The Installation and Support of Internationally Distributed Equipment for People With Dementia

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The Installation and Support of Internationally Distributed Equipment for People With Dementia

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***Abstract*—This paper describes the evaluation and support of assistive technology designed to increase the independence of people with dementia. Devices were evaluated by people with dementia in their own homes. Working with and supporting people with dementia requires relational skills not normally needed by installers and technical supporters.**

***Index Terms*—Dementia, evaluation, installation, international, support, technology.**

I. An Introduction

DEMENTIA is not an insurmountable barrier to the evaluation of assistive technology by users. This paper describes lessons learned by engineers and researchers assisting people with dementia to evaluate devices designed to support people with dementia at home. The term "evaluator" has been chosen to describe people with dementia who are evaluating equipment because they are able to make informed and useful evaluations of equipment installed in their homes rather than being passive experimental subjects.

The installation and support experiences described and analyzed in this paper are taken from installations of equipment developed for the Gloucester Smart House project and installed under the ENABLE project. The other authors are ENABLE researchers in the U.K. and Lithuania.

A. Gloucester Smart House Project

The Gloucester Smart House project was formed from a consortium of three organizations in 1999: the Bath Institute of Medical Engineering (BIME), a medical engineering design charity; Dementia Voice, a dementia services development center; and Housing 21, a major housing association. Following a survey by BIME of people with dementia and their carers in 1999, systems were designed to meet their identified needs [1]. Some of these devices have been included in the ENABLE project.

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B. ENABLE Project

The ENABLE project [2] was set up in 2001 to measure the impact of assistive technology on the quality of life of people with mild and moderate dementia in Norway, Finland, Ireland, Lithuania, and the U.K. ENABLE is not an acronym.

Evaluators with dementia were selected by their local social services department. The selection criteria included a mini mental state examination (MMSE)[1][3] score between 12 and 25 and a local primary carer or frequent social services care.

The ethical framework for the ENABLE project is based on the Technology Ethics and Dementia guidelines [4]. Informed written consent was required from the primary carer and the evaluator, who are free to leave the program at any time. They are also free to keep or return the installed devices. Two out of the ten different devices installed under ENABLE are described here; they are the Cooker Monitor and the Night Light.

The researcher visits the evaluators monthly to make sure all is well and assess the quality of life of the evaluator using the DQoL [5] quality of life measure.

II. Cooker Monitor

The Cooker Monitor [Fig. 1] is a monitoring and control system retrofitted to gas cookers. It is designed to detect potentially dangerous situations and intervene to make them safe by automatically turning OFF the cooker knobs. If the initial intervention is unsuccessful, the system informs the primary carer with a text message and isolates the cooker from the gas supply. Further use of the cooker is not possible until the system has been reset by the primary carer. If a technical fault is detected, the carer and BIME are informed.

A. Installation Procedures

A total of eight Cooker Monitors were retrofitted to evaluators' cookers in the U.K., Ireland, and Lithuania. Each installation took from 5 to 9 h.

First, the ENABLE researcher makes contact with the evaluator and primary carer to introduce them to the project and the installation site is surveyed by an engineer. If the survey is successful, the ENABLE researcher introduces the installers to the evaluator and the primary carer. After introduction, the researcher and installers talk with the carer and evaluator and explain the purpose and scope of the installation. The researcher then asks for written consent from the carer and the evaluator

[1]The MMSE is a brief, quantitative measure of cognitive status in adults. It can be used to screen for cognitive impairment, to estimate the severity of cognitive impairment at a given point in time, to follow the course of cognitive changes in an individual over time, and to document an individual's response to treatment. [Online]. Available: http://www.minimental.com/.

Fig. 1. U.K. primary carer and his Cooker Monitor, showing a heat sensor and two of the four cooker knobs.

before the installation can begin. On completion of the installation, the system operation is checked and the installers leave. If the evaluator and carer agree, the researcher leaves after about an hour.

1) Installations in the U.K.: One of the U.K. installations was in Poole. The primary carer is a friend of the evaluator who lives nearby.

