# Who Cares? Exploring the Concept of Care Networks for Designing Healthcare Technologies

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**Abstract.** Dealing with a chronic condition often involves daunting tasks and the participation of multiple people in care. Previous literature has documented collaboration between patients, clinicians, close relatives, friends, and paid carers. However, collaboration in care has been mostly examined as the work of dyads, such as patients and clinicians. In this workshop, we will explore the concept of care networks, which can better account for the numerous human and non-human actors and roles that compose care. We invite designers, researchers, and practitioners to participate in a full-day workshop in which we will reflect on empirical studies and theoretical accounts of care networks, and put forward an agenda for better acknowledging care networks in the research around healthcare technologies and systems.

# Background

Increased life expectancy of older adults and higher prevalence of chronic conditions have made studying care an urgent topic. To care is seldom a solo engagement; instead, there are many people, resources, activities, and plans involved around the person with a chronic condition (Von Korff et al., 1997).

Computer Supported Cooperative Work (CSCW) has been at the forefront of studying collaborative care engagements (Fitzpatrick and Ellingsen, 2013), but most studies have focused on dyads. Examples include collaborations between patients and family members (Berry et al., 2017; Nunes and Fitzpatrick, 2015), hospitalized patients and their family members (Miller et al., 2016), patients and volunteer carers (Foong and Zhao, 2016), patients and their doctors (Andersen et al., 2011), as well as between clinicians (Andersen et al., 2011). Few CSCW studies employed a broader care network perspective, despite being strongly influenced by Strauss et al. (1985) and their work on collaborative management of illness trajectories by patients, carers, clinicians, and care workers.

Few exceptions provided examples of the broad care network perspective. For instance, Consolvo et al. (2004) argued for supporting the broader care networks of elders, including family members, friends, neighbors, care workers, and clinicians. Their study of the elderly and their carers highlighted the need to support coordination between carers in these networks. Hong et al. (2012) developed *SocialMirror* for people with autism in their transition to independent adulthood to connect with a trusted network of family, friends, and other carers for advice on everyday life skills. Their study identified key design elements to protect the privacy and security of the individuals with autism, as well as to manage division of labor, coordination, and conflict resolution between carers.

These studies on care networks have primarily considered human actors in their descriptions of the networks. Consolvo et al. (2004) defined care networks as "support networks of people who provide the elder with care" (p.24). Similarly, Hong et al. (2012) focused on the "social networks" of the individuals with autism. However, some work has recognized both human and non-human actors[1] involved in care. Taking an infrastructure perspective on care, Danholt and Langstrup (2012) argue that living with a chronic condition "might fruitfully be regarded a practice in which a range of actors are at work" (p.514), where human knowledge, information, values, beliefs, and attitudes are related to "technical, material and situated circumstances" (p.515). This perspective builds on a relational understanding of practice initially developed in Science and Technology Studies (STS) (Barad, 2003; Suchman, 2007). This body of work provides theoretical foundations for CSCW researchers seeking to broaden analyses to consider care networks of human and non-human actors. For example, in Bjørn and Østerlund (2014) Sociomaterial-Design approach, by examining and questioning

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[1] The idea that non-human actors have agency in different processes and scenarios is well explored in actor-network theory. For an example see Latour et al. (2005).

presupposed boundings among human and non-human actors, researchers were able to better understand care practices and reveal opportunities for design.

Building on this work, our intention with this workshop is to open the concept of care networks to in-depth exploration and to set agendas for future work around healthcare technologies and systems.

# Why We Need to Explore Care Networks

Our own fieldwork and other literature provide examples of care situations that become richer analytically if we use a concept of care networks to investigate them. First, we have found that various human actors play a part in care networks in different ways and to various degrees, and their involvements are often intricately intertwined. For example, family members of shift workers, such as nurses and assistants, help manage unorthodox sleep rhythms for decades. Family members adapt schedules to be with the person and even call persistently to wake them during the day. Shift workers' direct managers from the hospital play a role in care as well. For instance, by enabling or hindering people from adjusting their schedules with co-workers, managers enable or prevent them from accumulating shifts or skipping mandatory rest periods, which has serious impacts on their health. If the analysis focused solely on the worker and kin it would disregard important actors involved in their care.

