

CONSUMER RESPONSE TO HOME MONITORING: A SURVEY OF OLDER
CONSUMERS AND INFORMAL CARE PROVIDERS

By

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To my husband, Michael; my son, Solomon; and my parents for all your love and support.

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LIST OF ABBREVIATIONS

WHO	World Health Organization
ICF	International Classification of Functioning and Disability
ADL	Activities of daily living
IADL	Instrumental activities of daily living
HMS	Home monitoring system
OARS	Older Americans Resources and Services Multidimensional Functional Assessment Questionnaire

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By

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As our population ages, the number of people with a disability, who live alone, and who wish to remain in their own homes, is increasing. These older individuals may require personal care and/or assistive technology. Home monitoring systems are assistive technologies utilized to track an individual's activity patterns promoting safety and independence. QuietCare is a home monitoring system embedded in the person's environment designed to detect changes in the user's behavior patterns that may indicate an emergency situation. There has been no research on systems like QuietCare relative to whether user needs are being met and if users are satisfied with the system. The purpose of this study was to explore the perceptions and experiences of home monitoring system users and informal caregivers.

The sample included 29 QuietCare users and 30 informal caregivers. Through an interview, users completed an assessment of functional capacity and a home monitoring survey. The informal caregivers participated in a telephone interview and completed a survey regarding their perceptions of the QuietCare home monitoring system. Data were analyzed using descriptive statistics.

The HMS user sample was mostly female (72%), white (97%), and widowed (83%) with a mean age of 80. The HMS caregivers were mainly female (60%), white (100%), and married

(87%) with an average age of 59. Both the users and caregivers were satisfied with QuietCare and felt it was easy to use. Only two of the users experienced emergencies; both were detected and users felt the response time was reasonable. Users and caregivers perceived peace of mind as an advantage of using the system. Overall, users were not concerned about privacy invasion in using the system and felt comfortable being monitored with QuietCare.

CHAPTER 1 INTRODUCTION

Background and Significance

By 2030, the number of older Americans is expected to nearly double to 70 million and will comprise 20% of the U.S. population (National Center for Health Statistics, 2007). This growth in population of older Americans poses a challenge in providing adequate care and support as some older adults age with or acquire disabilities.

Approximately 7 million older Americans have chronic disabilities (Federal Interagency Forum on Aging-Related Statistics, 2004). While the rate of disability is decreasing; the number of Americans over 65 who have chronic disabilities is increasing, due to the rapid growth in numbers of older adults (Federal Interagency Forum on Aging-Related Statistics, 2004). As older adults age, they are more likely to acquire a disability (Ostchenga, Harris, Hirsch, Parsons, & Kington, 2000). For example, 54% of Americans 75-79 have a disability and 16% of them require assistance; whereas 72% over 80 have a disability and 30% of those require assistance (Steinmetz, 2006).

The population increase of older adults will also create an increased demand for employees in the health care industry, which is expected to grow 22% by 2016, compared to 11% for all other industries combined (Bureau of Labor Statistics & U.S. Department of Labor, 2007). With the existing shortage of direct care workers, a drastic increase in demand will create a vast predicament with how to adequately care for older adults (Fleming, Evans, & Chutka, 2003; Hussein & Manthorpe, 2005; Piotrowski, 2003). It is necessary to consider both how to provide care and support for older adults with disabilities and where to provide these services.

Most adults over 45 want to stay in their home as long as possible (Bayer & Harper, 2000). This desire increases with age. Seventy-five percent of people 45-54 wish to remain in their

current home, 83% of those 55-64, 92% of those 65-74, and 95% of those 75 and over (Bayer & Harper, 2000). Interviews conducted by Tinker & Lansley (2005) confirm this desire of older adults to remain in their homes.

The ability to age in place may be upset by age-related chronic conditions. However, 82% of older adults want assistance provided in their home in the event they need help caring for themselves (Bayer & Harper, May 2000). Much assistance to older adults with disabilities comes from an informal caregiver (Li, 2005). Informal caregivers are generally spouses (38%) or children (41%) of the older adult with a disability (Wolff & Kasper, 2006).

With today's society being so mobile, adult children relocating for employment reasons and older adults often retiring to places with a mild climate, many older adults do not have children nearby to assume the role of informal caregiver. Nineteen percent of men and 40% of women over 65 live alone (Federal Interagency Forum on Aging-Related Statistics, 2004). The percent of older adults living alone increases with age (He, Sengupta, Velkoff, & DeBarros, 2005). The impact of living alone and away from children or other potential sources of informal care may make aging in place difficult for the older adult with a disability.

Conceptual Framework for Home Monitoring

Introduction to the International Classification of Functioning and Disability (ICF)

The World Health Organization (WHO) International Classification of Functioning and Disability (ICF) is a classification system for health and functioning (Arthanat, Nochajski, & Stone, 2004; Stucki, 2005). The ICF not only codifies health information, but is also useful in research for generating hypotheses, planning studies, and creating a common language useful in collaboration and disseminating information (Jette, 2006; Stucki, 2005).

The ICF model has two main components "Functioning and Disability" and "Contextual Factors" (Arthanat et al., 2004; Hemmingsson & Jonsson, 2005). These main components are

each further divided into two categories. “Functioning and Disability” is divided into “Body Functions and Structures” and “Activity and Participation.” “Contextual Factors” is divided into “Environmental Factors” and “Personal Factors.”

In classifying home monitoring, the first character would be ‘e’ because home monitoring is considered an environmental factor. Environmental factors are the physical, social, and attitudinal environments in which people live and conduct their lives (WHO, 2001). The remaining domains coincide with the following codes: body functions = b, body structures = s, activities and participation = d. These letters are then followed by chapter numbers (first, second, third, and fourth levels depending on what is being described). These codes may be followed by a decimal point and a qualifier. The qualifiers range from 1 = no problem to 4 = complete problem.

Further classification of home monitoring may be more complex because it consists of 2 components. As depicted in Figure 1-1, home monitoring is not only the technology, such as sensors and servers, but also the people who interact and interpret the data being retrieved to determine when and how to intervene. Considering the technological side, home monitoring could be classified under “products and technology,” which includes “natural and human-made products or systems of products, equipment and technology in an individual’s immediate environment that are gathered, created, produced or manufactured” (WHO, 2001). The prefix would be ‘e1.’ However, it is also reasonable to classify home monitoring under “support and relationships” when considering the people who are involved in home monitoring and providing support. “Support and relationships” includes “people or animals that provide practical physical or emotional support, nurturing, protection, assistance, and relationships to other persons, in their

home, place of work, school or at play or in other aspects of their daily activities” (WHO, 2001). This type of classification is ‘e3.’

If the product and technology route of classification is taken, home monitoring would end in a final classification of ‘e198’, which is “products and technology, other specified” (WHO, 2001). However, if the support and relationships route is taken, home monitoring would end in a final classification of ‘e398’, which is “support and relationships, other specified” (WHO, 2001).

Figure 1-1 demonstrates the interrelationship of the domains and that a change in one domain could potentially affect the other domains. This is denoted in the ICF diagram with bidirectional arrows. Home monitoring attempts to promote health and independence by intervening through a change in the physical and social environments (Schneidert, Hurst, Miller, & Ustun, 2003).

Home Monitoring and Older Adults

Home monitoring supports the resident at home by monitoring for unsafe situations, such as taking medications inappropriately or undesirable temperature inside the home. Home monitoring also attempts to intervene quickly when a problem arises. For example, a fall for an older adult living alone is a potentially life threatening situation, home monitoring may decrease the risk of not being found in time after a fall.

Home monitoring may not affect body structures, but it may have an impact on body functions. WHO (2001) defines body functions as “physiological and psychological functions of the body.” Home monitoring may help improve physiological functions by reminding the resident to take medications appropriately. For example, medication compliance may be achieved by utilizing a home monitoring system that tracks medication dispensing and alerts the caregiver when medications are consumed inappropriately. If an older adult takes the right dose

of their medication at the right time, they will be better able to maintain health and body functions than when following an erratic schedule.

Home monitoring may also affect psychological functioning through tracking medication compliance and providing alerts when non-adherence occurs. A person with bipolar disorder will demonstrate better psychological functioning when following an appropriate medication regimen (Colom & Vieta, 2002; Lew, Chang, Rajagopalan, & Knoth, 2006). Home monitoring may also impact a resident's psychological functioning by providing reassurance that someone is watching out for them. Home monitoring may reduce anxiety and increase sense of security, as has been shown in tele-homecare (Lamothe, Fortin, Labbe, Gagnon, & Messikh, 2006; Tsuji, Suzuki, & Taoka, 2003).

Home monitoring is not utilized to increase independence with an activity, but observes the resident to ensure certain activities are completed within specific parameters. Home monitoring may ensure the resident has exited the bedroom by 10 am or taken their morning medications by 11am. If these activities have not been completed, the home monitoring service may call and prompt the resident to perform the activity or contact the caregiver to cue the resident.

Personal factors may affect how well the person accepts the home monitoring service. Older people may not be as accepting of technology as young adults, or previous experience with technology may contribute to acceptance of home monitoring. Other personal factors that may influence the outcome of home monitoring include: gender, race, fitness, lifestyle, habits, education, coping styles, behavior pattern, and upbringing (WHO, 2001).

Summary

Home monitoring may be a beneficial tool in assisting older adults to remain independent and safe in their homes as long as possible and avoid premature assisted living or nursing home

placement. With growth in the numbers of older adults, the increased demand for direct care workers, and the desire for older adults to age in place, new methods for assisting older adults in their homes are needed. The QuietCare system represents the next generation home monitoring and emergency response system, but research is lacking to describe how older adults use the system and if it meets their needs. This study will describe older adults' perceptions of the QuietCare system, explore whether their needs are being met, and offer suggestions for improvement in home monitoring systems.

