as they sort everything out. This increased caregiver stress, along with the overwhelming feeling of a 'large' move for the elder can make this a more emotional transition than one down the street would be. With all these factors at play it becomes clear why the simple choice in geographic location of the facility can cause strife for decision makers.

## Dementia Understanding

A major part of the process is the acceptance of this new situation as part of your reality. This is oftentimes one of the first logistical hurdles that must be crossed for elders and for elders with dementia, it is also one of the most difficult parts of the transition. The literature at this point focuses on the first few months within an ALF for patients with dementia and solutions that help them during the tail end of the transition process. The biggest issues experienced at this point involve the lack of comfort one has in this new environment, their difficulty in communicating with others, and their lack of social participation. Although they are already in a facility, this point of the process still represents a transition as they struggle to find meaning among all these changes.

In order to give meaning to this new transition for elders dealing with dementia, it's important to understand how these individuals find ways to interact within the facility. With limited cognitive abilities in many dementia-plagued individuals, activities with minimal interaction can prove to be most effective in getting residents moving. Knitting was found to be an effective platform for facilitating social identity, conversation, and social engagement within a group of residents with similar abilities (Gjernes, 2017). Weekly knitting groups provided a structured environment on a routine basis where residents, both new and old, could congregate and interact in meaningful ways while improving their cognitive abilities. Knitting is a simple way to encourage participation within the facility and find a comfortable place within this new environment but there are more active ways to accomplish the same goals. In some facilities, creative dance was used as a

way to foster social engagement as well as physical movement. This combination of the social atmosphere, with a physical activity helped promote the retention of memory in residents with dementia. In addition to improving memory and social interaction, this activity helped improve the moods of residents who participated further assisting in the adoption of this new lifestyle (Zeindlinger, 2014). Through these two studies we can infer that a mild physical activity paired with a social environment can be extremely beneficial in supporting new residents in an ALF who suffer from dementia and are looking for new ways to engage in this environment to assist in the transition process.

One factor that aids in transition process is an educated and personalized nursing staff. The more that nurses are trained on conditions like dementia, the better service they are able to offer to residents. With this more personalized help, residents are able to feel more at home and welcome in the new environment contributing to an overall increase in wellbeing (Beer, 2012). The duty of a successful transition partly lies in the hands of the nurses who are now responsible for primary caregiving. In some instances, residents with advanced dementia have lost several of their main methods of communication. As a result, they appear to have little or no desire to communicate. A study of 30 interactive sessions in an ALF found quite the contradictory. Ellis and her team set out to discover various ways the new residents with dementia attempted to communicate and found that residents attempt communication through facial expression, touch, and imitation (2017). This finding illustrates that nurses need to be more aware of residents who are trying to make contact with them and others in this new environment.

Recognition of these unconventional modes of communication can help contribute to better care for the resident and an improved sense of belonging in the ALF. Those with dementia who must transition to an ALF have an added difficulty in doing so with their limited forms of communication and opportunities for social interaction. Understanding these limitations and overcoming them has proven to be one of the more difficult steps in transitioning for the large number of elderly who battle some form of dementia. While identifying meaningful ways to interact in this new environment is categorized as a logistical step, there are many emotional aspects to it. Through the literature it is clear that the emotional side of transitioning permeates many of the decision steps.

### **Emotional Sphere**

The second dimension of this transition process that comprises a majority of this literature review is the emotional side of issues that an elder and their family encounters. Emotions are present throughout the entire transition process but there are several points throughout where emotion impacts a decision more than it normally would. The largest points of emotional frustration for individuals revolve around maintaining their current roles, finding autonomy in their new environment, and traversing the parent-child role reversal that may occur.

### **Role Maintenance**

Many people feel a loss of control as they go into ALFs and it further alienates

them as they try and find out how they can be themselves in this new environment. It's important to find ways to keep your schedule and habits consistent so you change as few things as possible. A change in location, daily routine, and environmental outlook can be emotionally tolling in and of itself. Adding a role change to this further takes away the perceived power and control you have over your life. Throughout our lifetime we often refer to our occupation or other defining characteristics when identifying our roles. These roles become an integral part of what we do all day, who we interact with, and how we fit ourselves into the fabric of society (Heshmat, 2014). A move to an ALF can shakeup this entire notion of roles and force us to redefine who we are in an emotionally turbulent chapter of many people's lives. Moving to an ALF poses several threats to this idea of role maintenance. First, we lose the role of an independent person. This move is characterized by an influx of supports and structured living that inhibits personal choice to varying degrees. Additionally, we see a loss of the role of friend. Unless you're in the fortunate position of moving to an ALF with 5 of your best friends, you won't have the access to those meaningful connections you once did while living on your own or in a community of others you're familiar with. In her study, Mulry found that the loss of the role of 'friend' was one of the most difficult obstacles to overcome in transitioning. While a resident might find new companions within the facility, they often never find a close friend again (2012).

