Taking care

of end-of-life settings

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To my favorite sentient beings ever

Ale,
Bruna
Emilia
Letizia
Tullio

And to
room 7.

_ _ _ _ Acknowledgements _ _ _ _ _ _ _ _ _ _ _

Many sentient beings, theories and places supported me in this thick research path that I am still slowly reprocessing by entangling lives, materialities and experiences. To take in first person the responsibility of a collective story like this one, is still odd to me.

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Le parole sono importanti!

Nanni Moretti

Our task is to make kin in lines of inventive connection as a practice of learning to live and die well with each other in a thick present.

Donna Haraway

Abstract

End of life care concerns medical services dedicated to incurable patients that are living the last year, or months, of their lives. End-of-life patients have complex social, spiritual and medical needs, and they are usually cared for in family environments, such as home or residential care settings. This model of care involves the effort of both family caregivers and care professionals, which collaborate in the delivery of care. However, the critical health conditions of the patients bring organizational and relational complexities to both family and professional caregivers, who must deal with an emotionally challenging environment.

Nowadays, there is an emerging need of technology to support the collaborative care practices that entangle families and professionals. However, conducting design processes in sensitive contexts like end-of-life environments presents several challenges due to the high social complexity of the field. In this scenario, this thesis explores the realm of end-of-life, in order to inform the design processes in sensitive contexts.

This work is based on two different end-of-life contexts: pediatric palliative care and nursing homes. These studies explored two different types of end-of-life services, showing similar care dynamics but also different relational assets. In the pediatric palliative care context, I studied the care dynamics between family and professional caregivers in two home care services located in the northern Italy, which provided end-of-life care to children affected by incurable and degenerative conditions. In the nursing homes contexts, I focused on relationships and information sharing practices between relatives of the patients and the staff members of a network of six nursing homes, which take care of older adults with severe cognitive and physical impairments.

This thesis follows three research streams that aim to explore the challenges and the opportunities in taking care of design processes in sensitive contexts. The first stream provides an understanding of the recurring organizational, relational and communication dynamics that occur in socio-technical end-of-life care contexts. The second stream focuses on the role and potential of ICTs in end-of-life contexts, analyzing, for example, cases in which technology is appropriated to address collective sense-making and support collaborative care actions. In the third stream,

I provide a meta-analysis of the process conducted and of the methods adopted, discussing recourses and strategies to take care of end-of-life settings by conducting design processes.

The findings presented in this thesis can inform the conduction of design processes in end-of-life settings by: presenting the recurring organizational, communication and relational issues; analyzing the multifaceted role of technology in such contexts, which can be perceive both an enabler of quality care and a dangerous *thing*; providing also methodological insights to both embrace the stories of our informants and to also take care of the emotional wellbeing of design researchers.

Keywords

CSCW

PD

Healthcare technologies

End-of-life

Taking care

Caregivers

Informal caregivers

Formal caregivers

List of abbreviations

ICT	>	Information and Communication Technology
CSCW	>	Computer Supported Cooperative Work
PD	>	Participatory Design
NH	>	Nursing Homes
PPC	>	Pediatric Palliative Care
EMR	>	Electronic Medical Record

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1. INTRODUCTION

unwrapping a research path

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This thesis is dedicated to the topic of the design of collaborative care technologies, focusing on the role of technology in supporting the daily life of family and professional caregivers who take care of patients in end-of-life conditions.

In this thesis, I present the evolution of my research within two research fields in end-of-life care, where I worked on the topic of designing collaborative technologies to support coordination, relationships and communication between medical professionals and the relatives of the patients.

The following work is a paper-based thesis report, based on a collection of the most relevant articles that I wrote during my PhD. Due to this format, the chapters at the base of this report are composed by standalone articles.

Being compliant with the characteristics of this thesis format, the articles in the chapters, except for minor modifications, are exactly as they were at the time in which they have been published. Only the template of the articles changed, in order for the thesis to have an esthetically consistent report.
The articles are organized by three streams that mirror the research questions (See section: 1.4). In doing so, the chapters are grouped by topic and not presented in a chronological way, being written in different stages of my PhD research, with different narratives and for different audiences. For this reason, the chapters are coherent within the stream in which they are grouped, but, being based on standalone articles, the findings each publication are as a consequence scattered, and the outcomes are not strictly cumulative. In the final chapter (11) I try to collect all the findings in a coherent way.

This work, as with every paper-based thesis, relies on articles that are thought to stand alone and, for this reason, it can present repetitions of contents within the methodology or the state of the art sections of the chapters.

In order to guide the reader through the articles at the base of this report, I wrote introductions to each stream of the thesis (namely: Part 1, Part 2 and Part 3), summarizing the topic of the stream and the contents addressed. Moreover, each

chapter is presented by providing introduction and conclusion, framing the contribution of the articles within my research path.

Some articles have been relevant for their results, while others have been more important by virtue of their cathartic role within my path as a researcher. They have given me the opportunity to *test the water* of new collaborations with my colleagues of the social informatics group and to experience interdisciplinary research. Five chapters are based on articles that have already been published, while the remaining four refer to papers that are currently under revision.

This thesis is the outcome of a continuum that has lasted three years, and its narrative has been influenced by several contributions that slowly emerged, piece by piece, along my research path.

Now, this chapter will introduce this report, framing the topic of my research and the field works that conducted in end-of-life care.

The introduction is organized as follows.

In the first section (1.1), I present my journey as a *padawan*[1] within the research world. Since doing research is an activity of *storytelling* (Haraway, 2016), I decided to start this work by presenting myself and my path within interdisciplinary research, describing the sentient beings, the synchronicity and the materialities that led me to this PhD. Then, in section two (1.2), I present the topic of this thesis, introducing the extraordinary complexity of care contexts, the peculiarity of end-of-life care and the main challenges related to designing collaborative healthcare technologies. The

[1] In the Star Wars saga, a *padawan* is a Jedi student. This term is also used to describe someone that is engaged in a learning pathway.

third section (1.3) illustrates the end-of-life contexts where I conducted my two field works, which were in pediatric palliative care (PPC) and nursing homes (NHs), dealing with caregivers of children and older adults in end-of-life conditions. Section four (1.4) frames this research, describing the approaches that I adopted and presenting the three research questions that guided my work. In section five (1.5), I outline how the contributions and results are framed, mirroring the level of abstractions of the research questions. Section six (1.6) provides an overview of the structure of the thesis and the contents of each chapter. Finally, section seven (1.7) reports the list of the articles published and submitted during my PhD.

1.1 The background of this research

The path that led me here started in 2010, when I enrolled for a bachelor's degree in Sociology. There, I tested my passion for Sociology, starting then to show my interest in studying the impact and the potential of technologies in complex organizations. For this reason, once I completed the bachelor's course, I enrolled in a master degree in Sociology, focusing on Organization Studies (OS) and Science and Technology Studies (STS). During the MA I devoted myself to theories and methods, improving my qualitative and quantitative research skills in the field, thanks also to my first collaboration in an academic research project. I started collaborating with prof. Vincenzo D'Andrea (University of Trento – Department of Information Engineering and Computer Science) and prof. De Angeli (currently University of Lincoln – School of Computer Science, previously University of Trento) on SmartCampus, a research project where I collected qualitative data and conducted co-design workshops to support the design of a smart community platform. The SmartCampus project intersected HCI and Participatory Design, and it gave me the first opportunity to work as a sociologist in a multidisciplinary research group, using

qualitative methods to serve the design of solutions that mirror the needs of a community. This experience was a *eureka* moment for me.

In the same period, I met prof. David Hakken (Indiana University Bloomington – School of Informatics, Computing, and Engineering, he was visiting professor at the University of Trento), who afterwards became my supervisor during the master's thesis. During the thesis research, I had the unique opportunity to independently conduct an action research project in an IT company, where I headed an internal project, using both qualitative methods and surveys. Supervising me in doing this work, David Hakken showed me the methodological "tricks of the trade" (Becker, 2008), introducing me to the principles of conducting ethical and sustainable research. He taught me the true and deep importance of trust, empathy, and respect in doing sociological studies. He was and will always be an ethical mentor in my research path because he let me understand the true beauty of working with, and for, the participants of your study.

Before starting a Ph.D., I decided to work for a while as a researcher for a private research center on a European project on the potential role of Open Data in future governments' accountability. This project gave me the opportunity to work on a well-funded European project, experiencing the macro-political dynamics of doing research at the European Union (EU) level and having the unique possibility to influence the EU policies with our research.

The study paths and research works that I did before starting my PhD allowed me to intersect my background as a sociologist with approaches, topics, and people which laid the foundation of what I am becoming as a researcher and as a human being: a woman extremely curious about the potential of technology in complex environments, who wants to devote her insterest for sociology to support the design of human technologies.

Then, in November 2014, I started my PhD in Information and Communication Technology at the Department of Information Engineering and Computer Science of the University of Trento. I was interested in experiencing the potential of research insights to "provide useful real-world systems" (Schmidt, 1992, p.28), and for that reason I decided to apply for an industrial grant to collaborate with an industry in software design. This research started with the general aim of working technology design in relation to taking care chronic diseases in non-hospitalized contexts. This topic then evolved by being shaped by the course of the events and the research opportunity that I had, into the topic of degenerative diseases and specifically end-of-life care.

Thanks to the evolution of the events, I dedicated my PhD, and the last three years of my life on exploring the multifaceted role of technology in supporting coordination, collaboration and social support between professional and family caregivers in end-of-life settings. Specifically, I worked on the topic of designing collaborative technologies to support coordination, relationships and communication between medical professionals and the relatives of the patients.

During my PhD I worked in two end-of-life contexts: two pediatric palliative care units that took care of dying children and their families, and six nursing homes, where non-autonomous older adults lived.

To work in complex and end-of-life environments changed my life, making me grow both professionally, by developing methodological skills to approach such sensitive contexts, and as a human being. There, I had the opportunity to feel how much work can be done to support the quality of care in these contexts and how design processes and properly design designed technologies can make the difference.

Thinking about when, at the end of the first year of my PhD, Vincenzo, my advisor, told me about the possibility of working in a field in pediatric palliative care I remember that I felt instinctively the meaningfulness of doing a research in such a context. However, I took two weeks to accept this field work; I needed time to reflect on the emotional challenges that I would have face in such a sensitive field. When I decided to accept to work in this context, I did it for two main reasons.

On the one hand, I was interested in working on the potential of technologies in end-of-life care contexts because they are characterized by a high level of organizational complexity, due to the unpredictability of the care conditions and tacit knowledge of both professional and family caregivers. Moreover, they are challenging contexts, where many technological improvements can be achieved with the help of in-depth design processes.

On the other hand, I felt motivated in working on the topic collaborative healthcare technologies to help caregivers of end-of-life patients because, during the years before my PhD, I have also been the family caregiver for one of them. In that situation, I directly experienced how important it is for ill people to be cared for by their relatives and by the people to whom they are emotionally attached. Moreover, I experienced personally how important it is for a family caregiver to be supported by medical professionals both technically and emotionally. When I was a family caregiver, the close relationships that I established with an in-house nurse and after with a nurse of a nursing home have been precious. They provided a meaningful support in the care work both practically and humanly, allowing me and my relatives to be there by accompanying our dying loved-one. I will always be grateful to them for giving us this possibility.

1.2 The topic and its problems

Dying is a universal thing that is intrinsically related to life.

In the last decades, the population growth is consequently bringing an increase in the number of deaths, many of them related to severe chronic diseases or cancer (Hall, 2011). In this scenario, taking care of the dying is acknowledged as a public health issue and has been proposed to be advanced as a human right (Gwither et al., 2009; Wee, 2016). The evolution of incurable and degenerative diseases entails critical health conditions, intricate care paths and complex decision making, accompanying the dying (Albers et al. 2014). Taking care of patients at the end-of-life is linked to palliative care, which focuses on seeking for quality of life for dying patients in their environments through pain management, social, emotional and spiritual support (Rome et al., 2011).

End-of-life contexts, more than other contexts, are characterized by a focus on caring instead of curing and a need for continuity of care. Indeed, end-of-life is a special realm within healthcare. It focuses on taking care of patients who are in the last months or years of their life, while supporting the families that assist them (Rome et al., 2011). These environments are characterized not only by the canonical difficulties in managing articulated care processes, but also by the need to deal with the strong emotional involvement of patients, families and care professionals (Hudson et al., 2004).

In these contexts, both professional and family caregivers are considered *co-producers* of care (Buetow, 2004, Buetow, 2005). The amount of care work for family and professional caregivers, together with their strong emotional involvement, makes the collaboration work required by these contexts more difficult and contributes to turning these contexts into organizationally and relationally complex environments.

Many studies about care work concern the efforts of organizing care practices in spite of unexpected events that characterize the unpredictable contingencies of healthcare contexts (Carman et al., 2013; Strauss at al., 2014). Since, "good care strives for improvement while simultaneously respecting the erratic character of the disease" (Mol, 2008, p.31). In the light of the organizational complexity related to taking care of incurable patients, *trajectory of work* and *articulation of work* are two concepts that guided my study, helping me in the understanding of the healthcare context (Corbin & Strauss, 1984; Strauss et al. 2014). The former is more general and refers to the overall organization of work and its effects on the caregivers, while the latter is more specific, concerning the coordination efforts in managing unpredictable care paths, which is "invisible to rationalized models of work" (Star & Strauss, 1999, p. 10). These concepts focus on the importance of coordination and support among caregivers because, within healthcare contexts, heterogeneous care practices mutually intersect.

Care, and also death, has been studied by many disciplines within academia, including sociology, philosophy, anthropology, semiotics and HCI. With this thesis I explore the realm of designing healthcare technologies within the disciplines of Computer Supported Cooperative Work and Participatory Design.

As a *leitmotiv* of this work there is a use of the term care and of gerunds.

I address the concept of care as proposed in Participatory Design (PD) by Light & Akama (2014), recalling Haraway's (2007) and Puig de la Bellacasa's (2012) works. They claim that caring is an unavoidable aspect "as and in support of sustainable and flourishing relations" (Light & Akama, 2014, p. 8), highlighting the importance of making kinships in the *troubles* (Haraway, 2016).

The concept of care guided how I conceived my design research work in sensitive end-of-life setting as a way of *doing* (de la Bellacasa, 2012), thus conducting sustainable actions by engaging "with the inescapable troubles of interdependent existences" (de la Bellacasa, 2012, p. 199). In this way, I conceived doing research as a form of care work since "things and living beings matter" and are embedded in mutual connections and relationships (Light & Akama, 2014, p.153).

In this work I also wrote often with gerunds, using them both in the titles and in the text of the thesis (i.e. designing a technology, taking care of, understanding how etc..) to highlight how research work is *in* constant *becoming* (Akama, 2025). In doing so, I aimed to highlight the situated and changing nature of human dynamics as it is described by Haraway (2003): "reality is an active verb, and the nouns all seem to be gerunds with more appendages than an octopus" (p.6).

I framed this research in care contexts by gleaning the Computer Supported Cooperative Work (CSCW) and the PD literature. There, it emerged that in computer science disciplines the deep collaborative nature of care work is widely acknowledged (Chen, 2011), addressing that IT systems should support the coordination, information sharing, participation and mutual involvement of family and professional caregivers into care pathways (i.e. Bacigalupe, 2011; Chen, 2013; Marchibroda, 2008; Miller et al., 2016;). There is a claim for design processes able to embrace how complex the intertwined relationships between family and professional caregivers can be (Jacobs et al., 2014). Another relevant point that arose from the literature is also the need to overcome the limits of existing research that tend to focus on one side, providing a partial view of social issues within care contexts (Chen, 2013; Nunes and Fitzpatrick, 2015).

In the light of the gaps highlighted by the literature, in this work I address the topic of technologies for healthcare contexts by exploring their role in supporting continuity

of care, taking into consideration the social, organization, communication and information issues of both family and professional caregivers. Moreover, at the ground of this work there is a willingness to explore how to take care of these contexts through design processes, being inspired by the theoretical work of Akama, Haraway, Light and de la Bellacasa.

1.3 Contexts of research

My research started with the assessment of the issues that affect the collaborative care work and information sharing between care professionals and family caregivers, and then it evolved providing design guidelines and prototypes of a collaborative technology platform.

The studies were based on two independent projects, which were conducted within the Social Informatics research program of the University of Trento, Italy. In these contexts, thanks to my sociological background, I conducted user studies based on qualitative and quantitative methods, and I worked on the design and validation of prototypes. Moreover, both studies have been approved by the Ethical Committee of the University of Trento and by the hospitals that hosted the studies (See: Appendix B).

I conducted my field-work in two end-of-life environments: a network of Pediatric Palliative Care units that take care of children with incurable diseases; and a network of six Nursing Homes that take care of older adults in severe conditions.

There, I worked in end-of-life environments that were peculiar within end-of-life care itself because of the central role of the relatives of the patients within the care path. Indeed, both in pediatric palliative care and in nursing homes, the role of the family caregivers is at its most extreme due to the cognitive vulnerability of the patients

treated. In both studies, we have minors and older adults in end-of-life conditions who are affected by severe impairments.

These scenarios are characterized by severe psycho-social conditions of the patients; the role of the family caregivers becomes central, creating a mediated relationship between patients and professional caregivers. In this way, my work provides a study in an extraordinary care setting. It informs caregiving collaboration both in contexts where patients have severe cognitive limitations and also in "regular" care contexts based on caregivers' collaborations by analyzing these social dynamics in thick and trenchant environments. In both studies I focused on the role of technology in supporting collaborative work practices of care professionals and family caregivers.

1.3.1 Pediatric Palliative Care

My first research stream was related to a study in Pediatric Palliative Care that was conducted independently by myself, studying a network of care for in-home, hospitalized children affected by chronic degenerative or incurable diseases. Most of the children were infants (median age 3.7 years) with incurable diseases affected by diverse conditions, such as cancer (40%) and rare or congenital diseases (60%) that affected the cognitive and metabolic areas.

This study within the Pediatric Palliative Care network was conceived to define the requirements of a technology platform to support the coordination among caregivers in the care of incurable children. I worked in this context from summer 2015 to spring 2017.

In this study I worked independently, because family and professional caregivers explicitly asked to work with one researcher in order to have relationships with only

one trusted researcher. Being in the field, I then assessed that it would have not been feasible to have more than one researcher in such contexts due to the hectic care practices of the professionals and to the frailty of the families of the patients who needed a single reference point. I adopted qualitative methods: I undertook 50 days of ethnography observations in the hospitals and at the homes of the patients; and I conducted 18 interviews with doctors, nurses, social workers and parents of the children.

The outcomes of my study contributed to the design of a technology, leading to two published papers (see chapters: 5; 9), three papers that are now under revision (see chapters: 4; 6; 7) and one paper that is currently in the writing phase. The main issues that I faced during this project were the emotional challenges related to doing ethnography in such contexts; some of the children who I met during my research died, and I discovered how collecting painful stories can wound both the researcher and the human being behind the professional. However, I dealt with these issues developing my coping strategies, being guided by my informants (see chapter: 9).

1.3.2 Nursing Homes

My second research stream took place in a network of 6 nursing homes that take care of older adults, most of whom are over 85 years old, suffering from severe physical and cognitive impairments related to Alzheimer's, dementia or mental disorders.

The study carried out within the nursing homes was aimed at investigating the collaborative work practices of the caregivers to design a technology platform to enhance information sharing among care professionals and relatives of the residents. I worked in this context from autumn 2016 to summer 2017.

In this study, I worked in a multidisciplinary team composed of computer scientists, sociologists, software engineers and a graphic designer. I conducted a user study based on mixed methods, collecting and analyzing a huge amount of data collected from: 2 surveys, 27 interviews with family caregivers, 3 focus groups with professional caregivers, and 6 validation workshops with the future users.

The conduction of qualitative interviews was crucial for this research, and I wrote a paper on the topic of doing interviews in sensitive settings (see: chapter 10). Working in a team, I could experience an iterative design process, to verify the consistency of the often conflicting needs of the caregivers across the different Nursing Homes (see chapter: 2), and to validate the prototype of the technology platform (see chapter: 8). The outcomes of the parts of the research that I conducted were related to: the definition of the social requirements of the intended technology platform; the creation of personas and scenario; the prioritization of the features of the technology; the design of the prototypes and the validation of the prototype through workshops with the future users.

1.4 Research approach and objectives

In the broad world of HCI, this work is positioned in its more human-centered perspective (Bannon, 2011), focusing on the contributions of Participatory Design (PD) and Computer Supported Cooperative Work (CSCW). Both disciplines have been created by focusing on work contexts, reflecting on the dialectic between information systems and situated social relationships, and enhancing cooperative activities and collective sense-making (Schmidt and Bannon, 1992; UTOPIA, 1981).

CSCW supported my research with its consistent amount of studies on technology adoption, appropriation and healthcare technologies, providing reflections about the recurring issues in collaborative care work and studies on the limitations of existing

technological solutions (i.e. Ackerman, 2000; Ackerman, 2007; Christensen, 2011; Dourish, 2003; Fitzpatrick, 2013; Muller, 2015; Star & Strauss, 1999). CSCW was initially established to focus on remote collaborative environments with the aim to "allow people to effectively work together without being physically together" (Erickson, 1989, p.59) and to "transcend the boundaries of location and times" (Matsushita, 1999, p. 10). Afterwards, however, it evolved as a problem oriented discipline (Brown & Bell, 2004; Hosack et al., 2012), acknowledging the situated articulation of practices and local contingencies that characterize work environments (Schmidt and Bannon, 1992).

PD, on the other hand, originated with a defined political commitment, aiming to democratize work contexts, designing futures and technologies with and for the workers (UTOPIA, 1981; Teli, 2016). PD enriched my path, providing ethical, methodological and theoretical hints to my research (i.e. Akama, 2012; Akama, 2015; Bratteteig & Wagner, 2014; Bratteteig & Wagner, 2016; Ehn, 1993; Ehn, 2013; Kensing, 2004). It guided my work, highlighting the transformative role of design processes (Teli et al., 2016), and the issues and responsibilities related to the involvement of participants within an open-ended design path (Simonsen, 2012).

Backed by these rich roots, I framed my research, studying the challenges related to designing collaborative technologies and conducting design processes that can respond to the complex organizational and relational needs in end-of-life contexts. This study is an effort towards an understanding of the topic of caregivers' collaboration and continuity of care within the lens of CSCW and PD. This work has a focus on the conduction of (hopefully open-ended) design processes, providing situated methodological and design hints.

Despite the difficulties of arranging a consistent narrative upon a paper-based thesis, this work aims to inform the following research questions:

RQ1. Which challenges are caregivers experiencing in collaboratively taking care of end-of-life patients?

The first research question needs an overview of the social and organizational dynamics that characterize caregivers' collaboration and end-of-life care. Part one of this thesis is dedicated to answering RQ1, reporting a theoretical overview (see chapter: 2), and the social/organizational outcomes of two empirical studies related to nursing homes and pediatric palliative care (see chapters 3 & 4).

To have a part of this thesis (Part 1) mostly dedicated to the assessment of the situated dynamics of collaborative and end-of-life care helped me to better frame the contexts of my research, doing the groundwork for RQ2 and RQ3. Collaboration and relationships among caregivers in such sensitive contexts is characterized by a high level of social and organizational complexity due to the unpredictable care conditions of the patients, fragmented information sharing, and time and space constraints. In order to grasp the nuances of complexity, in this work I explored two apparently opposite end-of-life settings: home care services that take care of children with incurable and degenerative diseases, and residential care services (NHs) that take care of non-autonomous older adults in end-of-life conditions.

RQ2. What is, and can be, the potential of technology in supporting the collaboration challenges between caregivers in end-of-life care?

The second research question aimed to reflect on how the current adoption of technologies in such contexts is supporting the challenges of the caregivers (Part 2), providing chapters that compare the conducted studies by reporting cases of appropriation (see chapters 5 & 6), information sharing practices and conflicts (see chapter 7). The collaborative care practices showed appropriation of existing technologies (i.e. Whatsapp messenger) as collaborative telemedicine tools to better

communicate, collaborate and support each other. The assessment of the technology adoption and its dynamics helped me to look more deeply into the needs of the caregivers, drafting a first set of design guidelines that are at the foundation of answering RQ3.

RQ3. How can we (as CSCWers and PDers) nourish caregivers' collaboration in end-of-life contexts through design processes?

The third question is the final step of this research work, addressing reflections on the design processes conducted in end-of-life contexts (Part 3), evolving the challenges of the care context emerged to answer to RQ1, and framing the technology dynamics emerged answering to RQ2. To answer this question, I explored two streams, providing methodological hints related to conducting design processes in sensitive settings (see chapters 9, 10 and Conclusion), and discussing the outcomes resulted during the validation of design guidelines and technology prototypes (see chapter 8). Next reflections on how designers could nurture caregivers' collaboration in end-of-life contexts are also presented in the conclusion of this work (see Conclusion), wrapping up considerations on conducting design processes in sensitive settings.

1.5 Contributions and results

During an insightful conversation with Liam Bannon, we reflected together on how often in HCI the intention of taking care of the vulnerable is taken for granted, but how often this is not actually enacted in reality.

Taking care in a design process of contingencies that involves vulnerable people is a complex, demanding and unpredictable path.

In this scenario, the main contribution that I would like to leave with this work is to leave a trace of how *seriously taking care* of vulnerable contingencies is worthwhile for the people in such contexts, for the design process itself, and for us, as designers and as human beings. Design processes that take care of sensitive contexts should take seriously the *little things* (Austin et al., 2009) that matter the most and that can make the difference for the people who live in these places. CSCWers and PDers need to acknowledge the importance of being there, staying with the trouble (Haraway, 2016) with their informants, taking their side (Becker, 1966), taking time to listening to their voices (La Mendola, 2009), being ready to be the advocate of their participant, and being open to rethinking their initial ideas.

During my research I realized how deeply important it is to relate with grace to your informants, listening and supporting their needs while respecting their contingencies. Moreover, to conduct this research working within a computer science department gave me the chance to work on tangible issues, acknowledging the importance to "embrace situated technical problems and their people (…) since they can do many important things for staying in the trouble and for making generative oddkin[2]" (Haraway, 2016, p. 3).

This PhD research aims to contribute to academic knowledge in relation to the three streams which mirror the research questions described above.

1. It **frames** home and residential care contexts and provides knowledge related to collaborative dynamics between caregivers in end-of-life settings, analyzing how people relate to each other, conflicts, information sharing, and social and organization needs (RQ1 – see chapters 2, 3, 4).

[2] Donna Haraway uses the term oddkin to describe the effort of *seeking to become kin with all sort of creatures and things* (Jacobs, A., 2016).

2. Studying phenomena of appropriation and social **impacts of technology** adoption, revealing how the caregivers filled the gaps within the available care technologies by proactively seeking solutions to solve their communication, coordination and relational problems. It contributes to a deep comprehension of technological issues and challenges within the realm of collaborative technologies for end-of-life care (RQ2 – see chapters 5, 6, 7).
3. It informs **design processes** in end-of-life settings, providing methodological hints and design guidelines supported by validated technology prototypes (RQ3 – see chapters 8, 9, 10).

Since my PhD research is based on an industrial grant funded by the GPI group, which is the largest Italian IT company working in healthcare, part of my research outcomes were used by the company. The research contributions related to the pediatric palliative study were used to redesign some of the GPI group's software, aligning it with the complex needs of sensitive end-of-life contexts. Furthermore, the contributions related to the nursing homes' study refer to a regional research project and were used to design collaborative software for nursing homes that will be developed during 2018, and released in 2019.

1.6 Thesis structure

The chapters of this thesis are based on conference papers, book chapters and journal publications that I wrote during my PhD with the colleagues of the Interaction Lab and the Life participation research group.

These works have been published or are under revision for conferences and journals that encompass several disciplines, including: PD, CSCW, HCI, Health Informatics, Sociology, Medicine and Software Engineering. Working with an interdisciplinary approach on a topic that ranged from organizing medicine to computer science gave me the opportunity to experience several writing narratives.

1.6.1 Part 1

Part 1 of this work presents a theoretical overview about defining social requirements for home and residential care contexts (see chapter 2) and describes the main social and organizational issues emerged in the two field works conducted in PPC and NHs (see chapters 3 & 4).

Chapter 2 – Open issues in designing technologies for home and residential care

This theoretical chapter is based on two threads. On the one hand, it problematizes how three computer science disciplines differently face the problem of defining social requirements. On the other hand, it highlights some social, organizational and technological key issues to take into account when defining social requirements for technologies that should support continuity of care in home and residential care settings.

The main content of the chapter has been extracted from a Springer book chapter published titled *Mobile E-Health* (Marston, 2017), specifically from chapter 10 (Di Fiore, A., & Ceschel, F., 2017).

Chapter 3 – Design consideration to support nursing home communities

Nursing homes are care settings that take care of older adults in critical conditions. Usually the residents join these facilities after a long period that often lasts years, where their relatives autonomously took care of them at home. On the one hand, often family caregivers find it hard to leave their loved ones in the nursing homes, creating trust issues with the staff members there. On the other hand, staff members of nursing homes are often understaffed and overwhelmed by tight care routines, which do not leave time to relate properly with the relatives of the patients.

In the light of this scenario, this chapter presents the outcomes of our field work in NHs, presenting the recurring relational issues between family and professional caregivers and drafting some preliminary design considerations.

The main content of the chapter has been extracted by a paper that have been published at the C&T, Communities and Technologies conference 2017 (Di Fiore, A., et al., 2017)

Chapter 4 – Factors influencing the continuity of care in pediatric palliative care: a qualitative study

Pediatric palliative care is a medicine field that deals with a phenomenon that can be one of the less acceptable for human beings: dying children. These care contexts are usually based on home care services and provide several emotional, collaborative and information challenges to both the professional and family caregivers.

This chapter presents the outcomes of my study in PPC contexts, which consist of seven organizational and social factors which most affect the continuity of care and quality care in such contexts. The paper, which this chapter is based on, has been submitted to the Quality of Life Research journal and is currently under review (Di Fiore, A., et al.). The narrative of the paper mirrors the one of the journal that focuses on medical topics, being straightforward and data oriented, but on the other hand I tried to give credit as far as possible to the voices of my informants.

1.6.2 Part 2

Part 2 of this work presents empirical outcomes of the field studies in the form of comparative chapters that describes the current and potential role of technology in both PPC and NHs. In particular, it describes the dynamics of technology appropriation enacted by caregivers to cope with their recurring issues (see chapters

5 & 6), and presents the conflicts and challenges of communication and information sharing through technology (see chapter 7).

Chapter 5 – Understanding how software can support the needs of family caregivers of patients with severe conditions

This chapter is a brief preamble to chapter 6, which describes how the advancement of the investigations in PPC and NH environments, was characterized by appropriation of existing social media (such as Whatsapp messenger and Facebook). It is based on a short paper and I thought a lot about whether or not include it in my thesis work because it forecasts contents that are later presented in chapter 6, and it has also a sharp engineering narrative. In the end, I decided to dedicate a chapter of my thesis to this work because I am grateful for the effort that my co-authors and I put in this work. Indeed, this chapter has been important in the story of my PhD research, not for its specific contents but for the vibrant interdisciplinary environment that I and my colleagues had the possibility to create by starting to collaborate on this work. It gave to me and to my engineer colleagues the possibility of testing the waters of our collaboration and, for this reason, I have an emotional bond with this work; it allowed us to become *significant otherness* (Haraway, 2003). It has been a sort of boundary object within our path of interdisciplinary collaboration, where we recognized each other in our efforts, our mutual contributions and our backgrounds.

This chapter is based on a short paper published at ICSE 2017 (International Conference of Software Engineering) within the track of Software Engineering in Society (Di Fiore, A., et al., 2017).

Chapter 6 – What is appropriation telling us? A study on collaborative end-of-life care work.

This chapter provides empirical and theoretical reflections on the concept of technology appropriation, which have been a milestone in this thesis work, allowing me to look more in depth into the needs of our informants, both in PPC and NHs. Here, I address how family and professional caregivers adopted social media as collaborative telemedicine tools to better communicate, collaborate and support each other. Discovering and analyzing these dynamics helped me in defining design guidelines, since this phenomenon revealed how the caregivers filled the gaps with the available care technologies by proactively seeking solutions to solve their problems. Moreover, this work gave me the possibility to address theoretical reflections inspired by the theories addressed by Pelle Ehn and Paul Dourish.

These outcomes are currently under review at ECSCW 2018 – European conference on Computer Supported Cooperative Work (Ceschel, F., & Di Fiore, A., et al.).

Chapter 7 – Taking care of the Golem. Reflections from end-of-life contexts.

Caregivers show contrasting opinions of how information sharing should be carried out to enhance collaboration in complex care contexts. In both PPC and NH studies, we explored information sharing and communication routines by analyzing how the practices related to collecting and sharing information and data are perceived. We used, as a theoretical insight, the concept of Golem, proposed by Collins and Pinch (1998) to communicate the need to handle technology design with care and to address the reality in a situated way.

The contents of this chapter are under review at Science, Technology & Human Values – Sage (Di Fiore et al.).

1.6.3 Part 3

Part 3 focuses on the design process itself, providing both methodological and design insights in relation to end-of-life contexts. It describes the overall design process based on mixed-methods that we conducted in NHs, providing design guidelines for end-of-life contexts (see chapter 8). Then it goes deep into the *thickness* (Geertz, 1987) of conducting qualitative studies in sensitive contexts, providing observations on conduction of interviews and coping strategies for the research, in order to deal with emotionally challenging fields (see chapters: 9 & 10).

Chapter 8 – Designing a technology platform to support collaboration between family and professional caregivers in nursing homes

This chapter focuses on the design process that we conducted and that led to prototypes and guidelines for collaborative technologies for NHs. Here, we describe the exploratory study and the participatory design sessions that we conducted to support collaboration between professional and family caregivers. The findings of our study confirmed the organizational and the relational complexity of nursing homes, highlighting how cultural frictions and poor communication practices hinder collaboration and mutual understanding between family and professional caregivers. In the light of the findings, we present our prototype and provide design guidelines to support relationships among formal and informal caregivers. This chapter is based on a paper submitted to PeerJ Computer Science (Ceschel, F., & Di Fiore, A., et al.).

Chapter 9 – Taking care of sensitive milieus. A story about dialogical interviews

To be engaged in design processes in healthcare environments that take care of people in critical conditions often implies dealing with sensitive contexts, and, in turn, in unique and delicate emotional settings. In this chapter, we address

reflections related to our research experience adopting dialogical interviews in sensitive design contexts. This chapter arises from our field work carried out in NHs, reflecting on the 27 dialogical interviews that we conducted with family members of older adults in severe end-of-life conditions. This contribution, within this thesis, aims to address methodological reflections, highlighting the importance of taking care of the human relationships while working with emotionally frail informants, as a way to comprehend in which direction the design of a new technology should be driven.

This work has been published at InfraHealth 2017 (International workshop on Infrastructures for healthcare)- (Ceschel, F., & Di Fiore, A,, et al. 2017).

Chapter 10 – "We are human." Coping strategies in sensitive settings

Sensitive settings refer to research contexts that involve human situations which can strongly influence both the researchers and the informants due to the delicate subject of the study. The peculiar nature of the end-of-life can raise several issues related to the emotional wellbeing of the researcher.

This paper, combining ethnographic and interview data, discusses the role of coping strategies in a sensitive research setting, illustrating the ones that have been developed by me in the field of pediatric palliative care. This short and final chapter discusses the need to take the researcher's commitment in sensitive contexts seriously, and it has been the first paper that I wrote independently during my PhD.

The main content of the chapter has been extracted from a workshop paper presented at CHI 2016 within "Ethical encounters in HCI" (Di Fiore, A., D'Andrea, V., 2016).

1.6.5 Wrapping up

Chapter 11 – Conclusion. But… how to make sense from all this?

Chapter 11 is the last one of this thesis report, concluding it. It provides a summary of the chapters, reflections related to the findings presented within the research streams, limitations and future works.

1.7 List of publications

1.7.1 Published papers that form part of this thesis

Di Fiore, A., & Ceschel, F. (2017). Open Issues in Designing Home Care Technologies. In Mobile e-Health (pp. 215-233). Springer, Cham.

_ _ CHAPTER 2

Di Fiore, A., Ceschel, F., Nurgalieva, L., Marchese, M., & Casati, F. (2017, June). Design Considerations to Support Nursing Homes' Communities: Short. In Proceedings of the 8th International Conference on Communities and Technologies (pp. 64-67). ACM.

_ _ _ CHAPTER 3

Di Fiore, A., Ceschel, F., Fiore, F., Baez, M., Casati, F., & Armellin, G. (2017, May). Understanding how software can support the needs of family caregivers for patients with severe conditions. In Proceedings of the 39th International Conference on Software Engineering: Software Engineering in Society Track(pp. 33-36). IEEE Press.

_ _ _ _ _ CHAPTER 5

Ceschel, F., Di Fiore, A., & Casati, F. (2017). Taking care of sensitive milieus: a story about dialogical interviews. In Infrahealth 2017-Proceedings of the 6th International Workshop on Infrastructure in Healthcare 2017.

_ _ _ _ _ _ _ _ _ CHAPTER 9

Di Fiore, A., D'Andrea, V. (2016). "We are human." Coping strategies in sensitive settings. Workshop paper at CHI '16 Conference on Human Factors in Computing Systems https://ethicalencountershci.files.wordpress.com/2016/03/we-are-human-angela-di-fiore.pdf

_ _ _ _ _ _ _ _ _ _ CHAPTER 10

1.7.2 Submitted papers that are part of this thesis

Factors influencing the continuity of care in pediatric palliative care

_ _ _ _ CHAPTER 4

What is appropriation telling us? A study on collaborative end-of-life care work.

_ _ _ _ _ _ CHAPTER 6

Taking care of the Golem. Reflections from end-of-life contexts.

_ _ _ _ _ _ _ CHAPTER 7

Designing a technology platform to support collaboration between family and professional caregivers in nursing homes

_ _ _ _ _ _ _ _ CHAPTER 8

1.7.3 Additional papers arising from this PhD

Macchia, T., D'Andrea, V., Mazzini, R., Di Fiore, A., & Cozza, M. (2016, August). Exploring theater of the oppressed for participatory design. In Proceedings of the 14th Participatory Design Conference: Short Papers, Interactive Exhibitions, Workshops-Volume 2 (pp. 125-126). ACM.

Abstract. Design challenges refer to a difficulty of corresponding human and contextual complexity (i.e. needs, roles, and resources) in design practices. Such an issue calls for combining deep investigations with relevant design experiences. We propose a workshop for disentangling and discussing design practices by adopting the Theatre of the Oppressed techniques. These techniques allow enacting personal performances as well as the construction of a shared narrative about the participants' roles, needs, and resources. By this workshop, we aim to improve the participants' competence in understanding people's needs and developing a design solution accordingly. Finally, possible outcomes are: a special issue of an international peer reviewed journal, and/or a live performance that the conference attendees can enjoy as an experiential design occasion.

Teli, M., Di Fiore, A., & D'Andrea, V. (2016). Computing and the common: an empirical case of participatory design today. In Proceedings of the 14th Participatory Design Conference: Full paper -Volume 1 (pp. 1-10). ACM.

Abstract. With this paper we contribute to the ongoing discussion on the transformations of Participatory Design to address current societal transformations. We focus on how the implications of the emergence of financialized capitalism, characterized by "accumulation by dispossession", could be reduced by the nourishment of the "common". In taking this approach, we claim that nourishing the "common", which refers to the ensemble of the material and symbolic elements that tie together human beings, would allow a renewal of Participatory Design, reinvigorating its political agenda. We base our reasoning on a project called *ThinkDigiTank*, the goal of which is the construction of a digital platform supporting a network of Italian "think tanks", which refers to organizations aimed at producing political and cultural thinking. In this paper, we theoretically articulate the needs of a PD process nourishing the common and we discuss the empirical case, highlighting the possibilities of a renewal in PD and practical strategies to support *commoning practices*.

Teli, M., Di Fiore, A., & D'Andrea, V. (2017). Computing and the common: a case of Participatory Design with think tanks. CoDesign, 13(2), 83-95.

Abstract. This paper presents the ongoing discussion on the political agenda of Participatory Design in the light of the current societal transformations. We discuss how capitalism could be reduced by the nourishment of the common. In taking this approach, we claim that nourishing the common, which refers to the ensemble of the material and symbolic elements that tie together human beings, would allow a renewal of Participatory Design, reinvigorating its political agenda. We base our reasoning on a project called *ThinkDigiTank*, the goal of which is the construction of a digital platform supporting a network of Italian organizations aimed at producing political and cultural thinking.

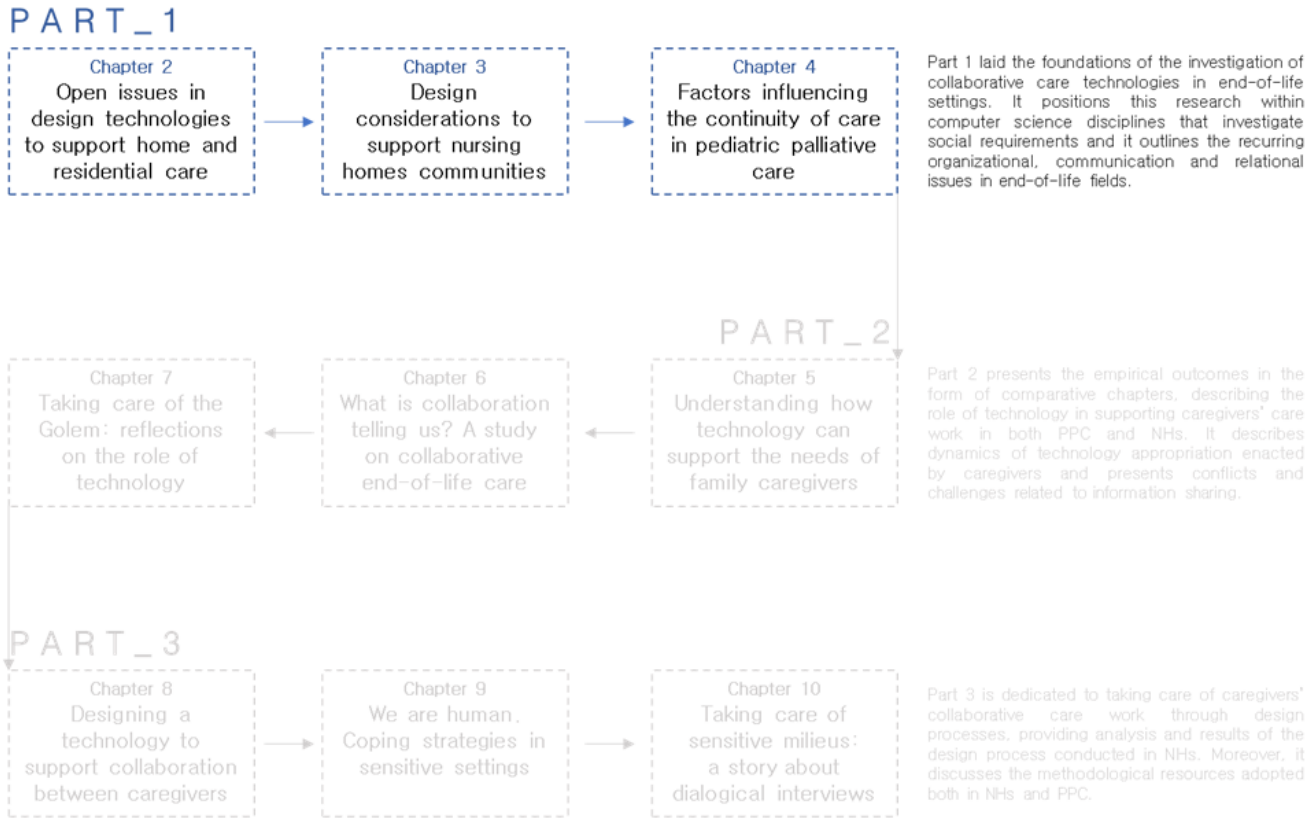
Work in progress

Computing and the common. Reimagining Participatory Design in the age of platform capitalism.

