

Collaboration and Coordination in the Context of Informal Care (CCCiC): Concepts, Methods, and Technologies

Hilda Tellioglu*, Myriam Lewkowicz**, Aparecido Fabiano Pinatti De Carvalho*, Ivan Brešković*, Susanne Schinkinger*, Matthieu Tixier**

* Vienna University of Technology
Favoritenstr. 9-11/187
A-1040 Vienna Austria
{hilda.tellioglu, fabiano.pinatti, susanne.schinkinger,
ivan.breskovic}@tuwien.ac.at

** Troyes University of Technology
12 Rue Marie Curie - CS 42060
10004 Troyes Cedex France
{myriam.lewkowicz, matthieu.tixier}@utt.fr

ABSTRACT

Increasing attention is currently paid to informal care and the physical, emotional, and psychological burden stemming from it. Research findings suggest that such a burden might be intensified when informal caregivers are at older ages. Aiming at reducing the burden associated with informal care, some research studies have focused on developing innovative technologies to support caregivers with their activities and responsibilities. These studies highlight the importance of understanding the many variables that characterise different care situations, emphasizing the relevance of user-centered and participatory design approaches. Following up the successful first edition of the CCCiC workshop held at the 2014 ACM CSCW conference in Baltimore, this workshop elaborates on the resulting roadmap for future research in the domain: concepts, methods, and technologies. This workshop seeks contributions exploring issues of collaboration and coordination for informal care addressing concepts emerging from field research, methodological challenges, work-in-progress, and the design and evaluation of technological solutions.

Categories and Subject Descriptors

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

General Terms

Design, Human Factors.

Keywords

Collaboration, coordination, CSCW, user-centered design, ethnographic study, qualitative research, informal care.

1. INTRODUCTION

Informal caregivers are often exposed to huge responsibilities and long-term multi-layered hard work. Aware that computer technologies can offer support to several activities involved in caregiving, research studies (e.g. [1, 2]) have explored the potential to develop services and technologies for people who engage in it.

On the one hand, supporting informal caregivers on informational and tangible dimensions may facilitate their daily care activities

Permission to make digital or hard copies of part or all of this work for personal or classroom use is granted without fee provided that copies are not made or distributed for profit or commercial advantage and that copies bear this notice and the full citation on the first page. Copyrights for third-party components of this work must be honored. For all other uses, contact the Owner/Author.

Copyright is held by the owner/author(s).

GROUP '14, November 9–12, 2014, Sanibel Island, FL, USA.

ACM 978-1-4503-3043-5/14/11.

<http://dx.doi.org/10.1145/2660398.2660430>

(e.g., by clarifying proper way to deal with care procedures or providing services that may support them to accomplish their tasks), and the organization and management of their free time. On the other hand, providing caregivers with emotional support, which can be achieved, for example, through sociability and social awareness, may help them cope with their inner burden. Hence, addressing these three interwoven dimensions of social support can potentially create opportunities for a balance between caregivers' duties and their personal lives to be achieved. Besides tackling efficiency and utilitarian pursuits, technologies aiming at fostering sociability, inclusion, and social awareness need to take into account different underlying design aspects.

One aspect is the development of relationships among users which can lead to the development of communities grounded on information and experience sharing [3]. The development of such collectives over the Internet can range from the provision of social support between caregivers to the coordination of larger groups in order to influence healthcare practices and even policy makers [4]. Free from time and geographic constraints, online communities also open questions about cross cultural support and cooperation in health.

Another aspect is the design of technologies for recreational or ludic experiences [5]. Here informal caregivers appear as key actors for the organization of healthcare at home and the deployment of associated technologies who should also care for themselves. 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, and institutions.

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 [6]. Therefore, participatory approaches are not only desirable from an ethical point of view, but also necessary for the design of appropriate technology. Such a relevance has been emphasized during the presentations of the first

¹ Ambient Assisted Living, <http://www.aal-europe.eu>

edition of the CCCiC workshop held during the 2014 ACM CSCW Conference in Baltimore.

2. CHALLENGES FOR SUPPORTING INFORMAL CARE SITUATIONS

Supporting every-day activities within home environments 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.

In the elaboration of the roadmap for the design of ICT providing social support for informal caregivers discussed during the first edition of the CCCiC workshop (at CSCW'14), the need for further research and discussion on concepts, methodologies, and technologies emerged. According to speakers and attendees, these questions can be translated into issues of *user biographies*; *data definition, sharing, and management*; *information and learning needs*; *collaborative sense making among stakeholders and care practices*; and *socio demographic differences and gender issues in caregiving processes*.