This shakedown rids a person of their personal identity and leaves them scrambling for ways to define themselves in this new social hierarchy. A certain level of despair can kick in and leave the elder feeling hopeless. This emotional

battle to define one's self was found to be crucial to a successful transition in Mulry's study. Identifying ways to maintain certain roles in this new situation deemed paramount in the healthy, emotional transition to an ALF. Another factor related to role maintenance that aids in this continuity of role keeping in the new facility is the establishment of a personal daily routine, often associated with a person's level of autonomy.

### Autonomy

According to Colleen Bennett in her study of Resident Autonomy, autonomy is defined as "the ability of the individual to make and carry out decisions about how, with whom, when, and where to spend one's time" (2017). Moving to an ALF represents a loss of personal choice in many aspects of life, which elicits a number of emotional responses. Bad behavior that shows up in individuals shortly after moving to an ALF may seem unwarranted on the surface, but is related to this topic of autonomy once nurses and family members are able to identify the pain points that cause these tantrums (Lavery, 2013). These facilities often have structured schedules that allow for a minimum expression of individual interests in terms of the time and place of social engagement. In Bennett's study, she elaborates on the importance of recognizing that a cognitive deficiency does not mean there is a decreased desire for autonomy (2017). Unfortunately, we see a linear relationship between the level of personal choice allowed for an individual and the amount of cognitive ability they hold. This distinction is important to note so that nurses in particular are aware of the autonomy desired by these residents despite their



physical limitations. This lack of autonomous ability can wear away at an individual's self-concept, making a transition to an ALF even more difficult.

One of the strongest determinants of success in a new ALF setting was the ability to choose one's routine (Mulry, 2012). The routine choice carries with it a slew of other decisions that influence personal tasks such as bathing, eating, and social interaction. Allowing residents to choose these certain aspects in their routine can drastically improve the morale and acceptance rate of this new living situation. A separate study on how the elderly define happiness further backs up this point. Elders have a shift in what makes them happy from excitement and variation in their routine to more calmness, peace, and low states of arousal (Bhattacharjee, 2014). Most ALFs would support a low arousal environment but giving residents increased chances to personalize their routine would allow for increased expression and attention to their personal happiness. Another important form of autonomy that influences the acceptance of this transition is whether or not the elder themselves decided to move in the first place. Those who made the conscious choice were found to be more accepting and have more comfort in their new situation than those who had the decision made for them. Bennett accurately identified the goal of all of this, which is to create a positive sense of self thus leading to positive health promotion in this new setting (2017). This reversal of autonomy can be emotionally scarring for elders who experience it. The transition to an ALF is often characterized by a number of life reversals similar to this, one of the most personal being the parent-child role reversal.

### Parent/Child Relationship Reversal

One of the most emotionally straining pieces of this transition that occurs is the role reversal of the parent-child relationship. This is a key intersection between the two major parties in this discussion. There are several psychological underpinnings in this relationship that affect the way elders and their children interact throughout this transition.

One model that helps explain this relationship involves the influence of exchange principles and perceived familial obligation. The theory of exchange principles states that someone who is both dependent on another individual and holds power over that same individual will eventually have to succumb either power or their dependence to make the relationship harmonious (Pyke, 1999). In the case of an elder transitioning to an ALF, this means relinquishing that parental power they once held over their children to receive more forms of care from their child. When it comes to this power struggle, there are two groupings where most elders in this situation fall. The first group is the collectivist group, which is comprised of individuals who are willing to give up some of their power to receive more help from their children. These elders have a more communal view of their situation, which leads them to take into account their children's views over their own when conflicts arise. The second group of elders is the individualist group, which is filled with elders who prefer to keep more power in the relationship and sacrifice additional help from family around them (Pyke, 1999). This group is where many struggles in this relationship reversal tend to appear as parents have a hard time letting their adult children make decisions for them.

