

Caregiver Needs from Elder Care Assistive Smart Homes: Spouses of Elder Adults Assessment

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ABSTRACT

Elder care is a growing concern in the United States. As a large upcoming cohort begins to enter retirement age, the currently available health care resources cannot expand quickly enough. Assistive smart technology may be the answer to this growing health care problem. To meet the needs of those caring for loved ones with end of life illnesses, assistive technology engineers must know the needs of those in a caregiving position, nurses, children taking care of their parents, and spouses taking care of their loved one. This research is a continuation of interviews which ask what are the needs of caregivers of different types so that the technology may cater to more users and deliver data in a useful and accessible way. This assessment expands prior research to improve understanding of the needs of spouses to assist with medication, appointments, and checking in while he or she is away.

ACM Classification Keywords

H.5.2 User Interfaces: User-centered design; J.3 Life and Medical Sciences: Medical information systems

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Assistive smart home technology; caregivers; elder care; needs assessment; pervasive computing

INTRODUCTION

Caregiver stress is a real and detrimental issue, especially for spouses taking care of their partners [8]. With a growing number of older adults needing care in the US and health care not being able to keep the pace, care for those with serious health issues ends up the burden of children and spouses [6]. Technology is poised to help assist those caring for loved ones with greater than average health issues.

Assistive smart homes embed technology into residential surroundings. The Center for Advanced Studies in Adaptive Systems (CASAS) research group builds smart home research testbeds with the primary goal of developing accurate models

Activity Dashboard

Click on plots to switch between day, week, and month.
Click on an apartment number to get the resident's activity profile.

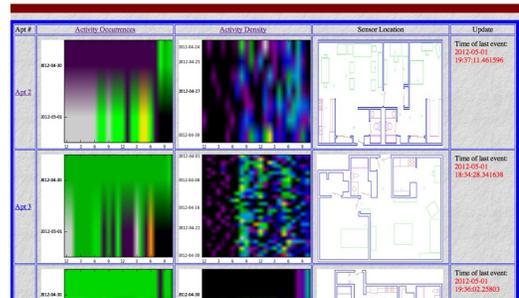


Figure 1. Original CASAS smart home visualization with daily and monthly heat maps.

of the residents to support health care applications. CASAS smart homes have resulted in new methods for measuring physical and cognitive health, better decision support tools for caregivers, and providing a comprehensive view of the resident to their care providers [3].

The CASAS assistive smart home generates data in the form of sensor events, activity models, and metrics on the quality of daily activities, such as sleep or mobility. However, there is very little research on what are the exact needs of caregivers who will interact with this data. Nursing staff, assistive living facilities management groups, children of older adults, and spouses are all important caregivers who will need to interface with this data on a day-to-day basis. At this time, engineering and nursing researchers have performed focus groups and usability tests with elderly participants to better understand the needs of residents [5]. While it is important to understand which activities are key for the individuals residing in the homes, it does not tell us what the caregivers require. These caregivers are often the individuals requesting the assistive technology to help aid them in their care, and these stakeholders should have greater input on what is needed.

Researchers at CASAS created a visualization to assist them in looking at the data that came from the smart home (see Figure 1). The initial design centered around using heat maps of activity over time. These heat maps describe the type of activity in the left column, the amount and variation of activity happening throughout a month in the center column, and a floor plan of the home in the right column. These visualiza-

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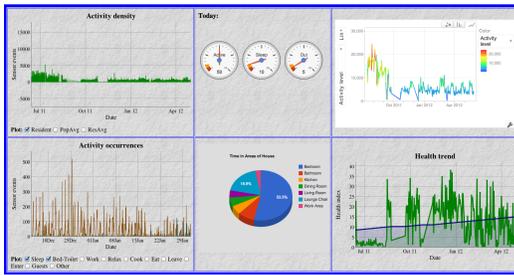


Figure 2. Second version of the CASAS smart home visualization with line, graphs and pie charts. This visualization was better than its predecessor but utilized axes with unusable units and created metrics that were not useful to caregivers

