THE RELATIONSHIP BETWEEN CARE-RECIPIENTS AND HOME CARE PROVIDERS, VULNERABILITY AND QUALITY HOME CARE

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Title of Study: THE RELATIONSHIP BETWEEN CARE-RECIPIENTS AND HOME CARE PROVIDERS, VULNERABILITY AND QUALITY HOME CARE

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Abstract: Americans are living longer so the number of citizens 65 and older is expected to increase at a rate never before seen. In 2012, about 8.7% of older adults lived below the poverty level. Low income adults are eligible for the Medicaid ADvantage in-home services that help clients remain in their homes instead of moving to nursing care facilities.

The purpose of this study is to examine differences between subgroups of the Medicaid ADvantage population (gender, geographical location,) on their ratings of relationship quality with personal care assistants [PCAs] and case managers [CMs] and also on their ratings of home care quality. It is also to examine the role of multiple vulnerability factors (gender, age, race, activities of daily living, ADLs, and instrumental activities of daily living, IADLs) in predicting home care quality and PCA relationship quality.

Three types of analyses were used to investigate the experiences of care-recipients in the ADvantage program. First, *t*-tests were used to compare gender with PCA relationship quality, CM relationship quality and home care quality. Second, a one-way ANOVA was used to compare PCA relationship quality by geographical location (urban, mixed and rural counties); CM relationship quality and PCA home care quality. Third, a linear multiple regression was used to determine the predictive power of vulnerability (i.e., a combination of gender, age, race, ADLs and IADLs) on PCA relationship quality and home care quality

The results did not fully support the research hypotheses used in this study. However, the results from the regression did confirm that one factor (age) significantly predicted home care quality. Although significance was not found in each hypothesis, lack of significance proved to be important findings for the Medicaid ADvantage program.

Future research is recommended to conduct more in depth qualitative investigations of this population using objective measures of social support, vulnerability and home care quality. Clinical implications were that Marriage and Family Therapy programs ensure that their curricula prepare students to competently work with the needs of this aging population by increasing their knowledge in aging issues and equipping them to work in diverse settings like assisted living facilities.

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CHAPTER I

INTRODUCTION

Americans are living longer so the number of citizens 65 and older is expected to increase at a rate never before seen (Administration on Aging [AoA], 2012). By the year 2030, 1 in 5 Oklahomans will be over 65 (AoA, n.d). Research shows that as adults age, their physical, emotional and cognitive functioning changes, and in many cases, declines (Blieszner, 2006; Charles & Carstensen, 2009). As a result of these changes, individuals are at risk of becoming frail and losing their autonomy, authority, mobility and cognitive ability. This can lead to greater vulnerability to exploitation and greater reliance on the limited systems in place to help (Calasanti, Slevin & King, 2006; Cloutier-Fisher & Kobayashi, 2009; Pinsker, McFarland & Pachana, 2010). Over time, many older adults experience shrinking support systems as family and friends die or relocate (Cloutier-Fisher & Kobayashi, 2009; Pinsker et al., 2010).

According to the Administration on Aging approximately 8.7% of older Americans lived below poverty in 2012. As a result of their low income levels, many aging adults are eligible for and depend on Medicaid (need-based program) in addition to Medicare (age-based program), to cover in-home services, including nursing services, personal care services and medical supplies and equipment (Gelfand, 2006). These services enable care-recipients to stay at home rather than move into an institutionalized setting like a nursing home (Gelfand, 2006). In short, these programs are referred to as nursing home diversion programs.

Research shows a correlation between the positive nature of the relationship between home care-recipients and their home care providers and the perception of good quality in-home care (i.e., personal and homemaker services) (Eustis & Fischer, 1991; Piercy, 2000; Piercy, 2001; Piercy & Dunkley, 2004; Piercy & Woolley, 1999; Woodruff & Applebaum, 1996).

The purpose of this study was to examine how home care-recipients' vulnerability to mistreatment affects the relationship between the care-recipient and the home care providers (e.g., case managers [CMs] and personal care assistants [PCAs]) and the care-recipients' perception of quality. A random sample of 350 of the 19,000 Medicaid eligible ADvantage members receiving in-home care services in Oklahoma participated in the current study. The sample ranged in age from 28 to 97 years. Findings revealed that gender and geographical location (i.e., rural, mixed and urban counties) had no effect on personal care assistant relationship quality, case manager relationship quality or home care quality; vulnerability (i.e., a combination of gender, age, race, activities of daily living [ADLs] and instrumental activities of daily living [IADLs]) predicted perceived home care quality but not personal care assistant relationship quality.

Data from this study were analyzed using *t*-tests and analysis of variance, ANOVA, to determine any differences in gender and geographical location (i.e., rural, mixed or urban) in terms of personal care assistant relationship quality, case manager relationship quality and home care quality. A regression analysis was ran to compare vulnerability (i.e., a combination of gender, age, race, ADLs and IADLs) to home care quality and PCA relationship quality. The results from this study can help researchers and clinicians better understand this population so that services can be designed to meet the unique needs.

CHAPTER II

REVIEW OF LITERATURE

Medicaid is a federal and state funded health insurance program for individuals who meet strict income requirements despite age. This program provides services, in part, for those needing home care assistance (e.g., children, individuals with disabilities and elders) (Social Security Administration, n.d.). The impoverished in society are covered by this program provided that they are either U.S. citizens or permanent residents (Social Security Administration, n.d.). Medicaid eligibility is based strictly on income requirements determined by the state and the recipients' Supplemental Security Income (SSI) (Centers for Medicare and Medicaid Services, n.d.; Gelfand, 2006). SSIs are monthly payments to individuals with low wages and limited resources, and who are 65 years or older or have disabilities (Social Security Administration, 2014). For example, an Oklahoman who is a frail older adult (65 years and older) or who has physical disabilities (21 years or older) with a monthly income of no more than $2,094 and a resource limit of $2,000 would be eligible for Medicaid. Although Medicaid can be helpful to all age groups, this review will focus on the adult membership of Medicaid (i.e., adults 65 years and older in frail health and adults 21 years and older with physical disabilities).

Research has shown that the U.S. population will continue to experience an upward trajectory in the number of older Americans, 65 years and above (AoA, n.d.). By 2030, the older adult population is projected to grow to about 72 million; it was about 40 million adults (i.e., one

in eight Americans) in 2009 (AoA, n.d.). As for adults with disabilities, the prevalence is shown to be higher for older adults than younger adults (e.g., 1 in 8 adults ages 34 to 64 and 1 in 3 older adults, ages 65 and older in 2010 had disabilities (National Center on Elder Abuse, 2012). The longer life span and the growing prevalence of disabilities have increased the demand on the health care system serving this population. Many of these adults have needs that previously would have require they be institutionalized in nursing homes or other long-term care facilities. However, with the advent of home care services (i.e., personal and homemaker services) these adults can have their needs met in the comfort of their own homes at a cheaper cost to the state than if they were placed in institutions. Although the percentage of older adults living in institutional settings increases with age (e.g., in 2012, 1% of 65-74 years, 3% of 75-84 years and 10% of those 85 and above were institutionalized), the majority of them remain non-institutionalized, living in a community/residential area with a spouse or alone (AoA, 2013).

Services (see Figure 1) in the home include case management, nursing services, personal care services and medical supplies and equipment (Gelfand, 2006). Home care services require home care workers (e.g., personal care assistants [PCAs] and case managers [CMs]) to be in direct contact with care-recipients. Personal care services are provided by PCAs for clients who need help with activities of daily living (ADLs) such as bathing and dressing (Gallo & Paveza, 2006; Gelfand, 2006). Homemaking services are provided for those who need assistance with tasks like light housekeeping, budgeting and food preparation (i.e., instrumental activities of daily living, IADLs) (Gallo & Paveza, 2006; Gelfand, 2006). Case managers are considered home care workers as they generally communicate with care-recipients in-person and/or by phone on a monthly (Oklahoma Department of Human Services [OKDHS], 2013). Case managers are advocates and liaisons for care-recipients and their families to ensure that they have access to and receive quality resources (i.e., community and medical) and that their goals and needs are met in a timely and cost effective manner (Case Management Society of America, 2012; OKDHS, 2007). When care-recipients are unhappy with the services being provided by their agency, PCA

or other services, it is the case manager who is responsible for helping them find better alternatives.

What are home care services and who provides them?