Familial obligations and how each side perceives the level of obligation in the relationship also play a large role in this reversal. Mancini, in their study surrounding this relationship dynamic, found that elders who expect a high level of commitment to caregiving from their children were often disappointed and less satisfied with the level of help they received from their family members (1989). Where issues arise are in the lack of communication regarding the level of care an individual expects from those around them versus what is delivered. Those who took a more communal approach to caregiving and placed less stress on their children to provide saw increased levels of satisfaction from the care that they did receive from their family members, showing an inverse relationship. What further differentiates this level of care is the relationship status of the child or family member providing primary care services. Children, who have relationships that have ended in divorce, or are otherwise unstable, tend to provide less care to their aging parents than those who are in stable marriages or other positive relationships (Mancini, 1989).

The types of caregiving tasks that are requested also have an impact on how family members perceive the level of care they are providing. Personal care tasks such as bathing, feeding, and clothing were seen to be more stressful and produce more caregiver burden on the family providing that care. Compared to personal care, secondary tasks such as grocery shopping and transportation were viewed as much less burdensome and family members were much more willing to complete these kinds of tasks (Mancini, 1989). Mancini also found in their study that the previous relationship that existed between the elder and adult child had an effect on

the degree of strain that would be produced by providing primary care services. The closer the bond between the parent and child before primary caregiving was involved tended to yield more strain on the relationship than if the two were less close before caregiving was necessary (1989). From this, it seems that those who have a deep parent-child relationship who must transition power from one to the other have a harder overall time doing so than those who were less close to their parents or children beforehand.

## Methods And Results

The literature reviewed up to this point identified several pain points that the elder and their family experience throughout the transition process to an ALF. A large majority of literature directly addresses the perspective of the elder, who provides an important view of these issues. However, it failed to adequately incorporate the view of the family members who help the elder through this transition. These families have an insight into unique issues the elder may deal with or what they deal with themselves. Family members act as the source of primary caregiving for many elders who cannot function daily on their own. This personal perspective into the lives of these elders is something neither nurses nor researchers are accurately able to depict. Currently, there are holes in the transition process where elders and their family struggle. The family perspective is crucial in order to develop successful strategies that effectively patch these holes.

The process for extracting the primary data that follows was carefully constructed and planned to avoid topics that were not relevant and ensure data was collected in a randomized way. A website was determined to be the best source for information due to the tight time restrictions present, the qualitative information sought, and the widespread access it created for users coming from all parts of the United States. The website used to gather data is called Agingcare.com. The site's mission statement involves "Helping caregivers of elderly parents find answers on senior housing, home care, elder care, caregiver support, senior financial and legal information" (Agingcare.com, 2017). This site is specifically for assisted living discussion and topics surrounding this transition process. Data was sourced from 3 years worth of forum posts concerning a caregiver and their particular issues surrounding their elder's transition to an ALF. A total of 53 posts were collected with roughly 140 unique users participating on these posts. Information was gathered from every other post on the website, only including posts that had upwards of three comments. Posts with less than three comments were deemed to be not relevant to other personnel who frequent the site. A ranking system to categorize posts was needed to eliminate bias and introduce an element of randomness into the data sample. A forum is not the most reliable set of data so this ranking system attempted to alleviate some of these possible issues. In addition, a third party was utilized to employ the same system to eliminate any bias I could've carried throughout the ranking process. The system that was employed made use of the number of comments a post had as well as the type of post it was categorized as.

In organizing this data, four major buckets emerged to signify the four most cited issues that individuals were seeking help for. These posts were printed out, organized based on themes, and then further organized based on the main objective or pain point the user was attempting to address. The four categories are outlined and discussed below.

### Social Community for Struggle

The transition to an ALF represents an emotional and trying period for many people as they struggle to release the care of their elder to an institution that is foreign to them. For many, this rapid change is the first time they've had to deal, to this extent, with a loved one of theirs and so there is often a feeling of loneliness that pervades these families. One of the functions of Agingcare.com is to act as a social community for those who are struggling. One of the largest categories that posts fell into lacked a specific question or struggle, but was focused on reaching out to this support system for emotional guidance, practical advice, or an outlet for people to vent about their situation. One post made by username Butterfly57 sums up this point perfectly as they update this community on their situation, "I am glad she is in assisted living and keeping her on schedule. Even though I have not always lived with my mother, I have been providing care for her over a decade". There is no specific request made of the community, yet it serves as a release for the user who is able to talk about this personal situation with others who understand their position.