With the evaluator, primary carer, installers, and gas fitter present, consent was obtained and the installation began. The gas fitter installed the safety valve and then left.

The evaluator in Poole was interested in the installation, checking on progress from time to time: " Are you boys still here?" She was not distressed. However, after about 2 h she came to the kitchen door and waited without saying anything. The installers were not sure what she wanted. One of the installers realized that the bathroom was on the other side of the kitchen and asked her if she wanted to go to the toilet. She did, but had not wanted to cross the room where the installers were working. Subsequently, the installers made clear to evaluators that they could be disturbed at any time for any reason.

A survey attempted in Poole illustrates the impact of short-term memory loss on evaluations. An engineer and a community mental health occupational therapist visited a woman to conduct a survey. The appointment was arranged the previous day. The engineer had not previously met the evaluator, but the occupational therapist was in regular contact with her.

On arrival, the therapist went to meet the evaluator alone. The evaluator came to the door when the doorbell was rung but refused to open it. She did not recognize the occupational therapist at the door and would not allow entry. The evaluation was abandoned.

2) Installations in Lithuania: The Lithuanian installations were not so straightforward as those in the U.K. A national gas company fitter was recruited to install the safety valves and provide technical support.

The first installation was in the flat of a couple in Kaunas. The woman leaves the gas cooker on without lighting it. In Lithuania, unlike a U.K. installation, there had been no prior survey and everything was to be completed in one visit. Consent was given, and the installation began at about 1:00 P.M.

The gas fitter installed the gas safety valve and left. Problems were encountered during installation of the knobs and with the electrical power supply: Lithuania has adopted the European two-pin plug system, but some buildings are still fitted with the older Russian system. The power supply in Lithuania is not as reliable as in Western Europe, with many variations in supply voltage that caused damage to the Cooker Monitor controller microprocessor.

The Lithuanian ENABLE researcher and her manager stayed at the house throughout the evaluation providing translation and reassuring the evaluator and her husband. On completion at about 10:00 P.M., the evaluator and her husband insisted that they serve the installers a meal.

The following day another cooker installation was completed. This evaluator lives on her own in a flat in Kaunas. Her primary carer is her next-door neighbor, who was supplied with a basic mobile phone for the evaluation.

The gas fitter attended with the installers, the researcher, and the primary carer and there had been no prior survey. This cooker had a critical dimension that was different to every other cooker surveyed throughout the entire project. With the help of the ENABLE researcher, a local machinist was found and some parts were modified in a very short time.

The gas fitter installed the safety valve while the knob parts were being modified. During the valve installation, a large volume of gas leaked out of the open pipe while the valve was fitted. The fitter was not concerned about this.

The rest of the installation was completed without further problems. The installers arranged to stay for a further two days to troubleshoot any emerging problems. The evaluators were encouraged to use their cookers as much as possible during these two days while the installers were available.

B. Technical and User Support

User support and technical support were provided: user support by the ENABLE researcher and technical support by BIME. The local researcher was able to provide very basic technical support with guidance from BIME.

1) Supporting U.K. Installations: One of the evaluators cooks his own breakfast. This activity is important to him as it represents his ability to look after himself. One morning, the Cooker Monitor failed and isolated his cooker. He became distressed and telephoned his primary carer for help. Meanwhile, the Cooker Monitor had automatically sent a short message service (SMS) message to a BIME engineer, who immediately drove to Poole. When the evaluator contacted the engineer for technical support, the engineer was five minutes away from his

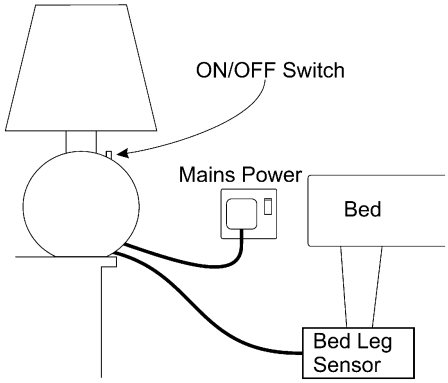

Fig. 2. Schematic diagram of the Night Light.

house. The evaluator was pleased with the rapid response and continued to support the project.