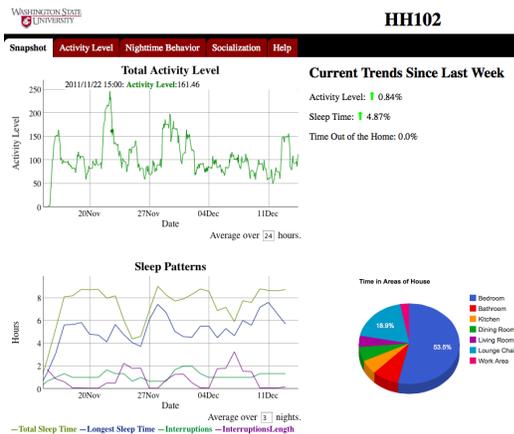


Figure 3. Current version of the CASAS smart home visualization with data separated into different tabs depending on what the user wishes to learn.

tions of the data were useful for researchers, but were found to be overly complicated for nurses and families. The design provided plenty of information, however map keys are hidden behind a difficult to find link and it had a significant barrier in learning how to interpret the high density information provided by the heat maps. The terminology was also very technical, and beyond most user's level of expertise.

A second visualization was created with easier to read graphs and figures (see Figure 2). This visualization was tested with nursing staff to determine the usefulness of each graph and element [10]. This research indicated that the graphs needed to be broken down by main activity for better readability and that x and y axes needed to have more relevant information. The terminology was still too complex and specialized for most users.

This led to the third version of the CASAS smart home visualization (see Figure 3). This version was tested with children taking care of their parents [9], with much better results than earlier CASAS visualization tools. This is also the version used for this study to assess what needs would need to be met for spousal caregivers.

The outcome of the child caregivers and this spousal caregivers studies will help to create more efficient, usable, and intuitive

visualizations of the assistive smart home. With an improved user experience and well designed visualization of information, the stress related with elder care can be greatly reduced for all involved. The net results include lengthening the amount of time that an older adult can stay independently living in their homes, lowered financial burdens on families, and an overall improved quality of life.

METHODS

Participants

Eight informal familial caregivers with experience in caring for their spouse were interviewed. These caregivers were drawn from the nearby community. The university's Institutional Review Board approved the study, and informed consent was obtained from each participant. Participants were 4 female and 4 male, with an average age of 72 years of age and a range from 58 to 93. They had care experience ranging from 4 years to 12 years, with all care being daily in the home. All participants indicated that the person they cared for had some level of impairment from 2 to 6 on the Functional Assessment Staging (FAST) scale. This score ranges from 1 (no difficulties and is functionally independent) to 7 (requires a great deal of day-to-day care and may not have control of mobility or biological functions), with a 2 indicating subjective issues that only the individual is bothered by and a 6 indicating extensive issues including problems with putting on clothes, inability to bath alone, and inability to handle toileting.

Materials and Procedures

Interviews took place at available quiet locations, either in the home, at a neutral public meeting place, or over a voice over IP (VOIP) internet connection. Each was recorded using a voice memo application on a smartphone and later transcribed. Viewing of the current smart home visualization tools was made available on a laptop screen with an attached USB mouse or through a link on the individual's personal computer.

Participants were led through a directed interview which contained questions about level of care provided, functional difficulties of care recipient (FAST scale), demographics, computer experience, willingness to learn new technology, and general needs from technology. They were then shown the CASAS smart home visualization of assistive smart home data (Figure 3) and allowed to explore it for several minutes. A walk through of the interface by the interviewer was given upon request. Next, the Systems Usability Scale (SUS) was administered and feedback about the website was obtained. The SUS is a 10-item questionnaire with a 5-point Likert-like scale assessing the ease of use and understandability of a system [1]. Scores are modified for reversal questions, then totaled and multiplied by 2.5 to give a score out of 100. Finally, the participant's needs for the system were obtained, along with any final thoughts.

A secondary observer was present for all proceedings.

RESULTS

Interviews proceeded smoothly, and the system was generally well received. Some went so far as to want one for themselves and their partner. The caregivers stated that the system was:

- “For home care workers, this is exactly what they need.”
- “This would allow nurses to see if [health] interventions have been of assistance.”
- “This is better since when going to dependent care you lose so much privacy.”

Caregivers’ computer experience on a 1 to 10 scale was an average of 5.75, with a range from 3 to 8. Their comfort with technology on a 1 to 10 scale was an average of 7.8, with a range from 5 to 10. Lastly, their willingness to learn a simple new technology on a 1 to 10 scale was an average of 7.8, a median of 8, a mode of 10, and a range from 4 to 10. The results of the SUS varied greatly with a score as low as 22.5/100 and as high as 95/100, with an average score of 55.36. Higher scores correlated to higher reported comfort with computers and reported willingness to learn a new technology.