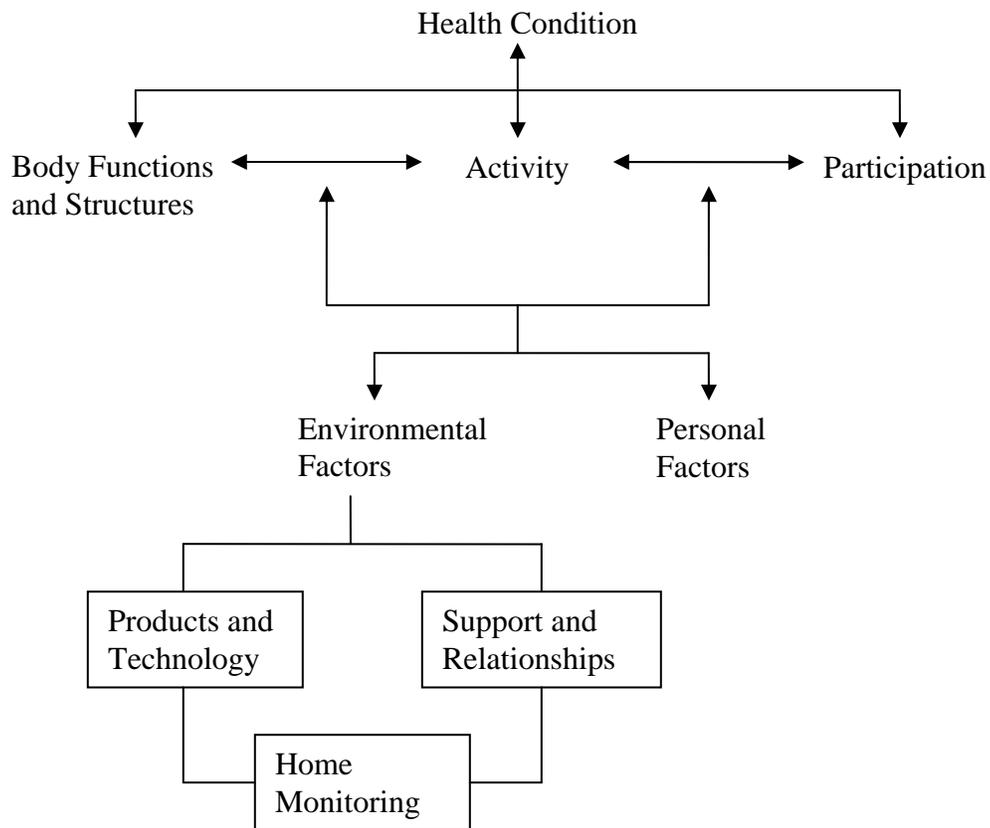


Figure 1-1. Home Monitoring Embedded in the ICF Model.

CHAPTER 2 LITERATURE REVIEW

This review focuses on the use of home monitoring to help community living older adults maintain independence and age in place. Home monitoring to help older adults age in place may range from something as complex as a smart home or as simple as a Personal Emergency Response System (PERS).

Smart Homes

A smart home is an environment constructed with various technological applications and devices to assist residents in performing daily activities. The idea of a smart home has been around since the early 1980's, with the goal of helping a person live more comfortably and conveniently (Stefanov, Bien, & Bang, 2004). Research on smart home technology is now being conducted worldwide. This technology has the potential to maximize independence and help older adults age in place. Allen (1996) describes the smart house as holistic, being directed by a central control unit and interpreting the user's needs. The smart home is then able to execute actions to respond to the user's needs.

Smart homes have the potential to restore functional status and slow decline in older adults. Smart homes have an extensive list of possible benefits because of the integrated systems, and added benefit of potentially being connected to remote health care providers and caregivers. To realize the potential of smart homes, many research teams are creating and improving smart home systems. In addition, the user's interaction and perception of the technology is being studied to maximize user satisfaction and create useful and usable applications.

Tiger Place--University of Missouri--Columbia

Tiger Place is a senior living community near the University of Missouri-Columbia (MU) campus. At Tiger Place, MU is using technology and developing smart apartments to help older adults age in place and promote independence. Through focus groups, MU found older adults are receptive to technology (Rantz et al., 2005). Sixty-six percent of their participants used e-mail and surfed the Internet. In addition, the older adults were willing to install technology in their homes if it was reliable, able to detect emergencies, affordable, non-intrusive, and required minimal action by the user.

Older adults felt they would benefit from smart home technologies that could provide emergency help, assistance with visual and hearing problems, prevention and detection of falls, temperature monitoring, automatic lighting, monitoring of physiological parameters, stove and oven safety control, property security, intruder alarm, reminder announcements of upcoming appointments or events, and information on adverse drug events and contraindications (Demeris et al., 2004). Many of these applications are for monitoring rather than altering a task to make it easier.

Gator-Tech Smart House University of Florida

The Gator-Tech Smart Home (GTSH) is a free-standing single family smart home near the University of Florida campus. The purpose of the GTSH is to develop smart home technologies that assist older adults in maximizing independence, maintaining quality of life, and aging in place. The home is equipped with a smart front door that allows the user to identify the visitor and open the door remotely. The smart mailbox announces when the mail has arrived, preventing unnecessary walks to the mailbox. The lights, blinds, and television are also voice controlled, eliminating the need to move about the home and physically interact with these devices. A SmartWave utilizes radio frequency identification (RFID) technology to

automatically program the microwave for a frozen meal and plays a video helping the user sequence through the task of putting the meal safely into the microwave.

The floor of the Gator-Tech Smart home is equipped with pressure sensors and integrated into the home's main computer to track the resident's movement throughout the home. With software programming, this system will potentially be able to ask the resident if they are well upon detecting the absence of movement for an unusual length of time. If the resident does not answer or says 'no, I am not okay', the home would call for help. Researchers at the Gator-Tech smart house are also working on cognitive prompting applications to assist an individual with mild dementia in sequencing through activities of daily living, such as washing hands or oral hygiene.

Center for Future Health--University of Rochester

The University of Rochester's Center for Future Health is attempting to monitor people's behavior patterns and figure out what an altered pattern means (University of Rochester Medical Center, 2005). This is important because many smart home projects are tracking behavior and using a deviation from a "normal" pattern as a potentially dangerous situation. The Center for Future Health is also trying to monitor physiological parameters wirelessly and communicate the information to a call center with the goal of preventing and detecting disease early (Knecht, 2001). They monitor vital signs, gait, sleep, behavior pattern, and exercise.

AwareHome--Georgia Institute of Technology

Georgia Tech's AwareHome is used to create smart technologies for older adults to age in place (Sanders, 2000). The goal of the AwareHome is to allow older adults to be proactive regarding their health care, assist them in their daily activities, increase opportunities for social communication, and ensure safety and well-being (Mynatt, Melenhorst, Fisk, & Rogers, 2004). The AwareHome uses the gesture pendant, a wireless pendant with both a camera and motion

sensors. The pendant responds to the resident's hand movements. Some of the commands the resident can give are to close the blinds, lock the doors, open the front door, dim the lights, or adjust the thermostat temperature. In interviews, older adults felt they did not need the technology now, they were afraid of becoming dependent on technology and losing abilities, and viewed the technology as something that would compensate for a disability, rather than standard features in future homes.

Georgia-Tech is also working on the "digital family portrait" that provides a graphical view of the resident's activity level to a remote caregiver. The "digital family portrait" provides the caregiver with information regarding the outside weather and the inside temperature (Mynatt et al., 2004). Movement between rooms is displayed in 15 minute increments and background shading indicates day or night. Regarding home monitoring, the older adults were interested if it was necessary, but not before. They were agreeable to 1 or 2 family members viewing their information, but no more. They did not want people to know more information than was necessary to maintain their independence.

BT Exact--United Kingdom

In the UK, BT Exact is working on a project to track a resident's well-being and alert a caregiver when a problem is detected (Brown, Hine, Sixsmith, & Garner, 2004). The researchers monitor 6 activities: leaving and returning home, visitors, preparing and eating food, sleeping patterns, personal appearance, and leisure activities. To monitor the activities, sensors are strategically placed throughout the home. In the future, the person's activity pattern could be sent to a call center and monitored (BT Exact, 2005).

Place Lab--Massachusetts Institute of Technology

MIT's Place Lab is a one-bedroom condo with hundreds of sensors (House_n Research Group, 2005). The goal is to track activities and interactions with the environment. MIT is able

to monitor a participant's activity in their own home before and after their stay at Place Lab using a portable system (House_n Research Group, 2005). Some of the areas of study at Place Lab are proactive health (encourage healthy diet, exercise, and medication adherence), disease management, and accident prevention, which are all areas that could help an older adult age in place (House_n Research Group, 2004).

MavHome--University of Texas--Arlington

MavHome is a smart home designed to learn its inhabitant's behavior patterns and automate certain tasks, such as lighting and temperature (Cook, Youngblood, Heierman, Gopalratnam, Rao, Litvin, & Khawaja, 2003). The home is also attempting to monitor a resident's health status and alert to any long or short term changes. The refrigerator would be able to identify its contents and reorder groceries on-line. The microwave would search for recipes on-line and the home entertainment system would automatically record programs the resident might enjoy.

MavHome has a reminder system that can be triggered if the resident deviates from normal routine or wants to know about upcoming activities (Cheek, Nikpour, & Nowlin, 2005). These reminders can be helpful for taking medications correctly, locking doors, and turning off bath water. Residents can automate some of the home functions, such as climate control, water temperature, and lighting. Once the house learns the user's preferences, it can automate those settings. If the house provides a reminder and the elder does not respond, it could automate those activities such as shutting off the bath water, turning off the stove, and locking the doors.

Telehealth

Smart homes and telehealth technology can be used to collect and track data on the home's residents. The data may be monitored by a caregiver, a company, or a health care center. The caregiver may wish to ensure their family member is taking medications correctly and getting

about the home. The monitoring company may monitor the resident for emergencies or potential risks and intervene upon detection by calling a local caregiver. The health care center may track specific health parameters to keep a chronic condition under control or look for certain signs to catch ailments early. An overall goal of home monitoring and telehealth is to keep the resident safe and healthy in the home for as long as possible. These interventions also help maximize independence and may allow the individual to age in place.

Tele-homecare is used to remotely monitor individuals' health parameters and provide medical services to high-risk patients and those unable to travel. Typically, the tele-homecare remote monitoring system has a base unit that communicates with a care coordination center at a hospital or clinic using telephone lines. The base unit may have peripheral attachments to monitor a variety of health parameters including: medication compliance, blood pressure, weight, pulmonary function, glucose level, and more. Mann et al (2007) reported the most common uses for home health monitoring were for blood pressure, blood sugar, and pulse.

Tele-homecare allows health care providers to intervene quickly when measurements are beyond the desired range. Individuals are able to sit in the comfort of their own home while health care providers conduct medical monitoring procedures in their offices. Older adults have a strong acceptance of home health monitoring devices (Mann, Marchant, Tomita, Fraas, & Stanton, 2002) and 80% are satisfied with their home health monitoring systems (Mann et al., 2007).

Tele-homecare enhances feelings of safety and security and increases confidence for the user (Sixsmith, 2000). Home health monitoring devices also relieve personal and family worry (Mann et al., 2002). For those who do not use home health monitoring systems, most cite lack of perceived need and cost as the reasons for non-use (Mann et al., 2007).

Tele-homecare has shown promise in decreasing home health care costs, as well as cost savings through the elimination or reduction of providers' travel costs (Binder, Hoffman-Wellenhof, Salmhofer, Okcu, Kerl, & Soyer, 2007; Finkelstein, Speedie, & Potthoff, 2006; Litzinger, Rossman, Demuth, & Roberts, 2007). Moreover, numerous telemonitoring programs have reported decreased emergency room visits, reduced hospital admissions and hospital bed days of care, and decreased hospital readmission rates (Frantz, Colgan, Palmer, & Ledgerwood, 2002; Jerant, Azari, & Nesbitt, 2001; Stensland, Speedie, Idelker, House, & Thompson, 1999).

