Social Awareness Support for Meeting Informal Carers’ Needs: Early Development in TOPIC

Ivan Breskovic, Aparecido Fabiano Pinatti De Carvalho, Susanne Schinkinger, Hilda Tellioglu
Vienna University of Technology, Multidisciplinary Design Group, Austria
{ivan.breskovic, fabiano.pinatti, susanne.schinkinger, hilda.tellioglu}@tuwien.ac.at

Abstract. This paper explores the use of social awareness support as a potential solution to alleviate informal carers’ burden stemming from the heavy physical, psychological, and emotional load habitually associated with their duties. This is a preliminary contribution of the Vienna University of Technology to TOPIC project that is currently under development. In this paper we report on relevant literature, identify and consider technological and interaction challenges, and suggest mobile and ubiquitous computing for ambient solutions. We illustrate our approach by presenting briefly a prototype from our pre-study before concluding the paper.

Introduction

In Europe, as well as in other parts of the world, the number of people in need of special care is increasing (Magnusson et al., 2002). In the majority of the member states of the European Union family carers are responsible for more than 80% of all the care provided. Hence, both elderly and working-age family carers are submitted constantly to heavy physical, psychological, or emotional burden resulting from taking care of someone else. Past research has shown that these

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1 Authors are listed in alphabetical order.
people are more susceptible to both psychical and physical morbidity (Chwalisz & Kisler, 1995; Coon & Evans, 2009), facing an increased risk of mortality compared to their non-care giving counterparts (Schulz & Beach, 1999).

Literature highlights that informal carers often express the need for help, not only in terms of financial assistance, as often proposed by social institutions, but also in regards to social and emotional support (Brownsell et al., 2012; Magnusson et al., 2004; Nies, 2004). They clearly lack a means of expressing their feelings and finding a hearing for their problems in order to obtain information and comfort. Projects addressed in this paper have already explored possible solutions for such needs; however, there is still room for research on the matter (Levine et al., 2010).

Acknowledging the need for further investigation and technological development in this area, TOPIC², a European project by the AAL³ Joint Programme, aims to advance the understanding of informal carers’ needs and design information and communication technology (ICT) solutions to support them in their daily needs. The project addresses the lack of an integrated social support platform and the lack of accessible ICT applications for elderly. The project congregates 10 partners located in Austria, Germany, and France⁴.

As a first step towards meeting these challenges, the research group in Austria is currently investigating the state of the art of the field and exploring innovative ways by means of prototypes to support informal caregivers. This paper reports on some of the findings from the literature and explores some preliminary ideas to address technological and interaction challenges. We focus only on social awareness in this paper. Other aspects of support will be part of our future work.

In the following section, we present briefly some related projects, comment on the methodology they employed, and the outcomes they generated. Then we illustrate our approach in TOPIC by presenting one of the prototypes we designed and implemented as a pre-study. Finally, we stress out the importance of support for social awareness and delineate the next steps.

Related Research on Support for Care Giving

Increasing attention has been paid to technological support for care giving in the past few years (Brownsell et al., 2012; Kraner et al., 1999; Nies, 2004). The main reason for pursuing these projects is that population is aging (Magnusson et al., 2002). CARMEN worked on elaborating a research agenda for design and developing technologies that could be used for integrated care of older people (Nies, 2004). It identified different research themes, elaborated on methodological

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² The Online Platform for Informal Caregivers, http://www.topic-aal.eu
³ Ambient Assisted Living, http://www.aal-europe.eu/
⁴ We would like to thank the Ambient Assisted Living Joint Programme for financial support and the members of the TOPIC consortium for the insights and input in the project development.
issues yet to be overcome, and searched for conditions and measures to implement and assess the support that they would provide. ACTION has worked on developing ICT solutions to support family carers and the ones they were caring for with their needs. ACTION followed a user-centred design approach, focusing on people older than 60 years of age caring for frail older people, and employed different data collection methods (surveys, semi-structured interviews, and focus groups) (Kraner et al., 1999; Magnusson et al., 2002). As a result, a TV-screen based solution and a range of multimedia programs were made available, which impacted positively on enhancing carers’ competence and supporting them in a way that they would feel less isolated by creating a sense of presence and facilitating access to care professionals. SOPRANOs goal was the development of a supportive environment for older people to increase their independence and quality of life (Müller et al., 2008). It used a user-centred design approach based on interviews, surveys, and focus groups. Carers need something to reduce social isolation, enhance safety and security, minimise effects of forgetfulness, and remain healthy and active. The suggested solution was based on participation and contribution to local communities of people in the similar situation, access to information, as well as to stores and services. The findings also highlight the importance of designing solutions that overcome users’ anxiety and intimidation by technology and their fear about breaking or becoming dependent of such technologies. Same observations were possible in other projects and studies (Akesson et al., 2007; Brownsell et al., 2012; Chambers & Connor, 2002).