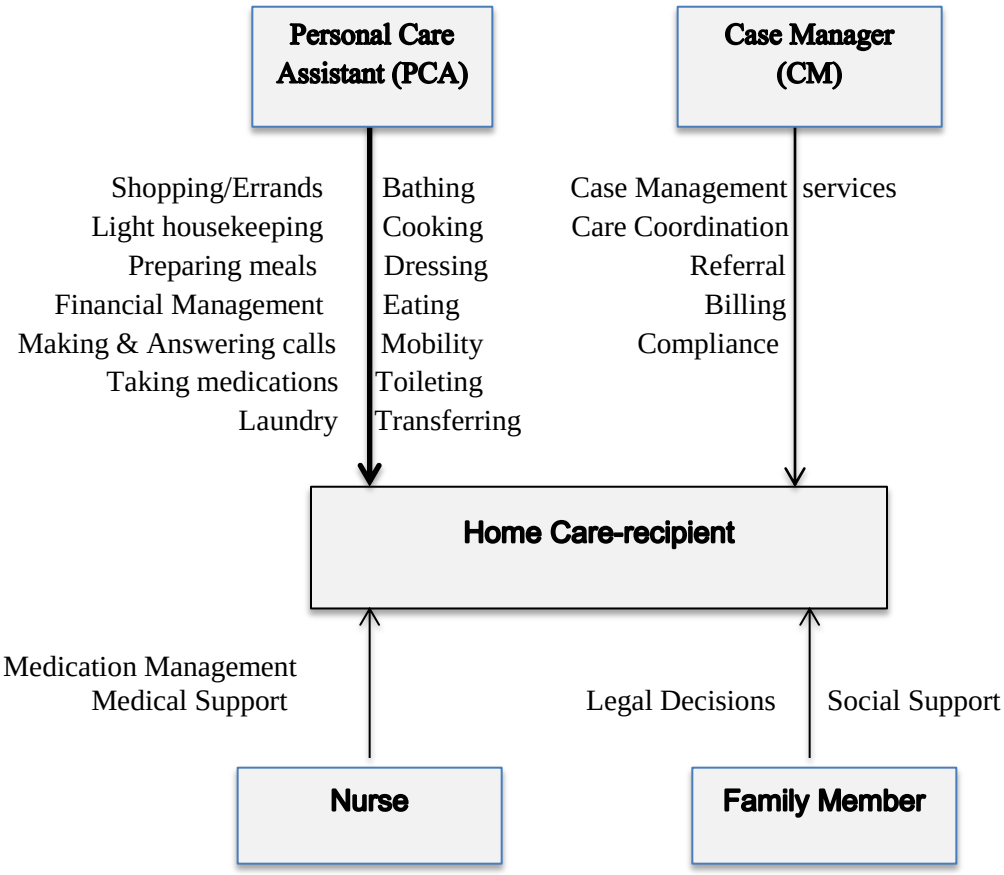

Figure 1. The figure illustrates the in-home services provided by care providers to home care-recipients in the ADvantage program

What makes these care-recipients a vulnerable population?

Vulnerability is defined as the susceptibility to being harmed physically, mentally and/or emotionally. Those who are vulnerable (e.g., the uninsured, elders, those living in poverty) are more likely to be mistreated by others. This mistreatment can occur at the hands of any caregiver whether family, friend or paid home care worker (MedlinePlus, 2014). Mistreatment can take the form of abuse (e.g., physical, sexual, emotional or financial abuse), neglect or abandonment (MedlinePlus, 2014). In 2004, researchers (National Center on Elder Abuse, 2012) found that

30% of adults with disabilities who used personal care services experienced multiple forms of abuse including physical, verbal and financial abuse. Another study found that recipients of personal care services who had disabilities reported having trouble with their care providers arriving late or leaving early, stealing money; withholding, stealing or overdosing on the care-recipient's medications; and having equipment destroyed or disabled (Powers & Oschwald, 2004). As for older Americans, over 500,000 are said to experience some form of elder abuse each year (Center for Disease Control and Prevention, 2013).

Care-recipients are at risk of exploitation when there is a power imbalance between the care-recipient and the home care worker (Powers & Oschwald, 2004). Other reasons care-recipients become vulnerable include fear of further harm, going without services, not being believed by others, being fully reliant on others for help, not having a way to leave and being socially isolated (Powers & Oschwald, 2004). This vulnerability is especially true when a medically frail, impoverished citizen relies on a health program to keep them at home. The working conditions of PCAs can be conducive to high work stress, burnout, and high turnover (Dill & Cagle, 2010; Powers & Oschwald, 2004). One research study found that PCAs who were male, inexperienced and worked for about 50 hours of home care services a week were more likely to mistreat care-recipients with disabilities than those without disabilities (Oktay & Tompkins, 2004).

The nature of the relationship between care-recipients and home care workers requires trust; the worker is not only coming into the client's home but is also providing services of an intimate nature like dressing and bathing. These clients are reliant upon their home care workers for basic needs to be met, and as such are vulnerable to being taken advantage of. It is also notable that without home care services; institutional care is the logical next step. Therefore, care-recipients may be less likely to report negative behaviors of home care staff, adding a level of vulnerability.

Theoretical viewpoint. Feminist family theory posits that the privileged in society are those who have power and are of value in that society (Ingoldsby et al., 2004). This privilege is evident based on one's race, age, physical ability, sexual orientation and the social status applied (Ingoldsby et al., 2004). Although feminist family theory looks at the power differences in the gender roles, which are socially constructed, this assumption can be expanded to other vulnerable members of the population beyond females (Ingoldsby et al., 2004). Thus, feminist family theorists would argue that care-recipients' reliance on others, limited access to services based on socioeconomic status and potential social isolation create a power differential between care-recipient and home care providers. Consequently, the home care provider holds a position of power, particularly in situations where the care-recipient is in desperate need of a PCA.

What vulnerability factors contribute to the care-recipients' vulnerability?

Medicaid members are living at or below the poverty line based on meeting the low-income requirement. Poverty affects individuals with disabilities at a higher rate than those without; poor older adults are more likely than those who are not poor to have disabilities or some limitation that can prevent them from being autonomous (Half in Ten, 2013). Although there are several vulnerability factors (e.g., disabilities, social isolation, race, age, gender) that contribute to someone's vulnerability, many of these vulnerability factors on their own do not automatically mean that the individual would be vulnerable. King's (1988) concept of *multiple jeopardy* applies here. It is defined as "not only to several, simultaneous oppressions but to the multiplicative relationships among them as well. In other words, the equivalent formulation is racism multiplied by sexism multiplied by classism" (King, 1988, p. 47). See below for an examination of several vulnerability factors faced by care-recipients in the Medicaid program.

Disabilities (as determined by their ADLs and IADLs). Individuals with disabilities are more at risk for abuse than those who are not (World Health Organization, 2014) and are more likely to report poorer overall health and less access to health care than those who are not (Center for Disease Control and Prevention, 2013). Physical disabilities occur when there is

complete or partial loss of an individual's mobility and dexterity (e.g., muscular dystrophies, spina bifida, arthritis, cerebral palsy) and/or the complete or partial loss of a body part (e.g., amputation) (Physical Disability Council of NSW, 2009). Such disabilities prevent the individuals from completing their activities of daily living (ADLs; e.g., bathing, eating or dressing) and instrumental activities of daily living, (IADLs; e.g., money management, house keeping or meal preparation) on their own so they become reliant on others to help them with those needs (Gallo & Paveza, 2006).

Lack of social support. Care-recipients who have strong social networks have greater psychological well-being, self-esteem, sense of belonging and health (e.g., a slowing down in cognitive impairment) (Adams & Blieszner, 1994; Cornwell, Laumann & Schumm, 2008; Tomaka, Thompson & Palacios, 2006; Voorpostel, 2013). However, as their social network shrinks they can experience social isolation especially if they are located in geographical areas that are sparsely populated (e.g., rural areas) and/or there is minimal involvement of their family members and friends (Cloutier-Fisher & Kobayashi, 2009; Pinsker, McFarland & Pachana, 2010). This social isolation can cause care-recipients to lose contact with important others who may be key to their care (Cloutier-Fisher & Kobayashi, 2009; Pinsker et al., 2010).

Geographical location (rural, mixed or urban areas). Rural areas tend to have higher rates of poverty (United States Department of Agriculture: Economic Research Service, 2013) and have more poor older adults living there than in urban areas (Center for American Progress [CAP], 2008). Rural older adults tend to retire and stay put while younger rural adults are more likely to move elsewhere to find jobs and better opportunities (CAP, 2008). These rural adults rely more heavily on private transportation as there is limited access to public transportation in these areas (CAP, 2008). The lack of transportation and the great distances to be traveled hinder the rural poor access to basic resources such as social and medical services (Cloutier-Fisher & Kobayashi, 2009; Johnson, 2006; Pinsker, McFarland & Pachana, 2010; Tomaka, Thompson & Palacios, 2006). Research has shown that older adults will use public transportation when it is

available, increasing their mobility and their access to social support (CAP, 2008). Unlike urban areas, rural and mixed communities have fewer health care facilities, particularly for specialized medical care, available for those living in these areas (Johnson, 2006). These limitations in the access to services can increase the risks of exploitation to these adults, as they would need to settle for any quality of services available to them.

