

Workplace Response to Virtual Caregiver Support and Remote Home Monitoring of Elders: the WIN Project

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Abstract

Research has demonstrated the health and financial cost to working caregivers of older adults and the cost to business in lost productivity. This paper describes the implementation of the Worker Interactive Networking (WIN) project, a Web-based program designed to support employed caregivers at work. WIN innovatively linked working caregivers via the Internet to home to monitor elders' status using wireless sensor technology and included an online information and support group for a six-month period.

Twenty-seven employees from thirteen business sites participated. Despite problems with wireless carrier service, feasibility outcomes were achieved. We were able to collect six months of continuous real time data wirelessly from multiple types of homes across 4 states. This model demonstrates that businesses can offer a similar program and not be overwhelmed by employee demand or abuse of technology access. Reluctance to consider home monitoring was apparent and was influenced by familial relationships and values of privacy and independence.

Keywords: *On-line Support Group, Internet-based Intervention, Nursing Informatics*

Introduction

The literature suggests that over 60% of informal family caregivers are working full or part-time, that they dedicate on average 18 hours per week to provide care for older persons, and even more time when the person has multiple disabilities.¹ The MetLife Juggling Act Study found 40% of respondents passed up career advancement opportunities involving promotion, training or new assignment.² Moreover, caregiving has been found to negatively affect physical and emotional health.³⁻⁴ The cost to business in lost productivity due to caregiving has been estimated between 11 and 29 billion dollars per year.⁵ Less than one-quarter of businesses with more than 100 employees offer elder care assistance; primarily resource and referral services.⁶ A literature review at the time of this study revealed 80 reports of interventions to reduce workplace injury, increase healthy behaviors and stress reduction related to

work, but none targeted to help employees balance the competing demands of work and caring for an elderly relative.⁷ To address this void, we initiated the WIN project. Given our potential to serve as an example of integrating caregiving technology into the workplace, we report on the key lessons learned to date through our formative evaluation that describes the response to our WIN program by business, workers, and elders.

Since this is the first application of wireless technology development linking the home and the workplace, we designed a technical feasibility study. Given the lack of understanding about workplace elder caregiving interventions, a descriptive exploratory approach integrating qualitative content analyses of interviews was chosen for the formative evaluation.

The WIN project is designed to support caregiving employees during work time through the use of wireless Internet based technology. Employees of our business partners could enroll if they were age 21 or over, understood English, provided oversight for an adult or older person who lived alone during working hours and had cognitive and /or health disabilities. Elders routinely attending out of home activities such as adult day care or who had in-home companions were excluded. In order to participate, employees must have had at least one health or safety concern about their relative, and planned to remain in the New England area for six months. After employees gave their consent, they were offered the intervention, which consisted of two aspects; an Internet based worker support group and the remote activity monitoring of the elder at home.

Research Questions:

1. Will businesses be interested?
2. Will working caregivers be interested?
3. Will elders be interested?
4. Is it possible to deploy a completely wireless sensor based home monitoring system in the New England Area?

Technology Description

The WIN program includes a discussion group module and a home monitoring module. Only WIN study participants can access the WIN program by using

confidential user name and password. The discussion group includes four on-line functions. 1) Participants are able to post and read messages as part of a bulletin board discussion group that includes a 'live chat room' window for simultaneous users. 2) An e-mail function allows participants to e-mail each other and the discussion group moderator. 3) A direct link to the designated counselor at the Alzheimer's Association for memory loss issues. 4) A direct link to a geriatrician on staff at our research institution, who is available to respond to a variety of elder health concerns.