With Maurizio Teli and Linda Tonolli

Abstract. Participatory Design (PD) originated with a strong political commitment, characterized by an attention to the labor – capital conflict in the workplace, through which practitioners and researchers intertwined the design of computing systems, the social relation in the (work)place of use, and the ambition to affect policy making at the state level. In this paper, we refer to one attempt to bring a political agenda at the foreground of PD, the call for designers to look at ways to "nourish the common", that is to strengthen the symbolic and material resources that tie together human beings and the relative practices, a way to promote social collaboration in the light of recent transformations of capitalism. We draw upon such call, and its reference to four main strategies PDers can engage with: i) to identify an arena of action that is potentially socially transformative; ii) to clarify the relations among the different social groups and their capacity to express and enact their agency; iii) to promote an open ended design process; iv) and to discuss how the conditions of participants gets improved. We used these four strategies as lenses to conduct a literature review including the last four years of TOCHI, PDC, CHI, the International Journal of Human Computer Studies, Codesign, and the Scandinavian Journal of Information Systems, in order to elucidate how recent research in PD is discussing the four strategies and, therefore, constituting the basis for a re-imagination of PD that is able to reinvigorate its political ambitions.

PART_1


PART_1
Chapter 2
Open issues in design technologies to support home and residential care
Chapter 3
Design considerations to support nursing homes communities
Chapter 4
Factors influencing the continuity of care in pediatric palliative care
Part 1 laid the foundations of the investigation of collaborative care technologies in end-of-life settings. It positions this research within computer science disciplines that investigate social requirements and it outlines the recurring organizational, communication and relational issues in end-of-life fields.
PART_2
Chapter 5
Understanding how technology can support the needs of family caregivers
Chapter 6
What is collaboration telling us? A study on collaborative end-of-life care
Chapter 7
Taking care of the Golem: reflections on the role of technology
Part 2 presents the empirical outcomes in the form of comparative chapters, describing the role of technology in supporting caregivers' care work in both PPC and NHs. It describes dynamics of technology appropriation enacted by caregivers and presents conflicts and challenges related to information sharing.
PART_3
Chapter 8
Designing a technology to support collaboration between caregivers
Chapter 9
We are human. Coping strategies in sensitive settings
Chapter 10
Taking care of sensitive milieus: a story about dialogical interviews
Part 3 is dedicated to taking care of caregivers' collaborative care work through design processes, providing analysis and results of the design process conducted in NHs. Moreover, it discusses the methodological resources adopted both in NHs and PPC.

Part 1 _ T H E _ C O N T E X T S

Part 1 collects articles that introduce the reader to the topic of my PhD research, describing the contexts of the research and grounding the literature at the base of this work.

In this way, it addresses the first research question of this thesis work:

RQ1. Which challenges are caregivers experiencing in collaboratively taking care of end-of-life patients?

This part is structured in 3 chapters based on standalone articles, which grouped together present an initial theoretical understanding of the the topic and descriptions of the recurrent organization and relational issues that arose in the two research field in NHs and PPC.

This part provides an introductive theoretical overview on designing technologies to support caregivers (Chapter 2), plus two chapters that separately describe the main challenges of each context at the base of my research (Chapter 3 and Chapter 4).

The papers at the base of the following chapters have been written in different stages of my PhD research and for different audiences: Chapter 2 has been written for a general medical informatics audience; Chapter 3 has been written for a CSCW audience; Chapter 4 had been written for a medical journal.

The articles are not presented in a chronological way, because they are grouped by mirroring the research question of Part 1. Dealing with a thesis format based on a collection of standalone publications, the common thread between the chapters is of course the common thread in each article, but the findings of each publication are as a consequence scattered.

Chapter 2 is based on a book chapter published for Springer, that helped me to

frame my work in two ways.

On the one hand, I analyzed three computer science disciplines that deal with the understanding of human environments in order to design or develop (depending on the discipline) technologies. In this way, there, I motivate why I decided to rely on CSCW and PD as disciplines that guided the rationale of my research work. On the other hand, in this chapter, I provide a theoretical overview of the main issues emerging in the literature on the topic of home and residential care technologies.

Chapter 3 is based on a short paper published at C&T conference 2017, which focuses on the field work that I conducted in Nursing Homes. This paper allows the reader to place himself in the world of Nursing Homes, presenting an assessment of the relational dynamics of professional caregivers and the relatives of the residents.

Chapter 4 is based on a paper under revision at Quality of Life Journal Journal. It is dedicated to deepen the context of Pediatric Palliative Care, describing the communication, relational and organizational challenges that family and professional caregivers face in taking care of end-of-life children at their homes.

_2. OPEN_ISSUES_IN_DESIGNING

technologies to support home and residential care[3]

coauthored with Francesco Ceschel

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These contents are based on Chapter 10 of a Springer book titled *Mobile E-Health*, which has been published in January 2017. However, this chapter has been written during the first months of my PhD, specifically between December 2014 and March 2015, before starting any field work or data collection. It reflects the general exploratory focus that I had during the first year of my PhD, where I tried both to frame a new research topic, and to root myself in computer science environments, searching for disciplines to guide my investigation. For this reason, this is to be considered as a wide opening of this collection of articles, more focused theories will emerge in the course of the other chapters of the thesis.

In this scenario, this chapter provides an initial theoretical overview to frame the

[3] The main content of this chapter has been extracted from a Springer book chapter published titled *Mobile E-Health* (Marston, 2017), specifically from chapter 10 (Di Fiore, A., & Ceschel, F., 2017).

recurring issues that can be found while identifying social requirements for collaborative care technologies thought for the realm of residential and home care.

In the light of these premises, this chapter provides:

- an introduction to home and residential care – which are the contexts where end-of-life care is delivered in the case studies at the base of my research – and to their key concepts (paragraph 2.1);
- a theoretical overview of the disciplines that highlight the relevance of defining proper social requirements, presenting the contributions of CSCW, Participatory Design and Requirement Engineering (paragraph 2.2);
- a description of the open issues in managing the complexity of home and residential care, from telemedicine and sociology literature (paragraph 2.3);
- a discussion on the previous contents: defining key open issues to consider when eliciting social requirements in home and residential care, and discussing why I decided to rely on CSCW and PD (paragraph 2.4);
- conclusions recapping the contributions of this chapter (paragraph 2.5).

Note: This chapter has been written for a book thought for a general *medical informatics audience*. For this reason, the description related to computer science disciplines is kept at high level, and also the discussion related to lacks in healthcare technologies refers to the realm of *medical informatics*.

2.1 Introduction

Nowadays, there is a rising demand for home care and residential services to assist people with complex and incurable conditions (European Commission 2015; World Health Organization 2002; Gesano et al. 2009; Fernández-Ballesteros et al. 2013).

Residential care and home care are being increasingly adopted as they improve both the quality of life of the patient and the quality of care. In these contexts, the design of technologies often faces several complexities, such as relational, organizational and communicational challenges related to the necessary collaboration between family caregivers and professional caregivers.

In this introduction, we outline the topic of home and residential care, with a focus on designing technologies within these contexts. The rest of the chapter is specific to the challenges in defining people's needs in these domains.

Home care and residential care are umbrella concepts that refer to "the care provided by professionals to a person (…) with the ultimate goal being not only to contribute to patients' life quality (…) but also to replace hospital care with care in the home" or in dedicated facilities (Thomé et al. 2003, p. 871). Several studies recognized that home and residential care has the potential to increase patients' quality of life, to decrease costs of healthcare, and to leave patients in human places where they are emotionally attached to (Bodenheimer 2008; Koch 2006; Postema et al. 2012, Delloitte 2016). In these environments, "good care strives for improvement while simultaneously respecting the erratic character of diseases" (Mol, 2008, p.31).

Home and residential care are complex environments, characterized by a dynamic context where a network of diverse stakeholders have heterogeneous and conflicting needs (Christensen and Grönvall 2011; Wagner et al. 1996; Wagner 2000; WHO 2008). Indeed, home care engages several stakeholders in the care activities, involving both care professionals (such as nurses, family doctors, specialists) and family caregivers. Due to the intertwinement of actors, care activities, agendas and knowledge, the coordination of the care activities, the information exchange and the management of the care plans have a central role in home and residential care (Wagner, 1996; 2000). In this scenario, technology is perceived as a relevant asset,

having a great potential in supporting the complexity of providing collaborative care work between family and professional caregivers (Fatehi, 2012). In particular, technologies to support continuity of care have to deal with interrelations between places, healthcare providers, individuals' needs, sensibilities, data and information exchange (McGee-Lennon 2008). Due to the human and organizational complexity that characterizes home and residential care, there is a peculiar demand for solutions that can support care work, backing coordination and communication (Abowd et al. 2006). The potential of technology can become a call for action for designers and researchers (Beer and Takayama 2011; Delaney 2015).

Recent trends in design conceive reality and human practices as dynamic and constantly changing. They focus on the ontological problem of the attempt of formalizing reality through the definition of stable requirements of a technology (Dourish and Bellotti 1992; Ehn 2008; Akama 2015; Moran and Anderson 1990). If this problem is relevant in every design process, it is even more central in designing for a domain like healthcare. Indeed, care contexts are generally known for being characterized by unpredictable events and extreme micro-social variability (Strauss 1984; Corbin and Strauss 1984).

This work outlines the key open issues in the definition of people's needs in these domains. In particular, acknowledging these key open issues can orient designers' efforts, helping them to navigate the complexity of continuity of care in home and residential care contexts.

In the first section, we highlight the contribution of three computer science disciplines in the definition of the social requirements[4] of a technology. We present the ways of defining social requirements and people's needs in three disciplines: Computer

[4] Requirements in general are the criteria that define the technical and social features of a future technology (Van Lamsweerde 2009), but in this work we focus specifically on social requirements.

Supported Cooperative Work (CSCW), Participatory Design (PD) and Requirement Engineering (RE).

In the second section, we discuss the features that characterize home and residential care settings, from sociology and telemedicine literature. In this way, we highlight some of the open issues that can be useful to consider when doing design research in such contexts.

In the discussion, after we synthesize the arguments presented in the preceding section, we draw attention to a shortlist of key open issues we believe fundamental to consider when designing technologies to support continuity of care in home and residential care.

2.2 Disciplines in Defining Social Requirements

In this section, we discuss the disciplines in computer science that, in our best knowledge, can inform the definition of requirements in dynamic and situated contexts, such as home and residential care. We specifically address the concept of social requirement, which refers to requirements that focus on the reconciliation of the needs of the society and of the individuals, and not on technical – hardware and software – aspects (Whitworth 2009). This concept "is centered around knowing which (and how) social arrangements need to be satisfied" by a technology (Ackerman 2000, p. 195). We propose the concept of *social requirement* as an intellectual tool that can guide the design processes for collaborative care technologies, informing the investigation of the people's needs. It is an interesting resource in a design process, because it can act as a bridge between different disciplines in computer science that provide positive contribution in understanding, formalizing and reflecting on users' needs and technology constraints.

In this section we address three computer science disciplines that deal with social requirements and user's needs: Computer-Supported Cooperative Work (CSCW), Participatory Design (PD) and Requirement Engineering (RE).

Social requirement is a concept proposed by CSCW. In our opinion, it can be a nexus between disciplines that focus on the indexicality of human reality (such as Participatory Design) and the ones that are more on the formalizations that are needed to develop a technology (such as Requirement Engineering). In this section we analyze the positions of these disciplines in relation to social requirements, in order to assemble the potential of this fascinating intellectual tool.

2.2.1 CSCW

Computer-Supported Cooperative Work is a discipline that investigates the role of technology in fostering interaction and collaboration among individuals within their working environment (Dourish and Bellotti 1992). Computer-Supported Cooperative Work is a transformative and design-oriented discipline, which focuses on how to best design a technology to support collaboration among humans, and, hence, it attributes much attention to the social requirements a technology should embody. Indeed, it is engaged in a more epistemological conception of requirements, focusing on the so-called social requirements that refer more to the process of understanding of users' needs and their work practices in order to develop better technologies (Bannon et al. 1988; Schmidt and Bannon 1992). In the light of this peculiar attention, CSCW broadly focuses also on healthcare contexts (i.e. Fitzpatrick and Ellingsen 2013).

One of the most relevant epistemological problems in CSCW concerns the definition

of requirements and is known as the so-called sociotechnical gap. Sociotechnical gap is a concept that refers to "the great divide between what we know we must support socially and what we can support technically" (Ackerman 2000, p. 180). This gap represents the main challenge of the disciplines we are discussing here and highlights the complexity of the social dimension in relation to the intrinsic and ontological limits of technology. Computer-Supported Cooperative Work stresses the importance of the social requirements, because they allow to evaluate which are the boundaries within which technical solutions can fully address social needs. For this reason, this discipline attributes considerable importance to the experience of professionals who work within a working environment because they can identify the limits of a technology and, consequently, the sociotechnical gap (Bannon et al. 1988; Schmidt and Bannon 1992; Ackerman 2000).

CSCW considers both the social and technological side, concerning them as matters in co-evolution within working environments. Therefore, this discipline ascribes much attention to the work practices and how these practices are shaped by the setting of technologies in place (Ackerman 2000; Bannon et al. 1988).

Studies on CSCW (Bannon et al. 1988; Schmidt and Bannon 1992) highlight how technology, in some cases, fails to support and satisfy the social complexity that characterizes the interactions among workers. According to Bannon and Schmidt (1989, p. 360) CSCW "should be conceived as an endeavor to understand the nature and requirements of cooperative work with the objective of designing computer-based technologies for cooperative work arrangements".

As we mentioned above, the literature stresses the importance of understanding the people's needs, their work practices and how their work is articulated and interconnected among individuals. In particular, there are various contributions that address healthcare contexts and provide a clear picture about the complexity of the

work practices and the use of technologies within it (Fitzpatrick and Ellingsen 2013; for an extended review see chapter: 6). With regard to healthcare in particular, CSCW stresses to investigate on the influence of the technology on three levels, in order to better identify the sociotechnical gap: (1) technologies do not provide enough "complexity" to support a wider "social use"; (2) technologies are not socially flexible and are anchored to fixed roles, without considering the diversity of professional roles and work tasks; (3) technologies do not allow sufficient ambiguity and mostly aim to create quantifiable and measurable, tasks and processes (Ackerman 2000).

Overall, CSCW is the appropriate discipline to support the comprehension of social requirements. Therefore, it provides a lens to better comprehend complex sociotechnical environments, such as healthcare contexts.

2.2.2 Participatory Design

Participatory Design is a democratic approach to design that aims to involve and commit participants into decision making processes (Simonsen and Robertson, 2012), focusing on the design of future things to support the life and the wishes of the people involved in the design process itself (Ehn, 1993). Participatory Design is a design-oriented discipline that aims to empower people through different techniques that support participation and democratic involvement, paying attention to power dynamics (Bratteteig & Wagner, 2014). Participatory Design emphasizes that "human activities are carried out in cooperation with others and so new technologies need to be designed to support cooperation" (Simonsen and Robertson 2012, p. 8). For this reason, Participatory Design stresses the need to comprehend how to enhance commitment and foster cooperation and mutual support among future users. In other words, Participatory Design calls for a deep understanding of the people's needs. In this, the design process is paramount, because it is conceived

as way to structure the future relations among humans and between humans and technology (Light and Akama 2014). Moreover, in this process of participation, a technology is conceived as a 'future thing' that will, eventually, derive from a further negotiation among the future users, which will adopt and adapt the technology itself (Ehn 2008). That is why, through PD, design researchers aim to develop technologies in accordance with the perspective of their participants, in order to improve their working and daily practices (Simonsen and Robertson 2012).

Across the literature on PD, participants are deemed the main actors of the process, as they will assume the role of future users once the design is completed (i.e. Bratteteig & Wagner, 2014; Kanstrup & Bertelesen, 2016; Lindberg et al., 2014; Rothman et al., 2016). Conversely, the role of researchers and designers is focused to facilitating, validating, adjusting and monitoring the design path (Simonsen & Robertson 2012).

In our opinion, the strongest contribution of PD is the enhancement of human relations through participation, mutual understanding and democratic processes, and conceiving a design process as open-ended (Akama 2015; Ehn, 2008). Indeed, the process primarily focuses on understanding the individuals involved, the relationships they established within their collectivity, in which context these relations take place and the dynamism of their practices. This helps to display the design and the subsequent development of technologies, as dialectic enacted by the *co-evolution of services and human practices* (Suchman and Trigg 1995). This is the reason why the Participatory Design community focuses on human experiences and social meanings, rather than drawing the attention on mere technical requirements.

The Participatory Design literature offers a wide variety of studies on the epistemological problem of empowering people, both with the technology and with the Participatory Design process itself (i.e. Bossen, 2006; Briggs & Thomas, 2015;

Halskov and Hansen 2015; Modol, 2014; Light & Akama, 2012). Yet, the literature is also rich with empirical papers that illustrate the design processes, and ethical and methodological dilemmas related to the engagement of participants in order to co-design and let their needs emerge (Halskov & Hansen 2015; Kanstrup & Bertelesen, 2016). These studies present an extensive empirical knowledge on narrative techniques, qualitative methods and concepts, which support the understanding of situated contexts where new technology may be adopted.

The peculiar attention of PD for situated contexts makes it particularly appropriate for healthcare contexts. In Participatory Design there is no reference explicitly made to the concept of social requirements; however, its attention to the micro-social level provides several methodological and ethical reflections useful to define the social requirements.

2.2.3 Requirement Engineering

Requirement Engineering (RE) is a discipline originally established in the 1970s, with the aim to investigate which requirements should lead the development of a software (Zave and Jackson 1997). Differently from Software Engineering, which aims to design 'things right', the declared purpose of Requirement Engineering is to design the 'right thing' by focusing on the identification and documentation of requirements (Boehm 1981). RE provides models and taxonomies that use diagrams, mathematical analysis and unified modeling language (UML) notation to support the formalization of technical and social requirements (Van Lamsweerde 2009). This discipline investigates the reality from a macro perspective, focusing on the standardization and generalization of how a technology should be designed.

Requirement Engineering has a transformative rationale, and it encompasses four

main phases: (1) requirement elicitation, which refers to the gathering of requirements working with prospective users; (2) requirement specification, in which the requirements are classified and defined; and (3) requirement validation, which is the phase in which the requirements are organized and tested (Sommerville 2010).

As we stated above, this section focuses on analyzing the disciplines the aim to define social requirements in order to design better home and residential care technology. Hence, to better frame Requirement Engineering, in this subsection we draw particular attention on the contribution that RE delivers on the phase of requirement elicitation. This phase aims to define the social requirements by understanding the context of use of a hypothetic technology and the consequent needs and constraints of potential users, in order to acquire the knowledge that will shape the technology (Van Lamsweerde 2009). In other words, it focuses on acquiring knowledge about the current state of a system. An inadequate development of requirement elicitation may lead to several problems, such as delays in the project, resulting in failed expectations that may lead to a poor design of a software (Azadegan et al. 2013; Duarte et al. 2012; Geisser and Hildenbrand 2006; Van Lamsweerde 2009).

The elicitation phase is an iterative activity that encompasses various sources of data. This phase includes several research techniques, which are mainly qualitative, including interviews, focus groups, brainstorming and ethnography (Van Lamsweerde 2009; Geisser and Hildenbrand 2006; Nuseibeh and Easterbrook 2000). These techniques are aimed to collecting information from three different domains: (a) information about the organizational context – such as: stakeholder mapping, roles and conflicts – where the system will be implemented; (b) information about the general domain, in terms of organization structure and logistics aspects; and (c) information about the system as is – if any – that the stakeholders implemented to

support their practices (Van Lamsweerde 2009).

RE provides structured models to face the requirements elicitation, which can be divided into two categories: (1) models focused on the adoption of specific methodologies and techniques and (2) models focused on a high-level conception of elicitation. The former prescribe steps and techniques to adopt during the elicitation phase, whereas the latter are focused on assumptions on the domains to take into account during the elicitation (Hickey and Davis 2004).

The literature provides a few general examples. We propose as an example the CoRea model (Geisser and Hildenbrand 2006), which adopt meetings, brainstorming sessions and contextual inquiry (Van Lamsweerde 2009), combining interviews and ethnographic observation to focus on the work activities of the users.
Overall, the models proposed by RE are holistic, and they provide general guidelines for elicitation and techniques, without targeting specific domains. Specifically, they do not target healthcare contexts (McGee-Lennon 2008). These models tend to address activities without an in-depth understanding of the professionals who perform them. This results in the risk of a poor comprehension of the context and, consequently, a poor definition of the social requirements.

The contextual knowledge of the professionals is essential during the elicitation of the social requirements, especially in a healthcare context. In this sense, requirement elicitation, as conceived by RE, focuses on the specific role of business analysts, which masters the techniques and enacts the requirements (Hickey and Davis 2004). However, the literature on Requirement Engineering does not completely valorize the role of facilitators that investigate the needs of the future users, which is paramount in the understanding of complex contexts, such as healthcare (Hickey and Davis 2004).

To summarize, to our best knowledge Requirement Engineering lacks to address the specificity of complex situated contexts – which require a deeper understanding of the practices in place – and does not fully consider the involvement of the facilitators and the prospective of future users in the investigation.

2.3 Open Issues in home and residential care

After presenting the disciplines that provide hints for the definition of social requirements, this section focuses on the social, organizational and technological specificities of home and residential care contexts.

Home and residential care seek the best practices to carry out the care path of patients in emotionally safe places. In particular, home care aims to let patients live in their home as long as possible, a place to which they are emotionally attached to (Bossen et al. 2013). Studies (Thomé et al. 2003; Bossen et al. 2013; Abowd et al. 2006; Mynatt et al. 2001; Christensen and Grönvall 2011) suggest that patients would gain additional benefits from being 'treated' within familiar environments. The literature lists several benefits that familiar care environments may entail, fostering compliance to care plans, improving patients' awareness about the care treatments, reducing hospitalizations, reducing costs of care and improving patients' quality of life (Rojas and Gagnon 2008).

Yet, to better understand this perspective, we need to introduce a new concept. Home and residential care are strongly linked to the concept of *continuity of care*. Continuity of care is an approach that proposes a change of paradigm by shifting from an overall primary care system – focused on an acute care organization – to a long-term care system, which puts a regular and longitudinal path of care in the middle (Berwick 2009; Fatehi and Wootton 2012). This transition is perceived as a fundamental challenge that is changing the paradigm of healthcare services

organizations towards the engagement of a dense network of actors in home and residential (Berwick 2009; Bodenheimer 2008).

Continuity of care was developed by focusing on the management of chronic conditions (Wagner et al. 1996). It deals with high organizational complexity, involving a large number of care providers, and encompasses diverse care medical locations (Wagner 2000). These issues lead to a greater demand of home care services in the developed countries, to allow families to deal with the care path within a "protected environment" (Bodenheimer 2008; Koch 2006; Postema et al. 2012). Continuity of care aims to establish a solid network of all the caregivers involved in the care path of an individual/patient, by also ensuring the coordination among the caregivers (Gröne and Garcia-Barbero 2001). The literature (Haggerty et al. 2003; Schoen et al. 2005) suggests that continuity of care enhances coordination among medical locations, such as central hospitals, local hospitals, specialist centers, clinics, residential facilities and patients' homes. Moreover, it provides a continuum of care, reshaping the care system by focusing on the needs of the patients and their caregivers.

Within this framework, Haggerty et al. (2003) proposed the concept of using three dimensions:

- *information continuity*, which refers to the patients' sense of predictability, which is instilled by a coherent information sharing;
- *management continuity*, which refers to the patients' sense of safety that derives from responsive protocols and clear interactions between providers;
- *relational continuity*, which refers to the sense of predictability and coherence among relationships with the professionals.

Care technologies can be an important resource towards reducing the risk of care

fragmentation in home and residential care services (Kripalani et al. 2007; Montenegro et al. 2011, Schoen et al. 2005). Care fragmentation is a phenomenon that leads to a fragmented understanding of a care reality, and it may derive from underestimating the illness of a patient (Stange 2009). This may lead patients, family caregivers and care professionals to an inconsistent understanding of the healthcare situation, and, subsequently, it would bring inefficiency, ineffectiveness, inequality, commoditization of health, de-professionalization and depersonalization (Stange 2009).

Studies (Wagner 2000; Gröne and Garcia-Barbero 2001; Stange 2009) suggest that technologies can hinder the care fragmentation by supporting the care management on three levels: (a) at the micro level, it can enhance information sharing and collaboration between patients and caregivers; (b) at the meso-level, it can foster mutual awareness and collaboration among heterogeneous caregivers; (c) at the macro level, it backs the supervising of an overall care service.

As an example, to better frame the home care domain, we can identify a macro area within which technology intervenes: "ageing in place" (Mynatt, Rogers 2001; Demiris et al. 2004; Beer and Takayama 2011). This area should support the independence of older adults, in order to leave them the possibility to cope with their health issues in their home. This area of research investigates on how to create a safe environment for older adults, while allowing family and professional caregivers to keep a hidden control of the older adults (Van Hoff et al. 2011). In this sense, the design of a suitable technology could ease the independence, but, in the same way, it could grant the possibility for the users to easily interact with the professional and family caregivers when needed or to allow the caregivers to coordinate and intervene when necessary (Van Hoff et al. 2011). The next subsections outline the topics of home and residential care from telemedicine and sociological perspectives.

2.3.1 Telemedicine studies

Technology has an important role in supporting care work and the management of care programs across family and professional caregivers (Celler et al. 2003). However, there is an open issue on how the relation between technology and healthcare should be theoretically framed (Fatehi and Wootton 2012). Therefore, this domain is opaque due to a proliferation of different technical definitions, which may appear unclear. To tackle this issue, we focus on how to better frame this domain by clarifying the different definitions and their corresponding perspectives.

The literature (Berwick 2009; Eysenbach 2000; Fatehi and Wootton 2012; Koch 2006; Silverman 2005) provides several examples of the terms that are generally used to describe technology-healthcare: telemedicine, E-health, telehealth, telehomecare, home-telecare, home-telehealth and telecare.

'Telemedicine', the oldest definition, was first used in 1972. It refers to systems used to remotely monitor patients. Basically, telemedicine exploits services of tele-communication to transmit medical information (Fatehi and Wootton 2012; Koch 2006; Silverman 2005). The other terms previously mentioned generally refer to systems to exchange medical data. Specifically, "E-health" concerns the management of information within health services, with particular attention to the role of the Internet (Eysenbach 2000). 'Telehealth' is conceived as a way to promote health, in terms of medical education, to raise awareness among patients (Celler et al. 2003, Koch 2006). 'Tele-homecare' and 'home-telecare' are used as synonyms. These terms refer to monitoring systems used to remotely control patients' vital signs, using interactive communication and biological assessments (Celler et al. 2003; Koch, 2006). 'Home-telehealth' encompasses a general use of telecommunication systems – with remote assistance – to exchange information

about general health topics, including health education and care information (Koch 2006). 'Telecare' takes into account the importance of information sharing and its relative assessment, as well as the role of technology in managing a home care network built on human relations (Celler et al. 2003). Specifically, telecare is an interdisciplinary research field that focuses on collaborative technologies; it is related to "the ability to connect healthcare services across space and time, and provide treatments usually performed by physicians and nurses within hospitals or health care centers to citizens in their homes" (Bossen et al. 2013, p. 190). The literature seems to suggest that systems built on the principle of telecare may deliver several benefits to the users: a lower readmission rates, a more efficient collaboration among care providers and a higher collaboration of patients. From this perspective, telecare appears the term that is more comprehensive of the social complexity of home care. In this sense, it is recognized that there are needed technologies that are multi-user, multi-stakeholder, distributed, multimodal and dynamic, since this domain needs ad hoc technologies to manage the interrelation between places, healthcare providers, individuals, needs, sensibilities, data and information (McGee- Lennon 2008).

Nonetheless, from the literature we collected, we could identify two major features that characterize technological solutions for health contexts: (1) the medical data exchange and (2) the support of relations and care activities within the network of care (Milligan 2012).

Indeed, there seems to be a greater availability of papers concerning technical studies based on biological measurements and virtual specialized visits (Fatehi and Wootton 2012; Silverman 2005; Koch 2006) and cost reduction (Delloitte 2016; Rojas and Gagnon 2008), compared to the availability of research on the role the technology may have in supporting collaboration and the human relationships

between caregivers (such as Mynatt et al. 2001; Consolvo et al. 2004). Hence, the literature appears to focus more on data exchange and on the lack of universal data protocols to allow technologies to communicate by the same standard (Berwick 2009; Eysenbach 2000; Fatehi and Wootton 2012; Silverman 2005), whereas the literature on telecare systems to support collaboration in complex networks of healthcare seems to receive less attention (Fatehi and Wootton 2012; Silverman 2005; Koch 2006; Rojas and Gagnon 2008; Delloitte 2016). Hence, telemedicine calls for a greater multidisciplinary effort to accurately define social requirements (Celler et al. 2003; Fatehi and Wootton 2012; Silverman 2005), and we believe that this literature deserves greater attention in order to better comprehend how to define the social requirements (Bossen et al. 2013).

In particular, Koch (2006) identifies three common barriers related to home care services, which are the lack of standards and protocols, the lack of a shared frame-work of analysis and the lack of guidelines for the development of ad hoc solutions. In agreement with Koch (2006), a lack of guidelines and frameworks to support the definition of social requirements for continuity of care is affecting the quality of the existing telemedicine technologies. In relation to the design of home and residential care technologies, more work needs to be done, both with the requirement disciplines and with the knowledge about the healthcare's complexity.

2.3.2 Sociological studies

As we anticipated in the preceding section, a greater focus on technical factors, rather than on social needs and human factors, would not allow for a precise comprehension of the social requirements. Indeed, there are issues that may limit the effectiveness of the design of technologies for healthcare contexts, which deserve more attention. We identified three areas that summarize the recurring social

issues in home and residential care and that can hinder the design of effective technologies: (1) the coordination of family and professional caregivers involved in the care delivery, (2) the communication issues within stakeholders and (3) the complexity of the organizational setting of the healthcare sector.

Coordination and organizational complexities

The organizational complexity of the healthcare contexts is normally related to the variability of social dynamics, which are characterized by a strong individual know-how and tacit knowledge of the professionals (Polanyi, 2009).

Healthcare contexts do not generally have a fully formalized structure. In particular, there are soft and hard aspects that need to be considered (Kelman and Hong 2012). The latter refers to the tangible aspects of an organization, such as the structure, the functions of each organizational level and the control protocols (Bruni et al. 2007), whereas the former refers to the intangible dimensions of an organization, such as the culture, the common "language" and "symbols" and the shared values (Kelman and Hong 2012). These aspects are constantly renegotiated and readopted by the member of an organization (Weick 1969). Within organizational contexts, the individual skills and the organizational routines are conceived as the "building blocks of the organizational capability" (Dosi et al. 2008, p. 5). Accordingly, in healthcare contexts, individual skills and work practices are strongly related to soft aspects that are, by definition, difficult to handle (Kelman and Hong 2012; Bruni et al. 2007).

Moreover, the unpredictability of a medical condition does affect the physiological state of a patient, as well as care providers while assisting the patient itself.

Bodenheimer (2008, p. 1064) suggests that "given this level of complexity, the coordination of care among multiple independent providers becomes an enormous challenge". Several studies (Strauss 1984; Corbin and Strauss 1984; Bruni et al.

2007; Kripalani et al. 2007; Rojas and Gagnon 2008), carried with a peculiar attention to organizational issues, suggest that home and residential care contexts encompass a large variety of care providers, each one with different expertise and skills, which could lead to several communication problems. Generally, there are many and very diverse formal caregivers involved in the care of a single patient. For instance, 47% of patients in severe conditions are attended to by an average of four doctors and as many nurses (Schoen et al. 2005).

Within this framework, Weinberg et al. (2007, 2008) conceptualized care providers, distinguishing between formal and informal caregivers (or providers), but both perceived as co-producers of the care (Buetow, 2004, Buetow, 2005). Formal caregivers are defined as experts, precisely healthcare professionals, whereas the informal ones are the relatives of the patient, who become 'experts' through a learn by doing approach, while assisting their loved ones. Formal and informal providers can also be distinguished by the tasks they perform, respectively, assistance during medical crisis and medical routine. Both can occur, unpredictably, due to the contingencies of the medical condition (Strauss 1984). Indeed, Corbin and Strauss (1984) stated "even the most routine and everyday tasks can vary in the manner in which, the time at which, and the person by whom they are performed, according to the tasks to be done and the contingencies that arise" (p. 228).

Often, the unpredictability of a medical condition can influence the care in two ways: (a) it can hinder the scheduling of medical examinations and, subsequently, the coordination among nurses, primary care physicians and secondary care physicians (Bodenheimer 2008); (b) it can affect the personal life of informal caregivers, who may face situations they are not formally prepared to (Corbin and Strauss 1984; Strauss 1984). In fact, "each change in illness conditions not only brings about changes in trajectory management but also affects the management of everyday

life" (Corbin and Strauss 1984, p. 229).

Communication Issues

The second area concerns communication issues, which can be grouped into five main domains. Firstly (i), formal and informal caregivers have roles and expertise that do not facilitate the information exchange. On the one hand, informal caregivers manage the information on the medical situation (in terms of tests, exams, etc.) of the patients, and they need to share the information with the formal caregivers to coordinate and to acknowledge the care pathway. Patients and their families do not always have the right expertise to deal with medical issues which would require the assistance of professionals (Bodenheimer 2008; Kripalani et al. 2007; Schoen et al. 2005). Secondly (ii), primary and secondary physicians struggle to coordinate because of the absence of communication protocols. The discharge letters historically refer to acute care protocols, and currently there is still a lack of communication protocols between physicians that are able to embrace the complexity of a long-term care plan for disease (Kripalani et al. 2007). Thirdly (iii), there is a poor mutual involvement of primary and secondary physicians on the care plan and the discharge plan. Fourthly (iv), the unpredictability of a medical situation often hinders the possibility to follow a strict schedule of treatments and medical appointments (Corbin and Strauss 1984). Finally (v), there is a lack of universal data protocols to support information systems in communicating using the same standards.

Several studies (Kripalani et al. 2007; Silverman 2005; Fatehi and Wootton 2012) highlight the importance of these domains. In particular, poor communications and, consequently, a limited information flows lower the quality of care. As a consequence, this leads to discontinuity in the services and high rates of hospital readmissions and relapses, creating the suspension of home and residential care.

2.4 Discussion

The healthcare contexts and, specifically, home and residential care contexts display many peculiarities that open the discussion on how to better address the requirements that should support the design of proper technologies. These contexts encompass a large variety of stakeholders, each one with different roles, tasks, expertise, experiences, expectations and needs. Therefore, as the literature suggests (Ackerman 2000; Whitworth 2009), social requirements are the nexus of the design of a technology, and, hence, inaccurate analysis of people's needs and contexts may affect the overall design process and the potential of a technology.

For this reason, we explained the importance of understanding the needs of the future users, and we stressed the significance of the key open issues that would deliver the terrain from which to build a consistent design process. Therefore, we presented a series of disciplines that support the design of technologies – CSCW, Participatory Design and Requirement Engineering – and we highlighted their strengths and weaknesses in relation to the definition of social requirements.

On the one hand, the great contribution of CSCW and Participatory Design is to focus on social requirements by deeply exploring the needs of the future users. In this sense, they intend to comprehend the relationships that people establish, the practices that they carry out and the contexts that they experience. These two disciplines draw attention to epistemological problems, ethical and methodological dilemmas and empirical case studies, in order to address the main challenges in designing with and for people. For this reason, they do not deal with generic models on how to elicit requirements, but they are mainly engaged in flexible and situated design processes with the users. Computer-Supported Cooperative Work and Participatory Design mainly rely on qualitative and narrative techniques and are less

structured than Requirement Engineering. The effort of CSCW focuses more on collaborative technologies for working environments, and it draws particular attention to the care contexts, whereas Participatory Design focuses more on design challenges and on the engagement of users through a participative approach. Each one delivers contributions that can mutually enrich one another, supporting the definition of the social requirement a technology should be built on.

On the other hand, Requirement Engineering provides a groundwork for the definition of structured technical requirements focused on the development of a software, creating generalizable models. Yet, it lacks models for requirement elicitation that are thought for specific environments, such as care contexts. Indeed, the few existing models are considered holistic and inappropriate to valorize the specificity of the care contexts (Hickey and Davis 2004). In summary, Requirement Engineering provides a structured model, which allows for a formalized way to grasp the social requirements but that is problematic in facing the complexity of care environments.

For this reason, we suggest refer to CSCW and PD when designing healthcare technologies since they provide theoretical and methodological resources to support more the comprehension of the situated needs of patients and caregivers in need of continuity of care.

Stange (2009) suggests that the issue of continuity of care is an open challenge that "requires a deeper than surface understanding of the problem" (p. 100). In fact, the network of home and residential care is a mosaic where heterogeneous caregivers co-produce together the care (Weinberg et al. 2007), and for this reason, it requires a major effort to raise awareness and collaboration among the professional and family caregivers. This is fundamental in order to create ICTs to allow for a transversal and continuous care (Haggerty et al. 2003).

Moreover, to better understand the complexity of healthcare contexts, the literature we addressed in the paragraph 2.3 highlights three key open issues that characterized home and residential care, influencing the design of collaborative care technologies:

- the presence of coordination and organizational issues among the actors involved in the process of care;
- the fluctuating and erratic nature of the healthcare;
- a poor information continuity duo to the lack of patient data, communication protocols among professionals and communication resources between medical professionals and relatives.

As we observed in the previous paragraphs, the literature on technology for home and residential care shows a lack of attention to the social concerns that may emerge within these three issue. Conversely, studies appear to focus more on medical information, such as biological data and vital sign parameters. This seems to have brought a contribution to the field of telemedicine, rather than a contribution to support the organizational and communication issues that lie behind the home and residential care contexts.

Hence, we can affirm that home care and residential care domains face a series of challenges, with the need to address issues on collaboration, heterogeneous actors, variability of the working practices and communication. These challenges limit the understanding of the social requirements. Therefore, there is a need to support the definition of the social requirements to better investigate the interrelations among places, healthcare providers, individuals' needs, relationships and expectations, as well as data and information delivery, which characterize home and residential care.

2.5 Conclusion

In this chapter, I reported one of the first papers that I wrote during the course of my PhD. At that time, this work helped be to have an initial framing of the topic on which I would have work in the upcoming years, and it also gave me the possibility to dedicate time to explore computer science disciplines that, being a sociologist, I did not have the possibility to get familiar with before.

Here, I introduced the positive and negative contributions of the disciplines that support the definition of social requirements, highlighting how CSCW and PD provide resources to address the challenges of designing technology for complex care environments.

Then, I focused on key open issues we believe are important to consider in home and residential care, and that guided my research work in the subsequent years. This emerging key open issues are: coordination and organizational issues among all the actors involved in the process of care; unpredictability of the contingencies of care contexts; poor information continuity; lack of communication protocols and communication resources.

_ _ _ 3. D E S I G N _ C O N S I D E R A T I O N S

to support nursing homes communities[5]

coauthored with Francesco Ceschel, Leisan Nurgalieva, Maurizio Marchese and Fabio Casati

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This chapter is based on a short paper presented at C&T conference, 2017, which describes the study conducted in nursing home environments. Within the narrative of this thesis, this chapter contributes to the aim of Part 1, which is to explore the challenges that caregivers experience in collaboratively taking care of end-of-life patients. In doing so, this chapter is dedicated the context of nursing homes, investigating the practices of caregiving and the relational problems that occurs between family and professional caregivers in collaboratively looking after take the residents. It is based on data that emerged during the exploratory study that we

[5] The main content of the chapter has been extracted by a paper that have been published at the C&T, Communities and Technologies conference 2017 (Di Fiore, A., et al., 2017).

conducted in nursing homes before the design and testing of mockups.

It describes how caring for institutionalized older adults is a complex issue both for families and professionals, showing the necessity to support professionals' work practices in relating with the relatives of the residents.

This chapter provides:

- Theoretical overview on organizational issues in nursing homes and related opportunities for ICT design;
- An analysis of the work practices of care professionals, which are characterized by fluctuations between regular daily tasks and unplanned crisis tasks;
- A description of the recurrent relational and communication issues between professional and family caregivers;
- A discussion focused on potential implication for design, taking into consideration relational, technology and organizational needs of caregivers.

3.1 A glance at nursing homes

Nursing homes (NHs) are long-term care institutions that provide a 24-hour care to non-autonomous elderly "guests" with health conditions that vary from mild to severe impairments (Hazelhof et al., 2016). In Italy the residents are usually addressed as "guests", highlighting how, differently from hospitals, they are assisted rather than treated. Families normally draw on NHs to provide a complex assistance to their loved ones, and because of the accessibility of professional caregivers.

In this chapter, we focus on the community dynamics among staff members and the guests' families in NHs. In particular, we investigate knowledge sharing among professionals and between professionals and family members. Knowledge sharing

is, in fact, a critical concept within healthcare communities (Castle & Engberg, 2005). A shared knowledge could facilitate the managements of emergencies, work shifts, and the interaction with the guests' families, whereas its absence may hinder work practices. Investigating organizational context, we pay special attention to the professional caregiving practices and the perception of the NH apparatus from the families' point of view. Hence, in order to facilitate the care process, we address the importance of technologies to support collective knowledge among caregivers and the information and relational continuity between the families and the professionals (Haggerty et al., 2003).

A number of studies (Almberg et al. 2000; De Pasquale et al. 2014; Hazelhof et al., 2016; McFall & Miller, 1992; Zwijsen et al., 2014) focused on work and physiological issues of nursing homes, emphasizing the impact of work shifts on job efficiency and satisfaction of the staff, health implications for the guests' family members and the staff of the NH. In fact, besides the guests, NHs encompass two main groups of actors: the care professional (formal caregivers) and the family caregiver (informal caregivers) (Weinberg et al., 2007). The former refers to the medical staff (socio-health operators, nurses, doctors) and the latter to the guests' family members. NHs are healthcare facilities that provide a certain medical attention towards older adults, as well as coordination of their family caregivers (Weinberg et al., 2007), which makes professional caregivers alternate medical, managerial, and social tasks. Therefore, we can identify a series of issues that provide the framework upon which we can highlight new opportunities for ICT solutions.

3.1.1 Work and relational issues

NHs staff face difficulties working with guests, not only from the medical and professional point of view, but also due to the emotional exhaustion of disruptive and

challenging behavior of older adults suffering from severe impediments (Almberg et al. 2000; Hazelhof et al., 2016; Zwijsen et al., 2014). These hardships increase stress and, hence, higher chance of burnout, health problems, work dissatisfaction, and general decrease of the quality of care (Hazelhof et al., 2016).

Often, in coordinating the care, communication between professional and family caregivers and among professional caregivers is affected by various factors, such as medical and organizational issues (Matziou, 2014). Indeed, "even the most routine and everyday tasks can vary in the manner in which, the time at which, and the person by whom they are performed, according to the tasks to be done and the contingencies that arise" (Corbin & Strauss, 1985, p. 228). According to Hertzberg et al. (2014), family caregivers are seen as a resource, but professionals perceive them also as part of their work that could be "time consuming and had low priority" (p. 431). Despite being well informed about the situation of their loved ones, family caregivers still do not have professional competences and they may interfere with the staff's working routine (Hertzberg et al., 2014). The study suggests that, occasionally, professionals do not feel recognized by peers or managers, in their effort with the relatives.