Some posts are made at the beginning of this transition, like one made by katiekat2009 who states, "She [her mother] is apprehensive but accepting it better

than I thought she would. Wish us luck!”. Again, we see a simple post that aims to reach out to the broader network of individuals going through similar experiences in hope that they will comment with additional support. On this same post several users offer their words of encouragement like the ones used by username Perserverance, “May I highly recommend that you continue to be her strong advocate. Don't be fooled by the glitz of an expensive ALF”. These messages may seem miniscule but can make a worlds difference in the users who are looking for a hand reaching out in support. Username hvluv2ski made a similar post to katiekat2009 when they set the stage for their mother’s transition to a facility that would occur the following week. Hvluv2ski had been acting as their mother’s primary caregiver with 24/7 service over the past year and had finally experienced enough strain in their situation. “I am WORN OUT...ANYONE dealt with the transition to Assisted Living can give me some pointers?”. The following comments below are filled with detailed paragraphs of other users’ specific advice for hvluv2ski. Hvluv2ski responds further down in the thread with an emotional post of gratitude for all the support and care she has received from her initial post, “I pray Blessings and Strength for both of you (Peace) to our Parents afflicted with this terrible DZ [disease]”. A solid bond has been seemingly formed between two strangers online who are afflicted by the same situation with their aging parents. Posts like this speak to the need to have outside signs of strength and reinforcement in these trying periods.

While some people make posts at the very beginning of their ALF process, others are seasoned professionals when it comes to dealing with these emotional

times and therefore offer posts of encouragement for others experiencing what they've gone through. Username Aferrino offered their story up to inspire others that there is still hope throughout this process, "Although she is still struggling with dementia, she is in a place where the people know how to care for her. I am so, so thankful. We had to sell mom's house to be able to afford this, but in the end it is totally worth every dime we spend". In response to this post another user, Jessiebelle, offered their congratulations for Aferrino being able to traverse such a tough road, "aferrino, loved reading about this. I know you were dreading the way that it was going". In another, more dismal post, username Windyridge told the story of all the tribulations they are currently going through with both parents being placed in an ALF. After posting about their mother suffering a large cut on her forehead and their dad "acting like a mess" as a result, they found solidarity in the comments section. Username Sunnygirl1 responded to this post in a comforting manner saying, "My goodness, Windyridge. What a night. Prayers for your parents and whole family. That's an ordeal for anyone to endure. It sounds like your parents are in good hands though". This community has shown the importance in the social component of this transition. Lending your ears to someone's troubles and letting them know that they're not alone has proven to go a long way for these individuals struggling to see the light at the end of the tunnel.

### Dementia Comfort

With the sheer number of elders dealing with some form of Alzheimer's or memory loss it's no surprise that many posts revolve around an issue dealing with



dementia. More specifically, users' posts dealt with the comfort, a state free of physical or emotional pain, of an elder in their new environment. Concerns over comfort occur towards the end of the transition cycle when elders are living in the facility and experience difficulty fully adapting to it. One of the simplest ways users wanted to provide comfort for their elder's new living situation is to make it feel more like home. Oftentimes, personal items like jewelry, clothing, and other unique items can be used to make them feel less like they're in a foreign place. Username Grace1234 wanted something to give their mother in an ALF for the holidays, "Her space is so limited to about 7'x13' If I give her candy/chocolate or food she will sit and eat it all at one time. She has dementia and I wish she just didn't even know the holidays are here". Later down the thread, Grace1234 mentions instances where other residents or the staff have stolen her real jewelry when she thinks she's just misplaced it. This creates a unique problem of being able to provide enough perceived value in gifts that won't be an attractive item for others to steal.