On another of the Poole installations, the cooker knobs were activating when the oven was ON. This was due to heat from the oven triggering the knobs without any electrical input. The insulation around the oven is minimal so it heats the whole cooker. Temperatures as high as 120 °C were measured on the cooker surface. The evaluator and her husband showed great patience with the engineers and a malfunctioning system while the problem was worked on. It was not solved, and the Cooker Monitor was replaced by a non-ENABLE device.

2) Supporting Lithuanian Installations: A week after the installers left, a fault was reported by the evaluator who lived alone. Diagnosis was attempted over the telephone, but the mobile phone coverage was insufficient. A diagnostic procedure was designed and sent by SMS text message. The local technical supporter was not competent to solve the problem, so a BIME engineer travelled to Lithuania the next day. On arrival in Kaunas, the engineer solved the problem within an hour. The evaluator reported that she would continue the evaluation if there were no further technical faults.

This evaluation continued until the evaluator reported that her cooker was turning itself OFF unnecessarily. She informed the researcher that she no longer wished to be a part of the evaluation program and asked for the system to be removed. The problem appeared to be caused by smoke from her oven triggering the smoke sensor, or possibly heat from the oven activating the automatic knobs. This evaluation may have been saved by a rapid technical support, however, this was not possible and the evaluation was abandoned.

III. Night Light

People with dementia often walk about at night. They are not always able to find light switches and sometimes fall. Discrete lighting can reduce falls. The Night Light [Fig. 2] uses a sensor under two bed legs to detect when a person gets out of bed. On detection, the Night Light turns ON a bedside light. The light turns ON gradually over about 1 s so as not to startle the user.

The sensor continuously measures the weight of the bed and detects large positive or negative changes in weight. Such changes are evaluated as "PERSON GETTING INTO BED" or "PERSON GETTING OUT OF BED" events which are passed to the Night Light. The sensor is self calibrating for different weights of bed and people. It works with single and double beds.

The Night Light retains the normal bedside lamp interface, which is always functional, even when the light has been operated under automatic control.

The Night Lights have been installed and supported by the ENABLE researchers rather than by the BIME engineers as in the case of the Cooker Monitors. The lights were supplied to the researchers with full written instructions for installation and operation.

Technical support has been provided on a swap in/swap out basis. This has enabled problems to be dealt with quickly and efficiently, with a minimum of disruption to the evaluator.

IV. Installation and Support Guidelines

People that are embarking on or engaged in evaluation work with people with dementia, should be aware of the needs of people with dementia, and be prepared to adapt working practice. Below are guidelines, summarized from the authors' experiences, for designers, installers and supporters.

A. Investigate, Inform, and Prepare

Thorough preparation and investigation prior to installation is essential to minimize problems during installation and support. There are two parts to this stage: investigation of the site and the potential evaluator; and preparation of the evaluator, carers, and equipment in advance of the installation.

The key objectives of this preparatory stage are the establishment of trust between the evaluator and carer and the installers, and a thorough investigation of the installation site.

1) Present the Evaluation as a Collaborative Project: The authors have found greater acceptance of their work by people with dementia when it is presented as a collaborative research project that the evaluator is helping with, rather than offering the evaluator a piece of technology that can help them with a "problem" that they have. Carers should be approached before the evaluator so that there is consistency in the introduction of the work.

Some people with dementia have reacted strongly to an offer of equipment to help with a problem they do not believe they have. Carers may respond negatively to the potential evaluator's reaction. On one occasion, a carer refused to have anything more to do with the person with dementia after "another refusal of help" following the introduction of an evaluation as "help for a problem."

2) The Team of Evaluator and Carer Should be Carefully Chosen: There should be a good relationship between the carer and evaluator to ensure consistent communication and support during the evaluation. Both should be prepared to work with the engineers in a collaborative evaluation effort. Without this cooperation, the evaluation is not likely to last long, especially if there are technical difficulties.

3) Check for the Availability of Services: A service such as mains electricity or water is only available if it is physically present *and* the evaluator accepts the use of that service. The carer and the evaluator should be consulted about service availability.