The Internet based Home Monitoring Nursense© system allows participants to monitor the functional health patterns of their care recipients while at work. Prior to system use, the nurse installer visits the care recipient's home with the caregiver present, to install the home monitoring equipment. The equipment includes a transponder, similar to a laptop, plugged into an electric outlet anywhere in the house, a computer interface, about the size of a deck of cards, a transceiver plugged into an outlet approximately in the middle of the house and up to five wireless motion event sensors, about the size of a book of matches. The sensors are located in the house according to care recipient monitoring needs and preferences. The transponder sends continuously collected data to the computational server site via the wireless cellular modem. There, the data is stored and configured into an easy to read on-line report and electronic alerts generated, if desired by the caregiver. The caregiver can log into the Internet to view an updated report about their family member's activity, from work. If a monitored event does not occur within the time parameters set by the family, an alert notice automatically appears in the report and the system is capable of sending an electronic alert according to the caregiver's preferences, such as to a pager. For example, if an elder who is routinely up by 7:00 AM is not detected as have gotten out of bed by 9:00 AM, this absence of movement triggers an alert. We have the caregiver-care recipient dyad select the type of information to be monitored, give them control over the placement of the sensors in their homes, and timing of the monitoring. Privacy concerns are reduced by the integration of customized features that allow participants control over what is monitored when.

Methods

Interested persons signed up and were contacted afterwards by phone and screened for eligibility. The project was described, the consent process was reviewed and the consent form was mailed out. Upon receipt of written consent, we contacted the employee and their supervisor to complete a baseline assessment that included both standardized, validated measures and project specific measures. We then scheduled a home visit with those care recipients' agreeing to the Home Monitoring option. A 30-minute training session at the

participant's work site was scheduled to train them on system use. Installation visits were arranged for evenings and weekends to accommodate working caregivers. The nurse installer explained the project and reviewed the consent form with the care recipient, answered any questions, and obtained the elder's written consent. Following our Nursense© protocol, the nurse assessed the caregiver's and care recipient's monitoring desires and tailored the installation of the monitors accordingly. The system was installed and tested to ensure signal transmission and data capture. The care recipient's activities were monitored for six months.

Univariate analyses were conducted to identify the baseline characteristics of the worksites, participants, and their caregivers. Qualitative analyses were conducted to identify key themes that emerged from telephone semi-structured interviews with business managers and screening refusers and in person interviews with the participating workers and their family members. All interviews included open-ended questions and comments were recorded verbatim and these data were subject to content analysis. We conducted a substudy of the 7 families that were nonadopters.

Results

Question 1. Will Business Be Interested?

Of the 30 businesses approached, five participated. Aggressive marketing of the program, personal referrals and numerous contacts and presentations were necessary to gain entrée. Participating companies were immediately receptive to the idea and cooperated, while other companies simply did not respond or quickly declined, indicating their concerns about worker abuse of Internet access and related loss of productivity. Once administrative approval was secured, Human Resources staff facilitated recruitment activities. Three of the participating businesses had multiple work sites, allowing the research team to recruit from a total of 13 locations. Information Systems at all the participating sites were responsive to our inquiries about technology compatibility and security issues, and technical linkages with our system was less complex and time consuming than anticipated. Human Resource and Information System staff struck a welcome balance of supporting participant recruitment and the program technology without intruding into individual employee privacy.

Question 2. Will Working Caregivers Be Interested?

Recruitment took much more time and effort than anticipated. At the company level, there was no way to identify working caregivers. Consequently we had to outreach to all 7,182 employees knowing that the majority of these employees were much younger in age than our target group. We conducted on-site recruitment events, with company sponsored newsletter and e-mail follow-up publicity. We specifically targeted non-managerial, ethnically diverse workers who normally

didn't use a computer and the team included a bilingual research associate from the community to foster minority recruitment. Participants were recruited from CT, MA, NH, and RI with more than half coming from RI, corporate headquarters of the business with the largest employee base. Potential participants seemed initially interested in the research because of access to the WINCaregiver discussion group, but became more interested in the home monitoring once they had a full understanding of the program. The home monitoring option appeared to polarize responses: people quickly realized the benefits and were willing to engage the process or believed it would arouse privacy issues among family members and refused it. Overall the recruitment efforts generated 61 contacts, from which thirty were screened eligible (non-eligibles were interested in non-elder and pet monitoring) and 27 enrolled thereby producing a 44 % yield. Seven employees refused to be screened because of parental (3) or family (2) concerns about loss of privacy and/or hassles of technology and another reported that her care recipient was 'too paranoid' to tolerate home monitoring. Three eligible employees refused to enroll; two said that their care recipient refused home monitoring, and the third reported that her care recipient's health had improved and she felt the program would not be of use