Another example that highlights the importance of a care network approach is the role of self-care technology, particularly with its automation in care. For instance, the developers behind the OpenAPS community (Omer, 2016) built a system that uses insulin pumps to respond to changing blood glucose levels. Instead of always injecting the same level of insulin, an algorithm running on a raspberry-pi adjusts insulin levels to moderate the sugar levels of patients with type 1 diabetes. Kaziunas et al. (2018) called attention to ways that OpenAPS may shift existing collaborative care practices involving patients and providers. In another example, *AffectAura* continuously predicts the user's emotional state and correlates this information with contextual data to enable reflection (McDuff et al., 2012). The algorithms of OpenAPS and the predictive model of *AffectAura* play important roles in care, but it is not common for researchers to refer to technologies as carers. A care network approach could account for technology actors as recognized carers in the network.

Lastly, using care networks as a frame of analysis enables the exploration of multidirectional care relationships, and relationships where the network's center is not fixed. For example, Riche and Mackay (2010) described a group of older ladies who took care of one another by keeping an eye on window shutters and ringing each other on the phone. One cannot say that one of the ladies was the patient at the center of the network, as none of them were acutely ill or the sole focus of attention; however, by setting up and maintaining a care network, the ladies were able to address emergencies and provide care as needed.

We contend that using a broader care network perspective can open up novel opportunities for analysis and design of care support. In particular, it can bring attention to different engagements and arrangements, potentially identifying human and nonhuman actors that have not been considered before.

The expected outcome of the workshop would be to generate attention points for design considerations and to generate inspiration from multidisciplinary and co-creation perspectives into the design and development of new socio-technical solutions to support and sustain care networks.

## Workshop Goal and Themes

The goal of this one-day workshop is for participants to explore the concept of care networks in CSCW and to devise a plan for future research on healthcare technologies and systems.

In the workshop we will discuss collaborative care situations that are better understood by exploring various aspects of care networks. We are also interested in contributions relevant to the design and development of future technologies for care, and the impacts of these technologies on care. We will take a co-creation approach, bringing diverse perspectives together to speak to various potentials as well as consequences of such technologies. Possible themes include, but are not limited to:

- Who/what cares (/is involved in care)?
- How do different actors of a care network engage in care?
- What tensions exist in the care network? How are different perspectives integrated and negotiated?
- How is the care network structured? How are relationships among actors enacted? How do actors manage the multidirectional nature of care? To what extent are care networks (de)centralized?
- Does focusing on care networks change how we conceptualize care?
- How to design for care networks? How to incorporate different perspectives (including needs, attitudes, beliefs, values, knowledge, activities, resources, functions)? How to enable collaborative decision making for care networks?
- What are some novel methodological approaches or challenges to studying care networks?
- What are the socio-technical-cultural challenges for design, adoption, and interaction with existing technologies for caregiving?
- What can be learnt from the current health system/technology use? What can we brainstorm new thoughts into emergent technology in caregiving work?
- What else has been examined around care networks in CSCW community?

## Pre-Workshop Plans

### Position paper submission and selection

For the workshop, we encourage submissions from researchers, designers, healthcare providers, and any others who are interested in care work and healthcare technology design. We invite position papers that describe or discuss collaborative care situations that are better understood in terms of care networks, including: case studies or reports on recent experiments or prototypes, ethnographic fieldwork or qualitative studies, theoretical accounts, and critical reflections. Authors can make contributions that discuss issues relevant to the design, development, or use of technologies for care, or impacts of technology use on care. Possible topics include, but are not limited to, the workshop goals and themes listed above. Position papers should be submitted in ECSCW template, and should not exceed 4 pages, excluding references. The submitted papers will be lightly reviewed by the workshop organizers with input from members of the program committee (listed below). Position papers will be selected based on quality, originality, diversity, and relevance to the workshop goal and themes. We will give priority to papers that are likely to foster fruitful discussions during the workshop. We aim to have a diverse group of up to 20 participants to facilitate cross-disciplinary sharing of experiences and expertise. Participants will receive notification of acceptance on May $2^{nd}$. Final versions of accepted papers will be posted to the workshop website at least two weeks prior to the workshop.