Because tele-care is becoming more widely used, companies like Cnow, Inc. are emerging. Cnow Inc. provides residents with a way to get face-to-face help over the Internet at all times (Cnow Inc., 2006). If a home health company or health care center wishes to set up a tele-health program, Cnow will take care of all the equipment and offer 24 hour technical support. Cnow provides 2-way real time video for customers.

In one home tele-health intervention study, older adults utilized either a hand-held in-home messaging device; a telemonitor with 2 way audio-video and peripherals that monitored blood pressure, heart rate, weight, oxygen saturation, and heart and lung sounds; or a video phone with 2-way audio-video communication (Chumbler, Mann, Wu, Schmid, & Kobb, 2004). A control group received usual care. The home tele-health group improved significantly on all outcome measures, including instrumental activities of daily living (IADLs), FIM- functional independence measure, and MMSE- mini mental state exam. The control group declined significantly in IADL function and cognition as measured by the FIM. Other outcome measures remained stable for the control group. The control group and the tele-health group were significantly different from each other at 12 months on the IADL and FIM-motor (functional independence). The tele-health group also differed significantly on the FIM- cognitive, but not

the MMSE (cognitive) measure. This study indicates home tele-health programs have the potential to improve function and keep frail older adults independent and safe at home.

Personal Emergency Response System (PERS)

A study of people found incapacitated in their homes reported the average amount of time someone spends down before being found is 15 hours (Gurley, Lum, Sande, Lo, & Katz, 1996). Of those who are down and unable to call for help, 28% die. The difference in time spent down before being found is crucial. The average down time for someone found alive is 2 hours, compared to 18 for those found dead (Gurley et al., 1996). One way older adults can try to prevent becoming stranded in their homes is by using a home monitoring system.

Personal emergency response systems (PERS) typically consist of an emergency call button worn on a pendant or bracelet, a base unit, and an emergency response center (ERC). When the older adult has an emergency, the button is pressed and a signal is transmitted wirelessly to the base unit. The base unit then places a phone call to the ERC. The ERC communicates with the older adult through the base unit and calls a responder if help is needed.

Fall risk is the most common reason older adults subscribe to a PERS (Mann, Belchior, Tomita, & Kemp, 2005). Subscribers want to know if they fall or require assistance that help is immediately available. Subscribers may even forego adult children as responders in order to utilize a close neighbor (Porter, 2003).

Older adults report the most important way their PERS helps them is by giving them a feeling of security and decreasing the worry of family members (Mann et al., 2005). However, their sense of security may be disturbed if they experience false alarms that result in a responder entering their home unexpectedly or hear an unfamiliar voice in their home when the ERC is trying to communicate with them through the base unit (Porter, 2003). False alarms may contribute to the older adult not wearing the pendant or canceling the service.

Less than 50% of PERS subscribers wear their pendant when alone at home (Levine & Tideiksaar, 1995). Besides false alarms, older adults are often concerned with how the pendant looks to others. In a study by Porter (2005), one of the older women took her pendant off because the button could be seen under her clothes. Others removed their pendants when people came to visit, feeling they did not need it unless alone.

Cost, lack of awareness, and perceived lack of need are the most common reasons an older adult does not obtain a PERS (Bernstein, 2000; Mann et al., 2005). PERS are typically paid for out of pocket by the user and their family (Bernstein, 2000). In Porter's study (2003), 5 women obtained PERS after a recommendation from a home care nurse or case manager and the other 3 obtained PERS at the request of family members. None of the women obtained the device because they were aware of it and independently determined they needed it.

These types of emergency response systems require the person to wear the device, to be conscious and able to press the button. If the older adult forgets to wear the device or chooses not to wear the device and falls, they may be unable to call for help. To alleviate some of these problems, home monitoring systems such as QuietCare have been developed.

QuietCare Home Monitoring System

QuietCare is a passively activated emergency response and behavior tracking system. The QuietCare system utilizes 5-6 strategically placed motion sensors in the older adult's home, the ADL Communicator (base unit), and the QuietCare Server. The motion sensors are installed in the kitchen, bathroom, bedroom, and near medications to monitor the resident's activity. The sensors wirelessly transmit information about the resident's movement to the ADL Communicator. The ADL Communicator stores the information and transmits it via telephone lines to the QuietCare Server every 2 hours. When the server recognizes changes in the

resident's behavior, it alerts the response center and the user's caregiver. Caregivers may login to a secure website and view the older adult's activity charts at any time.

During the first 2-3 weeks following QuietCare installation, the system learns the user's typical activity patterns. Once the QuietCare system has baseline ranges of normal behavior patterns, the system is able to determine when the user's pattern is abnormal. The QuietCare system monitors the user's following types of behavior:

- Waking and leaving the bedroom by their normal time
- Exiting within a certain amount of time after entering the bathroom
- Visiting the medication area at appropriate times
- Entering the kitchen regularly for meals
- Moving around the home in their normal activity range
- Visiting the bathroom within the range of their normal number of visits

The QuietCare home monitoring system may provide a method of responding to emergencies and possibly early detection of illness without user action. However, there has been no research on home monitoring systems like QuietCare, in terms of user needs and satisfaction.

Study Purpose

The purpose of this study was to examine user needs and satisfaction of the most currently advanced, commercially available, home monitoring system, QuietCare. User sense of security and privacy in using this home monitoring system was also investigated.

CHAPTER 3
MATERIALS AND METHODS

Introduction

In this chapter the specific aims and hypotheses are presented, the sampling criteria and processes are explained, the data collection methods are discussed, and the data analysis is presented.

Specific Aims and Hypotheses

Aim 1: To Determine If an Advanced HMS Meets the Needs of Older Persons with Disabilities Living Alone.

Hypotheses:

- (a) The HMS detects emergencies and alerts the call center and/ or caregiver within a reasonable time frame according to the user and informal caregiver.
- (b) The HMS user does not experience emergencies that go unanswered by the HMS and call center.
- (c) The HMS caregiver does not experience significant stress in relation to using the HMS.

Aim 2: To Determine Whether the HMS Users and Caregivers Are Satisfied with the Current System Features and What Changes May Improve the System.

Hypotheses:

- (a) HMS users and caregivers perceive the system as easy to use and are satisfied with the system.
- (b) HMS users and caregivers recommend additional features and changes to the system to improve the home monitoring system.
- (c) HMS users and caregivers experience advantages and disadvantages of using the system.

Aim 3: To Determine the HMS Users' Level of Concern Regarding Invasion of Privacy in Utilizing a HMS.

Hypotheses:

- (a) HMS users are comfortable with the way QuietCare monitors them.

- (b) HMS users have minimal concern of privacy invasion in using the QuietCare system.

Note: Emergencies are defined as situations when the user is in danger and unable to obtain assistance (e.g. a fall, medical emergency).

Participants

Participants were recruited from a QuietCare distributor in central Florida. The distributor gathered the list of current users and caregivers who met the inclusion criteria and contacted them to determine their interest in participating in the study. The distributor determined 41 HMS users and 42 HMS caregivers met the criteria described below. All were invited to participate in the survey.

Inclusion Criteria for User

- Over 60 years of age
- Lives alone in the community
- Has used the home monitoring system for at least 3 months
- Able to provide informed consent
- Ability to speak and understand English

Inclusion Criteria for Caregiver

- Cares for a home monitoring system user
- Able to provide informed consent
- Able to speak and understand English

Exclusion Criteria

- Presence of any health problems or disabilities that would interfere with the ability to participate effectively in the interview process, such as severe hearing or speech impairment based on the investigators clinical impression

Informed Consent

If the potential participant wished to participate in the study, the distributor advised that their contact information would be given to the investigator at the University of Florida. The

investigator contacted the participants by phone, explained the study, answered any questions, and obtained informed consent.

Data Collection

Of the 41 HMS users who were invited to participate in the survey, 29 accepted and were part of the study. Of the 42 HMS caregivers who were invited to participate in the study, 30 agreed to participate and became part of the study.

HMS Users

Seven HMS users were interviewed in-person with the remaining 22 interviewed via the telephone. The interviewer administered the HMS user survey and the Activities of Daily Living section of the Older Americans Resources and Services Multidimensional Functional Assessment Questionnaire (Fillenbaum, 1988). The interviews lasted an average of 39 minutes and were scheduled at the participant's convenience.

HMS user survey

The HMS user survey was implemented to understand perceptions of the QuietCare user: the advantages/ disadvantages in using the system, what they would change about the system, and concern for privacy while being monitored. The survey consisted of open ended, closed ended and partially closed-ended questions. Questions were assembled using guidelines from Dillman's "Mail and Internet Surveys: The Tailored Design Method" (Dillman, 2006). The guidelines Dillman (2006) suggests are as follows:

- Ensure each question requires an answer
- Form questions so respondents may provide an accurate, ready-made answer easily
- Form questions so the responder can recall and report past behaviors easily
- Refrain from asking the responder for information they may be unwilling to reveal
- Refrain from using vague quantifiers, such as "on a scale of 1-10"
- Choose simple rather than specialized words
- Be succinct
- Use complete sentences

- Develop mutually exclusive response categories

The home monitoring survey ends with demographic questions including items such as age, gender, marital status, and type of residence.

Once the survey was assembled, it was distributed to two individuals for expert review.

The suggested changes to the survey included:

- Create an Access database and organize the survey to easily transfer responses from the paper survey into an Access form.
- Ask demographics last as they are the least interesting to the participant
- Never give respondent more than 4 options in a list, with seniors not more than 3
- Ask them about the last month, more than that may be difficult to remember
- Break down Likert scales, rather than giving them 4 categories start with 2. For example, rather than “Are you very satisfied, somewhat satisfied, somewhat dissatisfied, or very dissatisfied?” ask “Are you satisfied or dissatisfied?” and then ask “Are you very satisfied or somewhat satisfied?”
- Most interesting questions go first, most threatening or embarrassing go towards the end

A final suggestion was to break down the survey questions considered too difficult for the respondents. For example, one question asked the respondent to estimate how long it takes QuietCare to respond to emergencies. It was recommended to start by asking how many times in the last month the individual had to use QuietCare, when was the last time it was used to respond to an emergency, and how long did it take to get a response.

Once the survey was reconstructed following the advice of the expert reviewers, it was administered to the first 2 participants. The data from these surveys was reviewed to determine which questions were confusing, superfluous, on-target, and missing. The survey was finalized and administered to the remaining participants.