Matziou et al. (2014) claim that an effective communication among professional caregivers is crucial for quality of care. Several studies (Matziou et al., 2014; Zwarenstein et al., 2009) suggest that the absence of, or the poor communication among professional caregivers may affect their work practices. In particular, deficiency in communication not only negatively affects the quality of care, but also increases tension among professional caregivers.

Other studies (Duncan & Morgan, 1994; Maas et al., 2004) investigate the communication between professional and family caregivers and show that families need a better emotional connection and more information about their loved ones, as

well as greater involvement in the care. Family caregivers often face problems that require social and physiological support (Breskovic et al. 2013). Indeed, "it has been stated that communication problems are related to a lack of a shared framework and approach to communication" (Matziou, 2014, p. 527). Hence, improving inter-professional collaboration may boost knowledge translation and evidence-based care in health care workplaces (Zwarenstein et al., 2009).

Institutionalization of older adults becomes a source of burden for family caregivers. Sense of guilt and lack of trust towards professional caregivers interfere in the personal life of the family caregivers and, often, this distress is reflected on how the informal caregivers relate to formal ones (McFall & Miller, 1994). Studies (Almberg et al., 2000; McFall & Miller, 1994) show that placing older adults in nursing homes does not lower the weight of caregiving for family members. While alleviating related "technical" aspects, it does not eliminate the emotional side of caring for their loved ones.

Hence, formal caregivers become not solely professionals working with people who have various physical and mental impediments related to ageing, but also play the role of a go-between between guests and their families in a vulnerable situation (Zwijsen,2014). This evokes ethical difficulties that create frustration in the working life of the personnel and negatively affects their quality of life (DePasquale et al., 2014).

3.1.2 Opportunities for ICT

Recent studies (Hastall et al., 2014; Huh et al., 2016; Savenstedt et al., 2006) provide examples of how technology can serve the community of professional caregivers, in particular, discussing how to motivate them to use it and how to address caregivers' needs. However, there is still a problem of resistance in adopting

ICT tools by nursing home professionals. Literature provides three main reasons for that: *i)* the belief that caregiving cannot be replaced with technologies; *ii)* the belief that technology may have ethical implications on the work of professionals (such as the loss of empathy towards the guests and their families) *iii)* the lack of interest (Savenstedt et al., 2006). Nonetheless, Fatehi and Wootton (2012) state that there is a growth of ICT usage in medicine and caregiving. Recent studies suggest that formal caregivers find it useful to have ICT features that would include functions "for more efficient care documentation and for a simplified access to care information and care therapy material collections" (Hastall et al., 2014, p. 54). Possibilities of time and cost saving are seen as a motivation to use ICT tools by professional caregivers (Hastall et al., 2014). Therefore, addressing these issues may result in a better management of work practices to the benefit of the relational continuity (Haggerty et al.,2003). To our best knowledge, these issues have not been fully addressed yet.

3.2 Case study

We carried out our study within 6 nursing homes located in Northern Italy. The NHs were different in terms of the structure of the facilities and, subsequently, could host different numbers of guests, from 220 to 68 guests. They were similar in terms of work tasks because they were located in the same region, having the same local regulations. During our investigation we mainly focused on the communication dynamics and relational issues that occurred between staff members and family caregivers within the nursing homes. The investigation that we discuss in this chapter took place from March 2016 to December 2016. It is part of a broader regional research project that aims to design a collaborative technology to support the relationships between professional and family caregivers in NHs.

3.2.1 Methods

During our investigation we conducted 27 semi-structured interviews (Silverman, 2006) with the family caregivers. The interviews were based on an interview guideline we used to explore the following topics: *i)* why they drew on the NH; *ii)* frequency of visits; *iii)* their relationship with the staff; *iv)* their relationship with other family caregivers; *v)* the management of medical information; *vi)* ICT literacy; *vii)* what would they change about the NH. The guideline presented a flexible list of topics we used to let family members freely reflect on their care experience in the NH. Each interview lasted from 40 minutes to one hour and was recorded. Interviewees were randomly chosen, and only included if willing to participate and able to provide the informative consent. Because of the delicacy of the context, we had the ethical approval of the University of Trento. We paid particular attention towards the people involved, avoiding any questions or situations that could cause distress to the participants, in order to guarantee an efficient and respectful data collection. Moreover, three audio- recorded Focus Group Discussions (FGD) (Kitzinger, 1995) with the professional caregivers of the involved NHs have been conducted. The FGDs allowed us to investigate the work dynamics within the NHs among the staff members. For each FGD we had from 7 to 9 participants, and the same moderator and assistant moderator, who respectively facilitated the focus group and took notes. The FGDs investigated the following topics: *i)* the daily routine of the staff; *ii)* the frequency of unforeseen episodes; *iii)* what generally worries family members; *iv)* which topics the staff believe important to communicate to the family caregivers; *v)* the channels of communication. Participants were randomly selected, but to have a good coverage we tried to include all types of professional caregivers (social-health operators, nurses, doctors). Each FGD lasted about one and a half hours. The data from the interviews and focus groups have been enriched with *in situ* visits. Due to

logistical limitations, we conducted a one-day visit to each NH. During every NH visit, there were at least two researchers from our research group who took notes. Visits were scheduled and always accompanied by a gatekeeper; either the director or the chief nurse. Each NH provided us with their official regulations, which we cross checked with the gathered data in order to distinguish between informal practices and formal work tasks.

3.2.2 Findings

In our investigation, we paid attention to the organizational contexts of the NHs that we analyzed, focusing on the practices of professional caregivers and on how these are intertwined with the realm of the family caregivers. We observed that the NHs differ in some aspects. They allow visits within different hours, and they have different facilities, which determine the number of guests they can host and the number of professional caregivers they have. Nevertheless, these differences do not appear to interfere on a work level; we noticed no actual implication on the situated work practices. Indeed, the work tasks appear the same in all the NHs. We identified four macro areas of analysis: *daily tasks, crisis tasks, understaffing, communication issues*.

Daily tasks.

In general, all the NHs host older adults in different conditions; most of them were there due to physical and cognitive impairments related to dementia, femur fractures, and Alzheimer's. Furthermore, a minority of the guests were receiving palliative treatments because they were affected by rare diseases. Because of this, the daily routine of each NHs is built on a series of work tasks that follow one another in a tight schedule that can be heterogeneous and depend on the specific conditions of the guests. It includes: the delivery of the medical therapy; the delivery of the

meals; recreational activities; washing and toilet procedures.

Crisis tasks.

Other tasks that deeply influence the organization of work in NHs are the crisis tasks (Glaser & Strauss, 1975). Crisis tasks occur randomly and are linked to the delicate health conditions of the guests, such as deaths, exacerbation of medical conditions, special treatments and unexpected events. Such events are usually time demanding and mess up the planned daily activities, consuming the time dedicated to the guests and to the relationships with their family members. The staff stated that they care a lot about the relationships with the family caregivers, because are an integral and paramount part of their work. However, often those relationships are forcedly put aside.

"How can it be possible to have relations during emergencies? If someone doesn't feel well everything becomes a mess!! If someone has diarrhea or pukes you have to wash him, because if you wait he will get bedsores, so you have to leave everything you were doing."
(Interview)

Understaffing.

A common problem that affects the overall coordination and quality of care in NHs is that the facilities were understaffed. They usually run from one task to another during all their shifts, bringing stress and high levels of turnover. In this scenario, only autonomous residents can keep their autonomies related to ambulation and washing activities. Those who are not autonomous, however, have to use diapers and are moved using wheelchairs, since this is less time consuming.

On the one hand, the family caregivers understand that the staff of the NHs are

overwhelmed by their workload.

"The only thing that I can say about this structure is that maybe if we had an additional care professional during the shifts it would be better for everyone. It would be better for them, but also for the guests, because they [the staff] really cannot run in every room continuously!"
(Interview: wife of resident)

On the other hand, this, as a reaction, generates frustration in the family caregivers, hindering trustee relations.

"They [the staff] have to be more present. (...) I feel that some of them are lost (...) however, the director should see these things, not me.
(Interview: daughter of a resident)

"My mother walked, (...) she wanted to go to the toilet autonomously, then they decided to use diapers and to put her in the bed and that was it for her autonomy.
(Interview: daughter of a resident)

"I know about the lay off of the staff, but I had my battles here.
(Interview: niece of a resident)

Communication issues.

In the NHs we observed some similarities. They have the same structure in terms of hierarchy that is imposed by the Italian law, and upon which work practices are based. Doctors, nurses, and socio-health operators (SHO) work in different areas: *a)* doctors decide and manage the medical plan of each guest; *b)* nurses deliver medical therapy, and deal with basic medical treatments; *c)* SHOs deal with the basic physiological needs of the guests, and they practically manage most of the activities mentioned above.

The NHs are divided into wards that generally encompass guests with similar conditions and the professionals are grouped into work units that are assigned to each floor. The units are usually formed of one nurse and several SHOs. Doctors are not always present in the facility. Their physical availability is limited to their work shift, and in case of emergency the paramedics are called.

Organizational and hierarchical structures have an important impact on how communication practices are carried out among professional caregivers, and between family and professional caregivers. Specifically, SHOs can communicate every type of information apart from medical. Only nurses and doctors can communicate medical information to family caregivers. This practice is defined by law, but the limited number of doctors and nurses – widely outnumbered by SHOs – often creates difficulties when family caregivers need or require certain information.

"If I report something to someone [member of the staff] I need this information to reach the right professional. I totally can't go around through the whole structure! (...) We need to be facilitated in doing that. (Interview: son of a resident)

Often the work shifts may lead to information loss, which is often forgotten or not transmitted to the specific professional to whom it is intended. Both professional and family caregivers respectively stated and noted that communication has to be carried out in between the work tasks.

3.3 Design considerations for NH communities

In this chapter, we framed the issues that characterize the care work in NHs, providing an overview of the organizational structure, working and communication practices of the caregivers. We drew an overall picture of the contexts we investigated, highlighting the communication practices within the NHs, describing the caregivers' experiences in collaborating and maintaining relationships. Our data

suggest that information exchange between the staff and family caregivers is necessary to build a solid relationship. Yet, the fluctuation of daily tasks – between planned routine and crisis tasks – and the lack of technologies supporting information flow affect the creation of a shared knowledge among caregivers and hinder empathetic relationships. NH professionals admitted that communication with family caregivers is time demanding and, due to NHs being usually understaffed, they are frequently overwhelmed by the tasks they carry out with limited resources. Conversely, the absence of a reference point among staff members – due to frequent work shifts – often leads them to frustration.

We cannot provide a recipe to solve these frictions yet. However, we can claim that the majority of problems emerging from our study can be linked to the division of labor in NHs. Staff reductions and overwhelming workloads appear to result in fragmented care and fragmented relationships. Staff members constantly rotate, working across planned and unplanned tasks. This leads to poor communication methods that hinder the creation of community dynamics among professional caregivers, as well as between professional and family caregivers. In this scenario, the technology cannot be used as a panacea, because technology can support, but not fix, organizational issues by itself, when they call for organizational changes.

However, the need emerges for a technology to facilitate social interactions beyond the medical framework and fulfill work tasks, in order to allow formal and informal caregivers to establish trustworthy relationships and a shared knowledge of the guests' situation. We thus provide some issues that we believe technology design should consider in supporting the relationships between staff and relatives in NH contexts:

- professional caregivers should be supported in sharing both medical and social knowledge of all patients among colleagues;

- professional caregivers should be constantly informed about the family network and the care team of the guest respectively;
- family caregivers should have a reference point within the staff, being able to directly contact or communicate to the care professional closest to the their loved one;
- the technology should support the planning of face-to-face meetings, easing appointments between family caregivers and care professionals;
- the technology should provide a place of informal interaction among all caregivers to nourish trustful relationships, exchange of thoughts and information sharing about the guests.

3.4 Conclusion

In the development of my research work, this exploratory study helped me to frame issues in nursing homes. It supported me in the acknowledgement of the need to design technologies for the realm of NHs by providing a better micro-sociological understanding of the limitations of current care and communication practices.

This preliminary study in nursing homes showed me how designers:

On the one hand should focus on supporting communities in the creation of technologies able to take care of this delicate human setting, addressing collective sense-making and supporting relationships;

On the other hand, should also respect the stratification of issues that can be found in such environments, being careful and avoiding to push for technology solutions by conceiving them as *panaceas*.

Indeed, the complexities that I found in nursing homes represent a perfect case that illustrates how relevant design processes could be for end-of-life contexts, as design processes themselves can enhance community building and support mutual

understanding among caregivers, also revealing the unfairness of the work dynamics that can hinder collective actions.

___ 4. FACTORS_INFLUENCING
continuity of care in pediatric palliative care[6]

coauthored with Natalia Kolianowska, Francesco Ceschel and Vincenzo D'Andrea

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This chapter is based on a paper that has been written during summer 2017 and that is currently under revision at the Quality of Life Journal.

It contributes to RQ1 by focusing on the challenges that caregivers experience in collaboratively taking care of frail patients. Specifically, it analyzes the social and organizational factors that characterize pediatric palliative care, influencing quality care for end-of- life children and their families.

With this work, I present the recurring issue of the delivery of quality care to pediatric palliative patients, since palliative care concerns a complex care work that involves a thick network of caring actors. Indeed, this chapter shows how pediatric palliative care is an uncommon care context, full of challenges.

On the one hand, family and professional caregivers need to collaborate and to have trustful relationships to produce effective interventions, increasing the quality of the

[6] The paper, which this chapter is based on, has been submitted to the Quality of Life Research journal and is currently under review (Di Fiore, A., Kolianowska, N., Ceschel, F., D'Andrea, V.).

remaining time the pediatric patients have left.

On the other hand, care professionals face several challenges in carrying out their work, dealing with coordination issues, unpredictable care conditions and burnout.

This chapter provides:

- a state of the art that introduce the context of pediatric palliative care and its problems;
- a data analysis that led to the identification of seven factors that aim to inform the future strategies in PPC, by revealing the social and organizational dynamics that hinder continuity of care and the delivery of quality care in such contexts;
- reflections on continuity of care in PPC, drawing on the topic that have been theoretically introduced in chapter 2.

4.1 Introduction and state of the art

Pediatric Palliative Care (PPC) is a healthcare approach that "aims to improve the quality of life of patients facing life-threating illnesses, and their families, through the prevention and relief of suffering by early identification and treatment of pain and other problems, whether physical, psychosocial, or spiritual" (Liben et al., 2008, p.852). PPC involves several actors in sensitive settings, with a high level of human and management complexity. PPC, like healthcare in general, is composed of the process of caring and the structure that supports it. The former refers to the process of interaction among caregivers, and between caregivers and patients, including the coordination and management of the care among several stakeholders, whereas the latter refers to the organizational infrastructure that provides the care (Campbell et al., 2000; Donabedian, 1988). This research acknowledges how this conceiving is particularly crucial for PPC by involving several actors, relationships, complex

infrastructures and heterogeneous needs of patients and their families. In this scenario, this research aims to clarify a series of PPC issues that needed to be analyzed, identifying the social and organizational factors that hinder continuity of care and quality care being provided to incurable children and their families.

Studies suggest that PPC services should work with disease-directed treatments from diagnosis onward. In this sense, the goal of PPC should be "to ensure that the children are as comfortable as possible and that their families receive support and guidance necessary to make decision, cope and maintain family functioning" (Klick & Hauer, 2010, p.120). Hence, PPC services should have a rationale based on family-centered care (Browning & Solomon, 2005; Jacobs, 2005). PPC should recognize the whole spectrum of the family's needs: not only those directly related to the care of ill children but also those related to the necessities of the other family members, such as burden relief and psychological support (Hudson et al., 2004; Groh et al., 2013; Contro et al., 2002; Verbene at al. 2017). Other studies (Browning & Solomon, 2005; Klick & Hauer, 2010; Liben et al., 2008) suggest the inclusion of end-of-life support for the families of the patients.

Studies on families' satisfaction with PPC services have increased only over the last few years. Evidence suggests that psychological support, together with practical support on management issues, appear to be the most valuable aids for the families (Groh et al. 2013; Verbene et al., 2017). Moreover, studies state that the PPC service should provide relief to families and contribute to peacefulness in the dying phase, even dealing with unsuccessful treatments and poor prognosis, referring to illnesses that will worsen (Vollenbroich at al., 2016). Clear communication is a key issue in providing psychological relief to parents, helping to understand children's conditions and reducing uncertainty by presenting possible future scenarios. Yet, communication issues, as well as treatments deemed uncaring by the parents, may lead families to dissatisfaction toward PPC services (Contro, 2002).

Conversely, according to Hudson and Liben (2004; 2008), the understaffed care professionals and the fragmentation of care impede the quality of care in PPC. The authors also highlight the existence of common stressors among PPC professionals, such as the "exposure to childhood suffering and death, communication difficulties, team conflicts, and the inadequacy of support systems for care providers." (Liben et al. 2008, p.858). These factors may hinder care professionals to properly locate and respond to the needs of the family members. Moreover, the difficulties in communicating the negative outcome of diagnoses, which are called the conspiracy of silence (Liben et al. 2008), may affect the relationships between families and care professionals; for example, the idea of dying may be treated as a taboo. The conspiracy of silence could also be a consequence of the lack of preparation of professionals.

Studies suggest that, in some cases, care professionals lack the appropriate preparation and training to fulfil the need of support of the families (Browning at al., 2005). In particular, pediatricians interviewed by Klick et al. (2010) and Neilson (2011) stressed their lack of preparation, and uncertainty about their role within PPC networks, as hindering factors in supporting families. Indeed, Liben at el. (2008) state that research should better address the care professionals' need for adequate training and support.

Researchers and clinicians who work in the field are consistent in conceiving PPC as an interdisciplinary team of care professionals who accompany the family throughout the care pathway of the ill child (Browining & Solomon, 2005). Furthermore, a home care model is suggested in PPC to provide a proper continuity of care (Groh et al., 2013). Home care (Bossen et al., 2013) aims to prolong the care of patients in critical conditions within their home environments as long as possible. Studies (Abowd et al., 2006; Bossen et al., 2013; Christensen, 2011; Mynatt, 2001; Thomé et al., 2003; Rojas et al., 2008) suggest that home care contributes:

a) To the compliance of the patients and their families to the care plans;

b) To increasing the awareness and knowledge of the care treatments among the patients;

c) To reducing the incidence of hospitalization.

The home care model proposes a change of paradigm from an overall primary care system that focuses on hospitalized care, to a system that is conceived for longitudinal care pathways (Berwick, 2009) that involve a thick network of actors. Home care needs coordination and information sharing among many caregivers, managing complex patients across different locations (Wagner, 1996; Wagner, 2000; McGee Lennon, 2008).

This need can be synthesized by the concept of Continuity of Care, which aims for a coherent, transparent, and intelligible care process that should be supported by the coordination and integration of tasks among caregivers. Haggerty (2003) suggests a model to conceive the continuity of care on three levels.

i) Information continuity, which is a consistent information sharing that attributes a sense of predictability to the care pathway;

ii) Management continuity, namely a clear managerial protocol among caregivers that would allow patients to increase their sense of safety;

iii) Relational continuity, a clear and predictable structure of relationships among caregivers and between caregivers and patients.

In PPC, it is recognized that further research should acknowledge and better address continuity of care and the needs of professional caregivers, helping them in providing high quality service (Liben et al., 2008).

4.2 Case study and procedure

The work presented in this chapter is based on MIUCHI, a research project that works on relational, coordination and communication issues in pediatric palliative care contexts. It relies on one case study carried out within two PPC home care services

in northern Italy. The study focuses on the perspectives of the professional caregivers involved in the care, and on the experiences of the families of the young patients. The study was conducted from summer 2015 to fall 2016 and received the ethical approval of the committee of the University of Trento and from the Hospitals that hosted the research.

4.2.1 Data collection

The data collection relied on qualitative methodologies, summarized in Table 1. We performed semi-structured interviews and participant observations (Silverman, 2016). Given the strict relationship between the quality of care and the relational, coordination, and communication issues that may affect it, we deemed these methodologies as the most appropriate to comprehend how caregivers experience their context. The family members who joined the study were involved thanks to the mediation of the psychologists who assist them along the PPC intervention.

Due to the specific sensitive setting of the research, only a few families (n=2) were formally interviewed; whereas the majority of them (n=9) were involved in the study within informal dialogues during the ethnographic observations. The data were collected by only one researcher by focusing on creating trustful relationships with both the professional caregivers and the family members. The data gathering continued until the theoretical saturation was reached.

Conducting this research, we also took into account the challenging nature of PPC networks, bringing an extremely sensitive research experience. Hence, we also considered ethical and methodological dilemmas of how to preserve the researchers from the difficulty of the research subject (Di Fiore & D'Andrea, 2016).

Interviews.

We conducted a total of 18 interviews. Participants were professionals (including: pediatricians, doctors, nurses, psychologists, social workers and specialists) and

families of the patients. The interviews were based on an outline that covered the following topics:

i) The nature of the care context from the perspective of the interviewee;

ii) The interviewee's perception of the quality of the care;

iii) The daily schedule and practices carried out within the home care network;

iv) The problems in communicating, coordinating and relate to one another;

v) The role of technologies in their daily practices.

The interviews followed a dialogical approach (La Mendola, 2009) to increase the attention towards the emotional status and distress of the interviewees. Participants were recruited through a snowball sampling (Atkinson & Flint, 2001), since it is recognized as particularly effective in working with isolated and vulnerable social groups. The participants have been included in the study only if willing to participate and able to sign the informed consent. Interviews were recorded and transcribed, lasting approximately one hour.

Ethnography.

In addition to the interviews, we performed approximately 50 days of participant observations (Taylor et al., 2015). The ethnography was conducted thus: in the hospital headquarters of the home care networks; during the road trips that led the care professionals to provide home visits; during the coordination meetings between care professionals; and in the houses of the families of the patients assisted by the PPC service. During our observations, we mainly focused on how family and professional caregivers established and nurtured their collaborations, assisting one another in articulating their practices. Moreover, we structured our observations according to a collaborative ethnography rationale (Lassiter, 2005). Thus, we created moments of informal discussion of the issues that may have emerged along the observations; we also discussed with our informants the results our research was producing. Participant observation was divided into several short-term sessions (Pink

& Morgan, 2013), focusing on a series of sensitizing concepts (Blumer, 1986) linked to those investigated during the interviews:

i) The network of actors involved in the care;

ii) The fluctuation of work practices;

iii) The daily practices that PPC professionals and family caregivers carry out every day;

iv) The communication practices, and relative problems;

v) The factors that support and interfere with the home care practices.

4.2.2 Data analysis

The collected data have been analyzed and coded using inductive thematic analysis (Braun & Clarke, 2006). Two researchers independently coded the data and then reached an agreement on the interpretation of the data. Data coding was performed separately for the two settings of the research by using the same procedure:

i) Joint meetings to discuss specific case settings;

ii) Individual reading of the transcripts of the interviews to grasp the general meaning;

iii) Further individual reading sessions, annotating codes;

iv) New joint meetings to discuss the coding and, therefore, the attribution of the codes to the themes;

v) Lastly, a joint meeting to refine the themes to later graphically represent the data with the support of mind maps. Throughout the procedure, we identified a total of 258 codes and 39 themes. Afterwards, during the refining sessions of analysis of the data, we merged the findings and the themes of both case studies. Then, we focused on the identification of high-level factors that can represent the main social and organizational issues that influence quality care in Pediatric Palliative Care. A final count of 7 factors that affect PPC were identified.

Table 1. Summary of the Methods

Interviews	Amount	Subjects
Setting A	10	Care professionals and families of the patients
Setting B	8	Care professionals and families of the patients
Observations	**Duration**	**Contexts**
Setting A	A total of 35 days of observations. The observations included:	The observations were conducted within the hospital headquarters of a PPC team and at the home of the patients – Participation in 2 formal meetings where the PPC professionals discussed the care plan of the patients. – Participation in 2 workshops in schools with teachers and students who would have become classmates of the patients of the PPC service.
Setting B	A total of 15 days of observation. The observations included:	The observations were conducted within the hospital headquarters of another PPC team. – Participation in 9 meetings where the PPC professional negotiated the care plans of the patients with the specialists. – Participation in 2 meetings that involved the care professionals to discuss the implementation of new managerial settings in the PPC service. – Participation in a 3 day course that trained the care professionals who will work in the PPC service.

4.3 Findings: connotative factors in PPC

According to the results of our data analysis, we investigated the factors that are perceived by care professionals and family caregivers as those that primarily characterize the Pediatric Palliative Care. In this scenario we identified 7 factors:

1. The identity of PPC, its definition and how the caregivers conceived this care

approach;

2. The resistance to PPC, and the dynamics that hinder the delivery of this care approach;
3. The expertise related to care professionals in PPC;
4. The relevance of relationships in PPC;
5. PPC as characterized by the management of complex clinical cases with unpredictable pathways;
6. The role of end-of-life support for the dying and their families;
7. Burnout and emotion management of the care professionals.

Tables 2-8 report an overview of the factors by providing exemplary quotes (Bernard, 2012) that show the shared experiences of the respondents.

F.1 Identity.

Both care professionals and family caregivers agreed in defining PPC as an approach to care that goes beyond the mere medical needs of the patients by addressing a holistic view of the young patients and their families. The perceived goal of PPC is to support the children and their environment, pursuing medical, social, human, spiritual and psychological needs. According to the care professionals, PPC focuses on care interventions that take place with incurable children when cures are no longer effective, which are based on the assumption that the people are cared for, while only the diseases are cured. Care professionals claim that PPC does not deny the use of medical treatments, but it focuses on taking care of the life changes that are generated by the exacerbation of medical conditions connected to unfavourable prognosis. The perceived mission of PPC is to support the quality of the time that remains, working on projects and wishes that can be feasible for the patients and their families. Moreover, the end-of-life of a child is difficult to accept for both care professionals and families. Due to the unacceptability of their short lives, incurable

children are considered as a social category to protect, because they are often subjected to unsustainable therapeutic obstinacy. In such a scenario, it is necessary to form a close collaboration and shared knowledge between the care professionals who daily support the families, and the specialists who work on the disease [See table F.1].

Table F.1 IDENTITY: exemplary quotes

Themes	Explanatory quotes
Going beyond	"We (PPC) go beyond the health needs to make them feel our presence"; — "We follow the needs of the patients and their families"; — "We have a holistic view of the patients and their context"; — "The diseases are cured, while, the people are cared"; — "Palliative care means working on the feasibility of the people's desire"; — "The palliative specialist doesn't deny the treatments; we reflect on how to intervene to support a processes of change due to the exacerbation of the medical conditions"; — "Our goal (PPC) is the child and the child's needs management".
Timing	"We (PPC) work to enhance the time that remains… I am now taking care of a little girl, I often also have positive news from the care point of view."; — "In the terminal phase of a disease a child can be treated to gain some time to live"; — "The treatments have to be contextualized into a framework, the goal toward which we must work is to reach what can be done of good"; — "What is the project that we want to accomplish? We work on feasible projects".

Peculiarities	"Healthcare is a special context, the power of the professionals during the decision-making is higher than in any other professions. We have ethical responsibilities and we have to reflect on the impact that this work has"; — "We (professionals) need a shared knowledge, and to collectively decide how to develop a care process"; — "The rest of the world has a therapeutic strategy, whereas the PPC has a healing intent... We have to ask ourselves: Can we support these care relationships?"; — "If we decide for a nasogastric intubation, the core is not about putting the tube... it is about the frame with which you put it in... Because the quality of life lies behind relationship and desires".
Creating care pathways	"Children risk becoming the subject of arbitrary processes, which lead us to try everything because we are tied to the children, because we are tied to their parents, but in the palliative field this cannot be done!"; — "We don't work on the illness, we work on the dignity of the people, because diseases are inside the people"; — "To work better, we need recognition of our role, we must defend the specificity of our work, we need to enhance an end-of-life culture"; — "When the chemotherapy fails, the palliative care should prevail, being there, hand in hand with the families"; — "We have to create a care process before the very end-of-life. We are vehicles... toward wellbeing, toward chronicity, toward reality"; — "We have to give a respectable life (to the children), we have to work with their parents".

F.2 Resistance.

Resistance to PPC was a typical experience reported by care professionals. In particular, negative preconceptions of PPC emerged among specialists and family members, because the label of palliative care seems to be perceived as something that creates barriers in the planning of palliative interventions. Pediatric palliative care professionals also stated that they are not autonomous and recognized, because in most of the cases their work depends on other healthcare services that have different approaches, such as the adult palliative care services or the pediatric wards inside hospitals. Another fact that negatively affects PPC is related to the relationships with the specialists. PPC and the realm of the incurability are perceived as not recognized by the specialists who work on curing the disease. For this reason, often the pediatric patients are on boarded too late, or in the worst cases never receive palliative care. The specialists recognized that this is partially culturally-driven since they are trained to fight the diseases and never give up. Moreover, they do not have the experience nor the training to properly communicate a negative prognosis. In this scenario, therapeutic obstinacy is recurrent, worsening the quality of life in end-of-life care by hindering the intervention of PPC [See table F.2].

Table F.2 RESISTANCE: exemplary quotes

Themes	Explanatory quotes
The concept of PPC	"The name palliative care scares the people; it should be changed because it creates barriers with patients"; — "Palliative is a "noun" that no one likes" — "The palliative specialist is perceived as a threat".
Relationship with the specialists	"For the oncologists we are those who kill people"; — "The relationships with specialists is a recurring problem"; — "We (PPC) are seen as a shifting the blame service!"; —

	"The oncologists are afraid to handle the situation (incurability), they do not know how to say: there is nothing left to do"; — "The specialists are fighters, they cannot give up, that's nice wow... but... in this way you can make many mistakes!" — "To give up on the secondary cure, yeah it's beautiful ... very romantic but then it damages the child!" — "They (specialists) send us the patients too late and you get them… almost dead! He (the oncologist) panicked, sent us the child during the night and the child died the morning after. What did he expect me to do? A miracle?" — "Incurable oncology young patients are difficult to accept for the specialists. PPC should begin with the diagnosis, thus a shared plan can be created with the families, that how it should be".
Therapeutic obstinacy	"Chemotherapies until the day before death is an ordinary thing"; — "The third-line chemotherapy conveys only illusions;"; — "The patient does not know that the disease is evolving, but I (professional) know, and I pretend that everything is ok because I don't want to tell the patient that the illness is incurable, because it's bad news. So... I start doing crazy treatments to hide the situation. And, thus, we build fictional cathedrals, baroque, rococo, because we can feel the fear of the emptiness, and we must fill all the spaces"; — "The younger the patient the more frequent is the chemotherapy until the last day. Because there is a constant exchange between the oncologist and the palliative specialist"; — "Chemotherapy until the last day is as if something has to be done, as if palliative care was not considered a concrete action"; — "If I proceed with therapeutic obstinacy I do not bring back a person to life, I force that person to live"; — "I talked to a colleague who followed a patient with a brain cancer, who clinically was cured from cancer, but after 8 interventions was in a vegetative state".

F.3 Expertise.

The knowledge of the care professionals who work in pediatric palliative contexts is linked to a dialectic between the need of mapping the formal expertise and the need to recognize the relevance of the experiential knowledge and attitude of the workers. On the one hand, PPC needs to train care professionals so that they have defined expertise in working with specific medical devices (i.e., CVC) and procedures (i.e., chemotherapies and transfusions) both in pediatric and end-of-life contexts. On the other hand, as PPC recognizes the individual inclination of care professionals as essential in providing quality care, those professionals must feel comfortable to work in such contexts and in being available for patients and their families even in the most difficult situations. Some of the professionals stated that they felt a calling towards caring about this kind of patient and care approach. In PPC, the situated experience and the tacit knowledge of the care professionals (Polanyi, 2009) are paramount, particularly concerning their trustful relationships with the families of the patients. For these reasons, due to their expertise and their close bonds with the families, the care professionals are usually perceived by family caregivers as unique and irreplaceable [See table F.3].

Table F.3 EXPERTISE: exemplary quotes

Themes	Explanatory quotes

Attitude	"I like this kind of patient (the PPC ones), they need more attention than an average patient"; — "You have to devote yourself to this job, you must be available also during harsh situations"; — "Here everything depends on the sensitivity of the single care professional"; — "Here (at PPC), you have to recruit the professionals by taking into consideration their attitude, because here you have to feel able to deal with these contexts"; — "Working here must be a voluntary choice, and it is fair to say 'I do not feel like doing it', to say I don't feel capable of working with kids"; — "Here (at PPC) we have a self-reporting path, whoever does not feel able to do this job, does not join us to do it".
Being unique	"We acquired so many competences that we are unique"; — "There is no one else who does what we do"; — "We are irreplaceable; during the summer when we go on vacation it's a mess!"
Experiential knowledge	"Our whole experience is an asset"; — "This job is a matter of practice, some people are more insecure and do not feel comfortable working here, it depends on one's character"; — "There are doctors who are able to collect blood samples, but there are other doctors that are unable to collect blood samples".
Parental expertise	"The Parents have great medical expertise on children and medical practices"; —

	"At first, before I (mother) could figure out my daughter's situation, we were in the hospital and they (the care team) trained us to do all the medical procedures"; — "Now we (parents) change the CSC alone because you know … the time to go to the hospital and come back… it is too late"; — "We (parents) have the courage to handle him (son) by ourselves, we try to avoid going to the hospital because we have everything here at home"; — "Mothers take care of their children almost always by themselves"; — "Parents are super trained, we train them because we cannot be there every day, there is a mutual exchange of knowledge and skills with the parents".

F.4 Relational care work.

The families are central actors within the PPC network since they are both care providers and subjects of care, since the care professionals humanly and psychologically support them. Moreover, the relationship between care professionals and patients is always mediated by the relatives. Indeed, the family caregivers are perceived as co-producers of care, managing the children independently at home and collaborating with the care professionals providing the care tasks. Mothers have a central role in taking care of children, and most of them leave their job to provide 24/7 care. In this way, families act as caregivers in PPC, and the care professionals are engaged in tight care relationships with them, collaborating on care tasks, supporting them at home, and being a point of reference in the relationships with the specialists. The relatives usually have close bonds with a few selected care professionals, being guided by them in important medical decisions (i.e.: DNR) and being supported in their human needs. PPC is characterized by mutual knowledge sharing and trustful bonds between care professionals and family caregivers, even

though those relationships are not always easy to manage. In this scenario, pediatric palliative interventions should start ideally with the diagnosis of incurability and not during the last weeks of the patients' life, to allow the caregivers to create bonds, laying the foundation for having collaboration and trust [See table F.4].

Table F.4 RELATIONAL WORK: exemplary quotes

Themes	Explanatory quotes
Make kinship	"If the parents have problems, they refer to our team, we are an important reference point"; — "We go beyond the health needs to make them feel our human presence"; — "If a parent needs the first aid they don't care which doctor it is. But if they have a shared end-of-life plan with their care professional, they want the team that they know, they want those people to be there and to stay with them"; — "We need to be work a lot on the relationship with them, they are fragile children and fragile families"; — "Some families allow the staff to "adopt" them. Others don't, they remain very reserved"; — "You have to know how to deal with them (families), you have to create a circle of trust, these relationships are not easy"; — "The relationship with the child is not like the one with the adult because you are in a very mediated relationship, the relationship is filtered by the parents, so you have also to be a little bit like a psychologist"; — "I expect the families to create obstacles, it is up to us to smooth things over"; — "For us the family is essential, we work with the family, we support them and they support us"; — "The people who know the most about the children are moms, and we also control if the mom is ok, we try to figure out if she needs

	social support".
Being guided by the parents	"Parents have a great knowledge and we have the expertise to be guided by them in order to be able to listen, understand and decide with them"; — "I (a mother) arrive and I tell the nurses how to perform the procedures with her [daughter]" — "It is important to let yourself be guided by the parents and I let myself be guided"; — "We have the problem related to continuity of care";
Taking care at home	"In the terminal stage of a disease only a few professionals can enter in the homes, I had to exclude some nurses because they were too much, and because the families ask for a few trusted persons"; — "At the beginning, the parents are worried about staying at home without the support of the professionals"; — "To go to the home (of the patients) is always like entering in the nest, you have to enter gently, because you know that if you lose the family's trust you cannot enter that home any more"; — "If the parents close the doors we are out and we cannot work with them anymore. To be allies with the parents means that the parents trust you and are willing to follow our advice"; — "The ones that think that you can do palliative care in hospital are taking the wrong way"; — "When we go to the home it is important to check the baby but also the family, taking a look if there is a psychological crisis"; — "The child needs a family that is calm and serene, a family that asks if it needs something; it is fundamental to have a healthy, attentive family, with which we can work in peace".

F.5 Management complexity.

Children in palliative care need ad hoc care interventions. Moreover, they need also to be supported in their social and cognitive development. For this reason, PPC requires a high level of collaboration and integration between up to 30 care professionals that take care of the young patients, including: PPC nurses, PPC doctors, specialists, physiotherapists, pediatricians, socio-health-operators, psychologists, social workers, educators, etc. Pediatric palliative patients are usually children with chronic diseases (most of them have rare genetic diseases) and children with oncological conditions. The chronic patients are difficult to manage before the diagnosis, but after they become relatively stable they are framed in predictable degenerative pathways. Whereas, the oncology patients are instead initially easy to manage because there are protocols that define the medical interventions, but become more difficult to be managed on a daily basis because the evolution of cancers is variable and uncertain. Indeed, the PPC can last a few weeks or years, since the time span of each child is unpredictable. Uncertainty is an integral part of the PPC world, and in such a scenario, the care work is always flexible, heterogeneous and difficult to organize because the care tasks of the care professionals fluctuate continuously between routine tasks and unplanned emergency tasks [See table F.5].

Table F.5 MANAGEMENT COMPLEXITY: exemplary quotes

Themes	Explanatory quotes
Complex cases	"As the disease evolves, we identify new needs"; — "We have to continuously identify and redefine palliative care actions"; — "We must create preferential paths for these fragile situations"; — "There is a need for more precise procedures. Our work is a very

	flexible and diversified one, because there are changing needs. We "sail" in the dark, like a ship that follows unknown routes"; — "The world of rare diseases is a huge world… Before the diagnosis it is a complete mess, you can't predict what will happen"; — "Blood samples, transfusions, hospitalizations, collapses, white blood cells …. Here it is chaos!"
Continuity	"We guarantee a cross-disciplinary service to these children in order to keep continuity"; — "We have so many things to do to provide collaboration between the care professionals and continuity of care"; — "We have a problem related to continuity of care".
Uncertainty	"We do not know how much time remains for our patients"; — "Uncertainty is an integral part of our job, we try to reduce it"; — "Talking with the parents about life expectancy of their child is complex, but it is necessary to decide together what to do during the time that remains". — "In this case, when we do not yet have a diagnosis, the paths are quite variable… We do not know how long she will live, how she will live, when…"; — "Dealing with rare diseases the path to end-of-life is longer. The degenerative stages that the child will reach are already known, but you don't know when these stages will occur, it very depends on how long one's organs can work"; — "In this period, the mother of a patient is angry because we are not able to tell her anything, but we cannot predict the situation. We know that it can go wrong soon, but we cannot know when and how…"; — "We do not know how long the terminal phase of a patient will last"; —

	"Often we can't organize our job. We try to follow the agenda but there are unforeseen events"; — "We try to organize home visits on a logical schedule but then something always goes wrong!"

F.6 End-of-life counseling.

A relevant part of the work of the care professionals is to support families to accept the negative diagnoses of their children and to help them in using the time that remains on their wishes and projects that are possible to realize. In this scenario, it is crucial to create an honest dialogue with the relatives about the conditions of the young patients, limiting the false hopes. Here the care professionals have to be there, giving a sense of presence and providing relational continuity by supporting these families in one of the most painful moments of their life. The human and psychological support in end-of-life care is paramount because family caregivers and patients have no experience of what is going to happen, and for this reason, they need to be accompanied in this path by trained care professionals. Conversely, care professionals need time to provide an effective palliative intervention, approaching the families carefully, getting to know them, and creating trustful relationships. Pediatric palliative care professionals need a deep understanding of the families' context to deliver care and human support sustainably. However, these efforts require long a meticulous training [See table F.6].

Table F.6 END-OF-LIFE COUNSELING: exemplary quotes

Themes	Explanatory quotes
Recovery and acceptation of loss	"The parent needs a psychologist, a physician, and a nurse who support them in a process of the acceptation of loss"; —

	"The parents (of the patients) have no experience of what will happen to their child; we do. This is why there is the need for them to be assisted by us"; — "The thing that always concerns me is that the parents are surprised when a care professional listens to them and supports them"; — "The problem is how to support the family regarding what the future holds for their child"; — "When we take care of those patients [kids] we do it without boundaries".
Remaining time	"A good care process increases the quality of the remaining time. In the tragedy of the illness the parents can be able to enjoy their child;"; — "A mother told me: "In July the specialist proposed the radiation therapy, but I think we will go to the seaside" And... after the holiday the child's condition decreased. In this way, they had quality time to stay with their child, and they have been able to take this chance because they received the end-of-life support"; — "We need to be able to help the children to express their wishes, and to make them realize them. And we need to help and accompany the parents to follow the possible desires, which will be scaled up according to the time that remains".
Telling the truth	"It is necessary to tell the truth otherwise we cannot build a care process. We cannot negotiate a care path with the family members if there are things that they just do not know"; — "We must know how to use the right words to tell the truth to the parents, such as "we are at the end", "we are worried" ... we need a culture of end-of-life counseling"; — "At a certain point we arrive at the moment where there is nothing left to do. So we have to say to the family: "we have to stay together, doing the little things that are possible to do now".
Doing	

counselling	"Only together can we handle and deal with a path of accompaniment, in order to lead the families to a mourning that shouldn't be devastating"; — "Most of the counseling activities are conducted with moms"; — "We must accompany the families on everything including the things they need at home"; — "I really like the end-of-life counseling but I need to feel safe and prepared"; — "He (a patient) died poorly… the consternation of having such child, and feeling like being inadequate. He was dying and I knew who the mother was only because she had him in her arms. We hadn't met the mother; we knew nothing… To do our job we need to be prepared".

F.7 Emotion management.

Working in such contexts leads the care professionals to interiorize distress and grief. In this way, care professionals protect themselves by seeking for coping strategies and trying to find an emotional balance in the most painful phases of the end-of-life support. In this scenario, care professionals are often overwhelmed by their workload, and such a phenomenon creates turnover and fear of losing human resources due to burnout and distress. Care professionals stated that feeling supported by colleagues and having community relations at work is essential to preserve themselves from burnouts. Moreover, care professionals agreed that pursuing their mission of supporting the dignity and the quality of these short lives, it is helpful to hang in there by adding motivation and satisfaction to their work [See table F.7].

