

Taking care of sensitive milieus: a story about dialogical interviews

Francesco Ceschel, Angela Di Fiore, Fabio Casati

Department of Information Engineering and Computer Science, University of Trento

francesco.ceschel@unitn.it, angela.difiore@unitn.it, fabio.casati@unitn.it

Abstract. To be engaged in design processes in healthcare organizations often implies to deal with sensitive contexts, which, in turn, deal with a unique and delicate emotional setting. In this paper, we address reflections related to our research experience adopting dialogical interviews in sensitive design contexts. These reflections arise from a field work carried out within a network of nursing homes, within which we conducted 27 dialogical interviews with family members of patients in severe end-of-life conditions. With this contribution, we want to address the importance of taking care of the human relationships while working with sensitive participants, as a way to comprehend to which direction the design of a new technology should be driven.

Our fieldwork

The work presented in this paper represents only a part of a broader ongoing project financed by the Province of Trento, Italy (Di Fiore et al., 2017), which aimed to provide a picture of the relational issues that occur between the care professionals and the relatives of the residents of a network of six Nursing Homes (NHs) located in the province of Trento. The project was conceived to explore the potentials of ICT solutions in supporting communication between the professionals and family caregivers.

The initial idea was to comprehend how technologies could tear down the boundaries that often hinder the communication between family and professional caregivers. NHs, as healthcare contexts, were conceived as based on a mere

exchange of medical information (Storni, 2010) and, therefore, the quality of the communication was considered correlated to the ability to deliver reliable and rapid medical information to relatives. Hence, the project believed that a better communication would have been allowed by an improved way of transmitting medical information to the relatives; this would have helped to improve the quality of the human relations between professionals and families. In addition, it was expected that a clearer understanding of the medical situation of a resident would have decreased the level of emotional distress that the relatives often experience (McFall & Miller, 1992). Conversely, a system that allows users to automatically deliver real-time medical information, was expected to help care professionals to better concentrate on their tasks and decrease their level of stress, while informing relatives on what is necessary to know (Hazelhof et al., 2016).

Despite the initial ideas - now fallacious - which drove to the design of the project, we structured the research to have first a “gaze” within the context of the NHs, in order to comprehend how to approach and enter the field. We aimed to explore the context we were about to study by comprehending how it was experienced by the families of the relatives. Therefore, we first conducted 27 dialogical interviews with family members of the network of the six NHs.

The dialogical interview is conceived as a dialogue based on reciprocity, a process where the interlocutors are *immersed in the relational flow*, finding a balance between staying focused on the outline, and open to interviewees’ human needs (La Mendola, 2009). Our interviews aimed to explore the reality and the daily routine within the nursing homes, and also to comprehend the logistical and communication problems experienced by professional caregivers and family caregivers. The interviews also served to understand to which extents, if really needed, a technology could solve the relational issues within the NHs.

Our preliminary study led us to comprehend the nature of the issues that affect the relations between the care professionals and the relatives. Differently from what initially believed, the relatives lacked a “listening space”, and this, in our design framework, shed light on different ICT potentials.

In this paper, we refer to how we took care of the relational settings, conducting the interviews. In particular, we stress the importance of our experience in helping us to better frame and understand the issues that emerged from the interviews.

Experiencing dialogical interviews in sensitive contexts

Working within delicate contexts like nursing homes, we encountered several difficulties that challenged our capabilities as researchers, as well as human beings. On the one hand, we faced a strong emotional attachment to many

interlocutors and to their stories. On the other hand, we often questioned the possibility to gather concrete data that could inform our research and support our design process.

As mentioned above, we conducted 27 dialogical interviews as part of an exploratory study to evaluate the feasibility of the design process we aimed to accomplish. The interviews were built on a guideline that focused on investigating the communication and relational issues that the family caregivers experienced in relating with the staff members. In particular, the guideline considered how the family members approached and dealt with the transition from being the primary caregivers of their loved ones, to visit them in the nursing home, sharing the care activities with the staff members. Specifically, during the interviews we focused on the following topics: *i*) the history that led the family caregivers to draw on the NH; *ii*) what is their relation with the staff; *iii*) if they have any relation with family caregivers of other residents; *iv*) how they manage the medical information; *v*) their ICT literacy; *vi*) changes they would like to have within the NH.

We interviewed the relatives who agreed to participate to our invitation, and the interviews were conducted within the NHs where the relatives had their loved one hosted. Each interview was conducted in a private office by only one of the researchers who participated to the study. The interviews were recorded and transcribed. Each interview lasted approximately one hour.

From the interviews, we understood that the detachment from the loved-ones creates a deep distress (McFall & Miller, 1992) in the family caregivers, hindering also the possibilities to establish positive relations with the staff members.

