Supporting Carers in Their Caring Role Through Design and Technology

Andrea Taylor

Distance Lab

Forres Enterprise Park

Forres IV36 2AB

andrea@distancelab.org

Richard Wilson

Distance Lab

Forres Enterprise Park

Forres IV36 2AB

richard@distancelab.org

Stefan Agamanolis

Distance Lab

Forres Enterprise Park

Forres IV36 2AB

stefan@distancelab.org

Abstract

Carers are people who look after family, partners or friends who could not manage without them because of frailness, illness or disability. Our contribution is to show the potential for design and technology to better support carers in their vital caring role. We describe why it is important to recognize and consider carers in the design of new home health monitoring technology, and why it is important to help carers maintain their health and well being. We also present a new home monitoring prototype system called @Hand. @Hand is informed by a survey distributed to carers in Moray, North East Scotland on sharing health information. The main difference with current systems is the focus on information sharing between cared-for and carer, rather than cared-for and health professional, and carers are encouraged to use the system to monitor their own health.

Keywords

Carer, survey, self care, home monitoring

ACM Classification Keywords

H5.2. Information interfaces and presentation (e.g., HCI): User Interfaces – Screen design, User-centered design.

Definition of Carer

In the UK, a 'carer' is someone who, unpaid, looks after a family member, friend or partner who could not manage without them because of frailness, illness or disability. The term carer does not include professional care workers who receive payment for looking after someone as part of employment.

Introduction

Home Health Monitoring Technology

New healthcare technology can support people to take more control and responsibility for their own health and well being (self care). Home monitoring systems enable health professionals to remotely monitor patients' vital signs in the patient's own home to look for signs of change in their condition, enabling an early intervention and avoiding hospital admission. The information can also be made available to carers, as secondary users, often via a password-protected website. However, carers play a crucial role – a primary role – in the healthcare of the person they look after. Thus, it is important to acknowledge and support carers as full partners. This includes quick and easy access to the information they need.

Carers and their Caring Role

"Is it a day when its ok to talk or is it a day when we should be quiet? Is it a day when he hates everything or is it a day when he's quite content. Can't put the washing on, too noisy or the hot tap to wash up. Can't leave the house because I don't know how he'll be when he wakes up, can't risk it." By ginger31 [ref]

Three in five people will take on a caring role at some stage in their lives (people move in and out of caring situations) [2]. This number is increasing as the population ages and more people require care. Caring involves a range of tasks, including emotional and social support (e.g. reassuring and listening), assistance with medication and/or other medical care, and basic tasks (e.g. shopping). Carers may share the same household as the person they care for, or live close-by or far away. Caring can be constant, stressful and have an impact financially, practically, physically, socially and emotionally. Carers who provide substantial care are more than twice as likely to suffer from poor health compared to those without caring responsibilities [ref]. The costs associated with carers' ill health include the direct cost in treating the carers' own health problems and the indirect cost to the state if the carer is less able to provide care.

In Scotland, central themes of evolving health care policy are supporting self care and supporting carers – carers are recognized as important yet currently undervalued. Accordingly, the design of home monitoring technologies can be improved by broadening the current focus on individual use and rehabilitation to encompass a shared use by friends and family.

This paper presents research on carers' and their views on information sharing. We distributed a survey to carers in a rural part of North East Scotland called Moray. From the survey findings and a follow-up discussion at a Moray Carers Forum meeting, we distilled a list of design guidelines for home monitoring technology. We used these guidelines to design a new home health monitoring system called @Hand.

Carer Research and Design Guidelines for Home Monitoring Technology

Carers Survey

We distributed a survey to 1200 carers registered with the Moray Carers Project (local charity). The aim of the survey was to find out more about what carers do, and their relationship with the people they care for. We particularly wanted to find out carers' views on sharing health information. We received 86 returns – a not unusual low response rate. The findings from this small and self-selected sample are therefore preliminary. The format of the survey was ten multiple-choice questions and a space for free text comments.

FINDINGS

- Background Information. Carers were asked about their age, caring responsibilities, and relationship with the people they care for. Respondents are mostly: adults aged 18-70 years; looking after a partner or relative; sharing the same household as the person they care for; and providing continuous care. The main reason for providing care is long-term illness. The main types of help given are emotional (support) and shopping/paying bills/collecting and delivering medication.