Table F.7 EMOTION MANAGEMENT: exemplary quotes

Themes	Explanatory quotes
Feeling able	

	"If I am not able, being a professional, of thinking through and watching their kid dying, then how can I think that a parent can do it as well?"; — "I used common sense to go through that experience, I let myself be guided by the parents who, thank God, had the fortune of being aware of the prognosis and about the evolution of the disease"; — "Many times my job has rational and psychological implications end sometimes I ask myself if it is too much"; — "In our job when there are moments of sorrow there is almost a "desert" [at our workplace], because it is difficult"; — "If you do not deliver the right end-of-life support you feel lonely, they give us custody of their kids during the moment of their death, can you understand this?"; — "When I know that the downfall begins I just set something aside to protect myself"; — "I try to be there, but I try to not give all of my heart; — "It is necessary to find an inner balance to be able to be there for them (family and patients)".
Bad feelings	"At the beginning of every poor diagnosis we are always scared by these diseases that are so terrible"; — "To accompany the families is wonderful, but it can be difficult in the long-term… You can get sick, PPC is a tough job, it is extremely difficult because it is arduous"; — "There is a huge pain in internalizing the powerlessness and the difficulties, we cannot allow ourselves to give up"; — "The oncologists give many hopes at the beginnings but also a lot of pain later postponing the truth"; — "In many situations we feel impotent, we are used to see all kind of sufferings. It is not easy, it's a hard job"; —

	"The reality is cruel, guys! When you run as we do… we meet many families who have kids that will die soon"; — "I am afraid, I don't want to gamble with my life and emotions working here"; — "We experience losses continuously, and that affects your soul".
Community relationships	"It is important to be recognized within the network [of care] and feel supported"; — "I was working with a real team for a while, we had affection. We were really close and supportive. We had our own way of minimizing the situations… if someone heard us would have said "those assholes"! But it was useful to cool things down and stop the pain"; — "I realized that I can make it only by working within a team, and that PPC can only be done by teams. We cannot deliver PPC alone, we cannot work alone. We need a group to face our feelings and emotions together"; — "Working in a team is about sharing expertise and taking care of your colleagues, because taking decisions during tough moments bring sorrow and grief"; — "We reflect together and we talk about what went wrong, because a few words can help you, they support, they comfort, they help".
Acceptance	"You have to live with the fact they (patients) won't recover, but at least they can live with dignity, this allows you to have some satisfaction"; — "We have to accept that many kids who come here will die anyway" — "I have to accept it and find some strategy to cope with that otherwise I would quit" — "The parents of the patients are amazing, and in the end, I say to myself 'I did my part'".

4.4 Discussion

This study aimed to address the factors that affect the delivery of quality care in pediatric palliative care, clarifying of how caregivers conceived PPC, relational issues among caregivers, and the aspects that would support caregivers in delivering care. Specifically, we found that 7 factors characterize the care dynamics in PPC:

1. Caregivers conceiving of PPC identity;
2. Resistance dynamics to PPC;
3. Peculiarity of the caregivers' expertise;
4. Role of relationships in care dynamics;
5. The medical complexity of PPC;
6. The practice of end-of-life support;
7. Emotion management.

Table 2 provides a summary of the outcomes of each dimension.

A key feature of PPC identity is that it goes beyond the mere healthcare needs, focusing on the overall needs of the patients and their families. It enhances the remaining time the patients have, claiming for shared knowledge to develop care pathways that protect the children and their context. PPC professionals also acknowledged that there are several barriers that burden PPC. These resistance dynamics are mainly related to a lack of shared information, coordination and reciprocity with the other specialists, which often bring phenomena of therapeutic obstinacy. Experiential expertise characterizes the care work in PPC, which is recognized as a matter of time, attitude and practice. Also, the expertise of the parents of the patients is essential, who need to be trained and supported to take care of the children at home. PPC is recognized as a relational work. Indeed, PPC professionals and the parents of the patients need to work together. This cooperation is enabled by real bonds and information sharing, and it is paramount to delivering

care at home.

PPC has a high level of management complexity by involving several care actors that take care of vulnerable critical patients. The management issues that the PPC professionals face are mostly related to management of uncertainty and issues in ensuring continuity of care. An essential part of the work of the PPC professional is to provide end-of-life counselling to the patients and their families, communicating in proper ways unfavorable prognoses and addressing acceptation of loss. Such activities are focused on supporting the feasible wishes of patients and their families, increasing the quality of the remaining time. Working in PPC and doing end-of-life counselling requires emotion management. To accompany young patients and their families in end-of-life paths can be exhausting and isolating for the PPC professionals. In such contexts, community relationships with the colleagues can help the care professionals to properly manage the bad feelings that can arise in doing PPC.

In accordance with the perspective of Haggerty et al. (2003), PPC needs strategies to improve the continuity of care, and the achievement of many improvements can be supported with organizational change and collaborative technologies. This chapter emphasizes how PPC teams struggle to provide the categories of continuity provided by Haggerty et al. (2003), ensuring management continuity, information continuity and relational continuity. Indeed, palliative professionals needed for strategies and solutions to enhance a palliative culture or incurability culture. There is a need of acknowledgement of their work, recognizing the complexity of such environments and the heterogeneous human and medical needs of the pediatric patients and their families. In such scenarios, the proposed factors are focal points that aim to inform the future strategies in PPC, by revealing the social and organizational issues that characterize continuity of care and the delivery of quality care in such contexts.

Table 2 – Summary of the exemplar quotes of the study, reported per dimension

Factor	Summary
1. IDENTITY:	– Going beyond the mere healthcare needs – Work on the time that remains to live – It is a special care context – The importance of creating a shared care pathway
2. RESISTANCE:	– Issues with the concept of palliative care – Difficulties in relating with the specialists – Protecting the young patients from therapeutic obstinacy
3. EXPERTISE:	– The importance of the individual attitude of the professionals – The issue of being irreplaceable – The role of experiential knowledge of the caregivers – The role of the parents' expertise in PPC
4. RELATIONAL WORK:	– The importance of making kinship with the patients and their families – Professionals work with the parents and are helped by them – The peculiarity of providing care at home
5. MEDICAL COMPLEXITY:	– The issues of working on complex cases – Providing continuity of care – Management of the uncertainty
6. END-OF-LIFE COUNSELING:	– Providing recovery and acceptation of loss – Feeling able to face such situations – Hindering bad feelings – The importance of having community relationships – Acceptation of the disease paths
7. EMOTION MANAGEMENT:	– Support the parents in spending their remaining time with as much quality of life as possible – The importance of telling the truth to the parents – The difficulties of doing end-of-life counseling

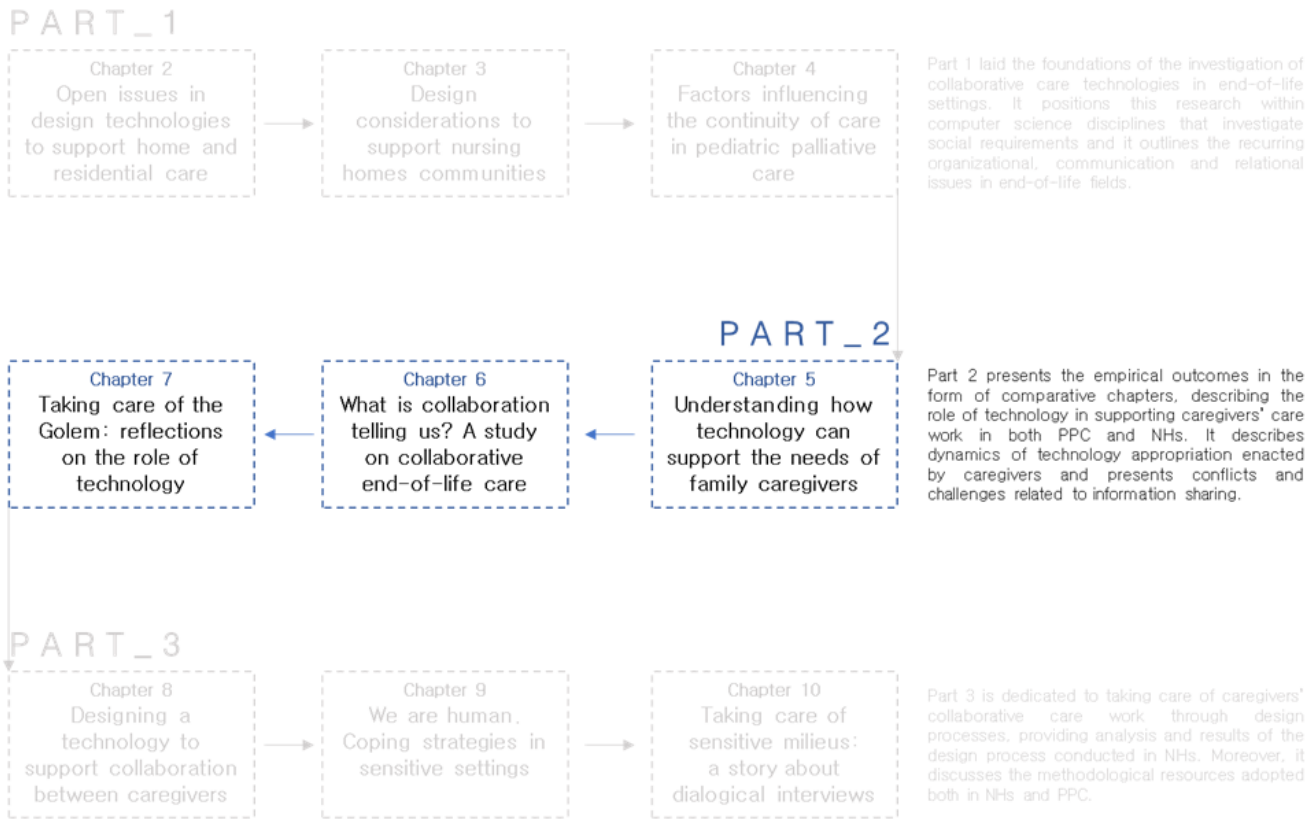
4.5 Conclusion

With this work, I deepened the challenging nature of the PPC contexts by frame the specific theories on pediatric palliative care and by analyzing an amount of qualitative data. This led to the definition of seven connotative factors that summarized the most common issues that characterize PPC: Caregivers conceiving of PPC identity; Resistance dynamics to PPC; Peculiarity of the caregivers' expertise; Role of relationships in care dynamics; The medical complexity of PPC; The practice of end-of-life support; Emotion management.

Within this paper based thesis, this chapter frames the outcomes concerning the social and organizational dynamics that influence the delivery of continuous pediatric palliative care.

Since this paper has been written at the end of the last year of my PhD, the specific seven factors identified are not used in the following chapters. However, throughout the overall thesis report can be found a peculiar attention in the crucial dialectic between relational needs, management/organization needs and information needs, which also lay the foundation of this paper.

PART_2


PART_1
Chapter 2
Open issues in design technologies to support home and residential care
Chapter 3
Design considerations to support nursing homes communities
Chapter 4
Factors influencing the continuity of care in pediatric palliative care
Part 1 laid the foundations of the investigation of collaborative care technologies in end-of-life settings. It positions this research within computer science disciplines that investigate social requirements and it outlines the recurring organizational, communication and relational issues in end-of-life fields.
PART_2
Chapter 5
Understanding how technology can support the needs of family caregivers
Chapter 6
What is collaboration telling us? A study on collaborative end-of-life care
Chapter 7
Taking care of the Golem: reflections on the role of technology
Part 2 presents the empirical outcomes in the form of comparative chapters, describing the role of technology in supporting caregivers' care work in both PPC and NHs. It describes dynamics of technology appropriation enacted by caregivers and presents conflicts and challenges related to information sharing.
PART_3
Chapter 8
Designing a technology to support collaboration between caregivers
Chapter 9
We are human. Coping strategies in sensitive settings
Chapter 10
Taking care of sensitive milieus: a story about dialogical interviews
Part 3 is dedicated to taking care of caregivers' collaborative care work through design processes, providing analysis and results of the design process conducted in NHs. Moreover, it discusses the methodological resources adopted both in NHs and PPC.

Part 2 _ J O I N T _ C O N S I D E R A T I O N S

Part 2 collects articles that discuss the field studies in a comparative fashion, focusing on how caregivers include technology in their care practices.

In this way, it addresses the second research question of this report:

RQ2. What is, and can be, the potential of technology in supporting the collaboration challenges between caregivers in end-of-life care?

This part is composed by 3 chapters based on standalone articles, they are grouped on the base of the second stream of this thesis report, providing reflections on how caregivers consider technology in supporting collaborative end-of-life care. Specifically, I reflect on how the current adoption of technologies in such contexts is supporting the relational, information and organization challenges of the caregivers. As a consequence of grouping the papers by stream, the articles are not presented in a chronological way, for this reason there is not a strict cumulative flow between the outcomes of Part 1 and the outcomes of Part 2. Indeed, the papers at the base of this report have been written in different stages of my PhD research, for different audiences and with different aims.

Chapter 5 is written for a Software Engineering audience, Chapter 6 for a CSCW audience and Chapter 7 for an audience in between organization and ICT studies. In Part 2 the fieldworks are not presented in separate chapters like in the case of Part 1, but each article discusses them together, reflecting on common grounds and differences. Two chapters describe the similarities between the fieldworks, discussing how existing technologies are adopted by caregivers to deal with the complexity of care work (Chapter 5 and Chapter 6), while the last chapter focuses on the differences between nursing homes and pediatric palliative care in perceiving

technology (Chapter 7).

Chapter 5 is based on a short paper published at ICSE 2017 (International Conference of Software Engineering). It is the first article that I wrote with a specific comparative intent. It discusses how, in NHs and PPC, there is a lack of specific healthcare technologies, which is overcome by adoption of technologies normally used in the daily life (mainly social media) appropriated as informal telemedicine tools.

Chapter 6 is based on a long paper under revision at First Monday journal. It deepens the topic of adoption of informal technologies in healthcare context that is introduced in Chapter 5. It compares the context on NHs and PPC, exploring how caregivers collaborate each other, specifically focusing on practices of appropriation of existing technologies. Dedicating a long paper to studying appropriation phenomena helped me to better understand the resilience strategies that caregivers enacted to cope with the lack of proper technology solutions.

Chapter 7 is based on a paper under revision at Science Technology and Human Values. It focuses on describing the main differences between the field of NHs and PPC. In particular, it discusses the different reactions that caregivers from PPC and from NHs had in relation to the possibility to codesign a technology to support knowledge sharing. To address these reflections, this chapter propose the concept of Golem, which has been used in STS studies to highlight the heterogeneous nature of technology that can be both a good allied and dangerous creature for humans.

__5. UNDERSTANDING_HOW_SOFTWARE_CAN_SUPPORT

the needs of family caregivers of patients with severe conditions[7]

coauthored with Francesco Ceschel, Marcos Baez, Francesca Fiore and Fabio Casati

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This chapter derives from a short paper written in 2016 for ICSE 2017 (International Conference of Software Engineering), mirroring the narrative of software engineering contents. This work reports a comparative analysis of NHs and PPC, describing how they are contexts where the care relationships between doctor and patients are mediated by the relatives of the patients. This chapter presents how our findings showed that the collaborative relationships between caregivers were supported by adoption of existing social media (such as: Whatsapp messenger and Facebook) to cope with the lack of proper telemedicine solutions.

This work is part of this thesis for two reasons.

First. It contributes to Part 2 of this report, exploring the potential of technology in end-of-life contexts. Indeed, it outlines the topic of technology adoption and appropriation in my research work, introducing a more detailed study of this topic in Chapter 6.

[7] This chapter is based on a short paper published at ICSE 2017 (International Conference of Software Engineering) within the track of Software Engineering in Society (Di Fiore, A., et al., 2017).

Second. This work is an important milestone of my PhD path, because it allowed me to collaborate with the Social Informatics group of the University of Trento, dealing with a vibrant and challenging multidisciplinary environment. With this work I had the possibility to work with researchers with highly technical backgrounds, finding common points in our research work, mutual enriching our backgrounds developing shared knowledge and reflecting together on our research paths.

This chapter provides the following contents:

- An overview of information, coordination and social support challenges that arise by dealing with both NHs and PPC;
- A discussion about how existing technology are appropriated by caregivers to cope with the challenges that they face;
- A discussion that provides suggestions that could be useful to develop IT systems for such environments.

5.1 Background and objectives

Pediatric palliative care refers to the end-of-life way of care for children with incurable diseases (Miller at al., 2015), while, nursing homes care for older adults with severe physical and cognitive impairments. Both PPC and NHs are two areas of healthcare characterized by complex social and emotional challenges, in addition to medical ones (Tellioglu et al., 2014; Wiegand et al., 2013).

Although the patients and diseases are very different, the two scenarios present important similarities:

1. Patients are typically affected by incurable and degenerative conditions. This is always the case in Pediatric Palliative Care (PPC), but also Nursing Homes (NHs), due to continuous budget cuts, have been focusing more on care for persons affected by severe conditions (this is the case in Italy, where we

performed our studies). Cases of people leaving a nursing home because their condition improved are a minority. For this reason, in both contexts, the treatments mainly focus on maintaining quality of life.

2. These care scenarios are characterized by a mediated relationship between care professionals and patients where not the patient, but the family caregiver (typically the parent in PPC and the child in NH), is the person that interacts with the care structures and takes decisions. This means that the healthcare institutions take charge of both the patients and their families. Indeed, when the patients are children or very old adults in the end of life, the provision of care often involves a family caregiver as the main point of contact for the health service.
3. PPC and NHs are characterized by emotional complexity, since incurable diseases expose the family caregivers to a heavy care load and human distress.
4. Patients are restricted to living permanently in the same building until the end-of-life, this is obvious for NHs but often the case also for PPC, where children are cared most of the time at home.

An important difference is that in PPC the family also manage the care, while in NHs the patient is in charge of the NHs staff and the family caregiver is mainly for support. In both scenarios, adults find themselves thrown into uncharted territory, managing a situation that they have never experienced before. To make things more emotionally challenging, the transition is often sudden and may provoke tensions within the family, as it marks the start of a progressive health deterioration and a end-of-life phase. The relevant literature in this broad area comes from different disciplines.

Healthcare studies show that patients with severe conditions are looked after by two typologies of caregivers: formal (health professional) and informal (family)

caregivers (Weinberg et al., 2007). They are co-producers of care, and their collaboration and mutual trust are essential in the care of the patients (Gittell et al., 2008). However, several studies highlight gaps in communication between formal and informal caregivers, revealing that often the family members have confusion and unanswered questions about the life expectancy of their relatives (Kripalani et al. 2007; Schoen et al., 2005).

Healthcare models, such as *continuity of care*, focus on integration between caregivers to provide a coherent, transparent and predictable care service (Bodenheimer, 2009). They support the contribution of all caregivers engaged in the care, by enhancing coordination and focusing on the needs of the patients and their family (Wagner, 2000). This model stresses the need to work on technologies to facilitate the dynamics among all caregivers for information continuity (the need for proper and coherent information), management continuity (the need for clear protocols) and relational continuity (the need of safe relationships and human support) (Haggerty, 2003).

Most of the existing technology studies (Bossen, 2013; Milligan, 2012; Ruan et al., 2010; Yeong at al., 2008) focus on solutions that foster coordination and information exchange issues. However, there is an emerging demand for technologies that help informal caregivers in both care and emotional concerns. Indeed, family caregivers are especially affected by above average burnout and depression because these sensitive care contexts can be emotionally draining and stressful (Di Fiore & D'Andrea, 2016; Gittell et al., 2008; Savage & Baily, 2004). The recognized lack of suitable technological solutions for supporting informal caregivers is a call for action for software and design researchers (Tellioglu et a., 2014).

In this chapter, we describe the results of analyses performed over the past two years to understand which role software applications can play in helping people

cope with the challenges that these contexts present. We aim in particular at understanding:

- which technologies are used today by the caregivers, why, and how effective they are;
- how can – existing or novel – software applications better address their needs.

As we will see there is space both for novel use of existing applications as well as new applications, whose requirements were not obvious to us in the beginning. We start by describing our analysis method and then report on our findings and recommendations.

5.2 Methods

To understand the needs of family and professional caregivers, we carried out an exploratory study in two different contexts in Northern Italy. We based our studies mainly on qualitative methodologies, although in the NHs case we also developed a data warehouse to analyze populations and processes because information from NHs IT system can be very detailed. In PPC, where patients are at home as long as possible, we studied the dynamics between formal and informal caregivers in PPC networks. We interviewed 15 families, and performed observations in the houses of three families. Data have been collected from July 2015 to March 2016 (by only one researcher, due to the sensitivity of the context). A second set of studies focused on six NHs to understand the issues and needs related to family caregivers. NHs have a larger population and we had access to a large number of subjects. The visits were conducted in the fall of 2015 and in the spring/summer of 2016, and all attended by at least three researchers, to collect different perspectives and reduce the chances of biases (Taylor, 2015).

Specifically, we adopted the following research methods:

i) we carried out in situ observations in all the contexts, to grasp the organizational and social dynamics that occur among and between family caregivers and care professionals, as well as the communication practices that take place among all the subjects involved, by also creating moments of informal discussion on the emerging issues with our informants (Lassiter, 2005);

ii) we interviewed formal and informal caregivers to focus on their emotional discomfort (La Mendola, 2009), and on the technological solutions they adopt to cope with their tasks and communication needs;

iii) we involved several formal caregivers in focus groups to have a deeper understanding of their perspective.

5.3 Findings

The analysis of the gathered data show that there are four main areas of problems where technology could be of help (See Table 1).

Communication with the care professionals

This emerged as a major issue in both PPC and NHs.

In PPC, formal and informal interactions (e.g., photos of patients and information on treatment) travel on the same channel, which is typically Whatsapp. Whatsapp enhances collaboration between formal and informal caregivers, allowing real-time exchange of clinical documents (such as discharge letters and tests results) and quick remote medical consultations. Usually, the mother sends a photo or a video that shows the exacerbation of a medical condition to the members of the PPC unit by asking what to do. While this has many positive aspects (chat software is free, easy, fits into the natural daily behavior and everybody uses it), it also creates a problem in terms of lack of traceability and monitoring, unclear management of privacy, as well as communication overload (chats using Whatsapp messenger happen frequently and at any time) which results in the risk of losing important messages.

In NHs the interaction is by phone or face-to-face. The same problem of overload exists here, but in NHs they complement much bigger problems which are: lack of trust in the abilities and willingness of NHs staff to provide care, and belief that the loved one may be mistreated, due to news of criminal behaviors in NHs that is sometimes reported in the national media. Furthermore, the family also feels there is a lack of clear and timely information. The interesting, and for us unexpected, aspect in NHs is that our exploratory data show that the staff members, due to the interaction overload and frustrating feeling of lack of trust, are extremely supportive of any system that provides transparency into the life in a NH. Notice that, while the interaction problems with a given family tend to reduce over time, most NHs (as we understood from the warehouse data) have a turnover ranging from 20 to 40% per year. This means that there are always new families to cope with.

Furthermore, we learned that the care professionals interact differently with the families based on their classification of "personas": with some family members they are more open and direct, with others they are more careful in the information they reveal, because of the perceived risk of over-reactions. Finally, an important finding was that in PPC they have paper-based health records, while in NHs there are information systems populated in great detail. Thus most of the information needed to provide information and transparency is there, though not always in digital formats and forms that can be understood by relatives.

Interaction within families

PPC and NHs both create very strong tensions within the family, mostly related to different emotional reactions to the problem or to disagreement about how to handle it. For example, in NHs the children of the resident sometimes disagree on the choice of taking the parent to a NH, on who should go visit and on who meets the financial obligations We also observed frustration in family caregivers who visit more often towards those who come less often. The technology used to involve the family more

in this case is again chat software, used to both inform the whole family of the situation but in part also as a tool to make relatives feel a bit "guilty" because they are not visiting as much.

Social support for the Family.

The transition to care for a relative in incurable condition is always very painful. In addition, this transition often brings with it a social isolation because of the need (or desire) to spend time with the loved ones, but also because it can become difficult to spend time with people who do not understand what you are going through. Social support is known as a useful method for coping with traumatic situations.

In PPC, family caregivers rely on Facebook groups to connect with other parents who experience the same situation from all over the world, allowing for peer-to-peer conversations to find social support, and to receive useful suggestions. However, the specificity of each illness, which in many cases is some form of rare disease, makes it difficult to find people who are living an experience similar to yours.

In NHs the problems are more "standardized" since most of the residents are affected by Alzheimer and Dementia. The family caregivers often organize peer-support groups using Whatsapp messenger, while, the family caregivers that are relatively old themselves do not use technology to relate with other family members in the same conditions and prefer to meet them at the NHs.

Learning and Managing Expectations.

A huge source of problems and misunderstanding between family and professionals is the lack of knowledge and wrong assumptions on how the patient's health will evolve and what the care professionals can do about it. We found that very often family believes the action of the professionals should be cure and rehabilitation, but this is often impossible due to the incurable and severe medical conditions of the patients.

The problem of erroneous expectations is manifested by the fact that often the patients and the relatives are not totally aware of the situation. In this case, family caregivers told us that searching for information and web browsing is essential to better frame the situation, but this is sometimes the cause of the problem which is indeed fostered by the use of diverse and inconsistent sources on the web. For example, this can create unrealistic life expectations or suggest "magical" solutions avoiding the use of medicine (i.e. the case of *Di Bella method* in Italy).

5.4 Discussion

The previous section has shown that technology adoption is either absent or, when present, comes in the form of appropriation of technology normally used in the daily life, but used as informal telemedicine tools. In this section, we summarize opportunities for novel software applications and usages of existing technology that fit the issues at hand for each problem category. We decided to focus on what we found more interesting and surprising and omit discussions on security, privacy, data integration, usability, and other concerns the reader may expect.

Three key requirements emerged from the analysis.

(1) Communications between family members and care professionals could be supported by acknowledging that the relatives react to news in different ways. In the light of this, software design processes should take this into consideration, allowing different communication strategies. Information also needs to be classified according to the level of approval required before sending it to the relatives: some information can be sent to all relatives automatically, some information requires explicit prior approval that it is ok to send, and other information needs to be edited/rewritten to avoid unnecessary concerns or to make them understandable. Because the relative might ask for clarifications, it is important that each staff member can have easy access to exactly what the relative has seen in their side of

the Information System. An additional observation that emerged is that today it is not common that EHR collect information about subjective wellbeing of both patients and relatives, although, it would be important to do so given that a broad conception of quality of life is a key aspect of care. In the specific case of the PPC services that we studied, the opportunity lies more in taking the instant messaging paradigm and (semi-automatically) extracting messages related to coordination and administration of care. Ad hoc software applications may also be proposed there like we will do in NHs, but it is unclear that they would be adopted because a network of PPC caregivers can be really wide and ad hoc applications become effective only if everybody uses them.

(2) For interactions within the family, an opportunity that emerged is the obvious extension of the software application drafted above, where the entire family can be given access. What appeared, however, even more strongly is the need to involve the family members beyond the family caregiver using the instruments they already use. For example, in NHs, grandchildren of residents can be involved by pushing involving images or information to chat (as we experimented with telegram bots for telegram users) or Instagram, as well as add events and visits scheduled to a calendar. In those PPC networks where a dedicated app is not adopted for the reason stated above, a way to easily map Whatsapp exchanges into calendars or structured information storages would already be beneficial.

(3) Opportunities for social support and learning are, instead, more in terms of reusing existing technology but with better aggregation of content and people. For example, PPC would benefit from a single place that contains a set of forums, one for each rare disease, so that parents know where to go. Similarly, for NHs the relatives would benefit from illness-specific forums as well as forums related to NHs in their region, both for support but also to compare care practices and manage their

expectations. All this can be integrated into a single portal and app, though the challenges here are in terms of content organization.

Table 1 summarizes the common points for each scenario. In summary, there are several directions in which we, as software and design researchers and engineers, can contribute to make a difference in this difficult and stressful context, essentially by enabling easy access to information that provide predictable care processes and an understandable overview of the physical and care conditions of vulnerable patients.

Table 1. Summary of problems, current practices and opportunities for the technology

Contextual problems	Opportunities for technology
Communications with the care professionals	
• Lack of transparency and traceability • Lack of clear and (timely) available information • No record of interactions • Overload of the communication channels. • Formal and informal exchanges going through the same channel. • Lack of mutual trust. Tech practices and limitations. • Care activities are scheduled and registered in EHR systems. Information collected is mostly focused on health-related data. • Communications are done face to face, via phone, WhatsApp or email (formal / informal with no trace and manually). • Facebook pages are used for events and general announcements.	• Integration of informal channels with EHR, to keep track of interactions and activities while making use of existing familiar channels. • (Semi-)Automation of the information flow through the different channels – to the extent allowed by the local regulation – to reduce communication overload on the Staff / family. • Expand data collection to aspects of social and psychological wellbeing, and so accounting for this recurrent information need. • Personalization of information delivery to key indicators of the patient and preference of the final receiver. • Translation of the information to a format that is understandable in terms of its meaning, implications and curse of action. • Structured interactions to account for type, priority, sensitivity of information and so facilitate retrieval and processing.
Communications within the family	

• Internal coordination issues, and different workload • Information not uniformly spread Tech practices and limitations. • Face to face coordination, no trace of performed activities and effort. • Sharing via WhatsApp and physical document by one person	• Traceability and visibility of family efforts. • Coordination tools that account for the care schedule, and activities of individuals and family as a whole. • Sharing tools that facilitate information flow among family members while still in control of the main responsible.
Social support for the family	
• Social isolation • Emotional distress • Need to be and to feel understood Tech practices and limitations. • Social support groups enabled via Whatsapp and Facebook private groups but problems finding relevant groups /peers. • Psychological consultations, though not available in all institutions.	• Widening the support network, facilitating the discoverability of relevant support groups. • Organizing online peer support networks with existing technology, (possibly) moderated by an expert. • (Self-) Coaching systems implementing existing successful programs to improve the psychological, emotional and social well-being. • Monitoring of the psychological well-being of the relatives
Learning	
• Confusion in what to do and expect. • Lack of medical/care knowledge and medical language. Tech practices and limitations. • "Doctor Google" and Facebook groups leading to inconsistent info. • Exchanges with other caregivers	• Peer-to-peer networks that allow sharing of practices and experiences, (possibly) supported by the moderation of medical experts. • Facilitating access to portals with certified information. • Expert support systems to help family in care activities.

5.5 Conclusion

This chapter has been a brief preamble to chapter 6. This work allowed me to provide a quick, but wide, overview of the forms of technology adoption within end-of-life contexts. Its contents are preliminary reflections that I, together with my colleagues,

addressed on technology appropriation, and that will be deepen in the next chapter.

In this chapter, I reported the emotional, relational, and communication problems that professional caregivers and family caregivers must deal with in providing care.

The chapter described how information technologies can be appropriated as informal telemedicine tools to help family caregivers in coping with both the disease and the life changes that the disease itself imposes to their lives. Moreover, it highlights how this phenomenon conveys a lack of suitable solutions, and a strong need of informal and quick care tools to improve the coordination and the social support among families and professional caregivers.

__6. WHAT_IS_TECHNOLOGY_APPROPRIATION_TELLING_US?

A study on collaborative end-of-life care work[8]

coauthored with Francesco Ceschel, Maurizio Marchese, Fabio Casati and Vincenzo D'Andrea

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This chapter is based on a standalone long paper that is under revision at First Monday journal, I wrote it mainly with my colleague Francesco Ceschel during the

[8] These outcomes are currently under review at First Monday Journal (Ceschel, F., & Di Fiore, A., et al.).

course of 2017. This work expands the structured comparative analysis of NHs and PPC proposed in chapter 5, focusing on exploring in a wider way the potential of technology in end-of-life healthcare contexts. It still compares the studies in PPC and NHs with the aim to investigate technology appropriation, observing how caregivers readapt the use of existing technologies to serve their care practices.

Chapter 5 proposed a brief overview of these phenomena, addressing specific categories in a structured narrative, while, chapter 6 addresses this topic in a different way. Here, we focused on how caregivers experience their daily care practices, how they interact with one another to articulate their practices, and the role technology appropriation plays in their daily routine. In this way, we explored appropriation phenomena as sources to reflect on design implication, being based on resilient actions that convey a need to design care tools to support the collaborative care work among families and professional caregivers.

Doing so, allowed me to better understand the nature of the issues that negatively affect collaborative care work, looking more in depth into the needs of my informants.

This chapter provides:

- Extensive theoretical reflections on the concept of technology appropriation;
- Analysis on how family and professional caregivers in both NHs and PCC adopted social media as collaborative telemedicine tools to better communicate, collaborate and support each other;
- A discussion that provides design guidelines derived from this exploration of appropriation phenomena.

6.1 Introduction

End-of-life care focuses on taking care of patients that are in the last months or years of their life, while supporting the families that assist the patients, especially

within palliative care units, hospices or nursing homes (Murray & Sheik, 2008; Teno et al., 2004). These environments are characterized not only by the difficulty in managing the care process, but also by the need to deal with the strong emotional involvement of the patients, the families and the care professional (Strauss et al., 1985). Both professional and family caregivers articulate their roles through a continuous negotiation on how to address the care of the patients, and, as a consequence, their effort in managing the care pathway is often emotionally burdening.

Researchers have been trying to find suitable ICT solutions to alleviate the burden of care (i.e. Mynatt et al. 2001). The literature includes studies that stress the necessity of mitigating the emotional burden of managing the care pathway, but there are limited ICT tools that provide suitable solutions (Chen and Park, 2013). In addition, the research struggles to approach (Dickson-Swift et al, 2007; Jones, 2013; Morse, 2007; Rager, 2005) these contexts due to their delicacy, and because of the difficulty of investigating the intimacy of the experience of the actors involved. In this context, the existing design considerations and guidelines are often focused on the specific point of view of one actor, providing only partial views of healthcare contexts (Nunes and Fitzpatrick, 2015).

The objective of this chapter is to study technology appropriation and assess how caregivers in end-of-life contexts adapt existing technologies to support their care practices and, subsequently, how the result of this observation can deliver new hints for a design process within CSCW contexts.

In this sense, we observe the appropriation of existing technologies to investigate the collaborative practices that caregivers articulate in managing their care work within end-of- life contexts. Here, we stress how studying appropriation can help to approach healthcare contexts without overloading and interfering too much with the actors involved. In other words, we focus on how caregivers adapt the use of existing

technologies to serve their daily care practices. We also discuss how appropriation within healthcare contexts informed a new design process.

The goal of this chapter has been shaped by the first case study described, which drove our focus towards the study of appropriation to guide the researchers when exploring the context at hand. Indeed, this chapter is based on two studies carried out in end-of-life contexts characterized by the critical conditions of patients and by a low level of technological adoption.

The first is based on palliative pediatric care (PPC) networks that provide home-care for children with terminal illnesses. During this study, we observed interesting dynamics of technology appropriation among caregivers, which deeply informed the design process that we were conducting. The focus on appropriation highlighted that all caregivers created their own ways of communicating and coordinating with one another through the use of social media. This focus, led to the disclosure of the potential for a new design. Therefore, in the light of the contribution of studying appropriation within the first study, we decided to investigate and evaluate the potentials of studying appropriation within a second study as well.

The second study was conducted within a group of Nursing Homes that take care of older adults with severe physical and cognitive impairments.

To accomplish our investigation, we relied on qualitative methodologies: observations, focus groups, and interviews. We chose these methodologies to focus on the care practices and the relational dynamics among caregivers, in order to have a greater focus on how the actors involved appropriate existing technologies. Hence, we relied on these methodologies to explore the relational dynamics between professional and family caregivers, in order to comprehend which issues between care professionals and families interfere with the care process.

Pediatric palliative care and nursing homes differ under various aspects, but they also have several similarities that allow us to combine our research in these two

fields. In both our studies, we analyzed the relational dynamics, the communication practices, and the appropriation of existing technologies used as collaborative tools to coordinate the care of the patients. The actors involved in the care process adopted and adapted technologies and spaces to renegotiate their boundaries of their roles within these care organizations, in order to establish collaborative relationships.

Our findings show that both family and professional caregivers adopted and adapted common technologies (i.e. WhatsApp, Messenger and Facebook) to better participate in the care process. However, our findings also show that family caregivers and professional caregivers often struggle to coordinate with one another and sometimes face tense relations, while dealing with the treatment of the patient. Exploring appropriation helped us to understand how people use technology in their own ways in order to fulfil their needs (Dix, 2007). For this reason, in this chapter we observe technology appropriation as a core object to study sensitive design contexts, exploring its potentials in guiding designers in investigating the users' needs. Appropriation informed our design process, allowing us to better understand how caregivers collectively negotiate the adoption of existing technologies, roles, and spaces to support their daily, collaborative care work. The outcome of our study stresses the need for technologies to support collaboration beyond the medical framework – a collaboration based on the contingency of the human relations, rather than conveyed by standardized procedures.

As to our contribution, we report how our study on appropriation within end-of-life contexts identified the following: (i) the needs of caregivers, (ii) how caregivers take care of fragile patients through the use of existing technologies, and (iii) the design guidelines that a designer should embed into a new technology platform to support caregivers' collaborative practices.

In summary, appropriation, while revealing the needs of caregivers, also provided us with useful indications for the design of a new platform to support caregivers' practices.

Section 6.2 describes the state of the art: it first addresses studies on collaborative care technologies (6.2.1.); then, it frames the concept of appropriation (6.2.2.); afterwards, it delivers an overview of the results presented by other studies on technology appropriation. In Section 6.3, we introduce our studies and the methodologies we used. In Section 6.4, we present the findings of the two studies, firstly by drawing attention to each individual context, whereas later by merging the results and the analysis of both contexts. The discussions in Section 6.5 provide design and empirical considerations on our studies, by also providing a series of design guidelines and some hints on how we investigate and conceive appropriation.

6.2 Framing technology appropriation in CSCW and care contexts

In this section, we explore the specificity of the chapter, proving a theoretical overview to better ground our work within the CSCW community.

We present (6.2.1) the current literature on empirical studies on collaborative technologies for healthcare contexts to frame the specificity of care organizations and care technologies. Then (6.2.2), we discuss the state of the art on appropriation of technologies, framing this concept from a broad theoretical point of view. Afterwards (6.2.3), we focus on the existing empirical studies that analyze technology appropriation in healthcare contexts, discussing the emerging design considerations. Moreover, we discuss studies that also implicitly refer to technology appropriation, without directly mentioning this concept.

6.2.1. Framing Care technologies

Some healthcare contexts, like nursing homes and PCC, are based on the carework of both family caregivers and professional caregivers (Büyüktür and Ackerman, 2017; Tixier and Lewkowicz, 2015; Di Fiore et al., 2017).

Most of the studies on care work and caregivers' collaboration in healthcare contexts originate from sociology studies that introduced the terms trajectory of work and articulation of work. The concept of trajectory of work conceives the care pathway as something that not only refers "to the physiological unfolding of a patient's disease but to the total organization of work done over that course [of the physical condition], plus the impact on those involved with that work and its organization" (Strauss, 1985, p. 8). This concept is strictly related to the articulation work (Strauss, 1985), which is the "work that gets things back 'on track' in the face of the unexpected, and modifies action to accommodate unanticipated contingencies. The important thing about articulation work is that it is invisible to rationalized models of work" (Star & Strauss, 1999, p. 10).

In other words, within healthcare contexts, care practices often intersect with one another and therefore, the care actors need mutual support to articulate their work. These concepts emphasize the need for focusing on how actors coordinate with one another, while re-shaping their environment and re-negotiating the boundaries of their roles and their social and power dynamics, as in our case studies was investigated by focusing on technology appropriation. Trajectories of care and articulation of care work highlight the relevance of having a network of coordinated actors that, because care practices often intersect, support one another in articulate their work (Strauss et al., 1985).

Traditionally, part of the CSCW community studies the collaboration of caregivers (Büyüktür and Ackerman, 2017; Schorch et al., 2016). In the context of this chapter Strauss's thoughts remain a memento for us – technology designers – that a

healthcare technology should be designed upon the needs of all the actors involved into the care pathway of a patient, in order to nourish collaboration and cooperative practices (Strauss et al., 1985, Star & Strauss, 1999). Indeed, the collaborative nature of the care work requires for responsibility and information to be shared in defined flows (Chen, 2011; Büyüktür and Ackerman, 2017).

Most of the CSCW healthcare literature focuses on papers that study collaboration dynamics in healthcare contexts and provide design considerations, guidelines, and gaps in the existing solutions.

Here, we provide an overview of design considerations and technology gaps that are acknowledged by the CSCW literature on family and professional caregivers. Collaboration between family and professional caregivers regards intricate and complex care practices (Jacobs et al., 2014), and there is a novel need to focus on collectives and their forms of collaboration to overcome the issues in care technologies (Nunes and Fitzpatrick, 2015). Hence, the imbrication of situated practices cannot be rationalized, and it is often managed with the support of both unstructured and structured information to address the complexity of this contexts (Amsha and Lewkowicz, 2016).

Within the CSCW community, it is widely accepted the need to design technologies that create a mutual awareness on the care process, in order to enact collaboration between formal and informal (Miller et al., 2016). Moreover, the literature emphasizes the need to focus not only on what patients need, but also on what informal caregivers require to coordinate their lives while articulating the care work, highlighting the need to design IT systems that take into account the logistical and relational needs of caregivers (Chen et al., 2013, Consolvo et al. 2004). It is also paramount a complete understanding of the care process articulated among caregivers, providing a temporal perspective on care tasks and articulation of collaborative practices (Bossen et al., 2013). Indeed, studies highlight the

effectiveness of collaborative technologies that focus on caregivers' relationships (Huber et al., 2015), acknowledging the paramount role of family caregivers (Amsha and Lewkowicz, 2016; Schorch et al., 2016; Tixier and Lewkowicz, 2015), the potential in decreasing their level of stress, while increasing their quality of life and supporting the management of the care tasks (Czaja & Rubert, 2002).

In this sense, the contribution of Nunes and Fitzpatrick (2015) argues that the care literature is often polarized on the study of the patients' perspective or on the study of the caregivers' perspective, providing only a partial view on the care dynamics. Due to this polarization the care contingencies are often oversimplified, leading to the design of technologies that do not answer the needs of all the actors involved in the care.

These studies are based on the understanding that healthcare contexts need to be comprehended from the articulation work that lies behind the care process, within which formal and informal caregivers are involved in a situated way. From this perspective, system design within healthcare contexts should support patients and caregivers in their care work trajectories. It is our opinion that this understanding could be nourished by paying attention to technology appropriation to better understand how actors carry out their practices, coping with the existing technologies and artifacts within their environment.

6.2.2. The concept of appropriation

A broadly used definition of appropriation can be found in Dourish (2003). The author defines it as "a way in which technologies are adopted, adapted and incorporated into working practice" (p. 467). It is a process where a technology is re-interpreted, enacted, and assimilated by people through their actual practices of use. Appropriation is recognized as a process through which "a user completes the work of designers by making interactive systems functional within the scope of their

situated activity" (Belin and Prié, 2012, p. 645). In this sense, it is conceived as a way through which people embed and adapt a technology in their daily lives.

According to the literature, the concept of appropriation is considered a matter of both interpretation and tangibility. According to Salovaara (2008), appropriation considers the interpretation (or re-interpretation) that an individual has on the potential opportunities for action of an artifact. This view focuses on the reflective and interpretive dimension of appropriation. Gamboni (2002) suggests considering the individuals as interpreting subjects that tend to appropriation. However, appropriation also has an empirical dimension. This dimension is linked to the concept of affordance (Redström, 2008), which refers to the intersection between the possible uses of an artifact and the aesthetic capabilities of the individuals (Gibson, 2014). Indeed, Flint & Turner (2016) conceive appropriation as a matter of perception, which is related to active and perceptual skills of individuals rather than to a passive phenomenon. The authors explain that perception "is not merely about the transduction of physical sensations: it is about having sensations and knowing what to do with them" (p. 44).

Therefore, in the light of the literature, we may synthesize that appropriation refers to the effort of people in the realm of sense-making of artifacts, going beyond empirical or intellectual dimensions by intertwining interpretation and perception.

Appropriation is also characterized by a collective dimension that gathers the contributions of the people involved in the process (Pipek, 2005). It can be described as a collaborative effort that individuals undertake collectively to make sense of a technology within their environment. Ackerman et al. (2007) argue that users collectively try to grasp the potentials of a technology to turn it into a resource by discovering, structuring, iterating, and promulgating new practices.

