

Feasibility of Telehealth Technology for Pain Assessment in Adult Family Homes

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Abstract

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America's current healthcare system is not equipped to meet the healthcare needs of our aging population due to diminishing resources and a lack of nurses and primary care providers. For older adults, untreated pain is a healthcare need that can significantly diminish functional independence and quality of life. Older adults prefer to age in place in home-like environments, and the adult family home (AFH) is one residential option that meets varying levels of care needs of many community dwelling older adults (Hedrick, Sullivan, Sales, & Gray, 2009). Telehealth that uses communications technology to bridge geographic distances from healthcare organizations to AFHs is one innovative way to deliver resources to caregivers in the care of AFH residents. However, there is limited research on AFH caregiving, technology use, learning needs of direct caregivers, and the best model of community-based nursing oversight of care practices. Composed of two studies, this dissertation assessed the different types of technology used in AFHs and the feasibility of using telehealth for pain assessment and caregiver learning needs regarding pain assessment.

Study one used a cross sectional descriptive survey design to assess AFH technology usage. Findings demonstrated diverse profiles of technology usage in AFHs. Study two used a mixed methods approach to assess the feasibility for AFH caregivers to use telehealth for pain

assessment of older adult residents. Results indicated that caregivers and older adult residents have positive perceptions toward telehealth. Both survey and qualitative results support the use of telehealth technology to deliver educational resources and nursing care oversight.

The results of this study help to inform the development of a community-driven curriculum for care of diverse community dwelling vulnerable older adults in settings such as adult family homes. This study also informs development of service learning strategies and care delivery programs that use telehealth in the AFH setting. Findings from this study contribute important evidence to understanding care giving in AFHs, their technology infrastructure, and the potential for telehealth interventions in the community setting to support aging in place.

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DEDICATION

To the One who made me His workmanship

Chapter 1: Overview of Dissertation

INTRODUCTION

America's healthcare system is not well equipped to care for our growing aging population where the number of adults over 65 years old is projected to be approximately 72 million by the year 2030 and expected to increase to 88 million by 2050, according to a 2010 report from the Federal Interagency Forum on Aging-Related Statistics (FIFOARS). Many residential living options are available to independent, community-dwelling older adults; however, fewer options are available to older adults who require assistance to remain in community. It is important to note that advancing age is a risk factor for chronic health conditions (Seshadri & Wolf, 2007), and pain is the characteristic symptom of many of these conditions (e.g., diabetes and arthritis). Although untreated pain can significantly diminish functional independence and quality of life for older adults (Horgas & Elliott, 2004), pain is often under treated in this population (McCarberg et al., 2008), due in part to inadequate or insufficient assessment (American Pain Society, 1999, 2000, 2010). Consequently, innovative approaches are desperately needed to improve access to pain assessment and thus extend pain management programs to at-risk community dwelling and frail homebound elders.

The adult family home (AFH) is one type of community residence that is meeting the long-term care (LTC) needs of some older adults (Hedrick et al., 2003; Hedrick, et al., 2009). Direct caregivers in AFHs not only help with activities of daily living and protective supervision, they may also engage residents in physical activities and mental exercises or games. If AFH direct caregivers are given appropriate training and resources for pain assessment, they may significantly improve pain management and the potential for older adults to remain active and age-in-place successfully.

With the shortage of healthcare providers in home health care (Karvounis, 2008), telehealth delegation via real time interactive audio and video, such as through use of videophones, provides a viable option for improving access for training and resources (Arriaga, et al., 2010; Kitamura, et al., 2010). However, the technology infrastructure and use of this type of telehealth platform for pain assessment has not yet been studied in the AFH setting for older adults with varying levels of functional dependence. Most studies to date have focused on patients in acute care settings.

This dissertation study aimed to assess technology use in AFHs and the need for education about pain assessment for AFH caregivers who care for frail older adult residents. The Aging-in-Place model informed the basis for this study. Central to the theoretical framework for this study were the concept of self-efficacy from Albert Bandura's Social Cognitive Theory, and the concept of pain assessment as being fundamental to pain management. This pilot feasibility work used mixed methods to explore: 1) use of technology in AFHs, 2) whether the videophone is usable by direct care providers and older adult residents of AFHs, 3) overall perception of using videophones for telehealth in the AFH setting, and 4) factors to consider when designing telehealth programs using this platform in this setting.

This dissertation study consisted of two studies. Study one used a cross-sectional descriptive design to survey AFH owners about their technology usage. Study two used a mixed methods approach to assess the feasibility of using telehealth technology to deliver pain assessment educational materials to AFH caregivers and receive information from the caregivers about residents' pain ratings. Firstly, a qualitative approach was used to capture the experiences of residents and caregivers with use of videophone technology in the AFH setting, and to ascertain pain assessment learning needs of AFH caregivers. Secondly, quantitative data were

used to assess usability of videophone technology for telehealth in this setting. Lastly, pilot survey data before and after pain assessment by videophone were analyzed to describe pain experiences of AFH residents.

The specific aims of this study were as follows:

Study One: AFH Technology Usage

Specific Aim: Describe the type of technology currently in use in AFHs and user characteristics in Washington State.

Study Two: Feasibility of Telehealth Technology for Caregiver Education

Specific Aim #1: Assess the usability of videophone technology to deliver pain assessment resources for AFH caregivers and older adult residents.

1.1 Evaluate the quality of connectivity, ease of use, and quantity of use.

1.2 Assess the amount of time needed to train caregivers to use a pain assessment tool over videophone.

Specific Aim #2: Describe AFH caregivers' and older adult residents' experiences with using the videophone to receive telehealth resources for pain assessment that supports aging-in-place.

2.1 Identify caregivers' and residents' perceived priority needs and concerns regarding using the videophone to receive telehealth resources for pain assessment

2.2 Describe learning needs of AFH caregivers regarding pain assessment.

Specific Aim #3: Evaluate pain assessment and AFH training outcomes to inform future studies.

3.1 Describe elderly AFH residents' reported pain levels, functional levels, and quality of life prior to and after pain assessment via videophone program.

Organization of the Dissertation Content

This dissertation presents the results of a two-phase mixed methods study to explore the feasibility of using telehealth technology to improve pain management of community dwelling older adults in adult family homes by improving access to training resources for AFH caregivers. The two phases of this dissertation are composed of two studies. Each study is presented as a separate chapter, as each had a distinctive design, methods, and results that fully informed the topic of this dissertation.

Chapter Two presents the introduction, methods, results and discussion of study one for this dissertation. Using a cross-sectional design, this study involved a survey of adult family home owners about technology usage in their AFHs. This study was approved by the University of Washington Institutional Review Board as exempt. Owners of all AFHs listed in the Washington State database as of June 2011 were sent a survey that inquired about the types of technology used to assess or provide care in their AFHs. In addition, the survey assessed the composition of caregivers and residents in the AHFs.

Chapter Three presents the introduction, methods, results and discussion of study two for this dissertation whereby caregivers and residents tested the videophone as a platform for using an established pain assessment tool to report resident pain levels. This mixed methods study was reviewed and approved by the University of Washington Institutional Review Board. Participants received instructions over the videophone from a nurse and reported pain assessment scores over this technology platform. Caregivers and residents completed demographic questions and provided their perception of using this technology for this study through semi-structured interviews.

Chapter Four discusses the implications of the results of each study; provides recommendations to stakeholders on the provision of resources for improving care of older adult AFH residents; and recommends future studies for telehealth usage in AFHs to achieve successful aging-in-place

Chapter Five concludes this dissertation with reflections on conducting research in the AFH setting.

BACKGROUND AND SIGNIFICANCE

Health Care Needs of the Aging Older Adult Population

The global population is aging. The United States Census Bureau estimates that one in five Americans will be over 65 years old by the year 2030 (FIFOARS, 2009). Therefore, changes in the U.S. healthcare system are imperative for meeting anticipated increased demand for services concurrent with the predicted rise in our aging population to 88 million adults over 65 years old by 2050 (FIFOARS, 2009; Norris, et al., 2008).

In a National Health Interview Survey, 26.8% of adults 65 years and older reported having fair or poor health during 2007 (National Center for Health Statistics, 2009). However, a survey by the AARP Public Policy Institute (2006) discovered that 89% of those aged 50 years or older hope to remain in their homes for as long as possible as they age. When they do require some functional assistance, older adults prefer to remain independent for as long as possible with a preference for staying in a loving home environment (Boisubin, Chu, & Catalano, 2007). With the first wave of baby-boomers turning 65 years old in 2011, effective models of residential care that promote the concept of aging-in-place are essential for meeting the spectrum of needs of our older adult population. Unfortunately, there are inadequate numbers of primary care providers, particularly those trained in gerontology (Karvounis, 2008). Since age is a risk factor for many chronic conditions (Seshadri & Wolf, 2007), innovative approaches are urgently needed to improve access to a variety of healthcare programs for at-risk community dwelling elders and frail homebound elders.

One technique for improving access to health care is to bridge the geographic distance from providers to patients through the use of technology. The American Telemedicine

Association (ATA) defined telemedicine as “the use of medical information exchanged from one site to another via electronic communications to improve patients' health status” (ATA, 2010). “Telehealth” encompasses additional health care services that may include continuing education or remote monitoring of vital signs. Telemedicine using videophones or real-time audio-video conferencing has been shown to be beneficial and cost-effective in many care settings (Demiris, Edison, & Vijaykumar, 2005; Elliott, Chapman, & Clark, 2007; Finkel, et al., 2007). However, current research also indicates that not all programs are successful (Despont-Gros, Mueller, & Lovis, 2005). Consequently, new research approaches are vital to overcome obstacles to the implementation of existing information technology tools that might optimize healthcare delivery for vulnerable older adults.

Care Giving in Adult Family Homes

In preparation for the growing aging population, government agencies such as the U.S. Department of Health and Human Services (DHHS) and private organizations such as the John A. Hartford Foundation are supporting research on issues related to care for older adults. Topics of particular concern for these groups are residential care, access to health care, health outcomes, health-related quality of life (HRQOL), and use of technology (Agency for Healthcare Research and Quality (AHRQ), 2008; Cohen, 2010; DHHS, 2010). The adult family home (AFH) is one residential care option for older adults that is receiving some attention (Curtis, Kiyak, & Hedrick, 2000; Hedrick, Sullivan, Sales, & Gray, 2009; Reinhard, Kassner, & Houser, 2011).

Board and care homes and various forms of congregate housing have been operational since the late 1930's after the enactment of the Social Security Act of 1935 (Administration on Aging [AoA], 2009). Adult family homes offer personal care services and delegated nursing

care, and some even deliver varying levels of skilled nursing care for up to six older adults in a family-like home environment (Aging and Disability Services Administration [ADSA], 2007; Curtis et al., 2000; Washington State RCW 70.128, 2007). Among available residential care options, AFHs have the most consistent definition and are most distinguishable by their single-family style structure and small size in terms of number of residents per home (Curtis et al., 2005; Guihan et al., 2009). Optimal operations of AFHs help to promote the concept of aging-in-place for older adults as they experience health decline by providing the care they need without the necessity of moving to an institutional facility (ADSA, 2007; Hedrick et al., 2009). Interestingly, modified versions of the AFH model of care are being implemented in an effort to change the culture of standard nursing homes and decrease residents' loneliness, helplessness, and boredom by altering the habitat into a more home-like environment (White-Chu et al., 2009). These models include such projects as the Eden Alternative (Tavormina, 1999; Thomas & Stermer, 1999), and the Green House Model (Rabig, et al., 2006; Ragsdale & McDougall, 2008).

AFHs enable older adults to remain "at home" rather than being relocated to a nursing home. The goal of AFHs is to provide residents with holistic support for their well-being and promote their ability to function independently despite any physical or cognitive limitations from their medical conditions (Berens, 2010a, 2010b). Direct caregivers in AFHs not only help with activities of daily living and protective supervision, they may also engage residents in physical and mental activities such as exercises or games similar to larger long-term care facilities such as skilled nursing facilities (SNFs). In comparison studies, AFH residents were thirteen times more likely to be satisfied with their environment (Curtis, et al., 2005), and AFHs were significantly rated by evaluators, residents, and family members to be the most home-like, with staff-resident relationships as more familial than in larger assisted living facilities (Morgan et al., 2004).

Although several studies have described AFH caregiver characteristics (Hawes et al., 1995; Hedrick et al., 2007; Hedrick et al., 2009; McCurry et al., 2009), literature about caregivers in long-term care has primarily focused on those in traditional nursing homes and assisted living facilities. Therefore, little is known about AFH caregivers or about their contributions to the care of older adult residents.

Pain Assessment in Older Adults

Suffering from chronic pain is prevalent in the United States, affecting more than 76.5 million Americans (National Center for Health Statistics, 2010). Of particular concern is that approximately one-fourth of adults aged 65 years and older report experiencing pain, yet pain is the most under-treated condition in this population (McCarberg et al., 2008). Even though pain is not a normal part of aging, it is the presenting symptom for many acute and chronic diseases such as diabetes and arthritis, and the likelihood of developing a chronic illness associated with pain increases with age (D'Arcy & Sigma Theta Tau International, 2010; McCarberg, 2007). Promoting optimal functional status for older adults requires adequate management of pain, and improved pain management enhances quality of life (Ferrell et al., 1994).

Successful management of pain in older adults includes comprehensive assessment, selection of appropriate treatment options, and reassessment for treatment effects (Etzioni et al., 2007; Herr, 2002; Horgas et al., 2007). The American Pain Society (1999, 2000) reported that under-treatment of pain among seniors is directly related to inadequate assessment of pain by healthcare providers. Some key elements in pain assessment include identifying the location, intensity, duration, and quality of pain, as well as any aggravating and alleviating factors (Bruckenthal & D'Arcy, 2007). It is also important to discover whether the pain experience has

impacted functional and cognitive abilities (D'Arcy, 2008). A study by Williams, Zimmerman, Sloane, and Reed (2005) found that elder residents of assisted living facilities and nursing homes tend not to receive regular pain assessment, and although staff perceive they have adequate ability to manage pain, only approximately half have received such training. Subsequently, in that study, 40% of those in pain did not receive pain medication (Williams et al., 2005). There is immense potential for overcoming obstacles to chronic pain assessment and management using telehealth technology for community dwelling older adults (Anatchkova et al., 2009; Johann, Shapourian, & D'Arcy, 2007). In residential care settings such as AFHs, caregiver access to pain assessment and management resources via telehealth technology also has tremendous implications for maintaining functional ability in older adult residents. However, there is currently a paucity of relevant research in this setting.

Use of Telehealth Technology

The Veterans Affairs Health Care System has demonstrated the effectiveness of using telehealth technology for their integrated service network to enhance health care for veterans with a variety of illnesses in urban, rural, and isolated locations (Billingsley et al., 2002; Chumbler et al., 2005; Darkins 2006; Kobb et al., 2003; Nazi, 2003; Ryan, Kobb, & Hilsen, 2003). However, these services are not readily available to the general population. In addition, although many new computer technologies are available for accessing web-based resources, these are sometimes difficult and tedious to navigate. Data are lacking to indicate how many AFHs have access to these advanced technologies. In contrast, videophones use existing telephone wiring, offer visual interactive capabilities similar to some computers or other

advanced communication devices, and require minimal user instructions. Accordingly, this existing technology may be an appropriate platform for telehealth delivery in the AFH setting.

Studies have assessed some community telehealth programs (Celler, Lovell, & Basilakis, 2003; Maudlin, Keene, & Kobb, 2006; Wertenberger & Wilson, 2005) and evaluated the use of videophone technology for informal caregivers (Demiris et al., 2008; Hensel et al., 2006; Oliver et al., 2006). Additional studies used the videophone in home healthcare settings to examine the delivery of teaching and consultation about wound care (Jonsson & Willman, 2007, 2008). Evaluations of telehealth programs have used quantitative research designs to test efficacy and effectiveness (Wakefield et al., 2008; Wakefield et al., 2009). Some studies even used randomized controlled trials of telehealth programs to test hypotheses related to health outcomes (Wakefield, Bylund, et al., 2008; Winter & Gitlin, 2006). Although these studies demonstrated positive outcomes, such as significantly longer time to hospital readmission, no studies have explored the use of assistive telehealth technology for elderly residents of AFHs or their direct caregivers. Moreover, no studies have addressed the question of whether telehealth technology might be acceptable in the AFH setting nor the reasons for acceptance or non-acceptance from the perspectives of study participants. Gaining an understanding of how AFH caregivers and residents experience the use of technological devices for telehealth is essential if the development of telehealth services in this setting is to be effective and appropriate.

Conceptual Framework

The Aging-in-Place model provides the context for this study. Aging in place is a multi-dimensional term used in reference to the context of housing and support for the elderly (Heumann & Boldy, 1993). Many people and organizations use this term to refer to staying in one's own original home to avoid moving to high-density institutional care facilities. For the purposes of this study, aging in place is broadly defined as solving the need for assistance with independent living in current housing or an appropriate level of housing to prevent a costly, traumatic, or inappropriate move to a dependent care facility (adapted from Heumann & Boldy, 1993, p. xi).

Albert Bandura's Social Cognitive Theory underpins the rationale for providing pain assessment training as the intervention for AFH caregivers. Social Cognitive Theory (SCT) describes a learning model based on interactions between personal human agency of the self, proxy agency with reliance on others, and social collective agency in the group environment (Bandura, 2001). Within this theory, "intentionality" refers to a plan for future action and differs from "intentionality" as used in the phenomenological perspective. SCT sees people as agents of action and self-reflection, which contributes to a perception of self-efficacy whereby people build beliefs about their ability to perform intentioned actions. The current study is based on the premise that developing AFH caregivers' self-efficacy in pain assessment using telehealth will lead to improved pain management for older adult residents in AFHs and support aging-in-place. Studies in diabetes management (Walker et al., 2014) and smoking cessation (Smit et al., 2014) have found that high self-efficacy is associated with improved self-care and adherence. SCT identifies four factors that influence self-efficacy: experience, modeling by others, social persuasion, and physiological factors, all of which underpin the pain assessment intervention for

testing telehealth feasibility during Phase 2 of this study. The intervention was designed to provide an opportunity for AFH caregivers and older adult residents to experience increased self-efficacy with regards to pain assessment via telehealth education and modeling of the use of a pain assessment tool by a nurse within a healthcare system.

Innovation and Implications for Research

Multiple research approaches are needed in order to improve and optimize health care delivery that utilizes information technology tools. Studies are needed to assess how pain assessment by AFH caregivers might inform and augment healthcare providers' pain management plans. Data are also needed to discover how telehealth is currently utilized in AFHs for accessing pain management resources. These questions may be difficult to ascertain when using only quantitative research methods that cannot capture acceptability or usability factors. However, qualitative methods may help to discover themes specific to AFH care giving and reveal underlying intentions and hidden perceptions toward receiving telehealth through technological devices.