Age. As care-recipients age, their cognitive, emotional and physical functioning declines (Blieszner, 2006; Charles & Carstensen, 2009). According to Courtney et al. (2011), older individuals are more likely to be admitted to a hospital than the general population; to experience serious decreases in their functional abilities while in the hospital; and have increased rates of readmission due to falls and other complications. These adults become increasingly vulnerable and more reliant on others and the limited systems in place to help them when they are frail and lose their autonomy, authority, mobility and cognitive ability (Calasanti, Slevin & King, 2006; Cloutier-Fisher & Kobayashi, 2009; Pinsker, McFarland & Pachana, 2010). This growing reliance on others reduces the care-recipient's ability to control the decisions about their finances, health and well-being (Cloutier-Fisher & Kobayashi, 2009). According to Calasanti et al., ageism in the labor market causes elders to lose both status and money since many are no longer able to earn an income. Calasanti and his team argued that these restrictions were oppressive, thereby resulting in the loss of financial security for these older individuals. They added that the old are not only marginalized, but are subjected to elder abuse and other forms of exploitation (Calasanti et al., 2006).

Gender. Generally women's life expectancy exceeds that of men, hence, they are likely to experience more illnesses/disabilities associated with old age than men and do so alone (Pinquart & Sörensen, 2001; United Nations Women Coordination Division [UNWCD], 2012). Women are more likely than men to live with inadequate health insurance since many were reliant on their partner's health insurance and lost it via divorce or partner death (Angel, Karas Montez & Angel, 2011; Center for American Progress [CAP], 2008). As women grow older, their

risk of living in poverty also increases. For example, women over 75 are three times more likely to be poor than men (CAP, 2008). Additionally, 19% of women 65 years and older who are widowed, single or divorced are categorized as poor (CAP, 2008). Women with disabilities have similar risks for abuse as women without but are more likely to experience abuse for longer periods than women without disabilities (Center for Research on Women with Disabilities, 2014). Research has shown that men with disabilities are at risk for abuse by those who provide personal care services (Nosek, 2002). Piercy (2000) also found that gender homogeneity between care-recipient and home care worker promoted more favorable experiences with home care services and closer relationships with between them.

How does the care-recipient's vulnerability affect their relationship with home care workers?

Due to the personal and frequent nature of these services, home care workers who provide consistent care to the same care-recipients can create a level of familiarity and trust that can impact the home care worker's ability to maintain professional boundaries (Adams & Blieszner, 1994; Piercy, 2000). Consequently, the professional expectation of home care workers is that they maintain a therapeutic relationship with care-recipients by balancing compassion with effective job performance (Alberta Association of Registered Nurses, 1997; Aronson & Neysmith, 1996; Morton, 2004; Piercy, 2000). These boundaries can become disrupted when care-recipients and their home care workers mutually self-disclose (e.g., sharing personal information) and exchange resources (e.g., gift giving) and when these workers complete tasks that go beyond their job requirements (e.g., visiting the care-recipient outside of scheduled hours; staying longer hours than required) (Piercy, 2000). According to the College and Association of Registered Nurses (2011), "social relationships are not therapeutic relationships" (p. 6) and as such it is the responsibility of the home care worker to ensure that the care-recipient does not confuse "professional caring with friendship" (p. 6). This therapeutic relationship keeps the

relationship safe for the care-recipient and respectful for both the care-recipient and the home care worker.

Researchers (Newsom & Schulz, 1996; Piercy, 2000) found that home care-recipients were more likely to have close bonds with their home care workers if they were older, had poor social support (i.e., due to geographical location, minimal family involvement) and impaired functional ability (i.e., ability to perform activities of daily living). This relationship was likely to develop if the home care workers provided consistent care based on the duration of service and the frequency of visits. However, this relationship could be hindered from developing due to the high turnover rate among providers of in-home care services as a result of their low income, few benefits and heavy workloads (Dill & Cagle, 2010). Without this consistency in care, the care-recipients are left at the mercy of their home care worker's availability.

How does this relationship between care-recipients and home care workers affect the care-recipient's perception of care?

Piercy (2000) found that the care-recipient's satisfaction with home care services was based more on the personal attributes of the home care providers (e.g., caring, hardworking) than on formal training; and on the home care worker's ability to form positive relationships with their home care-recipients. However, caregivers (e.g., family) and care-recipients do view good quality care as a combination of task performance and relational skills (Eustis & Fischer, 1991; Piercy, 2000; Piercy, 2001; Piercy & Dunkley, 2004; Piercy & Woolley, 1999; Woodruff & Applebaum, 1996). Task performance has to do with successfully completing all items on the care-recipient's service plan such as house cleaning weekly or changing bed linens daily. Relational skills include being respectful and trustworthy.

The direction of this study

Although research shows that care-recipients who have a positive bond with their home care workers will tend to be more satisfied with their home care, research continues to be lacking on how the care-recipient's vulnerability to mistreatment (abuse and neglect) due to several

vulnerability factors (e.g., lack of social support, disabilities, age) affects their relationship with their home care workers and their overall perception of home care service quality.

The current study will explore whether or not research cited in this review is confirmed with this Medicaid population (older adults ages 65 years and older in frail health and adults with physical disabilities, ages 21 and older) across Oklahoma and examine what impact the vulnerability factors (i.e., disabilities, old age, rural location, female and social isolation) have on the outcomes. Based on the review of the vulnerability factors among this population, it is hypothesized that the care-recipients who are older, female, socially isolated and have disabilities will have more positive relationships with their home care workers, thereby resulting in positive ratings for quality of care.

The results of this study could be helpful for care-recipients in the ADvantage program and those receiving home health and mental health services in the state of Oklahoma. By understanding how care-recipient's exposure to vulnerability factors affects their relationship with their home care providers and, in turn, their satisfaction with their home care services, could lead to the improvement of services provided to this population.

CHAPTER III

METHODS

Oklahoma's ADvantage Waiver Program

The ADvantage Administration Unit of Oklahoma Department of Human Services, Aging Services Division, manages the ADvantage Waiver Program. The ADvantage program provides Medicaid-funded home and community-based services to more than 19,000 frail older adults and adults with physical disabilities. This program enables nursing-home level clients to continue living at home or in an alternative residential environment of their choosing instead of going to a nursing facility. According to Oklahoma ABLE Tech (2014), the eligibility criteria for this program is as follows:

- Be a resident of Oklahoma;
- 65 years of age or older;
- Be age 21 or older with a physical disability but without a development disability
- If age 21 or older with a clinically documented, progressive degenerative disease process that responds to treatment and previously has required hospital or nursing facility (NF) level of care services for treatment related to the condition and requires ADvantage services to maintain the treatment regimen to prevent health deterioration;

- If diagnosed with a developmental disability, and between the ages of 21 and 65, but does not have a diagnosis of an intellectual disability or a cognitive impairment related to the developmental disability;
- Nursing home level-of-care needs;
- Meet Medicaid financial criteria established by the Oklahoma Health Care Authority;
    - Have a monthly income limit of $2,094, with a resource limit of $2,000

When deemed eligible by the ADvantage program, the care-recipient chooses an agency to provide certified case management (Oklahoma Health Care Authority, 2013). These case managers will assess for service needs by the care-recipient, create a plan of care that includes services necessary to keep the person out of a nursing home and ensure that those services are being fulfilled. Based on these needs, personal care workers are assigned by the ADvantage program to provide in-home care services. Some PCAs visit daily and as infrequently as once per week depending on individual needs of each care-recipient.

Participants

Participants in this study were selected from the population of the ADvantage members. The ADvantage Administration Unit (AAU) provided the contact information for the entire population of ADvantage members. Approximately 350 of the 19,000 enrolled members (i.e., potential evaluation participants) from across Oklahoma's 77 counties were selected via random sampling.

The broader purpose of this project was to evaluate the Oklahoma's ADvantage program in 2013. For the purposes of this thesis study, those data were used to investigate how home care-recipients' vulnerability affected the relationship between the care-recipient and the home care providers (i.e., PCAs and case managers) and the care-recipients' perception of quality home care.

General Procedures

After receiving IRB approval, researchers used the contact information (addresses and phone numbers) of all ADvantage members to determine the sample participants. A sample target was generated based on the enrollment percentages for each county (i.e., x% of 350). Subsequently, a participant list was calculated that was five times that of the sample target number for each county. This participant list was randomly selected (i.e., every 5th person was selected until the quota was met) to receive pre-notice letters (see Appendix A). Pre-notice letters notified each recipient of the evaluation and the possibility of receiving a phone call from the evaluation team. Those who were contacted via phone calls were read a calling script (see Appendix B) by an evaluation team member. This calling script reviewed consent procedures, confidentiality and the rights of the person being contacted. If the individual consented, then the phone survey was given. Phone calls were expected to last approximately 30 minutes. From the participant list, every 5th person was called no more than 7 times; if no one answered then the evaluators moved onto the next person. However, if the quota was not met by the end of the list, then evaluators started back at the top of the list. There were no remunerations for participation.