Appropriation draws attention on how individuals negotiate the sense of a technology to support their everyday practices (Rodden et al., 2004). Similarly, it can be

conceived as a process of collective discovery (Balka and Wagner, 2006) that is the result of shared practices (Dourish, 2004). Thus, the communities of practice are significant in the appropriation process (Ehn, 2008), since they enhance the alignment of agency around the technology. Indeed, studies on appropriation (Dourish, 2003; Flint and Turner, 2016; Balka and Wagner, 2006) have a strong focus on the socio-technical environment within which a design process takes place. Dourish (2004) stresses the importance of the context as situated and related to human interactions, and which arises from practices and within which contextual features are defined dynamically. Indeed, context and content cannot be separated and for this reason, we should focus on the meaning of practices in order to interpret how users attribute a sense to a context by reshaping technologies (Dourish, 2004). By focusing on appropriation, "we know the technology has become the users' own [and not simply what the designer gave to them]" (Dix, 2007, p. 27).

Figure 1: The Technology Appropriation Cycle (Carroll, 2004)

To grasp appropriation from a temporal perspective, Carroll (2004) developed a model that displays appropriation as part of a cyclic process involving users and technologies: The Technology Appropriation Cycle (TAC) (see Figure 1). The TAC is formed by six phases that follow one another in an evolving cycle that can be summarized as follows: 1) the technology-as-designed in the design process; 2) the adoption of the technology by end users; 3) the process of appropriation, where the users collectively negotiate their conception of the technology; 4) the stabilization of appropriation practices by the end users; 5) the technology in use; 6) a new design process, nourished by the hints deriving from the appropriation process.

Carroll underlines a tension between technology-as-designed and technology-in-use (2004), focusing on the real-use in place of the technology (Simonsen and Hertzum, 2012). The author describes the appropriation cycle as a continuum without a clear starting point, stressing the necessity to design malleable technologies for

appropriation, to let users shape and be shaped by them (Carroll, 2004). In particular, both Carroll (2004) and Dix (2007) distinguish between two types of appropriation in relation to design contexts: design for appropriation, and design from appropriation. Design for appropriation refers to the design of flexible technologies that can be easily domesticated by the users (Dix, 2007). It affects the technology-as-designed, in accordance with the idea of designing flexible technologies that can easily fit in the daily routines of the users. Design for appropriation can be perceived as a contradiction because it concerns the challenge of designing while anticipating the possible future uses of a technology (Ehn, 2008). Whereas, design from appropriation (Carroll, 2004), concerns the continuous design of a technology and the technology-in-use, driven from how people appropriate and use it. This view concerns design through an open-ended perspective, where "the boundaries between use, design, implementation, modification, maintenance, and redesign are blurred" (Karasti, 2014, p. 96).

According to Dourish "Understanding appropriation is a key problem for developing interactive systems, since it is critical to the success of technology deployment. It is also an important research issue, since appropriation lies at the intersection of workplace studies and design" (Dourish, 2003, p. 1). The literature provides several practical examples on how studies on appropriation are carried out and interpreted. Here, we present two representative empirical studies on technology appropriation.

Dourish (2003) explains the process of appropriation within the development of a collaborative document management system, conceiving appropriation as a dynamic process which nourishes the evolution of a designed technology. In this sense, the author sees the changes in the use of the technology through appropriation as a phenomenon that challenges the beliefs of the designers. In other words, the author defines the appropriation as a process that leads to the re-adaptation of a technology and, in turn, supports the design itself. Similarly, Flint et

al. (2016) studied the appropriation of a virtual environment: Minecraft. Minecraft is a sandbox video game where gamers create buildings with extreme liberty, with the possibility of establishing their own play dynamics. The study suggests that the users reinterpreted this socio-technical environment by shaping Minecraft, seeking new opportunities for agency. Authors embraced appropriation by focusing on how the users reshaped their gaming practices to make sense of the environment.

The literature review presented above allows us to frame the concept of technology appropriation as it will be conceived and used throughout the framework of this chapter.

It is well established within the CSCW framework that the design of information and communication technologies requires the involvement of the potential future users as active actors in the design processes, with the purpose being to design technologies able to match their needs (Karasti, 2014). Many design studies are combined through a common denominator (i.e. Redström, 2008; Dourish, 2003; Ehn, 2008; Simonsen and Hertzum, 2012; Bannon et al., 1988): it is widely acknowledged that people individually and collectively use, adopt and adapt technologies according to their practices. As we previously discussed, this process of adaptation is defined as appropriation (Dourish, 2003).

From a theoretical point of view, it is widely accepted that when we observe the real-use in place of a technology (Simonsen and Hertzum, 2012) there are often frictions between the expected use-through-design and its actual use-through-use (Redström, 2008). The use- through-design refers to when the use of an artifact is aligned with the use that the designers conceived for it: the script (Akrich and Latour, 1992). Whereas, the use through use (Redström, 2008) refers to the definition of the meaning of a certain artifact through the way in which this thing is used by its users. Hence, in this work, we conceive technology appropriation as a form of real-use of

a technology, which implies always a dialectic between resilience of the users and script, interpretations and affordances of a given artifact.

Moreover, we address technology appropriation as linked to concepts related to open design, such as design-after-design, unfinished design (Ehn, 2008), unfinished things (Tonkinwise, 2005), continuing design (Karasti, 2014), and continuing design-in-use (Henderson & Kyng, 1992), which conceive design as an open-ended process, aiming for "seeing every use situation as a potential design situation" (Ehn, 2008, p. 96). These concepts open the conceptual boundaries of the design process, by extending its limits beyond a close, temporal perspective. Therefore, we address appropriation as an intrinsic part of design processes. In agreement we Storni (2010), we conceive technology appropriation "as a form of innovation- in-use, which creates a new use value" for both designed and future technologies (p. 540). In this sense, our study focuses on technology appropriation as an evolving process which can nourish and enrich the evolution of a designed artifact by increasing its collective meaning, and informing the design of future things. In this work, we study the phenomenon of technology appropriation to focus on the phase within which the reinterpretation of a technology occurs. Moreover, we analyze the technology appropriation phenomena not after- design, but before the beginning of a design process, using it to deliver design guidelines and explanations of what needs lie behind the practices of the people that adapt technologies.

6.2.3. Technology appropriation in care environments

The literature addresses technology appropriation as a design phenomenon that is independently carried out by users who rely upon collaborative sense-making processes and collectively negotiated practices. In the light of the role of collaboration in appropriation theories, this subsection reports empirical studies within healthcare environments that refer to appropriation both directly and indirectly.

This literature also delivers several contributions that highlight how technologies can be designed in accordance with how people re-shape their socio-technical environment in healthcare contexts.

Balka & Wagner (2006) illustrate the implementation and configuration of a wireless call system in a hospital. The authors explain that the implementation of the system required the reconfiguration of the physical spaces inside the hospital. Its configuration called for the collective effort of technicians and staff of the hospital. In this study, the authors focused on re-modelling the social context through the configurability of a technology. They argue that in designing a technology, it is more important to configure the social needs over the technical ones, since this would support collective appropriation practices by enhancing reciprocal relations.

Bardram & Bossen (2005) talk about mobility work in hospitals and the need to let people appropriate technology in order to bring about an ideal configuration of people, resources, knowledge and place (p. 137).

Muller et al. (2015) analyzed appropriation in the realm of ageing at home and Ambient Assisted Living (AAL). They studied how older adults with low technology literacy used a technology to coordinate themselves with their care network. To study collaboration between elders and their care network the researchers used the concept of community of practice, which, in their opinion, highlights the collective dynamics.

In another study, Storni (2010) explores how chronically ill patients appropriate medical devices, such as glucose meters or blood pressure monitors. Starting from reflections about the role of self-monitoring devices in chronic care delivery, he suggests that appropriation practices can hinder the risk of the technological determinism in the care pathway of the chronic patients.

Lastly, Aarhus and Ballegaard (2010) analyzed the use of boundary objects to support the management of care in home settings. Specifically, they studied how

care artifacts, such as care technologies, can be used and adopted by both patients and caregivers in providing self- care and care. Indeed, Aarhus and Ballegaard state that care objects enhance the creation of orders at home through the negotiation of their meaning and their use by both caregivers and patients.

These studies emphasize the advantages in focusing on technology appropriation as it deepens the understanding healthcare contexts.

As mentioned above, over the last few years, several studies investigated the role of existing technologies in enhancing collective care dynamics while mentioning neither adaptation nor theories on appropriation. However, they indirectly engage the topic, discussing design processes and studies where individuals arranged existing social media in their care practices. In particular, studies describe online health communities of Facebook, analyzing how participants of thematic groups on specific diseases create remote relationships to provide advice and mutual support (Greene et al., 2011; Newman et al., 2011). They found that such technologies help patients and informal caregivers in having emotional support, information sharing, and a sense of community (Greene et al., 2011).

Likewise, studies on health video blogs on YouTube, confirmed how vlogs are used – similarly to Facebook – to share experiences and knowledge on diseases, and to make patients feel less lonely and isolated (Huh et al., 2014).

These contributions highlight the importance of appreciating the complexity of healthcare from heterogeneous perspectives, suggesting how the study of technology appropriation can deepen social needs, community relationship and ideal configuration of practices.

6.3 Research contexts and methods

Here, we present two studies carried out in two different end-of-life contexts: (i) a pediatric palliative care (PPC) network, (ii) and a network of six nursing homes (NHs). The studies are based on two independent projects, which are conducted within the

Interaction Lab and the Life Participation research group of the University of Trento, Italy. The studies were respectively built on the project *Miuchi* and the project *Collegamenti*.

Miuchi (身内) is a Japanese word, which means a broad family and at the same time a close community, describing one's folks It is similar to the concept of community of spirit proposed by Tonnies. *Miuchi* project focuses on PPC, studying a network of care for in-home, hospitalized children affected by critical degenerative or incurable diseases. PPC is conceived as a home-based service which builds collaborative relations with the parents of the children. This study was carried out before the *Collegamenti* project and it influenced the development of the study in the nursing homes. Indeed, the study within the PPC network was conceived to re-design a technology platform to support the coordination among caregivers in the care of incurable children. Initially, the methodologies were chosen to focus on the collaborative work practices of care professionals and family members. Nonetheless, the advancement of the investigation highlighted processes that, despite belonging to collaborative work practices, were actually related to appropriation of existing technologies. Thus, to comprehend the social requirements that the platform needed to be built on, we refocused our investigation on how technologies were appropriated.

The second study, based on the *Collegamenti* project involved a network of nursing homes that take care of older adults, most of which are suffering from severe conditions. *Collegamenti* in Italians means "connections", and it is also conceived as the merge of the word *collega* with the word *menti*, which respectively mean *connecting* and *minds*. The nursing homes generally host non-autonomous older adults in end-of-life situations, treating them in collaboration with their families. The study carried out within the nursing homes aimed (similar to the preceding case) at investigating the collaborative work practices of the caregivers in order to design a

technology platform to enhance information sharing among care professionals as well as between care professionals and relatives of the older adults. In this case, the methodologies and the focus about the data collection were chosen according to the results of the PPC study carried out earlier. Therefore, given the results of the preceding study was built on the study of appropriation as well.

Both studies were based on qualitative methods and included ethnography and observations, interviews and focus groups, focusing towards the appropriation of existing technologies. Both PPC and nursing homes are critical contexts that posed a variety of ethical and methodological dilemmas due in part to the fact that many subjects, in particular the family caregivers, faced difficulties in participating in our study due to the frail conditions of their relatives.

For both research contexts, we obtained the ethical approval of the University of Trento to carry out our study. Therefore, for privacy reasons related to the ethical approval protocols, the names of the cities where the PPC networks and the nursing homes are located cannot be declared.

6.3.1. Exploring pediatric palliative care

We studied PCC in the context of two home care services. Home care is now increasingly common in healthcare, because it allows patients to be cured in their own home, in an emotionally safer context (Bossen et al., 2013). PPC is a multidisciplinary care approach that takes care of incurable children and their families, providing care treatments as well as psychological and human support. Data on the PPC study derive from *Miuchi* project that is an exploratory project, which had the goal of supporting the re-design of a collaborative technology platform by studying the potential of information and communication technologies to enhance coordination, collaboration and social support between care professionals and family caregivers.

We explored the dynamics between the family of the patients and the care professionals by studying the PPC services of two cities in Northern Italy. These networks engage care professionals and family caregivers in an ecosystem of therapeutic and human relations involving over two hundred young patients. Due to the delicacy of the context, this part of the study was based on qualitative methodologies, in order to explore the stories of our participants, their emotional background and the issues they face. The core methods used are ethnography and interviews. At the beginning of the study, the observations highlighted the appropriation phenomena and, therefore, this focus has also been included in the interview outline. The data were collected from July 2015 to December 2016 by a single researcher as the research subject was extremely sensitive and participants could then refer to one trusted person. Indeed, conducting interviews and ethnography in pediatric palliative contexts can be emotionally challenging for a researcher, who also needs the time to reflect on their emotional experience.

Ethnography.

We adopted participant observation (Taylor et al., 2015) to study the care practices, organizational dynamics and the collaborative relationships within the PPC service we investigated. Doing ethnography (Blomberg & Karasti, 2013) in CSCW research, we focused on how formal and informal caregivers collaborate and support each other, on what their care tasks are and on how they communicate. We adopted a Collaborative Ethnography rationale, creating moments of informal discussion with our informants, in order to validate the emerging issues and research results (Lassiter, 2005). We used sensitizing concepts (Blumer, 1986) to address the field notes, which were related to: 1) the network of actors; 2) the variability of collaborative work practices; 3) the daily practices of the caregivers; 4) the communication practices and gaps; 5) the impeding and facilitating factors of the

home care practices. Then, when during the course of the research work, we added a sixth sensitizing concept: 6) the use of social media and existing technologies to support collaborative care practices.

The ethnography was based on several short-term sessions of participant observation that lasted approximately 4 days each (Pink and Morgan, 2013). We had a 35-day ethnography conducted both in the hospitals and in the family homes of the patients. The observations within the hospital included medical visits, informal moments between colleagues, 11 meetings where care professionals decided the care pathways of the patients, meetings with school teachers of the patients, a 3 days' course of PPC professional training, and managerial meetings.

In the first PPC network that we studied, access to the field was supported by a gatekeeper (a pediatrician) who introduced the researcher to the other informants in a very informal way, positively influencing such access. Conversely, in the second PPC network, field access was supported by a very formal head physician, who introduced the research that we were conducting to our informants with solemnity. This slowed down the access to field, but constructive relationships with our informants were created nonetheless.

Interviews.

We conducted 18 interviews with the care professionals and the parents of the patients. We adopted a dialogical approach since it pays particular attention to empathy with the interviewees, supporting them in the description of their personal life by embracing their narratives (La Mendola, 2009).

The care professionals involved included PPC doctors, nurses, psychologists, social workers and head physicians. The outline of the interview was based on fifteen questions that investigated the following topics: i) how family caregivers and care professionals perceive the care context; ii) how the interviewee perceived the

relationships between family and professional caregivers; iii) what the interviewee thought about quality of care and the provision of PPC care; iv) what the daily care practices of the caregivers are; iv) what the information and communication gaps between family and professional caregivers are; v) appropriation, and what the role of technologies and social media is in supporting the home care provision; vi) the collaborative care dynamics among caregivers; vii) what the wishes, needs and hopes in relation to care delivery are.

Specifically, we explored issues related to providing care at home and the collaboration between several caregivers. We focused on the factors impeding or facilitating their work, paying attention to the relevance of having human relationships in coordinating care tasks between places and actors.

We interviewed participants willing and able to participate. The interviews lasted about one hour. The care professionals were interviewed during their working hours and according to their availability. Due to time constraints related to the unpredictability of their work, they were often interviewed during the journey to a patient's house. Conversely, the parents of the patients were interviewed at their home, in a place where they felt emotionally safe. The selection of the families to be interviewed was supported by the psychologist of the PPC team, to ensure respectful interventions that did not create emotional distress to the family members.

6.3.2. Exploring nursing homes

The study was conducted within *Collegamenti* project, with the aim of developing a new information system to support the collaboration and the communication among professional caregivers and between professional and family caregivers of the nursing homes. The field investigation was carried out in six NHs located within the Province of Trento, Italy form March 2016 to January 2017. The study received the approval of the ethical committee of the University of Trento.

In light of the findings of the PPC study, we decided to observe the appropriation of technologies also in this project in order to evaluate its potential. We adopted two different methodologies that were chosen in accordance with the actors involved. On the one hand, we approached the family caregivers as individuals within the context of their respective NH and had to be studied individually and in relation to their personal history and experience. On the other hand, we approached professional caregivers as a community of practice that needed to be studied as a whole. Specifically, we chose to rely on individual, semi-structured interviews to comprehend the personal story and background of every family caregiver, to better understand their situation and how it related to the context of the NH. We instead conducted focus groups with the professional caregivers to understand how they coordinate and attribute meanings to their work environment, and how they articulate the relational practices with the family caregivers.

Interviews.

We conducted in-depth interviews with each of the 27 family caregivers. We designed a semi- structured interview guideline (Silverman, 2016) configured in line with the concept of a topic guide as proposed by Arthur and Nazroo (2003). The guideline covered the following topics: i) what led the family caregivers to rely on the nursing homes; ii) how frequently the family caregivers visit their loved ones; iii) the relationship that family caregivers have with the NH staff members; iv) the relationship the family caregivers have with other family caregivers, if any; v) how family caregivers manage the communication flow of medical information with the staff of the nursing homes; vi) their technological literacy and current use of ICTs; vii) appropriation and the role of technologies and social media in supporting the provision of home care; viii) the things the family caregivers would like to change within the nursing home. The guideline served as an interview agenda in order to

explore relationships within the care work of family and professional caregivers. The topic guide provides only a minimum of structuring in order to allow "the pursuit of unanticipated but nonetheless highly relevant themes that emerge" (Arthur and Nazroo, p. 115) and, therefore, is very suitable for our exploratory research design. Together with the staff of the nursing homes, we randomly selected the interviewees. Those willing to participate were recruited by the staff members of the nursing homes. Eventually, we obtained a sample of people mostly retired and with a large availability of time, which enables them to visit their respective NH more frequently. Interviewees were, however, diverse in terms of gender and age.

The interviews were held within private offices in the nursing homes where the loved ones of the interviewees were hosted, and were scheduled together with the directors or the chief nurses of the NHs upon confirmation of the interviewees. Interviews were conducted individually and in parallel by two researchers. The researchers agreed on following the guidelines without limiting the possibility for the interviewees to explore new topics. They also met after each interview to update each other on new topics that emerged within the interviews. All the researchers who conducted the interviews had a background in social science and previous experiences in conducting interviews. Interviews were recorded and transcribed, and lasted approximately one hour.

Focus groups.

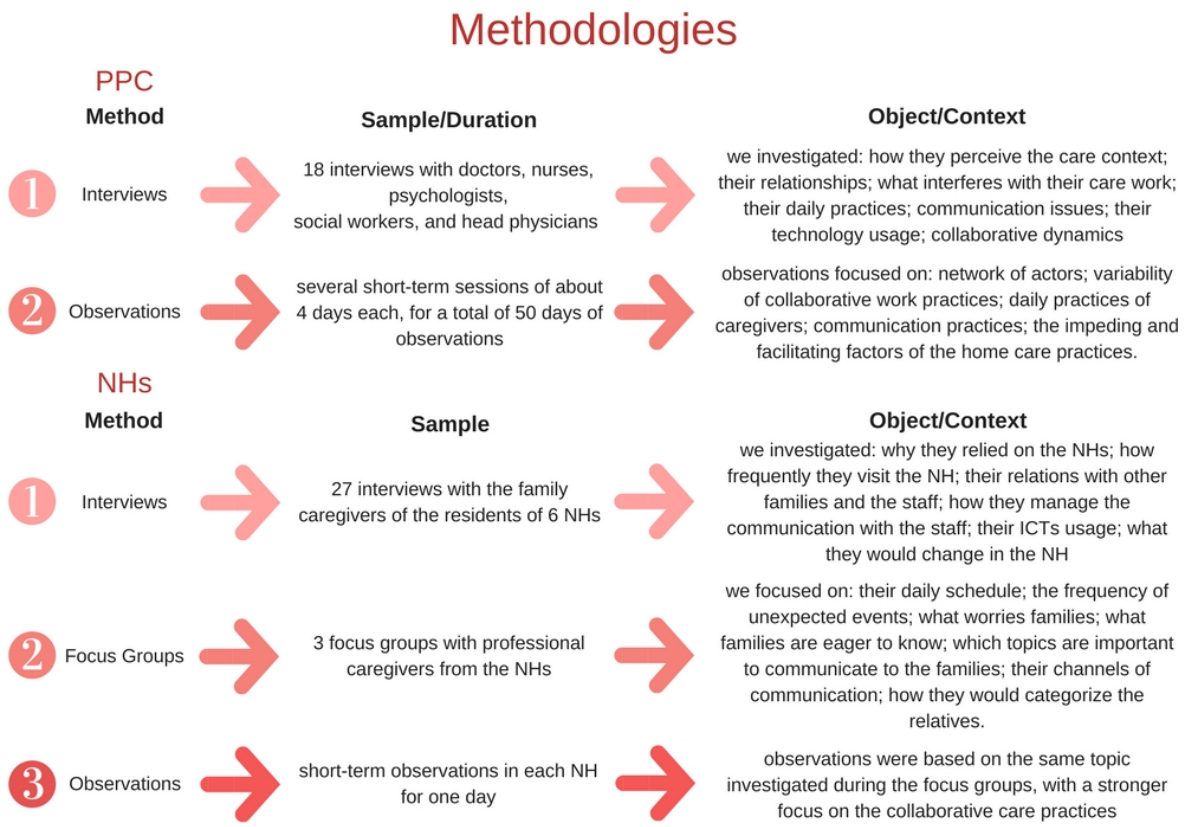
We conducted three focus groups with the staff members of the nursing homes, since several studies (Kitzinger, 1994; Kitzinger, 2002; Green & Thorogood, 2013) support the view that focus groups are an appropriate method for health research, allowing researchers to also experience the internal dynamics, such as jokes, innuendo, responses, sensitivities and interactions among group members. The focus groups offered new insights into the substantive topics under investigation,

with a more extensive perspective (Hyde et al., 2005). The focus groups aimed to understand the context of the NHs from the point of view of the care professionals. The focus groups were based on a guideline that investigated the following topics: (a) the daily work schedule of each professional; (b) the frequency of unexpected events that may interfere with the work schedule; (c) what generally worries families and what families are eager to know concerning the situation of their loved ones; (d) which topics the staff believe important to communicate to families; (e) the channels of communication among staff members and with the family caregivers; (f) what the staff thinks about the appropriation of social media by the family caregivers.

Care professionals were randomly selected, together with the directors or chief nurses of the nursing homes, in accordance with their willingness to participate and their availability, since the focus group had to be held in the nursing home during working time. We tried to involve at least one staff member for each professional role, including nurses, socio-health operators, doctors and office workers.

Focus groups were scheduled based on the availability of the nursing homes and the care professionals, and conducted within the nursing homes in private meeting areas. Each focus group was made up of 7 to 9 participants. Throughout the study, the same moderator and the same assistant moderator, who were chosen for their sociological background and experience, conducted the focus groups. The former facilitated the focus group, whereas the latter assisted the moderator and took notes. The focus groups were managed so as to allow all participants to express their ideas and to foster the exchange of thoughts. All focus groups were recorded and transcribed, and lasted approximately one and a half hours.

Image 1. Summary of the Methods.



6.3.3. Data analysis

We analyzed the data collected via thematic analysis. The adoption of this method supported the identification of social processes and patterns within our study (Braun and Clarke, 2006). In both research contexts we collected and produced a considerable amount of data that have been analyzed to provide a rigorous contextualization and interpretation. For the PPC context, we identified 39 themes that allowed us to identify the primary issues fostering the emergence of the appropriation of technologies, finding common topics from the two case studies. Thus, we focused on the use of existing social media among caregivers in order to support their PPC network, enhancing interpersonal relationships. In the case of the nursing home context, we identified a total of 36 themes that allowed us to explore

the relational setting between family and professional caregivers, and the difficulties of relying on available technologies to establish places of interaction. The analysis was conducted independently by three researchers who participated in the study in order to reach agreement about the data interpretation and the identification of themes.

6.4. Findings

The following subsections explore the findings that emerged from the two healthcare studies that we conducted: the former analyzes Pediatric Palliative Care Services, and the latter study a network of six nursing homes.

The findings stress the importance for caregivers in PPC and nursing homes to be assisted by technologies that support coordination and information sharing, while allowing users to nurture human relations. In the following paragraphs we will consider the two case studies separately. Each case will be introduced by a short explanation of the research context, thus to contextualize the findings and have a clearer understanding.

6.4.1. The pediatric palliative care

The PPC services that we studied were differently organized in that one was based on a core, small team with a bottom-up organization, while the other had a heterogeneous team managed in a top-down way, but both the PPC services shared similar collaboration and appropriation dynamics. Both PPC teams were composed of pediatricians, nurses and psychologists. On the one hand, they organize and put into action the care plans provided by specialized doctors, providing the home service, home visits and specialized services, such as blood tests and specialized examinations. In our use case, a PPC care plan can involve up to 30 care specialists, in addition to the family members of the patients. This makes it difficult to manage

the relationships among care professionals that work in different places with different health specialties. The PPC teams work as a bridge among all the care professionals involved in the care plan. On the other hand, the PPC teams are also a reference point for the families of the patients, providing care at the homes of patients and at the same time furnishing social and psychological support to them.

The PPC networks we studied have a family-centered care rationale. The care professionals work, in the homes of the young patients, side by side with the families, which are conceived as core actors in providing care. The care professionals are responsible for both the patients and their families, working across specialties, addressing medical, social and psychological needs. The families of the patients are essential in this home care network, since the relationships between the patient and healthcare professionals is always mediated by the family. The possibility of having an effective collaboration with an engaged and, hopefully, serene family is perceived by the professional caregivers as a fundamental enabling factor of the care service. In particular, the mothers are essential, since this is whom the care professionals mainly work with. This PPC network includes approximately 60% of patients affected by chronic diseases, while the remaining 40% of the patients have cancer.

In the PPC, the relationships among caregivers raise several coordination and communication issues that are related to the fact that in Italy there is a lack of Electronic Patient Records and of information systems that support collaboration and information sharing among caregivers. In this context, both care professionals and family caregivers appropriated social media to fulfil their needs. Specifically, WhatsApp, Facebook, and Facebook Messenger have been appropriated as an informal telemedicine tool to support coordination and information sharing on three different levels: (i) a professional level that covers the communication among the care professionals of the PPC teams; (ii) a professional-to-family external level that

covers communications between the care professionals of the PPC teams and the parents of the young patients; (iii) and an external level where family caregivers seek peer support via thematic groups on social media.

Firstly, the PPC teams created a dedicated WhatsApp group to rearrange the daily care plans when emergency tasks occur, and to exchange medical information that is difficult to trace due to the low-quality of the available information systems and computers. One doctor said, *"Please write that we have substandard computers, by the way, Laura's (a nurse) is particularly clunky!"*

The general goal of this appropriation practice is to create a common thread between the relationships of the professional caregivers. Indeed, one of the WhatsApp groups used by the PPC teams is named *a network with no gaps*. The PPC teams also use the internal WhatsApp group to ask for advice from colleagues.

As an interviewee (nurse) said, *"When we are at a patient's home maybe we find out that the skin around the PEG [the Percutaneous Endoscopic Gastrostomy, a medical device] is red or there is something that doesn't quite fit... so...we take a picture and send it on our internal WhatsApp group, asking, 'what should I do?' Then, the doctor checks it, and we decide what to do. It helps. It helps a lot in responding quickly or in avoiding redundant examinations."*

Moreover, they stated that WhatsApp, being an informal tool, fosters closeness, sympathy, human support and spontaneous conversations among colleagues.

"It is (WhatsApp) a great tool, since we started using it we communicate more and we are closer" (Interview: nurse).

WhatsApp, used outside the group framework, allows family and professional caregivers to establish real-time collaboration and information sharing. Indeed, in PPC, both the professional and the family caregivers deal with, on a daily basis, care tasks that, due to the contingency of the diseases, fluctuate in unpredictable ways between routine care tasks and emergency tasks. In this context, family caregivers

rely on WhatsApp in case of a medical emergency, sending photos or videos that show the care professionals the medical conditions of the children, while seeking advice. Conversely, the unit exploits WhatsApp to provide a remote medical support to the families. For instance, they provide updates about therapies, test results, or scheduling new visits, since WhatsApp allows the exchange of clinical documents and quick remote medical consultations. It is also used as a means of providing remote social support and empathic relations, enhancing trust and togetherness among family and professional caregivers.

As an interviewee (psychologist) said:

"at the beginning I was skeptical about using WhatsApp with the families, but now it is an important part of my work, helping me to be there with them".

While, another interviewee (mother) said:

"I am very happy to know that if I have a problem with my child I can just text it to the doctor and have a quick answer."

As a nurse said:

"WhatsApp pictures are not like medical visits, but they help us in solving some of our problems".

Thirdly, in PPC, the contingencies that the family caregivers have to deal with may lead to social isolation and discomfort. For example, parents rarely have the possibility of going out together since they are unable to leave their children alone. Facebook groups and dedicated forums help parents in making contacts with other parents that experience the same situations. Active participation on social media gives parents the possibility of having peer-to-peer conversations, finding social support, and obtaining useful advice. As an interviewee (mother) said:

"During the day I am totally engaged on my child's care. It is during the night, when she sleeps, that I can get in touch with the world to chat on Facebook on our group with the parents of children that have the same condition as my daughter."

6.4.2. The nursing homes

The six nursing homes that were part of our study differ, not only in the number of residents they host and the facilities they have, but also on the degree of freedom they allow their residents. The nursing homes provide similar services but with different approaches, and each nursing home is structured differently. Yet, the work practices and the mission are the same. The nursing homes provide residential care, and work on creating a comfortable and cozy environment for both the residents and their families. Family caregivers differ in terms of their relationship with the resident: they can be the partner, the son or daughter, a relative, or a friend, but most of them were over 50.

Although the nursing home staff provides constant assistance to the residents, the family caregivers are involved in the care plan because they are considered a resource by the staff. Yet, the staff also stated that since the family caregivers are emotionally involved, they are taken care of as well.

The director and a nurse of two nursing homes respectively said: *"family caregivers are a resource for us, we want them to be involved in the decision making process (...) we welcome the families as patients as well. They are additional patients, we take the whole package".*

When a new resident arrives in a nursing home, the care plan prepared for the patient involves the family member as well, because most of the patients are neither cognitively nor physically able.

As a professional caregiver said, *"In this first phase it is right and mandatory to involve the family caregiver"*.

However, some nursing homes prefer to have private internal preliminary meetings before discussing care plans with the families. Indeed, as a nurse said, *"If we want*

to tackle the situation in the right way, involving the family caregivers may be an interference".

Family caregivers are considered a resource for the nursing homes, but the relationships between staff and family caregivers are often characterized by a strong emotional involvement of the latter and, in the case of the former by an undervaluation of the relatives' relational and information needs.

In the nursing homes we observed several shades of appropriation that can be summed up in three aspects: (i) how family caregivers and care professionals communicate and collaborate by appropriating spaces; (ii) how family caregivers of different residents rely on one another in creating relations, and seek support through the appropriation of social media; (iii) how relatives use social media to stay in touch with the rest of the family and share information about their loved ones; and (iv) how family caregivers look for peer support on social media. Firstly, in nursing homes the communication between formal and informal caregivers is managed according to the reciprocal belief in revealing only as little information as is. A common desire of family caregivers is better interaction and information sharing with the staff and greater participation in the care of the loved ones. Conversely, staff members asked for recognition of their professionalism. Nursing homes involve both groups of caregivers in a perpetual negotiation. Differently from the PPC, in nursing homes family and professional caregivers do not actually work side-by-side to carry out the care pathway, especially because the care is carried out within a private structure, not at home. However, family members and staff members articulate their care work informally. For instance, many family members generally visit their loved ones during lunchtime to feed them or to assist in their primary needs. This does not follow a precise scheme, but allows caregivers to collaborate on a daily basis. By doing so, family caregivers appropriate the caring spaces within the nursing home facilities,

turning them into places of interaction. This fulfills the need of family caregivers to nurture a human relation that goes beyond the medical framework.

Secondly, it emerged that family caregivers articulate their work with one another as well.

A family caregiver said, *"When a family member is not present, someone else [visiting another resident] feels like he/she needs to assist also the other resident."* In this sense, family caregivers rely on one another to control the situation of other residents, coping with the perceived lack of information and relationships between them and the care professionals. They appropriated WhatsApp for this purpose and this form of resilience emerged as a common phenomenon. It allows different family to count on one another, being in touch through WhatsApp groups by remotely monitoring if the staff members are taking proper care of their loved one.

However, this practice is hindered by professionals; *"Here, the relatives of the residents rely on one another. When we visited our mom, we updated on Messenger or WhatsApp, sharing pictures and so on... We were fully in tune. There were good vibes between us. However, this annoyed the staff members, they even told me 'it's because you exchange information'! But I'm an only daughter and when my cousin or a friend pass by it is easier for me... and there is nothing wrong with it!"*

Thirdly, the families will have nominated a specific person to liaise with the professionals in order to coordinate the care pathway. However, family caregivers also coordinate among themselves. They develop their own methods to collaborate and communicate with one another. Several family caregivers stated that they use WhatsApp groups to share pictures of the residents with family members and vice versa: *"My brother sends me pictures of his sons, and I show these to my mum [the resident] and she... just goes into raptures!".*

It is also used to allow other family members to feel closer to their loved ones as well as assisting relatives who struggle to cope with the situation of their loved ones.

For example, a family caregiver confessed that, because of the serious hereditary mental disease of her mother, she struggles to face the situation and feels unable to visit her mother frequently. She said that she uses WhatsApp to receive pictures or video of her mother by other relatives in order to feel closer to her. Family caregivers declared using WhatsApp to coordinate the visits and to exchange medical information with their relatives: *"We have a WhatsApp group, me and my brothers… we update on the health status of our mother… Sometimes we exchange pictures as well"*.

Or: *"I am here [at the nursing home] every day, and we [with the other relatives] keep up to date. We have a WhatsApp group for that".*

Fourth, family caregivers also use Facebook to get in touch with relatives of older adults with the same disease. For instance, a family caregiver declared that:

"there is a local Facebook group for Alzheimer's… it is really nice, because you blend in with others. There is the Facebook page where everyone can post, and there is also the chat. And we also exchanged WhatsApp contacts and telephone numbers, thus we also met in person! Look, when you have a person… like me… I had my mother at home and it was difficult to go to the monthly meetings when there were emergencies. Therefore, many times you stay up all night because she doesn't sleep and you have to take care of her… there are many solutions and Facebook helps!"

6.4.3. Final remarks: arising issues

Although PPC and nursing homes differ under several aspects, there are many common organizational issues that unite them. (i) We noticed that PPC and nursing homes are environments characterized by a high level of emotional involvement and distress. In both contexts, family and professional caregivers respectively deal with the burden and the sense of guilt of the situation; they feel responsible for the care of their loved ones (Schorch et al., 2016). (ii) In end-of-life care, family and

professional caregivers need to base their tasks on articulation work and collaboration that depends on the information flow. (iii) PPC and nursing homes are healthcare contexts that may be perceived as built upon the need to exchange merely medical information (Storni, 2010), but behind both cases lies the necessity to nurture human relations over medical ones. (iv) Professionals and families need to build trustworthy relations in order to facilitate one another in their complex care work. (v) The actors relied on the adaptation of technologies and spaces to reshape their environments in accordance with their need to articulate their practices. (vi) The actors of PPC and nursing homes established practices that depict the contexts differently from how they may appear. (vii) Medical information and medical data are often lost because they are shared through unstructured and informal communication channels.

Focusing on technology appropriation in these contexts highlighted a series of challenges that professional and family caregivers face. These challenges can be presented from two perspectives: the one of family members, and the one of staff members.

Family Caregivers

Family caregivers are always included in the decision making process and the care pathway of the patients. Nonetheless, they collaborate and participate as separate actors from the formal network of care. Subsequently, they face coordination issues due to asynchronous communications with the staff, or the impossibility of being up-to-date on the health situation of the patient. Family caregivers collaborate with the care professionals but the care pathway is primarily managed by the professional caregivers that know the entire medical situation of all patients.

Family caregivers both share and receive information from care professionals. Family caregivers often share part of their history with the patients and their disease, and they can be considered experts due to their direct relationship with the patient.

Moreover, since the care pathway is quite articulated and unpredictable, the professional caregivers sometimes rely on their professional skills rather than on the knowledge of the family caregivers. This situation can create barriers between caregivers, and it may hinder the mutual involvement of professional and family caregivers into the care.

In relation to the mutual involvement in the care pathway, family caregivers relate to a wide care network in frequent turnover, which hinders family caregivers in building trusting relationships with each care professional, or means they end up relying on a single, specific person. The management of the care is time demanding and a frequent cause of isolation for family caregivers, being occupied in assisting their loved ones. We observed that family caregivers seek ways to relate with others, in order to cope with the burden of assisting someone in critical conditions by sharing their fatigues.

Professional Caregivers

There is a specific hierarchy within nursing homes and PPC, upon which professionals are organized and are entitled or not entitled to carry out certain tasks or deliver sensitive information. This hierarchy can confuse the family caregivers who, often unaware of these limitations, do not discriminate from one professional to another and relate to them as if they are all interconnected and fully aware about the overall situation of the patient. As a consequence, care professionals struggle to accomplish their tasks and coordinate with the other staff members in attempts to relate to the family caregivers. This does not facilitate the possibility of establishing trustworthy relationships with the relatives.

Given the absence of proper technological infrastructure, care professionals need to rely on one another to coordinate, share information on patients, share notes on appointments or unexpected events. Staff members stressed the absence of a place to have a shared view on the collaborative work practices and a clearer general

overview on all patients. Although, professionals established methods to coordinate their work, the overall knowledge on patients remain fragmented among professionals.

6.5 Discussion

In this chapter, we studied technology appropriation as enacted within two socio-technical environments, observing how actors re-attributed meanings to their environments and collaborative care practices.

It is well established within the CSCW framework that the design of information and communication technologies requires the involvement of the potential future users as active actors in the design processes, with the purpose being to design technologies able to match their needs (Karasti, 2014). Similarly, to other studies presented in the literature (Büyüktür and Ackerman, 2017; Tixier and Lewkowicz, Schorch et al., 2016), our study was designed to investigate the possibility to develop a new technology platform to foster and support coordination and sociality among caregivers of patients in an end-of-life condition. However, even though the literature already offers several contributions that deliver interesting design opportunities, as well as design guidelines, healthcare contexts appear to be underestimate in their complexity (Nunes and Fitzpatrick, 2015). This, may result in technologies that do not completely fulfill the needs of target user groups. In this sense, we chose to tackle our research contexts from a different perspective, thus to deepen our understanding of the actual nature of the PPC and nursing homes.

With this work, we aimed to address the appropriation phenomena that took place before the beginning of a design process. We explored technology appropriation in situ, before the beginning of an institutionalized design process, studying practices of appropriation that took place earlier than the design that had the goal of fostering collective sense-making and collaborative practices. Redström (2008) defines use-

design as people radically re-define the use of an artifact, inscribing new ways of use. In the light of this, we could argue that in this work we addressed technology appropriation to inform our design process, conceiving it as a form of use-design that occurred before the beginning of a formalized design process. Thus, we aimed to reinforce the concept of design from appropriation (Carroll, 2004) as focused on designing technologies by starting from the appropriation practices of the future users.

In this way, the understanding of the two healthcare settings derives from our focus on technology appropriation. In the specificity of our case studies, we observed the appropriation of existing technologies that were not designed to fulfill the needs of our target user group. Indeed, it emerged as a form of coping mechanism that caregivers revealed with their seek for solutions to their needs. The appropriation phenomena we observed, pertain the adaptation of technologies, but it also included the re-adaptation of spaces into new places, and the negotiation of the boundaries of the actors' roles.

The appropriation that have been disclosed by the actors we investigated led us to formulate a series of design guidelines; which will be presented in the following section. This moves the focus from the design process as a closed thing, to a wider process that may begin with the adoption and adaptation of a more general technology. Indeed, from our work arises the need to address this concept with a novel temporal perspective, conceiving design as a perpetual becoming with (Akama, 2015) of relations, practices, understandings and appropriations (itselves) that can arise also before the formal design process. Yet, to better comprehend how our focus on appropriation opened to new design opportunities we need to analyze and draw some reflections on the results of our investigation.

The field studies we presented in this chapter, revealed a strong organizational complexity among the actors involved in the care practices, which have to deal with

emotional situations that are often difficult to bear. Both studies begin from the necessity to understand how family and professional caregivers can be supported by a new design in creating a greater mutual involvement into the care process. We focused on appropriation to comprehend how caregivers make sense of their environments, thus to elicit design opportunities for a new technology platform. Our focus on how actors "appropriated" existing technologies, revealed a need to foster human relations beyond the medical framework, in order to support family members and professional caregivers to cope with those issues that are actually at the origin of tense relationships and emotional distress.

Within the PPC context, professional caregivers were led to adopt and adapt new tools to create new meanings, in order to communicate with one another, and to build a solid and trustworthy network with the family caregivers involved. Caregivers adapted the technologies to make sense of an environment that, otherwise, would lack the sociality and the dynamism to support the actors involved, not only from a medical perspective, but especially from a social perspective. Indeed, in this context, caregivers have to face a strong level of emotional distress, which affects them on an emotional level and, consequently, it affects their collaborative practices. PPC is a context that seems to require a greater demand of attention of people's needs while allowing a close collaboration among actors. Caregivers appropriated technologies – such as WhatsApp – that could allow them to quickly collaborate while nurturing social relations and that allowed them to redefine the boundaries of their roles. They used WhatsApp to keep emotional ties between the PPC teams and the families, sending updates, photos and moral support messages, and they also appropriated social media – such as Facebook – to fulfill their need for social connections.

In the case of the nursing homes, the appropriation subtends a claim of the family caregivers for having closer relationships and being more involved in the process of

care. Here, family caregivers appropriated both the spaces in the nursing homes – turning them into places (Ciolfi et al., 2005) – and technologies to exercise their influence on the care pathway and to create trustworthy relationships. Whereas, the care professionals manage the relationships with the family caregivers by trying to keep their involvement close to a collaboration that does not have to interfere with the medical practices. In this settings, a strong need to communicate, to be informed, and to relate with other caregivers seems driven by the necessity of family caregivers to maintain an overall understanding and control over the situation, as well as a way to cope with the burden of it.

In the following subsections we discuss the design reflections and guidelines that arose from our studies.

6.5.1. What is appropriation telling us? Design opportunities

The work presented in this chapter conceived technology appropriation as a collective effort (Balka & Wagner, 2006) that, in the specificity of our two studies, is strictly related to the articulation care work "that gets things back 'on track' in the face of the unexpected, and modifies action to accommodate unanticipated contingencies" (Star and Strauss, 1999, p. 10). In this sense, the collective effort caregivers undertook in coordinating with one another, while re-shaping their environment and re-defining the boundaries of their roles, also encompasses the collaborative practices that are driven by the trajectory of work within healthcare contexts. Focusing on technology appropriation, we have the opportunity to explore how caregivers articulated their collaborative practices in accordance with their trajectory of work, and to better grasp the needs of the people involved in this care context. The healthcare contexts that we investigated display among family members and care professionals:

1. the need to have a shared understanding on the whole situation of a patient, having consistent information;

2. the necessity of communicating informally between formal and informal caregivers, in order to remain updated and relationally closer beyond the formal medical relationship;
3. the necessity of not losing data within the informal communication;
4. the need to have effective coordination within the network of care in order for all the members to better communicate and share information without losing quality in the relationship;
5. the necessity to have a clearer view of the members of the care network;
6. the need to extend peer-to-peer social interactions, in order to negate social isolation among family caregivers.