The majority of the participants were middle aged (mean age 49 years), female (89%), White (93%), had some college education (56%) and were most often the adult child of the care recipient (78%). A quarter of the caregivers (26%) reported having only poor to fair emotional health and a higher number (41%) reported physical health problems. They spent on average 3 hours a day providing direct assistance in comparison to four times as long the time they felt they needed to be there overseeing the care recipient. They had been providing caregiving assistance for approximately six years, only two participants had less than one year's experience

Question 3. Will Elders Be Interested?

The care recipients (n=27) were on average 78 years of age, the majority were female (63%), White (96%), widowed (59%) and their health status was rated fair to poor (70%). From a functional activity perspective they had few impairments in the activities of daily living (ADLs) such as needing direct help with bathing or eating. More commonly they needed the caregivers to help with the instrumental activities of daily living (IADLs) such as shopping and driving. Eight (30%) of the care recipients participated in the home monitoring component. Three of these care recipients lived with the caregiver, two lived with another family member (both of whom were also experiencing some physical impairment) and three were living alone in senior housing.

Based upon our qualitative analyses, we are able to provide composite examples of those who will find this

type of intervention most and least appealing. The adopters shared in common a view of technology as an enabler. The workers felt it gave them "peace of mind" knowing that they would be informed if something amiss occurred and they could now have more "enjoyable conversations rather than interrogations" about the occurrence of daily activities such as eating, bathing, and taking pills. The elders felt the system enabled their continued independence at home at a time when their families were suggesting limitations or relocation due to concerns about their safety. It also gave them a "sense of security" knowing that their relative would be alerted without their "having to do anything". There was a consensus among the families that the system potentially provided the worker and elder mutual benefits, putting their mind "at ease".

By contrast, families not receptive to the technology related differing opinions over the ability of the elder and the need for supportive services. If only the worker had concerns, then the home monitoring technology was refused. Among early non-adopters, we found themes of underestimating the elders' risk potential and overestimating their capabilities, as evidenced by a daughter's description of her 95 year old mother as "...in perfect health, able to take care of herself ..." amid occasional falls. There also arose a history of non-caregiving siblings sabotaging caregiving support, "My brother in New York keeps telling Ma she doesn't need to go to day care." From the technology perspective, non-adopters reported concerns about loss of privacy due to being "watched all day". Interestingly, they continued to attribute visual surveillance capabilities to the system despite our repeated assurances to the contrary. The notion that "others" could view a family member as they went about their daily activities was a tenacious, fallacious perception that was a substantial barrier to participation.

Question 4. Is Deployment of the Wireless System Feasible?

Our final question asked whether it was technically feasible to deploy a completely wireless sensor based home monitoring system in the New England Area given the predominance of old housing structures and the proclivity of electromagnetic interference known to reduce wireless sensor transmissions. The difficulty of this endeavor was evidenced by our need to replace our initial technology contractor for failure to provide a working version of their home monitoring system as promised during Year 1. Consequently we contracted with new partners and developed a different multi-component approach integrating the support group and educational linkages. We conducted extensive pilot testing and debugging in single, multiple family, and apartment dwellings prior to installing the monitoring system in the study participants' homes. We learned valuable lessons on how to best place motion sensors to maintain robust internal signaling to the transponder and

high enough to reduce pet interference. We also found repeated instances where the external wireless signals could not be transmitted to and from our server base due to dead zones or intermittent variability with the cellular signals. Despite carrier reports of signal coverage, we did lose participants due to “dead zones”. It was particularly difficult to convince the wireless carrier that signal problems existed despite our documentation. Particularly problematic was their refusal to assign the same technical support person to small accounts with less than 20 subscribers, thereby creating inconsistencies, failure to follow through on problem solving, and lack of accountability.