Another contributing factor to the level of comfort provided for dementia plagued elders relates to the level of personalized attention and care they receive in the ALF. Username SuziQ's mother moved to assisted living and within several months she was reaching out to Agingcare.com to see what to do, "She says she wishes God would take her. She get her oxycodone 10mg 4 times a day. I think that has made her dementia worse and not wanting to do anything. But she is in so much pain she needs them". Instead of digging into the real problems present in residents, staffs at ALFs have been routinely criticized for overmedicating patients in hopes that their issues will fade away. Overmedication is not an issue limited to those with

dementia, but posts tended to focus on elders who had some type of debilitating disease as such. Not only are their real problems not being addressed, but in this overmedicated state many residents turn into unsociable vegetables who are surviving but have no real quality of life. User Claire33 echoes this issue detailing their mother's experience with overmedication as a result of multiple UTI infections among other health issues, "She takes a bp med (Coozar), Arricept and Lexapro. Xanax was causing her problems (tremors & more) and it was stopped last Friday". This trend towards silencing residents with medication is detrimental to the successful transition of a person dealing with dementia. Individuals who are dealing with this disease have trouble communicating their thoughts to staff and, as a result, can have their opinions on medical issues silenced. This struggle is apparent in many families like Claire33's and SuziQ's.

A third common struggle that appeared from users' posts about their family dealing with dementia revolved around their social circles within ALFs. User 3kidsma speaks to their mother's discomfort in their new ALF saying, "Just moved my Mom into assisted living due to recent hospital stay. She says she's lonelier there than being in her own home with no one visiting..She's 85, dementia". This loneliness stems primarily from their mother's inability to make friends in the new home. As mentioned before, a strong social circle can make a world's difference in adapting to assisted living. User Jeannegibbs speaks about their mother's successful transition into her new schedule at an ALF saying, "Mother has been in the NH 9 months. three of those were on Hospice -- she improved dramatically and "graduated" out. She now seems very content". Jeannegibbs' mother had been

antisocial upon first entering her ALF, but decided to embrace daily social activities like a chili cook off, playing the accordion, and a host of other events. The move from hospice to minor assisted living is a tremendous switch and one that, according to jeannegibbs, couldn't have occurred without this new social regiment in their mother's life. Elders who deal with some form of dementia are traversing an uphill battle when moving to an ALF. Many users on Agingcare.com have illustrated this struggle including those who do not suffer from dementia, but the disease puts increasing pressure on an elder and can be a defining difference in an eventual successful transition.

### Advice on Cost Options

The lack of available information was already addressed as being a major issue that many families go through during this transition process. On Agingcare.com it was discovered that, more specifically, families in this position have a hard time pinning down accurate information relating to the cost of these facilities.

The cost of an ALF is tremendous with the median price for a year of care falling around \$42,000 (Stinson, 2014). This is an expense that many people don't have the foresight to budget for, leaving them worried about how much it will cost and how they will pay for it. With costs this high, it would make sense for facilities to make this information as clearly labeled and identifiable as possible. Sadly, this is not the case. Many individuals throughout Agingcare.com express their dissatisfaction and frustration with ALF costing. User dberryjr inquired about the

influence of Medicare/Medicaid on their situation relating to their ability to hold onto their assets if Medicare were to kick in. The 16 comments that follow all contribute to a confusing string of definitions and unique situations that illustrate the complexity of paying for ALFs. User concernedone further validates this frustration with their post that discusses the ambiguity concerning their parents' future in their current ALF. According to concernedone, "their savings is gone and they are unable to pay the full amount" and despite not being able to pay the entire cost of the ALF, concernedone remembers the facility quoting that "my area will accept all funds available as full payment after one year" allowing their parents to remain as long as all assets are used to pay for the ALF. This is not a common practice throughout the industry, but highlights an important issue in the transition process. Facilities are not highly regulated, allowing them to slide through with backdoor options for residents like the one that was presented to concernedone. This further distorts the total costs of an ALF making it difficult for families to discern what their true, actionable options are for a facility.

Cost can also be concerned with other frustrations during this transition process and become a barrier for making more important decisions. User Lashelle70 posted about their stepfather moving into an ALF and how their mother "concentrates on worrying about the cost, because it helps takes her mind off worrying about lots of other things". Emotions are running high when it comes time to make a real decision on where to place a loved one for assisted living. The process can be very conceptual up until the point that actual costs and structures are being discussed. Remaining on this early portion of the decision process can be

therapeutic in a way for individuals struggling to make changes. Families may relish the confusing costs of ALFs because it postpones the difficult decisions that are to come. However, this procrastination will only lead to more complications and issues down the road for the elder struggling to transition. Sometimes cost issues arise out of a lack of transparency, but other times they can be malicious in nature. User Daisy001 dictates their experience with a lack of rent control in their mother's new ALF, "My mom moved into a assisted living residence in mid-aug. and they are already raising the rent 4% They gave her a great price in August to get her in [very rushed 'deal'] and we agreed. Now I am worried we will not be able to afford it". Once again we see a lack of transparent cost structures resulting in a burdensome experience for a family to figure out for themselves. Whether the facility meant to raise rent in this rushed manner or not is left up to question, however, regardless of the motive this rent change put an undeserving worry on this user's shoulders.