A useful qualitative approach from a naturalistic paradigm is phenomenology. The concept of intentionality is at the core of phenomenology (Farber, 1928). However, this is not "intention" leading up to an action but rather an intentioned relationship to an object or the philosophical reflection about the object. Intentionality in phenomenology applies to the theory of knowledge rather than the theory of human action (Sokolowski, 2000). The central thought of intentionality in phenomenology is that within every experience there is consciousness and intention towards an object or about an object, whether in the performance of action or the design of the experience. Phenomenological approaches sort intentionalities so that the

descriptions help us to understand human knowing and the ways each person is related to the variety of components that are part of that individual's world. Hermeneutic phenomenology, as derived by Paul Ricoeur, takes a teleological approach to ontology that combines both descriptive phenomenology and hermeneutic interpretation as a means to analyze the signs, symbols, and text of language (Dauenhauer, 2008). This philosophical and theoretical approach focuses on the meaning of experience (Cohen, Kahn, & Steeves, 2000) within the context of the experience.

From a hermeneutic phenomenological perspective, qualitative content analysis is a useful systematic research method of analyzing text data that focuses on subjective interpretation through coding and identifying themes or patterns (Hsieh & Shannon, 2005). Hsieh and Shannon (2005) described three approaches to qualitative content analysis. First is the conventional approach, which derives coding categories from the text and is appropriate for describing phenomena that lack existing research. Next is the directed approach, intended to validate existing theory or add to prior research. Third is the summative approach, which quantifies words in the text before conducting interpretation to derive meaning and examine the context.

Within a naturalistic paradigm, semi-structured interviews using open-ended questions would encourage respondents to reflect on their lived experiences using telehealth technology. The conventional approach to content analysis of interview data may generate significant themes that describe what it means for AFH caregivers and residents to use technological devices for telehealth. Additionally, asking caregivers and residents to describe telehealth technology usage within the AFH setting would provide depth to this residential context. These results may further

reveal contributing factors for promoting successful aging-in-place within the context of the AFH setting. Results from this mixed-methods dissertation will help to inform the design of effective telehealth programs to extend healthcare resources for at-risk community dwelling and frail homebound older adults.

Chapter 2: A Study to Assess Technology Usage in Adult Family Homes

INTRODUCTION

The adult family home (AFH) setting combines caregiving services and independent living in a household environment (Curtis et al., 2000; Hedrick et al., 2009). The Centers for Medicare and Medicaid Services (CMS) utilization of AFHs for long-term care services has increased even as numbers of nursing home clients have decreased (Aging and Disability Services Administration [ADSA], 2009; Reinhard, Kassner, & Houser, 2011; Washington Aging and Long Term Support Administration Department of Social and Health Services [WA AL TSA DSHS], 2012).

Adult family homes are defined as residential homes located in the community and licensed to provide congregate housing and domiciliary care for older adults (Washington State RCW 70.128, 2007). AFHs are also known by several other names, such as boarding homes, adult foster homes, assisted living, adult care homes, and residential group care. Adult family homes offer supportive care services and delegated nursing care (in some states); some even deliver varying levels of skilled nursing care in a family-like home environment (ADSA, 2007; Curtis et al., 2000; Harris-Kojetin et al., 2013; Washington State RCW 70.128, 2007). Although regulations vary between states, among available residential care options, AFHs have the most consistent definition and are most distinguishable by their single-family style structure and small size in terms of number of residents per home (Curtis et al., 2005; Guihan et al., 2009). In most states, AFHs are licensed to provide room and board, personal and special care for up to six residents who are not related by blood or marriage to the service provider. Boarding homes, on

the other hand, are licensed to care for seven or more residents in a house or larger facility (ADSA DSHS, 2007).

Optimal utilization of the AFH model of care can promote the concept of aging-in-place by providing the level of care that older adults require as they experience health decline, without the need to move to an institutional facility (ADSA, 2007; Hedrick et al., 2009). Direct caregivers help with activities of daily living and protective supervision; they may also engage residents in physical and mental activities such as exercises or games. This model of care has been shown to decrease loneliness, helplessness, and boredom compared to standard nursing homes (White-Chu et al., 2009). AFH residents have been reported to be 13 times more likely to be satisfied with their environment (Curtis et al., 2005), and evaluators have rated smaller sized living facilities as significantly more home-like with more familial staff-resident relationships than larger assisted living facilities (Morgan et al., 2004).

The goal of AFHs is to provide residents with holistic support for their well-being and promote their ability to function independently despite any physical or cognitive limitations from their medical conditions (Berens, 2010a, 2010b). Little is known, however, about the staff that provides this holistic support. Although several studies have described AFH caregiver characteristics (Hawes et al., 1995; Hedrick et al., 2007; Hedrick et al., 2009; McCurry et al., 2009), the existing literature about caregivers has primarily focused on informal family caregivers or paid caregivers in traditional nursing homes and large assisted living facilities. Therefore, little is known about AFH caregivers, their contributions to the care of older adult residents, and their need for tools that will help them improve the services they deliver. Research is needed to describe caregiving in AFHs and the educational needs of AFH caregivers within that care setting. Gaining an understanding of these factors can guide healthcare systems

and government entities to provide appropriate support for direct caregivers that leverage their capacity in the care of older adults within health system reform.

An innovation to improve access to care: Telehealth

One technique for improving access to health care is to bridge geographic distance from providers to patients through use of technology. Telemedicine is defined as “the use of medical information exchanged from one site to another via electronic communications to improve patients' health status” (ATA, 2010). “Telehealth” encompasses telemedicine and additional healthcare services that may include continuing education or remote monitoring of vital signs. Telehealth using videophones or real-time audio-video conferencing has been shown to be beneficial and cost-effective in many care settings such as hospice (Demiris et al., 2011). Recent regulatory changes among many states are requiring increased initial and continuing education for AFH operators and caregivers (AL TSA, Updated June 4, 2013), and telehealth technology can be an innovative platform for delivering educational resources to these consumers.

Many new computer technologies are available for accessing web-based resources; however, these are sometimes difficult and tedious to navigate. Data are also lacking to indicate whether AFHs have these advanced technologies. Accordingly, little is known about which existing technology may be an appropriate platform for telehealth delivery in the AFH setting.

The purpose of this study is to assess and describe the types of technology in use in adult family homes. Recognizing the potential of telehealth applications to support existing and new models of care for older adults, the research question of this study addresses what technologies, if any, are AFHs currently using that may support the delivery of telehealth services or

interventions. Gaining an understanding of current technology usage will highlight opportunities for improved health delivery system re-design to enhance care in these settings.

METHODS

This study used a cross sectional descriptive design to survey AFH owners about technology usage in their AFHs. Cluster sampling of all AFHs in Washington State was used for this study rather than a national random sample of AFHs in the United States. A survey of technology usage for adult family homes was designed using a modified Delphi technique. Two nurse scientists with expertise in survey development and a statistician were asked to review the items for face validity. Once the items were refined based on their recommendations, members of the Washington State Residential Care Council (WSRCC), including one nurse who operates adult family homes, were asked to review the items for content validity and applicability of the items to the AFH setting.

The Survey Instrument

The questionnaire, called the Survey of Technology Use (STU) in Appendix A, was designed to query AFH owners about the type of devices they used in their homes, and whether any specific devices were used in the care of their older adult residents. The survey was divided into two parts. The first part included a list of common electronic devices such as telephone, television, cell phone (any type), answering machine, and facsimile machines. The first part also asked whether AFH operators were using health technology such as motion sensors or other monitoring devices. Part two of the questionnaire asked about the number of caregivers and numbers of residents that occupied the residence at that point in time. Finally, respondents were

queried regarding the types of illnesses or conditions that their residents had and whether they would be interested in receiving instructions on health topics, including pain assessment specifically, because pain is a symptom that is common to multiple chronic illnesses.

Procedures

Operators of all AFHs as listed by the Department of Social and Health Services (DSHS) AFH Locator on June 30, 2011 (approximately 3000 homes) were invited to participate in this study. The researcher approached the Washington State Residential Care Council and received their support of this study as well as their assistance with an email introduction of the study to their members.

A letter explaining the study was sent to owner/operators of all AFHs within Washington State. Three items accompanied the letter: 1) the Survey of Technology Use (STU), 2) a self-addressed stamped envelope for returning the survey, and 3) a self-addressed stamped response postcard to indicate whether they were interested in more information or would give permission for future technology studies to be conducted in their homes. Participants were invited to complete and return the STU, and they were instructed to fill out the response card if they were interested in receiving information about future telehealth studies. This study received approval from the Institutional Review Board of the University of Washington under exempt status. All returned surveys were anonymous and labeled with only a study number.

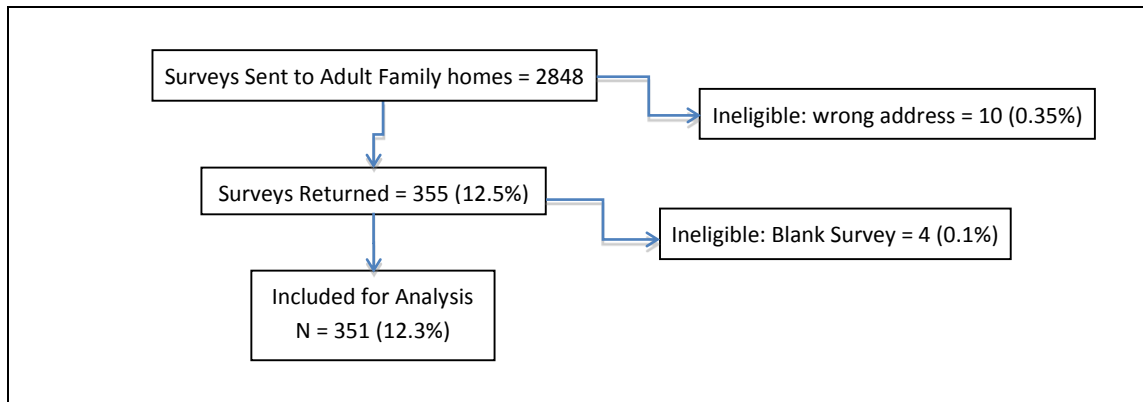
Analysis

Descriptive analysis of data was performed using SPSS 19 to summarize frequencies, means, modes, and standard deviations of technological devices that are in use in AFHs.

RESULTS

A total of 2,848 surveys were mailed via United States Postal Service in July of 2011. Ten mailed envelopes were returned unopened as undeliverable due to mailing address errors. Three hundred fifty-five surveys (12.5%) were returned. Of these, four were entirely blank, resulting in 351 surveys (12.3%), completely or partially filled out, that were eligible for analysis. The survey administration process with response rates is summarized in Figure 2.1.

Figure 2.1: Survey of Technology Use Response Rate



Adult Family Home Composition

The surveys were primarily completed by the owner or operator of the home. If the survey was not filled out by the operator, it was completed by a manager, administrator, or caregiver. On average, each home had five residents and 3.8 caregivers (SD=2.86). Only 9% of the homes housed residents younger than 65 years of age. The average age of AFH residents ranged from 59 to 86 years (SD=22.12). The youngest resident among the homes was reported to be 7 years old and the oldest resident was 107 years old.

Seventy-nine percent of AFH owners reported that their residents complained of pain. Eighty-two percent of the homes reported that some of their residents had dementia, but only 23% of the homes indicated that all of the residents in their AFHs suffered dementia. The most commonly reported illness conditions included arthritis (79%), joint pain (73%), and urinary problems (70%). A typical AFH cared for an average of seven types of illnesses/conditions among their residents. All illnesses and painful conditions that AFH owners and caregivers reported are described in Table AT1 (Appendix A).

Over half of the AFH respondents (58%) reported that they were very comfortable conducting pain assessments and 31% expressed that they were somewhat comfortable. Despite their level of comfort with conducting pain assessment, 69% indicated that they would be somewhat or very interested in pain assessment instructions.

Technology Usage in Adult Family Homes

For communication technology devices being used, almost all AFHs had a land telephone line (99%) and of those, 96% used it for AFH business. Ninety-eight percent of AFHs reported having a cell phone with 95% of those using it for AFH business, and a much smaller number using it for accessing the web (47%) or for playing games (14%). Other communications equipment also in use included facsimile (fax) machines (95%) and videophones (5%). Ninety percent of AFHs had a computer and 89% used it for AFH business. Some AFHs used the computer for accessing educational resources (77%), placing audio-video calls over the internet (31%), or even consulting with healthcare providers over the internet (31%). Looking only at AFHs that reported having computers, 97% used their computers for their AFH business, 84% were likely to use them for education, and 34% were likely to use them for Voice Over Internet

Protocol (VoIP) communications. For the list of technology usage in AFHs, please refer to Figure AF1 in Appendix A.

Several other common technological devices used in responding AFHs included television (96%), basic radio (91%), DVD player (93%), compact disc player (88%), VHS player (58%), and cassette player (54%). Varying levels of media access were also reported including cable TV (88%), wireless internet (68%), cable internet (59%), digital subscriber line (DSL) service (24%), and dial-up internet (9%).

Many AFHs reported using health-monitoring devices (42%) for the safe care of their older adult residents. Other technological devices (write-in responses) included wireless call systems, door alarms, floor alarms, motion sensors, audio monitors, security alarm systems, oxygen saturation monitors, blood glucose monitors, blood pressure monitors, and lift assist devices. The mean number of technological devices per AFH was 11.22% (SD=3.06). A detailed list of other technology in use in the AFHs is identified in Table AT2 (Appendix A).

Respondents were asked to rate their comfort with using technology on a Likert-like scale from 1 to 5, with 1=not at all comfortable and 5=very comfortable. The mean rating was 4.26, with SD=0.84. Most respondents were very comfortable (45.63%) or somewhat comfortable (39.1%) with using technology.

DISCUSSION

This study provides insight into the current technology use of adult family homes and informs us of AFH capacity to embrace and adopt new information technology (IT) based tools and interventions. The survey instrument used in this study, the Survey of Technology Use, explored types and level of technology usage in AFHs, general information about AFHs, and common illness conditions for residents of AFHs. Results from this survey showed that an average AFH had three to five caregivers who cared for five residents. Most AFH residents (approximately 90%) were 65 years of age or older, with the average age ranging from 59 to 86 years old. Over three-quarters of AFHs cared for at least one resident who suffered from dementia, and about one-quarter of AFHs report that all of their residents have dementia. This care giving ratio compares favorably to skilled nursing facilities where about 46% of residents have dementia (AoA, 2012). A typical AFH cared for about seven illnesses or conditions among their residents, and about three-quarters of AFHs cared for residents who complained of pain. The most prevalent illness conditions included arthritis, joint pain, urinary problems, and back pain. Most respondents (~89%) were somewhat or very comfortable with pain assessment; nonetheless, more than half (69%) indicated that they would be somewhat or very interested in receiving pain assessment instructions. Since the American Pain Society (2000) has issued a statement that pain is under-assessed, engaging AFH caregivers in structured approaches to pain assessment and regular reporting of resident pain level may contribute to improved pain management for older adults in this unique residential care setting.

With the numerous recent technological advancements in communication and health devices, it is interesting to note that almost all adult family homes (99%) maintained a telephone

landline and used it for their AFH business activities. Although almost as many AFHs (98%) had cellular telephones and used these for conducting AFH business, relatively few AFHs used these devices for accessing the internet (47%) or for playing games (14%). The study did not assess the ratio of simple cellular phone usage to the use of more complex “smart” phones.

Most AFHs in this study had a computer (90%) and used it for AFH business, but only three-quarters of respondents used this advanced technology for accessing educational resources, and only one-third used it for audio-video communications over the internet using programs such as Skype or Google Talk. The minimal use of VoIP could be due to concerns about privacy and security related to the Health Insurance Portability and Accountability Act (HIPAA). Large healthcare organizations utilize advanced IT and sophisticated security protocols that are not easily accessible or could be cost prohibitive to small-sized AFHs.

Almost all AFHs used a basic radio (91%) and television (96%). For video recording and playback, most AFHs (93%) used a digital video disc player (DVD), a few (23%) used the more advanced Blu-Ray disc player, but slightly more than half of the responding AFHs (58%) still used VHS videocassette players. This is not too surprising since, as noted by Rogers (2003), the diffusion of innovations requires variable lengths of time depending on perceived attributes of the innovation.

Access to media also varied among adult family homes. Most AFHs (88%) gained access via cable and a few (17%) accessed media using satellite service such as Dish TV. This may be due in part to geographic availability of service providers. For those AFHs with computers, most had wireless internet access (68%), about half used cable (59%), some used DSL (24%), and very few still used dial-up internet service (9%). Despite the range in level of

technological sophistication, most respondents (~85%) were somewhat or very comfortable with using technology. The readiness of AFHs to adopt technology could be inferred from the reported comfort with use and the reported actual use of additional health monitoring devices.

In general, AFH owners are embracing new technologies. The average AFH may not be a high-tech environment, but AFHs' readiness to accept new technology and their comfort level with using technological devices are both very important contributors for adopting innovations. As government entities and healthcare organizations look to telehealth as an innovative cost-effective option for bridging distance and increasing access to health care for community dwelling older adults, AFHs with the capacity for implementing advanced technology may play an integral part in helping older adults age in place.

Study Limitations

The Survey of Technology (STU) had a 12.5% response rate, which is lower than reported response rates from marketing mail surveys that target specific populations and use follow-up reminder postcards. One survey of primary care physicians received a 44% response rate (Hastings et al, 2014), and a survey of day care programs received 47% response rate (Wiert et al., 2014). However, other studies have found that the response rate may be influenced by age of the respondent (Gigliotti & Dietsch, 2014) and potentially targeted incentives (Link & Burks, 2013). It is possible that this study might have achieved a higher response rate had there been mail reminders or the offer of an incentive, but cost was a limiting factor. Nevertheless, this study had a slightly better response rate compared to auto-dial telephone surveying methods such as those conducted by the Pew Research Center that sampled telephone numbers nationally for

the Internet & American Life Project Spring Tracking Survey and reported a response rate of 11.5% (Smith, 2012).

The survey response rate of 12.5% for this study also means that approximately 88% of the AFHs in the state were not represented. Therefore, there could have been an over-representation of AFHs with more sophisticated technology usage. As government and healthcare entities increase their use of electronic formats for information dissemination, it will be interesting to assess whether there is a corresponding shift in technology usage in AFHs.