During our research experience, we somehow let the context drag us into the overwhelming nature of feelings and sentiments that the family caregivers experience. Although the interview guideline focused on communication issues, most of the interviewees displayed a need to talk about the experience of detachment from their loved-one, talking with us about their sense of guilt and burden. Despite our research purposes, we experimented the willingness of the interviewees to open up to us, due to their need of personal space where to be listened. The interviewees approached the interview almost as a way to open themselves on matters they could not discuss elsewhere. Because of this, we had role issues, struggling to be researchers and empathetic humans at the same time. Sometimes we even felt inappropriate to extrapolate *cold data* from their stories. As researchers, we had to approach the “talk” as a way to gain new information, but as human beings we were reconsidering our “role”. Hence, we needed to create a safe place within which we could safely interact; the relation between us and the interviewees was approached as a human-to-human dialogue, rather than a hierarchical perspective researcher-interviewee. The interviewees who participated welcomed us within their private lives and shared their experiences,

their feelings, and fears with us; we received the privilege to be considered worthy and trustworthy listeners. Conversely, we had the responsibility to comprehend, accept and keep these information as our own, and we could not avoid to be shocked by the often-difficult experiences interviewees shared with us.

We *took the side* (Becker, 1966) of the interviewees having a dialogue with them, without passively receiving their information. We understood that to better comprehend what they were trying to share, we had to put ourselves in their position with a reciprocal sharing process. We delivered something back that could correspond, and shared our own care experiences in a way that they could perceive our being human before researchers.

However, this does not signify that we interpreted the role of the peer over our intrinsic nature of researchers. On the contrary, we freed ourselves from the mask of the researcher to reveal ourselves as human beings as the interviewees did. In this way, we had the opportunity to feel more attached to the stories of our participants and to the related data, perceiving them as *warm data*. Hence, we had to grasp the perspective of the interviewees embracing their narrations without imposing timespan within the interviews and conceiving the topics of our guideline as flexible, in order to give more space to our participants' stories. In this way, we have been in touch with their experiences as we experienced them ourselves, rather than consider them from a perspective immune from any sort of emotional involvement.

Taking care of sensitive milieus

With this paper we attempted to restructure, as researchers, what we experienced and comprehend as human beings. Previous works on using qualitative methods in sensitive contexts already cover a wide range of topics, such as managing emotions (Rager, 2005), and detachment from the field (Morrison, 2012). Yet, we tried to convey the necessity to reconsider healthcare contexts as rich of information that cannot be treated as source of *cold data*. Contrarily to what the rationalising trends are telling us (Traweek, 1992), as researchers and human being we have to keep in our minds how doing research, especially in sensitive healthcare contexts, is all about *taking care* of others' stories. In this scenario, in accordance with Light & Akama (2014) we understood our engagement in sensitive milieus as a form of *carework*. We distinguished the concept of care from a paternalistic sense of caring, conceiving it as a way to entangling our experiences with others, or using Puig de la Bellacasa's (2012) words, as a way to do sustainable actions by engaging "with the inescapable troubles of interdependent existences" (p. 199).

Researchers involved into healthcare milieus, are likely to deal with sensitive research settings. Since sensitive milieus are emotionally powerful, they can bring

aftermaths that shake both the participants and the researchers themselves (Jones, 2013). Sensitive contexts can be hard to approach, especially in absence of previous experiences in such contexts. Indeed, Dickson-Swift (2007) highlight the need of care professionals to deal themselves with these sensitive contexts. The authors explain that, often, care professionals develop their own strategy to cope with the emotional distress that sensitive contexts may bring; care professionals protecting themselves by becoming insensitive to certain situations, perceiving them as *bizarrely ordinary*. On the opposite, as outsider in these contexts, we have been emotionally *thrown* into them, absorbing - sometimes too much - the distress and discomfort of the family caregivers.

In this work, we addressed our research experience in conducting dialogical interviews with relatives of critical end-of-life patients. We focused on taking care of human relationships by appreciating reciprocity when adopting qualitative interviews. This preliminary study highlights how important can be to open dialogical spaces, reflecting on the role that researchers should play within healthcare contexts. We discovered that approaching the interview guideline with flexibility helped us to focus on the stories of our interlocutors, giving space to the difficulties and the memories that for them were important to share. Thus, we had the opportunity to be more connected with their sense-making and understanding of the care settings in which they were involved. On the one hand, the interviewees approached the interviews as an opportunity to be listened and momentarily relieved of their burdens. On the other hand, by accepting our participants stories we had the opportunity to go deeper into their care experience, and reshape the initial design concept at the base of our project.

This approach allowed us to take care of this sensitive context by fulfilling the need of being listened of the interviewees, and by using their narrations to adjust the rationale of our project. In particular, throughout the interviews, we had the possibility to comprehend the hidden need of the family caregivers to establish better relations and more sensitive communications with the professional caregivers of the nursing homes.

Conclusion

Our reflections want to be memorabilia for both the novices that are facing such contexts, for those who are working there for some time and that need to remember the privilege of entering such unique others' lives, and also for us, the authors, grasping thoughts on our present experience and leaving a memento for our future ones. Indeed, "we are engaged in important, difficult research, but we must keep the purpose of our work in mind. What we do is significant and makes a difference for those who follow" (Morse, 2007, p. 1005).

Our experience in using dialogical interviews, shed a light on what was needed within the NHs context. The interviews made us comprehend that family

caregivers lack a “listening space” rather than a better strategy to be kept aware on the health situation of their loved ones. What we learned is that to take care of sensitive milieus it is fundamental to create open dialogical spaces, providing a place where the participants can feel listened and accepted, and where we, as design researcher, can take care of their stories by shaping the design processing that will affect them. In our case study, this opened up to greater potentials for a new design. Indeed, we understood that a new technology should support the family caregivers in having better communication with the staff members through a dialogical experience, as the one we had experienced with them.

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