
“We are human.” Coping strategies in sensitive settings.

Angela Di Fiore *

University of Trento
Via Sommarive, 9.
Trento 38123, Italy
angela.difiore@unitn.it

Vincenzo D’Andrea

University of Trento
Via Sommarive, 9
Trento, 38123, Italy
vincenzo.dandrea@unitn.it

* This paper refers to the field experience of the first author and for this reason is written using the first singular person.

Paste the appropriate copyright/license statement here. ACM now supports three different publication options:

- **ACM copyright:** ACM holds the copyright on the work. This is the historical approach.
- **License:** The author(s) retain copyright, but ACM receives an exclusive publication license.
- **Open Access:** The author(s) wish to pay for the work to be open access. The additional fee must be paid to ACM.

This text field is large enough to hold the appropriate release statement assuming it is single-spaced in Verdana 7 point font. Please do not change the size of this text box.
Each submission will be assigned a unique DOI string to be included here.

Abstract

Sensitive settings refer to research contexts that face human situations that can strongly influence both the researchers and the respondents due to the delicate subject of the study. Usually, the literature and the ethical committees illustrate the possible risks of these settings, focusing on the participants at the expense of the researcher protection. This paper is based on the preliminary study conducted within a Ph.D. research that aims to develop an information system in order to support the care activities of a paediatric palliative team. The peculiar nature of the context arises several issues related to the emotional wellbeing of the researcher. This paper, combining the existing literature and ethnographic data, discusses the role of coping strategies in a sensitive research setting, illustrating the ones that have been developed by the researcher on the field.

Author Keywords

Coping strategies; Ethical dilemmas; sensitive context; Researcher wellbeing

ACM Classification Keywords

H.5.m. Information interfaces and presentation (e.g., HCI); Miscellaneous.

Introduction

Dealing with emotions in a sensitive research setting is one of the hardest challenges that I ever faced in doing research. Talking about researcher wellbeing can be

difficult, especially in an academic context where the avoidance of personal language is common practice [1,2]. Said practice carries the risk of leaving behind the dignity and the academic relevance of the research experience. Doing research, and in particular doing qualitative research, always implies a strong personal commitment, projecting, especially in researches in sensitive contexts, a long shadow on the researcher's life. For this reason, it is important to talk about the researcher commitment and the emotional implication of doing research in this kind of contexts. In agreement with Morse[3, p. 1005]: "*we must recognise the influence of the research topic on one's self and one's own emotional wellbeing, and provide support and debriefing for the entire research team*".

In this paper, I address the vulnerabilities, the dilemmas and the coping strategies that are emerging from my field work on a paediatric palliative context.

Field work

The paper refers to a research that I am conducting for my Ph.D. My study aims to develop a collaborative information system to support the palliative care services of a paediatric oncology unit. Specifically, my Ph.D. research is based on *A casa è più meglio*, literally *it is better at home*, which is a care project held in a health district of a province in northern Italy. *A casa è più meglio* is a home care project that aims to ensure home care services to children who need palliative care. The project is coordinated by a Paediatric Palliative Care (PPC) team of the central hospital of the province, which provides home visits and secondary care services, such as specialised treatments. This team is composed by a palliative paediatrician, two nurses, a psychologist and a secretary and provides medical and social support to the family of patients at home and *across specialties*.

The PPC team assisted 97 patients from 2011 until now, an average of 20 new cases per year. In the last

four years the total amount of patients increased and the number of home care visits per year had an incremental growth. Thus, the need of an ICT System emerged, in order to foster communication, coordination and information exchange among the home care activities. My research project aims to identify the social requirements in order to develop a specific system to ensure the remote monitoring of vital signs parameters and a telemedicine system to foster communication and to support socially the families of the patients.

Palliative medicine for adults usually starts in the very terminal stage of a disease and deals with several domains, such as: "*communication and psychological support, pain and symptom management and end-of-life care*" [4, p.1536]. Instead, PPC starts with a diagnosis of incurability. For this reason, for example, in the case of rare chronic disease a PPC program can last many years. PPC, compared to palliative medicine for adults, has to deal with domains related to social support, including the stages of cognitive and social development of the child and the impact of the disease on the family [4].

The patients of *A casa è più meglio* are affected by incurable chronic diseases or cancer. The chronic patients are incurable children that are affected by diverse conditions, such as rare diseases, genetic disease, congenital malformations, metabolic syndromes, consequences of birth asphyxia or premature birth. They usually engage the PPC team in routine tasks, because they have a quite regular, slow and predictable path. While, most of the oncology patients are affected by leukaemia. These patients are characterised by waver and unpredictable acute phases and heterogeneous reactions to treatments, especially in the phase after the chemotherapy. The peculiarity of oncology patients is that some of them are curable. Due to their possible curability the members of PPC team are particularly emotionally attached to the

oncology patients.