Inclusion Criteria. Potential participants included ADvantage members who were willing to participate and had Mental Status Questionnaire, MSQ administered by the DHS intake nurse (Katzman et al., 1983) scores of 6 or less, indicating that they could answer at least 4 of 10 MSQ questions correctly. Program members who wished to participate but were unable to communicate on their own due to hearing and speech impairments were allowed to have a proxy (e.g. a spouse, adult child) complete the survey on their behalf. Any third party that completed the survey had to be identified on the actual survey so that coders would know the identity of each respondent.

Survey Instrument

During a series of three meetings between the project director, Dr. Whitney Bailey, and the ADvantage Administration Unit, the phone survey (see Appendix C) was created. This was

done to ensure that it was both extensive and inclusive of all the key elements for a thorough evaluation of Oklahoma's ADvantage program. Staff and researchers agreed upon the final list of questions. The survey focused on care-recipients' evaluation of the program, their case managers, personal care assistants, difficulties experienced and their program recommendations. For the purpose of this study, researchers focused on questions about relationship with personal care assistants and case managers, satisfaction with home care and personal care assistant's job performance and care-recipients' needs.

The evaluation team members (7 graduate research assistants, including the author) were trained on how to conduct phone interviews, use the same explanation of items on the survey and to code responses accurately. This was done to ensure consistency in the administration of the survey. The phone survey data were merged with data received from the AAU, which included ADLs, IADLs and MSQ scores. If respondents did not complete one or more questions in a subscale, then they were eliminated from analysis of that subscale.

During the phone interviews, evaluation team members generally received positive reports from respondents about their experiences with the ADvantage program and their home care workers. Many respondents were happy to describe specifically what they appreciated about the program, how the ADvantage program helped them stay out of nursing facilities and discussed their relationships with their home care workers.

Measures

In this study, I examined differences between subgroups of this Medicaid ADvantage population (i.e., gender, geographical location) on their ratings of relationship quality with personal care assistant and case managers and also on their rating of home care quality. I also examined the role of multiple vulnerability factors (i.e., gender, age, race, ADLs and IADLs) in predicting home care quality and PCA relationship quality. See Table 1 for a brief description of variables used.

Vulnerability

Vulnerability in this study is defined as an individual's increased risk of harm as it relates to reliance on others. Research shows that individuals are at increased risk of exploitation in the presence of multiple factors like disabilities, advancing age and poor social support systems; thus, they become more vulnerable in society. I considered responses on the survey that indicated any of the vulnerability factors discussed below:

ADLs. Each participant's ADL scores were calculated based on 10 questions (e.g., how much assistance do you need bathing?) Each question was rated on a 3 or 4 point scale (e.g., none, some, can't do at all). Total ADL scores were calculated by summing up the individual scores on the 10 questions. Total scores ranged from 0 to31 and with the higher scores indicating greater reliance on others for basic care.

IADLs. Each participant's IADL scores were calculated based on 10 questions (e.g., how much assistance do you need preparing meals?). Each question was rated on a 3 point scale (e.g., none, some, can't do at all). Total IADL scores were calculated by summing up the individual scores on the 10 questions. Total scores ranged from 0 to 30 and with the higher scores indicating greater reliance on others for instrumental tasks.

Rural vs. mixed vs. urban county classifications. Oklahoma State University Center for Rural Health provided information about the Oklahoma county classifications (rural, mixed or urban). See Appendix D for Oklahoman map

Age. The ages of participants were determined from date of birth data provided with the contact information of all ADvantage program members in the population from which the random sample was drawn.

Gender. The gender of participants was determined from the member information provided by the ADvantage program.

Race. The race of participants was determined from the member information provided by the ADvantage program. Participants fell into one of four categories (i.e., Caucasian, African American, Native American, Asian).

PCA Relationship Quality (PCARelQ)

Relationship quality was a measure of the care-recipients' relationship with their home care workers (i.e., PCAs). Responses on three survey questions addressed the nature of the care recipient-worker relationships (e.g., "do you feel the PCA listens when you express your concerns?"). See Table 1 and Appendix C for a more specific list of questions and responses. Relationship quality scores were based on the sum responses of three questions (see Table 1). Total scores ranged from 2 to 6. Higher scores indicated more positive relationship quality. All PCAs were females in this study. To evaluate inter-item reliability Cronbach's Alpha was calculated at .59, which means that this measure has poor internal consistency.

Case Manager Relationship Quality (CMRelQ)

Relationship quality was a measure of the care-recipients' relationship with their home care workers (i.e., case managers). Responses on six survey questions addressed the nature of these relationships (e.g., "does your case manager treat you with respect?"). See Table 1 and Appendix C for a more specific list of questions and responses. Relationship quality scores were based on the sum responses the six questions (see Table 1). Total scores ranged from 5 to 13. Higher scores indicated more positive relationship quality. To evaluate inter-item reliability, Cronbach's Alpha was calculated at .65, which means that this measure has acceptable internal consistency.

Home Care Quality (hcQUAL)

Home care quality is a measure of the care-recipients' perception of the quality of service provided by the PCAs. Responses on the survey that spoke about task performance and work ethic of the home care workers (e.g., "does your PCA routinely complete all tasks listed in your service plan?"). See Table 1 and Appendix C for a more specific list of questions and responses.

The measure hcQUAL focused on PCAs exclusively because PCAs are the frontline workers engaged in regular care (see Figure 1). The home care quality scores were based on the sum responses of five questions (see Table 1). Total scores ranged from 5 to 13. Higher scores indicated more positive home care quality. To evaluate inter-item reliability, Cronbach's Alpha was calculated at .76, which means that this measure has good internal consistency.

Hypotheses and Plan of Analyses

Hypothesis 1(a)

Females will have more positive relationship quality scores than males with personal care assistants. This was assessed using a *t*-test.

Hypothesis 1 (b)

Females will have more positive relationship quality scores than males with case managers regardless of the gender. This was assessed using a *t*-test.

Hypothesis 2

Females will have more positive home care quality scores than males with personal care assistants. This was assessed using a *t*-test.

Hypothesis 3(a)

Rural and mixed counties will have higher PCA relationship quality scores than urban counties. This was assessed using an ANOVA.

Hypothesis 3(b)

Rural and mixed counties will have higher case manager relationship quality scores than urban counties. This was assessed using an ANOVA.

Hypothesis 4

Rural and mixed counties will have higher home care quality scores than urban counties. This was assessed using an ANOVA.

Hypothesis 5

A combination of five vulnerability factors (ADLs, IADLs, race, age and gender) will predict home care quality scores and relationship quality between care-recipient and PCAs (see Figures 2 and 3). A linear multiple regression was used to determine predictive power of the model.

Table 1

Description of Variables in Proposed Study

Construct	Variables	Description
Relationship Quality		

PCA	<u>Relationship quality – PCA</u>
	• Do you feel the PCA listens when you express concerns
	  ○ Yes (2)
	  ○ No (1)
	• Do you feel safe when the PCA is in your home?
	  ○ Yes (3)
	  ○ Somewhat (2)
	  ○ No (1)
	• Who would you call during the night or early morning hours if you needed assistance?
	  ○ Family/friend (0)
	  ○ Neighbor (0)
	  ○ PCA (1)
	  ○ CM (0)
		N= 296
		Subscale scores were only calculated for respondents who completed all questions.
		
		The sum scores range from 2 and 6. A score of 2 represents low relationship quality and a score of 6 represents high relationship quality.

CM	<u>Relationship quality- CM</u>
	• Does your case manager involve your family in your care to the extent you want them to?
	  ○ Yes (2)
	  ○ No (1)
	• Do you believe that your Advantage case manager sincerely cares about helping you?
	  ○ Yes (2)
	  ○ No (1)
	• Does your case manager treat you with respect?
	  ○ Yes (3)
	  ○ Somewhat (2)
	  ○ No (1)
	• Does your case manager handle your needs with dignity?
	  ○ Yes (3)
	  ○ Somewhat (2)
	  ○ No (1)
	• Do you feel like they (case managers) listen to you?
	  ○ Yes (2)
	  ○ No (1)
	• Who would you call during the night or early
		N=331
		Subscale scores were only calculated for respondents who completed all questions.
		
