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CareWatch: A Home Monitoring System for Use in Homes of Persons With Cognitive Impairment

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Abstract

Currently, informal caregivers provide the bulk of care for persons with cognitive impairment who live in the home, often at significant cost in terms of their own physical, mental, and emotional health. This is a report of the development of a home monitoring system, CareWatch, designed for use in homes of persons with cognitive impairment such as Alzheimer's disease. The purpose of CareWatch is to prevent unattended home exits, particularly during the night, and to improve caregiver sleep. We report on the development of CareWatch and on 2 clinical trials underway to test its effectiveness in the home setting.

Keywords

Alzheimer's disease; autism; caregiver; dementia; sleep; technology

INTRODUCTION OF CLINICAL PROBLEM

A number of clinical disease states, such as dementing illnesses (eg, Alzheimer's disease, Lewy body disease) and pervasive developmental diseases (eg, autism, Down's syndrome), result in impairment of both sleep/wake cycles and cognition. When persons with dementing illnesses are studied in the sleep lab, virtually all individuals demonstrate abnormalities in the sleep-wake pattern. The profound changes in the sleep-wake cycle include an increase in time awake and number of awakenings during the night.^{1–4} Approximately 44% to 83% of children with autism experience sleep-related problems, including difficulty getting to sleep, long periods of wakefulness at night, early morning waking, and consequent daytime sleepiness.^{5,6} Frequently, the individual with cognitive impairment (CI) will not awaken the caregiver when he or she is out of bed.

The combination of unsupervised nighttime awakenings and CI is particularly difficult in the home setting. Because there is a risk that the individual with CI will make a judgmental error if left unsupervised during the night, caregivers must alter their sleep pattern in an effort to awaken and provide supervision. This becomes quite difficult for caregivers because the constant awakenings result in sleep fragmentation and insufficient restorative sleep.⁷ Lack of adequate sleep can have significant deleterious consequences for the mental and physical well-being of the caregiver.^{8–13}

The disturbance in the caregivers' sleep is particularly severe because there is little predictability regarding the nighttime activity of the individual with CI.⁷ For some nights, the individual with CI may be up multiple times, while other nights the individual may sleep through the night. However, because the activity is not predictable, the caregiver's sleep is disrupted every night, in essence, "sleeping with an open ear." Thus, caregivers awoken both when needed and at other unneeded times when they could have had a longer period of uninterrupted and more restorative sleep.

This situation seemed a natural fit for a technology solution. A monitoring system was needed that would reliably alert the caregiver when the individual with CI left the bed. The goal of the technology would be to ensure greater home safety for the individual with CI by ensuring the caregiver was correctly alerted when supervision was required. Furthermore, the technology would prevent caregivers from needlessly awakening to listen when no supervision was required, thus improving the sleep quality of the caregiver.

SEARCH FOR EXISTING SYSTEMS

Our first step was to identify the criteria of an effective home monitoring system, which were as follows:

- bed occupancy sensor
- messaging at the caregiver bedside
- ability to continuously identify the location of the individual with CI
- messaging to caregiver in form of customizable alarms, text, and voice
- different levels of alarm—one for emergency situations (eg, opening of an outside door) and one for nonemergency situations (eg, movement through rooms of the home)
- easy to use system interface

Our first effort was to identify existing systems that could provide these features, but none existed. Next, we attempted to take individual home security system components and configure them to do these functions; however, this was not feasible. Third, we undertook a reverse engineering project in which we tried to make hardware changes to an existing home security system. This also was unsuccessful both because of the amount of change needed and certain needed functions that could not be programmed.

Ultimately, we began the process of developing new technology to meet the project needs. This included working with the technology transfer offices at the university level and receiving funding for product development through the Small Business Technology Transfer program at the National Institutes of Nursing Research (1R41NR004952-01A1, 2R42NR004952-02A2, 3R42NR004952-03S1, 5R42NR004952-03). The small business for these grants was Amron Corporation, and the commercial partner was Honeywell Corporation. The basic platform for CareWatch was ADEMCO/Honeywell Security Systems' home security system. Honeywell will be the commercial producer for the device.

ADAPTATION OF HOME SECURITY SYSTEM TECHNOLOGY

Our current solution involves use of a security system control panel, wireless receiver, motion sensors, door opening sensors, and a bed occupancy sensor (described in the next section). Unique software was written to change the functions of the control panel. Honeywell Security Systems did this work, and a provisional patent for CareWatch is pending.

System modes

CareWatch can be used both during the day and at night. A unique feature of the night mode is that CareWatch is set when the individual with CI retires. The system remains inactivated though, allowing the family to move about the home without activating any alarms. However, once the individual with CI arises, CareWatch becomes active and alarms are sounded. Daytime mode is primarily used to alert the caregiver of outside door openings. This mode is very useful when the caregiver temporarily needs to be in a different part of the home than the individual with CI.