Another limitation is that the survey did not ask for respondent characteristics besides their role in the adult family home. This survey was intended to acquire only general characteristics of the homes; therefore, information on caregiver age and education were not captured. The survey also did not ask whether caregivers who were not owners/operators or managers would have access to the computers in the AFHs. This information would have assessed the level of impact that available educational resources over the internet may have on caregivers' ability to access them.

Other limitations to this study included: 1) the STU is a newly-designed tool and items have not been psychometrically tested for validity and reliability; 2) results may reflect technology usage in the state where the survey was administered but may not necessarily be generalizable to other states in the US; and 3) the survey was in English and non-English speaking AFH owners may not have participated.

Study Summary

Telehealth is an innovative approach within a new model of care that promotes the concept of aging-in-place by bridging geographic distance to improve access to care for community dwelling older adults. The small-scale, single-family dwelling environment of the AFH that includes assistive care services also supports aging in place. This study shows that AFH operators embrace technology while continuing to use less sophisticated technological devices that have proven utility such as the landline telephone, radio, and VHS videocassette player. Operators are also desirous of educational instruction. With new legislation that increased required continuing education for direct caregivers, it is imperative to find new cost effective options for delivering educational resources. Research is needed to test whether it is feasible to deliver educational material over existing, less-sophisticated technology to improve access for AFH caregivers that ultimately improves care of older adult residents.

Chapter 3

A Study of the Feasibility of Using Telehealth Technology for Delivering a Structured Educational Intervention about Pain Assessment for Adult Family Home Caregivers

INTRODUCTION

Untreated pain in older adults can significantly diminish functional independence and quality of life (Horgas & Elliott, 2004). In light of diminishing resources, inadequate number of primary care providers trained in gerontology (Karvounis, 2008), and the shortage of healthcare providers in home healthcare (Stone & Harahan, 2010), using the appropriate form of telehealth technology has great potential for increasing access and extending pain management programs to community dwelling elders at risk for pain-related functional decline.

Although almost 90% of adults 50 years or older prefer to remain in their own homes for as long as possible (Keenan, 2010), adult family homes (AFHs) are one type of community residence that is helping some older adults to age in place while meeting their long-term care (LTC) needs (Hedrick, et al., 2003). Around the United States, there has been a shift in long-term care of older adults from nursing homes or high density skilled nursing facilities to small scale home-like environments. For example, in Washington State, between 1994 and 2007, Washington State Department of Social & Health Services (DSHS) clients living in AFHs have increased from 700 to 5696 (DSHS, 2007). Legislation to increase the requirements for direct caregiver training has been passed across many states; however, budget constraints have made implementation challenging for regulatory bodies. The financial burden to obtain educational

resources for direct caregivers who are often paid at minimum wage is also a barrier to building caregiver capacity.

Improve Access to Care: Telehealth

Telehealth technology is an innovative and potentially cost effective solution for extending healthcare resources and services (Chetney, 2003). Recent technological advancements have generated many electronic platforms for accessing health information. Telemedicine uses electronic communications to exchange medical information from one site to another for the purpose of improving patient health status (ATA, 2010). Telehealth is a broader construct that encompasses telemedicine and other healthcare services such as health education and remote monitoring. One progressive telehealth solution for bridging geographic distance, conserving time, and extending limited healthcare resources is the use of real-time audio-video conferencing between healthcare providers and direct caregivers of older adults. Studies including those to evaluate technical requirements of adopting telehealth after a natural disaster during a shortage of providers (Arriaga et al., 2010) and video-consultation for oncology patient monitoring and management (Kitamura et al., 2010) have shown the feasibility, effectiveness, and value of telehealth using audio-video conferencing. Such approaches could be extremely beneficial for AFH settings. However, there is little information on the learning needs of direct caregivers in residential care settings and the best model of community-based nursing care oversight for adult family homes.

Using the Appropriate Technology

Study 1 of this dissertation surveyed AFHs about their technology usage (described in Chapter 2) and indicated that although some AFHs had access to various technologies such as a

personal computer, very few caregivers used these for communicating with healthcare providers or accessing educational resources. However, almost all AFHs (98%) used a basic telephone landline for AFH business and healthcare communications. Therefore, an older technology that uses existing telephone wiring but provides the addition of visual interactive capabilities similar to some computers may be an appropriate platform for telehealth in the AFH setting. These older technologies may also be applicable in AFHs located in rural settings where one cannot always assume that sophisticated information technology infrastructure would be available.

The videophone is a communication device with a camera and video screen that connects to existing hardwired telephone lines. It does not require sophisticated programming, assembly, or advanced technical skills to operate. It is a simple, out-of-the-box, “plug and use” device that makes video enhanced telephone communications possible. This technology has been studied for caregiver participation in hospice pain management in the home setting (Parker Oliver et al., 2010). However, use of this type of telehealth platform for pain assessment had not yet been studied in the AFH setting for older adults with varying levels of functional dependence.

This study aimed to describe the experience of AFH caregivers and older adult residents using videophone technology for the telehealth application of pain assessment education. This feasibility study used mixed methods to explore: 1) whether the videophone is usable by direct caregivers and older adult residents of AFHs as measured by connectivity and ease of use; 2) overall perceptions about using videophones for telehealth in the AFH setting specifically for pain assessment; 3) factors to consider when designing telehealth programs using videophones in AFHs (relevant themes from interviews with caregivers and residents); 4) pain assessment learning needs of AFH caregivers; and 5) AFH residents’ pain experiences and quality of life. Results from this study will help to inform future studies about AFH residents and their

functional ability, pain assessment, and the delivery of educational resources for adult family home direct caregivers that would benefit their older adult residents.

Conceptual Framework

A nested model consisting of the Aging-in-Place model and self-efficacy development from Albert Bandura's Social Cognitive Theory, where intentionality refers to a plan for future action, informed this study. This study explored the premise that the use of telehealth-delivered resources as a means to increase AFH caregiver self-efficacy in pain assessment may lead to improved pain management for older adult residents in AFHs, thereby promoting successful aging-in-place.

METHODS

Design

This pilot feasibility study used a convergent descriptive research design with both quantitative and qualitative methods to assess the usability (connectivity, ease of use, quantity of use) and acceptability of videophone technology for telehealth by AFH caregivers and older adult residents for pain assessment. This study received University of Washington Institutional Review Board (IRB) approval prior to any study activities.

Adult family home caregivers and residents were recruited as dyads for this study. A videophone unit was placed in the AFH for the usability test. Caregivers were taught how to use a pain assessment tool over the videophone. They assessed participating residents for pain using

this tool. Then, caregivers and residents used the videophone to report the pain assessment results to the researcher.

All participants used diaries to log videophone usage and user opinions each time the videophone was used. At baseline and post intervention, AFH residents completed standardized questionnaires (described later in this chapter) about their pain experiences, and caregivers were surveyed about their pain assessment learning needs. Interviews were conducted with residents and caregivers to capture their experience and perceptions about the use of videophone technology in the AFH setting. Interview sessions were audio recorded and transcribed for thematic analysis.

Operational Definition: Feasibility of Videophone Telehealth in AFHs

In this study, videophone technology was determined to be feasible for telehealth delivery of pain assessment resources in two ways:

- 1) usability of the videophone was rated positively by direct care providers and older adult residents of AFH as measured by:
 - a. positive ratings on connectivity, and
 - b. positive ratings on ease of use;
- 2) positive overall perception of using videophone for telehealth in the AFH setting based on:
 - a. perception of amount of time needed for training, and
 - b. perception of using videophone technology for pain assessment.

Data Collection Tools

- i. *Demographic Questionnaire for Caregivers and Residents*. This survey asked participants for their age, sex, educational level, ethnicity, and length of time at the AFH (residency or employment). In addition, caregivers were asked about additional care-specific training. Alternatively, residents were asked about painful health conditions they might experience.
- ii. *Mini Cog*. This is a 3-item screening tool that assesses the level of cognitive ability using word recall and accuracy in drawing a clock face to indicate a particular time (Borson et al., 2000). The Mini Cog has well-validated psychometric properties (Borson et al., 2003).
- iii. *Pain Thermometer Scale (PTS)*. This tool uses verbal descriptors (“none” to “pain as bad as could be”) to rate pain in tandem with a color-coded thermometer that has corresponding increases in color intensity (Herr & Mobily, 1993).
- iv. *Feasibility and Usability Diary*. All participating caregivers and residents kept a structured diary of their experiences using the videophone. They recorded the date, time, and length of their videophone interactions and their perception of the quality and effectiveness of the call. Each videophone call was assessed for quality of connection (clarity, interference, interruption, and unintended disconnection), ease of use (easy, need to review directions, or unable to use), and quantity of use (whether the videophone was used for other calls besides the calls to report pain scores). Participants were also asked to write comments about their perception of the device with each usage. The research assistant also kept a diary of each videophone interaction to record their own perceptions of use of this device for delivering and receiving pain assessment information.

- v. PROMIS Global Health Short Form V1.1(GHSF1.1) was administered to AFH residents. The Patient-Reported-Outcomes Measurement Information System (PROMIS) uses item response theory to improve reliability, validity, and precision of outcome measure instruments (Fries et al., 2005). The Global Health short form is a 10-item PROMIS questionnaire measuring quality of life through physical and mental health domains. Questions include “To what extent are you able to carry out your everyday physical activities such as walking, climbing stairs, carrying groceries, or moving a chair?” and “How often have you been bothered by emotional problems such as feeling anxious, depressed or irritable?” Each item has a rating from 1 to 5 and the question that asks about pain level is rated from 0 to 10. Using the formula outlined by Revicki et al. (2009), the EuroQoL (EQ-5D) quality of life scores were calculated.
- vi. PROMIS Pain Behavior - Short Form 7a (PBSF7a) was administered to AFH residents. This instrument has seven items that measure pain behavior. Reliability of the full item bank is 0.90 or greater and this short form has a correlation of 0.98 with the full-item bank (Cella et al., 2010). A sample question is “When I was in pain I grimaced...” Participants rate their pain behavior on a 6-point scale from “never” to “always”.
- vii. PROMIS Pain Interference – Short Form 6b (PISF6b) was administered to AFH residents. This short form version contains six questions, rated on a 5-point scale, from the 41 items in the full-item bank and has a correlation of 0.95 to the full set. The pain behavior scores have a correlation of 0.77 with the pain interference scores (Cella et al., 2010). A sample question is “How much did pain interfere with your enjoyment of life?”
- viii. Baseline Initial Interview Guides. There was a list of prompts, divided by categories or topics, to guide the researcher during the baseline interview process. There were separate

prompts for the caregiver interviews and for the resident interviews. Categories included an introduction, general questions about the AFH environment (to develop rapport with the participants), functional ability of the residents, and their pain experiences. An example of a specific prompt for caregivers is “Have you noticed whether pain might decrease their ability to do everyday activities? If so, by how much?” An example of a question for residents is “Please describe your ability to do the things you want to do on a typical day.”

- ix. *Post Videophone Testing Interview Guides.* The questions for this in-depth interview addressed the research aim to explore overall perception of using the videophone for telehealth in the AFH setting, specifically for pain assessment. There were separate prompts for the caregiver interviews and for the resident interviews. Questions were also grouped by categories such as post-testing pain experiences, and diary perceptions of using the videophone as a telehealth device.

Technology Toolkit

The telehealth technology device used in this study to deliver educational resources was a videophone. To maintain consistency for this study, a commercially available videophone unit was used by the AFH residents, caregivers, and the researcher for telehealth interactions. The unit was connected to an existing regular telephone line and was either used as a stand-alone unit or connected to the TV set for a larger video projection, as determined by the caregiver-resident dyad.



Figure 3.1: Videophone

Sample Population

Participants in this study included both men and women, individuals who represented various ethnic and racial populations, and those who met eligibility criteria. For this pilot feasibility study, the goal was to recruit between six to ten AFH caregiver and resident dyads.

Caregivers were eligible if they were age 18 to 65 years old, had worked in the same facility for more than 3 months, and cared for participating residents for at least 3 days per week to ensure that they were familiar with the residents in their care. Caregivers had to be able to read, write, and speak English in order to keep the Feasibility and Usability Diary. Multiple caregivers at each home were eligible to participate.

Residents were eligible to participate if they were 65 years old or older; were able to read, write, and speak English; and reported experiencing mild to severe pain on at least 3 days per week during the screening process. Residents were eligible to participate regardless of length of time they had resided at the AFH. Although residents might display some cognitive impairment, they needed to have a Mini-Cog score greater than or equal to two to indicate that they were non-demented. Resident participants had to be able to speak about their experience with videophone use during interviews. Residents needed to be able to make independent decisions without requiring signed permission from a Power Of Attorney. Residents could invite family members to be present at any or all parts of the procedures, including the screening process.

Procedures

According to Washington State law, adult family home owners hold the license to operate the AFH, and their permission was needed to conduct the study in their homes. Therefore,

caregivers and residents were purposively selected from a convenience sample of adult family homes that participated in Study 1 assessing technology use in AFHs, as described in Chapter 2. As part of that study, AFH operators were asked to return a post card to indicate whether they might be interested in testing telehealth technologies in their AFH. Approximately 140 homes returned the response postcard to indicate their interest and gave permission to be contacted for this study. Contact cards were stratified by telephone area code numbers, and homes were selected from different area codes on a rotating basis so that participating homes might represent a variety of geographic locations.

This researcher contacted the AFH operators to tell them about the study, and those who were interested were screened by telephone to determine whether any of their caregivers and residents could be potentially eligible participants. Those operators who gave verbal support of the study were asked to sign a written letter of support granting permission to conduct the study in their AFH. The adult family home operators were asked to refer potentially eligible caregivers and residents to the study by giving them an information sheet about the study. This researcher contacted the caregivers and the residents by phone to explain the study using a script and invited them to participate. Those caregivers and residents who wished to participate were screened to confirm eligibility. If the owner/operator was also a caregiver in the home, they were invited to participate.

During the initial in-person visit, baseline interviews with residents and caregivers were conducted separately unless the residents requested otherwise. Caregivers and residents were given all information consistent with requirements of the IRB in order to obtain signed informed consent before collecting any data. Caregivers completed the caregiver demographic questionnaire, and older adult residents completed the resident demographic and other baseline

questionnaires, as described earlier. Residents could write down their survey responses or they could choose to complete the assessment by interview if they were not able to read the surveys with ease. Residents and caregivers were interviewed about their pain and pain assessment experiences respectively. Caregivers also confirmed that participating residents had a pain management plan in place, as ordered by their healthcare provider.

The researcher began teaching about the videophone immediately after informed consent and administration of the questionnaires. Participating caregiver and resident dyads then assisted the researcher in identifying the best location to place the units within their homes where they were ensured privacy from other AFH occupants during videophone interactions while following manufacturer recommendations for optimal transmission and reception. If AFH operators were on-site, they also contributed to the placement of the videophone.

Physical Setting for Videophone Placement

In the research office where the videophone was set up for each of the video visits, the desktop unit was connected to a hard-wired desk phone that was connected to a wall-mounted phone jack. Figure BF1 (Appendix B) illustrates the videophone set up in the research office for conducting visits with the adult family homes.

All of the AFHs had similar types of telephone units with one primary base unit and multiple cordless handsets. These handsets also provided the audio portion of calls that were conducted in homes that used the television monitor project videophone units. In Appendix B, Figure BF2 demonstrates how a desktop videophone unit was set up in an AFH, and Figure BF3 illustrates how the videophone projection unit was set up using a flat screen television set.

This researcher demonstrated videophone use while giving instructions on its functions, how it is connected to the existing telephone system, and how to conduct videophone interactions using the units. After the units were set up, baseline interviews were conducted while waiting to coordinate the introductory test interaction with the research assistant (RA) located at the research office. Once the introductory call from the RA was established, participants practiced using the device to speak with the RA via the videophone until they demonstrated competency.

Testing Usability of the Videophone for 4 weeks

Four video-call visits were scheduled for testing the usability of the videophone as a telehealth platform to deliver educational resources. The choice of 4 weeks for the duration of the intervention phase was a balance between two important factors. First, participants needed to have sufficient uses of the technology to develop an informed opinion about the device and their experiences. Second, the duration was kept to 4 weeks to limit any unnecessary disruptions to the regular operations of the AFHs.

All AFH caregivers and residents were instructed that a standard interaction was to be used to test the usage of the videophone. During the initial in-person interview, the first videophone appointments were scheduled for a convenient day and time for participant dyads at the same AFH. Each week, the RA initiated the video-call at the pre-arranged time and followed a prescribed protocol and script for consistent videophone interactions.

During the first scheduled video-call visit, the RA taught caregivers via videophone how to perform pain assessments using the Pain Thermometer Scale (PTS). Once the caregiver indicated readiness to use the PTS, the participant resident was asked to join the video-call so

that the caregiver could use the PTS with the resident. After the resident validated the pain assessment scores, both the caregiver and resident recorded the score on their respective Feasibility-Usability Diaries. If pain was identified, caregivers were instructed to follow the pain management protocol as prescribed by the healthcare provider for that resident. Results of the PTS were collected as data solely for this study and were not included in the residents' medical records. Before ending the conversation/interaction, the videophone visit for the following week was scheduled at a convenient time for all participants. After the video-call visit, the caregiver, resident, and RA each filled out a Feasibility-Usability Diary sheet about the duration, quality, and their perception about use of the videophone platform for delivering pain assessment resources in the AFH setting.

During the second, third, and fourth video-call visits, the caregivers were asked to use the PTS with the resident. Both the caregiver and resident were present during the entire duration of the video-call visits. The RA reviewed the instructions for using the PTS as needed. They each completed their respective Feasibility-Usability Diary at the end of each visit. The RA also completed the Feasibility-Usability Diary at the end of each visit. As part of testing the feasibility to deliver educational information over telehealth technology, the researcher recorded the amount of time that was needed to set up and conduct each videophone interaction in the research office.

The videophone testing phase ended after four weekly visits. In Appendix B, Table BT1 describes the study activities by type and visit number of with the AFH residents and Table BT2 describes the type and visit number for AFH caregivers in the study. A random sample of video-calls was audio- and video-recorded digitally and reviewed by the researcher and a co-

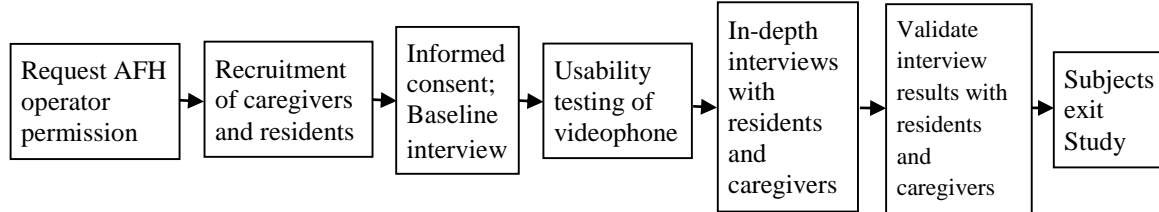
investigator to ensure consistency in the interactions. All participants were informed about this procedure during the informed consent process and permission was requested at the beginning of the videophone visits.