- Health Monitoring and Sharing Health Information. Carers were asked whether the person they care for uses any self-monitoring products, and if so, whether the results are shared with them. They were also asked if any (other) health information is shared with them. 31% respondents said that a product is used; the most popular are weighing scales, and blood pressure and blood glucose monitors. The results are mostly shared with carers, and sometimes it is the carer taking the measurements. 67% respondents said the cared-for person shares other personal health information. Typical comments are "Everything as she is dependent on me" and "As my wife we discuss everything".

- Information Carers Consider Important. Carers were asked what types of information they consider important to know about the person they care for. 67% of respondents said "Physiological data"; people most wanted to know weight, blood pressure, blood glucose and body temperature. Most important are mental well being/mood and calendar (87%).

- Appeal of Self-Monitoring Technology. Carers were asked if they would be interested in a system that monitors and shares with them the health of the person they care for. 56% respondents are "Not sure" and a roughly equal number said "Yes" (23%) and "No" (22%). The main reasons for being interested are to be better informed, to have peace of mind, and to regularly check-in e.g. "Would be able to seek help before a crisis takes place". The main reasons for not being interested are lack of need and cost e.g. "Can't afford it!". The main reason for not being sure was there was not enough information to go on.

- Carers' Comments. There was a space for comments at the end of the survey, and we asked specifically for carers' views on the benefits of regularly sharing health information. Comments include: "Just nice to know", "The value lies in knowing what is happening to the cared for, so the carer can better help, know what to watch for, when to seek outside help, and generally help to support the one being cared for", and "To help her with her health and try to avoid so many trips to hospital which cost us money". Only three people had privacy concerns.

Design Guidelines

We distilled a list of design guidelines for home monitoring technology from the survey findings and a follow-up discussion at a Moray Carers Forum meeting. This involved identifying and confirming themes based on the anecdotal and the percentage feedback.

- Data: systems need to collect and store vital signs measurements, mood, and calendar information. The importance of mood is consistent with the main type of help reported – emotional support

- Sharing: information must be immediately available to carers. This is important because carers regularly check-in e.g. "Useful to have knowledge to hand"

- Cost: systems need to be affordable to people who live on a low income or made available by the health service. Cost emerged strongly as a potential barrier to uptake and reflects the financial impact of caring e.g. "No doubt would be expensive and we do not have spare money having to live on a tight budget, as do many carers and their families"

- Accessibility and aesthetic: systems need to be accessible, acceptable and attractive to all ages. Carers are people of any age, including older people (70+), young people (under 18) and children. Some older people may have reduced dexterity such as arthritic fingers and be wary of new technology e.g. "Too many "gadgets" confuse elderly".

@Hand: A Home Health Monitoring System

Based on the design guidelines presented, we are developing a home monitoring system called @Hand for situations where the person has a carer. It is envisaged that the health service will finance and manage the system, including initialising the settings. @Hand will allow people to monitor physiological health, mood and calendar events, and share this information with their carers. Carers are encouraged to use the system to monitor their own health. On a day-to-day basis, information is circulated within the informal support network. Health data will be manually sent to the GP Practice as advised, e.g. if a measurement is outside set limits. Potentially, the system can support self care, and carers' in their caring role by helping to keep them well and better informed about the health of the person they care for.

User Interface Design

The design of the interface has been iterative, involving showing mock-ups (paper, screen) to carers in Moray.

MAIN FEATURES

- Glanceable display: information will be entered and displayed on an 8-inch colour touchscreen. The display will be 'always-on' and easy to monitor (Fig 1). The button size and spacing is suitable for older adults [1].
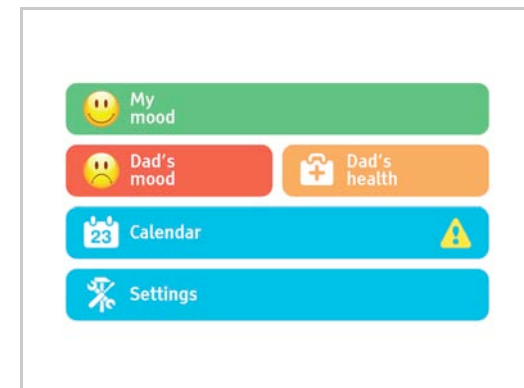
figure 1. Traffic-light colour coding and emoticons gives a glanceable indication of health and mood status.