		The sum scores range from 5 and 13. A score of 5 represents low relationship quality and a score of 13 represents high relationship quality.

	morning hours if you needed assistance? ○ Family/friend (0) ○ Neighbor (0) ○ PCA (0) ○ CM (1)	
Home Care Quality	<u>Quality of services rendered</u> • Does your PCA arrive when you are expecting her/him? ○ Yes (2) ○ No (1) • Does your PCA call if he/she will not be there? ○ Yes (2) ○ No (1) • Does your PCA routinely complete all tasks listed in your service plan? ○ Yes (2) ○ No (1) • Are you receiving the amount of PCA hours that you have been approved to receive? ○ Yes (2) ○ No (1) • One a scale of 1-3, 3 being excellent/best, where would you rate: a. Your aide or PCA (consider how s/he shows up on time, does her job, comes to work every day)	N=259 Subscale scores were only calculated for respondents who completed all questions. The sum scores range from 5 and 13. A score of 5 represents low home care quality and a score of 13 represents high home care quality.
Vulnerability	**Vulnerability factors**	
	<u>Total ADL score (totadl)</u> Would you say that you need assistance with 0=no assistance, 2=some assistance, 3= can't do it at all • Dressing • Grooming • Bathing • Eating • Transferring • Mobility • Stairs • Toileting • Bladder/bowel control ○ How do often do you have accidents? ▪ 0=never 2=occasionally 3=often 4=always	Total ADL score = sum of the 10 question responses with lower scores indicating independence and higher scores dependence. The ADL range is 0-31. Total IADL score = sum of the 10 question responses with lower scores indicating independence and higher scores dependence. The

	Total IADL score (totiadl) Would you say that you need assistance with 0=no assistance, 2=some assistance, 3= can't do it at all ▪ Answering the phone ▪ Making a telephone call ▪ Shopping errands ▪ Transportation ability ▪ Preparing meals ▪ Laundry ▪ Light housekeeping ▪ Heavy chores ▪ Taking medication ▪ Managing money	IADL range is 0-30
Counties **Urban** **Mixed** **Rural**	Geographical Location (Rural vs. Mixed vs. Urban) Four Oklahoman counties: ▪ Cleveland ▪ Comanche ▪ Oklahoma ▪ Tulsa Five Oklahoman counties ▪ Canadian ▪ Creek ▪ Logan ▪ McClain ▪ Wagoner 68 Oklahoman counties	Oklahoma State University Center for Rural Health provided information about the Oklahoma county classifications (rural, mixed or urban). See Appendix D for Oklahoman map

CHAPTER IV

FINDINGS

Data collection of all 350 completed member surveys occurred between February and July 2013. Attrition in this study was most commonly due to care-recipients' death, admittance to a nursing facility, or no longer being in the program. Those who were reached had a 33.7% response rate. The sample population was made up predominantly of females, Caucasians, rural residents and those who lived on their own (see Table 2 for summary of demographics).

Three types of analyses were used to investigate the experiences of care-recipients in the ADvantage program. First, the *t*-tests of gender with the personal care assistant relationship quality; case manager relationship quality and home care quality are summarized in Table 3. Second, a one-way ANOVA was used to compare PCA relationship quality by geographical location (i.e., urban, mixed and rural counties); case manager relationship quality and PCA home care quality are summarized in Tables 4, 5 and 6, respectively. Third, a linear multiple regression was used to determine the predictive power of vulnerability (i.e., a combination of gender, age, race, ADL and IADLs) on PCA relationship quality and home care quality. This chapter will summarize the results of analyses.

Table 2:
Demographic Characteristics

	N	Valid Percent	Population %
Gender			
Female	243	82.1	71.3
Male	53	17.9	28.7
Race			
African American	33	10.0	14.0
Asian	4	1.2	2.3
Caucasian	272	82.7	75.7
Native American	20	6.1	5.6
Do you live alone?			
Yes	191	55.7	51.2
No	152	44.3	48.8
Geographical Location			
Urban	111	31.7	-
Mixed	22	6.3	-
Rural	217	62.0	-
Age			
Range	28-97	-	21-109
Mean	66.9	-	67.61
Standard Deviation	12.56	-	14.44

Hypothesis 1(a)

An independent-samples *t*-test was conducted to compare personal care assistant relationship quality between females and males. There was not a significant difference in scores for females ($M = 4.97$, $SD = .43$) and males ($M = 4.91$, $SD = .69$) conditions; $t(61) = .62$, $p = .535$. These results suggest that females do not have higher PCA relationship quality scores than males.

Hypothesis 1(b)

An independent-samples *t*-test was conducted to compare case manager relationship quality between females and males. There was not a significant difference in scores for females ($M = 11.37$, $SD = 1.91$) and males ($M = 11.11$, $SD = 2.59$) conditions; $t(329) = .93$, $p = .124$. These results suggest that females do not have higher CM relationship quality scores than males.

Hypothesis 2

An independent-samples *t*-test was conducted to compare personal care assistant home care quality between females and males. There was not a significant difference in scores for females (M = 11.58, SD = 1.22) and males (M = 11.57, SD = 1.23); $t(257) = .04$, $p = .966$. These results suggest that females do not have higher PCA home care quality scores than males.

Table 3

Results of t-tests and Descriptive Statistics PCA Relationship Quality (hypothesis1a), CM Relationship Quality (hypothesis 1b) and Home Care Quality (hypothesis 2)

Outcome	Group							
	Male			Female				
	M	*SD*	*N*	*M*	*SD*	*n*	*t*	*df*
PCARelQ	4.91	0.69	53	4.97	0.43	243	0.62	61.385
CMRelQ	11.11	2.59	65	11.37	1.91	266	0.93	329
hcQUAL	11.58	1.22	215	11.57	1.23	44	.04	257

*p< .05, **p < .01, ***p< .001

Hypothesis 3(a)

A one-way between groups ANOVA was conducted to compare difference by geographical location on PCA relationship quality in urban, mixed and rural counties. There was not a significant differences by geographical location on PCA relationship quality at the $p < .05$ level for the three conditions [F (2, 310) = .17, $p = .845$]. These results suggest that rural and mixed counties do not have higher PCA relationship quality scores than urban counties.

Table 4

One-Way Analysis of Variance of PCA Relationship Quality by Geographical Location (hypothesis 3a)

Source	*df*	*SS*	*MS*	*F*	*p*
Between groups	2	.08	.04	.17	.85
Within groups	310	70.38	.23		
Total	312	70.46			

Hypothesis 3 (b)

A one-way between groups ANOVA was conducted to compare differences by geographical location on case manager relationship quality in urban, mixed and rural counties. There was no evidence of significant differences by geographical location on case manager relationship quality at the $p < .05$ level for the three conditions [F (2, 347) = 1.33, p = .265]. These results suggest that rural and mixed counties do not have higher CM relationship quality scores than urban counties

Table 5

One-Way Analysis of Variance of Case Manager Relationship Quality by Geographical Location (hypothesis 3b)

Source	*df*	*SS*	*MS*	*F*	*p*
Between groups	2	10.73	5.37	1.33	.27
Within groups	347	1397.33	.23		
Total	349	1408.06			

Hypothesis 4

A one-way between groups ANOVA was conducted to compare differences by geographical location on PCA home care quality in urban, mixed and rural conditions. There was no evidence of significant differences by geographical location on home care quality at the $p < .05$ level for the three conditions [F (2, 271) = 1.01, p = .364]. These results suggest that rural and mixed counties do not have higher PCA home care quality scores than urban counties

Table 6

One-Way Analysis of Variance of PCA Home Care Quality by Geographical Location (hypothesis 4)

Source	*df*	*SS*	*MS*	*F*	*p*
Between groups	2	2.88	1.44	1.01	.36
Within groups	271	385.34	1.42		
Total	273	388.22			

Hypothesis 5

Multiple regression analyses were conducted to determine if five vulnerability factors significantly predicted PCA relationship quality. The results of the regression indicated that none

of the five vulnerability factors significantly predicted relationship quality with personal care assistants (R^2 = .01, F(5,288) = 1.14, p > .05).

Multiple regression analysis was used to test if vulnerability factors significantly predicted home care relationship quality. The results of the regression indicated that one factor (age) significantly predicted home care quality (β = .18, p < .01).

CHAPTER V

CONCLUSION

Results did not fully support the research hypotheses used in this study. It was confirmed that a combination of vulnerability factors (i.e., gender, age, race, ADL, IADL) that contribute to vulnerability do predict home care quality. Although significance was not found in each hypothesis, lack of significances proves to be important findings for this program. In this chapter, the findings of this study will be described with clinical implications for the field of home health and marriage and family therapy.

Hypotheses 1(a) and 1(b). It was hypothesized that females would have higher relationship quality scores for PCAs and CMs than males. It was found that gender differences did not exist on relationship quality between care-recipients and their personal care assistants and case managers. These findings suggest that relationship quality may be consistent across genders for members of the ADvantage program in the state of Oklahoma.