From the aforementioned observations, we summarized six main design guidelines, which describe a collaborative technology platform for groups of family and professional caregivers, conceived as an application for mobile devices. These guidelines will nourish the development of a technology platform that will be deployed within the two healthcare contexts presented in this chapter. The guidelines we provide, despite being grounded to the specificity of our two research contexts, are to be considered applicable to all contexts that present the same criticalities of the PPC and nursing homes we investigated.

The six design guidelines are unfolded as follows and are thought to directly answer the needs that emerged. These cover the following topics: (a) shared information and transparency; (b) internal communication; (c) data management; (d) family navigator support; (e) network awareness; (f) peer-to-peer communication.

A. Shared information and transparency.

Family and professional caregivers reconfigure the use of technologies – such as WhatsApp – to exchange medical information in order to coordinate the care pathway. In particular, the caregivers shared pictures, medical information and suggestions, thus to manage their care work and overcome the lack of a

conventional work platform. They also appropriated spaces to foster unformalized information exchange, in order to share as much information as possible, to save time for the care work. This display the necessity to have a conventional way for sharing information among all actors for making them mutually aware and engaged on the care pathway.

Several studies emphasize (i.e. Chen et al., 2013; Muller et al., 2015) that the technology should be designed in order to support the mutual involvement of the caregivers into the care of the patients, but fail to provide detailed guidelines on how to do so. In this way, all professional caregivers should have a shared knowledge on both medical and social issues concerning the patients. Thus, formal and informal caregivers should be able to homogeneously and consistently share and receive information and data about the patients. Differing from the way in which information is presented in the official Electronic Health Records, information should be synthetic, easily understandable and based on keeping traceability of examination results; past events and future scheduled events; and social and psychological information about the patients and their family. This would allow both professional and family caregivers to have a shared view on the overall situation of the patients. In addition, as already suggested by Bossen et al. (2013), to facilitate the coordination the technology should also provide an up to date calendar on all past and future tests the patient undertook and is planned to undertake. The calendar should be available to edit and view for both family and professional caregivers. In addition, and different to Bossen et al. (2013), the calendar should support the information needs of different caregiver roles, such as doctor, nurse, socio-health operator, primary family caregiver. In this sense, the calendar should be linked to all the other features of the technology platform, to allow users to quickly link the events on the calendar to the relative information and medical documentation.

B. Internal communication and coordination

Similarly to the preceding point, the appropriation of platforms for instant messaging subtends the caregivers' need to establish quick an efficient communications to rapidly coordinate when – as often happens within nursing homes and PPC contexts – there are emergencies or other impediments. However, the appropriation of "informal" technologies – such as WhatsApp – and common spaces also entails the necessity to build the coordination of the care pathway on informal relationships, to be nurture also face-to-face.

To enhance collaboration and mutual involvement in the care pathway, both family and professional caregivers should be able to communicate informally via instant messaging in order to support real-time information exchange, unstructured care work tasks and weak processes. In addition, the platform should support informal communication from care professionals to care professionals, and from family caregivers to care professionals. It would connect the members of a patient's care group by integrating face-to-face relations, rather than substitute them. It should also allow the scheduling of appointments through a shared calendar. In practice, family caregivers should be able to communicate to the care professionals everything they know on habits, tastes, attitude and medical history of their loved ones.

C. Data management

The appropriation of instant messaging platforms and the practice of informal communication among caregivers generate a huge amount of unstructured data and information. Although these practices facilitated family and professional caregivers in dealing with the care pathway of the patients, they impede to build a structured dataset and do not protect the sensitivity of the information exchanged.

To cope with this situation, the data contained in unstructured communication processes and real-time information exchange, should be automatically or semi-automatically integrated into the official EHRs. Moreover, privacy is an important

point that emerged from our study, as are the possible drawbacks in accepting everything that derives from the appropriation. The pervasive use of social media – such as WhatsApp – grant a great malleability, but also risk the loss of control over the main issues that characterize sensitive healthcare contexts. Using social media may entail privacy issues, traceability of communication, poor organization of communication, and may lead to confusing the nature of the tasks in hand. Hence, the technology should work within a private network accessible only by the users entitled to access it. It should also be designed in accordance with the privacy laws. The system should also allow for the protected exchange of sensitive documentation.

D. Family navigator support

The caregivers readapted WhatsApp and the spaces within the facilities for interactions and information exchange. However, the appropriation revealed that caregivers, especially family members, struggle to comprehend the hierarchy of care professionals and, even though they somehow can communicate, they do not always know with whom they should interact.

The technology platform should support the creation of a prioritized channel of communication between caregivers, acknowledging the role of reference points in the care network, such as a navigator that supports the family caregivers within the care pathway. This would facilitate direct and effective communications between professional and family caregivers. It would avoid the incomprehension and misunderstanding due to the fragmentation of information among several actors, and would facilitate the creation of a closer and more trustful relationship between families and care professionals. Therefore, the platform should give the possibility of acknowledging a particular care professional as the family navigator, and a family member as the main family caregiver, thus establishing a one- to-one communication when routing information.

E. Network Awareness

We observed that within nursing homes and PPC there are large networks of care professionals – among doctors, nurses, specialists, socio-health operators – and numerous relatives who rotate around a patient that often confuse and hinder the coordination among the actors involved, even though they readapt technologies to this end.

Given the wideness of the network of care professionals and family members, all caregivers should be aware of who the people involved in the care of a patient are, in order to better coordinate with one another. To enhance coordination and facilitate the communication between professional and family caregivers, the technology platform should display an overview of the whole network of care. There should be the description of the whole family network of the patient. Conversely, the family network should be aware of who are the professionals who assist their loved ones, in order to have a clearer understanding of the division of care work among professionals. Moreover, there should also be the opportunity to book appointments. The network of care should be depicted graphically, showing qualification or degree of kinship, contacts, pictures, and role for each caregiver involved.

F. Peer-to-peer support

The appropriation of social media – such as Facebook – and the particular appropriation of spaces within the facilities revealed that the caregivers – in particular family caregivers – sought peer-to-peer support and interactions that transcend the medical framework to feel less isolated and to cope with their burden.

Hence, the technology platform should also encompass a function for peer-to-peer support interactions (such as forums or blogs), areas dedicated to relatives' associations, and information on events organized for caregivers. Thus, it would allow users to establish face- to-face encounters, while keeping those who cannot leave their loved ones able to stay connected with others online.

6.6 Conclusions

In this chapter, the focus was on the communication, relational, and coordination issues that interfere with the care work within PPC and nursing home contexts. It explored technology appropriation to focus on how the actors, within the two research contexts, adapted technologies and spaces, and redefined the boundaries of their roles. This consolidated my focus toward the necessity to investigate how caregivers re-created their socio-technical environment through the adaptation of technologies.

This contribution enriched my PhD research by giving me the possibility to understand how studying technology appropriation can nourish, support and integrate a design process. Indeed, the appropriation that occurred within the two contexts provided design guidelines that emerged *from appropriation*. This study also revealed how the collaboration among caregivers requires the establishment of relations that go beyond the medical framework, highlighting the necessity to focus more on social aspects and collaborative practices within such healthcare contexts.

Within the path of my PhD, this work helped me to grasp the needs of the sensitive participants by drawing attention to the practices that they consolidated.

___7. TAKING_CARE OF_THE_GOLEM.

Reflection on the role of technologies and information sharing in complex care contexts[9]

coauthored with Francesco Ceschel, Maurizio Marchese, Vincenzo D'Andrea

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This chapter is based on a paper written in 2017, which is currently under revision at the Journal of Science Technology & Human Values.

This chapter discusses arising issues related to information sharing, comparing the studies. Both studies explored issues related to continuity of care by focusing on information continuity. In particular, we explored the contrasting opinions of caregivers on how and what information should be shared between relatives and professionals.

This work derives from the differences that I observed between the field studies in PPC and NHs. It contributes to answering RQ2, by providing insights about how the role of technology in supporting care practices was perceived in contrasting ways

[9] The contents of this chapter are under review at Science, Technology & Human Values journal (Di Fiore et al.).

by the participants of the two studies. Specifically, this work shows how some participants perceived technology as a fundamental enabler of their work, while others perceive it as a cold matter that can exacerbate conflicts. The concept of *Golem* guided this article, which describes how technology can be a powerful and a dangerous tool at the same time, depending on how it is situated in reality. Golem provided insightful reflections on the fickle role of technology in such contexts.

This chapter provides:

- A state of the art focused on information and data sharing;
- A comparative analysis of the contrasting opinions that the participants has about technologies and information sharing;
- A discussion that addresses reflections on technology as a Golem, highlighting how different organizational and relational settings can lead to positive or negative reactions to design processes.

7.1 Introduction

It is widely recognized that chronic and degenerative ill patients involve a thick network of caregivers whose, in the light of organizational complexities, struggle to communicate and relate each other (Bodenheimer, 2011; Schoen et al., 2005; Wagner, 1996; Wagner, 2000).

In recent years, it is emerging a need for care services and care technologies focused on chronic and degenerative ill patients in order to support caregivers in providing care collaboratively, communicating over different timing, places, information, and skills (Mc-Gee Lennon, 2008; Postema, 2012; Koch, 2006). However, as stated by Collins and Pinch (1998; 2008), science, medicine, and

technology are *Golems*, *powerful but clumsy and dangerous* creatures, which enact the mistakes and the successes that humans introject into them with our situated meanings. For this reason, it is paramount to take care of the *Golem* of technology when designing technologies for complex organizational environments.

Healthcare is an organizational environment that is characterized by heterogeneous actors who articulate their work according to shared understandings and distributed knowledge (Berg, 1999). Data and information need to flow through all the levels of an organization in order to allow coordination and sense-making by supporting actors to relate to each other and articulate their practices. Indeed, since routing the *care work* on collaboration, coordination and mutual awareness are at the base of quality care (Carman at al., 2013; Strauss et al., 2014; Strauss, 1985; Star& Strauss, 1999: Corbin & Strauss, 1984).

In this paper, we explore the role of technology in supporting continuity of care and information sharing within two healthcare contexts where family and professional caregivers collaborate on the delivery of care.

Our study took place in two end-of-life contexts that take care of patients affected by incurable diseases, who are in the last months or years of their life (Albers et al., 2014; Hudson et al., 2004; Rome et al. 2011; Siegel et al., 1991). The first study analyzes pediatric palliative care (PPC) services, exploring the role of relationships and information sharing in the articulation of care of incurable children at home. The second study is about nursing homes (NHs), studying relational and information issues between care professionals and relatives of older adults affected by severe impairments.

Both studies focused on how caregivers collaborate, analyzing the practices related to communication and information sharing. To explore the communication routines

of caregivers we relied on the theories that discuss the dialectic of data in shifting from information, to knowledge. Specifically, we studied how technology was perceived by professional caregivers and, as results, we obtained both extremely positive and very negative opinions. These results led us to formulate several hypotheses that, eventually, brought us to reflect about the concept of *Golem* (Collins & Pinch, 1998; 2008).

This paper is organized as follow. The next section discusses the state of the art, providing an overview about information sharing and healthcare technologies. Section 7.3 presents the case studies and the methods that we adopted. Section 7.4 reports the findings of our work. Whereas, section 7.5 presents the discussions, addressing theoretical reflections from our research outcomes.

7.2 State of the art

In this section we report the state of the art that composes the framework within which lies this research work. In particular, we present a literature review on healthcare collaborative technologies, drawing attention to their role in information sharing.

Information sharing is deemed an important factor that enhance the work of caregivers, since it provides sense of control and relief from the burden of care (Proot et al., 2003). Within this framework, information continuity, together with the concept of continuity of care, are recognized to be essential in framing how caregivers should take properly care of patients in critical end-of-life conditions (Proot et al., 2003).

Given the often wide network of caregivers that rotate around a patient, continuity of care concerns the alignment of all the communication, relational and

organizational needs of the caregivers of critical patients, thus to increase their work efficiency and, subsequently, the quality of care (Grone & Garcia-Barbero, 2001; Wagner, 1996; Wagner, 2000). Whereas, information continuity concerns a specific dimension of continuity of care, which refers to the sense of control and predictability that derives from a clear and consistent information flow related to the care pathway of a patient (Haggerty et al., 2003).

In the next subsections, we discuss the literature on healthcare technologies (see subsection: 7.2.1.), and we address the topic of information sharing (see subsection: 7.2.2.) by presenting the epistemological dialectic between data, information and knowledge.

7.2.1 Healthcare technologies for information sharing

Over the last years, the literature on healthcare technologies and medical information sharing has been focusing on the role of *Electronic Medical Record* (EMR) in supporting data and information collection, due to the fact that many healthcare contexts experienced the shift from on-paper medical records to electronic ones (Berg, 1999; Wintheireik at al., 2007; Pine et al., 2014).

Studies (i.e. Pine, 2014) discuss *the dual role of EMR*, stressing its coordinating and accounting roles. On the one hand, EMRs are described as artefacts that embodied policies, making care contexts compliant to laws. On the other hand, they are understood as information tools that support care work coordination and information sharing. In this sense, information sharing supports both transparency and articulation of care work.

The literature suggests that, complying with policies and governmental institutions, the EMRs would increase the efficiency of healthcare contexts, providing clearer

information flows that will bring an increase of integrated care work, safety, coordination and available data (Pine et al., 2014; Greenhalgh et al., 2009; Christensen & Ellingsen, 2014). However, these improvements should come along with the standardization of practices among all actors and care units. This subtends the possibility for EMRs to centralize the access to information, to create a structured shared knowledge among caregivers and thus to allow care professionals to operate through standardized practices (Pine et al., 2014; Christensen & Ellingsen, 2014).

Other authors depict a different scenario, describing this view as a *technological utopia (*Greenhalgh et al., 2009). Indeed, the sense of care work is strongly related to the intersection between unpredictable care contingencies and the enactment of situated practices (Strauss et al., 2014; Strauss, 1985; Star& Strauss, 1999: Corbin & Strauss, 1984; Osterlund, 2013). In this sense, Pine et al. (2014) observed that structured medical information may create negative organizational outcomes that interfere with the coordination of the care work, and it may also entail inaccurate accounts of work. Similarly, Greenhalgh et al. (2009) stress a series of paradoxes, highlighting how in the care delivery there is a strong need of qualitative human work to re-contextualize the medical knowledge *in-situ*.

These paradoxes are also evident in a series of studies (Berg, 1999; Pine et al., 2014; Christensen & Ellingsen, 2014; Fitzpatrick, 2004; Amsha & Lewkowicz, 2016).

Christensen and Ellingsen (2014) investigated medical practices during the process of standardization of information among hospitals promoted by the Norwegian healthcare system, showing that information practices are situated and context related, arguing that standardization seems a "myth because impossible to accomplish across different hospitals" (p. 11).

The same issues are investigated by Osterlund (2013), who noted that the distributed knowledge does not lies on how documents spread the knowledge across boundaries, rather on how actors share their knowledge within their shared practices.

Likewise, Fitzpartick (2004) highlights the constant manipulation of on paper medical working records by caregivers. The author explains that caregivers always manipulate the working records, as well as create personal ones, to match the medical records with their situated practices, stressing that the flexibility and tailorability of paper allow caregivers to shape the records according to the trajectory of their work.

Amsha and Lewkowicz (2016) analyzed the potential of coordinative artefacts in sharing medical information, data and documents in an unstructured way, since they embrace the situated care practices of the caregivers. They explored the *knot-working*, studying the need of caregivers to rearrange their care work and their information and data sharing according to the contingencies of the diseases.

The contributions presented above emphasize a polarization between "standardization" and "contingencies of care contexts". This suggests how the design of care technologies should be *handled with care* (Mol, 2008), making efforts to understand how caregivers perceive structured data and loosely coupled information, and how they intertwine these clues within their situated care practices.

7.2.2 Data-Information-Knowledge

It is widely accepted that caregivers usually share data they have and collect on records that, regardless being digital or on-paper, support information sharing (Fitzpatrick, 2004; Amsha & Lewkowicz, 2016). However, it is also recognized how

the knowledge that derives from this data is always indexical and, hence, comprehensible only through the sense-making deriving from situated practices (Berg, 1999; Pine et al., 2014; Christensen & Ellingsen, 2014Fitzpatrick, 2004; Amsha & Lewkowicz, 2016).

Giddens (1979) shows how knowledge is an integral part of social interactions, which allows people to have a collective understanding of their context that reflects social and organizational needs. In this way, the collective understanding frames the organizational knowledge, determining articulation of work and collaborative dynamics.

Managerial studies provided an interpretation on how data, information and knowledge are rooted within organizations and we believe that this view can enrich our analysis on care technologies to support information sharing. In particular, Ackoff (1989) distinguishes between *data*, *information*, *knowledge*, and *wisdom*, describing these concepts as connected through a logic chain (Ahsan, 2006). Ackoff (1989) proposes the so-called DIKW hierarchy, defining *data* as symbols that merely represent objects, which turn into *information* only when they are enriched with explanations and meanings. Ehn (1993) states that *artifacts do not exist in isolation*, and we believe that data and information do not exist in isolation either. In fact, is the appropriate collection of information that makes them useful and turn them into *knowledge* Ackoff (1989). The shift from data, information, and knowledge, it is only possible through understanding, which allows people to synthesizer new knowledge from knowledge previously acquired. Lastly, Ackoff proposes *wisdom* as the ability to move the knowledge towards the comprehension of future perspectives (Bellinger et al., 2004).

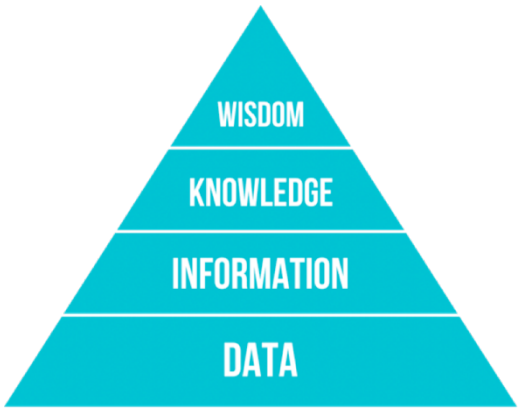


Figure 1. The DIKW hierarchy proposed by Ackoff (1989)

In our opinion, these principles can enrich the understanding of healthcare contexts as well. The chain of sense-making that links data, information and knowledge lies also on the intersections among the situated practices of caregivers. It can also inform the design of collaborative care technologies by highlighting how the data stored by ICTs need to be understood to become information, and how information need to be contextualized to become collective knowledge. Indeed, the shift from data, up to knowledge, passes through the ability of caregivers to articulate their work and to align their meanings according to the illness trajectories (Strauss et al., 2014; Strauss, 1985; Star& Strauss, 1999: Corbin & Strauss, 1984). Yet, the knowledge that derives from this is always situated and, hence, comprehensible only through the understanding of the situated practices and the collaborative relationships between caregivers.

These insights guided our investigation on how caregivers perceived information sharing technologies. In particular, the DIKW hierarchy, together with the theory of the *Golem* (Pinch & Collins, 1998; 2008), helped us to interpret the conflicting outcomes that emerged from the field studies that we conducted in PPC and NHs, supporting us in grasping the nuances of techno-social phenomena in care work.

7.3 Methods

This paper includes two studies we carried out within two different end-of-life settings in the northern Italy: a study in pediatric palliative care, a study in a network of nursing homes. The studies were conducted separately because belonging to two different projects.

The PPC study was based on *Miuchi,* a Participatory Design project that aimed to study the care work within home environments to elicit social requirements with the aim to re-design a telemedicine tool.

Whereas, the NHs study was based on *CollegaMenti,* a project carried out to study relationships between family and professional caregivers in order to develop a collaborative care technology platform.

Both studies were designed to investigate the collaborative care practices of family and professional caregivers, thus to comprehend how to design new technology platforms to support collaboration among caregivers on the care pathway of patients, while allowing for knowledge and information sharing.

In this paper, we specifically focus on the perspective of care professionals, as their view determined the results of the analysis presented here (see Section 4), and because, in our projects, they had a major role in deciding whether a new technology platform could be adopted within a healthcare environment or not.

We explored the contexts by conducting two in-depth qualitative investigations. Therefore, we relied on semi-structured interviews, focus groups, and observations (see Table 1). The data collection within the PPC was conducted from July 2015 to December 2016. Whereas, the data collection within the NHs was conducted from August 2016 to June 2017. We received the ethical approval from the committee of the University of Trento for both studies.

Table 1: summary of methods

Pediatric Palliative Care		
Method	Sample/Duration	Object/Context
Interviews	18 interviews with head physicians, medical doctors, nurses, psychologists, social workers and parents of the patients.	We investigated how caregivers perceive their working environment, their mutual relationships, what interfere with their care work, their daily routine, their usage of technology, their collaborative and communication dynamics.
Observations	Several short-term sessions of observations for a total of 50 days of observation.	The short term observations have been guided by sensitizing concepts related to care practices, the daily routine of the caregivers, the communication practices, the factors that either facilitate or hinder the home care work.
Nursing Homes		
Method	Sample/Duration	Object/Context
Focus Groups	3 focus groups with the care professionals working in the nursing homes.	We investigated the daily routines, the frequency of emergencies, what relatives are worried about and eager to know, what they believe is important to know for the relatives, how they communicate with one another within the staff crew, how they would categorize the relatives.
Interviews	27 family caregivers	We focused on the care practices of the family caregivers, communication practices between them and the staff members, the use of technologies, their opinions about the service provided by the facilities.

Workshops	6 workshops (3 with care professionals and 3 with family members)	We validated the consistency of our findings and we discussed the prototype of a technology to be.

7.4 Findings

In this section, we present our findings. Here, we highlight the dichotomy of expectations and opinions of the professional caregivers of PPC and NHs on the use of a collaborative technology platform to support information sharing sharing. The two case studies, presented separately, are introduced by a short explanation of the research contexts.

7.4.1 Pediatric palliative care

The *Miuchi* project aimed to explore the potentials of collaborative technologies in home-care settings, and it was built on a bottom-up and participatory design rationale. As design researchers, we were contacted by a member of a home-care network that provides pediatric palliative services who asked our help to design a collaborative digital platform, in order to support their information sharing among caregivers to render their communication practices more efficient. Therefore, the project rose from the intention of the PPC network to use our expertise to re-design a telemedicine tool, tailoring it upon their needs and context. This revealed their awareness of the issues that were affecting their communication practices, and of the importance of sharing information between family and professional caregivers.

The PPC networks involved in our study provide home-care services to children with incurable diseases. These services are provided at home in order to allow the little patients to be cured in an emotionally safer place, surrounded by their families.

The PPC networks were based on three main groups of actors: *(a)* the family caregivers who take care of the children at home; *(b)* the care professionals who are the members of the PPC team that provides the home visits and work side-by-side with the families; *(c)* the specialists that visit the patients occasionally and prescribe the care plans that are enacted by the PPC team and the families.

The PPC team are composed by different professionals, including pediatricians, nurses and psychologists. Whereas, differently from the care professionals, the families do not usually have any medical knowledge, but they quickly acquire clinical skills by taking care of their children and by being assisted by PPC team. Normally, the family members take care of the little patients autonomously at home, since they are usually visited by care professionals once per week. Hence, family caregivers are usually supported remotely.

The process of home-care of patients in end-of-life conditions requires a close and trustful collaboration between family and professional caregivers, taking care of the frail conditions of the little patients from both human and medical perspectives.

For instance, a doctor said: *"We work with the families, we support them and they support us"*. (Interview with a pediatrician)

Pediatric palliative home-care deals with many different stakeholders, roles, and locations, each one with different degree of involvement and different knowledge. This entails a complex articulation of work and, subsequently, a low quality of the information flows among caregiver may interfere with the care work. Moreover, the severe conditions of the little patients are often unstable, and they may lead to unpredictable exacerbation or unexpected events in handling medical devices and medications. Care professionals emphasized the delicacy of home-care: *"To go at*

home [of the patients] is always like to enter in the nest, you have to enter gently, because you know that if you lose the families' trust you cannot enter any more in that home". (Interview with a nurse)

Indeed, the home is an informal place that belongs to those who live in it. We observed that, differently form formalized healthcare environments such as hospitals, home-care requires a continuous negotiation of relational and medical boundaries between family and professional caregivers who jointly take care of the patients.

Within this context, the care professionals stated that to take proper care of the patients they need to be aligned on the information they have and share with the family caregivers. They explain that information flow is at the base of the functioning of care pathways, since it allows all caregivers to articulate their work – also remotely – and it allows them to deal with emergencies and unpredictable health conditions of the patient. Our studies revealed also a widespread use of a commercial mobile instant messaging application among caregivers. Specifically, family and professional caregivers relied on Whatsapp Messenger to share medical data, communicate updates, ask advices, and provide human support to each other.

This multi-sited setting was characterized by dense relationships which entail that the care practices of both families and professionals are inevitably intertwined and distributed. It is evident from our findings that caregivers perceived technologies that supported information flow as fundamental to provide an efficient care, embedding collective sense-making into the care practices.

7.4.2 Nursing homes

The *Collegamenti* project, aimed to design a new IT system to enhance coordination, exchange of medical information and collaboration between the professional and family caregivers of six NHs. The project had a top-down approach, arising from the willingness of the management of the NHs involved and the local authorities to design a technology platform to support communication and relationships between staff members of the NHs and relatives of the patients (residents).

The NHs we investigated are facilities that provide residential care, and work on creating a cozy environment for older adults with several cognitive and physical impairments. The staff members are social-health operators, nurses and one doctor, which follow a strict hierarchy that defines how they articulate their daily tasks and what kind of information they can communicate to the relatives of the residents. NHs generally organize their daily schedules on a series of standard activities with a specific time-line, which is related to the physiological and medical necessities of the residents. To coordinate the care path way, in recent years, the NHs adopted an EMR (Electronic Medical Record), upon which the staff members collect medical information about the residents. They revealed that they still struggle to use the EMR, which was initially rejected because the work related to data recording increased their workload with no perceived advantages comparing to the old paper records.

In the NHs, the family members of the residents are formally welcome in the facilities and are considered both a resource that can support the staff members, and an added patient. For instance, a nurse said: *"We welcome the families as patients as well. They are additional patients. We take the whole package"*. Still, the family

members are usually involved in the care pathway of the residents, attending the *individual health plan*, which is a meeting to plan the treatments for each patient, and to formally update the family caregivers on the situation of their loved ones.

"It is right and mandatory to involve the family caregivers" (Focus group – nurse). However, some staff members also stated:
"if we want to tackle the situation the right way receiving the family caregivers may interfere" (Focus group – staff member).

For care professionals the involvement of the families is a thorny issue, since they are perceived both as useful resources and as actors that can hinder the autonomy of their work. Family caregivers frequently visit the NHs to obtain additional information on their loved ones, but the information that care professionals deliver are often decided according to what they believe is worth to be said to the relatives. Moreover, the tight schedule of the care professionals does not often leave them the time to interact properly with family caregivers.

Conversely, family caregivers also displayed the strong necessity to contribute to the care of their loved ones. They informally articulate the care work with the care professionals, indeed, it is common for them to go to the NHs to feed or to assist their loved ones. Professional caregivers take advantage of this to lower their workload. Nonetheless, they stated that the involvement of the relatives need to be kept to a certain level to avoid any interference with their care work. According to them, family caregivers lack the competences and the comprehension of the conditions of the residents and of how the care work should be conducted. Therefore, family caregivers are given only the information necessary to understand the condition of their loved ones, but not the information to comprehend how to intervene on the care pathway. For example, during a workshop, we asked to the care professionals what they thought of a greater involvement of the families in care

work, and a nurse provocatively answered that relatives would excessively control the staff by holding them to ransom: *"This would be like ISIS!"* (referring to terrorism).

It appears that care professionals choose to which extents family caregivers can be involved and informed, as a way to protect their work. This practice emerged as an unwritten rule that do not regard the policies of the NHs, but as a shared practice that care professionals adopted to protect their work and to limit the intrusions and interference of the family members. Professional caregivers admitted to tailor and sometime avoid to disclose information according to the family caregivers they interact with, because they declared to be burdened by the overreactions of the family caregivers.

Somehow care professionals do not want family caregivers to develop a critical knowledge. They wish to keep the boundaries between them and the family caregivers to remain in control of the care path. In this way, care professionals displayed a strong resistance to the development of the new technological platform to enhance collaboration and information sharing between them and the family caregivers. They delivered design suggestions aimed at limiting as much as possible the involvement of the family caregivers. This outcome resulted as antithetical to the initial aim of the project, leading us to a re-shape our intervention within the NHs.

7.5 Reflections from our studies

Information sharing in care environments is presented in the state of the art as a mosaic of contributions. Most of the literature refers to studies on EMRs, revealing a polarization between the coordinating and accounting role of information sharing (Winthereik et al., 2007). Yet, efforts in reconciling this view are emerging

(Osterlund, 2013). Within care settings the efforts toward formalization often come into conflict with the *situatedness* of the contexts themselves. Studies (Christensen & Ellingsen, 2014; Fitzpatrick, 2004; Amsha & Lewkowicz, 2016emphasize issues related to standardization of medical data, showing how information sharing in healthcare context supports the articulation of situated practices according to the intrinsic contingencies of the care work.

In the light of the literature, we provided an overview of the process through which data become information by acquiring meanings, and by bringing a shared collective knowledge that is at the base of the articulation of care work. There, the quality of the relationships among caregivers is paramount in allowing an alignment of meanings among data, information, and knowledge. Indeed, sharing data and information has the dual role of distributing things that are meaningful, but also the role of aligning meanings, allowing collective knowledge.

In this paper, we presented two studies in end-of-life settings, discussing how technologies to support information sharing are perceived and integrated into the care routines that intersect the efforts of family and professional caregivers.

The two studies yielded opposite results on information sharing dynamics, highlighting the relevance of relational work with family caregivers. In this sense, as paraphrasing Giddens (1979), relationships are needed in care work to contextualize and make sense of data and practices of information sharing itself. These cases show a link between information sharing and relational work, since the data to support articulation of work need to become information and knowledge by acquiring sense and aligning collective meaning.

Comparing the outcomes of our studies in PPC and NHs, we noticed that the goals of our studies rose several expectations on the professional caregivers. Moreover,

we observed that our idea of delivering a technology platform created enthusiasm among the care professionals working within the PPC, and reluctance in the care professionals working within the NHs.

On the one hand, PPC care professionals displayed a positive attitude towards the possible use of a new technology platform, stressing their eagerness to have an external aid to support their care practices with the family caregivers. Care professionals emphasized that knowledge sharing between them and the family caregivers is a paramount activity upon which the care practices are built and, therefore, they put many positive expectations on the possibility to have a technology platform to support knowledge sharing. Moreover, our findings show that the caregivers used information sharing to make sense of their collective care practices, seeking for meaningfulness, and dealing with the uncertainty of the care conditions of the patients. The project within the PPC networks had a *bottom-up* approach. The data and the information work was unanimously perceived as enabling of their collaborative practices. In this context, the information symmetry was an essential requirement for the articulation of care work among different places and actors. The data and the information work were framed within a context that considered human relationships among caregivers an integral part of the collaborative care work. This attention to relational work and caregivers' relationships supported the alignment of knowledge that derived from information sharing.

On the other hand, NHs care professionals rose many resistances toward the possible use of a collaborative technology to coordinate the care pathway with family caregivers, since they displayed reluctance to share too much information with the family caregivers. Differently from the preceding case, the study within the NHs was built on a project with a top-down approach, where the need of a

technological solutions was pushed by the management of the organizations. There, we found many resistances to information sharing by the staff members. On the one hand, the professional caregivers did not look kindly upon data work due to bad experiences with the EMR. On the other hand, staff members were reluctant to share medical data and information with the family caregivers. The staff members were understaffed, and unable to have time to nourish the relationships with the relatives, which brought asymmetry of meanings between them and the family caregivers. Hence, the professional caregivers feared the possibility for the data to become information and knowledge that relatives could use to make new requests. The staff members developed aversion towards joint information sharing with the relatives, in order to protect their autonomy and care work against interference. This study highlighted the resistances of care professionals to the design of a technology to support information sharing, as they aimed maintain an information asymmetry based on *nonknowledge* (Bernstein, 2011).

In such contexts, technology was perceived as a *Golem* that if domesticated would have served its scope by enabling alignment of meanings, but without the right shape would have turned into a dangerous creature able to hinder the work of the professionals.

7.6 Conclusion

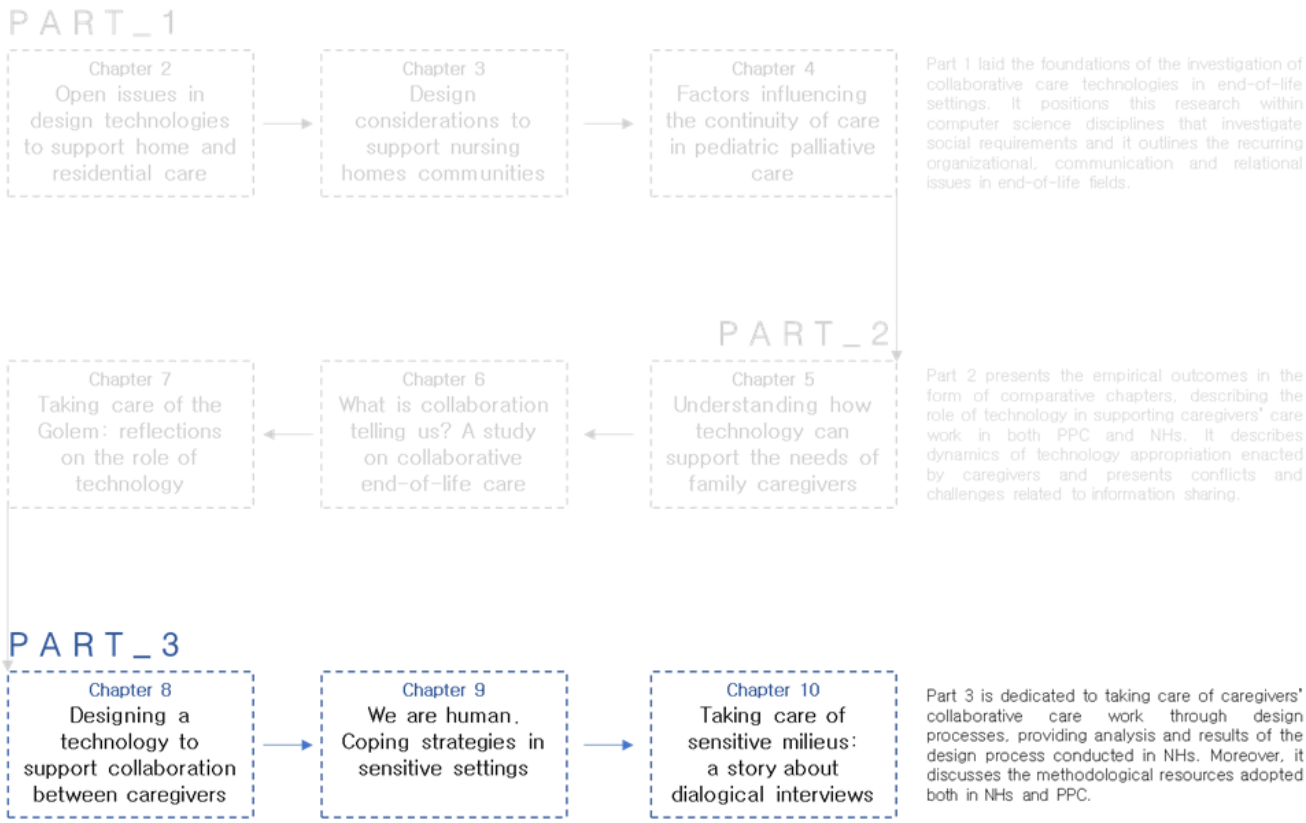
This chapter presented how information sharing among family and professional caregivers is a social, organizational and technological phenomenon that can be perceived as both an enabling and a hindering factor within healthcare settings. It revealed that the design of technologies to support information continuity needs to be *handled with care*.

This work made me realize that when conducting design activities in extreme sensitive contexts is needed to *take care of the Golem.* A strategy to do that can

be to explore collaborative and conflicting social dynamics, analyzing how the chain that connects data, information and knowledge is contextualized within the relationships of caregivers. In this case, doing so lead to a deeper understating of the expectations and the preconceptions related to technology design and also to the work that I was conducting with my colleagues. This work, showed how the collaboration between caregivers in PPC lead to a positive welcome of technology solutions, seeing them as precious tools for their work. While, in the case of NHs the complex and sometimes conflicting relationships between professional and family caregivers, lead the staff to reject the possibility to use a technology to support this collaboration because, first and foremost, this collaboration was not welcome.

Speaking with the words of Collins and Pinch (1998, p. I), this work shows how both in PPC and NHs study, technology to support information sharing *seems to be either all good or all bad*. *For some*, technology increased the amount of work without advantages, and the information sharing that can emerge from it can be dangerous. *For some*, technology is an integral part of quality care, supporting collective knowledge, information sharing and coordination of care. *Both of these ideas are wrong and dangerous. The personality of* technology *is neither that of a chivalrous knight nor that of a pitiless juggernaut.* Technology *is a Golem. A Golem is a creature from Jewish mythology. It is a humanoid made by man from clay and water. (. . .) It is powerful. (. . .) But it is clumsy and dangerous. (. . .) The Golem* technology *is not to be blamed for its mistakes; they are our mistakes.*

PART_3


PART_1
Chapter 2
Open issues in design technologies to support home and residential care
Chapter 3
Design considerations to support nursing homes communities
Chapter 4
Factors influencing the continuity of care in pediatric palliative care
Part 1 laid the foundations of the investigation of collaborative care technologies in end-of-life settings. It positions this research within computer science disciplines that investigate social requirements and it outlines the recurring organizational, communication and relational issues in end-of-life fields.
PART_2
Chapter 7
Taking care of the Golem: reflections on the role of technology
Chapter 6
What is collaboration telling us? A study on collaborative end-of-life care
Chapter 5
Understanding how technology can support the needs of family caregivers
Part 2 presents the empirical outcomes in the form of comparative chapters, describing the role of technology in supporting caregivers' care work in both PPC and NHs. It describes dynamics of technology appropriation enacted by caregivers and presents conflicts and challenges related to information sharing.
PART_3
Chapter 8
Designing a technology to support collaboration between caregivers
Chapter 9
We are human. Coping strategies in sensitive settings
Chapter 10
Taking care of sensitive milieus: a story about dialogical interviews
Part 3 is dedicated to taking care of caregivers' collaborative care work through design processes, providing analysis and results of the design process conducted in NHs. Moreover, it discusses the methodological resources adopted both in NHs and PPC.

Part 3 _ D E S I G N _ P R O C E S S E S _ & _ C O N F E S S I O N S

Part 3 collects articles that provide hints for reflections for what concern *taking care* of end-of-life settings.

In this way, it addresses the third research question of this report:

RQ.3 How can we (as CSCWers and PDers) nourish caregivers' collaboration in end-of-life contexts through design processes?

Like the previous ones, also this part is composed by 3 chapters based on standalone articles. This articles are grouped on the base of the third stream of this thesis report, providing reflections on how to support caregivers' collaborative practices through design processes. Indeed, this last chapters convey reflections on sustainable design processes (Chapter 8) and methodological dilemmas (Chapter 9 and Chapter 10).

Chapter 8 has been written for a general Computer Science audience; Chapter 9 for an audience focused on healthcare information infrastructures; and Chapter 10 for a HCI audience.

Chapter 8 is based on a long paper that is under revision at PeerJ Computer Science, presenting the overall design process conducted in nursing homes. Describing item by item the phases of the data collection, it provides reflections on how progressively exploring the contexts help us to conduct a process that was sustainable for the participants and that led us to reframe the initial aim of the research project.

Chapter 9 is based on a short paper presented at InfraHealth 2017, discussing the implications of using dialogical interviews in the context of nursing homes. This chapter offers reflections on how the choice to keep an open dialogue with the

informants influenced on the path of the research project, calling into question its initial goal.

Chapter 10 is based on a short paper presented at Ethical Encounters in HCI (CHI, 2016). It presents methodological reflections and coping strategies that I adopted as a researcher to emotionally deal with sensitive design contexts.

___8. DESIGNING_ A_TECHNOLOGY_PLATFORM

to support collaboration between professional and family caregivers in nursing homes[10]

coauthored with Francesco Ceschel, Maurizio Marchese, Vincenzo D'Andrea and Fabio Casati

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This chapter is based on a long paper written in 2017 that is under revision at PeerJ Computer Science. It discusses the participatory design process that we conducted with the NHs caregivers and describes the mixed methods that we adopted to assess the design guidelines defined in chapter 6.

The findings highlight how technology should support caregivers in dealing with managerial issues, while nourishing social relationships. Moreover, they show how cultural frictions and poor communication practices hinder collaboration and mutual understanding between family and professional caregivers.

Within the narrative of this thesis, this chapter contributes to Part 3 by minutely describing step by step the method adopted and the outcomes of each research

[10] This chapter is based on a paper submitted to PeerJ Computer Science (Ceschel, F., & Di Fiore, A., et al.).

phase, including questionnaires, interviews, focus groups, prototypes and provotypes. In doing so, this chapter retraces the iterative design process, discussing how the deep exploration of the needs of the informants revealed that they were unwilling to use a technology as conceived by the goal of the funded research project in which I was working on. This led us to deeply reshape the aim of the research project, toward a technology focused on supporting at relationships and sense-making among formal and informal caregivers.

This chapter provides:

- Theory state of the art on coordination and information sharing among caregivers;
- Findings that retrace the outcomes of both the exploratory phase and the validation phase of Collegamenti project;
- Description of the mock-ups and the functionalities of the proposed technology;
- Discussion that proposes formalized statements, illustrating the reasons why the original goal of the project has been reconsidered.

8.1 Introduction

Studies (Fernandez-Ballesteros et al., 2013) state that an aging population is a phenomenon that has been prominent in recent years. The latest "World Report on Ageing and Health" (Organization et al., 2015) shows that the older adult population will rapidly increase in coming years. Despite the policies that have been deployed to deal with this phenomenon, the healthcare sector remains the first support for the aging population (Adams et al., 2011; Stenner et al., 2011; Walker and Maltby,

2012; Walker et al., 1995). In particular, nursing homes are healthcare settings that provide assistance and support to older adults (residents) with severe physical conditions. Nursing homes also assist the relatives of their residents and these relatives often rely on nursing homes following on from experiences of having provided home care to their loved ones. As a consequence, feelings of guilt and luck of trust towards care professionals can develop. Therefore, nursing homes also try to mitigate the burden carried by relatives by providing support and by establishing relationships of mutual involvement into the care of the residents (McFall and Miller, 1992; Zwijsen et al., 2014).

In this scenario, care professionals and relatives need to coordinate with one another, in order to mutually participate in the care of the residents. Studies (Hastall et al., 2014; Jeong, 2008; Milligan, 2012; Bossen et al., 2013; Ruan et al., 2010) suggest that ICTs are a possible solution for improving the coordination between care professionals and family caregivers. Yet, healthcare environments and, specifically, nursing homes, are sensitive contexts and thus, difficult to investigate. Researchers strive to keenly understand what relatives and care professionals actually require and, often, this results in technologies that are unable to fully satisfy the needs of the target user groups (Nunes and Fitzpatrick, 2015).

In this chapter, we discuss the design process of a technology platform that aims to enhance coordination, collaboration and information sharing among caregivers within a network of nursing homes located in northern Italy. In particular, we work on how to enhance the mutual collaboration between the so-called

informal caregivers, which are the relatives of residents of the nursing homes, and the formal caregivers, which are medical professionals. This study focuses on how ICTs can enhance communication, coordina- tion, and the establishment of relationships across the two contrasting caring cultures of professionals and the

family. The study was based on qualitative and quantitative methodologies, and involved the following participants: the professional caregivers and the family caregivers of the residents of a network of six nursing homes. After we analyzed the needs of family and professional caregivers, we drew up a series of design guidelines upon which we design a technology prototype that we subsequently validated.

