

Infrastructures for Sense Making

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Abstract. This paper is about discussing infrastructures as enablers of users' sense making. Infrastructures facilitate process-oriented, interactive and socially sense making in case of complex problem settings like care giving. On an example of a platform that is used to support informal care givers, it expresses the importance of different channels in interaction mechanisms of infrastructures that are meant to support non-professional care givers in their daily activities, especially to deal with situations of uncertainty and mental overload.

Informal care

Care is a complex cooperative action involving several stakeholders. Informal care givers, who are in charge of caring of their partners or other family members, independent of their age, health condition or job situation, are often under high pressure for they have to: know how to take care of their care receivers; properly organise the care and the necessary treatments; be responsible for the care receivers' everyday activities; manage financial and legal issues concerning the care; and especially be 100% available and poised for care around the clock (Pinatti et al., 2016; Brouwer et al., 2004; Cranswick and Dosman, 2008). This situation requires their active involvement in seeking information. They are the first ones who are involved in deciding whether it is necessary to act based on certain symptoms or in case of unexpected change of care receivers' conditions. As *co-workers* of professional care givers, they are in charge of caring at times when professional care givers are not present – which is in most cases the most time of caring.

This big responsibility is difficult to carry and the most informal care givers are not trained for care. In case of an emergency or uncertainty in the health condition

of the care receiver, the first thing that an over challenged care giver does is to access the Internet and search for information about the symptoms. They hope they can find instructions or clear descriptions about the situation they are facing. But they are mostly frustrated because of several reasons: they don't find any relevant information to their question; or the information they find is not understandable for them, it is addressed to professionals; or the forum entries they find are either not complete or not representing their own situation and that is why the advice given or the data presented there are not applicable for their own situation, etc. In such cases, sense making becomes almost impossible for informal care givers. This is what we try to discuss in this paper and suggest *infrastructures* to help solve it. On the example of the *TOPIC CarePortfolio* we show what we mean with infrastructures in the context of care giving that facilitate multi channels for users' sense making.¹

Sense making for care giving

Sense making, as described by Lebiere et al., is a procedural activity involving a “[...] a meaningful and functional representation of some aspects of the world.” (2013, p.1). At the core of this process are interactions – be it between one person and another person or between a person and an information source, such as a book, an article or an instructional video. Given the importance of interactions for this process, Dervin argued that any attempt at creating technological infrastructure such as knowledge management systems with the goal of supporting sense making activities must be “[...] responsive and iterative and open.” (1998, p.44) This correlates with Klein et al.'s “Data/Frame Theory of sensemaking”, which is based on a continuous cycle of framing, elaborating and reframing data (2006, p.88ff). Within this system, there is an inherent, two-way relationship between data and the way it is framed by an individual: “Frames shape and define the relevant data, and data mandate that frames change in nontrivial ways.” (Klein et al, 2006, p.88).

In applying this argument to health infrastructure – in particular the ones aimed at informal, primary caregivers – these systems must not just allow, but encourage an iterative process of information-seeking and collaboration with colleagues, medical professionals and supplemental information sources alike. The act of questioning a particular frame of data is an integral part of the Data/Frame Theory's cycle; a corresponding action could be an informal care giver questioning their interpretation of a change of symptoms they observe in the person they care for.

¹ TOPIC was a European research project funded by the AAL Joint Program that aimed to advance the understanding of elderly informal carers' needs and design ICT solutions to support their daily lives (Breskovic et al., 2013; Hensely-Schinkinger et al., 2015). It addressed the lack of an integrated social support platform and the lack of accessible ICT applications for elderly people involved within informal care. The project congregated nine partners located in Austria, Germany and France. For more information visit the TOPIC project (AAL-2012-5-169) website available at <http://topic-aal.eu>.