In terms of *user biographies*, participants highlighted that further research is necessary to understand informal caregivers and their needs. We still do not have enough knowledge about the demographic development of caregivers and their care receivers as well as their relationships. Single use cases are interesting and show the richness of informal care situations varying in terms of distance [7], relationships to the care receiver [8] or institutional context [9, 10]. Among these studies, there is a need for the identification of complex scenarios, including other stakeholders like formal caregivers or health care professionals, and of (common) patterns occurring in care giving processes by informal caregivers. Developmental perspectives on the situation are also needed since informal caregivers may change in their relationship to the care receiver [11] along their experience and as well change their needs in terms of knowledge and social support.

Considering the importance of *data* of and for caregivers, we need to clarify what relevant, integer, correct, complete, clear, accurate, and trustworthy data means for care giving. *Creation, handling, and sharing* of care related data [12] need to be supported by secure, efficient, and integrated mechanisms which are facilitated by mobile and configurable IT systems. Two keywords emerged from the discussion: experience-based information and evidence-based caregiving. Attendees also highlighted the need to devise innovative ways to ensure and communicate quality and ownership of data. In TOPIC², issues of providing useful, validated, and accurate data have been a primary concern.

Information and learning knowledge about disease and caregiving is identified as a triggering and essential dimension in informal caregivers use of information and communication technologies [13]. Findings from extensive ethnographically-informed fieldwork have pointed out towards caregivers' need for assorted types of information (e.g., information about basic care procedures regarding the care situation in question, or about how to get financial support to bare with the expenses from the care work or with the need of leaving the job to take over care responsibilities). Identifying the relevant information and opportunities for learning according to the

care situation is a key challenge in order to design useful and relevant learning material.

Along the disease trajectory [14], informal caregivers have to *make sense and work* with a wide range of organizations and actors like health professionals, psychologists, social workers, external housework and home care services, health institutions and insurance services, professional carers assisting their ailing relative in daily duties (for instance, bathing, getting dressed). Engaging the participation and defining spaces for these different services on ICT based solutions aimed at supporting caregivers is an important challenge and appear as a clear example of sociotechnical gap [15]. For instance, communication and information sharing on the care receiver situation is identified as a problematic area for cooperation between informal and formal caregivers [16]. The development of comprehensive information material on the care situation and associated visualization [17] appear as a necessity. Such representation should enable coordination and the collaborative sense making of the care situation among the different perspective and values of the stakeholders.

As for care practices, the need for better understanding of conventions and values associated with informal care, the combination of formal and informal care, the development and impact of aggressive behavior in caregiving, as well as social aspects of care giving and receiving has been identified. This calls for research that helps to elaborate a better conceptual framing of the domain.

A special attention in the workshop will be paid to the *socio demographic differences and gender issues in caregiving processes*. By distinguishing the general kinship relationship between receiver and provider, the gender of the caregiver, and the specific familial relationship we can improve understanding of the caregiving paradigm. This has been repeatedly shown in the research community. For example, the study of Young and Kahana [18] showed consistent patterns of strain: females are the most likely caregivers to ailing elderly, but women, no spousal caregivers and daughters experience the most severe aftereffects. Del Bono et al. [19] suggested that gender differences in the provision of care among older people disappear only when considering married individuals and adjusting for the presence of other household residents affected by a limiting long-term illness. Gallicchio et al. [20] confirmed that there are gender differences in the caregiver population with respect to burden, but not with respect to depressive symptoms.

Knowing that female caregivers are significantly more burdened than male caregivers has important implications. Namely, since women have more frequent, intensive, and affective involvement while caregiving, adequate assistance must be given to them to ensure that they are not strained beyond what is considered clinically healthy.

The extensive list of themes in the roadmap for future research on informal care elaborated on the first edition of CCCiC urges the organization of future workshops to discuss an elaboration on them. Attendees of the first edition of the workshop showed interest in having the opportunity to participate in such an event twice a year and GROUP 2014 has been suggested as the place to have the next edition.

For this workshop we are looking for work-in-progress that can present some results from fieldwork and present preliminary design ideas. In terms of artifacts and technologies, the workshop wishes to gather research on systems improving communication and fostering

² TOPIC, The Online Platform for Informal Caregivers (<http://www.topic-aal.eu>), is a European project under the AAL Joint Program and aims to advance the understanding of informal caregivers' needs and design ICT solutions for them.