Moreover, intermittent signal problems, a blackout in the Northeast power grid, local power outages, and even a cleaning service disconnecting our electrical cord for vacuuming, all created the need for more re-installation home visits than planned. Most problems have been managed by rebooting the unit but we can already recommend that the next generation systems employ remote diagnostic and repair capabilities.

On average we found that 5 motion sensors (we used the X10 basic and waterproof types commercially available for approximately \$12 each) in each of the homes were adequate to cover the activity concerns expressed by the caregivers and could be installed by our nurse. It took her up to two hours during the initial home visit to meet the elder, build trust, administer the consent process, conduct the Nursense assessment, install the sensors, and run a reliability check on the system data recording. We found overwhelmingly that the elders enjoyed the installation “visit” by the nurse as well as her follow-up contacts. Attending to the interpersonal aspects of the visit time was important to facilitate the technical installation.

Discussion and Conclusions

The WIN project is innovative in five important ways. First the partnership with business was strategically designed to promote consideration as an employee benefit option. A workplace benefit avoids the reliance on government coverage for this type of technology that would take years to achieve. From the cost perspective, given that this is a prototype, it is too early for a cost benefit analysis but certainly the program would be in line with other benefits such as child day care. Many companies were concerned that there would be huge numbers of users that might overwhelm their benefit package, while others worried that granting computer access to the Internet would generate inappropriate use. We can allay these concerns, as our data demonstrates a very manageable number of working caregivers are interested and no inappropriate usage was reported. Thus we have identified a realistic way to use an employee benefit option to foster the market for home monitoring technology, a need which will increase in importance with the aging of today’s workforce.

Second, we established the first technology-based intervention for working caregivers. The program offers workers the means to gain access to the Internet, customize the program to address their particular concerns, and receive on-line support at the workplace, all sanctioned by employers as legitimate usage of workplace computers and time for caregiving oversight.

Third, we provide the first actual data reporting the workplace recruitment responses to this type of intervention. A major limitation was we did not know the true denominator of employees who were working caregivers since none of the companies had caregiving data. Additionally, this research occurred during an economic downturn and several of the companies who participated experienced some downsizing or realignment of their workplaces. It is feasible that some workers feared disclosure of caregiving responsibilities due to the possibility of job loss or reduction in work time given their competing responsibilities at home.

Fourth the wireless technology application was installed and tested in the “real world”. During the last few years several key companies and universities have established a single unit to test the development of “smart home” technologies. Moving into the “real world” requires recruiting actual caregivers and elders, much more difficult than using paid graduate students or employees as test agents. Installers need to consider positive and negative family dynamics as well as privacy concerns. Pre-existing family tensions and disagreements over elder autonomy and the need for oversight may be exacerbated. Installers need to have skills in caregiving and family counseling to mediate resistance and foster adoption.

Finally we were able to develop, design, and successfully deploy a completely wireless Internet based system in a manner congruent with our caregiving philosophy and gerontechnology principles. Unfortunately, we found there was much overstatement of home monitoring capabilities in this industry driven more by marketing rhetoric than research. By the end of our first year, the subcontractor who reported having an established behavioral monitoring system failed to deliver the product. However, their failure provided the impetus to design and develop a completely different nursing approach with multiple features. Fortunately, these additional components helped to attract workers. In conclusion: few studies provide discussion about the productive discomfort of the field work. We contribute to this discussion and offer the lessons we learned to critically inform the emerging field of elder home monitoring.

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