Several themes began to emerge from the interviews that helped to describe the overall needs of the spousal caregivers. These themes centered on reminder systems, health concerns, and delivery or importance of the data.

Reminders

Medication Information

Medication was important to caregivers to make sure that their partners take their medication on time, and that they not take too much or too little. If the spouse forgot to take medication or took their medications twice in the same morning, it might cause issues that required medical attention. This is often difficult for caregivers to keep track of, as spouses do not want to feel as if they are nagging their partner and some partners wish to continue to feel independent and may become annoyed at constant reminders. Several research labs have been attempting to gather medication compliance and reminders; however due to problems such as, medications moving around the house, the added expense of technology integrated into bottle caps, and notifications or reminders being ignored or missed, medication tracking is problematic at best.

Doctor Information

Caregivers often suggested that they used technology to look up what their doctors or hospitals had recommended for their partners care. This information was sometimes available through web portals made available by the specific care professional, hospital, or simply through looking up further information on websites like WebMD or Mayo Clinic. It was often the case that physician visits were frequent but did not give enough information for general day-to-day care. Providing extra information about the specific care problems of the individuals in the home may be useful for smart home residents. This suggests that further research is needed on what types of health care information would most benefit spousal caregivers.

Calendar Schedule

Caregivers in the home suggested that the added stress of caring for their partner meant an increased number of calendar events and issues with remembering all appointments that needed to be addressed. Caregivers used centralized paper

calendars to write down all appointments and scheduled activities, however appointments were sometimes forgotten or lost. Paper calendars also have the limits of being physically in one place at all times. Providing a smart home calendar which could be viewed from devices away from the home or by outside nursing or child caregivers would give this group of caregivers the most value added to a system. This could be easily implemented into any assistive smart home and greatly increase the assistance to partner care.

To-do Lists

Much like calendar events, caregivers in the home needed assistance with keeping track of items that needed to be taken care of around the house as well as errand to be run outside of the home. Normally caregivers used handwritten lists or attempted to keep track of these items by memory, however most found issues with forgetting to do all of the things that needed to be done. Providing a smart home to-do list which could be viewed from devices away from the home or by outside family would give this group of caregivers much needed assistance with their day-to-day activities. This could be easily implemented into any assistive smart home and greatly increase the assistance to partner care.

Daily Healthful Therapies

Beyond medications, caregivers often have to work with their partner on a set of ongoing therapies and must remember what, when, and how execute these therapies, such as remembering to get up and walk, changing positions, or stretching. Having a tool to enter the daily routine, update with physician’s recommendations, and detect exercises completed would be a powerful tool for many households. The system could also provide instructions, connections with available clinicians, and medical records integration for tracking results.

Health Concerns

Fall Detection

Falls are of major concern for any elderly individual, as they can easily mean hospitalization, rehabilitation, and have a serious potential to be fatal, especially if an immobilized individual goes undetected for an extended period of time. Spouse caregivers find falls especially worrying, as they may not feel strong enough to help their partner to get back up. They also express concern for their partner falling while the caregiver is out on errands and the distress that would be caused by coming home to find their partner has fallen. Most caregivers currently solve this problem by having their partner carry a phone around the home or by giving them life alert pendants. Effective automated fall detection with monitoring technology has proven to be difficult in real-world situations. Motion sensors alone have difficulties detecting falls, and the current technology required to detect falls is invasive into the individual’s privacy (e.g., cameras, seismic activity monitoring). Currently, there is no single approach effectively solving the falls issue at this time.

Cognitive and Psychological Wellbeing

Another difficult concept to ascertain from a smart home system is an individual’s cognitive or psychological health.

Spousal caregivers suggested that cognitive tests were infrequent and expensive. They wanted a way to know if their partner was declining cognitively or experiencing depression. Depression symptoms can sometimes be associated with health issues later in life. Assessing a person's cognitive capabilities will be an important part of the smart homes assessment for all caregivers involved in an individual's care. Preliminary work from the CASAS laboratory has demonstrated a relationship between cognitive and dementia staging diagnosis and quality of everyday task performances as measured by sensor data [4]. These new approaches may be useful for spousal caregivers in tracking the cognitive and psychological capabilities of their partners over time.