Post-testing Interviews

After the testing phase, the researcher returned to each AFH for an in-person visit to repeat the assessment questionnaires with AFH residents and conduct in-depth interviews with participating caregivers and residents about their perception of using the videophone for pain assessment. The videophones were removed from the AFHs at that time.

All interviews were digitally audio-recorded, and transcribed word-for-word. The interviews for AFH residents included question such as: “How helpful was it to have your pain assessed regularly during the past four weeks?” and “Please tell me about your experience with using the videophone.” For caregivers, in addition to describing their experiences with the videophone, interview questions also asked about their experience with using the PTS for pain assessment. After interview data had been analyzed for themes, participant residents and caregivers were scheduled for a final visit. To ensure fidelity and trustworthiness, as part of the final exit interview, the researcher reviewed the themes with residents and caregivers and asked them to validate their responses and confirm accuracy of the thematic analysis. The researcher also kept field notes of observations and personal perceptions and reflections throughout the study. Figure 3.2 below describes the flow of study procedures.

Figure 3.2: Flow Chart of Study Procedures



Each caregiver and older adult resident participant was given a \$50 gift card at the final interview as a token reimbursement to thank them for their time and efforts in the study. AFH operators were given the Washington Administration Code (WAC) section regarding minimum licensing requirements covering caregiver practice requirements and a resource offered by the American Geriatrics Society Foundation for Health in Aging that described caregiver guidelines for pain management, (available at www.healthinaging.org). They were also given a \$25 gift card when the study was completed as a token reimbursement to thank them for allowing the study to be conducted in their home.

Data Security and Confidentiality

Procedures that involved the AFH residents and caregivers were carried out in the AFH where they either resided or worked. The RA conducted videophone interactions from an office that ensured privacy to maintain confidentiality. Subject identities were protected by assigning a study number rather than using direct personal identifiers on data collection tools.

A risk management plan was developed in case the residents revealed inadequate or improperly treated pain related to particular caregivers during the videophone encounters or interviews. If there were observed harm or threat of harm to the resident (abuse, neglect, or exploitation) during videophone visits, this would have been reported to the Washington State

Department of Social & Health Services (DSHS), Aging & Disability Services Administration (ADSA) as required under the mandatory reporting law. This procedure was explained during the informed consent process at the initial in-person visit.

Analysis

Usability Diary data were reviewed to assess the feasibility of using videophone technology for delivering pain assessment resources. The SPSS 19 statistical program was used to produce summary statistics (frequency, mean, and range) of ratings by caregivers and residents on quality of connectivity, ease of use, and clarity. Ratings on these variables were compared among caregivers, residents and the researcher. The amount of time to train caregivers on the pain assessment tool use was described in elapsed time (mean and range). Summary statistics were used to describe demographic characteristics for caregivers and residents and resident cognition and pain rating scores.

Since the instructions and demonstrations about the videophone occurred throughout the in-person visit, the time needed for caregivers and residents to learn how to use videophone technology could not be accurately measured with a start-stop timer. Therefore, the amounts of time needed to learn the videophone were derived from proxy measures. The adjusted amount of learning time was calculated by subtracting the amount of time for informed consent and baseline interview time from the total amount of time for the visit as logged by this researcher.

Text data from baseline and post-testing interviews were analyzed using conventional content analysis procedures in which coding and identification of themes and sub-themes were derived from the text (Hsieh & Shannon, 2005). To ensure fidelity and trustworthiness, and to reduce bias of thematic analysis, caregivers and residents were asked to verify and clarify

preliminary results from textual analysis during the exit interview. This researcher also conferred with the dissertation committee chair, as a co-investigator on the study, to confirm analysis decisions.

Exploratory pilot data were collected using PROMIS surveys. The PROMIS survey raw scores were converted to T-scores according to the scoring guidelines. Then, paired sample t-tests were conducted to assess changes from baseline (Time 1, pre-intervention phase) to the end of the videophone testing period (Time 2, post-intervention).

RESULTS

A total of 24 adult family homes were contacted. Of those, 15 AFHs were willing to conduct the study in their homes, but only six homes had caregivers and residents who matched study criteria. All of the caregivers and residents who were given information about the study were screened and invited to participate. A total of six caregivers and seven residents were screened with six residents giving permission to be enrolled.

Once the six AFH operators had given permission to conduct the study in their home and both the eligible caregiver and resident indicated their willingness to participate, an in-person appointment was scheduled. During this first meeting, informed consent was completed and the resident was further screened for eligibility using the Mini-Cog, before questionnaires were administered. All resident participants scored greater than or equal to 2 and were able to maintain a coherent conversation and answer research questions.

All six of the AFHs had 24-hour on-site caregivers. Five of the homes were multi-level, and one of the homes was a single story duplex with the owner living in one side and the older

adult residents living in the other side. The distance of the participating AFHs ranged from 13 to 110 miles from the research office at the University of Washington.

Resident Demographics

The residents in this study had a mean age of 82.8 years ($SD = 7.5$), with the youngest being 74 years old and the oldest being 94 years old. Resident participants were all retired from paid work and five were female. They reported their ethnicity as non-Hispanic White ($N=5$) and being more than one race ($N=1$). Of the six participant residents, one was married, one had never been married, and four were widowed. Their highest attained educational level ranged from some high school ($N=1$) to completion of a graduate degree ($N=1$). One resident was a high school graduate and three residents had some college or technical school.

The length of time participant residents had lived in their AFH ranged from 0.04 to 4.38 years with a mean of 1.21 years ($SD=1.64$). The top five painful health conditions that study AFH residents reported were back pain ($N=6$), joint pain ($N=5$), neck pain ($N=5$), arthritis ($N=4$), and fractures ($N=4$). The complete list of health conditions that cause them pain are described in Figure BF1 in Appendix B.

Caregiver Demographics

Adult family home caregivers in this study had a mean age of 41 years and ranged from 25–55 years of age. All participating caregivers ($N=6$) were female; four were married, one was divorced, and one was married but separated. Two of the caregivers identified with two ethnic groups. One reported she belonged to both American Indian/Alaskan Native and Hispanic/Latino groups and the other identified with both Hispanic/Latino and non-Hispanic

White groups. One caregiver was Asian American, one was Hispanic, and two were non-Hispanic White.

The highest education achieved by caregivers in this study ranged from some college or technical school (N=5) to college graduate (N=1). Caregivers were employed as full time wage earning AFH caregivers (N=4) and part time direct caregivers (N=2). Three indicated they were self-employed, and one reported being a student. The amount of time each caregiver had worked in an AFH ranged from 1.3 – 5.1 years, with a mean of 2.5 years (SD=1.42). All AFH caregivers in the study were either a Registered Nursing Assistant (N=4) or Certified Nursing Assistant (N=2). Two caregivers had completed the Nurse Delegation Core Curriculum. AFH caregivers had also completed a variety of other state-required and additional training classes related to their work such as First Aid and CPR (N=6) and Food Handling and Safety (N=5). Figure BF2 in Appendix B displays a list of additional training classes completed.

Caregiving in Adult Family Homes

During the baseline interviews, residents were asked about what it is like to live in an adult family home. Caregivers likewise were asked to describe their experiences with working in adult family homes.

Residents' Perceptions of Caregiving in Adult Family Homes – Themes derived from the content analysis indicated that older adult residents felt at home in their AFH setting. They described feeling “at ease,” and being able to pursue their personal interests. They felt a sense of autonomy that was meaningful and that allowed them to do activities at their highest functional level. AFH older adult residents expressed having a sense of control over their schedule and

activities. Five of the residents had moved to the AFH from assisted living facilities, and one was residing in the AFH for rehabilitation therapy after a hospital stay.

Residents expressed feeling a sense of community where they felt accepted. They described having frequent opportunities through activities and/or interactions to build relationships with the caregivers and other residents. AFH residents perceived being able to receive accommodating assistance that could be adjusted to their level of need for different activities. They felt their caregivers were available, personal, and provided support to help them function at an optimal level. Older adult residents were generally able to exercise open communication with their caregivers about their needs and felt assured of receiving the appropriate assistance. They found their caregivers to be approachable and easy to talk to about their needs or concerns. They also found their caregivers to be trustworthy with the information they shared. Table 3.1 below lists the themes and sub-themes of caregiving as perceived by older adults living in AFH along with exemplar quotes for each theme from AFH residents.

Table 3.1: Older Adult Resident Experiences - Living in an Adult Family Home

Themes and Sub-Themes	Exemplar Quote (Resident ID)
1. Sense Of Autonomy <ul style="list-style-type: none"> • Sense Of Control 	<p><i>“I go to bed when I want to, and usually I get up when I want to.” (6R)</i></p> <p><i>“In the morning after breakfast, we usually, some of us, not that many, have exercise in front of the big TV. And then... I go in here and I keep track of certain things on my calendar and do odds and ends, clean up here and there and whatever. These things I do myself all right.” (2R)</i></p>
2. Sense Of Community <ul style="list-style-type: none"> • Relationship With 	<p><i>“It’s pretty natural, pretty at ease.” (1R)</i></p> <p><i>“I like it here. I’ve been at home...Basically [763C] makes it</i></p>

Themes and Sub-Themes	Exemplar Quote (Resident ID)
<p>Caregiver</p> <ul style="list-style-type: none"> • Relationship With Other Residents 	<p><i>very easy to be here. And I have no problem with going ahead and loading the dishwasher.” (3R)</i></p> <p><i>“I load and unload the dishwasher sometimes for her and talk to the boys... the other day-- I said ‘Hello, [A]--.’ He said ‘Hello. You’re so beautiful’, you know? Because I’ve never heard him talk that-- he doesn’t talk all that much. He talks, but, you know, and I was new, and that made me feel pretty good.” (5R)</i></p>
<p>3. Receives Accommodating Assistance</p> <ul style="list-style-type: none"> • Caregiver Is Available • Caregiver Is Personal • Able To Be At Optimal Functional Level 	<p><i>“I get ‘em to take care of me with the bell, I mean, to get up and get out of my chair.” (6R)</i></p> <p><i>“She cooks and that, and she washes my hair when I take a bath. She makes sure I don’t get in or out without her there, and then I take my bath, and then she comes in and washes my hair for me.” (5R)</i></p>
<p>4. Easy Communications</p> <ul style="list-style-type: none"> • Caregiver Is Approachable • Caregiver Is Trustworthy • Open Communication 	<p><i>“I talk direct to them. I’m clear that I don’t ask for very much right now.” (1R)</i></p> <p><i>“She is so helpful and friendly and good to everybody... When there’s something wrong with me I tell her, and I’ll talk it over with her.” (5R)</i></p> <p><i>“I’m very outspoken all right. If there’s something I don’t like, I will tell them. And usually that will work out pretty good.” (2R)</i></p>

Caregivers’ Perceptions of Caregiving in Adult Family Homes – Prior to working at their AFH, caregivers had varied backgrounds and experiences. They all chose to work in an AFH because they had a desire to care for older adults. AFH caregivers enjoyed and wanted to help people, and they found the relationships they built with AFH older adult residents to be fulfilling.

Caregivers described caregiving in the AFH to be stimulating with opportunities for learning. They looked forward to the challenges of caring for people with dementia in the AFH setting. These caregivers enjoyed the verbal and non-verbal interactions and found that caring for this population in this setting was extremely rewarding. Table 3.2 lists the themes and sub-themes of caregiver perspectives on caregiving in AFH with exemplar quotes for each theme.

Table 3.2: AFH Caregiver Perspectives on Caregiving in an Adult Family Home

Themes and Sub-Themes	Exemplar Quote (Caregiver ID)
1. Desire To Care For Older Adults <ul style="list-style-type: none"> • Enjoyment In Helping 	<p><i>“I like getting to know them, and listening to everything they’ve been through, and they’ve seen; they’ve seen a lot. I like helping them, because they are getting toward the end, and I like hospice care in particular” (761C)</i></p> <p><i>“I challenge myself as to how to take care of elderly and vulnerable adults, to learn more about them ” (763C)</i></p>
2. Sense Of Relationship <ul style="list-style-type: none"> • Being Personal • Sense Of Reward 	<p><i>“It’s the most rewarding thing I’ve ever done...instead of having 24 patients to work with, I’d rather have a few, take really good care of them, than just a mediocre job for everybody. That’s why. And I love people.” (765C)</i></p> <p><i>“I enjoyed this because it is a small amount of people...It’s more personal. And all my family is back in Michigan, so it’s like I have four grandparents here that I see five days a week.” (764C)</i></p>
3. Stimulating Variety <ul style="list-style-type: none"> • Challenging • Opportunities For Learning 	<p><i>“Every day is different...some of the residents have very advanced dementia... it’s kind of fun to see where her brain is at from day to day, and you know, even sometimes minute to minute, because sometimes she’s very lucid and she knows what’s going on, and then the next minute she’s off in la-la land again, and it makes the day interesting!” (762C)</i></p>

Themes and Sub-Themes	Exemplar Quote (Caregiver ID)
	<p><i>“After working with them long enough, you know the ins and outs and I know when I can have a full conversation or when I have to keep it with just yes and no answers, kind of thing.” (764C)</i></p>

Pain Experiences of AFH Older Adults Residents

Prior to introducing the testing of the videophone for pain assessment, residents and caregivers were asked to describe their perception of the experience and impact of pain.

AFH Older Adult Resident Pain Experiences – The older adult residents described variable levels of suffering from chronic pain that was dependent on the type and location of the pain. Their pain most often impacted the amount of activities in which they would choose to engage. Although they felt that they could talk to their caregivers about interventions that could offer pain relief, they would rather suffer in silence with the bothersome pain than become a bother to anyone else. This strategy would then result in diminished activities from intense pain before pain relieving therapies were employed. The therapy of choice by participating residents was most frequently a medication. However, they would also utilize complementary alternative therapies if and when they were available. Table 3.3 lists the themes and sub-themes and exemplar quotes from AFH older adult residents about their pain experiences.

Table 3.3: AFH Older Adult Resident Pain Experiences

Theme and Sub-Themes	Exemplar Quotes (AFH Resident ID)
1. Chronic	<p><i>“It varies all right. My shoulders do bother me quite a bit.</i></p>

Theme and Sub-Themes	Exemplar Quotes (AFH Resident ID)
<ul style="list-style-type: none"> • Interfering • Bothersome 	<p><i>And then I have some really tight muscles, which are not very good.” (2R)</i></p> <p><i>“On a typical, well, today, I’m not real comfortable, but I’ve hurt a lot worse and still make it through the day...” (3R)</i></p>
<p>2. Diminished Functional Ability</p> <ul style="list-style-type: none"> • Decreased Activities • Need More Assistance 	<p><i>“Mainly it stops me, and when I get the pain in my knee, I just stop doing anything for a while... I’m starting to use the walker to cut down on the pain when it comes” (1R)</i></p> <p><i>“Well, it stops my walking sometimes... if they see me sitting around, what am I doing, how come?” (4R)</i></p>
<p>3. Suffering in Silence</p> <ul style="list-style-type: none"> • Does Not Verbalize • Does Not Want To Be A Bother 	<p><i>“I don’t really say too much to her about it, because there’s nothing she can do that’s going to take it completely away.” (3R)</i></p> <p><i>“But my legs, like I said, ache sometimes...Even if I don't feel good I play...I try to keep on” (5R)</i></p> <p><i>“I don’t bother anybody, and I don’t bother the girls that takes care of me...” (6R)</i></p>
<p>4. Multi-Modal Interventions For Pain Relief</p> <ul style="list-style-type: none"> • Medication • Complementary Therapies • Positive Talk 	<p><i>“I just have certain medicines lined up that my daughter takes care of... I have somebody coming here every two or three weeks give me reflexology. That’s pretty good. And then lately she’s been giving me Indian head massage... when I come home from the chiropractor, I use ice packs.” (2R)</i></p> <p><i>“For me, it works. And I tell myself, this is working. My theory is, I’m not saying it works for everybody, honey, but for my theory, and it works for me is, if you dwell on it, it’s going to hurt worse. And I don’t get the “Woe, oh woe is me.” Well, maybe tomorrow in the day the sun will shine. Maybe if it’s nice enough I can go for a walk.” (3R)</i></p>

Caregiver Perceptions of Older Adult Resident Pain Experiences – Caregivers described their residents as having a wide range of functional abilities from complete independence needing minimal assistance to complete dependence requiring assistance with all activities of daily living. Often residents did not report or verbalize that they were having pain, but caregivers would observe diminished activities when residents were suffering from pain. Their non-verbal bedbound residents would display physical cues through facial expressions or pain avoidance behavior. Some even had a hypersensitivity to usual activities and cried out or vocalized. The caregivers would follow each resident’s prescribed pain management plan related to medications. They emphasized that there were strict regulations governing what AFH caregivers may assist residents with in regards to pharmaceutical agents. More frequently, they would try repositioning, massage, aromatherapy, ice, and heat as pain relieving measures for residents. Table 3.4 lists the themes and sub-themes with exemplars quotes from caregivers about AFH older adult resident pain experiences.