▪ Physiological health: users will be able to monitor a range of vital signs e.g. weight, blood pressure. The main health page will list the current day's readings and notes that users have written using an on-screen keyboard. Users will be able to enter a new reading, view history graphs (Fig 2), and compare graphs e.g. mood and weight. For a first prototype, readings will be input manually using an on-screen pad.
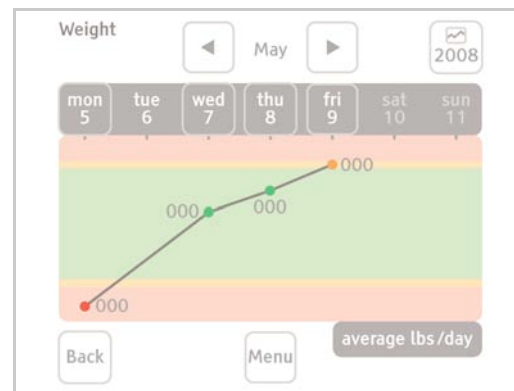
figure 2. Trends graphs allow users to track health over time and reflect on patterns in their day-to-day life.

▪ Mood: users will be able to monitor their mood. The main mood page will list the current day's entries and notes. In our discussions with carers, we found that a smiley faces scale is the preferred way to enter mood. The faces are rated 1-5 with face 3 indicating no overall effect (Fig 3). We are exploring the potential for the display to be responsive to the user's current mood (Fig 4).

▪ Calendar: users will be able to enter events in a calendar by touching the relevant day. Options available for each event include time, title, and repeat.
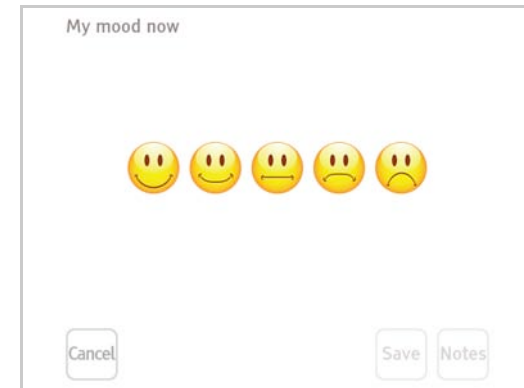
figure 3. Users select a smiley face to reflect their current mood.

Related Work

HOME MONITORING SYSTEMS

Our system is based on current home monitoring systems such as the "Telehealth Vital Signs Monitor" by Telemedcare [11], 'Doc@Home HealthHUB" by Docobo [6] and "Health Buddy" by Health Hero [8]. Physiological data is captured and stored on a home hub, and forwarded to a database via a telephone or broadband line. The main difference with our system is that the person's carer will ordinarily view the information rather than a professional care worker. The user interface has been designed accordingly. Potentially, people will be encouraged to better self care, and carers will be kept informed.

GLANCEABLE DISPLAYS

Glanceable displays enable users to understand information quickly and easily. E.g., "The CareNet Display" [3] is an interactive digital picture frame that augments a photograph of an older relative with information about his or her daily activities. The display is located in the carer's home to help with coordination of care; the elder does not use the display. Our system is similar in that it also has two modes of use: ambient and interactive. The main screen acts as an ambient display, where people can get a general idea of health status with a quick glance. And, people can touch the buttons for detail. However, our focus is on making the information accessible to all concerned, and supporting carers' health as well as the health of the cared-for person.

HEALTH WEBSITES

Increasingly, people are using health community websites, trading some privacy for support and motivation. E.g., "Healthvault" [10] allows a person to upload and store their personal health information and decide who can see the information such as a relative. Our approach differs in that information is available at a glance, without requiring time to turn the computer on and load a website. From a carer perspective, this is important because their role can be time-intensive, involving regular check-ins. One carer commented it's "Useful to have knowledge to hand" e.g. to know the cared-for person's mood on walking in through the door. However, our survey did not ask carers about internet access at home and their experience of using online information. Potentially, a web interface is a convenient solution for some people e.g. carers who continue working or distant carers. However, our software application will run on other devices running Windows and can be ported to the web. Based on further research, a future version could allow users to record, store and access information online.

Conclusions and Next Steps

The number of people requiring care is likely to grow; people are living longer and increasingly living alone. Unpaid carers make an important contribution to society by providing care to loved-ones and friends who are ill, frail or have a disability. However their own health can suffer: carers often focus on the needs of the person they are caring for and neglect their own needs. This is detrimental to the health of the carer and the cared-for person, and the health system.

This paper has presented research on why it important to consider carers in the design of new healthcare technology to support people to self care, as well as to support carers to keep well themselves. Our contribution is to show the potential for design and technology to better support carers in their vital caring role.

We are currently building a prototype system for a usability study to assess feasibility and acceptability.

Acknowledgements

References