Sleep

Many spouses indicated that they already knew how their partner slept because they slept next to them, but then later during the interview suggested they would still want to know the quality of their partners sleep. If it was not good, many caregivers worried that this might cause a decline in the future and wanted to look into ways of improving their partners sleep. Many aspects of sleep were important to caregivers. These include how often a partner is sleeping during the day time, how long they sleep uninterrupted at night, how many times they got up in the night, how long those interruptions were in length, and what they were doing if they were up and awake in the night. Much of this is currently modeled in the smart home, however caregivers were worried about being able to gather daytime sleep as their partners may doze off in an easy chair for only minutes at a time.

Mobility

The general ability to move around the home was important for caregivers; making sure that their partner was making it up and down stairs properly, that they got to the bathroom, or that they were up and getting exercise at all. Caregivers would like to see activity around the home over a sedentary lifestyle, as many suggested that their doctors recommended more activity for their partner. Activity is central to what the smart home attempts to gather, however it may be useful to know how much activity has been done outside of the home as well.

Eloperment

Some spouse caregivers wanted to know if their partner left the home for any reason, as this may be a serious health risk. Others suggested that their partner would never leave the house without them, and therefore they did not worry about this issue. The smart home can detect when the door is opened and someone has left the home, however this may capture times that someone is leaving the house for a good reason. Effective identification of the people exiting the home and the normalcy of the activity patterns should be included in the technology deployed. Further investigation for elopement and exactly when an alert for leaving the home is necessary is needed.

Delivery/Importance of Data

Current data

Caregivers in the home suggested that the current wellbeing of their partner was important, such as where their partner is and

what they are doing. The ability to know what is happening today, what was the sleep like last night, and what do I need to know at this moment was crucial and much more useful to spouses than information about their spouses health over time. It may be necessary to future smart home visualizations to prioritize "Current Status" for home caregivers, while accentuating more long term data views to nurses and care professionals.

Alerts

One often asked for feature of the current system was an alert system. Among many other things, caregivers described wanting to be told when their partner had fallen, left the house, needed assistance of any kind, began to climb the stairs, or tried to take their medications. To best help spouses, this alert system should be available through various mediums such as via home intercom, cell phone, and text message. Additionally, it should be modifiable to meet the specific needs of the given individual.

Kinds of Data Sought

Caregivers often requested more bio-health data points. Measurements such as blood glucose, O_2 saturation, blood pressure, and dizziness were often considered more important than general behaviors, daily activities, and sleep information. Earlier works with children of seniors and clinicians talked about both kinds of data being very important. However, spouses living with the ones they are caring for, so they feel that many daily behaviors of the house are already noted and having a computer system providing this information seemed somewhat redundant.

Text Size

An issue not entirely addressed by interviews with children taking care of their parents or nursing staff is that of text size. Spouses are an older group, generally with impaired vision. An interface built for this group will need to include either larger text or the ability to change the size of the text to make it more legible to the individuals in the home using the system.

Outside Caregivers

Spousal caregivers often thought that the CASAS system visualizations would be most helpful for their children to keep track of both of them in the home, for nurses who would need to look in on them, or for other outside help. They often described it as being helpful to them if they were still taking care of their own parents. Heavy modifications to this system will be needed to make it more appropriate for those who are living in the home as their needs are quite different than that of outside assistants.

DISCUSSION

This series of interviews continues to broaden our awareness of the different kinds of caregiver groups that any smart home interface will need to be built for. It is becoming apparent that while there is overlap between nurses needs and children caregiver needs, and overlap between children caregiver needs and spousal caregiver needs, that these groups all have their own concerns and needs. It is imperative that any fully developed smart home include several types of interfaces for these different groups. Nurses will require greater long-term

information and direct access to health data points. Children will require more alerts, tips for care, and information to share with health care professionals. Spouses will require more immediate knowledge of their partner's status, information about their conditions, and connections to outside assistance. The next step for this research is a full analysis of the various groups together, exactly where they differ and where they do not.

Smart home research in general will need to work towards answering some of these health care concerns such as: wearable mobility tracking, calendar and to-do assistance, and fall detection. Interfaces need to be clearer for users, and more logically organized [2, 7]. It is important for smart home engineers to utilize information about the needs of users in order to better cater to what will be most useful. In the future, assistive smart homes may be the best chance for older adults to stay in their homes independently for longer. It is the job of researchers and engineers to make sure that this technology meets the needs of its users.

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