Networks of Care in Rural Areas

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Abstract. The effects of demographic change in rural areas are increasingly noticeable. The concept of "caring communities" positions mutual care relationships of citizens in a wider network of community actors. E.g., in rural areas, church congregations and other rural associations may provide strong social networks and thus starting points for reflections and actions on the development of rural caring communities. Digital ICT tools may support and expand existing communities. However, how digital tools may be co-designed in multi-stakeholder settings, such as in a village of old and young citizens with more and less interest in digital support topics and digital literacy, poses some challenges. We report on and reflect the co-exploration and implementation of "off-the-shelf" tools and "low-threshold" designs such as a church camera, which may serve as tools for sense-making in diverse caring communities.

Widening the perspective of (health) care to caring communities

Rural areas are struggling with the consequences of demographic change, poor supply structures and long distances. Especially older people are affected. In principle, the digitisation of rural areas provides promising options to counteract these negative developments: it represents an opportunity for regional

development to reduce disadvantages such as long distances or poor infrastructure, and thus make life in rural areas more attractive again, particularly through fostering social participation. At the same time, rural areas are often characterised by community and mutual networking, which is of decisive importance, particularly in the area of care.

Human beings are interdependent, experience vulnerability and need care in some way (Tronto, 1993). Their shared humanity interweaves them in interpersonal care relationships (Puig de la Bellacasa, 2012). For the purpose of this paper we conceptualise care in broad terms as a fundamentally human practice, including formal and informal relationships of care. Care-giving is often reciprocal, for example when care recipients care for their loved ones and are also actively involved in the care they receive (Toombs et al. 2018; Mishra et al., 2016). Care can therefore be understood as mutual cooperation, which is characterised by mutual sympathy. Key stakeholders include patients, health workers and primary caregivers such as family, friends and neighbours. Due to a broader understanding of care, designers of health technologies, decision-makers in health policy and health technologies should also be included as stakeholders (Toombs et al., 2018).

Human- and value-oriented as well as participative strands of literature in socio-technical design communities find an analogy in the approach of "caring communities", "Caring communes (or communities) in essence are concerned about sustainability, children, integration, values and spirituality, towards others, towards the sick and the dying and the bereaved" (Klie, 2016, p. 198). Caring communities is increasingly seen as an inspiring approach for healthcare research and policies (Klie, 2016). Caring communities are collectives characterised by co-responsibility, co-production and the acknowledgement of interdependency and reciprocity that expand beyond families (Klie, 2016). At the same time, the approach defines a set of characteristics and orientations that communities and its members have or aspire to achieve. These include the strengthening and creation of spaces, networks and processes for mutual support as well as the promotion of solidarity structures, beyond religious, ethnic, national and class distinctions (Klie, 2016). Hence, caring communities is both a normative and an analytical concept, which is always process-oriented. The purpose of this paper is mainly conceptual. It focusses on caring communities as an analytical concept for participatory care research in rural areas in its widest sense.

Preparing for participation in IT projects in rural (multi-stakeholder) environments

Our research project aimed at the participatory development of advanced technologies to support both the quality of life and ageing processes of older

villagers at home. The research focused on the participatory integration of end users in the research, as well as the conception and design of practical and meaningful applications. The rural village at stake has 600 inhabitants and is located in the least populated regions of North Rhine-Westphalia, Germany, and is part of a network of seven villages. The region is characterised by demographic change and a sustained decline in population. Above all, the opportunities for everyday services of general interest, health care and the social participation of elderly people with reduced mobility and health are considerably limited. The three central loci of social interaction in the village are the activities of the local church community, a voluntary village shop, and the local family doctor's practice. The use of digital technology in the village is only possible to a limited extent due to the poorly developed networks and the undersupply of fast Internet.

We conducted interviews and workshops with local actors including the village shop owners, the local doctor, the medical assistants and the church community. In addition, ten senior participants (65-82 years) took part in a series of workshops over a period of 2.5 years. We conducted focus groups and "Experience-based Participatory Design Workshops" which provided a long-term mechanism for setting up a common learning space for designers/researchers and community actors. The focus groups and workshops allowed us to design ideas and prototypes in an iterative way which is grounded in the research participants' every-day practices, attitudes, and interests (Müller et al., 2015; Hornung et al., 2017, Fitzpatrick et al. 2015).

Preparing for participation of older and often not technologically savvy persons, the researchers faced many challenges. For example, it was difficult to find suitable methods for qualifying senior citizens for participation at "eye level" and to accompany them continuously and intensively for the entire project duration of three years. Amongst others, "off-the-shelf" digital tools and "low-threshold" designs, such as a church camera enabling telepresence in church services, served both as a result of the co-design process and as a measure and example of a meaningful technology tool, which can foster a joint discourse about the potential benefit of ICTs for (caring) communities.

Conclusion

There is a growing discussion on enhancing care networks with the idea of "caring communities" – locating care in its narrower sense in a web of social interactions and mutual reciprocal relationships of communities. However, the question of where, how and when digital tools might be successfully employed poses specific challenges in these multi-stakeholder settings. One such challenge is the aim of participatory design with persons who are not familiar with new technology. This means that the introduction and implementation of new innovative technologies requires the inclusion and co-operation of all

stakeholders involved. During the research project it became clear that it makes sense to start with "low-threshold" designs and to cooperate with existing community initiatives. Projects which both apply participatory design approaches and which are firmly rooted in their social context have a much greater potential of bringing about sustainable change (Bratteteig & Wagner, 2010, Meurer et al. 2018).

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