Data collection

The nature of this field opened several methodological challenges by conveying several issues, including ethic, communication, predictability, organisational complexity and collaboration. In such context it became fundamental to adopt a research approach that focuses on the involvement and the commitment of the end users, being flexible and allowing in-depth and situated analysis in order to grasp better the social and organisational complexity of an healthcare context. That is why I adopted a Participatory Design (PD) approach and qualitative methodologies [5]. PD is a *democratic approach to design* that has the goal to commit users and involve them in decision making processes regarding their context [5]. At the base of PD there is a continuous process that enhances commitment, reflection, mutual support and a deep understanding on the needs of the people involved in a project [5]. Thus, taking this approach implies the creation of trustee relationships among and a strong sense closeness and responsibility for the stories of the participants. In the preliminary phase of this research I adopted ethnographic observation and interviews to frame the context of my field. In particular, I adopted the approach of *dialogical interviews*, which is based on empathy and a profound and free exchange with the interviewed person [6]. This paper refers on the research experience of the preliminary phase of my study, which is based on two weeks of participant observation and six interviews.

At the beginning of my research I decided to focus the preliminary phase of my study on the perspective of the PPC and not on families or patients for two main reasons: (a) the dynamics of the PPC professionals were the fulcrum of the complexities to be handled in my project; (b) I decided to take the long way because I worried to not be emotionally ready to conduct a full time ethnography directly with terminal children and

their families.

Developing coping strategies

A sensitive study is conceived as a research that faces a context that can create "*potential consequences or implication for researchers and respondent*" [7, p. 117]. Usually, the literature and the ethical committees use to pay particular attention to the possible wellbeing implication that the research could have on the participants, neglecting the safety of the researcher [8]. However, several studies show how the researcher that approaches sensitive contexts can run risks in relation to both physical and emotional risks [9; 10]. Most of the literature refers to researcher safety in relation to physical safety. However, the protection of the emotional self is paramount and the emotional safety can be risky as well as the physical one by deeply influencing the researchers' psychological wellbeing [3; 9]. Indeed, the researcher saturation is considered as a possible secondary effect of the emotionally challenging research subjects [11].

The researcher wellbeing in sensitive contexts addresses ethical dilemmas in particular in relation to two issues: (a) the responsibility that a research team and an advisor has in relation to be alert for the emotional safety of the colleagues that work in this kind of context; (b) the sense responsibility related to the participants of the study in case of burn out of the researcher.

My experience in a sensitive context led whom to become strongly emotionally attached to people that I talked to and their stories. In the light of this commitment I felt often the need to find a balance between the sense of responsibility in relation to the research and the participants; and my vulnerabilities related to doing research in a paediatric palliative unit.

Working on sensitive subjects, I am learning how important it is to consider the researcher wellbeing by

focusing on way to develop coping strategies. In taking this approach, it is possible to protect the researcher and the outcome of the research as well, reducing the psychological and emotional impacts. According to Morse [3, p. 1005]: *"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"*. The coping strategies have been, and actually are, an important resource in my field work. These strategies are guiding me and are supporting my field activities, putting in the centre both my wellbeing and the sense of responsibility regard the outcome of the research and its participants.

During the preliminary phase of my research I decided to have a soft start, focusing on the practices of the PPC team. I thought that most of the initial effort would have been dedicated to acquire basic medical and oncology knowledge in order to understand the conversations and identify recurrent problems. However, this phase was so emotionally hard. In my first 10 days of ethnography I followed the PPC team in their daily practices and doing so I participated to a meeting where the physicians discussed pain control therapies for a little girl, I attended chemotherapies and transfusions to children with leukaemia, and I was in the next door when a child died. In some moments my emotions have been so challenging, hindering my work and making me feel like a voyeur of the pain. The preliminary phase of my study has been a strong initiation for me. As a field long learning, these drastic episodes led me to start to develop coping strategies to face the emotional challenges of my research subject. Below I illustrate what I am learning.

Let your informants guide you.

The PPC team is composed by healthcare professionals that are specialised in end life care and that worked in since since minimum ten years in field, most of them did also a master in death studies.

For this reason, they were so used to work in this kind of situation that they didn't realise that I was not. In the first phase of my field experience I felt so emotionally unprepared. However, since I didn't want to be more of hindrance than a help, I pretended to be strong. In that period, they were so overloaded and the last thing that I wanted for the first days in the field was to steal their time, asking to be reassured and encouraged. So I decided to avoid to burden them with my worries and listen them, and learn from them, having trust in their feelings.

"Today, Jessica (the nurse) talked to me about Emily, the little girl with a terrible and painful skin degenerative disease. I remembered her because the very first activity that I did when I arrived here was a meeting about her case. The physician talked a lot about her pain and medication and I had a terrible stomach-ache during the meeting by thinking about her situation. Jessica told me that her disease in the last month worsened and for this reason Emily had operation to get a PEG (a medical aid that provide nutrition by placing a tube in the stomach and bypassing the mouth) because her disease has inflamed to much her oesophagus and eating for her has become too painful. When Jessica told me that about Emily I became sad, but Jessica was not. She noticed that I was little bit sad, and she explained me that the PEG surgeon was a good news, because in doing so Emily had the possibility to eat again, but without suffering. This has been a good hint for me, I have still to work a lot on that." (Ethnographic note)

The interviews have been another important resource to learn from the PPC team how to handle emotions. The interviews have been useful to have quality time with the member of the team, letting them time to talk to me about their story and their experience in the field. During the interviews they talked to me about their individual strategies to set boundaries and handle the emotions at work. For example, a nurse told me

that in order to not have a burn out she usually avoids to attend to the funerals of the patients. Another one told me that since when she started to work in this field, she started to avoid dramatic movies and dramatic books, reading and watching only comedies. *"I can't do that, I totally can't watch or read sad stories. Before working here, I watched all kind of movies, now only comedies"* (Interview). By being with them, it slowly emerged how every member of the PPC team developed in the course of time her/his own strategies. Their stories are helping me providing tips to develop my own strategy.