Table 3.4: AFH Caregiver Perceptions about Older Adult Resident Pain Experiences

Theme and Sub-Themes	Exemplar Quotes (AFH Caregiver ID)
1. Diminished Functional Ability <ul style="list-style-type: none"> • Decreased Activities • Hypersensitivity 	<p><i>“They don’t move as much, they don’t walk as fast, but it doesn’t totally inhibit.” (764C)</i></p> <p><i>“The Alzheimer one will be...very pain sensitive. If you just touch her, it hurts, everything hurts for her...so her pain level is very very high.” (763C)</i></p>
2. Change In Body Language <ul style="list-style-type: none"> • Non-Verbal Cues • Facial Expressions • Pain Avoidance 	<p><i>“I have a resident who has pretty severe contractures in her left hand, and both legs, but, the left hand especially. She’s also my non-verbal, so, I can tell when she’s in pain ‘cause she’s holding on to it. And she’s kind of nursing it, or, she’s</i></p>

Theme and Sub-Themes	Exemplar Quotes (AFH Caregiver ID)
<p>Behavior</p>	<p><i>kind of huddled around it.” (762C)</i></p> <p><i>“The one lady that doesn’t really communicate...she’ll hold her head and she’ll kinda get a really scowly kind of face, and so we assume she has a headache.” (764C)</i></p> <p><i>“If he is moving around a lot, because I think he’s trying to get comfortable and can’t, or something hurts, he’s trying to get away from it.” (765C)</i></p>
<p>3. Suffering In Silence</p> <ul style="list-style-type: none"> • Resident Do Not Report/Verbalize Pain 	<p><i>“They won’t tell you, so if they are grimacing or if they are grabbing their leg...that’s how I can usually tell” (761C)</i></p> <p><i>“She doesn’t really tell us when she’s in pain...We kind of assume that she’s in pain.” (762C)</i></p>
<p>4. Use Of Non-Pharmaceutical Therapies For Pain Relief</p> <ul style="list-style-type: none"> • Use Of Positioning • Complementary Therapies (e.g., heat, ice, aromatherapy, massage) 	<p><i>“When this is leg pain, I put them on the chair or tell them lay down right away and put their legs up. Or when it’s on the back, I put them on the more comfortable place to relieve the pain.” (766C)</i></p> <p><i>“Some of them have physical therapy and range of motion exercises to keep things loose and not contracted...they have pain medication, and sometimes just repositioning them, calming things help them sometimes, like we have an aromatherapy bear that can help relax them a little bit.” (761C)</i></p> <p><i>“We do warm washcloths on foreheads, or you know, icepacks, that kind of thing.” (764C)</i></p> <p><i>“Music really helps calm one of my clients...Warm blankets work...Quiet is important. If the TV’s on, I turn it off. Because sometimes nothing is better.” 765C</i></p>

Testing Feasibility of Using Videophones in Adult Family Homes

The caregivers and residents of four homes selected the desktop unit and two dyads chose the TV projection unit based on residents' preferences. The maximum amount of time to set up and provide videophone instruction was 2 hours and the minimum amount time was just under 45 minutes. The time needed for set up was influenced by the complexity of the physical location in the AFH where the videophone unit was placed. Table BT3 (Appendix B) provides the adjusted set up and instruction times with comments from the field notes for each home.

The maximum amount of time needed by the research assistant to set up and conduct the video call was approximately 2 hours. The minimum amount of time needed for the research assistant to set up and conduct the video visits was one quarter of an hour. The average length of time decreased with each progressive weekly session during feasibility testing.

Video Call Duration

A total of 25 video call visits were conducted, excluding the initial interview visit when the researcher taught caregiver-resident dyads how to use the videophone units while introducing them to the research assistant who would be conducting the weekly sessions. Research assistant video call times were measured using a timer, and caregiver and resident measures were by clock time or recall.

During the first session with AFH 1, the resident was called away to a treatment appointment without notice and was not able to participate on the call with the caregiver to assess the pain intensity score with the Pain Thermometer Scale (PTS). A second appointment was made for the following day for the dyad to complete the interaction. Therefore, AFH 1 had one additional videophone diary entry by the caregiver.

Mean call duration reported by caregivers was 6.63 minutes (S.D. 3.86), whereas resident reported mean call duration was 7.7 minutes (S.D. 3.46). The average length of video calls from the research assistant diary was 9.05 minutes (S.D. 3.75). The minimum length of video call visits was 2 minutes, and the maximum video call length was almost 16 minutes.

Video Call Connectivity: Establishing Connection

Connectivity was measured in terms of how difficult it was to establish the connection, interference during the video call, and clarity of the connection. Residents were not involved with establishing the video call connection, so they did not have that question on their diary page. Therefore, there were a total of 48 diary entries between the RA and caregivers' records. According to the research assistant's diary entries, 88% of the calls did not have any difficulty with establishing a connection. Caregivers reported that 74% of video calls did not have any difficulty with the connection. Only two entries noted that there was "a little" difficulty with establishing the video connection.

Video Call Connectivity: Interference

Call connections were tracked for interference for the duration of each video visit. There was one unexpected disconnection noted, and it was due to RA operator error and not equipment malfunction. Caregivers experienced minimal or no interference in 76% of the video calls, and one call was rated as "very much" interference.

Video Call Connectivity: Clarity

Once the call was established, caregivers and residents as well as the research assistants all rated the clarity of the connection. There were a total of 74 diary entries. Two connections

(2.7%) were considered “fair.” The remaining 72 (97%) were rated as good to excellent. Other measures of the clarity of the video calls were sound and picture quality.

Sound Quality – Sound quality was rated on a Likert-like ordinal scale labeled poor, fair, good, very good, and excellent. Most video visits were rated as good to excellent on sound quality (N=73 records, 98.6%).

Picture Quality – Picture quality received four records of being “fair” (5.41%) but the remaining 70 records reported good to excellent picture quality (94.6%).

Technology Usability: Ease of Use

Caregivers and residents all rated the videophone technology as easy or very easy to use (N=48 records). However, one resident noted that she did not like to use it at all. One caregiver chose the neutral response for each video visit. Reasons for these ratings were later explored during the qualitative interview (reported later in this chapter).

Technology Usability: Level of “Like” for Use of Videophone Technology

All caregivers were neutral or liked using the videophone for enhanced telephone visits. However, some resident entries rated “not at all” in response to whether they liked using it (N=4; 8.3%). Resident perceptions of videophone technology and its uses were explored during the qualitative interviews after the testing phase.

Delivering Educational Resources on Pain Assessment

The amount of time used to teach the Pain Thermometer Scale (PTS) was measured from the start of introducing the tool to when the caregiver had no questions remaining about using the tool and was able to demonstrate using the PTS with the resident. On average, it took just under

5 minutes to instruct caregivers on the use of the PTS and have them use it with their partner residents (Mean=4.97 minutes, SD=0.65). The minimum amount of time used was 4.08 minutes and the maximum was 6 minutes.

Use of the PTS during videophone visits was measured from the time the caregiver began interaction with the resident to show them the PTS to the time they received a rating response from the resident and reported this to the researcher. During the first videophone visit, this time was incorporated into the total time for the first teaching session. All residents reported spending approximately one minute to report their pain intensity score using the PTS during each videophone visit. Caregiver diaries indicated using approximately one minute to use and report pain ratings (Mean=1.25 minutes, SD=0.37), and the average time the research assistant recorded was 0.81 minutes (SD=0.46).

Caregivers and residents were asked to rate how much they liked using telehealth technology to report pain scores. Rated on a Likert-like scale, almost all caregivers and residents (47 diary entries, ~60%) reported liking it; 16 (34%) were neutral towards using this technology for reporting pain; and four entries (8.5%) by residents logged “not liking it at all.” These responses were explored during the post intervention interviews.

Pain Thermometer Scale: Pain Intensity Scores

Pain intensity scores were collected at each video call session as part of the standardized interaction. Residents’ reports ranged from no pain to moderate pain. One resident used the visual analog portion of the scale to indicate pain level along the color gradient, which equated to a numeric rating of 1.5 or approximately half the distance between mild to moderate pain.

Caregiver assessment of resident pain level were correlated to residents' reports (Pearson's $r=1.00$, $N=24$ resident diary records, $p=0.53$).

Experiences and Perceptions of Telehealth Pain Assessment with Videophone Technology

During the post-intervention interviews, participants described their experiences, explained their diary entries, and provided insights regarding telehealth and telehealth technology. Themes discovered through content analysis were reviewed and confirmed with caregivers and residents during the exit interview. In general, caregivers and residents expressed ease of use with videophone technology for pain assessment and the PTS used for this study. They were enthusiastic about testing an innovative approach to health care and found the experience to be enjoyable while making a contribution towards future technology usage in adult family homes. They felt that the technology worked well despite the time required for the videophone to 'line adjust' in order to connect the calls. Caregivers and older adult residents considered these to be minor issues.

Telehealth Pain Assessment: Resident Perspectives

The residents liked using the videophone units for pain assessment, but they were somewhat irresolute about adopting this technology. Themes that described residents' experiences and perception of using videophone technology for pain assessment included an overall positive impression of using technology. Residents reflected that the videophone was an effective tool that provided a visual connection and gave access to health care. They described variable engagement during the video-calls and were uncertain about adoption.

Older adult residents described an overall positive impression of using technology for pain assessment with an emphasis on the innovative approach to being able to communicate with

healthcare providers. There were overarching references to the importance of innovative solutions, and the applicability of having technological options. Participating residents felt that using videophone technology for pain assessment is relevant and has great potential for further uses. They found the videophone to be an effective tool that was easy to use, convenient for receiving a timely response, and almost seemed like they were talking in-person. Residents expressed that using the PTS for pain assessment gave them an opportunity to reflect upon how best to describe their pain. They described the experience as providing better access to health care by bridging the geographic distance they would have to travel to see their respective healthcare providers. They felt that videophone visits were not a bother and could substitute for some office visits. They explained that having the video in addition to the regular telephone call gave them a visual connection that was personal and enjoyable and seemed to be more accommodating than the simple phone call. Since they were not responsible for setting up the videophone call, residents described being engaged but at varying levels, from passive to dynamic. Despite the positive comments about using the videophone, residents expressed some uncertainty to using the device themselves. Even though they said that it seemed to be easy to use, they consistently described this technology as something for the future and for people with more knowledge than they had.

Table 3.5 below lists the themes and sub-themes that describe residents’ perceptions about using the videophone for telehealth pain assessment and exemplar quotes for each theme.

Table 3.5: Telehealth Pain Assessment: AFH Resident Experiences and Perceptions

Themes and Sub-Themes	Exemplar Quotes (Older Adult AFH Residents)
1) Overall Positive Impressions <ul style="list-style-type: none"> • Important 	<p><i>“I think it is important” (1R)</i></p> <p><i>“I think that’s wonderful, absolutely, yeah. But it seems still too</i></p>

Themes and Sub-Themes	Exemplar Quotes (Older Adult AFH Residents)
<ul style="list-style-type: none"> • Applicable • Relevant • Has Potentials 	<p><i>far-fetched, but then this is something you're thinking of in the future... there's not all that much they can do for my pains, uh-huh. But now in the case with all my stomach trouble and all that, they could maybe come in handy.</i>" (2R)</p> <p><i>"Great to know that they can use that thing in everyday life with the questions and answer periods...I think it'd be great if you have the right personnel to use it, people with their own knowledge."</i> (4R)</p> <p><i>"I feel like I experienced it."</i> (1R)</p> <p><i>"On a whole it was pretty good. I'm not used to computers or anything... I think it was a good idea."</i> (5R)</p> <p><i>"I liked it. You know, to help someone."</i> (3R)</p>
<p>2) Effective Tool</p> <ul style="list-style-type: none"> • Easy To Use • Invitation For Reflection • Timely Response • Convenient • As Though In Person 	<p><i>"It seemed an easy way to separate out any experiences people were having, it worked well, for as far as I could tell... I think anytime we encourage a person to be specific about their pain experience, then we stand a better chance of being able to alleviate it."</i> (1R)</p> <p><i>"Well, that was pretty easy as far as that goes. I just told them what was bothering me, but I wasn't hurting that bad really whenever."</i> (2R)</p> <p><i>"And she gave you a chance to think through it before you answered. And I appreciated that because sometimes I started to say something and I can't remember what it was I was going to say. And I think a lot of times it was because I wasn't used to it on the radiophone and you know things like that."</i> (3R)</p> <p><i>"Real easy, 'cause I don't have a lot of pain."</i> (4R)</p>
<p>3) Access To Health Care</p> <ul style="list-style-type: none"> • Bridging Distance To Healthcare Providers • An Alternative For In-Person Meeting • Usage Not A Bother 	<p><i>"It was kind of nice to see the person's face that you're talking to...I'm not a computerized person, so... Well, I'd kind of rather talk to my doctor in person, go over there. If you can't get over there, I guess you could do it... It was all right."</i> (5R)</p> <p><i>"So, you know, something like that, as long as I can talk to a nurse practitioner, then that's okay with me, too."</i> (2R)</p>

Themes and Sub-Themes	Exemplar Quotes (Older Adult AFH Residents)
	<i>"It didn't bother me that much." (4R)</i>
<p>4) Visual Connection</p> <ul style="list-style-type: none"> • Enjoyable • Personal • Accommodating 	<p><i>"I liked the personal, transmitting your image, it made it seem personal." (1R)</i></p> <p><i>"That was quite nice to be able to see who you're talking to." (5R)</i></p> <p><i>"Oh yes, I enjoyed seeing the other person." (6R)</i></p> <p><i>"Because you were right there, you didn't have to stop and did I say this or did I say this? See what I'm saying? It was right there and all, you could turn it back and you could hear it." (3R)</i></p>
<p>5) Variable Engagement</p> <ul style="list-style-type: none"> • Passively Engaged • Dynamic Interaction • Simple 	<p><i>"I just sat there...It's just sometimes I had a hard time hearing, but then they got it turned up a little bit so I could hear better... it was fine." (2R)</i></p> <p><i>"Well, just like we did when they were there, back and forth, talking to the girl, talking to you..., I think it was just a regular question and answer period." (4R)</i></p> <p><i>"Well [766C] did most of the talking over the video,...it was alright" (6R)</i></p>
<p>6) Uncertainty About Adoption</p> <ul style="list-style-type: none"> • Hesitant With The "New" • Want For Additional Knowledge • Need For Practice 	<p><i>"It might be good in the future there, whatever... Well, right now, the technology are not up to where you want it to be, so I don't know... Like I say again, a specialist like that would not talk to you about your pain. See, that's just so far-fetched, for me anyway, that it is hard to say." (2R)</i></p> <p><i>"Well, I thought it was good, but I'd like to have tried it, tried it before I used it for the first time, you know." (3R)</i></p> <p><i>"Not for me personally ... Trying to do something that I didn't know how to handle it... It wasn't that hard a thing. It wasn't a bad experience... Just like everyday life, nothing that required special knowledge or something like that.... That was all new experience to me... I didn't realize it as very hard. I think it takes a lot of experience to work with it or use it properly... 'cause I never did anything like that in my life time" (4R)</i></p> <p><i>"When you're looking right at somebody, it's really hard for-- I don't know what to say. I think it would be a good idea the way</i></p>

Themes and Sub-Themes	Exemplar Quotes (Older Adult AFH Residents)
	<p><i>modern medicine goes. But I'm not really up on any of this stuff"</i> (5R)</p> <p><i>"There was nothing that I didn't like about it...Well it didn't bother me at all. I don't know if that means anything or not but it didn't bother me."</i> (6R)</p>

Telehealth Pain Assessment: Caregiver Perspectives

Caregivers described similar experiences to their paired residents; however, they were more active and directly involved in the video call visits. Caregivers expressed readiness to adopt this technology for bridging distance and improving access to healthcare providers for their residents. They also described how this device could improve their access to educational resources at the point of care to increase application of interactive didactic instructions. Themes for caregiver experience with the videophone intervention and perception for telehealth included effectiveness, convenience, visual connection, improved access to care, clear communication, impact on care giving, and potential for cost savings. Caregiver descriptions of their experiences focused primarily on how use of this technology would benefit the care of AFH residents. The caregivers consistently framed their positive perceptions in terms of potential usefulness in the AFH setting. Themes and subthemes that describe caregiver experiences with videophone technology for pain assessment and their perception of telehealth are listed in the table below with exemplar quotes.

Table 3.6: Telehealth Pain Assessment: AFH Caregiver Experiences and Perceptions

Themes and Sub-Themes	Exemplar Quotes (AFH Caregivers)
<p>1) Effective</p> <ul style="list-style-type: none"> • Easy To Use Technology 	<p><i>"This is really easy, you just push a button, and there wasn't any problem with the connection, it's really very simple to use."</i> (761C)</p>

Themes and Sub-Themes	Exemplar Quotes (AFH Caregivers)
<ul style="list-style-type: none"> • Useful For AFH • Timely Measure Of Pain 	<p><i>“There were some hiccups but it was pretty easy to work around and no, I don’t see anything negative about it.” (762C)</i></p> <p><i>“It’s very ideal for adult family home to have that kind of unit, notifying the doctors, notifying whoever” (763C)</i></p> <p><i>“It’s good...because the resident can explain to the nurse by the videophone exactly where she’s having the pain and how kind of pain she have...and also the nurse can see that. And it’s much better...on the thermometer scale, the resident is showing us exactly no pain, moderate pain, more pain and et cetera, et cetera, et cetera, but that is nice, it’s more easy for me.” (766C)</i></p>
<p>2) Convenient</p> <ul style="list-style-type: none"> • Accessible To Resident • Flexible 	<p><i>“If we were reporting, any kind of symptoms to the doctor or nurses and it’s easier for the residents to express their symptoms through the video, using the video. It’s very convenient for them that they don’t have to go out and make an appointment and whatnot.” (763C)</i></p> <p><i>“I knew that at that time we could have the interaction and it was just a matter of push a button and do your thing. I found it very easy; I really liked that.” (765C)</i></p>
<p>3) Visual Connection</p> <ul style="list-style-type: none"> • Personal • Image Recognition • Interactive • Enjoyable 	<p><i>“Well, just being able to put a face with a stranger...talking to somebody on the phone that I’ve never met and yet I can see them. ... that was really nice.” (762C)</i></p> <p><i>“I liked being able to talk to the person, know who I was talking to, and it wasn’t just a conversation; they were able to see us as well as us see them.” (764C)</i></p> <p><i>“What I really liked about it was the ability to actually talk to someone, it’s not like a canned recording that you’re working from, you’re actually interacting with a person face to face and I found that very good. I like that in any interaction.” (765C)</i></p>
<p>4) Impact On Access To Care</p> <ul style="list-style-type: none"> • Bridging Distance To Healthcare Providers • Alternative For In-Person Visits 	<p><i>“I liked that a doctor or nurse could just look over and see the resident, instead of dragging them off to a doctor’s office, ‘cause that’s really hard on them, especially if they have dementia” (761C)</i></p> <p><i>“I feel like she thinks ...she’s getting the answer right away, and</i></p>