User interface

Since many caregivers of persons with dementia are themselves older, it was essential to design a user interface that would not require any previous experience with operating technology. A simple set of keystrokes activates and deactivates CareWatch. In addition, a wireless fob can be programmed with shortcuts to the various modes. The keypad needed to be redesigned to maintain a backlight in the screen throughout the night hours so that the caregiver could easily determine the location of the individual with CI. A wireless keypad is under development to enable caregivers to use CareWatch throughout the home.

Wireless solution with semipermanent installation

Because the needs of individuals with CI will change as they age or the disease worsens, it was essential to install CareWatch in a manner that could be tailored without making major changes in the home. All the sensors are wireless, making installation easy, lowering installation costs, and preventing any permanent changes to the home. In order to easily remove the sensors as the needs of the individual with CI change, we attached the sensors with Command™ Removable Interlocking Fasteners by 3M™. We have found these to be a strong-bonding, long-lasting material that is easily removable, leaving no damage to the home surface.

Individualized systems

CareWatch needed to be installed differently depending primarily on the ability of the individual with CI to ambulate. Caregivers of individuals with CI who were frail or unsteady required rapid system response as the individuals with CI began to exit the bed, whereas caregivers of more physically stable individuals did not want notification of nighttime activity until these individuals had actually left the bedroom/bathroom areas. Some caregivers wanted a number of rooms monitored, while other caregivers wanted only the bedroom and the nearest bathroom monitored. It was not unusual to need to change the areas monitored over the course of a year as the needs of the individual with CI changed.

DEVELOPMENT OF BED OCCUPANCY DETECTOR

A bed occupancy sensor is intended to report the presence of a person in bed, and is used in devices that detect wandering by confused or demented persons at home or in a hospital. Tests by Amron Corporation in 2 Phase II Small Business Innovative Research grants have shown that there is no reliable bed occupancy sensor commercially available, and suggested that we should develop our own. Here we describe our Bed Occupancy Detector, which consists of an air bag placed between the box springs and the mattress in the user's bed, connected by a hose to a pressure switch, which is, in turn, connected to a transmitter.

The air bag is a slightly modified camping air mattress, and is 26" wide by 75" long by about 1.5" thick and filled with very light foam. We removed the valve from the air mattress nozzle and glued a short plastic tube over it. The tube leads to an air pressure switch, which is open when pressure in the mattress is low and closed when it is high. The air pressure switch is

connected to a Honeywell Security Systems transmitter, which sends a signal to a remote receiver when the pressure switch terminals open or close.

In use, we place the Bed Occupancy Detector between the box spring and the bed mattress, with the hose free, not connected to the pressure switch. The weight of the bed mattress compresses the foam within the air mattress, driving some, but not all, of the air out of it. Then, we connect the hose to the pressure switch, placing the pressure switch and the transmitter between the bed mattress and the box spring. The pressure switch remains open, as it was before connection to the tube.

When a person sits or lies anywhere on the bed, his or her weight compresses the air mattress and increases the air pressure within it, causing the pressure switch to close and the transmitter to send an “On” signal, reporting the increased air pressure to a central location, and, in effect, the presence of the person on the bed. When the person gets off the bed, the air pressure within the mattress drops, the switch terminals open again, and the same transmitter will send an “Off” signal, in effect indicating that the person has left the bed.

It matters very little where the person lies or sits on the bed. His weight is distributed over a large area of the air mattress, compressing it almost everywhere, and this raises the air pressure within it enough to close the pressure switch. We have been successful using the Bed Occupancy Detector in twin, full, and queen size beds with the subject sleeping alone. For a king size bed in which the individual with CI slept on all parts of the bed, we used 2 Bed Occupancy Detectors put side by side width-wise in the bed. The Bed Occupancy Detector has correctly monitored only the individual with CI when sleeping with a caregiver in full, queen, and king size beds. The Bed Occupancy Detector has been continually used in our initial test homes for almost 2 years without failure or adjustment being required.

CAREWATCH EFFECTIVENESS IN CLINICAL TRIALS

Installation procedure

Prior to beginning installation in subjects’ homes, we did extensive tests of CareWatch in homes of researchers. This ensured that we were proficient with system operation and installation, and allowed us to develop teaching materials for the caregivers. This phase lasted several months.