OARS- ADL subset

The OARS- ADL subset is a 15 item inventory assessing the amount of assistance the individual requires to complete Instrumental Activities of Daily Living (IADL), such as housekeeping and shopping, as well as Basic Activities of Daily Living (BADL), such as bathing and dressing (Fillenbaum, 1988). To establish criterion validity, the ADL subset was compared to physical therapist ratings of individuals' performances of ADLs (Fillenbaum, 1988). The two measures were correlated using Kendall's tau ($tau = .83, p < .001$) and Spearman's rank order ($r_s = .89, p < .001$) correlations (Fillenbaum, 1988). Interrater reliability was established on the ADL subset by having 11 raters score 30 participants. Then the interclass correlation coefficient was derived from an ANOVA performed on the subset ($ICC = .865, p < .001$) (Fillenbaum, 1988).

In scoring the OARS-ADL subset, the individual's capacity to perform ADLs is categorized by one of five categories (Fillenbaum, 1988).

- Excellent ADL capacity- can perform all ADLs without assistance and with ease
- Good ADL capacity- can perform all ADL s without assistance
- Mildly impaired ADL capacity- some help is required with 1-3 ADLs
- Moderately impaired ADL capacity- requires assistance with at least 4 ADLs, but can get through a single day without help. Or regularly requires help with meal preparation
- Severely impaired ADL capacity- needs help each day but not necessarily throughout the day or night with many ADLs
- Completely impaired ADL capacity- needs help throughout the day and/ or night to carry out ADLs

HMS Caregiver Survey

Prior to initiating the interview, the researcher explained the study and obtained informed consent from the participants. The interviews were scheduled at the caregiver's convenience and

lasted an average of 22 minutes. All 30 caregivers were interviewed by telephone and administered the HMS caregiver survey.

The survey items were designed to obtain caregivers' perceptions on what it is like to be a caregiver for a person using the QuietCare system, what they would change about the system, and what works well for them. As with the HMS user survey, the HMS caregiver survey consisted of open ended, closed ended and partially closed ended questions. It was also formed using Dillman's (2006) guidelines for developing survey questions. The survey ends with demographic questions including items such as age, gender, marital status, and type of residence. The expert review procedure discussed for the HMS user survey was also applied to the HMS caregiver survey.

Data Analysis

Surveys were recorded by hand during each interview and then entered into an Access database. Queries were executed to analyze variables of interest. All analyses were done with quantitative data. In Chapter 5, the qualitative information gathered was used to compliment the quantitative data. All data were analyzed using descriptive statistics (measures of central tendency and frequencies).

CHAPTER 4 SURVEY RESULTS

This chapter covers the survey response rate, demographic information and ADL capacity for HMS users, caregivers' demographic information, and the results for each hypothesis.

Survey Response Rates

The sample consisted of 29 HMS users and 30 HMS caregivers. The survey response rate for HMS users was 70.7% and the response rate for HMS caregivers was 71.4%. These response rates are high compared to other studies that have utilized telephone interviews for data collection. In a study by Blieszner, Ronberto, and Singh (2001), the researchers used telephone interviews to assess service use by older adults and achieved a 50.2% response rate. Another study utilized a telephone survey to assess quality of life in older adults with chronic illnesses; the response rate was 47% (Bayliss, Ellis, & Steiner, 2007). A study used a telephone survey to compare ethnicity and reluctance to use the emergency room and achieved a 56% response rate (Reime, Tu, Tzianetas, & Ratner, 2007).

HMS User and Caregiver Matching

Not all of the HMS users and caregivers were pairs. Some of the HMS users had caregivers who were unable to participate. Examples for non-participation of the caregiver included the caregiver's lack of time or the caregiver was a professional from an agency such as hospice. Likewise, some HMS caregivers cared for QuietCare subscribers who were unable to participate. Some examples were the subscriber was hard of hearing, unable to speak, or experienced short term memory loss. Of the total sample, 17 HMS users matched 20 HMS caregivers. Three HMS users had two caregivers each who were interviewed as part of the study. The remaining users and caregivers did not have counterparts.

User Demographics

The home monitoring system users' demographic information was obtained from the HMS User Survey. As seen in Table 4-1, the HMS user sample was mostly female (72%), white (97%), and widowed (83%) with a mean age of 80. In addition, the majority (52%) of the HMS users had at least one child living within 20 miles of their home.

The majority (55%) of the HMS users resided in single family homes and lived in their homes for an average of 14 years as can be seen in Table 4-2. In addition, HMS users subscribed to QuietCare for an average of 7 months. Most of the HMS users were introduced to the system by their adult child (31%) or through church (31%).

User Functional Capacity

The HMS users' functional ADL capacity was assessed with the OARS- ADL subset (Fillenbaum, 1988). As seen in Table 4-3, 55% of the HMS users were able to perform all ADLs without assistance. Twenty-eight percent of the HMS users reported mildly impaired ADL capacity, the ability to perform all but 1-3 ADLs and able to prepare their own meals. Seven percent reported moderately impaired ADL capacity, regularly needing assistance with at least 4 ADLs or with meal preparation. Finally, 10% of the HMS users reported severely impaired ADL capacity, requiring assistance each day with many ADLs.

In 2004, 27% of Medicare participants over 65 had difficulty with 1 or more ADLs and those plus another 14% had difficulty with IADLs (U.S. Administration on Aging, 2006). A remaining 59% of Medicare participants over 65 did not have difficulty with IADLs or ADLs, which is close to the 55% reported in the HMS user sample if those with excellent and good ADL capacity are combined.

Caregiver Demographics

The caregivers' demographic information was obtained from the HMS Caregiver Survey. As seen in Table 4-3, the HMS caregivers were mainly female (60%), white (100%), and married (87%). The HMS caregivers' average age was 59, which closely resembles the average age of 60 for caregivers in a meta-analysis conducted by Pinquart and Sorenson (2007). Likewise, the 1999 Informal Caregiver Survey reported the average age of caregivers as 62.5 (Wolff & Kasper, 2006). Considering gender of the caregiver, the HMS caregiver sample resembles that of an AARP and the National Alliance for Caregiving study (2004), which reported caregivers in the U.S. as 61% female and 39% male. Only 27% of the HMS caregivers still had children at home. The number of children at home ranged from 0-6.

HMS Caregiver and User Relationship

As seen in Table 4-5, an adult child (73%) was the most common HMS caregiver. According to the Family Caregiver Alliance (2001), the adult child is the most common caregiver (41%), followed by another relative (27%) and a spouse (23%) for a person over 65. However, the meta-analysis on physical health of caregivers by Pinquart and Sorenson (2007) indicated that 50% of the caregivers were spouses and 38% were adult children. Since the HMS user sample only included people who lived alone, few (if any) spousal caregivers were expected.

Aim 1: To Determine If an Advanced Home Monitoring System Meets the Needs of Frail Older Adults Living Alone.

To determine if the HMS was meeting the needs of community based older adults living alone, HMS users and caregivers were asked several questions from their respective surveys. The questions posed to the user included the number of emergencies experienced in the last month, if the system detected all emergencies, and if help came in a reasonable amount of time.

The caregiver was also asked if the person for whom they provide assistance experienced any emergencies within the last month, if emergencies were detected, and if a responder was contacted within a reasonable amount of time.

Finally, the caregiver was asked several questions concerning the burden of being a responder. The questions posed involved whether the system has helped the caregiver, consideration of discontinuing the service, frequency of checking the Internet to track the individual, system ease of use, and the frequency of false alarms.

- **Hypothesis 1a: The home monitoring system detects emergencies and alerts the call center and/ or caregiver within a reasonable time frame according to the user and informal caregiver.** When the HMS users were asked if they had an emergency within the last month, 1 of the 29 users reported they had. When asked about the last time they had an emergency, only one additional person experienced an emergency during the time in which they had been using the HMS. The emergency occurred 3 months prior to the interview. Both emergencies were detected by the QuietCare system. The types of emergencies experienced were a fall and a medical emergency. The users felt QuietCare responded to their emergencies in a reasonable amount of time.

None of the caregivers reported caring for a user who experienced an emergency within the last month. None of the caregivers matched the two HMS users who experienced emergencies.

When the users were asked if the QuietCare system has helped them, 21 of the 29 (72%) stated that it has helped them. The ways in which the HMS has helped the participants are discussed in Chapter 5.

- **Hypothesis 1b: The home monitoring system user does not experience emergencies that go unanswered by the home monitoring system and call center.** When the HMS users

were asked if they had experienced an emergency in the last month that the QuietCare system did not detect, none of the 29 users reported having an undetected emergency. Likewise, none of the caregivers interviewed reported the individual they monitor experienced an emergency that went undetected within the last month.

In addition, the HMS users were asked if the system makes them feel more or less secure. Twenty-four of the 29 HMS users stated the QuietCare system makes them feel “more secure.” Of those 24, 18 stated the system makes them feel “much more secure.” Two of the 24 said the system makes them feel “a little more secure” and the other two said “just more secure.” The remaining 5 HMS users stated that the system does not make them feel more secure or less secure.

Where the system makes the majority of people feel more secure, it does not make them feel more or less independent. When the HMS users were asked if the system makes them feel more independent or less independent, 18 of the 29 (62%) stated neither. The other 11 stated the system made them feel “more independent.” Of those 11, 7 stated it made them feel “much more independent” and 4 said “a little more independent.”

- **Hypothesis 1c: The home monitoring system caregiver does not experience significant stress in relation to using the home monitoring system.** When asked if the QuietCare system has helped them, 29 of the 30 (97%) of the HMS caregivers stated that it has helped them. The one participant who said that it hadn’t helped stated her mother was very independent and she doesn’t worry about her.

When the HMS caregivers were asked if they had ever considered discontinuing the QuietCare service, 11 of the 30 caregivers indicated they had considered discontinuing the

service. The most common reason given for consideration of discontinuing the service was lack of need.

When the HMS caregivers were asked how often they check on their friend or relative using the QuietCare website, 2 caregivers do not check the e-mail or website, but entirely rely on the call center to telephone them if there is an emergency. Seventeen caregivers only check the daily e-mail report to view the user's activity level. Eight people check the website once a day to once a week, as well as the daily e-mail report. Two people check the website 2-3 times per day and read the daily e-mail report. One person says she checks several times a day because she is on the computer constantly anyway.

When the HMS caregivers were asked if the QuietCare system was easy or difficult to use, 29 of the 30 caregivers stated that it was "easy to use" and one did not answer this item. Of the 29 that answered, 26 stated that it was "extremely easy to use," two stated it was "somewhat easy to use," and one stated it was "just easy to use."

When the HMS caregivers were asked how often they receive false alarms, 10 of the 30 caregivers experienced one false alarm within the last month. Five of the false alarms were because the user was out of town and the system was not placed on vacation mode. Two of the caregivers received false alarms because of too much bathroom activity. In both instances, the user had company and the system was reporting the activity of everyone inside the residence. One alarm was for a possible bathroom fall, but the user was actually spending more time in the bathroom because she was cutting her hair. Two alerts were for low meal preparation because the user had gone out for a meal. None of the false alarms were because the system was reporting inaccurate data.