### Lack of Trust

Trust is an important element in any relationship. When talking about an ALF, elders and their family need to be able to trust that the care being administered is always in the best interest of the residents, unencumbered by profits, simplicity, or any other distractions. What many people on Agingcare.com have issues with is this idea of trusting an organization enough to transfer primary caregiving of their family member over to an institution.

One quote from user pmculliney sums up the issue of trust within these organizations, "They have chairs outside the med station, you can walk by and see

pills on the floor, i have seen one resident give her pills to another. It happens a lot". Inconsistencies in caregiving administration, including severe mismanagement of medication in this instance, leave many people second-guessing the ability of an ALF to care for their elder. Not all issues of trust are this extreme. Another user, Thistledown3, posted about their concern over staff members leaving the ALF where their mother was housed, "Some have approached me to share that they'll be leaving. There are tears in their eyes and expressions of "not what I'd want", but silence with an explanation". What Thistledown3 and pmculliney are both suffering from is a lack of transparency in how processes and ALF matters are communicated to both patients and their family members. In both instances, there was a discrepancy in what they expected and what was being administered, causing a rift in their relationships with these institutions.

This issue of transparency is further echoed with a post by user malloryg8r stating, "Wouldn't it be so much better if all assisted living were required to put their complete rates for rent and services, on their website or they would tell you everything about their prices, without an in-person visit? It is so time-consuming to drive out to each one". A lack of upfront and genuine interactions causes a distance to be created between those who are searching for an ALF. Not only does this harm the experience of those looking for a facility, but it could also prevent facilities from bringing in additional residents. Malloryg8r responds on her own post later to detail their frustration in searching for accurate cost structures of ALFs saying they've "been to about 2 dozen in 18 months" and found no straightforward answer in any facility they've visited. This shows that the issue of transparency is not an isolated

instance. Family members aren't the only ones experiencing this lack of trust, either. User DaveDoc is a current resident of an ALF and they posted about their current struggles within the facility mentioning, "it is impossible to get others taking action other than complaining to me as their "leader." The only practical alternative I see is the increased active involvement of family, which has the negative aspect of only furthering the resident's feelings of powerlessness". This unique post from a current elder's first hand experience shows the continuity of issues that are prevalent within ALFs that contribute to this lack of professionalism. Ultimately, this lack of transparency could prevent individuals from admitting elders to ALFs even if it is in their best interests. If a high level of care is paramount for the elderly who cannot live alone then something must be done to alleviate the barriers of communication present within facilities today.

## Discussion and Implications

There are many conclusions to be drawn from both the literature review and primary research that was conducted for this paper. The distribution of these findings can be grouped into three main areas of focus.

### Widespread Mistrust

There is a lack of trust that exists between these two entities. Current cost structures make it difficult to discern accurate expense forecasts for individuals looking into ALFs and the personnel who work at these institutions have little

knowledge in how to address these types of questions. This lack of professionalism and transparency makes it more difficult for individuals to form a comfortable, mental relationship with these ALFs. In addition to this lack of trust, ALFs can take away the autonomy of residents, which can be detrimental to their overall health and comfort level in a situation they are adjusting to. The facility itself represents a tremendous hurdle that needs to be overcome by both elders and their families who are struggling to relinquish control of primary caregiving to a facility that appears to lack professionally adequate service options.