These hypotheses were intended to explore the validity of feminist family theorist claims that women are more vulnerable (less privileged) than men and as such are at greater risk for exploitation by those with greater power like home care workers (Ingoldsby et al., 2004). Some studies did show that women's extended life expectancy increased their risk for exploitation when faced with illness/disabilities, poverty and poor access to quality health insurance coverage as

compared to men (Angel, Karas Montez & Angel, 2011; CAP, 2008; Pinquart & Sörensen, 2001; UNWCD, 2012). However, this study's findings did not confirm or disprove this theory's perspective. An alternative explanation for these results could be that female care-recipient scores were somewhat higher as a result of there being only female PCAs, therefore offsetting any potential gender differences. This would support Piercy's (2000) findings which reported that same sex care-recipients and PCAs had higher relationship satisfaction and home care quality reports. Therefore, future studies will need to specifically examine any gender differences in this population's relationship quality with home care workers by looking at the gender of the workers and differences in vulnerability factors experienced by care-recipients who have positive relationships with their worker in order to determine if gender really does play a role in the quality of relationships formed.

Hypothesis 2. It was hypothesized that females would have higher PCA home care quality scores than males. It was found that gender did not have a significant impact on the personal care assistant home care quality. These findings reveal that, in Oklahoma, males and females did not report significantly different experiences with home care quality from their PCAs.

Although Piercy (2000) found that matching the gender of care-recipient and PCA, especially male to male, promoted more satisfaction with home care, it is unclear if this relational dynamic had a significant impact on my findings. Future studies should explore how matching genders between care-recipients and PCAs could impact satisfaction with home care quality.

Hypotheses 3(a) and 3(b). It was hypothesized that there would differences in geographical location (i.e., rural, mixed or urban county classifications) in terms of relationship quality with the PCAs and CMs. The main premise of this hypothesis was that rural and mixed counties would have fewer care agencies and options for ADvantage members. This issue of fewer agencies relates to home health but also to nursing facilities. So it was believed that some ADvantage members in rural areas might stay on the ADvantage program longer due to a lack of nursing facility options. Hence, the hypothesis that relationship quality and home care quality

would be rated lower by care-recipients in rural and mixed areas as opposed to urban ones. Further, the issue of social isolation of medically frail ADvantage members was expected to be more significant in rural areas.

Hypothesis 4. It was hypothesized that care recipients living in rural or mixed counties would report better PCA home care quality than those living in urban counties. It was found that there were no significant differences in PCA home care quality across geographical locations. These findings imply that across the state of Oklahoma care-recipients report consistent home care quality regardless of the county classification.

These findings do not support previous research (Cloutier-Fisher & Kobayashi, 2009; Johnson, 2006; Pinsker, McFarland & Pachana, 2010; Tomaka, Thompson & Palacios, 2006) that found rural older adults had limited access to quality social and medical resources, as these adults were able to experience home care quality that was no different than those in the urban or mixed counties. Future studies should consider the care-recipient's age when assessing differences in home care quality based on geographical locations.

Finally, researchers found that care-recipients determined good quality care based not only on job performance but the nature of the relationships formed with home care workers (Eustis & Fischer, 1991; Piercy & Woolley, 1999; Woodruff & Applebaum, 1996). This study could be inferred as true since both relationship quality and home care quality show uniformity across Oklahoma in my findings.

Hypothesis 5. It was hypothesized that the combination of five vulnerability factors (i.e., ADLs, IADLs, race, gender and age) would predict home care quality and the PCA relationship quality. It was found that the regression of vulnerability factors did predict the home care quality but not the PCA relationship quality. More specifically, age was the vulnerability factor that predicted home care quality accounting for 17.5% of the variance. These results indicate that combined vulnerability factors of care-recipients did not significantly predict the nature of the relationship with the PCA.

The difference in predictability in relationship quality and home care quality could be due to the fact that the five items used to measure home care quality measured more objective behaviors (e.g., does the PCAs show up on time, does your PCA call if s/he will not be there?). It is possible that the more vulnerable individuals are more dependent on their PCAs to perform tasks well. For example, care-recipients who need their PCAs to feed them or give them required medicine would be more aware of lateness or unexplained absences as their lives depended on it. The results did show that age was the most significant predictor of home care quality. This makes sense as the older a person becomes the more vulnerability factors they are likely to experience.

These findings do not fully confirm previous research that found the more vulnerable or reliant an individual, the more likely they were to have a close relationship with their PCA and in turn show satisfaction with their home care services (Eustis & Fischer, 1991; Piercy, 2000; Piercy, 2001; Piercy & Dunkley, 2004; Piercy & Woolley, 1999; Woodruff & Applebaum, 1996). Similar research also found that satisfaction with home care services was based on the PCA's relational skills and their job performance (Piercy, 2000).

Limitations

One limitation in this study is that all of the participants are heavily reliant on the ADvantage program because without it they would have to enter nursing homes. As a result, they may be inclined to minimize or hold back their dissatisfaction with services for fear of losing them altogether. Piercy (2000) also drew similar conclusions of minimization of dissatisfaction among populations of older adults. Procedures in this study were crafted to minimize such concerns, for example, an external entity (Oklahoma State University) to the ADvantage program was used, pre-notice letters were sent, the project director fielded calls from concerned ADvantage members and family, and ADvantage providers (PCAs and case managers) were not allowed to serve as proxies for care-recipients.

A second limitation in this study was the lack of consistent coding schemes for subscale questions. It is recognized that two-item and three-item questions create a weighting issue within

the subscales. Thus, future researchers should use the same coding scheme for all subscale questions to avoid any weighting problems that could potentially affect their data..

Another limitation is that the study sampled a highly vulnerable population (i.e., ADvantage members are at or below the poverty line, are frail or older adults and/or have disabilities). As a result, very little variance may exist between the participants on the level of vulnerability. For example, the fact that this sample is nursing home eligible and Medicaid eligible places them at a higher level of vulnerability overall. Consequently, future studies will need to look more closely at differences in vulnerability within this population by exploring specific subgroups (such as females, those with disabilities, age categories) in order to pinpoint real differences overall.

Finally, the original study sought to evaluate the ADvantage program rather than examine the specific research questions and hypotheses of the current study; I would recommend that future studies conduct more in-depth qualitative investigations of this population using objective measures of social support, vulnerability, relationship quality and home care quality. The respondent's descriptions of their experiences with the ADvantage program and their home care workers were not fully represented by closed ended questions and multiple choice answers. A more qualitative approach to this research would provide better context for researchers; clinicians and home health providers to understand the recipients' experiences and lead to better focused quantitative studies about relationship and home care quality. Future data collection could include in-home and face-to-face interviews as well as phone interviews.

Clinical Implications

The increasing life expectancy of older adults means that there will be a growing presence of this population seeking therapeutic services unlike prior generations of older adults (Lambert-Schute & Fruhauf, 2011). Hence, it is important for Marriage and Family Therapy programs to ensure that their curricula prepare their students to competently work with the needs of this population by increasing their knowledge of aging issues, reducing aging biases or

stereotypes and equipping them to work in diverse settings (e.g., assisted living facilities, nursing homes, hospitals) (Yorgason, Miller & White, 2009).

Like therapists, home care providers should at least have basic training in systemic thinking in order to shift their conceptualization of care-recipients from an individual perspective to one that is all encompassing of their environment, social support, medical needs and level of autonomy. Without this understanding, home care providers could miss that several vulnerability factors could have led to a particular outcome instead of focusing solely on one area. In fact, I believe that making Marriage and family therapists a part of the ADvantage program could be beneficial as they are already trained to consider clients experiences from a systems perspective and could be additional advocates for care-recipients.

A requirement of the ADvantage program is that members have someone to help with decision making and support like a family member or friend. Research shows that older adults who have a strong support system have greater psychological well-being, self-esteem, sense of belonging and health (Adams & Blieszner, 1994; Cornwell, Laumann & Schumm, 2008; Tomaka, Thompson & Palacios, 2006; Voorpostel, 2013). Keeping this in mind, family therapists can assess for the quality of this population's support system as they decide upon treatment. If there is little or no support system, then these individuals are even more vulnerable to exploitation by others.

Finally, although my findings show uniformity in home care quality and relationship quality across genders and geographical locations, it is vital for therapists not to assume that their clients are receiving the best possible care. Seeing these older adults as having unique experiences and coping strategies will encourage family therapists to do a thorough assessment with these clients for things like their support systems, experiences with their home care workers, mental health history, access to needed resources and more. The more informed a family therapist, the better the services provided to this population.

Future Research

The findings in this study for home care quality and relationships with care providers align with previous research on a similar sample. Researchers (Brosi, 2007) found that ADvantage members were overwhelmingly satisfied with their home care, providers, and reported overall positive experiences. These positive reports call for further research to better understand what is influencing these outcomes. Therefore, future research should investigate whether the quality of the care-recipients' support systems or their relationships with home care providers is equally or uniquely important to how the recipient's overall satisfaction with services. Based on my phone interviews with these respondents, there were several references to the home care providers being part of the family and these providers having positive relationships with the care-recipients' family members as well. I would recommend that researchers qualitatively explore these different relationships to understand from the care-recipient's perspectives how these relationships influence their overall experiences with their home care services.

Additionally, I believe that it would be beneficial to explore how the relationship dynamics change when the care-recipients get to decide whom their PCAs and CMs are rather than the program deciding for them. Would this shift in power for the care-recipients embolden them to express when they were dissatisfied with services and even change the nature of their relationships with their home care providers.