4) The Installation Site Should be Checked for Technical Suitability: The installation site should be assessed for technical suitability. This includes making all necessary measurements. Any information that might reduce the installation duration should be gathered at this stage.

5) The Evaluator and Carer Should be Fully Informed: The evaluator and carer should be fully informed of the installation process, including how long it will probably take and what they can expect if problems occur. They should also be fully informed of what support they can expect during the evaluation and what will happen if things go wrong.

B. Install Efficiently and Sensitively

The installation of a system should be carried out efficiently and with sensitivity to the state of mind of the evaluator. For a person with dementia who may not remember why an installer is working in their house, or who the installer is, a prolonged installation can be distressing.

1) Always Send Two Installers: It has been found that having two installers present allows one of the installers to temporarily leave the site and return without loss of access. It also enables one of the installers to work or make a confidential telephone call while the other talks to the evaluator.

2) Be Prepared to Answer the Same Questions Many Times: People with dementia may ask the same question many times. This may be because they do not remember asking it previously or they cannot remember the answer given. Installers should answer each time as though it is the first time they have been asked. The authors found that evaluators did sometimes remember the purpose of an installation after explaining it six or seven times.

3) Listen to the Evaluator: As well as asking the same questions many times over, evaluators may tell the same stories many times over. Such life stories can provide insight later in the evaluation into why the evaluator is reacting to a situation in particular way.

4) Be Sensitive to the Evaluator's State of Mind: Try to be observant of cues that may indicate the evaluator's state of mind such as repeated actions, facial expressions, tone of voice, persistent questioning about a particular aspect of the installation and so on. If the installers are unsure if the evaluator is distressed, they should ask the evaluator first, and a carer, if present also. If the evaluator is becoming distressed, stop progressing the installation in time to allow it to be returned to a fully functional state before leaving the site.

C. Provide Rapid and Sensitive Support

Technical support will always be necessary for prototypical equipment. When such equipment is installed in the homes of people with dementia, timely and sensitive delivery of support will lead to evaluations being interrupted rather than aborted when the inevitable technical difficulties occur.

1) If Possible, Design the Installed System to Automatically Report Technical Failures: Automatic monitoring and reporting of system failures is valuable and enables rapid technical support to be provided, as well as alerting carers to problems requiring immediate intervention.

2) Ensure That Carers and Evaluators are Able to Contact Supporters When They Want to: Support should be readily available. Supporters should emphasize that they may be asked for support at any time and be prepared to provide that support, especially during the first two weeks after installation. The ENABLE team provide 24-h on-site technical support to some of their installations. It is not often called upon, but the fact that it is available reassures carers and evaluators.

3) Do Not Make Assumptions About the Causes of Technical Difficulties: Sometime technical difficulties are caused by the evaluator or the carer. People with dementia are curious about new equipment and are often uninhibited about dismantling it to "find out how it works." In advance of installation, prepare a diagnostic fault-finding tree that can be used with a nontechnical carer over the telephone or even by SMS text message if phone coverage is poor.

V. Conclusion

Evaluation of equipment by people with dementia is a challenging and rewarding process that is an essential part of the design and development processes for anybody developing such equipment. The results returned are often surprising. They are frequently detailed and insightful into the impact of equipment on a person's life.

The authors have found that good relationships between evaluator, carers, and project staff, and consistent communication and presentation are essential for effective long-term evaluation. People with dementia need rapid responses to perceived difficulties, as they are often unable to understand the reason for a fault occurring or work around it.

In conclusion, the evaluation of equipment for people with dementia by people with dementia is essential and possible with patience and understanding. Such evaluations are the only way that the technology currently being developed for people with dementia will reach its full potential for the good of its users.

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Kerry Jones holds the Bachelor's degree in social policy and politics and a Master's degree in applied population research.

She was a Researcher for the U.K. ENABLE project. She has been working in psychotherapy and enabling technologies for people with dementia since 1995, and in social work and healthcare for 17 years. She teaches psychology and sociology of aging to undergraduate and postgraduate students.

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