### Identity Crisis

Another common theme was the presence of an identity crisis that occurs for several parties throughout the transition process. On Agingcare.com one of the most cited objectives of posting was to convey the struggle they were experiencing in hopes of reaching out to a social community. These individuals were experiencing varying levels of crisis as they struggled to find their role in this new process. The parent/child role reversal that occurs affects both the elder and their family members, specifically the adult children. Types of caregiving tasks, the previous relationship between the parent-child, and the relationship style all have an influence over how these key stakeholders identify themselves throughout this transition. The factors specifically affecting the elders' identity in this transition deal with the maintenance of roles in this new environment as well as the level of cognition that is present in the elder. The loss of various roles, such as the role of a friend, which occurs during this transition combined with the lack of availability of



new roles in these facilities, creates a difficult conundrum for elders moving to an ALF. Diseases like dementia also exacerbate these identity issues. Elders who deal with dementia can become confused why their environment is changing and become irritable. This becomes even more troublesome when there is no effective mode of communication for the elder. Physical and social engagement can help spur memory healing in these individuals but above that, the staff at ALFs need to better understand how residents with dementia relate and communicate to their environment so they don't miss out on meaningful interactions.

#### Lack of Resources

There is no "one size fits all" institution that can handle all types of elders and their personalized care. Because of this, there is also no uniform resource that families and elders can use to search for ALF options. There are many variables at play when considering the long-term placement of an elder in assisted living, which is why the process of seeking information can become so problematic. How certain individuals react to moving to a far location versus one that is down their street can have a tremendous impact on the rate of adoption of their new environment but is not readily known to many people transitioning. For people with dementia, personalized care can make a world's difference in terms of their comfort level in the ALF and how they socialize with other residents. Both of these factors are vitally important for people suffering from dementia to successfully transition.

One of the biggest surprises in conducting primary research was the lack of emphasis placed on logistical elements in the transition overall. While there were

many instances of pain points throughout specific logistical steps in the transition, most worries and issues contained an emotional tie within it. Posts on Agingcare.com that detailed a facility's oversight or inadequate service were less focused on the actual mistake than they were on the effect of that mistake on their elder's quality of care. I expected logistical complaints to comprise a majority of posts due to the difficulty in conveying emotion across technological mediums. However, individuals were successfully able to cross this barrier and provide intangible expressions of their feelings throughout this process and make them the center of what was burdening them.

### Limitations

While this paper aimed to be comprehensive of the transition process there were several key limitations that might hinder the results that were produced. This phenomenon of an aging population as well as the field of gerontology in the United States is relatively new. As a result, studies and an overall emphasis on this demographic have been increasing but still remain premature in many respects. More research needs to be conducted in order to have a more full grasp on the issue at hand. In addition, the limited regulation of ALFs makes it difficult to find uniform sources on the subject. These institutions are often compared to the Wild West so pinning down accurate, holistic research is difficult.

Another major limitation of this paper stems from the primary research that was conducted. Although this data was collected in the most systematic way possible, it yields from a single source so there is an inherent possible error that

could've been produced from the information on Agingcare.com. Still, the limitations come primarily from the nature of the time-crunched situation, rather than the source selection and collection process.

### Future Implications

As awareness of our aging population grows, it will be imperative for more research to be dedicated to studying individuals in this stage of life. Better understanding the pain points in transitioning that these families experience will aid in providing more quality care for the vast amount of elders who will be subjected to some type of assisted living in the future. A deeper understanding of needs and gaps in this process will point academics and innovators alike in the right direction for what specific issues need more attention. In addition to continuing research, it will be important to communicate these findings to relevant outlets such as assisted living organizations, the AARP, and other large entities who have the ability to enact change in our institutions to better serve the elderly population. Aside from research, these findings should fuel the next wave of innovation within this space. Investigating these opportunities where further advancement and improvement is needed will be a major next step in the application of this paper.

There is always a need for more information in a field that is rapidly expanding with many pain points associated with it. However, the primary objective of this paper is to provide actionable insights into how quality of care throughout the transition process to an ALF can be improved. These findings have real world

application, which widens the scope of this paper considerably outside the realm of academia.

First and foremost the issues described in this paper should help bring awareness to the pain points in this transition process so others are aware that these difficulties exist for millions of Americans today. The complaints listed out in the primary research that was conducted should also help ALFs determine what specific areas need to be remedied in order to deliver better care for their residents. In addition, families and elders who are about to go through this transition can look to this research as a guide for problems they may encounter or a checklist for issues that they had not yet considered in their search for assisted living. This can help contribute to a more prepared population of elders and their families who are searching for a new situation to better fit their current and future needs as they age. Above all else, this information should be used as a springboard to spur entrepreneurial innovation in this industry.