During our investigation, we observed several complex human and organizational circumstances. However, we relied on a set of methodologies that allowed us to build a clear picture of the research context. We drew on an iterative rationale that, along the course of the design process, progressively revealed new data and helped us to redefine our initial expectations on how the technology platform should have been designed. Indeed, our findings show conflicting needs between family and professional caregivers, revealing a clash of care cultures. Moreover, the results of our study failed our initial expectation for technologies to be used to transmit medical information in a real-time fashion, as our target user group rejected this possibility. Such situations led to negotiations aimed at conveying a mutual alignment of expectations, needs and wishes, which we condensed into a technology prototype.

The chapter is structured as follows: in the next section we discuss the state of the art on collaborative healthcare technologies, and nursing home contexts; in the section "Methods and Procedure", we present our research setting, the methodologies we used, and how we applied them; we then present the findings of our study; finally, in the "Discussions" section and, in the light of our results, we deliver suggestions on how to design collaborative cross-cultural technologies for healthcare settings.

8.2 Related work

In this section, we present the state of the art concerning nursing home environments

and collaborative care technologies. We start by discussing the existing literature on the relationship between family and professional caregivers and nursing homes, and following that we focus on technology studies.

Family caregiving is recognized as an area that will become more and more relevant in coming decades due to demographic and economic changes as the delivery of informal care work to older adults increases (Gaugler and Kane, 2015). According to Gaugler and Kane (2015), it is paramount to take into consideration the direct experiences of family caregivers in order to have a reliable understanding of how to support this phenomenon. Indeed, "the personal experience of family caregivers cannot be disengaged from technological changes or solutions facing family caregiving (. . .) [and] experts would be wise to listen to families and their stories as we strive to understand and better serve them on their caregiving journey" (p. 377).

The literature shows a lack of works on the involvement of informal caregivers in taking care of residents in nursing homes (Hertzberg and Ekman, 2000; Hertzberg et al., 2003). Family caregivers are seen as a useful source of information when attempting to settle new residents joining the facility (Robinson, 1994), helping to frame their temperament and special needs (Hertzberg et al., 2003; Hertzberg and Ekman, 2000; Ryan and Scullion, 2000). However, usually, this information is informally gathered and is often lost because there is no dedicated space for such information on the nursing homes' formal records (Robinson, 1994). There are not recognized processes or protocols to define the involvement of family caregivers in nursing homes. As a result, the inclusion of informal caregivers in partaking in the care of residents depends on the sensitivity of the care professionals (Laitinen and Isola, 1996), who are often committed to tight work schedules based on performance parameters (Bowers, 1988). In this scenario, the literature shows how

family and professional caregivers belong to different caring cultures, perceiving themselves in different ways.

On the one hand, the relatives make themselves entirely available to help the staff members in the care delivery, considering themselves as a paramount figure that is the custodian of the biographical and emotional expertise of the resident (Ryan and Scullion, 2000). The family caregivers often feel they have limited influence on how their loved-ones are cared for and this is a source of burden, mistrust and sense of disempowerment (Ryan and Scullion, 2000).

In contrast, the care professionals trust in their technical knowledge, underestimating the sentimental care work of the relatives (Fagerhaugh, 1997). Usually, medical professionals do not appreciate the intrusion of relatives in their care tasks (Ryan and Scullion, 2000; Dobrof and Litwak, 1977).

In nursing homes, the care work of the care professionals and the family members who assist their older relatives often overlaps. Hence, formal and informal caregivers need to understand how to exist side by side, joining their effort in caring for the older adults (Chen et al., 2013; Chen, 2011; Chen and Schulz, 2016; Chen et al., 2009). In this scenario, there is an emerging need to enhance communication exchange, empathy (Hertzberg et al., 2003; Hertzberg and Ekman, 2000), and mutual understanding between caregivers (Ryan and Scullion, 2000), with this being the basis of quality care delivery.

In nursing home contexts, many technological improvements can be achieved by designing collaborative care technologies. Most of the existing studies on collaboration between the caregivers of older adults' focus on active ageing at home, but not within institutionalized facilities such as nursing homes (Bossen et al., 2013; Czaja and Rubert, 2002; Consolvo et al., 2004; Huber et al., 2013). They investigate

how to ease and support the home care work of caregivers through the use of ICTs by helping remote coordination among the caregivers and the independence of older adults. However, their contribution is interesting because they stress the need to focus on how professional and family caregivers collaborate to comprehend how to develop IT systems able to foster and support their practices. In this sense, Miller et al. (2016); Miller (2015) stress the need to design information systems able to create a widespread awareness among caregivers on the care pathway, thus allowing remote and asynchronous coordination.

Similarly, Chen et al. (2013) argue for attention to be given to the social and logistical needs of caregivers when designing information systems. Nunes and Fitzpatrick (2015), draw attention to the informal caregivers as involved in the care pathways in the same way that the formal caregivers are. In addition, Amsha and Lewkowicz (2015, 2016) worked on a management system to support coordination between a broad network of medical professional, older adults and family caregivers, paying attention to the complexity of the care environments and the unpredictable dynamics that can occur during a design process. This study is particularly interesting because it provided a technology able to support both the management of the care work and the sense-making of caregivers. Despite the existing gaps in the literature, it is clear that great coordination and mutual understanding is required in order to provide care in cross-cultural care environments where family and professional caregivers exist side by side. Hence, technology designers can play an important role, focusing on the friction that is present in the relationships and on how the different caregivers manage their intersecting work.

8.3 Methods and procedure

The work presented in this chapter derives from the project *CollegaMenti*. The project

involved the Department of Information, Engineering and Computer Science of the University of Trento, an industrial partner, and the Autonomous Province of Trento, Italy. It aimed to investigate the collaborative and communicative dynamics of the family and professional caregivers of the residents of a network of six nursing homes located in northern Italy. The purpose of the project was to use a data warehouse on the medical data of the residents of the nursing homes, thus to design a new technology platform to improve and sustain collaboration and information exchange between family and professional caregivers. In particular, the new platform was conceived to be linked with the Electronic Medical Records (EMR) (Berg, 1999) used by nursing home staff, in order to allow for the real-time delivery of the medical information to the family caregivers. The technology had to be designed primarily for portable devices (such as tablet and smartphones).

In this study, we relied on an iterative design research process. We built our research process on both qualitative and quantitative methods, in order to keenly comprehend and validate the needs of the caregivers, upon which the technology platform had to be designed and developed. We conducted a thorough investigation to refine the needs of the caregivers, in order to verify their consistency across the different nursing homes, and to validate a prototype of the platform. The study was conducted from the fall of 2016 to the summer of 2017 and it received the ethical approval of the ethical committee of the University of Trento (protocol 2017-003). We divided our research into two phases: an exploratory phase, and a design phase.

We started (Phase 1) our research by conducting an exploratory study in order explore the relationships and the communication routines between the relatives of the residents and the staff members of the nursing homes. Once we arrived at the theoretical saturation (Sandelowski, 1995), we started Phase 2, which aimed to design the mock-ups on the basis of the data collected in the previous phase, and

to validate the mock-ups with the participants.

8.3.1 Phase 1

We began with an exploratory study to comprehend the relationships and the communication dynamics among professional caregivers, and between professional and family caregivers. In this phase, we relied on both qualitative and quantitative methodologies. In particular, we drew on focus group discussions, dialogical interviews, and questionnaires.

Focus Groups

The study begun with three Focus Group Discussions (FGDs) (Silverman, 2016; Kitzinger, 2002, 1994) to investigate the work dynamics within the nursing homes. We interviewed 18 professional caregivers. Participants were randomly selected, but together with the management of each nursing home we chose at least one person from each of the core professional roles among the staff members and, therefore, we always included at least one doctor, nurse, and social-health operator. The outline of the FGDs drew on the following topics: *(a)* the daily routine; *(b)* the frequency of emergencies; *(c)* topics that concern and worry family caregivers; *(d)* information that family caregivers should be aware of; *(e)* communication dynamics. The FGDs lasted from one hour to one and a half hours. Each of the FGDs was facilitated by the same moderator and assistant moderator who recorded the meeting and took notes. The conversations were later transcribed and analyzed using thematic analysis (Braun and Clarke, 2006).

Interviews

After the FGDs were completed we interviewed (Silverman, 2016) 27 family caregivers, in order to comprehend their personal experience in assisting their loved ones. Due to the sensitive nature of the context, we used dialogical interviews that

allowed us to focus on a relational flow with the interviewees (La Mendola, 2009). Participants were randomly chosen. They were mostly retired and female. Precisely, we interviewed 9 men and 18 women, who ranged between 55 and 70 years old. All the interviewees resided in the same town, or within its hinterland, where their family member's nursing home was located. The interviews were based around an outline focused on the following arguments: *(a)* Why they chose the nursing home in question; *(b)* How often they attend the nursing home; *(c)* Their relationship with the care professionals; *(d)* Their collaboration with other family members in taking care of the resident; *(e)* Their relationship with the relatives of the other residents, if any; *(f)* how they manage medical information; *(g)* Their frequency and proficiency of ICT usage. The interviews were recorded, and lasted from 40 minutes to 1 hour. The conversations were later transcribed and analyzed, using thematic analysis (Braun and Clarke, 2006). The interviews were carried out individually by three researchers who participated in this project.

Questionnaire

We also designed a questionnaire (Kazi and Khalid, 2012) which was distributed to the six nursing homes involved in the study. The questionnaire was aimed at deepening the understanding of the sample of family caregivers, and at validating the qualitative data. Hence, in collaboration with the management of the nursing homes, we delivered the questionnaires across all the facilities in order to be carried out by family members of residents. The questionnaires were self-administrated and returned to the nursing home's secretariat. The interviewees had to answer 35 questions, mainly on a Likert scale. The questionnaire explored the following topics: *(i)* Demographic data of the interviewee; *(ii)* Demographic data of the assisted resident; *(iii)* Proficiency of ICT usage; *(iv)* Frequency of visits and satisfaction with the services provided by the nursing homes; *(v)* Relationship with the staff; *(vi)* Information exchange with the staff, and satisfaction with the information received;

(vii) Interaction with the family caregivers of other residents; *(viii)* Emotional state; *(ix)* Relationships within their family network. Eventually, we collected 89 questionnaires from the relatives of a sample of 657 residents. We used descriptive statistics to analyze the data with STATA.

8.3.2 Phase 2

In the second phase, we designed the prototype of the technology platform, supported by the creation of personas and scenarios. Then, we validated the prototype using participatory workshops, a validation questionnaire and prioritization sessions. In these activities, we included both family and professional caregivers to validate the concept of the technology, its features and the prototype.

Personas & scenarios

In the light of the outcomes of Phase 1, we developed seven personas and four scenarios. The personas depicted five family caregivers and two care professionals. We created them by using part of the guidelines provided by Hensely-Schinkinger et al. (2015) for the development of technologies for caregivers, including: age, gender, living situation, care situation, care received, care receiver, social environment and technical skills. Also added to the personas were the emotional situation of the caregiver and their medical skills.

Validation Workshops

In the course of Phase 2 we held six validation workshops (see Figure 1), in order to verify the consistency between the prototypes and the results of our studies, and to validate the design guidelines upon which the prototype was designed. We carried out 3 workshops with family caregivers, and 3 workshops with professional caregivers. Overall, 33 people participated in the workshops. The workshop followed a participatory approach (Karasti, 2014; Simonsen and Hertzum, 2012; Ehn, 1993).

Participants reviewed the mock-ups extracted from the two versions of prototype, one for family members and one for care professionals; they reviewed 20 and 18 screens respectively. Using comments on adhesive notes, each participant tagged the printed version of the mock-ups while discussing particulars with the other partici- pants. The mock-ups were grouped in 6 categories that represented the features of the technology.

Figure1. Picture of a Validation Workshop.

We presented regular prototypes and also some *provotypes*. Provotypes (Mogensen, 1992) are prototypes that aim to provoke its users and address critical reflections. In these workshops we included some screens that were deliberately provocative in order to validate some contradictions that we identified by analyzing the data of Phase 1. The workshops lasted from two to two and half hours, and were facilitated by two researchers. The workshops were recorded and analyzed with thematic analysis (Braun and Clarke, 2006).

Prioritization. Once participants finished reviewing all the mock-ups, they were asked to perform a prioritization of the 6 features embedded into the prototype. Precisely, we gave each of the 33 participants a deck of 6 cards, each one with an image of

the category it represented. The participants had to write on each card a number from 1 (the most important) to 6 (the least important) to indicate how they prioritized the categories. We used this prioritizing activity in order to understand which constituted the most important matters for the participants.

Validation Questionnaire. At the end of the workshops, we asked to the participants to fill out a validation questionnaire that was already validated (Czaja and Rubert, 2002; Kazi and Khalid, 2012; Kamin and Lang, 2013). We adopted a validation questionnaire to collect quantitative data on the satisfaction of the participants with the prototype. The questionnaire was designed in two versions, respectively for family and professional caregivers. Participants had to answer 24 questions on a Likert scale. The questionnaire investigated the opinion of the participants on the following topics: *(a)* impact of the use of the platform on the relationships, information exchange, and care work of the caregivers; *(b)* perceived usefulness of the technology platform to be; *(c)* reasons for using the platform; *(d)* reasons for not using the platform; and, *(e)* expected benefits from the use of the platform. The questionnaire was administrated with the assistance of the researcher who facilitated the workshops.

8.4 Results

Here, we present the results of our study by following the chronological unfolding of the study.

8.4.1 Phase 1

The data gathered during Phase 1 allowed us to grasp the main issues that interfere with the care work of the family members and care professionals (Di Fiore and Ceschel, 2017). In particular, these issues led us to comprehend which functions the

new technology platform should put in place.

Focus Groups Outcomes

The care professionals stated that they manage a complex relationship with family caregivers. The staff took the opportunity to open up on topics that are not easily disclosed within their working environment, providing us with their reflections on the relational issues with family caregivers. Therefore, they explained the issues that make their care work challenging. The FGDs highlighted four main issues:

1. The exchange of information with the family caregivers is a complex task that consist in many different and connected parts:

- Care professionals always prefer to communicate sensitive information to the family caregivers face-to-face;
- Care professionals think that sensitive information must not be delivered via technological media;
- Because of their care work, care professionals do not always have time to properly interact with the relatives, even though they believe that it is important and they wish they could dedicate more time to that;
- Care professionals often have to communicate information while delivering medical procedures;
- For the relatives the information is never enough – according to the staff, relatives are eager to receive more and more information;
- Care professionals are aligned in disclosing only fundamental information to avoid the potential reaction of anxiety of the relatives.

2. The management of the relationship with family caregivers is demanding. Most of the times staff members feel misunderstood and unappreciated by the relatives:

- Staff members struggle to make family caregivers understand the difficulty of their care work, the care work is time demanding and care professionals have a tight schedule and various tasks to carry out, in particular due to understaffing;
- Family caregivers require empathy from the care professionals, but care professionals think that they do not want to reciprocate that with the staff;
- According to the staff members, the relatives socialize with one another in the nursing homes, family members exchange information on their negative personal experiences and relationships with the staff;
- Staff members said that often family members grouped together "against" the nursing home staff;
- Care professionals said that sometimes they struggle to deal with these groups of relatives;
- Care professionals feel judged, and they respond to the relatives' behavior by forming closed groups as well, in order to protect their work.

3. Family caregivers are often perceived as hostiles:

- They often complain and try to take control of the care pathway;
- Staff members said that they tend to act as medical experts, and often they question the medical decisions of the care professionals;
- Staff members feel they are constantly being questioned and as a result they act to protect their work in order not to be disheartened;
- The staff place boundaries between them and the family members, thus protecting their care work;
- The staff moderate the personalized tasks for the residents to avoid exaggerated expectations from the family members.

4. The staff understand that the family caregivers deal with emotionally challenging situations:

- Care professionals stated that they understand that the emotional distress of caring for their loved ones can lead some relatives to hostile behavior;
- The staff stressed that the relatives that are difficult to relate with are a minority, but these are often responsible for driving other relatives to act in a similar manner;
- Professional caregivers declared that these dynamics directly pertain to their care work and, therefore, they conceive the relationships with the relatives as an intrinsic part of their care work with the residents.

Interviews Outcomes

The interviews also allowed us to understand the perspective of the family caregivers. In particular, (and similarly to the FGDs) the interviewees took the opportunity to disclose issues that regarded their feelings and their experiences of taking care of a relative in critical or end-of-life conditions (Ceschel et al., 2017). In particular, the interviews rotate around the personal experience of the interviewees and their relation with the nursing home staff. We identified five main topics.

1. Their experience in looking after their loved ones:
   - Most of the interviewees had previously looked after their loved ones at home for lengthy periods and now they rely on the nursing homes because they are unable to continue to provide adequate home care;
   - relying on the nursing homes led family members to develop feelings of guilt for the "abandonment" of their love ones;
   - They struggle to leave the entirety of the care of their loved ones to the staff

of the nursing homes, because they still feel a responsibility;

- They think that the quality of care lies in the little things and in a thoughtful care environment;
- They believe the staff should personalize the care more;
- Relatives stress the importance of their intimate care knowledge as family caregivers;
- Looking after their loved ones is time demanding, and family caregivers sacrifice their personal lives to be present in the nursing homes;
- They suggest that care work should focus more on the humans behind the patients.

2. The relationship and information sharing with the nursing home's staff:

- Since they regularly visit the nursing homes, they normally interact with the staff through informal face-to-face talks;
- According to the family members, the staff show curt behavior and the interactions are shallow and short;
- Relatives feel disoriented by the high number of care professionals and often they do not know who to relate to and, as such, would like a single reference point within the staff;
- They claim that sometimes the staff hide information, while they would like to be better informed on the situation of their love ones;
- The concealing of information creates trust issues with the staff members;
- They would like to establish better relationships with the staff, believing that care professionals should be more empathetic;
- Family caregivers feel they are not listened to by the care professionals, as they would like to participate more in the care of the residents;
- Relatives do not feel recognized by the staff as informal caregivers, despite

their previous experience of home care;

- They would like to provide more of the information they hold as a result of their personal and private relationship with their loved ones in order to ensure better quality care.

3. How they manage the information on the situation of residents:
   - Relatives do not rely on specific methods to manage the medical information they receive;
   - Relatives want to receive information in "narrative" fashion, medical information should be delivered in a comprehensible way;
   - Relatives want to remain updated on the situation of the residents in person and with designated and formal meetings, and through written summaries;
   - Family caregivers normally rely on what they learned from their experience of home care and they generally feel confident in dealing with medical matters;
   - They would like to have greater access to medical and social information on the residents to have an overview about the situation of their loved ones;
   - Relatives communicate with each other through phone calls, but they often use WhatsApp to update their loved ones' conditions and to exchange pictures of the residents when another family member or close friend visits;
   - Family caregivers have positives relationships with the relatives of other residents, they often leverage these relations to have information about how the staff members take care of their loved ones;
   - Several interviewees use social networks to find peer-to-peer support and/or belong to groups of mutual support via social media to feel less alone.

Questionnaire Outcomes

The surveys supported the validation of the data collected during Phase 1, highlighting frictions and gaps within the relationships between family and professional caregivers. The majority of the respondents were women (62%), of which 64% were daughters,

or, more generally, the majority were close relatives. Most of the respondents declared they visit their loved ones every day (72%) or at least once a week (25%). The survey provided detailed data on the information needed by the family caregivers and on how they deal with their situation as caregivers:

- Most of the respondents were quite satisfied (54%) or fully satisfied (39%) with how the staff members assist the residents;
- 91% of the respondents declared they talk with the staff on most of the occasions that they go to the nursing home;
- However, in an open question the respondents declared that, from the staff, they receive only general and superficial information on the condition of their loved one.

In an open question, 55% of the respondents declared that they wish to receive more information regarding residents. In another open question, they expressed the need to better understand the medical conditions of their loved ones, and to receive more information on the implications of ailments on the quality of life of their loved ones, asking for greater availability of the staff. Concerning the importance that they attribute to information, we divided this information into three main categories that respondents assess on a scale from 1 (very important) to 4 (not important at all):

- 76% of the respondents defined as "very important" the information on the primary needs of the residents, such as sleeping, eating, caring activities, and personalized care;
- 70% of the respondents understood as "very important" the medical information, such as blood pressure, vital signs parameters, medical treatments, examinations, etc.;
- 50% of respondents saw social information as "very important", including

behavioral notes, participation in social activities etc. (the relevance of this information was considered lesser due to the fact that most of the residents have severe cognitive impairments that hinder interactive activities).

- 72% of the respondents declared feeling quite confident with the medical knowledge related to the condition of their loved one.

Investigating the source of their knowledge we discovered that:

- 81% of the respondents acquired medical knowledge by talking or engaging with peers, such as other family members who had visited and relatives of others residents;
- the remainder of the respondents used journals, books, the web or asked their family doctor or specialists outside of the nursing homes;
- these data suggest that the relatives do not rely on the staff members of the nursing homes to be informed and trained on the medical matters that concern the conditions of the patients.

Most of the respondents (71%) declared that it is hard and burdening to take care of relatives in end-of-life conditions, and that talking with people and receiving human support are a source of relief.

From the data, we understood that the lack of interaction with the staff led family caregivers to find support within their family network and with others who had experience of similar situations. The data show how these relationships and information exchanges among family caregivers provide a sense of control of the situation by feeling understood and kept up to date with the care conditions of their loved-ones.

8.4.2 Phase 2

In Phase 2, we applied the results collected in Phase 1. We relied on our findings to design and validate a prototype of the technology platform we intended to develop. As previously mentioned, the research project was firstly conceived to create a technology platform to allow remote monitoring and transmission of real-time information to the family caregivers of nursing home residents. However, in Phase 1 we realized that caregivers were unwilling to use such a system because they had problems that needed to be solved earlier, as well as because they did not want to rely on a technology for the transmission of medical information, which family and professional caregivers believe should only be conveyed face-to-face.

As described in a previous work (Di Fiore et al., 2017b), in order to re-frame the goal of the technology, using the results of Phase 1 we defined a series of design guidelines upon which we designed the prototypes. Then, we created personas and scenarios upon the results of the exploratory study in order to represent the contexts of the nursing homes we investigated. According to our data and, hence, according also to the personas, the technology should facilitate caregivers in establishing relationships beyond the medical framework. We used personas and scenarios as metaphors to allow the developers of our research group to better understand, and then emphasize, the unexpected problems of the target user group, accepting the slight re-frame of the project toward a wider collaborative tool. Therefore, we actualized the needs that we elicited into a tangible artefact. In light of the friction between the initial aim of the project and the needs of the caregivers, we decided to include some provotypes into the prototypes. In this way, we included some provocative screens in order to validate the frictions with the original concept of the *Collegamenti* project. Thus, in some screens we proposed the real-time sharing of information that the caregivers refused in Phase 1. As a provotype, we proposed two

screens: *i)* a real-time sharing function for raw medical data related to blood pressure; *ii)* a real-time sharing function for softer information on the fulfillment of the primary needs of the residents (such as meals, toilet use etc.).

The mock-ups were grouped in six categories that represented the main features of the technology, providing areas dedicated both to information sharing and to collaborative/relational support.

(1) Health status: the overall status of a resident, comprehensive of all the clinical data (i.e. tests' results, EMR), and of real-time notification system of critical events (such as falls and emergencies).

(2) Primary Needs Fulfillment: Information relating to the completion of basic tasks during the day including meals, toilet use, bathing, etc.

(3) Relational Areas: the profile of a resident that included their demographic data, medical history, personal history, family network (including the primary family caregiver) and corresponding contacts.

(4) Activities: a bulletin board with information on the activities carried out by the residents, and events organized by the nursing homes which are open to family members.

(5) Forum: a forum platform for caregivers of the same nursing home.

(6) Calendar: an editable calendar with all past and future events regarding the residents – such as activities and medical visits – automatically uploaded.

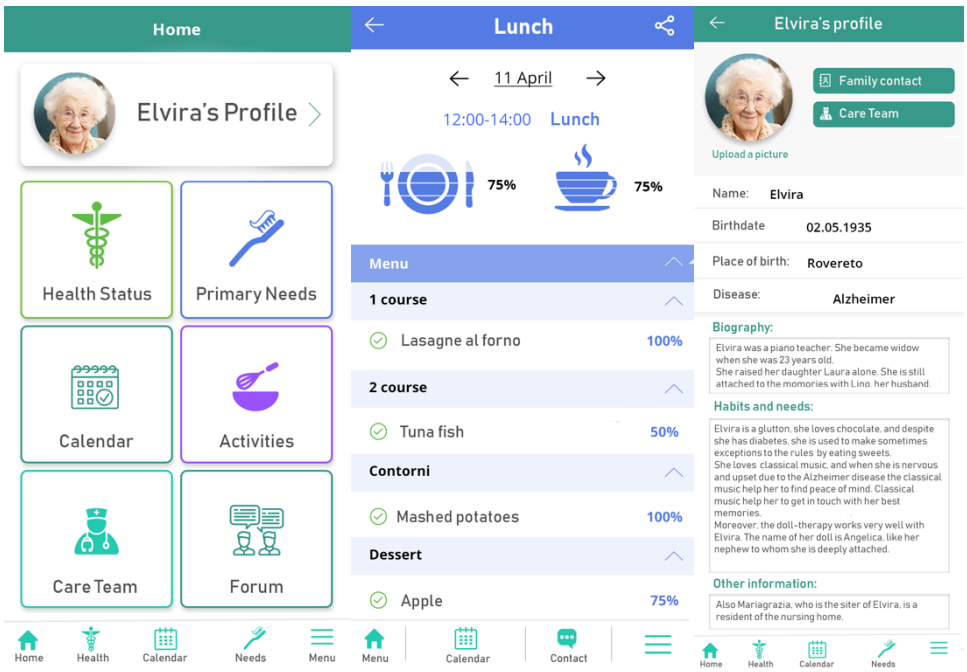
The prototype displayed two different interfaces for family members and care professionals, in order to personalize the interface according to the needs of the target user group. It was conceived to be accessible through a personal account. In terms of aesthetic, the two versions of the technology were similar; they differed only on the levels that could be edited either by the staff or by the relatives.

Validation Workshops

During the workshop, we proposed the screens that represented the main features and thematic areas of the technology (see i.e. Figures 2 and 3), including the provotypes.

Family Caregivers. Once again, according to the validation outcomes, the rationale of the technology platform switched from a technology focused on real-time monitoring to a collaborative information space. It should be used primarily by the main family caregiver who can also forward contents on several media (such as e-mail, Whatsapp, Telegram) to other family members by using a share button.

Figure 2. Examples of The Mock-Ups A



(a) *Dashboard* (b) *Primary Needs Fulfillment* (c) *Resident's Profile*

The main areas of the platform that are used by family caregivers consist of the following (see Figure 2a):

- *Health Status.*

A) *Events history.* The relatives could have real-time access to medical parameters and to incidents such as falls or other severe happenings of their loved one. We used this part as a provotype and, in order to validate the use of real-time data, we presented the possibility of receiving both regular medical news (such as blood pressure values) as well as news relating to negative incidents such as falls.

Reaction. Relatives found it useful to have a collection of medical parameters but they declared that they did not need to remotely monitor the situation with real-time data. Participants proposed a repository with the passed tests and parameters, in order to have an overview of the conditions of their loved ones, but they rejected the idea of having real-time data. Indeed, they stated that they want the notification of negative incidents or bad news to be communicated only face-to-face, or, in the case of emergencies, by telephone.

B) *Monthly reports.* Family caregivers could access a health status report and a therapies report, designed ad-hoc and written in a "narrative" way (see Figure 3b).

Reaction. Relatives liked the idea of receiving a narrative monthly report that summarizes the conditions of their loved ones, but they suggested adding information on the behavioral situation of patients if cognitively impaired. They suggested for the reports to be sent every 15/30 days.

- *Primary Needs Fulfillment.*

Relatives could access the physiological situation of their loved ones, to have real-time information (provotype) on their sleeping habits, meals consumed, and the toilet necessities (see Figure 2b).

Reaction. Similar to the health status, the family caregivers refused the idea

of receiving this information in a real-time fashion. However, they admitted that it could be useful to receive a daily summary of information on the primary needs fulfillment, allowing them to know if the situation is stable.

- *Relational Areas.*

  Family carers could create a profile of their loved ones (see Figure 2c). This could be updated as necessary and would allow the sharing (with nursing home staff) the information considered important to properly take care of their relatives, such as: biography, habits, attitude, tastes, hobbies etc. They could also create a genogram of their family network with the degree of kinship, roles and contacts, and they could also see the diary of their loved one edited by the staff (see Figure 3a).

  Reaction. Relatives approved the idea of having a space which provided information about the little things that are important for their loved one. However, they stated that they were not sure that the staff members would take into consideration such information, so some of them asked to add read receipts.

- *The Care Team.*

  The family caregivers could check the profiles of the care professionals who assist their loved ones, with photos and direct contacts. There, they could also check who was their reference point within the care team and ask for appointments.

  Reaction. Relatives appreciated the idea of having the list of the staff members with a profile picture, in order to connect the faces of the staff members with their names and roles. Moreover, they totally approved of the idea to formalize a reference point within the staff members, because this

would grant relation and information continuity.

- *Activities.*

  The family members could visualize the activities organized by the nursing homes, they could check those attended by their loved ones, those they could participate in, and those to which they could volunteer to help the staff.

  Reaction. The relatives did not like the idea of monitoring the activities attended by their loved ones, but they agreed on having an interactive board to check labs or workshop that they could attend with their loved ones. Moreover, they liked the possibility of proposing events and of volunteering at the nursing home events, because they stressed the will to participate in turning the nursing homes into a meaningful place that supports the sociality of the residents.

- *Forum.*

  The families could connect with other family members, to socialize, share information, and have peer-to-peer support.

  Reaction. Most of the participants approved of the idea of having a forum to share problems, solutions and experiences, but some of the participants were unsure on the idea of using this feature. Some of them suggested keeping the forum closed to those who belong to the nursing home network.

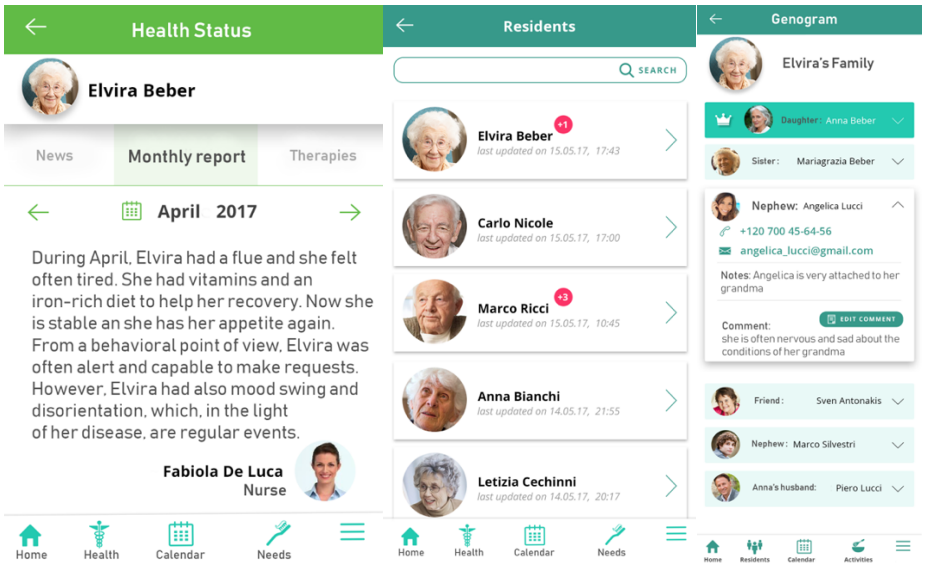
- *Calendar.*

  The family members could organize their appointments in the nursing homes, especially with their staff member "reference point". They could check the scheduling of medical tests, visits, and social activities, which would be automatically updated by the staff.

Reaction. Participants were unsure about the functionality and benefits of the calendar. The older participants were used to using paper planners, whereas others already used digital calendars and did not want duplications.

Professional Caregiver. The version for care professionals differs from that of family caregivers on only a small number of features, which allow them to update the medical data and to have an overview of conditions of all the residents. The two versions match with each other and, therefore, the interactions between the two groups of caregivers will be based on the same levels of the platform. Most of the medical and primary needs information is already present in the EMRs that are linked to the new technology. The dashboard of this version of the prototype displayed the list of all the residents grouped in wards and alphabetical order (see Figure 3c). Here professional caregivers could access the specific profile of each resident that encompasses five sub-levels. The staff members showed enthusiasm for the possibility of having an overview of the residents, each with profile pictures, and grouped by their needs. They asked to add flags and symbols to mark the medical and social characteristics of the residents in order to check the situation at a glance.

Figure 3. Examples of The Mock-Ups B



(a) *Genogram* (b) *Monthly Report* (c) *Residents' List*

The levels of this version are:

- *Health Status.*

  Here, staff could edit, update and visualize the contents accessible to the relatives, such as the real-time history of events (provotype), and the narrative reports related to health status and therapies (see Figure 3b).

  Reaction. The medical professionals strongly rejected the real-time information flows function. Some of them harshly stated that "you [we] are [were] crazy" to propose this feature. They feared the possibility of this function becoming another source of anxiety for relatives, which could worsen the already complex relationships they have with the family members. They also rejected it because they do not have time to work on this function in such a way for it to be effective. However, care professionals acknowledged the importance of providing narrative reports.

- *Primary Needs Fulfillment.*

  Here staff could edit, update and visualize the real-time information (provotype) on the fulfillment of primary needs of the resident for the family caregivers.

  Reaction. This feature was strongly rejected by the staff participants. They declared that relatives who are more relaxed about the state of their loved one would not check this information in real-time nor on a daily basis, whereas, the relatives that are difficult to deal with would become even more anxious, worsening the relationships between nursing home staff and family and making it more difficult for these relationships to be smooth. Moreover, like in

the previous case, they suggested that their care work would not allow them the time to carry out this function in a way that would be effective.

- *Relational areas.* Here, staff could check the profile of the residents edited by the family members and, hence, they could visualize the genogram of the family of the resident and add private notes about how to better approach each relative (see Figure 3a). They could also access the diary of the residents, which they could edit adding pictures and information on the events and activities in which the residents participated.

  Reaction. Staff members approved the idea of using a digital platform to collect the histories and the human needs of the residents, in particular because staff do collect this information but only on paper, which is often lost. This, stimulated conversations about the lack of this function in the existing EMRs, and it emerged that the staff members need to have more relational time and social information to better take care of the residents. However, they partially rejected the diary feature, saying that it was a nice idea but that they have no time to do more data work.

  – *Care Team.* The staff could access the "Care Team Organogram" where they could create, update, modify and add profile pictures to the organigram of the nursing home.

  Reaction. Some staff members rejected the idea of giving the relatives the possibility of consulting the care team. This minority strongly disagreed with providing profile pictures, names and roles' descriptions, because they wish to maintain certain boundaries between themselves and the relatives.

- *The calendar.* Here the staff could consult and/or schedule medical visits and tests, and consult events and appointments.

Reaction. Staff members liked the idea of having a flexible calendar that leaves space to schedule social- related events because they already have a calendar connected to the EMR described as inflexible and strictly related to medical events. However, they were concerned about duplication, and they partially rejected this feature.

- *Activities.* The staff could update the overall activities they organize in the nursing homes, and the relatives could propose activities and join up with volunteering opportunities.
  Reaction. The staff members agreed to have an interactive board to publish the activities organized in the nursing homes. However, some of them disagreed with allowing the relatives the opportunity to propose events.

- *Forum.* For the prototype that care professionals had to validate, we also included the Forum section that we proposed to the family caregivers in order to investigate how they perceive such an area.
  Reaction. They were firmly against a forum section believing it to be dangerous for both residents and staff.

Prioritization

The participants indicated which value they attributed to each feature of the technology. We asked them to prioritize only those areas that match across the two versions of the platform: Health Status; Primary Needs Fulfilment; Relational Areas; Activities; Forum and Calendar.

From the "votes" (from 1 to 6) that the participants attributed to the levels, we calculated the mean. Thus, we obtained 2 scales of prioritization, summarized in

Table 1. The scales are consistent with the importance that caregivers attribute to the features. Relatives agreed (1.1) to give more importance to the Health Status area, which, overall, contained the hard indicators of the conditions of the residents. Then, Primary Needs Fulfillment and Relational Features, were graded with the same score (2.6), showing an appreciation of the areas dedicated to care, to the valorization of informal caregivers' knowledge, and to the relationships with the staff members. Similarly, the professional caregivers gave importance to the Health Status area (2.1) and Primary Needs Fulfilment (2.5), but with lower scores compared to the relatives. Despite the resistances, they acknowledged the relevance of providing clear and understandable information flows. They then scored as third (2.8) the Relational Areas, showing a willingness to collaborate and relate to the family caregivers. For both groups, the other areas' results were ancillary in the concept of the future technology.

Table 1. Prioritization (mean of a scale 1 to 6)

Levels	Family Members	Levels	Care Professionals
1. Health Status	1.1 (SD 0.3)	*1. Health Status*	2.1 (SD 1.6)
2. Primary Needs Fulfillment	2.6 (SD 0.7)	*2. Primary Needs Fulfillment*	2.5 (SD 1.1)
2. Relational Areas	2.6 (SD 1.0)	*3. Relational Areas*	2.8 (SD 1.2)
3. Activities	4.4 (SD 1.2)	*4. Activities*	3.7 (SD 1.0)
4. Forum	4.7 (SD 0.8)	*5. Calendar*	4.4 (SD 1.3)
5. Calendar	5.5 (SD 0.7)	*6. Forum*	5.6 (SD 1.1)

Validation questionnaire

We gathered 32 validation questionnaires. The respondents showed a generally positive attitude towards the technology platform and its features. Part of the results are summarized in Table 2. Family and professional caregivers found the platform useful (relatives 100%; care professionals 65%).

They would mainly use the platform to:

a) Schedule meetings and communicate among caregivers (relatives 81%; care professionals 70%)

b) Have shared information and data among caregivers (relatives 100%; care professionals 82%).

Both respondents stated that the main benefits of the technology are related to the possibility of:

a) involve the family caregivers in taking care of their loved-ones (relatives: 81%; care professionals 65%);

b) and check the overall situation of the residents (relatives: 87%; care professionals 82%).

Moreover, relatives stated that the platform would support their peace of mind (87%) and their involvement in the care activities by providing useful information (94%). Whereas, according to the staff members, the platform would be useful to show the positive activities that occur in the nursing homes (94%). The only discordant result regarded the risk for such technology to impoverish face-to-face relations: 56% of the relatives agreed, whereas only 18% of the staff members agreed with this statement.

In general, we elicited positive opinions by both groups of respondents. The answers given by the family members were extremely positive, whereas the answers from staff members were influenced by the hard-liners who were the most critical during the workshops.

Table 2. Validation questionnaire (n=32)

Question	Family Members	Care Professionals
The platform would be useful for the care work	100% answered "yes"	65% answered "yes"
The platform would allow me to schedule meetings with the other caregivers	81% agreed/totally agreed	70% agreed/totally agreed
The platform would allow me to have shared data with the other caregivers	100% agreed/totally agreed	82% agreed/totally agreed
The platform would allow me to check the overal situation of the residents	87% agreed/totally agreed	82% agreed/totally agreed
I am worried that the platform could hinder face-to-face relations	56% agreed/totally agreed	18% agreed/totally agreed

8.4.3 Reflections

The findings of Phase 1 emphasized the conflicting relational dynamics between family and professional caregivers. On the one hand, professional caregivers acknowledged the importance of having closer relationships with the relatives and a clearer information flow. However, their working conditions negatively influence the time that they have to spend developing relationships with the families of the residents, bringing low quality information sharing, and incomprehension. They feel unappreciated and not respected by the relatives who can become "hostile" and extremely anxious. In this way, they tend to create relational boundaries to protect their work.

On the other hand, although the family caregivers are usually regulars at the nursing homes, they struggle to obtain clear and complete information on the condition of their loved ones. They perceive that the information provided is shallow and this creates trust issues with the care professionals. They experience a burdening situation. They need more acknowledgement of their knowledge of the residents, a sense of control of the situation, empathy and understandable updates. To cope

with the lack of positive relations with the staff and the lack of information, they tend to associate themselves with the family caregivers of other residents and to search for expert information outside of the nursing homes.

The findings show a series of communication and social needs, which reveal a series of missed collaborative opportunities between the two groups of caregivers. This led to a clash of culture that can manifest itself with misunderstandings, boundaries, fragmented information, mistrust and even hostility. From the exploratory study, a relationally complex environment emerged, but both professional and family caregivers showed willingness to join the project in order to improve the situation, exposing their wishes, strengths and weaknesses. Care professionals asked us to help them to show the relatives the good things and the hard work they do. Family caregivers were willing to provide suggestions to improve the quality of relationships and communication, finding a nexus between their worlds. In this way, the results of Phase 1 suggested a slight re-framing of the initial concept of the project, working on a wider collaborative solution to share information, support relationships, and enhance mutual understanding and collective sense making between family and professional caregivers.

In Phase 2 we validated the existence of the friction that emerged between family and professional caregivers in Phase 1. We understood that this friction can be attenuated by a clearer method of communication and by improving the chances for allowing positive relationships to develop. Contrarily to our initial goal and expectations, both groups of participants rejected the possibility of using real-time information relating to the conditions of the residents, having a propensity for narrative and contextualized information. The validation process confirmed the necessity of developing a tool that allows family members and care professionals to establish better mutual communication and support face-to-face encounters, while

creating a space where they can jointly contribute to the care pathways, thus permitting collaboration and collective sense-making.

8.5 Discussions

The preliminary investigation we conducted in Phase 1 allowed us to identify the issues that interfered with the care work of the care professionals and the relatives. We noticed that the nursing homes that were the object of our study, even though they are environments within which older adults are well taken care of, are sensitive healthcare contexts that display a conglomeration of tense relationships due to the different sense-making practices and different approaches that caregivers have. In particular, despite the medical nature of nursing homes, it appeared that the necessity to build relationships that transcend the medical framework is highly important in order to enhance collaboration, coordination, and trust between family and professional caregivers. From these findings, we understood what a technology artefact could do to try to align caregivers' contributions to the care work. The core findings regard the necessity of supporting the relationships between family and professional caregivers through clear communication procedures and mutual information sharing, creating preferential channels to establish reciprocal acknowledgement. Therefore, the prototype we designed represented a digital space within which caregivers could build relationships and coordinate their care work, while increasing their mutual understanding. The prototype encompassed all the functions that could sustain caregivers in accomplishing these goals. However, despite the result of Phase 1, we decided to add a provotype – the exchange of medical information in a real-time fashion that the projects originally planned – to test this feature twice.

Indeed, different from the initial goal of the project *CollegaMenti*, our study

highlighted that:

- Caregivers emphasized the importance of the “information” over the “data”, specifically the necessity to talk and to exchange information, rather than receiving raw medical data;
- Family and professional caregivers are not interested in exchanging medical information in a real-time fashion, they want such information to be exchanged face-to-face, thus avoiding misunderstandings;
- Family and professional caregivers always prefer to talk when it comes to sensitive matters;
- When receiving information remotely, family caregivers prefer to receive it in a “narrative” way, not as raw medical data, in order to have a deeper understanding of the situation;
- Family caregivers are not interested in “monitoring” their loved ones to have a sense of control, rather, they are interested in participating in and establishing dialogue with the care professionals;
- Caregivers agreed on having a technology that, while allowing them to remotely interact, also fosters face-to-face communication.