### Workshop promotion

To promote the workshop, we will leverage our connections in academia and industry, and distribute workshop information via various listservs (e.g., ACM, CSCW, HCI, design, and STS-related email groups). We will also promote the workshop on social media.

We will create a website for the workshop that will include the workshop goals and call for participation, as well as brief bio-sketches of the organizers. The website will also include the time, location, and final schedule of the workshop.

### Equipment and supplies

We will need space for a maximum of 25 participants (including the organizers) and walls for posters. The organizers will bring paper, post-its, pens, as well as laptop and projector.

## Workshop Activity Overview

The overall plan for the workshop is roughly as follows:

*Poster presentations*: After welcoming remarks and brief participant introductions, each participant will give a five-minute poster presentation. Discussion will follow each presentation, with questions from the other participants. The organizers will take notes during this session to gather a list of themes that emerge from the presentations and discussion. These notes will be shared and participants will be invited to add or edit the document with their own notes (e.g., through a Google Docs Document). *Reflection around care network examples*: We will ask workshop participants to draw care networks that they know well or have experienced. These examples can be based on previous field research, acquaintances or friends, or from their own experience. We will be careful to communicate that sharing health information that is personal or otherwise protected is voluntary and not required to participate in the workshop. Participants will be invited to share their drawings in small groups, focusing on members, relationships, and other relevant attributes. This activity will ground subsequent discussions in concrete examples of care.

*World Café Method*: We will select a few of the themes that emerge from participants' presentations, reflections, and interests of the group, and assign each theme to a discussion table. We will invite participants to discuss these themes in small groups, and after some minutes, rotate to another table that has a different topic. We will try to mix group composition during this activity so that participants have chances to work with different individuals.

*Whole group reflection*: We will host discussions with the whole group on design issues and challenges. Discussions about future research agendas will also take place during this activity. *Evening activities*: Although participation is not required, participants are encouraged to join a group dinner to continue discussions and to build relationships with people that share their interests around care networks.

## Post-Workshop Plans

We will publish a final report of workshop proceedings on the workshop website and summarize the discussion and reflections from the workshop in a collective article for ACM Interactions. Besides our website serving as an information repository from the workshop, we will create a sustainable communication channel (e.g., Slack channel, mailing list, or online group) to stay connected as a group, share work and resources related to the topic, and facilitate future collaborations.

## Workshop Organizers

*Sun Young Park* (PhD UC Irvine) is an Assistant Professor in the Stamps School of Art and Design and the School of Information at the University of Michigan. Her research focuses on patient engagement, patient-provider collaboration, patient-centered health technology, and technology adaptation.

*Francisco Nunes* (PhD TU Wien) is a senior researcher at the Human-Centred Design department at Fraunhofer Portugal AICOS. His research focuses on understanding and designing technologies for self-care and informal care contexts.

*Andrew Berry* (PhD University of Washington) is a PhD candidate in Human Centered Design & Engineering. His research focuses on designing support for collaborative care for people managing multiple chronic conditions.

*Ayşe Büyüktür* (PhD University of Michigan) is a researcher at the School of Information and the Michigan Institute for Clinical and Health Research (MICHR) at the University of Michigan. Her research focuses on the design and use of health information technologies to manage care in chronic illness and disability.

*Luigi De Russis* (PhD Politecnico di Torino) is an Assistant Professor at the Department of Computer and Control Engineering of Politecnico di Torino since 2018. His current research focuses on Human-Computer Interaction, with a particular interest on interaction techniques applied to complex settings (such as in Ambient Assisted Living).

*Mary Czerwinski* (PhD Indiana University) is a Principal Researcher and Manager at Microsoft Research in the area of human-computer interaction. Her research interests of late include technology for health and wellbeing as well as information worker productivity.

*Woosuk Seo* (University of Michigan) is a PhD student in School of Information. His research focuses on designing support for effective communication in care for pediatric patients and their caregivers managing chronic illness, such as cancer.

## Program Committee

- Mark S. Ackerman, University of Michigan
- Yunan Chen, University of California Irvine
- Claudia Müler, University of Siegen
- Aisling O'Kane, Bristol University
- Anne Marie Piper, Northwestern University
- Cristiano Storni, University of Limerick
- Nervo Verdezoto, Leicester University

## Acknowledgments

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