There are several ideas that I built out during the creation of this paper that address several needs of the transition process that were currently unmet. The first is a structured elderly transition program that aids elders in the preparation, logistics, and emotional healing that is necessary throughout this difficult time. An organization like the AARP could sponsor such a program with the goal of promoting a more informed and prepared population of aging individuals. This program would directly address the specific changes that one should expect in a transition including asset management, the logistical search for an appropriate facility, and how to maintain as much of the status quo as possible throughout the

entire ordeal. In addition, this program could help elders find new, meaningful ways to interact in ALFs and show their families how to help in making their loved one more comfortable in their new home.

Another viable option for bringing transparency into the ALF industry would be to create a database that holds both user and professionally provided information relating to the cost structures and options on various facilities throughout a given area. The primary issue this tackles is the high rate of under quoting that goes on in the industry. Elders and their families can be drawn into facilities with a low-ball offer that turns into an expense much larger than they anticipated. Having this level of transparency would also force ALFs to offer more reasonable rates in order to rise above their competition.

The last problem I wanted to tackle with a proposed solution deals with the lack of personalized care present in ALFs today. A popular classroom management tool called Class Dojo is used to keep parents, teachers, and students on the same page regarding class progress, grades, and other academic matters. A similar system could be developed for ALFs to allow elder's families to input personalized care options that are needed in the routine care of their elder. Nurses would have a unique chart of preferences and care options for each resident and be able to deliver a more customized experience. This would not only help with residents dealing with dementia, but those struggling to find comfort in their new home. This application would allow all three primary parties to communicate and stay informed on the level of care being provided for the elder in an ALF.

There are major marketing-specific findings within this paper that can be communicated to companies across the US, with the possibility for international application as well. The major pain points in transitioning that were discussed in both the literature review as well as the methods and results sections offer detailed insight into where companies can come in and influence individuals along the path of transitioning. Aside from these marketing trends, there are other actionable ways companies can make use of this information. To start, companies should now be aware of the needs of employees who act as primary caregivers for family members. With this aging population comes a greater need for extended familial caregiving, which will put burdens across people who hold regular day jobs as well. Companies need to recognize this difficulty and be as flexible as they can with paid leave and more customizable work schedules to allow their employees to care for elders that depend on them. Transparency is another major lesson that can be learned from this research. Specifically, companies should learn from the mistakes of these ALFs in their inattention to detail. Transparency in any industry yields more informed consumers, which leads to better decision-making and a more satisfied customer base. Implementing strategies to become more transparent with client facing tasks should be a major goal of organizations today. Overall, this research has great potential in spurring future interest in the field of gerontological transitions. The number of cited pain points shown through various levels of research demonstrate a clear need and gap in the ALF industry.

## Conclusion

The presence of this emerging, aging population in America is enough to warrant further research and innovation in the assisted living industry. A lack of personalized care and knowledge on this transition process will prevent more people from accessing the care they need and deserve leaving an entire age demographic vying for a better quality of life. The increasing life expectancy in the US proves that this is an issue that is not going away, but becoming ever more prevalent.

The key findings of this research illustrate several points. Distrust, a lack of autonomy, and confusing cost structures make it difficult the elderly to fully adapt to their new home. Elders are forced to relinquish power to their family and institutions. Some are able to make this switch in return for care while others struggle to find a new balance. How elders define themselves in this new home is a crucial part of acceptance, and one of the more difficult niches to carve out. Finally, the facility research process is spotty, with limited resources to find accurate information on facilities in any given area. Compounding on this lack of information is the absence of personalized care that can address many of the issues cited both online and through anecdotes provided by individuals dealing with dementia. Tailored care programs can help get to the roots of problems faster and, in the case of those battling dementia, help create a holistic plan that addresses both socialization and mental healing in the new home.

My grandparents will be making these difficult decisions in the near future, which is why I started research in this specific area of gerontology. I believe by

outlining the most difficult steps in the transition process it will both highlight where people need to prepare and show ALFs where they can improve to meet their residents' needs. These findings should not be stagnant; they have shown where current gaps are in the transition process that need to be addressed with more awareness and innovation. In my own life I will be sure to educate my family and friends with this information so they are able to make informed decisions and understand the uphill battle they could be facing. Additionally, I would like to take one of the proposed solutions and implement it in test locations to see if it could be viable in a large-scale market. One of my passions is lending myself to be an asset to others and I see this newfound information as the perfect way to make an impact in an industry that needs meaningful change.

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