Finally, future studies should investigate the impact of making mental health services a requirement for care-recipients like home health and case management services are. Several of the respondents were so happy to have someone ask them about their experiences that they tried to delve into personal issues that were not relevant to the survey. If many of these respondents had access to mental health services rather than them having to seek them out on their own, then they could receive the support necessary to process their experiences.

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APPENDICES

APPENDIX A

DATE

Dear ADvantage Member,

The Advantage Administration Unit of DHS wants to know if you are satisfied with the ADvantage services that you receive. The best way to answer this question is to ask you and others who receive these services. The answers that you provide will be used to improve programs, increase availability of services, and find better ways to help Oklahoma's families. Your name along with the names of many others was randomly selected from a list of all those who receive ADvantage services. We are writing you today to invite you to participate in an interview that will let us know what you think about the services you receive.

Oklahoma State University has been asked by the ADvantage Administration Unit (AAU) of DHS to make the telephone calls and conduct the interviews. Should you agree to participate, all of your answers will be **kept private**. In fact, your name will NEVER be written on the same page as your answers in order to protect your privacy. **Furthermore, NO ONE who has provided or will provide services to you or your family will know how you answer the questions. Any services that you or your family receives will NOT be affected.**

- Sometime between _____ and _____, you may be called, and asked if you would like to participate in the phone survey.

During these dates we will be calling Monday through Saturday between 9:00 am – 6:00 pm.

If you have any questions about these calls or the project in general, you may call me directly:

Dr. Whitney Bailey (Project Supervisor, OSU-Stillwater): 405-744-3350

If you have any questions about your rights as a potential participant in this project, you are encouraged to contact the research compliance office at 405-744-3377.

Thank you in advance for your consideration!

Sincerely,

Whitney A. Bailey, Project Supervisor
Human Development and Family Science
Oklahoma State University

APPENDIX B

Hello, my name is _____ from Oklahoma State University. May I please speak with _____? The Advantage Administration Unit of DHS has asked us to conduct a survey of ADvantage Members. You should have received a letter alerting you to my call. The purpose of the survey is to gather feedback regarding how satisfied you are with the services you receive.

If you decide to participate in this 15-20 minute survey, any information you give will be kept private and confidential. Names will not be connected to answers, and no one who provides services will know that you participated or what answers were given. Participation is optional, and, even if you decide to participate, you may refuse to answer any question at any time without penalty.

Are you willing to participate in the survey at this time? If yes, proceed.

(IF NO) Would you be willing to participate in the survey at another time that is more convenient for you?

(IF YES but not now, set callback time during specified interviewing hours).

(IF NO) Thank you very much for your time.

APPENDIX C

Background

1. How long have you been a Member of the ADvantage program?
2. What kinds of services do you receive through the ADvantage program?
3. When you joined the ADvantage program, a service plan was created for you. Were you provided with a copy of your Service Plan/goals? Yes/No
    a. Each year your service plan is reviewed and revised. Do you have a copy of your most current service plan
    b. How recently have you reviewed your service plan?
4. Do you know how to report any changes in your financial situation (including property transfers) to your OKDHS county social worker? Yes/No
5. Do you have or are you eligible for Indian Health Services? Yes/No/DK [Don't Know]
6. Do you have or are you eligible for Veterans Administration Services? Yes/No/DK [Don't Know]
7. Do you have or are you eligible for Medicare Services? Yes/No/Don't Know
8. Do you live alone? Yes/No
9. How often do you communicate with friends? Daily, 2-6 times a week, Once a week, 1-3 times per month, Less than once a month, Never
10. What type of housing do you have?
    i. Own home
    ii. Rental
    iii. Assistive Living
    iv. Other_____

11. Who would you call during the night or early morning hours if you needed assistance?

Family/Friend

Neighbor

Personal Care Assistant

Case Manager

Other [Who]_____

You are receiving services provided through the ADvantage Waiver Program because you met eligibility requirements. This Waiver is intended to serve Oklahomans who are Nursing Home/Nursing Facility level of care but wish to remain in their own homes. The services provided by the ADvantage Waiver are intended to help you remain safe in your home and have your current needs met there.

a. Without the ADvantage program would you enter a Nursing Home/Nursing Facility? Yes/Probably/No
b. At least once a year a Certified Case Manager or DHS Nurse should complete a reassessment to see if you continue to meet the medical requirements to remain on the ADvantage Waiver Program? Does this occur? Yes/No
c. [True or False] Have you been advised that you can request another provider agency if you are unhappy with the service you are receiving? True/False
d. [True or False] Have you been advised you have the right to request a Fair Hearing if you do not agree with changes made in your Plan of Care? True/False.
    i. Who would you contact if you wished to request a Fair Hearing?

Member Needs

12. Tell me about your current needs (prompt with examples such as personal care, assistance with medication, meals, etc.).

13. We understand that no one program can meet all needs. Are there needs that you have that are not covered by your ADvantage care plan?
    a. Prompt for nutritional needs, safety needs, other needs
1. In your opinion, what other programs might serve your needs that are not met under your current ADvantage care plan?
    a. Prompt for Medicare, Veteran benefits, Indian health services (if eligible)
2. What was your greatest need(s) when you applied for ADvantage?
3. When you think about staying in your home, what specific services helps you remain in your home safely?

Your information has been so helpful already. Thank you!

The next questions are about the specific ADvantage staff members that serve you. First, we will ask about your Case Manager. Then we will ask about your Personal Care Assistant. Finally, we will ask questions about your ADvantage Nurse. We understand these roles can be a bit confusing so we will be sure to help clarify as we visit.

First, can you provide us the names of any of the agency's that serve you? Keep in mind there will likely be more than one.

_____

_____

_____

<u>The Case Manager</u>

1. When it came to selecting services, were you given a choice of available provider agencies? Yes/No
2. Do you know how to contact the agencies? Yes/No
3. Who is your case manager [Knows name]? Yes/No;
4. Does your case manager return your calls within 24 hours? Yes/Sometimes/No
5. Are you able to reach your case manager if needed? Yes/No
6. Does your case manager provide information to you in a way that you understand? For example do they explain your service plan, what to expect and when to expect it (processes), who is responsible for what, etc. Yes/No

7. Has your case manager given you information on/or assistance obtaining other community resources that may be of some assistance to you? Yes/No
8. Has your case manager talked to you about your safety; issues such as abuse, neglect, and exploitation? Yes/No
9. Have you discussed your unmet needs with your case manager? Yes/No Do you feel like they listen to you? Yes/No
10. Does your case manager involve your family in your care to the extent that you want them to? Yes/No
11. Do you believe that your ADvantage Case Manager sincerely cares about helping you? Yes/No
12. In the past 3 months, how often has your ADvantage case manager called to talk with you?
13. In the past 3 months, how often has your ADvantage case manager visited you? Were the visits at your home?
14. Are there any needs you have that are not being addressed by your case manager? Yes/No; If yes, what?
15. Have you consistently had the same case manager? If no, please explain.
16. [DELETE, or if you keep reword something like: "Are you comfortable sharing confidential information with your case manager?"]
17. Does your case manager treat you with respect? Yes/somewhat/no
18. Does your case manager handle your needs with dignity? Yes/somewhat/no

<u>The Personal Care Assistant</u>

1. Does your PCA Agency return your calls within 24 hours? Yes/Sometimes/No
2. Are you able to reach your PCA Agency if needed? Yes/No
3. Does your PCA arrive when you are expecting her/him? Yes/No
4. Does your PCA call if he/she will not be there? Yes/No
    a. How often does this happen?
    b. Does your agency send another PCA if yours is unable to make a scheduled visit? Yes/No

5. [DELETE or if you keep reword something like: “Is the time the PCA takes providing assistance to you adequate?”]
6. Does your PCA routinely complete all tasks listed on your Service Plan? Yes/No
7. How many PCAs have you had within the last year?
8. Do you feel like your PCAs are trained appropriately for the services they provide to you? Yes/No
9. Are you receiving the amount of PCA hours that you have been approved to receive? Yes/No
10. Do you receive PCA visits on the weekends? Yes/No
    a. If no, do you need assistance on the weekends? Yes/No
11. Do you feel the PCA listens when you express concerns? Yes/No
12. Do you feel safe when the PCA is in your home? Yes/Somewhat/No
    a. Why or why not?
13. Is your ADvantage PCA related to you? Yes/No If yes, how are they related? Spouse/Child/Sibling/etc.
    a. If yes, have you ever had a PCA that was not related to you? Yes/No
14. The following questions are for Members who have hours allotted on their service plan for meal prep.
    a. Does your aide know how to cook meals? Yes/No
    b. Is your aide able to make something to eat that you enjoy? Yes/No
    c. Is your aide able to use both the microwave and stove? Yes/No

<u>ADvantage–Pros, Cons, General Questions about Program</u>

1. On a scale of 1 to 3 with 1 being poor, 2 being acceptable and 3 being excellent, how would you rate the following:
    a. Case Manager,
    b. PCA,
    c. Overall Services,
    d. Clarity of Options,
    e. Helpfulness of staff,
    f. Ability to get needed information.