Aim2: To Determine Whether the HMS Users and Caregivers Are Satisfied with the Current System Features and What Changes May Improve the System.

Participants were asked questions to determine if the system was easy versus difficult to use and report their satisfaction with the system. In addition, participants were interviewed to determine what aspects of the system were advantageous, if there were disadvantages to having the system, and if there were things the participants would change.

- **Hypothesis 2a: The home monitoring system users and caregivers perceive the system as easy to use and are satisfied with the system.** When the HMS users were asked if QuietCare was easy or difficult to use, 100% felt the home monitoring system was “easy to use.” When asked if it was very easy to use versus somewhat easy to use, 100% stated that the system was “very easy to use.” Again 29 of the 30 HMS caregivers thought the home monitoring system was “easy to use” and one did not answer. Of the twenty-nine that thought the system was easy to use, 26 thought the system was “very easy to use,” 2 thought it was “somewhat easy to use,” and 1 just stated it was “easy to use.”

Of the 29 HMS users surveyed, 26 stated they were “satisfied” with the home monitoring system and 3 did not respond. Of the 26 who were satisfied, 24 were “very satisfied” and 2 were “somewhat satisfied.” Of the 30 HMS caregivers interviewed, 29 were “satisfied” with the system and one did not answer. Of the 29 that were satisfied with the home monitoring system, 28 were “very satisfied” and one was “somewhat satisfied.”

When the HMS users were asked if they had ever considered discontinuing QuietCare, only 5 of the 29 (17%) had. The most common reason given for possibly discontinuing the system was lack of need.

- **Hypothesis 2b: Home monitoring system users and their caregivers recommend additional features and changes to the system to improve the home monitoring system.**

When asked what they would change about the HMS system or what were things they wish the system did that it doesn't do now, 8 of the 29 users had suggested changes or additions to the home monitoring system to improve its capabilities. About twice as many (17 out of 30) caregivers had suggested changes or additions. The changes recommended are discussed in Chapter 5.

- **Hypothesis 2c: The QuietCare users and their caregivers experience advantages and disadvantages of using the system.** When asked about the advantages of having the HMS, 27 of the 29 users reported advantages of having the home monitoring system. The most common advantages were peace of mind for the user and peace of mind for the family. All of the caregivers reported advantages of having the home monitoring system. Again, the most frequently reported advantage was providing peace of mind. The advantages of the system are discussed further in Chapter 5.

When asked about the disadvantages of having the HMS system, only 9 of the 29 users identified disadvantages of having the system. Cost was the most commonly identified disadvantage. Thirteen of the 30 caregivers reported disadvantages of the home monitoring system. Again cost appeared to be the most common disadvantage. Disadvantages are discussed further in Chapter 5.

Aim 3: To Determine the HMS User's Level of Concern Regarding Invasion of Privacy in Utilizing a Home Monitoring System.

To determine whether the HMS user was concerned about privacy invasion using the HMS, the HMS users were asked whether or not they were comfortable being monitored in the way QuietCare works. They were also asked if they were comfortable with their caregivers being able to see their activity information. Finally, the users were asked if they were concerned

about their privacy being invaded using the system and if they trusted their information was adequately protected on the website.

- **Hypothesis 3a: Users are comfortable with the way QuietCare monitors them.** When asked if they were comfortable or uncomfortable with being monitored in the way in which QuietCare works, all of the users reported they were “comfortable” with the way QuietCare monitors them. When asked if they were very comfortable or somewhat comfortable, 27 of the 29 users stated they were “very comfortable” and 2 of the 29 stated they were “somewhat comfortable.”

When asked if they were comfortable or uncomfortable with those who can view their activity information being able to see their information, 26 of the 29 stated they were “comfortable.” Three users did not answer the question. Of the 26 who were comfortable, 25 were “very comfortable” with people being able to view their information and 1 was “somewhat comfortable.”

- **Hypothesis 3b: Users have minimal concern of privacy invasion in using the QuietCare system.** When the HMS users were asked if they were concerned about their privacy being invaded using the QuietCare system, 28 of the 29 users stated they were not concerned. When the one HMS user was asked whether she was very concerned or a little concerned about her privacy being invaded, the user said she was “a little concerned.”

When the HMS users were asked if they believed their activity information was adequately protected on the QuietCare website, 26 of the 29 users stated they believed their information was adequately protected. Three users were unsure and did not wish to answer yes or no. When asked if they trusted that only authorized people were able to view their information, again 26 of

the 29 users stated they believed only authorized people could view their information. The same 3 people did not answer the question.

Summary

The HMS detected all of the users' emergencies; no emergencies went undetected. Most of the HMS caregivers have never considered discontinuing the system, they check the daily e-mail to view the user's activity, and they do not receive false alarms. Both the HMS users and caregivers were satisfied with the system and found it very easy to use. Most of the users and all of the caregivers identified advantages of having the system and less than half identified disadvantages of having the system. Overall, the users were comfortable with the way QuietCare monitors them and did not have concerns of privacy invasion.

Table 4-1. HMS user demographics

	Frequency (%) or Mean(SD)	Range
Age	80(10.1)	61 - >89
Gender		
Female	21 (72%)	
Male	8 (28%)	
Race		
Black	0	
White	28 (97%)	
Hispanic	0	
Asian	1 (3%)	
Other	0	
Educational Level		
High School (9-12)	9 (31%)	
Some College	11 (38%)	
Bachelor's Degree	4 (14%)	
Master's Degree	2 (7%)	
Ph.D/ MD	3 (10%)	
Marital Status		
Widowed	24 (83%)	
Married	1 (3%)	
Divorced	3 (10%)	
Single	1 (3%)	
Other	0 (0%)	
No. of Children	2.5 (1.5)	0 – 6
No. of Children w/in 20 miles	.9 (1.2)	0 – 5

Table 4-2. Home and HMS user facts

	Frequency (%) or Mean (SD)	Range
Type of Home		
Single Family	16 (55%)	
Multi-unit Bldg. (condo)	5 (17%)	
Mobile Home	8 (28%)	
Semi-detached (duplex)	0 (0%)	
Other	0 (0%)	
Years in Home	14.4 (15.6)	.5 – 56
Months of HMS Use	7.3 (5.3)	.25 – 24
Referred to HMS by:		
Adult child	9 (31%)	
Church	9 (31%)	
Hospice	4 (14%)	
Friend	3 (10%)	
MD	1 (3%)	
Independently	1 (3%)	
Other	2 (7%)	

Table 4-3. HMS users' OARS-ADL subset ratings

ADL Capacity	Frequency (Percent)
Excellent ADL Capacity	6 (21%)
Good ADL Capacity	10 (34%)
Mildly Impaired ADL Capacity	8 (28%)
Moderately Impaired ADL Capacity	2 (7%)
Severely Impaired ADL Capacity	3 (10%)

Table 4-4. HMS caregiver demographics

	Frequency (%) or Mean (SD)	Range
Age	59.1 (8.9)	38-69
Gender		
Female	18 (60%)	
Male	12 (40%)	
Race		
White	30 (100%)	
Black	0 (0%)	
Asian	0 (0%)	
Hispanic	0 (0%)	
Other	0 (0%)	
Educational Level		
High School	4 (13%)	
Some college	9 (30%)	
Bachelor's Degree	11 (37%)	
Master's Degree	6 (20%)	
Ph.D./ M.D.	0 (0%)	
Marital Status		
Married	26 (87%)	
Divorced	2 (7%)	
Single	1 (3%)	
Widowed	0 (0%)	
Other	1 (3%)	
No. of Children	2.8 (1.7)	0-8
Children at Home	8 (27%)	

Table 4-5. The relationship of the HMS caregiver to the HMS user they assist

Caregiver Relationship to User	Frequency (Percent)
Adult Child	22 (73%)
Daughter/ Son- in-Law	3 (10%)
Sibling	3 (10%)
Other	2 (7%)

CHAPTER 5 DISCUSSION

The purpose of this study was to explore the most currently advanced, commercially available home monitoring system, QuietCare. I sought to determine users' and informal caregivers' perceptions of the QuietCare system, in terms of satisfaction and ease of use. I examined the users' sense of security and privacy in using this home-monitoring device. The research method used was a survey. I felt this method was useful to provide an overview of how the QuietCare system was working for the older adults and informal caregivers. The compilation of survey results did provide a picture of the general perception of the home monitoring system.

The first part of this chapter includes a discussion of the major findings of the study, followed by study limitations, areas for future research are suggested, and study conclusions are presented.

Major Findings

Very few of the HMS users ever experienced an emergency while using the system. The two HMS users who had experienced emergencies used the system for 8-12 months. Even though the others had not been rescued from an emergency, they did feel that the QuietCare system helped them. Likewise none of the caregivers reported that the person they look after had experienced an emergency, but almost all confirmed the system helped them.

Initially, I sought to describe relatively objective measures of the usefulness and effectiveness of the HMS. I focused part of the survey on the number of emergencies experienced, the circumstances around the emergencies, the response time of the responder, and the outcome of the situation. However, the results indicated that while these measures are important, the subjective results of how the participants felt about the system were also essential. The subjective results provide insight into how the system is working for the participants as well.

If the participants felt the system was not reporting accurate data or there were a number of problems with the system, the participants may have expressed more negative feelings regarding the system. The following sections discuss some of the more subjective findings.

How QuietCare Has Helped the Users

When asked how the QuietCare system has helped them, 76% of the users who stated the system helped them said it was because it provides them and their families with peace of mind.

A sampling of their quotes follows.

I have peace of mind knowing my daughters will be alerted if there is no movement (in my home).

Knowing it is here gives me confidence that someone is looking out for me.

It provides (my children) comfort, even with their busy lives they can check the website.

Three participants also stated the system increased or improved communication with their children. One stated, "It has improved communication with my children. It makes them more aware of me and they check on me."

One participant recounted an event when the system noticed he was utilizing the bathroom more frequently, the user subsequently discovered a medical problem. While this was not technically an emergency, as the increased bathroom use was a warning that came through an e-mail rather than an urgent call to the caregiver, it still was seen as a benefit.

The same user stated the system allows him to check on his medication compliance. Occasionally, he will visit the QuietCare website to see if he consumed his medication. At times he experiences confusion or memory impairment and the website acts as a back up for him.

One HMS user reported the system saved her life. The individual was home after recent surgery. She experienced difficulty breathing and remained seated in her living room chair,

which was unusual. The system triggered an alert because her activity level was too low. Her caregiver was notified and contacted her physician, who detected a pulmonary embolism.

How QuietCare Has Helped the Caregivers

When asked how the QuietCare system has helped them, almost all of the HMS caregivers stated it has given them peace of mind. The caregivers appreciate being able to read the daily e-mail report or check the website and know their loved one is all right. Some of their comments are below.