Themes and Sub-Themes	Exemplar Quotes (AFH Caregivers)
<ul style="list-style-type: none"> • Relevant • Instant 	<p><i>talking to the doctor's office in video, ... Like, in face-to-face...The connection was very good...as soon as you call, turn it on and we'll just turn the button on, we can see your face.” (763C)</i></p> <p><i>“We have four people with dementia... Getting them dressed and out the door and in a car and out in public and waiting at a doctor's office...for them it takes out hours of their day. They feel it six, eight, ten hours later, the aggravation and-- it makes them anxious. Whereas with the video ... they wouldn't have to leave; they could stay in the privacy of their bedroom; and yet still see a doctor or a nurse.” (764C)</i></p>
<p>5) Clear Communication</p> <ul style="list-style-type: none"> • Concise • Accurate • Complete 	<p><i>“Using that video will allow her to notify how much pain she’s on for that moment.” (763C)</i></p> <p><i>“But with the thermometer scale, it was easy for her to kind of tell-- pointing out on the actual thermometer rather than just saying, "No pain"-- rather than me just reading all the words, she could actually, "Well, it's about here." So that was nice.” (764C)</i></p> <p><i>“I was able to get the information, ask the information and relay it back easily. So it was effective because it was clear what was expected... Easy to clarify so it keeps the information real and accurate I think.” (765C)</i></p> <p><i>“Because sometimes it's very hard for us to explaining the nurse exactly where the resident has pain. In the video we can say... in the leg, maybe right here or maybe any part of the body. That is the only difference between just the regular phone call than the video because she's showing us exactly how to using that one...it was nice.” (766C)</i></p>
<p>6) Impact On Care Giving</p> <ul style="list-style-type: none"> • Resident Engagement <ul style="list-style-type: none"> i) Decreased Anxiety ii) Higher Satisfaction • Caregiver Engagement <ul style="list-style-type: none"> i) Resident 	<p><i>“I think it was really easy, and I think it was really easy for the resident to understand.” (761C)</i></p> <p><i>“It is more advantage using the video, especially when their anxiety or whatever complaints they have that moment. The feeling of them to talk to someone besides me, helps</i></p>

Themes and Sub-Themes	Exemplar Quotes (AFH Caregivers)
Advocacy ii) Educational Resource Access	<p><i>tremendously, they feel like they were important.” (763C)</i></p> <p><i>“We enjoyed it. [4R] looked forward to it, and she felt bad that she didn't have any pain...Because for her, a month ago, before we started doing this-- she would wake up and, "My knees hurt. I need a pill." There was no, "It hurts a little," "It hurts a lot." It was just, "I need a pill." And after doing this the last time, "Well, maybe I should have waited. Maybe I could have walked a little bit first." ...So I think she enjoyed it for sure." (764C)</i></p> <p><i>“I can see the nurse to the other side so maybe, I can explain better or showing the place the resident has pain, that's it.” (766C)</i></p> <p><i>“I like it because ...to learn from the new technology that's being provided... it's always helpful for a provider to get some additional education, any kind... And the other advantage is using the scale ... or their anxiety level of scale ... it has more advantage for us, for a provider for adult family home ... to be able to help the residents.” (763C)</i></p>
7) Potential Cost Savings <ul style="list-style-type: none"> • Decreased Travel • Reduce Lost Work Time 	<p><i>“I think it would be beneficial, especially for those of us in the adult family homes, because we have to have so many hours per month per year of training, ... you could come in early or stay late and just do it here and not have to worry about the traveling and the missing work and-- because with the adult family homes, it's very small staff so it's hard to get time off for those kinds of things. So if you had the video class that you could just do it anytime, it would be nice.” (764C)</i></p> <p><i>“The technology was excellent; I really liked it... for me going to places to learn things, not easy and expensive. I have to hire someone to come in, I have to be able to trust them and I only have a few hours a week that I cannot be here, so for me it is like, it's worth everything. It's very convenient... Most people would use the Web over this; I prefer this... I like that it didn't take long because I'm all about whatever in five minutes, I can always find five minutes. An hour and five minutes, that would be hard.” (765C)</i></p>

In addition to sharing their experiences and perceptions, caregivers provided recommendations to consider when using this technology. Caregivers from homes that used the desktop videophone units suggested that although the screen size was quite adequate for this feasibility study, a slightly larger screen would provide more appreciable visualization for future educational offerings, especially if there might be complex visual content. Another consideration they raised was the applicability of using video interactive calls for their residents with more advanced Alzheimer's dementia. Some caregivers noted that these residents may not always be able to discern the difference between live interactive video calls from television programs. They may also be confused by the projection of their own image during the call because they might not recognize themselves.

Resident Health Status (Exploratory Aim)

Pilot data on the health status of participant residents were collected using PROMIS surveys (described in the Methods section). One of the residents was not available to complete the post intervention interview or complete the PROMIS surveys when the researcher returned to remove the videophone unit from the AFH. The resident had been hospitalized and was not available for 3 months. Upon their return to the AFH, the researcher was able to conduct the post-intervention interview during the same visit as the exit interview with the paired caregiver. However, the PROMIS surveys were not administered due to the length of time since the intervention phase and the interim alterations in health status. Therefore, there were data for six sets of pre-intervention PROMIS surveys and five sets of post-intervention surveys.

The mean pain interference score was 53.78 (SD=8.23) at baseline and 56.14 (SD=9.12) post intervention. The baseline and post-intervention mean Pain Behavior scores were 56.85 (SD=2.91) and 57.44 (SD=3.96), respectively. Scores from the Global Questionnaire were reported separately as Global Mental Health (GMH) and Global Physical Health (GPH). The mean baseline GMH score was 44.77 (SD=5.89) and mean post-intervention GMH score was 41.1 (SD=3.75). The mean scores for GPH were 39.50 (SD=4.94) at baseline and 37.36 (SD=2.45) post-intervention. Using the formula outlined by Revicki et. al. (2009), the EuroQoL (EQ-5D) quality of life scores were calculated. The mean baseline EQ-5D was 0.61 (SD=0.08) and mean post-intervention EQ-5D was 0.59 (SD=0.02). None of the measures showed statistical significance between baseline and post intervention. Detailed descriptive statistics can be found in Table BT5 in Appendix B.

DISCUSSION

This dissertation study is the first to assess the feasibility of using telehealth technology for delivering a structured educational intervention about pain assessment for AFH caregivers. Results of this study provide points of consideration for development of patient-centered technological devices. Furthermore, results from this study have implications for the design and delivery of health care educational resources for caregivers in AFHs.

Study results demonstrated that it is feasible to use videophone technology for delivering educational resources to direct caregivers in AFHs. Caregivers and their partner residents rated the technology to be very easy to use with minor connectivity issues that were easily resolved. Use of videophone technology for telehealth could improve care giving for older adult residents

by bridging their access to healthcare providers regardless of actual physical distance. During the post-intervention interviews, caregiver and resident participants expressed that they liked using this simple technology over more advanced sophisticated telehealth technology. Although some caregivers have used computer technology for learning materials previously, interestingly, they found the simplicity of the videophone to be more “user-friendly” and adaptable for the AFH setting.

Caregiving in Adult Family Homes

A total of six caregiver from six different AFHs were enrolled to do telehealth feasibility testing. With the varied types of past work experiences, participating caregivers were well qualified to speak to caregiving in AFHs and their observations of older adult resident pain expressions. Caregivers in this study chose to work in an AFH because they had a desire to care for older adults and found their relationships with AFH residents to be extremely rewarding and fulfilling. Despite some of the negative portrayal of AFHs in the media (Berens, 2010), reflections from participant caregivers about their own positive attitude towards caring for older adults were harmonious with residents’ perceptions of the quality of care they received in their AFHs.

One study reported by the Paraprofessional Health Institute (PHI) found that the level of job satisfaction was strongly associated with direct care workers’ intent to stay at or leave their jobs. Those researchers found that 35% of home health aides intended to leave their positions within the following year (Seavey & Marquand, 2011). The results of the current study showed that AFH caregivers do not report that level of dissatisfaction. Participating AFH caregivers have worked in an AFH for an average of 2.5 years and reported in interviews that they have

found their work to be extremely rewarding. Interestingly, five of the residents in this study had moved to their AFH from large assisted living facilities and one was residing in the AFH for rehabilitation therapy after a hospital stay. Notably, residents and caregivers in this study expressed satisfaction with the AFH setting unlike studies that examined larger long-term care facilities (Williams et al., 2008; Zimmerman et al., 2007).

The assessment of care giving in the AFH setting revealed that residents felt at home with a sense of autonomy that was meaningful and allowed them to do activities at their highest functional level. They felt a sense of community and had opportunity to build relationships with caregivers and other residents. Resident descriptions of their lived experiences in the AFHs were consistent with the principles of aging-in-place as explained by Heumann and Boldy (1993) where older adults could live autonomously in housing with appropriate levels of assistance that would prevent a costly, traumatic, or inappropriate move to a dependent care facility.

Pain Experiences of AFH Older Adults Residents

The pain experience was common to older adults in AFHs based on results in Study 1 (described in Chapter 2). This was consistent with previous studies and epidemiological surveys to determine prevalence of pain in older adults (Fox et al., 1999; Gibson & Lussier, 2012; Miller & Talerico, 2002). The residents in this study described variable levels of suffering from chronic pain that were dependent on type and location of the pain, which often decreased their ability to engage in activities. To relieve their pain, the residents seemed to prefer primarily pharmaceutical interventions, but some also utilized complementary therapies. Correspondingly, caregivers described using non-verbal assessment of pain as they observed diminished activity level when residents were suffering from pain. They also expressed that some of the pain

assessment tools they previously used did not always adequately provide accurate pain levels that reflected levels of suffering. However, they found the PTS easy to use and felt that the visual cue on the tool enhanced the ability for residents to communicate their pain levels. Although caregivers were required to follow prescribed pain management plans within the boundaries of state regulations, they also utilized comfort measures such as repositioning, massage, aromatherapy, ice, and heat as pain relieving measures for residents.

Testing Feasibility of Using Videophones in Adult Family Homes

Adult family videophone home test sites were located between 13 and 110 miles from the research office where the video call visits originated. Although several of the test homes were in urban locations, caregivers and residents expressed that there are benefits to using videophone technology in place of some of the in-person office visits. Caregivers also perceived that the time needed for setting up the videophone equipment was reasonable and could be accomplished without difficulty within their AFHs. The potential application of videophone technology as expressed by AFH caregiver and residents support its usefulness and have implications for health care organizations that provide oversight for care of older adults in the AFH setting.

A total of 25 video call visits were conducted, and caregivers, residents, and the RA all recorded the call lengths. However there were variances among the average call length reported by each group. The differences between the reported call lengths could be attributed to difference in methods of time measurement and the variable levels of involvement among participating residents. The RA's call length was measured using a digital timer and therefore was most likely to be the more accurate measure. It was reasonable that the RA had the longest average call length since the RA initiated all video calls and would have been connected prior to

caregivers and residents. Caregiver and resident call lengths either were determined by clock reading or by recall, which was a valuable assessment of their perceived call length rather than actual duration. Residents had the greatest variation in call lengths among the three groups of records. This was consistent with results from resident interview data about their videophone experiences. None of the residents participated in setting up the call or managing the equipment during any of the calls. Some residents were present as the calls were connected and others joined in after the calls had begun. Caregivers were always responsible for managing the equipment during the video calls.

Based on diary records from caregivers, residents, and the RA, most of the video calls did not have any connectivity issues and had minimal problems with line adjustment or interruptions. Clarity of the calls, sound quality, and picture quality were rated as good to excellent. All participants rated the videophone technology as easy or very easy to use. Caregivers were neutral or liked using the videophone for enhanced telephone visits while most residents rated that they “somewhat liked” using the videophone. Although responses were generally positive, it would have been difficult to determine the appropriateness of videophone technology as a platform for telehealth pain assessment if these ratings were the only results. However, post-intervention interviews with participating caregivers and residents provided greater insight into their perceptions toward using telehealth technology. Their reflections and explanations belied some of their less positive diary ratings. This substantiates the body of research that warns researchers to consider the numerous factors that influence a response. For this study, using only the diary records would have been insufficient evidence for determining feasibility.

Triangulation using qualitative interview data was necessary for a more robust determination of

feasibility and better understanding of AFH caregiver and resident perception of telehealth technology.

Experiences and Perceptions of Telehealth Pain Assessment with Videophone Technology

Content analysis of post-intervention interviews with caregivers and residents revealed themes that described their experience and perception of telehealth pain assessment using videophone technology. In general, caregivers and residents expressed ease of use with videophone technology for pain assessment and the PTS used for this study. They were enthusiastic about testing an innovative approach to health care and found the experience to be enjoyable while making a contribution towards future technology usage in adult family homes. The residents' perception that it would require a lot of knowledge about technology in order to use the videophone units could have resulted from not having a role in managing the videophone equipment during the calls. Several residents felt that they were supposed to be primarily passive participants or observers and were only actively involved during the pain assessment portion of the interaction.

Caregivers described similar experiences to their paired residents; however, they were more active and directly involved in the video call visits. They described how this device could improve their access to educational resources at the point of care to increase application of interactive didactic instructions. Caregivers expressed more readiness to adopt this technology for bridging distance and improving access to healthcare providers than their paired residents. Caregivers' expressed desire for self-improvement were primarily framed in terms of their goal to provide better care for their residents. These caregiver-expressed intentions seemed like a fitting extension of their attitude toward caregiving, as revealed during the baseline interviews.

On average, it took just under 5 minutes to instruct caregivers on the use of the PTS and have them use it with their partner residents (range 4.08 to 6 minutes). All residents reported spending approximately one minute to report their pain intensity score using the PTS. The majority of resident and caregiver reports (N=27, 60%) expressed liking to use telehealth technology to report the PTS score. Since residents tend to suffer in silence rather than bother their caregivers with complaints about pain, it is possible that residents' positive attitude about telehealth reporting of their PTS score was influenced by the intervention itself. In other words, their "like" for reporting over telehealth could have been due to 'liking' that they were asked about their pain.

Pain intensity scores were collected at each video call session as part of the standardized interaction. Residents' reports ranged from no pain to moderate pain. Twelve of the 24 sessions (50%) recorded no pain, and the remaining records ranged from mild to moderate pain. This finding was somewhat inconsistent with the reported frequency of pain during enrollment. However, during the post-intervention interviews, caregivers and residents revealed that after being instructed on the use of the PTS, residents seemed to be more aware of their pain levels and would request pain medication such that their pain was well controlled during a majority of the video calls with the RA and resulted in their reports of "no pain".

Resident Health Status (Exploratory Aim)

The exploratory PROMIS pain data did not show statistically significant change from baseline to post-intervention. This study had a very small sample and did not have sufficient power to accurately determine change from baseline to the end of the testing period. According to Vickers (2001), the use of percentage change from baseline would not be sufficient even in

randomized controlled trials. In addition, this study was conducted over a period of 4 weeks, which may not have been sufficient time to demonstrate significant changes in pain behavior or interference scores. It was also not expected that there would be much change in the residents' global health scores. It is possible that given a longer duration and larger sample size, there could have been significant changes in the PROMIS measures.

Study Limitations

Limitations for this study included having a small sample size, and a short intervention period (4 weekly interactions). The results of this study did not have measures of potential longitudinal effects of continued video interactive pain assessment of older adults. The testing sites were selected from AFH owners who responded to the first study about technology usage (Chapter 2); therefore, it is possible that they may have had a predilection towards using a new technological device. Related to the qualitative portion of the study, the sample size for this pilot feasibility study was small with six dyads. However, results from this study was consistent with the literature which has suggested that thematic saturation of qualitative interview data can be reached with a relatively small sample size (Guest et al., 2006). Another limitation was the use of indirect measures to determine the amount of time needed to teach AFH caregivers how to connect and use the videophone unit. This decision was made when this researcher discovered during the initial appointment with the first AFH that it was not feasible to use a timer or stop watch to measure each individual set-up and instructional activity.

This study was important because its results help to inform future studies of telehealth in AFHs, particularly in the areas of caregiver education and direct video enhanced telehealth interactions between AFH and healthcare providers. One future study of interest would be to

compare the use of videophone technology to personal computer technology for delivering educational resources to AFH caregivers. Another potential study would engage AFH operators, caregivers, and residents as key stakeholders in the design and implementation of a structured pain management program in collaboration with healthcare providers where regular video call visits assess resident pain status with real-time pain management interventions.

Chapter Four: Implications and Recommendations

The results of this dissertation study make important contributions towards understanding technology usage in AFHs and the feasibility of using telehealth technology to improve pain management of community dwelling older adults in AFHs by improving access to training for AFH caregivers. Findings from this study contribute important information to the understanding of care giving in AFHs, their technology infrastructure and the potential for telehealth interventions in the community setting to support aging in place.

In the first study (Chapter 2), an exploration of the technology usage of AFHs found that almost all AFHs utilized fundamental electronic and telecommunication devices such as landline telephones, facsimile machines, and radios. AFH cell phone ownership (98%) and usage compared favorably to the national average cell phone ownership of 85% in 2012 and 91% in 2013 as reported by the Pew Research Group (Rainie, 2013; Smith, 2012). As advancements in technology continue, this number can be expected to increase. Results indicate that AFHs are comfortable with using some types of technology. Findings from this study point to the importance of understanding use patterns and making technology an asset for nurse delegation and care oversight for AFHs.

Chapter 2 also reported other technology usage that helped to formulate a description of AFH technology infrastructure and capacity. For example, in addition to landline telephones and cellular phones, most AFHs reported having a computer (90%) that they used for AFH business. Of these, 77 % used their computers for accessing educational resources and 31% conducted voice over internet protocol (VoIP) calls and consulted healthcare providers. However, more AFHs still used the telephone to consult healthcare providers (42%). This could be due to

concerns about privacy and security related to the Health Insurance Portability and Accountability Act (HIPAA). Many VoIP options available commercially such as Skype or Google Voice do not provide the level of secure connection required for telemedicine. Large healthcare organizations have the resources to utilize advanced information technology (IT) and sophisticated security protocols, but these may not be easily available or could be cost prohibitive to small-sized AFHs. It is important to understand that AFHs are in a unique position among residential options in that they may not have the financial and personnel resources as compared to large organizational facilities.

Another possible reason for the higher use of telephone over VoIP could be due to low access to computers by AFH caregivers. Most of the survey respondents were AFH operators who were most likely to have used the AFH computer for administrative duties. The survey in this study did not ask whether all caregivers had use of the AFH computer for access to educational resources or other computer capable communication programs. Therefore, the level of access caregivers in the homes might have had to the AFH computer was uncertain. In addition, less than half of the AFHs with cell phones used their cell phones to access web-based resources. Therefore, although there are increasing numbers of web-based educational offerings, it is uncertain that caregivers who were not the AFH owners have the means to access those resources. This is an important factor to consider when designing educational resources for caregivers so that solutions recognize AFH limitations.