It is normal to be human

During the first period I often felt ashamed of my emotions and I pretended to always be strong when I was with the PPC team, because they were so confident and stable in the worst situations, like super heroes. Then, I discovered I was not alone in being ashamed of vulnerability. One day, when I was doing ethnography in the unit a child unexpectedly died. It was a blow for the team and for all the people involved in the paediatric unit, included me. In this circumstance I bonded with Masha, the cleaning lady of the unit. She told me how painful and difficult it is for her to deal with the death of a children. *"She entered in the office where I was, and told me: It is so difficult in these moments. Can I stay in this room for a moment? I don't want to see the dead body of the child passing along the corridor... (...) I don't even know how the doctors and the nurses are able to deal with that. They are so strong! I always feel so bad in these situations, but we are human. Aren't we?"* (Ethnographic note). Me and Masha looked in each other eyes. One look was all we needed to not feel alone in this situation, in being human, in being vulnerable.

Find some peer support outside the field

"Many researchers reported using informal support networks of colleagues, trusted friends, and family members for counselling and debriefing throughout the

research process. This informal peer support is important for researchers, particularly when considering that the emotional nature of research work is undervalued within the university culture" [9, p.19]. The informal support in my experience have been crucial. For a while it has been difficult to find people to talk with because of the nature of my field work. A couple of times happened to me that while I was searching some peer support with some friends talking about my experience my interlocutor started crying. I felt guilty. They were unprepared to this kind of emotions like me, or more than me. I realised that if you are searching peer support, it is necessary to be sensitive with others in order to check the lie of the land, without forcing a friend to be your emotional overload reference person.

Reflexivity

Reflexivity helped me in monitoring how my personal experience and my emotions informed the research and the data collection. The adoption of this approach also supported me in being conscious of the challenging emotions that I was experiencing and being aware of my endurance. I conceived reflexivity as a way to make explicit and reflect on how my-self, my personal story and my role as researcher were interconnected and were informed each other.

Conclusion

A researcher that works on sensitive subjects finds her/himself dealing with challenging emotions. These emotions can both influence the research and the researches' wellbeing. For this reason, it is important for every researcher to develop a shortlist of coping strategies that fit the situated context of the research. In taking this approach, the role and the tacit knowledge of the informants is crucial. It is useful as well to adopt a reflexive approach and to count on peer support both of colleagues and of people in the private life.

Acknowledgements

Many thanks to *A casa e' piu' meglio* team, for how you accepted me and for the accorded trust. I feel privileged for working with you.

References

1. Latour, B. (1992). Where are the missing masses? The sociology of a few mundane artifacts. *Shaping technology/building society: Studies in sociotechnical change*, 225-258.
2. Traweek, S. (1982). *Uptime, downtime, spacetime, and power: An ethnography of the particle physics community in Japan and the United States*.
3. Morse, J. M. (October 01, 2007). Ethics in Action: Ethical Principles for Doing Qualitative Health Research. *Qualitative Health Research*, 17, 8, 1003-1005.
4. Miller, E. G., Levy, C., Linebarger, J. S., Klick, J. C., & Carter, B. S. (January 01, 2015). Pediatric Palliative Care: Current Evidence and Evidence Gaps. *Journal of Pediatrics*, 166, 6, 1536.
5. Simonsen, J., & Robertson, T. (2013). *Routledge international handbook of participatory design*. New York: Routledge.
6. La Mendola, S. (2009). *Centrato e aperto: Dare vita a interviste dialogiche*. Grugliasco: UTET università.

7. Jones, K. (April 01, 2013). Adopting a Reflexive Approach to Researching Sensitive Subjects: Parental Experiences of Stillbirth and Neonatal Death. *Methodological Innovations*, 8, 1, 113-127.

8. Dickson-Swift, V., James, E., & Kippen, S. (2005). Do university ethics committees adequately protect public health researchers? *Australian and New Zealand Journal of Public Health*, 29(6), 576-582.

9. Dickson-Swift, V., James, E., Kippen, S., & Liamputtong, P. (January 01, 2007). Doing sensitive research: what challenges do qualitative researchers face?. *Qualitative Research*, 7, 3, 327-353.

10. Campbell, R. (2002) *Emotionally Involved: The Impact of Researching Rape*. New York:Routledge.

11. Wray, N., Markovich, M. (December 01, 2007). "Researcher Saturation": The Impact of Data Triangulation and Intensive-Research Practices on the Researcher and Qualitative Research Process. *Qualitative Health Research*, 17, 10, 1392-1402.