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 [21];
- Computer supported learning for informal caregivers;
- Accessible (mobile, tactile) ICT applications that might automate many tasks of general caregiving [22];
- Social interactive TV [23], also concerned with the design of innovative input devices;
- Social media for social support [24], 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.

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 data, etc.);
- Cross-cultural studies;
- Ethical issues;
- Usage studies of current technological solutions for informal caregivers.

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.

3. WORKSHOP ACTIVITIES AND GOALS

As the first edition of CCCiC workshop, this second edition is proposed as part of the activities for the TOPIC project. However, participation is not restricted to the members of the 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 the identification of elements for the elaboration of a conceptual frame for the domain of informal care and the discussion of an array of methodologies for conducting research within it. Furthermore, a list of implications for design for technological developments will be collaboratively elaborated and validated by participants at the end of the workshop.

In order to achieve these goals, we will invite not only position papers but also demo proposals from both academy and industry. The workshop will be split in three moments. At the first moment, there will be short presentations of 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.

Following the presentation of the position papers, there will be a session dedicated to demonstrations of existing systems for informal care or video prototypes of innovative technological concepts for it. Finally, a brainstorming session will be conducted in order to define the elements of the aforementioned conceptual frame for informal care and for the elaboration of the list of the implications for design of technologies for this domain. After the brainstorming, future goals, themes, and common activities will be planned, set up and articulated by the workshop organizers.

The GROUP conference is known as a great 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. Therefore having it as the venue for the new edition of the CCCiC workshop will truly contribute towards the workshop goals.

4. ORGANIZATION

- **Duration of the workshop:** One full day
- **Types of submissions:** Position papers and demo proposals
- **Means of selecting the contributions:** Those interested in contributing with a position paper have to send a submission with (max. 3000 words) containing a brief overview over the key ideas of the presentation and some information on their occupational background. The ones interested in contributing with a demo should submit an extended abstract describing the system to be demonstrated and the design rationale for it (max. 1500 words). Additionally, demos contributors can submit videos, links or any other relevant artifacts of the system to be demonstrated. Papers and demos 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 through EasyChair.
- **Publication:** Position papers and demos abstracts 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 contributions, 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).
- **Maximum number of participants:** 15 in order to have a more focused discussion and the possibility to produce interesting results – a few place will be available for participants not presenting in the workshop.
- **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.
- **Workshop website:** <http://ccci.wordpress.com>

5. IMPORTANT DATES

- **August 15th, 2014:** Deadline for position papers and demo proposals submission
- **September 26th, 2014:** Notification of acceptance
- **October 17th, 2014:** Camera ready
- **November 9th, 2014:** Workshop day

6. ACKNOWLEDGMENTS

We would like to thank the Ambient Assisted Living Joint Program for financial support and the members of the TOPIC consortium for the insights and input in the project development.