In another sector of the AFH telehealth infrastructure, although many AFHs (93%) reported using a digital video disc player (DVD), and a few (23%) used the more advanced Blu-ray disc player, however, slightly more than half of the responding AFH (58%) still used VHS

videocassette players. These results may sound surprising to those who work in settings that are immersed in technology; however, this may be reflective of the attitude of the older adults AFH residents, their perception of and comfort level with operating technology. The numbers also may be reflective of the burden of cost to replace their VHS tape collection with expensive DVDs/Blu-ray discs and all of the associated equipment to play them on, especially if they have a large inventory of VHS tapes.

Access to media also varied among adult family homes. Most AFHs (88%) gained access via cable while a few (17%) accessed media using satellite service such as Dish TV. This may be due in part to geographic availability of service providers. For those AFHs with computers, about half used cable (59%), some used DSL (24%), and about nine percent still used dial-up internet service. This variability in internet access is certainly another important factor to consider when designing educational resources for caregivers as to the type of platform and system of delivery that would offer optimal accessibility. Thus, AFHs may appear to be physically located in areas with seemingly full access to important IT infrastructure when in fact the infrastructure and its access may not be as available as compared to large city-based institutions. Again, these limitations would need to be assessed and addressed if AFHs were to be encouraged to adopt more advanced technological platforms. In contrast, it may be more feasible and cost-effective to design educational resources that would be accessible with simple-to-use existing stable technology platforms.

In Study 2 of this dissertation (Chapter 3), AFH caregiver and resident dyads tested the feasibility of using a less sophisticated telecommunication device, the videophone, for delivery of pain assessment educational resources to caregivers for improving pain management. This

study also solicited their perception of care giving in AFHs and using a telehealth technology device. Results from the quantitative measures and qualitative interviews indicated that it is feasible to use a commercially available video unit that connected to existing telephone lines for delivering educational resources to direct caregivers. Caregivers and resident dyads rated the technology to be very easy to use with minor connectivity issues that were easily resolved.

Caregivers in this study have not only completed all required training to be employed as AFH caregivers, some have also completed additional training in dementia care or nurse delegation. Survey results were supported by themes from the qualitative results that caregivers have a desire to care for people and learn about caring for older adults. Thus, study findings have important implications for healthcare organizations to consider offering educational resources to AFH caregivers as part of their care oversight of their older adult clients who might live in AFHs. Furthermore, healthcare entities with the resources to extend educational offerings via telehealth to AFHs could realize a cost saving if improved care for AFH residents led to decreased healthcare utilization.

Themes about care giving in the AFH setting revealed that residents felt at home with a sense of autonomy that was meaningful and allowed them to do activities at their highest functional level. They felt a sense of community and had an opportunity to build relationships with caregivers and other residents. Caregivers described varied employment backgrounds and experiences, but they chose to work in AFHs because they had a desire to care for older adults and found their relationships with AFH older adult residents to be fulfilling. The positive perceptions expressed by AFH residents and caregivers suggest support of aging in place where relationship and stability are core tenets. These study findings have implications for developing

inexpensive telehealth solutions that support such a desirable caregiving atmosphere at sites that may struggle with affordable access to IT resources because of their smaller size.

The results from this mixed-methods dissertation demonstrated that pain experiences were common to older adults in AFHs and that caregivers in this setting were interested in further instruction to improve pain assessment. In Study 1, most respondents (~89%) reported being comfortable with pain assessment; nonetheless, more than half of the AFH respondents (69%) indicated that they would be interested in receiving pain assessment instructions. In Study 2, caregivers expressed that some of the pain assessment tools they used prior to this study did not always adequately provide an accurate measure of resident pain levels. Even though they all expressed self-efficacy for pain assessment, they found that the PTS used in this study allowed their residents to communicate pain levels more effectively. Results from this study showed that telehealth could improve access to training and resources for more appropriate and applicable pain assessment tools and thereby improve pain management in AFHs. Thus, it is extremely important for any telehealth IT improvement efforts to include AFH caregivers and residents.

Although the videophone has been commercially available for a number of years, older adult residents were unfamiliar with this technology. To test the feasibility of videophone technology for telehealth pain assessment resources, this study used both the desktop and TV projection videophone units at AFH test sites that were located between 13 to 110 miles from the research office where the video call visits were initiated. This difference in distance was not associated with any differences in feasibility or usability results; thereby supporting the theme of impact on access to care through bridging the distance to healthcare services. These results have implications for telehealth as a means to access training resources, especially in remote or other

hard to access areas. As technological innovations continue to advance, it remains important to understand that older adults may be less familiar with the most recent IT tools and “older” tools need to be considered when developing telehealth interventions.

Ratings from the video call visits conducted during this study, showed that most video calls did not have any connectivity issues and were rated as good to excellent on clarity of the calls. Almost all video visits were rated as good to excellent on sound quality and picture quality as well. Caregivers and residents all rated the videophone technology as easy or very easy to use and were neutral or liked using the videophone for enhanced telephone visits. These results are consistent with results from Study 1 where most AFH survey respondents were comfortable with using technology. Thus, when a simple technological device and sufficient training time were made available, there were positive perceptions and satisfaction with telehealth. Future IT solutions will need to ensure a focus on the AFH audience (residents and caregivers, and telehealth providers) and their desire for simplicity, not merely on technological elegance.

From the qualitative interviews, residents liked using the videophone units for pain assessment, and caregivers expressed readiness to adopt this technology. Caregivers also described how this device could improve their access to educational resources at the point of care to increase application of interactive didactic instructions. AFH caregivers appeared to be ready to take advantage of technology to improve their skills in order to improve care of their residents. Thus, efforts to expand access to simple and low-cost technology tools will be an important next step. It will also be important to include consideration for the tools that are easy-to-learn and easy-to-use because they are more likely to be readily accepted and adopted.

The complexities of operating an AFH render many challenges for operator/caregivers to acquire the continuing education required for licensure in many states. Participant AFH caregivers identified tremendous potential with using the videophone instead of sophisticated advanced technology such as personal computers. Videophone technology offers a low cost, simple solution for government agencies, healthcare organizations, or private healthcare providers to collaborate with AFHs to increase healthcare access for older adult residents and improve care giving through offering educational resources for AFH caregivers. This is important because one of the factors identified by the Paraprofessional Healthcare Institute (PHI) as predictive of home health aide turnover is the lack of reimbursement for travel costs (Seavey & Marquand, 2011). Findings from this study showed that AFHs provide a type of long-term care setting that supports successful aging in place. This finding, in combination with the impending shortage of direct care workers needed to provide quality care for our increasing older adult population, indicate that it would be prudent for resourceful care organizations to design and offer education via low cost simple existing technology for AFH caregivers to support staff retention as well as improve care giving.

Recommendations for Future Research

Telehealth technology for educational resources holds tremendous potential for AFH settings. Results from this two-phase dissertation study inform future studies of telehealth in AFHs, particularly in the areas of caregiver education and direct video enhanced telehealth interactions between AFHs and healthcare providers. With the description of AFH technology infrastructure and demonstrated feasibility of using low cost existing technology to deliver pain assessment resources to AFH caregivers and residents, future research is needed to expand upon

this project to assess effectiveness of complex education topics delivered over videophone technology for caregivers such as in a randomized controlled trial. To further understand the role of AFH care giving for older adults to age in place in community, future studies should add additional measures on the impact of relocation to AFHs using tools such as the Index of Relocation Adjustment (Bekhet & Zauszniewski, 2014).

Data from the 2010 National Survey of Residential Care Facilities (RCF) showed that about half of RCFs were small with 4-10 beds (Park-Lee et al., 2011), which would include AFHs. Park-Lee et al. (2011) found that most AFHs were privately owned and not part of a chain or multi-facility system. This has important implications for researchers interested in studying the use of technology for the care of older adults in AFHs. From conducting this dissertation study, this researcher found that access to AFHs as research sites requires a long-term commitment from researchers to build relationships founded on trust. Due to negative publicity in mainstream media to vilify AFHs, owners are often wary of people who want to “study” their facilities. Researchers also need to consider the vulnerability of older adults who live in AFHs. They often are represented by a Durable Power of Attorney (DPOA) to protect them from exploitation. The DPOA controls access to AFH older adults as subjects or participants in research studies. Therefore, it is imperative to exemplify beneficence when designing research studies in the AFH setting.

One future telehealth study of interest would be to compare the use of videophone technology to more advanced technological platforms such as personal computers, “smart-phones” and “tablets” for delivering educational resources to AFH caregivers. Another potential study would engage AFH operators, caregivers and residents as key stakeholders in the design and implementation of a structured pain management program in collaboration with healthcare

providers where regular video call visits assess resident pain status with real-time pain management interventions. Studies are also needed to test the efficacy and effectiveness of using other audio-video conferencing platforms such as Skype or GoogleTalk in geriatrics settings, such as the AFH, that offer real-time telehealth education and other interactions that do not require or jeopardize HIPAA compliance.

Study findings have implications for healthcare organizations such as health departments and hospitals with home healthcare programs to establish telehealth programs that include education for AFH caregivers. Research is needed to explore partnership models between healthcare facilities, homecare agencies, and government entities for delivery of structured education interventions for AFH caregivers. Results from these studies will better inform further development of appropriate topics, types and formats of easily adoptable educational materials.

Chapter Five: Conclusions

Telehealth is an innovative approach within a new model of care that promotes the concept of aging in place by bridging geographic distance to improve access to care for community dwelling older adults. The small scale, single-family dwelling environment of the AFH, which includes assistive care services, also supports aging in place. Findings from this study contribute to the understanding of care giving in AFHs, their technology infrastructure and the potential for telehealth interventions in the community setting to support aging in place.

With the numerous recent technological advancements in communication and health devices, this study showed that AFH operators embrace technology while continuing to use less sophisticated technological devices that have proven utility such as the landline telephone, radio, and VHS videocassette player. They are also desirous of educational instruction. With new legislation in Washington State that has increased required continuing education for direct caregivers, it is imperative to consider cost effective and appropriate options for delivering educational resources to AFH caregivers in their efforts to improve care of their older adult residents.

This two-study dissertation research project provided a description of AFH technology infrastructure and demonstrated the feasibility of delivering educational material over existing, less sophisticated technology to AFH caregivers. Although the testing and intervention period was of a short duration, findings demonstrated improved pain management with implications for further improvements in care of older adult residents. Future research is needed to expand upon this project to assess the effectiveness of complex education topics delivered over videophone technology for caregivers. It is also necessary to assess the availability of more advanced

communications technology such as personal computers and smart phones or tablets for caregivers in order for them to access education resources over the internet. In consideration of cost effective health care for aging in place, research is needed to explore partnership models between healthcare facilities, homecare agencies, and government entities for delivery of structured education interventions for AFH caregivers. Results from these studies will better inform further development of appropriate topics, types, and formats of easily adoptable educational materials for AFH caregivers in an effort to assure quality care for community dwelling vulnerable older adults.

In conclusion, this study found that telehealth technology can be perceived as complex and difficult to navigate initially. However, use of videophone technology was viewed as feasible and easy. Therefore, it is important to keep in mind that the goal for quality care in AFHs is to provide affordable, effective, and accessible resources to support successful aging in place. Sometimes the most effective solutions are found in using simple and easy-to-use technological tools.

“Simplicity is the ultimate sophistication.” – Leonardo da Vinci

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Appendix A: Chapter 2 Tables and Figures

Table AT1:

Types of Adult Family Home Resident Illnesses Reported by AFH Operators

(Total N=351)

Illness / condition	“Yes”
Dementia	82.3%
Arthritis	78.5%
Joint Pain	72.9%
Urinary Problems	69.7%
Back Pain	66.5%
Diabetes	60.9%
Osteoporosis	57.4%
Skin Problems	54.3%
Stroke	50.3%
Indigestion	43.2%
Headache	43.1%
Asthma	30.9%
Hemorrhoids	30.5%
Neck Pain	29.3%
Abdominal Pain	22.2%
Fracture	19.6%
Chest Pain	18.1%
Cancer	17.7%
Fibromyalgia	7.9%

Appendix A: Chapter 2 Tables and Figures

Table AT2: General Technology Usage in AFHs Reported by AFH Operators

(Total N=351)

Other Technological Devices	“Yes”
TV	96.0%
DVD	93.0%
Radio	91.0%
CD	88.0%
Cable TV	88.0%
Flat Screen TV	81.0%
VHS	58.0%
Cassette	54.0%
Motion Sensor	43.0%
Health Monitoring Device	42.0%
HDMI	34.0%
iPod	27.0%
Wii	27.0%
Blu-Ray	23.0%
Dish TV	17.0%
MP3	14.0%
Play Station	12.0%
TiVo	5.0%

Appendix A: Chapter 2 Tables and Figures

Figure AF1: Survey of Technology Use Part 1

University of Washington, School of Nursing
Study of Telehealth for Adult Family Homes: Survey of Technology Use Date: _____

Part 1: Technology Use in Your Home

1) Does your adult family home have an existing regular telephone land line? YES NO
 1a) If yes, do you use this phone for adult family home business activities? YES NO

2) Is your phone service bundled with other services such as cable television or internet? YES NO

3) Do you have a cellular phone? (If yes, please answer 3a, 3b, and 3c) YES NO
 3a) Do you use your cellular phone for adult family home business activities? YES NO
 3b) Do you play games on your cell phone? YES NO
 3c) Do you access internet information on your cell phone? YES NO

4) Do you have a computer in your adult family home? YES NO
 (If yes, please answer 4a, 4b, and 4c)
 4a) Do you use your computer for adult family home business activities? YES NO
 4b) Do you use your computer for educational activities? YES NO
 4c) Do you use your computer to make audio-video phone calls such as Skype or Google Talk? YES NO

5) Has your adult family home ever used telehealth such as consulting with health care providers over the telephone? YES NO

6) Have you ever consulted health care providers over the internet? YES NO

7) What devices do you use in your adult family home? Please mark a check under yes or no for each item.

Yes	No	Yes	No	Yes	No
<input type="checkbox"/>	<input type="checkbox"/> Radio	<input type="checkbox"/>	<input type="checkbox"/> HDMI	<input type="checkbox"/>	<input type="checkbox"/> Fax machine
<input type="checkbox"/>	<input type="checkbox"/> Cassette player	<input type="checkbox"/>	<input type="checkbox"/> Cable TV	<input type="checkbox"/>	<input type="checkbox"/> Video-telephone
<input type="checkbox"/>	<input type="checkbox"/> CD player	<input type="checkbox"/>	<input type="checkbox"/> Dish TV network	<input type="checkbox"/>	<input type="checkbox"/> Motion sensor
<input type="checkbox"/>	<input type="checkbox"/> I-Pod	<input type="checkbox"/>	<input type="checkbox"/> TeVo	<input type="checkbox"/>	<input type="checkbox"/> Health monitoring device
<input type="checkbox"/>	<input type="checkbox"/> MP3 player	<input type="checkbox"/>	<input type="checkbox"/> Wii	<input type="checkbox"/>	<input type="checkbox"/> Other devices:
<input type="checkbox"/>	<input type="checkbox"/> Television	<input type="checkbox"/>	<input type="checkbox"/> Play Station	<input type="checkbox"/>	_____
<input type="checkbox"/>	<input type="checkbox"/> Flat screen TV	<input type="checkbox"/>	<input type="checkbox"/> Internet: dial-up access	<input type="checkbox"/>	_____
<input type="checkbox"/>	<input type="checkbox"/> VHS player	<input type="checkbox"/>	<input type="checkbox"/> DSL internet	<input type="checkbox"/>	_____
<input type="checkbox"/>	<input type="checkbox"/> DVD player	<input type="checkbox"/>	<input type="checkbox"/> Cable internet	<input type="checkbox"/>	_____
<input type="checkbox"/>	<input type="checkbox"/> Blue ray disc player	<input type="checkbox"/>	<input type="checkbox"/> Wireless internet	<input type="checkbox"/>	_____

8) Please add any comments you have about technology use in your adult family home:

Figure AF2: Survey of Technology Use Part 2

University of Washington, School of Nursing

Study of Telehealth for Adult Family Homes: Survey of Technology Use

Date: _____

Part 2: Demographics about the Technology Users

- 1) Are you the owner or operator of the adult family home? YES NO
- 2) If you are not the owner or operator, what is your job position? _____
- 3) How many caregivers work in your adult family home? _____
- 4) How many caregivers work with the residents for at least 3 days per week? _____
- 5) How comfortable are you with using technological devices in general? Please circle your choice.
(some examples are listed in question 7 of part 1 of this survey)
- | | | | | |
|-----------|----------|---------|------------|------------|
| Very Much | Somewhat | Neutral | Not Really | Not at All |
| 5 | 4 | 3 | 2 | 1 |
- 6) How many residents are you caring for in your home at this time? _____
- 7) Does your adult family home take care of residents ages 65 or older? YES NO
- 7a) How old is your oldest resident? _____ years old
- 7b) How old is your youngest resident? _____ years old
- 8) Do you have any residents with dementia? YES NO
- 9) Do all of your residents have dementia? YES NO
- 10) Do any of your residents complain of pain? YES NO
- 11) What types of illnesses/conditions do your residents have?
Please mark a check under yes or no for each item.
- | | | | | | |
|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| Yes | No | Yes | No | Yes | No |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| abdominal pain | | diabetes | | joint pain | |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| asthma | | fibromyalgia | | neck pain | |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| arthritis | | fractures | | osteoporosis | |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| back pain | | headache | | skin problems | |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| cancer | | hemorrhoids | | stroke | |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| chest pain | | indigestion | | urinary problems | |
- 13) How comfortable are you with pain assessment of your adult family home residents?
Please circle your choice.
- | | | | | |
|-----------|----------|---------|------------|------------|
| Very Much | Somewhat | Neutral | Not Really | Not at All |
| 5 | 4 | 3 | 2 | 1 |
- 14) Would you be interested in receiving instructions for pain assessment? Please circle your choice.
- | | | | | |
|-----------------|---------------------|---------|---------------------|-----------------------|
| Very Interested | Somewhat Interested | Neutral | Not Very Interested | Not at All Interested |
| 5 | 4 | 3 | 2 | 1 |

Figure AF3: Communication Technology Usage in Adult Family Homes (N=351)