Because of the potential that an unattended home exit could result in a death,¹⁴ we established a set of proofs of reliability that had to be met in each subject home after CareWatch installation. These proofs of reliability are to be met for 2 consecutive weeks:

- No false negatives (unrecognized exits) and less than 10% false positives (alarm but no exit) as compared to total number of bed occupancy alarms.
- No unannounced exit door openings and sound an alarm loud enough to awaken the caregiver within 2 minutes of every emergency alarm.
- Detect the whereabouts of the individual with CI during the night with a false-positive and false-negative alarm rate of less than 10% of the total room sensor activations.

During the reliability period, which was immediately after installation, caregivers were instructed repeatedly not to rely on CareWatch but continue to monitor nighttime activity as they previously had done. We connected a laptop computer to an RS232 data streaming port on the control panel of CareWatch. All sensor activations were recorded with a date/time stamp and the appropriate sensor codes. Files were saved on an hourly basis and were collected at least weekly for analysis during the reliability period.

The collected files were distilled and a program was written to display the data for analysis. We were able to examine all system codes indicating the system actions and all sensor codes, which revealed the activity in the house. We ensured that CareWatch was turned on each night by the caregiver, and then examined all the sensor activations and system codes during the night. In this way, we were able to identify problems and ensure we were making proper adjustments. The reliability period ended when all proofs of reliability were met for 2 consecutive weeks after the last system change.

CareWatch in homes of children with CI

Thus far, we have tested CareWatch in 2 different research studies. The first was a pilot test in homes of 11 families with children with CI, primarily autism. A time series design was used and the trial lasted approximately 7 months. We were able to successfully install CareWatch in all homes and all parents were able to learn to operate the system. Individualization of each system was accomplished after discussion with the parent and understanding of the child's needs. CareWatch had the required adaptability to meet all individual needs. Some examples of special needs included monitoring of refrigerator door opening at night, activity inside the bedroom, and monitoring other children going into the bedroom of the monitored child. Systems operated satisfactorily for the entire time period. All subjects who completed the 7 months of the trial chose to keep CareWatch and continued to use the system.

Most of the children in the study had previous unattended exits from the home, including some during the night hours. There were several interrupted night exits shortly after CareWatch was installed in the homes. After that, there were no attempted night exits. The reason this changed was that parents learned what activity patterns were "normal" and safe, and patterns that deviated from that. When the monitored child arose, parents often monitored the activity using messaging from CareWatch without leaving their bed. As soon as the pattern deviated for normal, a parent arose and supervised the child. Thus, the child never got enough time to open an exit door in the subsequent months. Most parents identified the ability to monitor activity through CareWatch from their own bed as the mechanism that improved their sleep. They indicated that avoiding getting out of bed with each child awakening allowed them to return to sleep more quickly.

For this sample, parents' sleep improved by approximately 30 minutes a night and they reported less daytime sleepiness. A larger trial will be needed to generalize these findings to the population.

CareWatch in homes of persons with dementia

We are currently conducting a randomized clinical trial of CareWatch in 55 homes of persons with dementia, mostly from Alzheimer's disease. Homes were randomly assigned to receive CareWatch (27 homes) or the control condition (28 homes). We successfully installed CareWatch in all experimental homes and individualized the system to the needs of the caregiver and person with dementia (PWD).

We individualized the installation to meet the needs of the caregiver and provide safety for the PWD. In general, there were 3 different installation patterns. The most common pattern was that caregivers wanted to be alerted when the PWD arose and started to walk away from the bed. Since our bed occupancy sensor has a combination of the Bed Occupancy Detector and 3 other logically connected sensors, we were able to monitor this pattern. In other homes, the PWD was so active during the night that caregivers would be awakened constantly if we used the same installation and notification pattern. Thus, in these situations, we changed the location of sensors so that the caregiver was not alerted until the PWD actually left the bedroom. In some situations, there were PWDs who were at very high risk of falls. Here, we needed to alert

the caregiver before the PWD stood up. Thus, we moved the sensors so that arm or leg activity that occurred over the edge of the bed was sensed and caused an alarm.

In this study, CareWatch has operated for more than 200 months of combined system operation with no major system failures. Caregivers became proficient at using the system within the reliability period and then continued to use CareWatch on a nightly basis. There have been no unattended exits when CareWatch was in use during the night. At the conclusion of the trial, we will determine whether caregivers' sleep, daytime fatigue, mood, caregiver burden, and depression were improved after using CareWatch for 12 months.

SUMMARY

CareWatch is a novel technology designed for use by informal caregivers providing care to a relative with CI. CareWatch has proven to be adaptable in meeting a number of different needs and home environments. The technology is unique because it focuses on supporting the job of the informal caregiver in providing care to an individual with CI. Also, it is designed to improve the quality of life for both the care recipient and the caregiver. Honeywell anticipates having the technology commercially available by the end of 2006. Individuals will purchase or lease the equipment through local home security installation companies who will install and provide technical support for CareWatch.

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