It continually gives me reassurance as to what she is doing. She has attempted suicide a couple times. This allows me to see that she is taking her medications and functioning. We live 30-40 miles apart. It is a comfort to me. She has said she doesn't need it, but my brother and I told her that we do.

Even when we were in South America we could get information. It is interesting to know what is happening. I have peace of mind knowing he has something more than a daily call from my sister. Once there wasn't any movement because he was gone on a trip and they called. So I know it responds.

I have a sense of peace about her being there alone.

One caregiver explained how the system improved her quality of life, "It has helped my quality of life. Sometimes the mother-in-law/ daughter-in-law relationship is not the best. This allows me to check the computer to see that she is okay without having to call her all the time."

Another caregiver also appreciated the reduction in demand to telephone, "The daily e-mail summarizes the last 24 hours. I like this because of the unobtrusiveness. I don't have to call her all the time to know she is okay."

Another interesting way the system has helped caregivers is that it allows them to check on their relative even when they cannot place a phone call. One caregiver stated, "We called her a couple times and couldn't get through. But we can look on the computer and see she is okay."

One caregiver moved the system with her father when he changed residences. Moving the system with him was beneficial because they were able to help him adjust to the move. "It

makes us more comfortable. Since we moved him he has a different routine. It allows us to see that he is adjusting well and lets us know if we need to tweak things. Like when he first moved, his days were thrown off and he was sleeping until noon. The QuietCare system let us catch that.” Another caregiver also uses the system proactively to watch for potential problems. “The QuietCare system helped us develop a pattern for mom. She has urinary issues; it helps us know if she has a UTI coming on.”

One caregiver appreciated the ability to handle problems from out of state, “I could tell he wasn’t taking his medications appropriately. Then once his AC quit and the temperature was over 90 degrees. I was able to deal with both of those problems remotely because I knew what was going on.”

Perceived Advantages of the QuietCare System by the User

While 21 of the users stated the QuietCare system had helped them, 27 pointed out advantages of having the system. This may be because the system could be helpful for the family or other individuals, but not them personally. Ninety-three percent of the users who identified advantages described peace of mind as a main advantage. Some of their quotes follow.

The system is insurance. I am (age), alone, and in good shape, but you never know. My family is (out of state) and it gives them peace of mind. It provides a sense of security.

My children don’t have to worry anymore. They can go on the computer and check on me.

It is good to know you are not going to lie on the floor for hours without anyone finding you.

I know they monitor and watch what I do. My children can see that I am doing all right. Before I had the system I passed out for 11 hours on the bathroom floor and I know that wouldn’t happen now.

Another advantage noted was the efficiency of getting information. One user stated, “It lets the nurses know how I am doing without them bugging me and it is efficient for them as well.”

Another advantage identified was that it was non-invasive. The system is non-invasive because it does not utilize cameras, but also because it does not require the user to wear anything or to interact with the equipment. Below are HMS users’ statements.

I had (a push button system), but I was more capable then. Now I would forget to wear the necklace.

The advantages are the communication the children have and that it is non-invasive.

Perceived Advantages of the QuietCare System by the Caregiver

All of the caregivers reported advantages of the system and 80% described peace of mind as a main advantage. Some of the caregivers’ statements follow.

The security of knowing if she needs help, she can get some in a reasonable time. I can’t be with her 24 hours a day, but I can know that everything is okay.

Peace of mind for the family and the person using it. That is the main thing.

The fact that you can go on with your own life and not have to worry about the aging parent (is an advantage). It gives me peace of mind, day or night they can get in touch with me.

Six of the caregivers also identified efficiency as an advantage of the system. They can get a picture of the person’s day quickly from the daily-e-mail report and know that if an emergency arises they will be called. Their quotes are included below.

It is an extra security alert with the system if something goes wrong you are quicker to notice it.

I don’t have to call every morning.

It keeps me from having to call her; you see it so you know everything is okay.

Gives people a means to check on the necessities. If I look on the web, I can see if she is missing medications or meals.

The normal range is enough detail. If her pattern is a little off, I don't get a (warning). I am not bombarded with (warnings).

The biggest (advantage) is that I can see her whole day.

Three of the caregivers stated its non-intrusive nature as an advantage. One caregiver explained, "It is a non-intrusive way of monitoring her activity and basic well-being." Another stated, "There are no cameras. He is very sensitive to that. The sensors are also hidden discretely, which is important or he would fiddle with them."

Some other advantages mentioned were that it lets the caregiver know when extra services may be needed in the user's home. It also has an advantage over the push button systems in case the user fell and was unconscious. Finally, one caregiver stated the cost was not bad for what it delivers.

Perceived Disadvantages of the QuietCare System by the User

Nine of the users identified disadvantages of which cost was the most frequently mentioned. Some of their statements follow.

The cost was too much for my friend.

The price may be hard to handle on some budgets.

I have it for a trial; otherwise I couldn't afford to pay for it. I can't see how it helps me that much. I have people that check on me daily.

Another disadvantage mentioned by the users was related to setting their system on "vacation." In Chapter 4, the caregivers reported 5 false alarms in the last month due to the user being gone from the home and the system not set to vacation mode. This may have been more prevalent because the month before their interviews was the holiday season. More people than usual may have been out of town and forgot to set their system to vacation. A sampling of the HMS users' comments follow.

If I don't let them know I am going out of town, it can cause problems.

If I forget to put myself on vacation (and go out of town), it scares everyone.

To get into the system on the website is complicated when putting it on vacation.

A couple of participants thought the system required a large amount of equipment in the house. One stated, "It is a lot of equipment in the house, but if I am going to have the system I need the equipment. Houses these days have a lot of equipment." The other stated, "The base system takes a lot of room on the shelf. It has to be near the phone and mine is in the kitchen."

One HMS user reported he does not like receiving a low meal preparation warning when he eats out. He stated, "If I am taken out for dinner, there will be a low meal preparation warning. So I have to wave my hand in front of the refrigerator before I leave." A low meal preparation warning would not produce an emergency alert to his caregiver, but may be more of an annoyance to him simply knowing low meal preparation was reported when he actually ate.

A couple of HMS users were concerned about the system's accuracy. Their comments follow.

Once I was taking cold medication every 4 hours and it reported none had been taken. I also do a lot of cooking and at times it has a meal preparation warning. Then one time it said I didn't get up and I had been up since 5 am taking care of my dogs.

I was concerned this morning because if I am not up by ten it is supposed to go off. I used the bathroom at 5 and slept late and it didn't go off.

Perceived Disadvantages of the QuietCare System by the Caregiver

When asked what the disadvantages of having the system were, 13 of the 30 HMS caregivers identified some disadvantages. Like the HMS users, the HMS caregivers mentioned cost most frequently. Some of their comments are below.

The price is too steep for people on a fixed income.

Everything costs way too much. It is out of reach for those who are elderly and retired at a lower income. The price is difficult for most seniors who need it. Those who can afford it go to a retirement community with all levels of care or have personal care.

The cost is high. It should be about 30-50 dollars a month.

Depending on income, the cost could be prohibitive for some.

Another disadvantage a few caregivers mentioned was the lag time between when an event occurs and when they are notified. A couple caregivers had concerns about the time between when a fall occurs in other areas of the home besides the bathroom and when an alert would be sent. Bathroom falls are detected and dealt with differently than falls in other areas of the house. However, in a study by Gill, Williams, & Tinetti (2000) looking at environmental hazards and nonsyncopal fall risk, more participants experienced falls in the living room, bedroom, and kitchen than in the bathroom. Some of the HMS participants concerns are expressed below.

Should he fall, I wish he didn't have to wait for 2 hours for help. A button to push may be nice.

If something happens, there may be a 3-5 hour lag before I find out about it.

A couple of the caregivers stated the website could use more explanation and is sometimes slow to respond. One caregiver stated the sensitivity may be a disadvantage because it doesn't actually tell if the user swallowed the medication. However, to see if the user swallowed the medication may necessitate the use of cameras and some participants identified the lack of cameras as an advantage.

Like an HMS user, a caregiver stated a disadvantage of the system as its reporting of low meal preparation when her mother goes out to dinner on Sundays. Another caregiver stated a disadvantage as "there are some false alarms like if the phone is off the hook, but I still want to know about it so it can be fixed."

Another caregiver identified the competing use of the telephone line between the QuietCare system and the home computer as a disadvantage since his mother is on the computer often and it causes problems with the QuietCare system. "When her computer is on, it ties up the

phone line and that causes problems with the system. My mom is always on the computer, it is her life. I guess she should put another phone line in.”

A final comment was that use of the system may require a lifestyle change, “It requires a bit of a lifestyle change. For example, my mom keeps her blood pressure medication on her nightstand. The rest of her medications are in the kitchen, which have the sensor by them. For me to actually see that she took her blood pressure medication, she would have to move it and change her routine.”

Recommended Changes to the QuietCare System

Five HMS caregivers and 3 users suggested changes related to putting the system on vacation. One caregiver would like it made clearer during the installation process of the need to put the system on vacation when the person is out of town. The others would like the process of putting the system on vacation made easier. Some of their comments are presented below.

I wish my mom could notify them easier when she is going on vacation. It has to be done by computer.

Improve the vacation setting. The computer isn't very smart about it. If say she is coming back at noon, I will get morning alerts for decreased activity.

Other suggestions related to the ability to turn the system to a different setting when they go out for a meal or have company over.

When she has company we get alerts for too much bathroom use. It would be nice if there was a way to let the system know there were visitors.

Maybe a way he could override the system if he was going out to breakfast.

Have an easy way to turn the system off when I go out.

Another aspect caregivers and users recommended to change were increased range of monitoring (i.e. yard) and better ability to detect falls in the rest of the house. Some of their comments follow.

Place a sensor low to the ground in some rooms to catch a fall.

Have something to alert them if I fell in the house. I know it does if I fall in the bathroom, but I would like it to alert for the entire house.

If I fell in the house, how could they tell I have fallen?

Increase the distance to monitor out in the yard or connect somehow to a cell phone. If I go for a walk, I have to grab the phone and push the button.

Maybe have a push button system attached to it.

A few people would like to have additional sensors in the house or on the outside doors.

Sensors are usually located in rooms the resident frequents regularly. Sensors may not be in every room of the house, such as extra bedrooms or rarely used family rooms. Participants' comments follow.

He has 2 bathrooms- one he showers in and the other he uses the commode. It would be nice for us to know which one he has gone to. Also, it would be nice if the sensor at the door could tell us if he actually went out the door rather than by the door.

I wonder if sensors should be added to his Florida room. Sometimes he goes out there.

I wish it had a sensor to tell when I go out the door into the garage. I could be passed out in the garage and they wouldn't know for a long time.

