
Collaboration and Coordination in the Context of Informal Care (CCCiC 2014)

Hilda Tellioglu

Vienna University of Technology
Favoritenstr. 9-11/187
A-1040 Vienna Austria
hilda.tellioglu@tuwien.ac.at

Ivan Brešković

Vienna University of Technology
Favoritenstr. 9-11/187
A-1040 Vienna Austria
ivan.breskovic@tuwien.ac.at

Myriam Lewkowicz

Université de Technologie de
Troyes
12 Rue Marie Curie - CS 42060
10004 Troyes Cedex France
myriam.lewkowicz@utt.fr

Marén Schorch

University of Siegen
D-57068 Siegen
maren.schorch@uni-siegen.de

Aparecido Fabiano

Pinatti De Carvalho
Vienna University of Technology
Favoritenstr. 9-11/187
A-1040 Vienna Austria
fabiano.pinatti@tuwien.ac.at

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Abstract

Past and current research studies recurrently acknowledge the relevance of technological developments to support informal caregivers with their activities and responsibilities. These studies highlight the demands associated with caregiving and suggest that further research in the area is needed to better understand such demands and to figure out more effective ways for technologies to support people who deal with them. In Europe, especial attention has been dedicated to informal caregivers for the past few years, due to indicators showing that more than 80% of the care for frail and old people, one of the major groups of care receivers in the region, is informally provided by family members and friends. The same scenario can be found across different continents, corroborating the relevance of the subject. Therefore, this workshop seeks contributions exploring issues of collaboration and coordination in the context of informal care. Early stage research studies in the area as well as contributions exploring the design and evaluation of computer technologies for it are most welcome.

Description of the theme

For the past few years, increasing attention has been paid to informal care with several studies suggesting that different technological solutions may effectively support informal caregivers with their duties [1, 2, 3]. These studies recurrently stress that care work is often demanding and that the results of these demands are different types of burden (e.g., psychological, physical, and emotional), which can be higher or lower depending on variables such as the age, gender, and type of illness of the person receiving care [4].

Author Keywords

Collaboration, coordination, CSCW, user-centered design, ethnographic study, qualitative research, best practice

ACM Classification**Keywords**

H.5.2. User Interfaces: User-centered design; H.5.m. Information interfaces and presentation (e.g., HCI): Miscellaneous.

Duration of the workshop: one full day

Maximum number of participants: 15 in order to have a more focused discussion and the possibility to produce interesting results.

Means of recruiting participants:

Call for Participation will be sent to different mailing lists like CSCW, HCI, HC, AAL, DBworld, EUSSET, etc., (international, English, French and German) flyers will be distributed during other upcoming events, and potential participants will be contacted directly. In addition, we will invite people with experience in industries with interests in social media for the informal care. Last but not least, we will widely advertise the workshop website in the lists above.

Important dates

- November 22, 2013: Deadline for position papers
- December 10, 2013: Notification of acceptance
- February 15, 2014 : Workshop day

Workshop website:

<http://cccic2014.wordpress.com>

Means of selecting participants:

Those interested in participating in the workshop will have to send a short position paper (max. 3000 words) containing a brief overview over the key ideas of the presentation and some information on their occupational background. Papers will be peer-reviewed by a program committee and selected on the basis of their quality, compliance with the workshop themes, and the extent (and diversity) of their backgrounds in design. The reviewing process will be managed by using EasyChair.

For example, Savage and Bailey [5] conducted some studies that suggest that informal caregivers are at a higher risk of developing psychological illnesses compared to the average population. According to the authors, the life satisfaction of informal caregivers is often compromised and they commonly feel depressed and worried about the future challenges they will have to face in terms of providing care. Also, it is difficult for them to get a balance between the care work that they have to perform and their personal lives. As a consequence, they are at a higher risk of suffering from burnouts [6].

Indeed, caregivers are exposed to huge responsibilities and long-term multi-layered hard work. To be more precise, informal caregivers commit themselves to many different types of activities to support the person(s) they care for, such as activities regarding [7, 8]: *direct care* (e.g., administration of medications, wound care and dressings, assistance with mobility, etc.); *indirect care* (e.g., obtaining medications, scheduling appointments and coordinating care, looking after medication side effects, etc.); *symptom and comfort management* (e.g., keeping records of symptoms and medications, reporting effects and effectiveness of treatments); and so forth. Therefore, they are actively working to provide proper care for the person(s) they are looking after and are often submitted to heavy physical, psychological, or emotional burden [9, 10, 11].

Knowing that computer technologies can offer support to several activities involved in caregiving, there is a large potential to develop services and technologies for people who engage in it, especially in regards to social support, which can possibly be achieved in three dimensions [12]: *informational* (in terms of flow of information, advices and opinions to help caregivers understand their problems), *tangible* (i.e., support in terms of goods or services for achieving daily tasks), and *emotional* (by demonstrating and/or conveying sympathy, empathy, friendship and/or love).

On the one hand, supporting informal caregivers on informational and tangible dimensions may facilitate their daily care activities (e.g., clarifying proper way to deal with care procedures or providing services that may support them to accomplish their tasks). On the other hand,

providing caregivers with emotional support, which can be achieved, for example, through sociability and social awareness, helps them cope with their inner burden, but also facilitates organization and management of their free time. Hence, addressing these three dimensions of social support can potentially create opportunities for balance between caregivers' duties and their personal lives to be achieved.