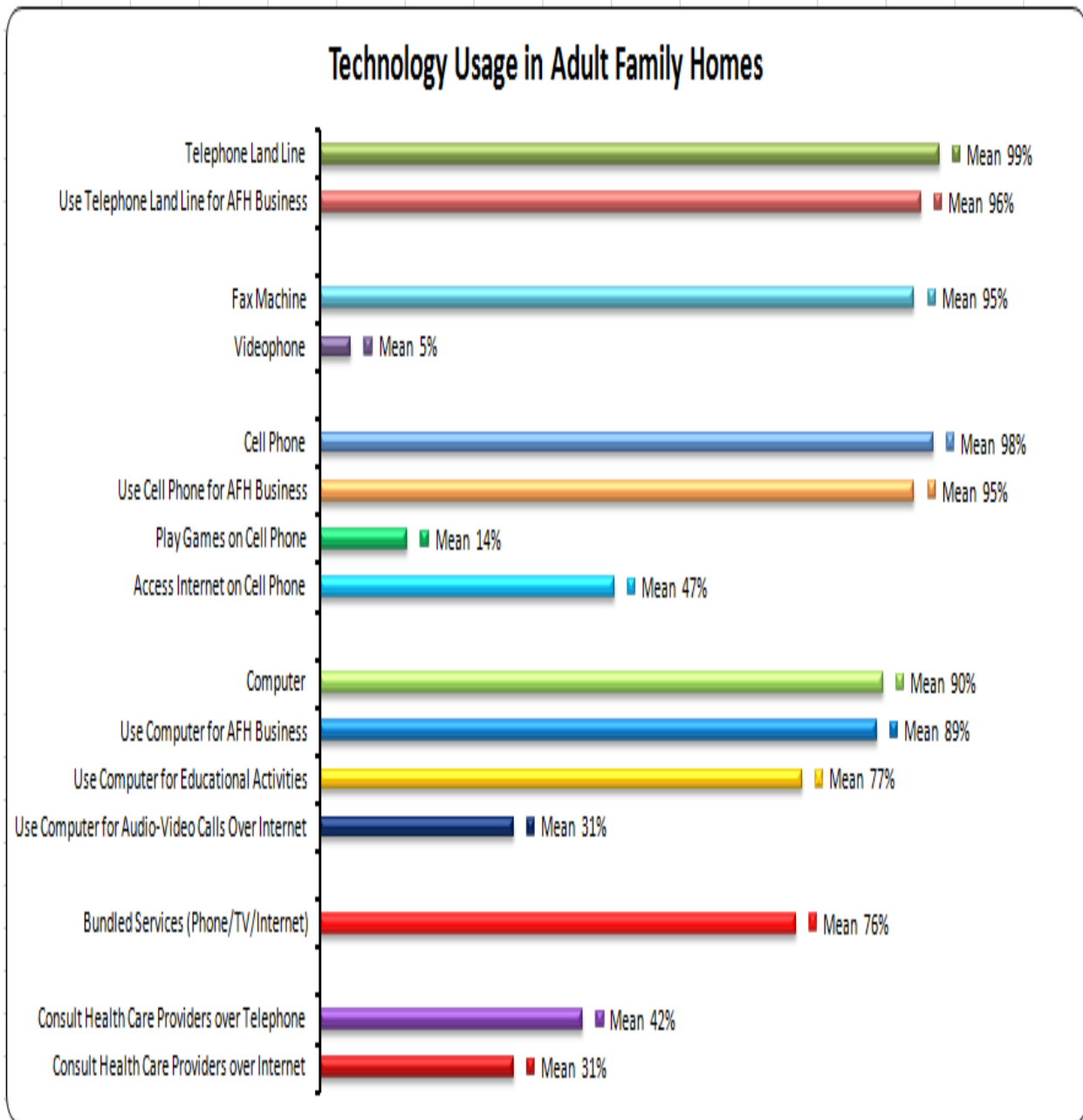


Table BT1: Study Activities for AFH Residents by Visit Number and Type

For AFH Older Adult Residents

Visit Number	1	2	3 - 5	6	7
Type of Visit	In-person with researcher	Videophone with RA	Videophone with RA	In-person with researcher	In-person with researcher
Study Activities	Informed Consent; Baseline Interview, Demographic questionnaire, Mini-Cog, PTS, GHSF1.1, PBSF7a, and PISF6b	Provide pain level and validate PTS result with caregiver and RA	Validate PTS results with caregiver and RA	In-depth interview about videophone usage Exploratory Outcome measures: PTS, GHSF1.1, PBSF7a, and PISF6b	Validate results/ themes from content analysis of transcripts

Key of abbreviations:

RA = Research Assistant

PTS = Pain Thermometer Scale

GHSF1.1 = PROMIS Global Health Short Form V1.1

PBSF7a = PROMIS Pain Behavior - Short Form 7a

PISF6b = PROMIS Pain Interference – Short Form 6b

Appendix B: Chapter 3 Tables and Figures

Table BT2: Study Activities for AFH Caregivers by Visit Number and Type

For AFH Caregivers

Visit Number	1	2	3 – 5	6	7
Type of Visit	In-person with researcher	Videophone with RA	Videophone with RA	In-person with researcher	In-person with researcher
Study Activities	Informed Consent; Baseline interview, Demographic Questionnaire	Caregivers receive training from RA to use PTS	Weekly report of PTS results	In-depth interview about videophone usage	Validate results/ themes from content analysis of transcripts

RA = Research Assistant

PTS = Pain Thermometer Scale

Table BT3: Amount of Time Used to Instruct About Videophone Use

Amount of time Researcher used to set up videophone and instruct AFH Caregiver and Resident (in hours)		
AFH Number	Videophone Set up and Instructions (adjusted time in hours)*	Comments from Field Notes
1	0.7	Videophone desk-top set was connected to the regular phone next to computer with phone...in front of a window and research assistant reported clear picture.
2	2	Live phone jack in resident’s room was located behind a roll-top desk that needed to be moved...Videophone projection unit was connected to resident’s pre-flat screen television set in private room...store behind a chair for access and set up during video calls.
3	1	This AFH is a two-story dwelling where residents reside in the lower level and the caregiver resides in the upper level. After assessing several locations...the caregiver chose to place the desk-top videophone unit on the kitchen counter with the regular telephone in the upper level of the house.
4	1.5	At the enrollment visit, the homeowner discovered that the phone jack in the resident’s room was not “live” or active. The AFH used a digital communications bundle that was only active for the office...researcher returned to the home to connect the videophone after the homeowner was able to activate the resident’s line. Videophone TV projection unit was connect to resident’s in-room flat screen TV set.
5	1	Videophone desk-top unit was connected to regular phone located next to kitchen sink.
6	1.5	AFH operator assisted with selection of best location... connected the videophone desktop unit to the phone in place of the FAX machine...Caregiver to adjust the unit to attain video capture of the resident during the video call.

*(Amount of learning time) = Total visit time (as logged by the researcher) – time for informed consent – baseline interview times

Appendix B: Chapter 3 Tables and Figures

Table BT4: Exploratory Outcomes: PROMIS Surveys

(Baseline N=6, Post-Intervention N=5)

Pain Interference Scores						
	Baseline	Post Intervention	Pearson's	t-test	Degrees of Freedom	P-value
Mean (SD)	53.78 (8.23)	56.14 (9.12)	0.3	0.19	4	0.86
Pain Behavior Scores						
	Baseline	Post Intervention	Pearson's	t-test	Degrees of Freedom	P-value
Mean (SD)	56.85 (2.91)	57.44 (3.96)	0.972	0.176	4	0.87
Global Mental Health Scores						
	Baseline	Post Intervention	Pearson's	t-test	Degrees of Freedom	P-value
Mean (SD)	44.77 (5.89)	41.1 (3.75)	0.01	1.1	4	0.33
Resident Global Physical Health Scores						
	Baseline	Post Intervention	Pearson's	t-test	Degrees of Freedom	P-value
Mean (SD)	39.5 (4.94)	37.36 (2.45)	0.38	0.95	4	0.39
Estimated Euro Quality of Life Index Scores						
	Baseline	Post Intervention	Pearson's	t-test	Degrees of Freedom	P-value
Mean (SD)	0.61 (0.08)	0.594 (0.02)	0.54	0.45	4	0.68

Figure BF1: Photo of Videophone Set Up in the Research Office



Figure BF2: Photo of Adult Family Home Desk-Top Videophone Setting

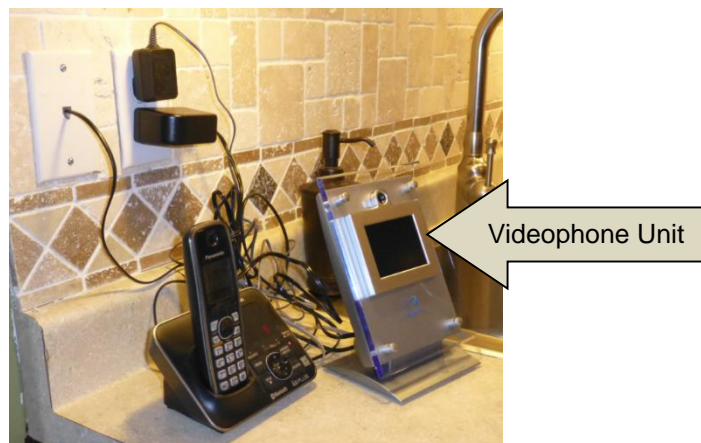


Figure BF3: Photo of Adult Family Home TV Projection Videophone Set Up

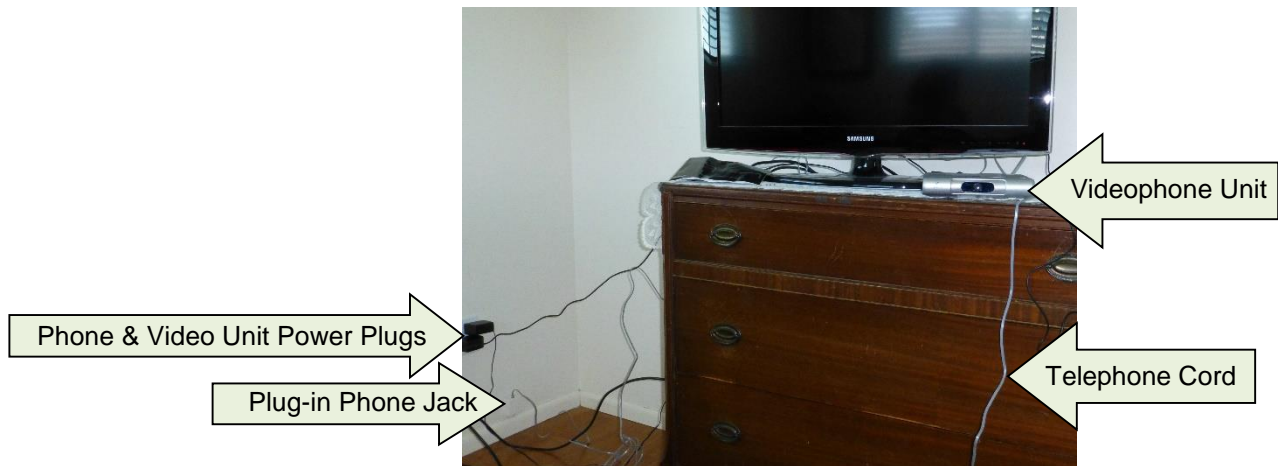


Figure BF4: AFH Resident Reported Painful Health Conditions (Total N=6)

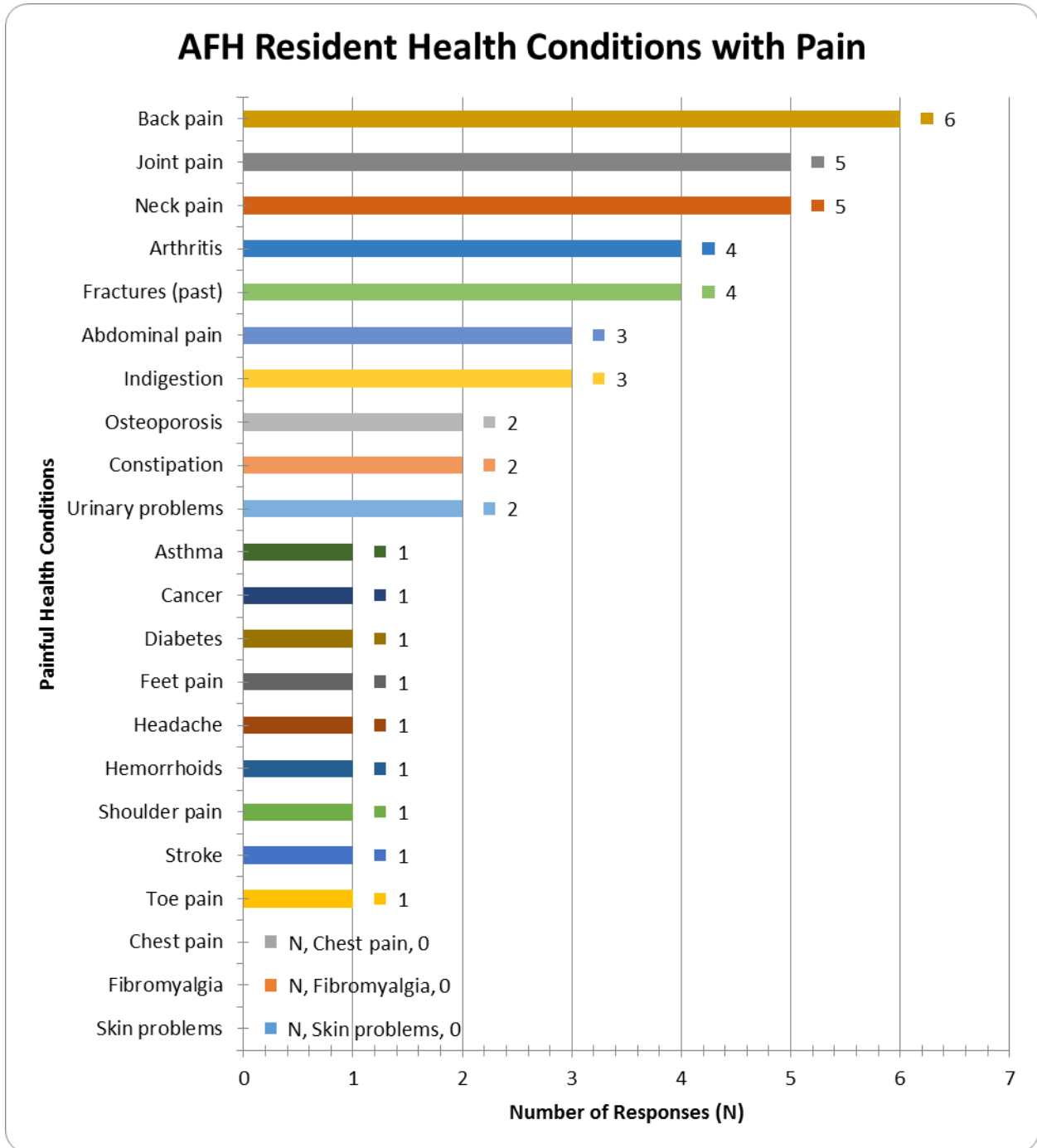
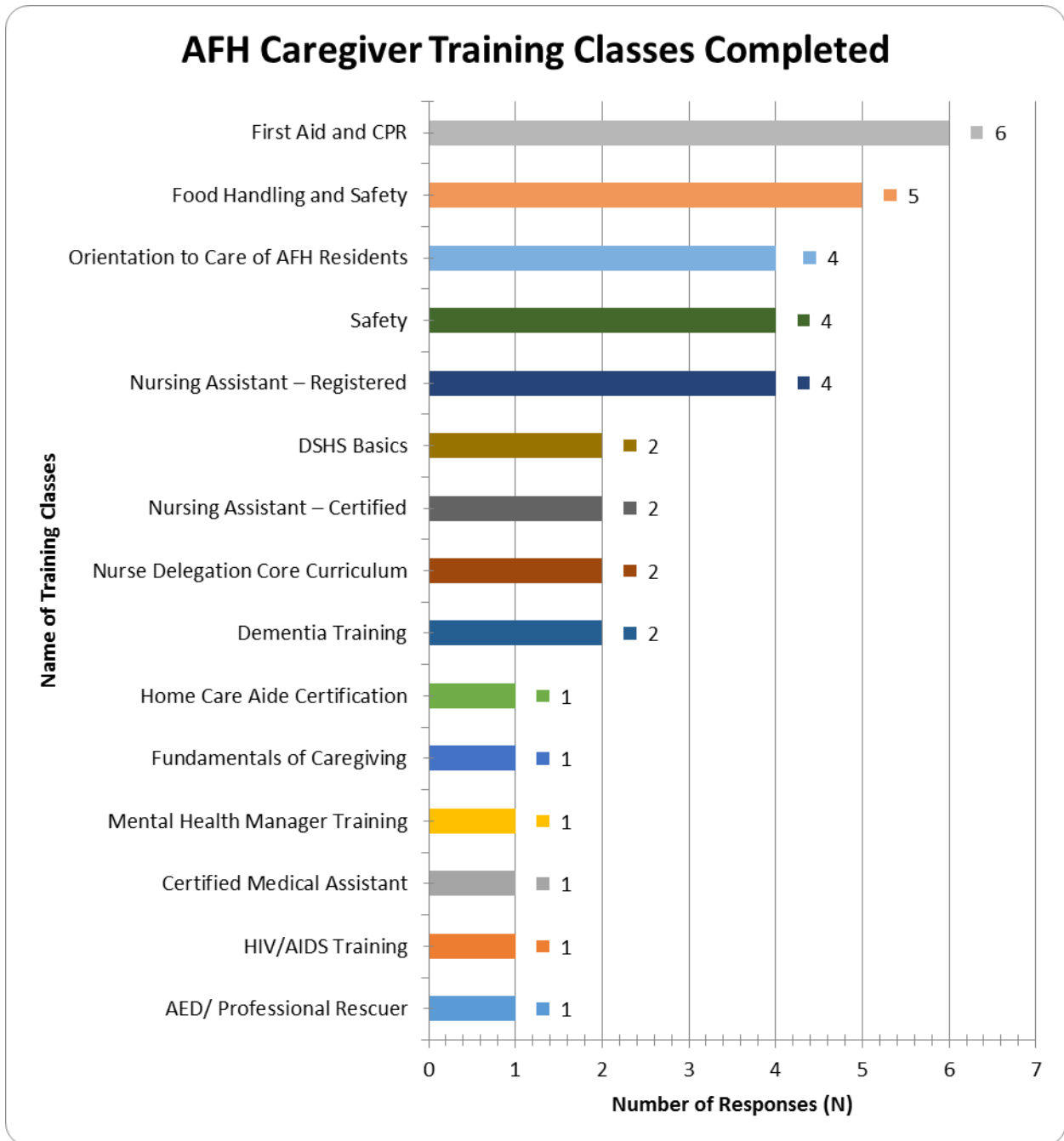


Figure BF5: AFH Caregiver Training Courses Completed (Total N=6)



AED = Automated External Defibrillator