Two caregivers suggested adding the ability to determine that medication was actually taken and the user didn't just go near the medication area. Medication areas may have a sensor in a cupboard or box with medications located inside or a sensor may be placed under a cabinet and over a counter where the medications are located. The caregivers' comments are below.

I wish the medication and food intake were more exact, but that balances with intrusiveness.

Something to make sure she has taken her medications and not just gone by them.

Other participants offered some unique suggestions. One caregiver had concerns that her loved one would wander from home and suggested to "incorporate a GPS into the system. I am looking into one that is an armband now." Another had experienced a false alert when the HMS

user had gone out of town and not placed the system on vacation. The emergency services arrived at the home and were met by the caregiver. The caregiver explained the HMS system to the rescuer, who had never heard of the system and was very interested in learning about it. This caregiver suggested education for the local 911 services to make them aware of the HMS system. Another caregiver suggested, “More definitive instructions on how to enter the program on-line and enter (the user’s) parameters. I am not sure they are set appropriately for my mom. Like the wake time may be an hour too long.” One participant suggested improving the marketing of the system, “It is geared at older women. They should also aim at men who have disabling conditions like MS or ALS.” Finally, a participant suggested the addition of a heart monitor for use at night in case a medical problem occurred while in bed. “At night it doesn't tell if you have died, gone in a coma, or had a stroke. It wouldn't know if anything was wrong with me from 8pm to 9am. Maybe include a wrist bracelet to monitor the heart.”

HMS User Privacy

Seven of the 29 users described feeling a bit apprehensive about the system at first because of privacy issues. A sampling of their comments is presented below.

At first I felt perplexed and uncomfortable because I am a private person.

I sort of felt self-conscious, but it wore off.

I was not sure about it. I wanted to know more. I sort of felt like it was a spy thing.

I was a bit concerned because I wasn't sure what it would show. Now I am okay with it because it just shows the time I went in and not a picture of me in the bathroom.

Even though some HMS users initially had reservations because of privacy, all of the users reported that they were comfortable with the way the system monitors them and of those who responded all were comfortable with their caregivers viewing their information. The three users, who did not answer whether or not they were comfortable with their caregivers viewing their

information, did not answer because they were unfamiliar with the website and felt they could not answer the question or did not have caregivers who checked the website. These are the same 3 users who did not answer as to whether they believed their activity information was adequately protected on the website.

Only one participant reported having a little concern of her privacy being invaded in using the QuietCare system. This user stated that nobody checks her activity information on-line because they don't want to be bothered with it. However, there was an incident where she unplugged her phone line for a period of time because she didn't want to be bothered. This resulted in the system sending an alert to her neighbor, who then came over to make sure she was all right.

ICF Model

When looking at the ICF model in relation to home monitoring, we see the implementation of home monitoring in the user's environment may impact the other domains of the model. For example, the home monitoring system may discover a health issue before it becomes serious or life threatening. This allows the person to remain active and participate in home and societal situations. This relationship as described earlier is denoted by the bidirectional arrows in the model (Figure 1-1).

For the ICF to adequately represent the relationships in this study, it may need to be expanded. The introduction of the HMS into the user's environment has the potential to impact the user in various domains, but also may impact the caregiver. In this study, the caregivers expressed greater peace of mind with the monitoring of the user. One caregiver stated, "The fact that you can go on with your life and not have to worry about the aging parent (is an advantage)." Perhaps the peace of mind allows the caregiver to become more active and participate in other home and societal functions.

Limitations

While a survey is a useful method to provide an overview of a topic, it has limitations. The major limitation is that it relies on self-report. Deception, poor memory, and misunderstanding of items may lead to inaccurate data. As for deception, people are more likely to give truthful answers to sensitive topics on a paper questionnaire than during a telephone survey (Bourque & Fielder, 2003). Some of the questions asked about sensitive material such as emergencies experienced and physical abilities. As an example of memory impacting the study, participants were asked how long they had used the HMS and at times could only provide a rough estimate because they were not able to remember the exact month the system was installed. Finally, the item regarding if the system made them feel more or less independent was unanswered 62% of participants because respondents felt it did not apply. This is discussed further below.

Even though 71% of the potential participants responded to the survey, the non-response by some may enter bias into the study. Those who chose not to respond may have felt negatively towards the system and been uncomfortable with expressing themselves. In addition, non-response occurred to some of the items within the surveys, which could have introduced bias. For example, 62% of the respondents did not say whether the system made them feel more or less independent, but refused to answer because they felt the question did not apply to them. Others answered this question based on the choices provided, but if given the choice of “neither” or “does not apply” may have picked a different answer. Non-response to this item could also make it appear as if the system really does make people feel more independent because 100% of those who responded to the item stated that it makes them feel more independent.

Another limitation of the study was the relatively short amount of time the HMS users had utilized the QuietCare system. Had the average length of use been longer, more emergency

experiences might have been reported and discussed. In addition, the participants might have expressed more ideas to improve the system. The average length of use was 7 months and the 2 individuals who experienced emergencies used the system for 8-12 months.

Due to the relatively small sample size and obtaining the sample through one distributor, the results may not generalize to the overall population of QuietCare users/ caregivers or other HMS users/ caregivers.

Future Research

While a survey provided an overview of the users and caregivers perceptions of the QuietCare system, an in-depth qualitative study would also be an appropriate method for future research. A qualitative study may provide additional insight into important constructs to study and assess when examining the user and caregiver perceptions of the HMS.

In addition, some of the unique findings of this study brought insight into future areas of research. Not only should the home monitoring of frail, older adults be further explored, but also the home monitoring of younger people with chronic disabilities or illnesses as well as those with mental health disorders. Based on results of this study, I would expect these populations to also benefit from home monitoring and behavioral tracking.

Another area for exploration is the acceptance of home monitoring among different racial groups. Twenty-eight of the 29 HMS users were white. When the distributor was asked about the predominantly white customers, they responded that one African-American customer used the system for a few months and then had it removed from the home. They were unsure why minorities are not as likely to subscribe to the HMS.

In this study, users completed the OARS-ADL subset so a description of their functional abilities could be obtained. In the future, a functional measure could be used to help describe when the system is most beneficial or no longer enough.

Recently, assisted living facilities in various parts of the nation have been installing the QuietCare system. Future research may explore how the facilities are using the system. Another interesting area would be to compare variables of interest (i.e. quality of life, quality of care) between a group of residents in assisted living who use the QuietCare system and a group who does not.

Finally, it would be beneficial to determine if increased length of use with the HMS provides more information on responding to emergencies and other aspects of the system. Also community-based QuietCare users could be compared to community-based older adults who do not utilize home monitoring on various outcome measures, such as functional ability and hospitalization.

Implications and Conclusions

As illustrated in the findings of this study, the HMS users and caregivers were satisfied with the system and found it easy to use. It has provided both the users and the caregivers with peace of mind knowing if something were to happen in the home, the caregiver would be notified in a reasonable amount of time. The HMS also provided the caregiver with necessary information about the user's day and activities while still allowing the user to maintain a comfortable level of privacy.

The findings of this research suggest the HMS system is meeting the users' and caregivers' needs. The HMS system has detected the emergencies which have occurred and has alerted users and caregivers to other potential problems allowing them to intervene. While very few of the users ever experienced an emergency and required assistance from the system, nearly all participants stated the HMS has helped them.

A home monitoring system such as QuietCare may be a solution for people who forget to wear, or refuse to wear, the pendant needed for an actively operated emergency response system.

However, the HMS explored in this study was more than an emergency response system in that several participants were using it to track behaviors and subsequently prevent potential problems. In that regard, this system may be a more powerful tool to help an older adult age in place than a system that solely provides a method of calling for help in an emergency.

APPENDIX A
HMS USER SURVEY

1. When did you have QuietCare installed?

_____ month _____ year

2. Who told you about QuietCare? (Examples: daughter/ son, friend, doctor)

3. At first how did you feel about getting QuietCare?

4. Why did you get QuietCare?

5. Has QuietCare helped you?

_____ Yes (continue below) _____ No (Go to #8)

A. How has QuietCare helped you?

6. What kinds of things do you expect QuietCare to help you with?

7. Have you ever used a personal emergency response system, such as Lifeline?

_____ Yes (continue below) _____ No (Go to #6)

A. When did you get the personal emergency response system?

_____ month _____ year

B. How long did you use it?

For _____ month(s) or year(s)

8. Before subscribing to QuietCare, did you consider any other alternatives to using the QuietCare system?

_____ Yes (continue below) _____ No (Go to #7)

A. What were they?

9. How many times in the last month did you have an emergency and need help?

_____ times (If '0', go to question #12)

A. Did QuietCare respond to all emergencies within the last month?

_____ Yes (Go to #10) _____ No (continue below)

B. What types of emergencies did QuietCare miss?

10. When was the last time you used QuietCare to respond to an emergency?

A. What type of emergency was it?

B. About how long did it take for someone to respond to your emergency using the QuietCare system?

_____ Hours _____ Minutes

C. In your opinion, was the response time fast enough?

_____ Yes _____ No

11. In the past month, has QuietCare called for help when none was needed?

_____ Yes (continue below) _____ No (Go to #17)

A. How many times in the past month has this happened?

_____ times

B. Why do you think this happened?

12. Is the QuietCare system easy or difficult to use?

_____ Easy (Go to A) _____ Difficult (Go to B)

A. Is it very easy or somewhat easy to use?

_____ Very easy to use _____ Somewhat easy to use

B. Is it very difficult or somewhat difficult to use?

_____ Very difficult to use _____ Somewhat difficult to use

13. Does QuietCare make you feel more secure or less secure?

_____ More (Go to A) _____ Less (Go to B)

A. Does QuietCare make you feel much more secure or a little more secure?

_____ Much more secure _____ A little more secure

B. Does QuietCare make you feel much less secure or little less secure?
_____ Much less secure _____ A little less secure

14. Does QuietCare make you feel more independent or less independent?
_____ More (Go to A) _____ Less (Go to B)

A. Does QuietCare make you feel much more independent or a little more independent?
_____ Much more independent _____ A little more self-confident

B. Does QuietCare make you feel much less independent or a little less independent?
_____ Much less independent _____ A little less independent