7. REFERENCES

- [1] Chambers, M. and Connor, S.L. 2002. User-friendly technology to help family carers cope. *Journal of Advanced Nursing*. 40, 5, 568-577.
- [2] Mahoney, D.F., Tarlow, B.J., and Jones, R.N. 2003. Effects of an automated telephone support system on caregiver burden and anxiety: findings from the REACH for TLC intervention study. *The Gerontologist*. 43, 4 (Aug), 556-567.
- [3] Preece, J. 1998. Empathic communities: reaching out across the Web. *Interactions*. 5, 2, 32-43.
- [4] Akrich, M. 2010. From Communities of Practice to Epistemic Communities: Health Mobilization on the Internet. *Sociological Research Online*. 15, 2
- [5] Gaver, W.W. 2006. The Video Window: My Life with a Ludic System. *Pers Ubiquit Comput* 10, 60-65.
- [6] Podtschaske, B., Glende, S., and Nedopil, C. 2010. Nutzerabhängige Innovationsbarrieren im Bereich altersgerechter Assistenzsysteme, 1. Studie im Rahmen der AAL-Begleitforschung des Bundesministeriums für Bildung und Forschung. Abschlussbericht. Available from: http://www.aal-deutschland.de/deutschland/dokumente/Abschlussbericht_AAL-Nutzerstudie_Final.pdf [last accessed: 26 Sep 2013]
- [7] Williamson, S. and Jimison, H. 2014. Information Technology Tools For Long Distance Caregivers: A Needs Assessment. In ACM CSCW Workshop on Collaboration and Coordination in the Context of Informal Care (CCCiC 2014), Baltimore, Maryland, USA.
- [8] Schinking, S., de Carvalho, A.F.P., Breskovic, I., and Tellioglu, H. 2014. Exploring Social Support Needs of Informal Caregivers. In CSCW 2014 Workshop on Collaboration and Coordination in the Context of Informal Care (CCCiC 2014), Baltimore, MD, USA, February 15, 2014. TU-Wien, 29-37.
- [9] Müller, C., Neufeldt, C., and Wulf, V. 2014. Moving into a Senior Apartment: Opportunities and Hindrances in Rebuilding Social Relationships among Elderly. In ACM CSCW Workshop on Collaboration and Coordination in the Context of Informal Care (CCCiC 2014), Baltimore, Maryland, USA.
- [10] Tixier, M. and Lewkowicz, M. 2014. "Respite that fits our needs": Learning from a Day Care Service Defined by Spouse Caregivers to Design a Social Support Platform. In ACM CSCW Workshop on Collaboration and Coordination in the Context of Informal Care (CCCiC 2014), Baltimore, Maryland, USA.
- [11] Montgomery, R. and Kosloski, K. 2009. Caregiving as a Process of Changing Identity: Implications for Caregiver Support. *Generations*. 33, 1, 47-52.
- [12] Morandell, M., Sandner, E., Steinhart, J., and Biallas, M. 2014. RelaxedCare – Connecting People in Care Situations. In ACM CSCW Workshop on Collaboration and Coordination in the Context of Informal Care (CCCiC 2014), Baltimore, Maryland, USA.
- [13] Ahmed, S. 2014. Internet and Parents with Children with Special Needs: A Meta-Analysis on PubMed Articles. In ACM CSCW Workshop on Collaboration and Coordination in the Context of Informal Care (CCCiC 2014), Baltimore, Maryland, USA.
- [14] Strauss, A.L., Fagerhaugh, S., Suczek, B., and Wiener, C. 1985. *The organization of medical work*. University of Chicago Press, Chicago, Illinois.
- [15] Ackerman, M. 2000. The Intellectual Challenge of CSCW: The Gap Between Social Requirements and Technical Feasibility. *Human-Computer Interaction*. 15, 2-3, 179-203.
- [16] Marcu, G., Dey, A., and Kiesler, S. 2014. Collaborative Reflection to Empower Primary Caregivers. In ACM CSCW Workshop on Collaboration and Coordination in the Context of Informal Care (CCCiC 2014), Baltimore, Maryland, USA.
- [17] Erickson, T. 2014. Enabling Care Provider Organizations to Make Use of Informal Resources: Visualizing Social Context. In ACM CSCW Workshop on Collaboration and Coordination in the Context of Informal Care (CCCiC 2014), Baltimore, Maryland, USA.
- [18] Young, R.F. and Kahana, E. 1989. Specifying caregiver outcomes: Gender and relationship aspects of caregiving strain. *The Gerontologist*. 29, 5, 660-666.
- [19] Del Bono, E., Sala, E., and Hancock, R. 2009. Older carers in the UK: are there really gender differences? New analysis of the Individual Sample of Anonymised Records from the 2001 UK Census. *Health & social care in the community*. 17, 3, 267-273.
- [20] Gallicchio, L., Siddiqi, N., Langenberg, P., and Baumgarten, M. 2002. Gender differences in burden and depression among informal caregivers of demented elders in the community. *International Journal of Geriatric Psychiatry*. 17, 2, 154-163.
- [21] Tixier, M. and Lewkowicz, M. 2009. Designing Social Support Online Services for Communities of Family Carers. In BIS Workshop. Springer-Verlag, Berlin/Heidelberg, 336-347.
- [22] Harley, D. and Fitzpatrick, G. 2009. YouTube and Intergenerational Communication: The case of Geriatric 1927. *Universal Access in the Information Society*. 8, 1
- [23] Rice, M. and Alm, N. 2007. Sociable TV: Exploring User-led Interaction Design for Older Adults. In Proceedings for the 5th European Conference on Interactive Television, Amsterdam, May 24-25.
- [24] Caplan, S.E. and Turner, J.S. 2007. Bringing Theory to Research on Computer-mediated Comforting Communication. *Computers in Human Behavior*. 23, 985-998.