While medical professionals might be able to assess the situation based on a large amount of (framed) data, an informal care giver has only limited data to base the interpretation on. Thus, the process of questioning the interpretation will be less informed and more of a struggle, and both care givers and their care receiver could profit from health care infrastructure that encourages collaborative sense making.

An Example: The *TOPIC CarePortfolio*

The *TOPIC CarePortfolio* implements different modes of interaction to facilitate users' sense making. It provides care information in listed text (instruction mode) (Fig. 1, bottom left), care video with text and audio complemented (multimedia mode) that is configurable by the users (Fig. 1, bottom right), easy access to interact with peers or professionals like email, push notifications, video/audio communication, digital notes board (interaction mode) (Fig. 1, top left), search for different conditions posted by peers or other professionals in form of forums (search mode) (Fig.1, top middle), as well as provide and share relevant care data with peers and others in form of groups (share mode) (Fig.1, top right). The informal care givers can choose between different modes to select the most appropriate channel for exchange or search for information. This depends on the care situation they are in and data frames provided for them. Sometimes they jump between different areas, e.g., read a latest post in a group, then search for information to find out a legal issue, and then again ask a question in their peer group, sometimes about something they have read but not understood in the information area. Sometimes they contact one, per a message or an ad-hoc video chat. Through the notification centre, they are easily informed about others' activities and responses.

In case of unexpected changes or uncertainties in the health condition of the care receiver in the course of progress of the health condition of the care receiver, the first thing informal care givers need is to interact with someone who is able to help them in these situations of need or to find the right information in the given context. How can this interaction be supported by technologies that are available for the care givers in their ambient environment?

The answer is to provide such infrastructures that, on the one hand, host relevant trustful information in an easy-to-understand multimodal format with adaptable interactive (data) frames defined by individuals and, on the other hand, facilitate simple and clear interaction mechanisms to encourage users to ask questions, contact others, search for help, share their own knowledge and experience with others, etc. to make sense of the data provided – sometimes in order to apply it in their real context. Designers need to think about interaction mechanisms that support access to information and social infrastructures as a major but also delicate-to-design factor in helping users sense making of complex information in sensitive areas like caring for others.

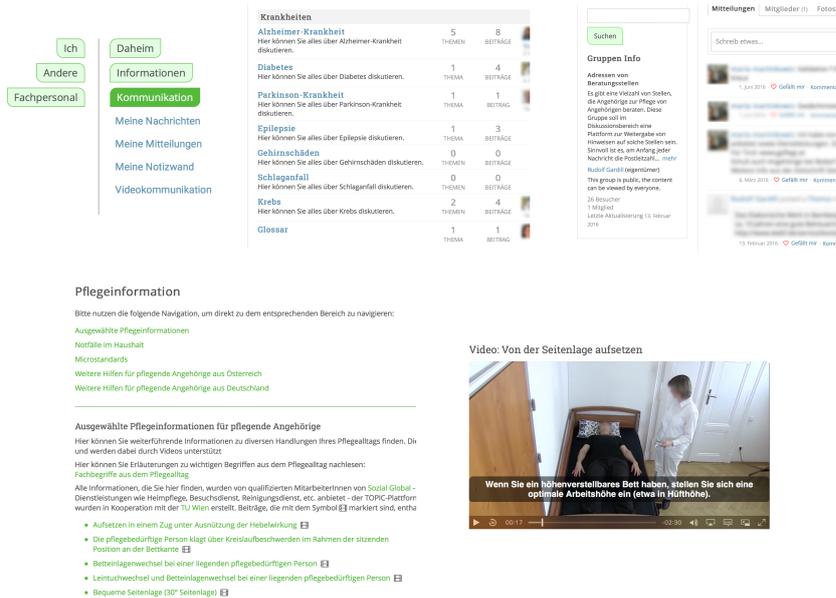


Figure 1. The TOPIC CarePortfolio: Example of an infrastructure providing different modes for interaction (from top left to bottom right): interaction, search, share, instruction, and multimedia.

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