15. Have you ever considered discontinuing QuietCare?
_____ Yes (continue below) _____ No (Go to #18)

A. Why have you considered discontinuing QuietCare?

16. What are some advantages of having the QuietCare system?

17. What are some disadvantages of having the QuietCare system?

18. What would you change about QuietCare?

19. Is there anything you wish QuietCare did that it does not do now?

_____ Yes (continue below) _____ No (Go to #22)

A. What do you wish QuietCare did?

20. Would you say you are satisfied or dissatisfied with QuietCare?

_____ Satisfied (Go to A) _____ Dissatisfied (Go to B)

A. Are you very satisfied or somewhat satisfied with QuietCare?

_____ Very satisfied _____ Somewhat satisfied

B. Are you very dissatisfied or somewhat dissatisfied with QuietCare?

_____ Very dissatisfied _____ Somewhat dissatisfied

21. Have visitors ever commented on the system?

_____ Yes (continue below) _____ No (Go to #24)

A. What comments have you heard?

22. Are you comfortable or uncomfortable with your activity being monitored in the way QuietCare works?

_____ Comfortable (Go to A) _____ Uncomfortable (Go to B)

A. Are you very comfortable or somewhat comfortable with your activity being monitored in the way QuietCare works?

_____ Very comfortable _____ Somewhat comfortable

B. Are you very uncomfortable or somewhat uncomfortable with your activity being monitored in the way QuietCare works?

_____ Very uncomfortable _____ Somewhat uncomfortable

23. Do you know about the website that displays your activity information to people who are authorized to view it?

_____ Yes _____ No

24. Have you seen the website that displays your activity information?

_____ Yes _____ No

25. Do you ever go on the website yourself to view your information?

_____ Yes _____ No

26. What things are you most interested in on the website?

27. Who has access to your activity information on the QuietCare website?

28. What kinds of information can they see?

29. Are you comfortable or uncomfortable with those who can access your activity information being able to view it?

_____ Comfortable (Go to A) _____ Uncomfortable (Go to B)

A. Are you very comfortable or somewhat comfortable with those who can access your activity being able to view it?

_____ Very comfortable _____ Somewhat comfortable

B. Are you very uncomfortable or somewhat uncomfortable with those who can access your activity being able to view it?

_____ Very uncomfortable _____ Somewhat uncomfortable

30. Are you concerned about your privacy being invaded in using the QuietCare system?

_____ Yes (Go to A) _____ No (Go to #29)

A. Are you very concerned or a little concerned about your privacy being invaded?

_____ Very concerned _____ A little concerned

31. Do you believe your activity information is adequately protected on the QuietCare website?

_____ Yes _____ No

32. Do you trust that only the authorized people are able to view your information?

Yes No

33. How old are you?

Years old

34. Gender: Male Female:

35. Would you describe yourself as African American, Caucasian, Hispanic, Asian, or another race?

36. What level of education did you complete?

Grade school (k-6) Some college Doctorate/ MD

Middle school (7-8) Bachelor's degree

High school (9-12) Master's degree

37. Are you married, widowed, divorced, single, other?

Married widowed divorced single

other

38. How many children do you have?

Children

39. How many of your children live within 20 miles of your home?

Children within 20 miles

40. Do you own or rent your home?

Rent Own

41. What type of a home do you live in? For example, a single family home, mobile home, condo, duplex, etc.

Single family house Multi-unit building (apt/ condo)

_____ Mobile home _____ Semi-detached home (duplex/ town-home)

_____ Other

42. How long have you lived there? _____ years

APPENDIX B
MULTIDIMENSIONAL FUNCTIONAL ASSESSMENT OF OLDER ADULTS: SELF CARE
CAPACITY SUBSECTION

Now I would like to ask you about some of the activities of daily living, things that we all need to do as part of our daily lives. I would like to know if you can do these activities without any help at all, or if you need some help to do them, or if you can't do them at all. (BE SURE TO READ ALL ANSWER CHOICES IF APPLICABLE IN THE QUESTIONS BELOW TO THE RESPONDENT)

Instrumental ADL

1. Can you use the telephone?
 - 2 without help, including looking up numbers and dialing;
 - 1 with some help (can answer the phone or dial operator in an emergency, but need a special phone or help in getting the number or dialing); or
 - 0 are you completely unable to use the telephone?
 - not answered

2. Can you get to places out of walking distance...
 - 2 without help (drive your own car, or travel alone on buses, or taxis);
 - 1 with some help (need someone to help you or go with you when traveling); or
 - 0 are you unable to travel unless emergency arrangements are made for a specialized vehicle like an ambulance?
 - Not answered

3. Can you go shopping for groceries or clothes (ASSUMING SUBJECT HAS TRANSPORTATION)

- 2 without help (taking care of all shopping needs yourself, assuming you had transportation);
- 1 with some help (need someone to go with you on all shopping trips); or
- 0 are you completely unable to do any shopping?
- Not answered
4. Can you prepare your own meals...
- 2 without help (plan and cook full meals yourself);
- 1 with some help (can prepare some things but unable to cook full meals yourself; or
- 0 are you completely unable to prepare any meals?
- Not answered
5. Can you do your housework...
- 2 without help (can clean floors, etc);
- 1 with some help (can do light housework but need help with heavy work);
- or
- 0 are you completely unable to do any housework?
- Not answered
6. Can you take your own medicine...
- 2 without help (in the right dose at the right time)
- 1 with some help (able to take medicine if someone prepares it for you and/ or reminds you to take it); or
- 0 are you completely unable to take your medicines?
- not answered

7. Can you handle your own money?
- 2 without help (write checks, pay bills, etc);
 - 1 with some help (manage day-to-day buying but need help with managing your checkbook and paying your bills); or
 - 0 are you completely unable to handle money?
 - not answered

Physical ADL

1. Can you eat...
- 2 without help(able to feed yourself completely);
 - 1 with some help (need help with cutting etc); or
 - 0 are you completely unable to feed yourself?
 - Not answered
2. Can you dress and undress yourself?
- 2 without help (able to pick out clothes, dress and undress self);
 - 1 with some help; or
 - 0 are you completely unable to dress and undress yourself?
 - Not answered
3. Can you take care of your own appearance, for example combing your hair and (for men) shaving...
- 2 without help;
 - 1 with some help; or
 - 0 are you completely unable to maintain your appearance yourself?
 - Not answered

4. Can you walk...
- 2 without help (except from a cane)
 - 1 with some help from a person or with the use of a walker, or crutch, etc.;
 - or
 - 0 are you completely unable to walk?
 - Not answered
5. Can you get in and out of bed...
- 2 without help or aids;
 - 1 with some help (either from a person or with the aid of some device); or
 - 0 are you totally dependent on someone else to lift you?
 - Not answered
6. Can you take a bath or shower...
- 2 without help;
 - 1 with some help (need help getting in and out of the tub, or need special attachments on the tub); or
 - 0 are you completely unable to bathe yourself?
 - Not answered
7. Do you ever have trouble getting to the bathroom on time?
- 2 No
 - 0 Yes
 - 1 have a catheter or colostomy
 - Not answered

If 'YES' ask:

a. How often do you wet or soil yourself (either day or night)?

1 Once or twice a week

2 Three times a week or more

- Not answered

8. Is there someone who helps you with such things as shopping, housework, bathing, dressing, and getting around?

1 Yes

0 No

- not answered

If 'YES', ask 'a' and 'b'.

a. Who is your major helper?

Name _____ Relationship _____

b. Who else helps you?

Name _____ Relationship _____

APPENDIX C
HMS CAREGIVER SURVEY

1. Why do you think your relative or friend decided to get the Quiet Care system?

2. What were the alternatives to getting the Quiet Care system?

3. Has the Quiet Care system helped you?

_____ Yes (Go to A) _____ No (Go to # 4)

A. How has the QuietCare system helped you?

4. Have you ever thought about discontinuing Quiet Care?

_____ Yes (Go to A) _____ No (Go to #5)

A. Why have you considered discontinuing QuietCare?

_____ Lack of need

_____ Cost

_____ False alarms

_____ Other, what were the other reasons?

5. How many times per day or week do you check on your relative or friend using the QuietCare website?

_____ times per day or

_____ times per week

6. In the past month, have you received alerts for an emergency from QuietCare?

_____ Yes (Go to A) _____ No (Go to #7)

A. How often do you receive emergency alerts?

_____ times per day or

_____ times per week or

_____ times per month

B. When was the last time you received an emergency alert from QuietCare?

C. What type of emergency was the alert for?

D. What was the outcome of the situation?

E. Do you feel that QuietCare alerted you to the emergency within a reasonable amount of time?

_____ Yes _____ No

F. How long did it take for QuietCare to alert you to the emergency from the time it arose?

_____ hours _____ minutes

7. How do you prefer to receive alerts?

_____ telephone call

_____ notice on website

_____ e-mail

_____ pager

_____ text message

_____ other, if other how _____

8. Is the QuietCare system easy or difficult to use?

_____ Easy (Go to A) _____ Difficult (Go to B)

A. Is QuietCare extremely easy to use or somewhat easy to use?

_____ Extremely easy to use _____ Somewhat easy to use

B. Is the QuietCare system extremely difficult to use or somewhat difficult to use?

_____ Extremely difficult to use _____ Somewhat difficult to use

i. What aspects are difficult?

9. In the last month, did you not receive an alert when your relative needed help?

_____ Yes (Go to A) _____ No (Go to # 10)

A. What type of emergency was it?

B. Why do you think you did not receive an alert?

10. Have you received false alarms in the last month?

_____ Yes (Go to A) _____ No (Go to # 11)

A. How often do you receive false alarms?

_____ times a day, _____ times a week, _____ times a month

B. For what type of emergency was the last false alarm you received?

C. Why do you think you received an alert?

11. What are some advantages of having the Quiet Care system?

12. What are some disadvantages of having the QuietCare system?

13. What would you change about the QuietCare system?

14. What are some things you wish the Quiet Care system did that it does not do now?

15. Are you satisfied or dissatisfied with the QuietCare system?

_____ Satisfied (Go to A) _____ Dissatisfied (Go to B)

A. Are you extremely satisfied or somewhat satisfied?

_____ Extremely satisfied _____ Somewhat satisfied

B. Are you extremely dissatisfied or somewhat dissatisfied?

_____ Extremely dissatisfied _____ Somewhat dissatisfied

16. About how many years have you been caring or providing assistance for your relative or friend?

_____ years

17. About how many hours each day or week do you currently spend caring for your relative or friend, including chores and errands?

_____ hours per day

_____ hours per week

18. Does your relative have any other help at home now, such as cleaning services or a home health aide?

_____ Yes (Go to A) _____ No (Go to #19)

A. What type of help do they have?

B. About how much time per day or week does that person help out?

_____ hours per day

_____ hours per week

19. How old are you?

_____ Years old

20. Gender: Male _____ Female _____

21. Would you describe yourself as African American, Caucasian, Hispanic, Asian, or another race?

22. What level of education have you completed?

_____ Grade school (k-6) _____ Some college _____ Doctorate/ MD

_____ Middle school (7-8) _____ Bachelor's degree

_____ High school (9-12) _____ Master's degree

23. Are you married, single, widowed, divorced, or other status?

_____ Married _____ Single _____ Widowed _____ Divorced

_____ Other

24. How many children do you have?

_____ Children

A. Are any of them living at home?

_____ Yes (Go to B) _____ No (Go to # 29)

B. How many are living at home?

_____ Children living at home

29. What is your relationship to the QuietCare user?

_____ Spouse, _____ Friend, _____ Child, _____ Other, who? _____

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