2. On a scale of 1-3, 3 being the excellent/best, where would you rate:
    a. How your CM takes care of issues for you
    b. Your aide, consider how s/he shows up on time, does her job, comes to work every day
    c. Your overall experience with the ADvantage Program?
3. On a scale of 1-3, 3 being the excellent/best, where would you rate:
    a. Your ability to obtain needed equipment (briefs, shower chairs, etc)?
    b. How was your overall experience with the DME company, consider how they explained their product to you, set it up for you, etc).
    c. How well the ADvantage program was explained to you.
    d. How satisfied you are with your current agency?
4. Do you know whom to contact if you are not satisfied with your PCA or your CM? Yes/No
5. Do you know who to contact if you no longer need or want ADvantage services? Yes/No
6. Do you know the ADvantage Care Line 800 #? Yes/No
7. Do you know whom to call should an emergency arise as it relates to your services? Yes/No
8. Do you know who to contact if you are returning to your home from a skilled nursing/or hospital stay? Yes/No
9. Are you familiar with the 211 number for other community resources, outside of the scope of what ADvantage provides? Yes/No
10. Are you aware that the ADvantage Administration Unit oversees the ADvantage Program and that you can contact them for issues your agency cannot resolve for you? Yes/No
11. Have you ever had to contact the ADvantage Administration Unit? Yes/No If yes, on a scale of 1-3, 3 being the excellent/best, how would you rate:
    a. How well the person answered your question?
    b. How polite was the person who answered your questions?

    c. Did your issue get resolved to your satisfaction?

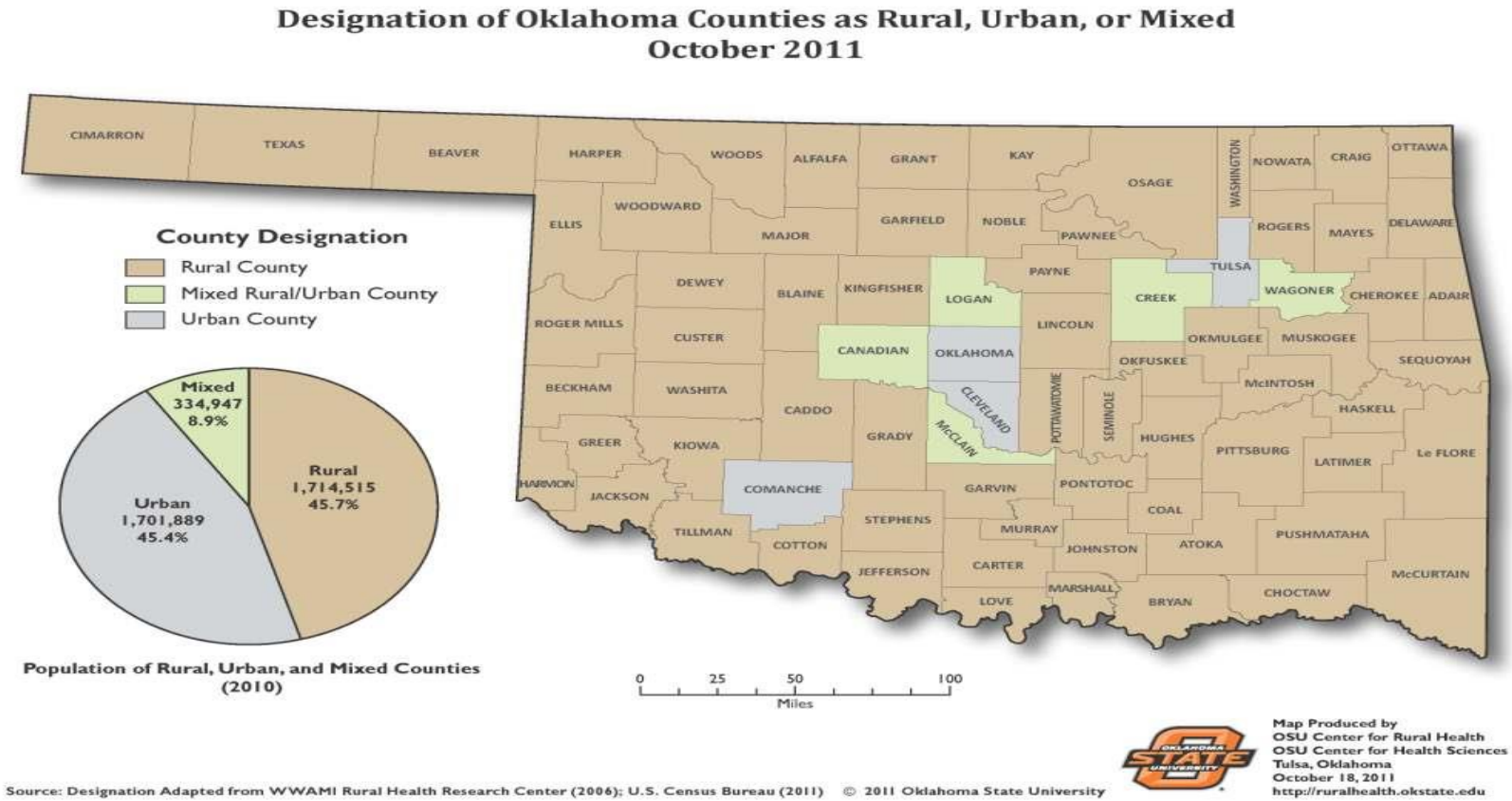
12. Is there anything the ADvantage Administration Unit could change to help you better? Yes/No; If yes, please describe.

We are nearing the end of our visit. I would like to ask your thoughts about a few more things that relate to the overall ADvantage program.

1. How does the program assist you at home?
2. What is the most beneficial part of being a member of the ADvantage program?
3. If you could change anything about the ADvantage program, what would it be?
4. What was the greatest challenge you have endured through the process from the time you first inquired about ADvantage services until which time services were first started?
5. Is there any service that you need done for you that the ADvantage Program does not cover? Yes/No If yes, what is that service?
6. Do you think there is a big enough selection of providers being offered to you in your area? Are there any that you would like to see added?

That is the last of my questions. You have been a wonderful resource! Let me remind you that your participation in this conversation will not be known to the ADvantage program or to any of your providers. Not only will they not know your individual answers, they will not know who participated. For this reason, this survey will not serve as a care plan change for your specific needs. If you have questions or concerns about your care, we encourage you to call the ADvantage Care Line at 1-800-435-4711. We will provide the ADvantage program with summary responses from more than 300 participants to help them reach their goal of understanding member experiences. We thank you, so very much, for helping us with this important work.

APPENDIX D


Designation of Oklahoma Counties as Rural, Urban, or Mixed
October 2011
County Designation
Rural County
Mixed Rural/Urban County
Urban County
Mixed
334,947
8.9%
Rural
1,714,515
45.7%
Urban
1,701,889
45.4%
Population of Rural, Urban, and Mixed Counties
(2010)
CIMARRON
TEXAS
BEAVER
HARPER
WOODS
ALFALFA
GRANT
KAY
OSAGE
WASHINGTON
NOWATA
CRAIG
OTTAWA
WOODWARD
ELLIS
MAJOR
GARFIELD
NOBLE
PAWNEE
ROGERS
MAYES
DELAWARE
DEWEY
BLAINE
KINGFISHER
LOGAN
PAYNE
CREEK
TULSA
WAGONER
CHEROKEE
ADAIR
ROGER MILLS
CUSTER
LINCOLN
OKMULGEE
MUSKOGEE
CANADIAN
OKLAHOMA
OKFUSKEE
SEQUOYAH
BECKHAM
WASHITA
CLEVELAND
POTTAWATOMIE
SEMINOLE
McINTOSH
CADDO
HASKELL
GREER
KIOWA
GRADY
McCLAIN
HUGHES
PITTSBURG
LATIMER
Le FLORE
HARMON
JACKSON
COMANCHE
GARVIN
PONTOTOC
COAL
TILLMAN
COTTON
STEPHENS
MURRAY
JOHNSTON
ATOKA
PUSHMATAHA
JEFFERSON
CARTER
MARSHALL
BRYAN
CHOCTAW
McCURTAIN
LOVE
0
25
50
100
Miles
Map Produced by
OSU Center for Rural Health
OSU Center for Health Sciences
Tulsa, Oklahoma
October 18, 2011
http://ruralhealth.okstate.edu
Source: Designation Adapted from WWAMI Rural Health Research Center (2006); U.S. Census Bureau (2011)
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VITA

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