Torp et al. (2012) explored whether informal caregivers made use of ICT to gain knowledge about caring and to form informal support networks to improve their health. Based on 17 interviews, they concluded that the prior experiences with similar networks have great positive impact on the satisfaction and extensiveness of the use of the tools. Manthorpe (2001) explored how the “distant” caregivers can be emotionally and practically supported and how their level of involvement in care services can be increased. In general, family members are highly involved whereas professional caregivers have to distance themselves from getting too much emotionally involved (Christensen & Grönvall, 2011). Bossen et al. (2012) discovered that the system CareCoor facilitated organisation of care for both informal and formal carers, but created redundancy in data management. Furthermore, the participants reported the lack of trust in the system in critical situations (e.g. urgent messaging) and relied on traditional communication media instead (e.g. telephone).

There exist several commercial projects5 applying telehealth and telecare services in the homes of older people to contribute to their independence. These

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services enable caregivers to remotely monitor patients and provide appropriate prompt support with regard to health education and treatment compliance. However, by focusing solely on remote surveillance and control, these works consider almost exclusively formal caregivers and not patients’ family members.

The PREP model is amongst one of the first telephone support models with the aim to help increase the knowledge and skills of family caregivers by working with a professional carer or a nurse who helps them in organisation, preparedness, enrichment, and predictability in terms of their caring situation by providing individualised telephone-based advice and support (Archbold et al., 1995). TLC applied a similar approach and demonstrated that this type of intervention mostly has an impact on female caregivers with high levels of anxiety and low mastery over their caring situation (Mahoney et al., 2003). Computer Link delivered support for dementia caregivers via the Internet by allowing them to discuss with each other via a public bulletin board, to have access to an electronic encyclopaedia for information, as well as the facility to seek personalised advice and support via private emails to a nurse who acts as facilitator for the overall service (Pierce et al., 2002; White & Dorman, 2000). The approach was not user-oriented and technical solutions are limited to a small number of purely web-based services.

Some Preliminary Ideas

As observable from past research, social and emotion support are important elements for the well being of informal carers. Besides home inhabitants there are intimate socials, who are persons having a tight relation to a person but not sharing the same home, and extended socials, who are important but not connected closely to a person (Neustaedter et al., 2006). To keep a relation active, social awareness must be maintained at least to a certain degree (Figure 1).

![Figure 1. Need for awareness and awareness information in relation to friends and family members.](image)

Whilst considerable effort has been put forward towards the development of effective ICT solutions (Brownsell et al., 2012; Kraner et al., 1999), informal carers’ reactions to these interventions are ambivalent: whilst they cherish the access to information that may support them to enhance their caregiving skills and the social contact that those solutions allow for, they recurrently notice that these systems are not the simplest to use or the most intuitive to interact with. This suggests that it is necessary to explore new forms of interaction that may provide them pleasant and easy use of the system and positive impacts on their lives. We propose to investigate informal carers’ reaction to the use of tangible artefacts and ambient technologies for social awareness.
To provide implicit and active awareness mechanisms to intimate and extended socials, without disturbing the ambient in users’ homes, we designed embedded solutions to integrate into the domestic environment. *Howdy?* is a RFID-based input and output device to support social awareness at homes\(^6\). *Howdy?* enables entering data created by a friend who is thinking of a friend and wants to make his/her friend aware of that. By means of holding a tag to the RFID reader, users can trigger the communication. *Howdy?* supports several modes. Friends can be represented by photos or images or by abstract colours or shapes projected onto a wall (Figure 2), or by colours or photos projected in a cube (Figure 3).

More often a friend thinks of someone, larger gets his/her photo on the wall (Figure 2). Users can configure more than one picture for a friend to display in a sequence. Depending on the amount of triggers done by a friend, the user-configured shapes increase or decrease. Another option is to change the number of shapes depending on the activity of a friend. Many shapes with same colour or larger shapes represent the friend who is interacting more often than the others.

The third mode of *Howdy?* is implemented in a cube projecting photos or colours assigned to friends (Figure 3). The colour of a friend triggered latest or triggered most can be shown. The cube allows users to start an animated projection: it changes the colour after a while depending how often a friend has activated the system, i.e., more often a friend was thinking, longer his/her colour is displayed.

The idea is originated by one of the authors. The prototype is developed in the scope of a master thesis by Stefanie Guggenberger („I think of you“ Visualisierung sozialer Interaktionen, Master Thesis at the Vienna University of Technology, Austria, 2013).

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Conclusions and Future Work

Taking account of current and past developments of technological solutions to support caregivers with their duties, it is evident that there is an urge for innovative research using the most recent technological developments in mobile, ubiquitous, and ambient computing, as well as in tangible interaction to tackle the challenges associated with it. TOPIC sets out to address this challenge and is currently working on ideas for meeting it. In this paper, we presented only one idea of many to illustrate that ambient technologies can be innovative solutions to facilitate social awareness when integrated and embedded in homes. To achieve the most appropriate interaction we need to work with our users, e.g., not only in a lab environment, but also in their real life situations. Participatory observations help us understand the challenges our users face and support our design process. Following this approach we will next launch an ethnographic study both for capturing the user requirements and to evaluate our suggestions.

References