However, besides tackling efficiency and utilitarian pursuits, technologies aiming at fostering sociability, inclusion, and social awareness need to take into account different underlying design aspects, like designing for recreational or ludic experiences [13]. This stresses the importance of ethnography-based and participatory design methods for informing domestic ICT (Information and Communication Technology) design, which will be able to address the specificities and needs of every-day life and especially social well-being of the informal caregivers based on interaction, coordination, and collaboration between actors of their networks, such as neighbors, friends, peers, remote family members, health professionals, etc.

An evaluation of the AAL¹ program has shown that the development of products and services in AAL have largely been driven by a focus on technology and a neglect of factual demands of the users, although their positive attitude is a precondition for success of assistive technologies [14]. Therefore, participatory approaches are not only desirable from an ethical point of view, but also necessary for the design of appropriate technology.

When considering the impact of ICTs upon empowerment and social capital of users Van Dijk [15] points out two dilemmas. The first is that many support-oriented technologies have led to a sort of participation paradox: those who need the most support remain most likely excluded. In order to support sustainability, one needs to address the "silent majority". Nonetheless, how this can be achieved remains unanswered.

¹ The Online Platform for Informal Caregivers, <http://www.topic-aal.eu>

Contributions are welcomed on the following themes, but not limited to:

- Design and development of technologies to support coordination, communication, and collaboration between informal caregivers, their friends, family members, and health professionals;
- User-centered and participatory design;
- Sustainable technology development;
- Ethnographic studies and associated challenges (e.g., getting access to the field, collecting and analyzing fieldwork data, etc.);
- Cross-cultural studies;
- Ethical issues;
- Usage studies of current technological solutions for informal caregivers.

Publication: Papers accepted and presented in the workshop will be published in the workshop proceedings, which will be edited by the workshop organizers. The proceedings will include the final versions of all accepted papers, adjusted to satisfy reviewers' recommendations. It will be issued under an ISBN number by Vienna University of Technology on paper and made available for online consultation and archiving at the ACM Digital Library (to be confirmed).

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The second dilemma is that problems are often seen as challenges that have already been understood and design is commonly interpreted as their "technological fix" – whilst one needs to understand the evolving problem constructions of users in order to become able to design up-to-date, usable applications.

The experience of many projects, some even with technologically fascinating ideas, has shown that factual appropriation is a precondition for the sustainability of project results, and that sustainability is a key factor of success. This means that it is necessary to understand informal caregivers, who are often not very experienced with ICT, in order to effectively support them.

Supporting every-day activities within home environments, therefore, reveals some of the challenges and opportunities for approaches to socio-technical design and evaluation that focus on the longer-term aspects of innovation, appropriation, and use in real-life settings, such as Living Labs [16, 17].

Living Lab approaches have also proven to be successful to include people with low technology affinity into the design process. New technologies can be tried out in real conditions and, through this, possible ways of integration of ICT in the every-day structure and the individual socio-cultural environments get transparent and discussable between user groups, researchers, and industry. To open up, ethical issues around home IT for care work is another important benefit of the Living Lab methodology [18].

Providing the relevance of the theme and the existence of several relevant unanswered questions we aim, through this workshop, to gather pertinent contributions with purpose of shedding light towards it.

Interdisciplinary participation from designers, developers, psychologists, and ethnographers, among others, is mostly appreciated. Therefore, this workshop will provide an important opportunity for researchers from both academia and industry to share ideas and possibly coordinate their efforts. In this way, it will be possible to gain insights that would otherwise be beyond reach.

Workshop activities and goals

This workshop is proposed as part of the activities for the TOPIC project. TOPIC is a European project funded by the AAL² Joint Program and aims to advance the understanding of informal caregivers' needs and design ICT solutions to support them in their daily lives. However, participation is not restricted to the members of this project. On the contrary, the workshop seeks contribution from a wide range of responses and encourages submission from researchers and practitioners from all around the world.

The main output of the workshop will be a roadmap for the design of ICT providing social support for informal caregivers. The CSCW workshop is known as a challenging place to gather researchers and professionals across different disciplines and research fields who are concerned with the support of social interaction for members of our target group.

In order to achieve these goals, we will start the workshop with short presentations on the position papers accepted for the workshop. Each author is encouraged to read another accepted paper and to comment on it after the original talk is delivered. That will contribute towards the generation of theses and antitheses, which will help the discussion to get started. The presentations will be gathered by themes. At the end of each theme, there will be a general discussion in order to elaborate on the possible paths of the roadmap to be established in the end of the workshop.

Authors will also be encouraged to give demonstrations or present video prototypes of their ideas. In the last workshop session, a mind map exercise will be carried out and the topics from the presentations will be positioned on a common future roadmap. Depending on the outcomes of the exercise and the interest of the workshop participants, publication plans for extended version of the papers presented at the workshop further delineating the paths of the established roadmap may be discussed. Moreover, future goals, themes, and common activities will be planned, set up and articulated by the workshop organizers.

² Ambient Assisted Living, <http://www.aal-europe.eu/>

In terms of artifacts and technologies, the workshop wishes to gather research on systems improving communication and fostering collaboration and coordination between informal caregivers and their friends, family members, and health professionals, such as:

- Integrated social support platforms that serve all relevant aspects of caregivers social support needs in form of adequate integration of products and services [19, 20];
- Accessible (mobile, tactile) ICT applications that might automate many tasks of general caregiving [21, 22];
- Social interactive TV [23], also concerned with the design of innovative input devices;
- Social media for social support [24, 25], such as online communities with special focus on social support for the elderly;
- Interoperability and interfaces among systems in use;
- Architectures of ICT supporting caring processes;
- Scalability and security of such systems.

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