These additional findings led us to formulate the new social requirements and, subsequently, the new mock- ups for the technology platform (see Section Findings). In particular, the validation process showed that the technology should provide the following:

- A presentation of medical information that concerns only events or matters that the relatives are already aware of;
- Structured medical information that the relatives are already aware of and that is made available in a shared repository;
- Short reports on the overall situation of the residents – written on a monthly or

fortnightly basis – that describe, in a narrative way, the care pathway of the patients;

- Information on primary needs fulfillment that can be exchanged on a daily basis in order to provide neutral information to allow relatives to know, in a general way, if everything is fine;
- Information allowing for mutual awareness among caregivers on who are the relatives and care professionals who assist the residents (*the care team* and the *genogram*);
- A capacity to facilitate the scheduling of meetings;
- The capacity to allow family members to contribute to the care by enriching the *resident's digital profile* by describing their history and the little things that can improve the quality of life of their loved-ones.

Our study explains how we prepared to develop the new technology platform, and how we tested and validated the social requirements and the prototypes upon which it should be built. We are aware about the necessity of achieving a full development of the platform, in order to fully test and validate our solution, and to do that our study will be expanded in coming years. However, this study provides insights on the world of cross-cultural collaborative care technologies, and the design process itself accompanied the caregivers in sense-making activities that made them more aware about their environment. The outcomes we presented here contribute to sustaining the following statements:

(a) Unlike what our project initially planned, the delivery of raw medical information is a thorny issue that, especially talking about collaboration between family/professional caregivers, can undermine frail relational dynamics;

(b) Raw medical data are not necessarily meaningful for family caregivers if they are not contextualized;

(c) As we saw with the hard-line staff members who were the most critical during

the workshops, encouraging too much change by pushing the boundaries that one side created to protect themselves can exacerbate the perceived conflicts;

(d) Collaborative technologies to support mutual relations across two different caring cultures, as family and professional caregivers are, should firstly foster mutual understanding and sense-making, in order to create the ground on which the technology will be rooted;

(e) Medical and sensitive information is more effective if it is contextualized, being exchanged face-to-face, or in a "narrative" way;

(f) The care work of both family and professional caregivers should rotate around the comprehension of each other's work and contribution;

(g) The care work is about dialogue and reciprocal understanding.

Our study within complex healthcare settings emphasized the importance of progressively taking into consideration care practices, organizational routines, and stakeholders' interests, in order to design proper solutions. Care technologies need to be validated several times before being deployed. This is especially true when technologies need to be designed to support collaborations among caregivers that are diverse in many aspects, as professional and family caregivers are (Balka and Wagner, 2006). Therefore, iterations and validation processes are fundamental to refining the social requirements upon which a technology is designed (Di Fiore and Ceschel, 2017), especially if there are social issues, organizational problems, and relational issues to solve (Di Fiore et al., 2017a). This is particularly clear if we consider that the original goal of the project – the exchange of medical information in a real-time fashion – was strongly reconsidered because the validation process with our target users' groups.

8.6 Conclusion

This chapter gave me the possibility to reflect on how technology should support caregivers in dealing with managerial issues, while nourishing social relationships. Indeed, the state of the art shows how, regard healthcare technologies, there is a tendency to propose solutions that focus on either managerial or social issues. In other words, the literature presents solutions that do not tackle the whole spectrum of issues that affect healthcare contexts and, in particular, nursing home settings.

The described design process was based on mixed methods that explored the context iteratively and with increasing depth. Working on such a wide article, gave me the possibility to have a clearer picture of the situation, deepening the social and collaborative complexity that lies at the relationship between professional and family caregivers.

This process showed me also the power of conducting design processes by *taking care* of contingencies, making the participants more proactive and aware of their environments. Indeed, even if the caregivers were dealing with an environment with complex power relationships, within the process that we conducted they felt free to say NO, rejecting the concept of the project.

This led to re-framing the highly rational concept of an institutional research project, and in addressing sense-making in our interdisciplinary group in relation to this change the use of personas has been crucial. In this way, the project shifted from a focus on real-time sharing of raw medical data, toward a wider collaborative solution to share information, support relationships, enhance mutual understanding and collective sense making between caregivers.

__9. TAKING_CARE _OF_SENSITIVE_MILIEUS:

a story about dialogical interviews[11]

coauthored with Francesco Ceschel and Fabio Casati

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The paper at the base of this chapter has been presented at InfraHealth 2017 (International workshop on infrastructures for healthcare – Aarhus). It has been written between 2016 and 2017 while I, together with Francesco Ceschel, were analyzing the outcomes of the collected interviews.
In these circumstances, we reflected on how to be engaged in design processes in healthcare organizations often implies dealing with sensitive contexts, which, in turn, led us to deal with a unique and delicate emotional setting.
This chapter addresses reflections related to our research experience adopting dialogical interviews in sensitive design contexts, specifically in the context of nursing homes. Writing this paper, I had the possibility to reflect on the experience I had by conducting 27 dialogical interviews with family members of patients in severe end-of-life conditions. This contribution addresses RQ3 that focuses on how to support caregivers through design processes itself. Indeed, in doing so, this chapter provides reflections on the importance of taking care of the human relationships while working with sensitive participants, as a way to deeply comprehend the contexts that we are

[11] This work has been published at InfraHealth 2017 (International workshop on Infrastructures for healthcare)– (Ceschel, F., & Di Fiore, A,, et al. 2017).

dealing with, and if needed, as a way to reconsider the fallacious preconceptions that guide our work.

This chapter provides:

- Framing of sensitive contexts and its problems;
- Reflections on the implication related the adoption of dialogical interviews in sensitive contexts.

9.1 The 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 concept of the project 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 relationships 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 of what is necessary for them 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 both 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 was initially believed, the relatives lacked a "listening space", and this, in our design framework, shed light on different ICT potentials.

In this chapter, we refer to how we took care of the relational settings, while 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.

9.2 Experiencing dialogical interviews in sensitive contexts

Working within delicate contexts such as 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 of gathering 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 evaluated 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 visiting 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 relationship with family caregivers of other residents; i*v*) 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, 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 in 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 relationships with the staff members.

During our research experience, we somehow let the context lead us into the overwhelming nature of feelings and sentiments that the family caregivers experience. Although the interview guidelines 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 appreciated the willingness of the interviewees to open up to us, due to their need of personal space where they could be heard. The interviewees approached the interview almost as a way of opening themselves up 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 when extrapolating *cold data* from their stories. As researchers, we had to approach the "talk" as a way to collect 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 of 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 of being considered worthy and trustworthy listeners. Conversely, we had the responsibility to comprehend, accept and keep this information as our own, and we could not avoid being 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 first, researchers second.

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 any 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 considering them from a perspective immune from any sort of emotional involvement.

9.3 Taking care of sensitive milieus

With this paper we attempted to restructure, as researchers, what we experienced and comprehended 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 a source of *cold data*. Contrarily to what the rationalizing trends are telling us (Traweek, 1992), as researchers and human beings 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 of 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 in 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 the absence of previous experiences in such contexts. Indeed, Dickson-Swift (2007) highlight the need for care professionals to deal with these sensitive contexts themselves 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 protect themselves by becoming insensitive to certain situations, perceiving them as *bizarrely ordinary*. On the contrary, as outsiders 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 it can be to open dialogical spaces, reflecting on the role that researchers should play within healthcare contexts. We discovered that approaching the interview guidelines 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 to 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 the interviewees to be listened to, and by using their narrations to adjust the rationale of our project. In particular, throughout the interviews, we had the possibility of getting closer to the hidden need of the family caregivers to establish better relationships and more sensitive communications with the professional caregivers of the nursing homes.

9.4 Conclusion

This work allowed me to collect methodological reflections on my research experience and leaving a memento for the future ones.
These reflections want to be memorabilia for the novices that are facing sensitive contexts, for those who have been working there for some time and who need to remember the privilege of entering others' unique lives and also for us, the authors. Since, as Morse said: "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" (2007, p. 1005).

These interviews gave me the possibility to comprehend that family caregivers lack a "listening space" rather than a better strategy to be kept aware of the health situation of their loved ones. What I learned is that to take care of sensitive milieus it has been fundamental to create open dialogical spaces, providing a place where the participants can feel heard and accepted, and where we, as design researchers,

can take care of their stories by shaping the design processing that will affect them.

Reflecting on how dialogical interviews have been shaped by being situating them in the NH context shed a light on what was needed by our informants itself. This, in some ways, anticipated also the findings presented in Chapter 8. Suggesting that the primary need of relatives was to have a technology to support them in having better communication with the staff members through a dialogical experience, similar to the one we had experienced with them.

In this case study, this gave me the possibility to opened up to greater potentials for a new design.

_ _ _ _ 10. W E _ A R E _ H U M A N

coping strategies in sensitive settings[12]

coauthored with Vincenzo D'Andrea

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This chapter is based on a paper to which I am emotionally attached, being the first paper that I wrote during my PhD about my research on the field. It is based on a short paper presented at Ethical Encounters in HCI (CHI, 2016) and refers to the preliminary study conducted in pediatric palliative settings, whose outcomes has been used by a company to redesign an information system in order to support the care activities.

It contributes to Part 3 of this report by focusing on dealing with sensitive settings, conceiving them as research contexts that involve human situations that can strongly influence both the researchers and the respondents due to the delicate subject of the study. In this scenario, the peculiar nature of pediatric palliative care raised several ethical issues, some of these related to the emotional wellbeing of the researcher. Here, I discuss the need to take the researcher commitment in sensitive contexts seriously, illustrating some of the experiences that I lived on the field.

This chapter provides:

- A combination of the existing literature and ethnographic data on the role of the researcher in sensitive contexts;

[12] The main content of the chapter has been extracted from a workshop paper presented at CHI 2016 within "Ethical encounters in HCI" (Di Fiore, A., D'Andrea, V., 2016).

- A discussion on the need of developing strategies and resources to cope with the emotional challenges that sensitive research setting present.

10.1 Introduction

Dealing with emotions in a sensitive research setting is one of the hardest challenges that I have ever faced in carrying out research.

There, I realized how difficult it can be to talk about the wellbeing of researchers, especially, in an academic context where the avoidance of personal language is common practice (Latour, 1992; Traweek, 1982). Said practice carries the risk of leaving behind the dignity and the academic relevance of the research experience.

Moreover, the literature and the ethical committees usually illustrate the possible risks of these settings, focusing on the participants of the studies at the expense of the protection of the researchers. However, carrying out design research by using qualitative methods, always implies a personal commitment, projecting, especially in sensitive research contexts, a long shadow on the researcher's life.

In this work, I address the vulnerabilities, the dilemmas and the coping strategies that emerged from my field work in pediatric palliative care contexts. Addressing how, in agreement with Morse (2007), "we must recognize 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" (p.1005).

10.2 The field work

The chapter refers to the research project that I conducted within my PhD, aiming to support the redesign of collaborative technologies for palliative care services that works in pediatric oncology. Specifically, this work is based on *A casa è più meglio*,

literally it is better at home, which is a home care project situated in northern Italy. *A casa è più meglio* aims to ensure home care services for children in end-of-life conditions who need palliative care. The project is coordinated by Pediatric Palliative Care (PPC) teams related to central hospitals, providing home visits and secondary care services such as chemotherapy, blood transfusions and specialized treatments. The teams are composed of palliative pediatricians, nurses, psychologists and provides medical and social support to the families of patients at home and across specialties. The PPC teams assisted about 200 patients from 2011 until 2016, an average of 20 new cases per team every 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. Such phenomenon happened mainly because the services were new, and year by year became more known, thus attracting more patients. In this situation, the need of an ICT emerged, in order to foster communication, coordination and information exchange among the home care activities.

My research project aimed to identify the needs of caregivers in order to redesign a specific system to support communication, collaboration, social support and the remote monitoring of vital signs parameters between medical professional and 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" (Miller, 2015, p.1536). Instead, PPC starts usually with a diagnosis of incurability. For this reason, for example, in the case of rare chronic disease a PPC program can last many years, providing a broad end-of-life support. PPC, compared to palliative medicine for adults, has to deal with complex social domains, including the stages of cognitive and social development of the child and the impact of the disease on the relatives (Miller, 2015).

As a care professional told me: *"Palliative care for adults face the illness in the very terminal stage, it focuses only of the strict terminality. Whereas in pediatric palliative care we focus on the incurability that can last one month, two months, one year or ten years".*

(Interview – pediatrician)

The patients of *A casa 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 engage the PPC team in routine tasks, because they usually have a quite regular, slow and predictable path. While, most of the oncology patients are affected by leukemia. These patients are characterized by waver and unpredictable acute phases and heterogeneous reactions to treatments, especially after chemotherapy. The peculiarity of oncology patients is that some of them can be cured. Indeed, the oncology patients that appear potentially curable but still critical are nonetheless involved in the end-of-life services due to the high level of unpredictable exacerbation of their diseases. Due to their possible curability the members of the PPC team are particularly emotionally attached to the oncology patients.

Data collection

The nature of this field opened several methodological challenges by conveying issues, relating ethics, communication, predictability, organizational complexity and collaboration. In such a 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 organizational complexity of a healthcare context. That is why I adopted a Participatory Design (PD) and a CSCW approach, using qualitative methodologies.

PD is a democratic approach to design that has the goal to commit users and involve them in decision making processes regarding their context (Simonsen & Robertson, 2012). While, CSCW addresses a situated approach to the development of technologies that supports people's collaboration (Schmidt & Bannon, 1992). At the base of both approaches there is a continuous process that enhances commitment, reflection, mutual support and a deep understanding of the needs of the people involved in a research project (Simonsen & Roberson, 2012). Moreover, taking qualitative methods implies the creation of trustee relationships among, and a strong sense of closeness and responsibility for, the stories of the participants.

In this field, I adopted ethnographic observation and interviews to frame the context of my research. In particular, I adopted the approach of dialogical interviews, which is based on empathy and a profound and free exchange with the interviewed person (La Mendola, 2009). This chapter refers to the dilemmas that emerged when, during the preliminary phase of my study, I dealt for the first time with pediatric end-of-life contexts. It is based on two weeks of participant observation and six interviews, where I focused on the perspective of the PPC and not on families or patients for two main reasons: (a) the PPC professionals were my gatekeepers and their coordination dynamics were the fulcrum of the complexities to be handled in my project; (b) I decided to take the long way because I worried about not being yet emotionally ready to directly relate with terminally ill children and their families.

10.3 Developing coping strategies

A sensitive study is conceived as a research project that regards context that can create "potential consequences or implication for researchers and respondent" (Jones, 2013, p. 117). Usually, the literature and the ethical committees used to pay particular attention to the possible wellbeing implication that the research could have

on the participants, neglecting the safety of the researcher (Dickson-Swift et al., 2005).

Several studies show how the researcher who approaches sensitive contexts can run risks in relation to both physical and emotional matters (Dickson-Swift et al., 2007; Campbell, 2002). Most of the literature refers to researcher safety in relation to physical safety. However, the protection of the emotional self is paramount and emotional safety can be at risk as well as the physical one through a deep influence of the researchers' psychological wellbeing (Morse, 2007; Dickson-Swift et al., 2007). Indeed, the researcher saturation is considered as a possible secondary effect of the emotionally challenging research subjects (Wray at al., 2007).

The researcher wellbeing in sensitive contexts addresses ethical dilemmas, particularly in relation to two issues: (a) the responsibility that a research team and an advisor has in respect of being alert for the emotional safety of the colleagues that work in this kind of context; (b) the sense of responsibility related to the participants in the study in the case of the researcher's burn out. My experience in a sensitive context led me to become strongly emotionally attached to the people who I talked to and their stories. In the light of this commitment, I often felt the need to find a balance between the sense of responsibility in relation to the research and the participants; and my vulnerabilities related to carrying out a research project that involved children in end-of-life conditions. Working on sensitive subjects, I learnt how important it is to consider the researcher's wellbeing by focusing on ways to develop coping strategies (Skovholt, & Trotter-Mathison, 2014). 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 (2007) "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" (p. 1005).

Reflexivity helped me in monitoring how my personal experience and my emotions informed the research and the data collection (Jones, 2013). 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 informed each other.

The coping strategies have been an important resource in my field work, guiding me and supporting my field activities, putting in the center both my wellbeing and the sense of responsibility regard the research outcome and my participants. For that reason, during the preliminary phase of my research I decided to have a soft start, focusing on the practices and the articulation of care work 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, but this phase was anyway emotionally very hard.

In my first 10 days of ethnography I followed the PPC team in their daily practices. While doing so, I had intense weeks getting in touch many sensitive situations, for example: I participated in a meeting where the physicians discussed pain control therapies for a little girl affected by the most painful disease that I ever heard about, I attended and helped nurses during chemotherapies and transfusions to children with serious leukemia, I helped the nurses that spoke only in Italian to calm down and reassure scared mothers that were only English speaker, I was in the room next door when a child died.

In some moments my emotions have been so challenging, hindering my work and developing in me a deep sense of guilt. I remember that I started feeling guilty by collecting data, because I felt like a *voyeur of the pain*, a standing vampire, without any possibility to do tangible actions in the real-time tragedies that were happening under my eyes. Later, I realized how meaningful and tangible for my participants the

design process that I conducted has been, but at the beginning of my research project that feeling of guilt prevailed.

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 some episodes that happened and what I learnt.

Let your informants guide you

The PPC teams were composed of healthcare professionals who are specialized in end-of-life care and each member of the team have been working in this field for at least five years. Most of them also hold a master degree in death studies. For this reason, they were accustomed to work in this kind of situation that they did not realize that I was not. In the first phase of my field experience I felt so emotionally unprepared. However, since I did not want to be more of hindrance than a help, I pretended to be strong. Moreover, when I started the data collection, the care professionals were so overloaded and the last thing that I wanted during the first days in the field was to steal their time, asking to be reassured and encouraged. So I decided to avoid burdening them with my worries and to listen to them, and learn from them, accepting the situation, having trust in their feelings, and in their ways of seeing the bright side in these situations.

Today, Alice (the nurse) talked to me about Emilia, 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 attend 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 due to thinking about her situation. Jessica told me that her disease had worsened in the last month and, for this reason, Emilia had a surgery to have a PEG

inserted (a medical aid that provides nutrition by placing a tube in the stomach, bypassing the mouth) because her disease had inflamed her esophagus too much and eating has become too painful for her. When Alice a told me that about Emilia I became sad by thinking about her situation because she is a lovely girl, but Alice was not. She noticed that I was little bit sad, and she explained me that the PEG surgery was good news, because in doing so Emily had the possibility of eating again, but without suffering. This has been a good lesson for me, I have still to work a lot on that. (Ethnographic note)

The interviews have been another important resource to learn from the care professionals how to handle emotions. The interviews have been useful to give me quality time with the members of the team, letting them take 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. Giuliana, a nurse told me that, in order to not have a burn out, she usually avoids attending the funerals of the patients. While, Sandra, another nurse told me that since she started to work in this field, she started avoiding 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 – nurse).
Marianna, the psychologist, told me how meaningful is for her to provide comfort in the end-of-life, *"I like everything about the end-of-life, specifically, I like to support children and families in the very end-of-life phase of a disease and I also like the after-death support to the relatives"* (Interview – psychologist).
Another nurse told me *"I chose to work here because I like this kind of patient, I think that they need more attention than the patients of a regular pediatric unit"* (Interview – nurse).

By being with the care professionals, 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 to understand the beauty of taking care of people in dramatic situation, to accept incurability, and to frame my experience.

It is normal to be human

During the first period in with the PPC team, 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 new child arrived at the hospital in critical conditions. The care professionals did not know him and his family because he was cured before by another hospital. When he arrived at the hospital, he and his mother were put in the room number seven. After a couple of hours, he unexpectedly died. The care professionals were overcome by this fact because the had not been able to properly face the situation, since they did not know the child, his mother and their story. I remember that the nurses, the psychologist and the doctor had a meeting where they assessed the situation, deciding what to do. They were so sad about what was happening that they were neither able to call this six years old boy with his name, referring to him as *Room 7*. Thet felt deeply guilty due to the fact that they felt unprepared in handling the situation because of the lack of relationship and information about *Room 7* and his context.

"We were not prepared to embrace them. (…) He died without quality care"

(Interview – psychologist)

It was a blow for the team and for all the people involved in the pediatric unit, including 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 child. *"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).

Masha and I looked into 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" (Dickson-Swift, 2007 p.19). The informal support, in my experience, has been crucial. My partner and my advisor became my emotional support persons, they supported my resilience, being my life vest.

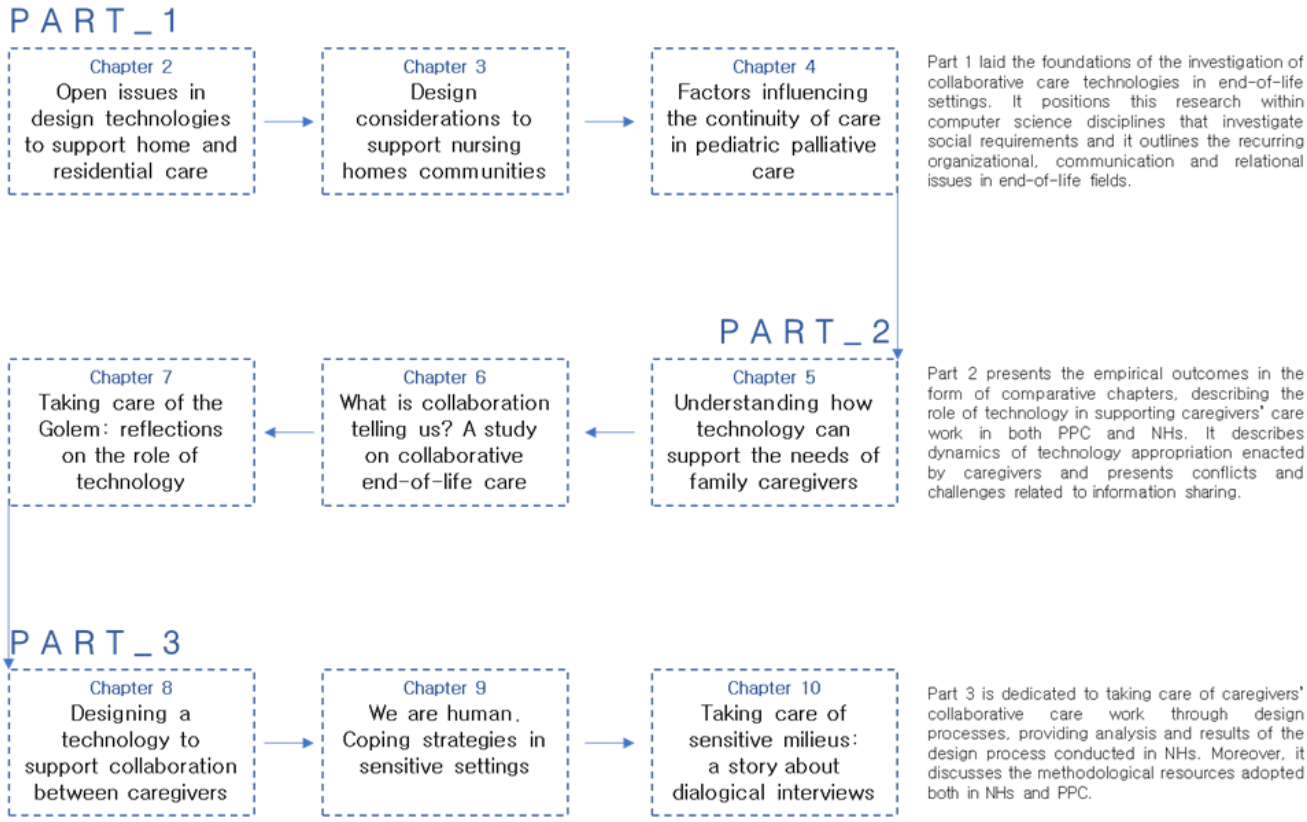
However, for a while it has been difficult to find people to talk with because of the nature of my field work. A couple of times it happened to me that, while I was searching for some peer support with some friends, talking about my experience, my interlocutor started crying. I felt guilty. They were unprepared for these kinds of emotions even more so than I was. I realized that, if you are searching for 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.

10.4 Conclusion

In this final chapter, I discussed how a researcher who works on sensitive subjects finds her/himself dealing with challenging emotions. These emotions can both influence the researcher's wellbeing and the research itself, putting for example the researcher in the conditions of not being able to continue the work on the field. For this reason, to take care of sensitive research setting it is also important to develop, as researchers, coping strategies or resources that fit the situated context of their research.

In this scenario, it has been useful for me to adopt a reflexive approach to assess the situation. Moreover, the humanity of my informants and the possibility to count on the peer support both of colleagues and of people from my private life has been paramount, helping to pursue my research work by normalizing potentially emotionally harmful experiences that I was not prepared to live in such direct way.

WRAPPING _UP


PART_1
Chapter 2
Open issues in design technologies to support home and residential care
Chapter 3
Design considerations to support nursing homes communities
Chapter 4
Factors influencing the continuity of care in pediatric palliative care
Part 1 laid the foundations of the investigation of collaborative care technologies in end-of-life settings. It positions this research within computer science disciplines that investigate social requirements and it outlines the recurring organizational, communication and relational issues in end-of-life fields.
PART_2
Chapter 5
Understanding how technology can support the needs of family caregivers
Chapter 6
What is collaboration telling us? A study on collaborative end-of-life care
Chapter 7
Taking care of the Golem: reflections on the role of technology
Part 2 presents the empirical outcomes in the form of comparative chapters, describing the role of technology in supporting caregivers' care work in both PPC and NHs. It describes dynamics of technology appropriation enacted by caregivers and presents conflicts and challenges related to information sharing.
PART_3
Chapter 8
Designing a technology to support collaboration between caregivers
Chapter 9
We are human. Coping strategies in sensitive settings
Chapter 10
Taking care of sensitive milieus: a story about dialogical interviews
Part 3 is dedicated to taking care of caregivers' collaborative care work through design processes, providing analysis and results of the design process conducted in NHs. Moreover, it discusses the methodological resources adopted both in NHs and PPC.

_ _ _ _ _ 11. CONCLUSION

but… how to make sense from all this?

"Writing always means hiding something in such a way that it then is discovered."

Italo Calvino – Se una notte d'inverno un viaggiatore

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The health condition of the patients at the end-of-life is critical and there is no possibility for healing. In such contexts, quality care means to focus on the quality of life of the patients, acknowledging the poor prognosis and supporting the quality of life during the remaining time the patients and their relatives have left.

The erratic nature of the patients' health conditions brings organizational and social complexities among the relationships between family and professional caregivers, who have to deal with an emotionally challenging environment where the patients have complex human and medical needs (Albers et al. 2014; Rome et al., 2011; Hudson et al., 2004).

According to Mol (2008) “what characterizes good care is a calm, persistent but forgiving effort to improve the situation of the patient” since “the art of care is to figure out how various actors might best collaborate in order to improve a person’s situation” (p.23-26). End-of-life contexts taught me how these collaborative efforts at the base of *good care* are enablers of care itself, allowing caregivers to bear the load of caregiving together.

Within this thesis work I explored, through the lens of CSCW and PD, the collaborative practices and the relationships between family and professional caregivers who take care of end-of-life patients. Thus, I conducted my PhD research in two apparently opposite end-of-life care contexts: a pediatric one, and a geriatric one. In this work, I focused on the experiences of caregivers, acknowledging how these experiences are situated, but strongly believing that their meaning can address significations at the macro level.

To take care of the organizational, relational, communication, information, design and technology needs of vulnerable caregivers has been demanding, and led me to follow the unpredictable outcomes which are related to giving care. As I mentioned in the introduction, with this work I would like to leave a trace of how *seriously taking care* in sensitive contexts is worthwhile for the people in those contexts, for the design process itself, and for us, as designers and as human beings.

But, the point is, how to take care seriously?

All through this work all this work, I tried to answer this big question, addressing the three research questions that guided my research work, focusing on the challenges that caregivers face, the potential of technology in supporting collaborative caregiving and the role of design and technology designers in supporting caregiving.

In this conclusive chapter, I reflect on the mosaic of narrations presented during the thesis, summarizing the contributions, discussing the achieved findings and presenting limitations and future works.

11.1 Summary of the chapters

During the writing process of this thesis I often thought that writing a "regular" thesis, instead of pursuing a paper-based one, would have been easier. However, going back to the papers which I wrote during my PhD gave me the opportunity to collect the traces that I left and to reflect on how my research evolved over the course of time. This being a paper-based thesis, the narrative continuity between chapters can be less fluid than in a "regular" thesis. For this reason, I now provide a summary of the chapters that have been presented within this work.

Part 1

Part 1 positioned the research and provided knowledge of collaborative dynamics between caregivers in end-of-life settings, analyzing relationships, conflicts, information sharing and social and organizational needs.

- C 2: A theoretical chapter that framed this research within CSCW and PD, discussing the problem of identifying people's needs in design research and presenting the issues related to providing at home and residential care to incurable patients.
- C 3: Definition of five issues that characterized the care work in NHs and that should be taken into consideration when designing collaborative care technologies. Identification of problems related to communication practices, describing caregivers' experiences in collaborating and maintaining relationships.
- C 4: Seven factors which affected the delivery of quality care in PPC. Analysis of how caregivers conceived PPC, the relational issues among the actors

involved in the PPC, and the aspects that would support caregivers in delivering care.

Part 2

Part 2 discussed the challenges and opportunities related to technology adoption in sensitive end-of-life contexts, analyzing techno-social dynamics and technology appropriation phenomena. Moreover, Part 2 compared PPC and NHs studies.

- C 5: Empirical insights that drafted an analysis of how the lack of technology adoption in care settings is filled by the form of technology appropriation. Definition of opportunities for novel software applications.
- C 6: Findings that described how caregivers appropriated technologies to support their care practices. Draft of design guidelines for care technologies to support collaboration between caregivers.
- C 7: Discussion of findings that addressed the contrasting opinions of caregivers related to the roles of information sharing and ICTs in their care practices.

Part 3

Part 3 provided the last step to this thesis, dedicated to informing and taking care of design processes in sensitive care settings. It provided methodological reflections and defined social requirements supported by the validation of technology prototypes.

- C 8: Presentation of the design process conducted in NHs, describing what worked and what did not. Elicitation of social requirements supported by the validation of technology prototypes.
- C 9: Methodological reflections related to the conduction of dialogical interviews in NHs.

- C 10: Methodological dilemmas and coping strategies that arose within the PPC field.

11.2 Contributions to research

This research work followed three research questions which contributed to pursue the attempt of this thesis: to explore how to take care of the sociomaterialities that characterize sensitive design settings. These research questions mirror three research streams that explore social, techno-social and design considerations to be considered when conducting design research in emotionally, humanly and organizationally complex care contexts. The three parts that compose this thesis are not, of course, in a vacuum-packet, but they are divided into themes (social/organizational; social/technical; processual/methodological) that are, by nature, permeable and continuous. Moreover, the field studies that I worked on in NHs and PPC led to the design and the re-design of two technology platforms, and the related research findings informed my thesis work.

11.2.1 Part 1

RQ1. Which challenges are caregivers experiencing in collaboratively taking care of end-of-life patients?

In Part 1 of the thesis (Chapters 2-3-4), I laid the foundations for the investigation of collaborative care technologies in end-of-life settings by positioning this research within computer science disciplines which investigate the realm of social requirements and by outlining the recurring social, communicational and organizational issues in the end-of-life fields.

These chapters highlighted several considerations related to end-of-life environments, discussing how the practices of family and professional caregivers were deeply interrelated and *knotworked* (Amsha & Lewkovicz, 2016). The language

and cultural *heteroglossia* between family and professional caregivers characterized how they worked together in a complex dialectic.

In the theoretical overview (see chapter: 2), I discussed the peculiarities of taking care of incurable patients in home and residential settings, addressing the need to listen to the situated needs of caregivers and the potential of CSCW and PD in supporting the identification of accurate social requirements. I presented some key points of attention, describing the issues that are mostly acknowledge by the literature. In particular, I highlighted the factors that hinder transversal and continuous care:

- coordination and organizational problems;
- fragmentation of care due to the lack of information, management and relational continuity between caregivers;
- erratic nature of care environments;
- lack of communication resources;
- lack of technologies that support social, communicational, and relational needs.

In the case of NHs (see chapter: 3), I have presented the issues that I collected in the field in relation to the delivery of care work in residential facilities, where the relatives co-produced and negotiated care with the care professionals in the territory of the care professionals (the NHs). In NHs contexts, information exchange and clear communication channels were enablers of solid relationships between family and professional caregivers. However, the fluctuating nature of care work, the power dynamics in NHs, the turnover and the fact that often care professionals have to cope with staff shortages hindered relational continuity with the relatives, bringing fragmented care, fragmented relationships, and conflicts between staff and relatives. From this field, I identified the following areas:

- care professionals need to be supported in sharing medical and social knowledge about the residents and their families;
- family caregivers need a reference point within the staff to establish easily informal, continuous and trustful relationships;
- a technology should support face-to-face interactions and clear information flows.

In the case of PPC (see chapter 4), I have presented recurring factors that affect care delivery in pediatric palliative home care settings, where the care professionals co-produced and negotiated care with the relatives in the territory of the family caregivers (the homes of the patients). The care professionals, as in the case of NHs, were over-stretched in their care work and had time constraints. However, in PPC, they were more than medical workers, they were in some way activists, being deeply engaged in taking care of incurable children. From this field, I identified the following factors:

- IDENTITY: PPC is a special care context where professional caregivers create a share care pathway with the relatives of the patients
- RESISTENCE: within the community of care professionals many prejudices related to palliative care exist, and this hinders communication, information exchange and collaboration between medical professionals;
- EXPERTISE: in PPC the individual attitude of the professional is crucial, which have deep experiential knowledge that share with the relatives of the patients;
- RELATIONAL WORK: PPC is acknowledged as a realm where relationships and trustful collaboration between family and professionals are paramount, being enablers of quality home care;

- MEDICAL COMPLEXITY: PPC is a complex care context where the professional struggle to endure continuity of care by managing uncertainty;
- END-OF-LIFE COUNSELING: providing recovery and acceptation of loss to the relative of the patient is an integral part of the work of the care professionals;
- EMOTION MANAGEMENT: care professionals are highly emotionally engaged in their work, which brings delivery of high quality and dedicated care, and high risks of burnout and stress at the same time.

In part 1 of the thesis, despite working in different fields in end-of-life situations, it emerged how family caregivers are active actors in the care pathways of their loved ones. On the one hand, they are precious gatekeepers of the specificity of each patient, knowing the little things that enhance quality of life, deserving the acknowledgement of their own knowledge about their relatives. On the other hand, relatives needed to receive technical medical information and human support from the medical professionals, who can be overwhelmed and burdened by their work, lacking time to properly relate with them. Moreover, as I said in chapter 3, in end-of-life contexts, *technology cannot be used as a panacea, because technology can support, but not fix, organizational issues by itself when they call for organizational change. However, the need emerges for a technology to facilitate social interactions beyond the medical framework, and fulfill work tasks, in order to allow formal and informal caregivers to establish trustworthy relationships and a shared knowledge of the patients' situation.*

Dedicating Part 1 of this thesis mostly to the assessment of the situated dynamics of collaborative care in end-of-life care helped me to better frame the contexts of my research, establishing the groundwork for RQ2 and RQ3.

11.2.2 Part 2

RQ2. What is, and what can be, the potential of technology in supporting the collaboration challenges between caregivers in end-of-life care?

In this work, I decided to keep Part 2 separate from Part 1 in order to dedicate a specific section of the thesis to isolating the discussion of the technological phenomena within the end-of-life field from the organizational ones. As I mentioned above, I am aware that we live in a socio-technical reality and I decided to separate the topic into two parts in order to better address both the organizational and the technological phenomena. This effort does not aim to frame technology as a *cold matter* that needs to be separated by a *warm*[13] social *matter* (Latour, 2005; 2012). Indeed, in the light of the organizational and social complexities of end-of-life care contexts that appeared *thick*[14] since the very beginning of the study, I preferred to dedicate a specific part to the specific and *warm* situated role of technology.

In part 2 of this thesis (see chapters 5, 6, 7), I focused on analyzing how ICTs were enacted in end-of-life contexts *as is*, comparing the fields in PPC and NHs. I discussed technology as a *warm matter* that was an integral part of the care pathways, being the subject of collaboration, appropriation and conflicting dynamics.

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[13] Often, Bruno Latour in his books describes how techno-social realities are characterized by warm dynamics, overcoming the dualism typical of the 80s that counterpose cold and rational technology to warm and situated social phenomena. I.e.: he "does not refer to the traditional sense of matters of fact —with their cold, disinterested claims to 'objectification'— but to the warm, interested, controversial building sites of matters of concern." (2005, p.125); or "In the virtual Paris, hot, virtualized and consequently filled with possibilities, there is no longer either a foreground nor a background – in fact there is no longer a ground." (2012, p.44)

[14] According to Clifford Geertz, doing qualitative research is not a matter of applying prescriptive methods. It means being there, bringing a thick description by: establishing relationships, selecting informants, making sense of a context, transcribing texts and floating in data. (Geertz, 1987)

In my studies on technology appropriation (see chapters 5 & 6), I discussed how in both PPC and NHs, due to the lack of existing ICT solutions, caregivers used common technologies (such as Facebook and Whatsapp messenger) as informal telemedicine tools and appropriated care spaces to support their care practices. In these situations, speaking with Marshall McLuhan, the medium was definitively the message (1967).

Indeed, observing technology and space appropriation, I had the chance to investigate how caregivers enacted acts of resilience by appropriating informal and open technologies to have ownership of their care practices. These studies nourished theoretical reflections and helped me to draft design opportunities in end-of-life contexts, highlighting the need to have care transparency, communication and support, reference points for the relatives, awareness of the care network and peer-to-peer support.

Interesting contrasting opinions about ICTs emerged in the study on how data, information and knowledge exchanges were perceived by the participants of my research fields (see chapter 7). I discuss how, in NHs and PPC, the data and information sharing distributed *things* that are meaningful, and how this can bring both alignment of meanings, and conflicting power dynamics.

On the one hand, in PPC the data and the information sharing through ICTs was unanimously perceived as a paramount enabler of their collaborative practices, because – for them – the information symmetry is an essential requirement for the articulation of care work between care professionals and relatives. In PPC, caregivers considered human relationships among caregivers to be an integral part of the collaborative care work, requiring for alignment of knowledge and dedicated technologies.

On the other hand, the professional caregivers in NHs were reluctant to share medical

data and information with the family caregivers through ICTs, whereas the relatives were eager to receive and share information to be better acknowledged as producers of care. The staff members, due to work problems, told us that they wanted to keep an asymmetry of both meaning and power between themselves and the family caregivers, having the fear that increasing the relatives' knowledge could interfere with the care practices.

Thus, ICTs have been confirmed as a *Golem* (Collins & Pinch, 1998; 2008), a creature that can be both powerful and clumsy at the same time, and its outcomes depend on how it is socially enacted within situated contexts.

Dedicating Part 2 of this thesis mostly to the role of technologies in situated care contexts allowed me to analyze it through several nuances. On the one hand, the appropriation of existing technologies that were used, as an act of resilience, to informally support caregiving. On the other hand, the technology as a *Golem* that can enhance both sense-making and conflicts. Part 2 supported the understanding of end-of-life contexts, laying the foundation of RQ3.

11.2.3 Part 3

RQ3. How can we (as CSCWers and PDers) nourish caregivers' collaboration in end-of-life contexts through design processes?

Part 3 of this thesis (see chapters 8, 9, 10) is dedicated to taking care of caregivers' collaborative care work through design processes, providing analysis and results of the design process conducted in NHs, and discussing the methodological resources adopted in both NHs and PPC (see chapters 9, 10).

In the report of the design process in NHs (see chapter 8), I discussed the gathered results by describing the adoption of mixed methods that led to the definition of the

basic features of the future technology, to the design and validation of prototypes and to the translation of the previous findings into social requirements. The overall findings confirmed the necessity of supporting caregivers in dealing with managerial issues, while nourishing social relationships. Moreover, the design process we conducted highlighted the importance of progressively taking into consideration care practices, organizational routines, and caring actors, in order to face, step by step, the imbricated complexities of collaborative care work. The findings also led to rethinking of the initial agenda of *Collegamenti* (the research project in NHs). In doing so, the personas have been crucial boundary objects, which supported interdisciplinary dialogues with my colleagues with technical backgrounds, conveying sense-making by letting them understand and empathize with the new emerging needs of our informants.

The analysis of this design process led to the identification of the following statements:

- collaborative care work between family and professional caregivers depends on dialogue and reciprocal understanding of each others' conditions;
- both family and professional caregivers emphasized the importance of "information" over "raw data";
- the exchange of raw medical information is a thorny issue that can undermine frail relational dynamics;
- encouraging too much change, by pushing the boundaries that one side created to protect themselves, can exacerbate the perceived conflicts;
- collaborative care technologies to support mutual relations across two different caring cultures, as family and professional caregivers are, should firstly foster mutual understanding, sense-making and mutual information sharing, in order to create the grounds on which the technology will be rooted;
- medical and sensitive information are more effective if contextualized and

exchanged face-to-face, or in a narrative way.

The discussion of the design process in NHs also showed a fear among caregivers of dealing with a new "cold" technology that could negatively affect the already complex relationships between relatives and staff members. In relation to the fear of technologies we, as design researchers, need to be aware that care is widely considered as a *warm doing*, which is different to what can be perceived as a *cold* technology. For this reason, we need to deeply acknowledge how, speaking with Annemarie Mol (2008), "care regards technology and the design of technology in such contexts need to be *handled with care"* (p.5).

Addressing the methodological reflections (see chapters 9, 10), working in sensitive contexts, I appreciated the adoption of situated methods in end-of-life contexts as a form of *bricolage* (Ciborra, 2002), an act of assembling from scratch that can lead to unexpected outcomes where people seek forms of agency by being engaged in a widespread virtuoso tinkering (p. 3).

I conceived myself as a listener with the role of embracing the stories of the caregivers in the attempt to support their path with the nourishment of participatory design processes (see chapter 9).

Throughout all my PhD I have been surrounded by a sense of responsibility in relation to the informants of my study, and I developed some coping strategies to handle the emotional load of end-of-life environments (see chapter 10). I often felt bad about asking my informants to spare me some time for my data collection, especially because staying with me often limited the time they could spend with their loved one or to support their patients who had precious little time left.
I discovered several strategies in order to conduct sustainable research activities, adjusting my approach to data collection along the way:

- I realized how incredibly fruitful short-term ethnography sessions can be. I used them by setting research priorities and sensitizing concepts *in itinere,* investigating the experiences of caregivers that were difficult to reach;
- I reinvented places for interviews, for example in the PCC study I often conducted interviews with the professionals in their cars during the journey from the home of one patient to another;
- I granted relational continuity to my informants because, being in frail conditions, they needed to be engaged, telling their stories with only one trusted person;
- I discovered how people in vulnerable situations need to be heard, understanding how being open to listening to them and being guided by them, embracing their stories, was in itself an act of caring.

Sometimes both my colleagues and I were moved by listening to such stories about love and attachment, and that happened also to our informants as they were telling us these stories. When that happened it was not unprofessional or improper; it happened because *we were human* and we cared. To distinguish between *empathy* and *exotopy* helped us in positioning our role as researchers within the PPC and NHs fields. Whereas *empathy* refers to the attempt to understand the experiences of others by interpreting them through our emotional framework, *exotopy* concerns the effort of embracing the experiences of others by recognizing that our own frameworks cannot be a lens through which to understand them. *Exotopy* is a concept that is linked to reflexivity; it has been useful in encouraging us to openly listen to the stories of our informants, acknowledging the uniqueness of their way of experiencing caregiving (Depalmas & Allodola, 2013).

Part 3 addressed reflections on design processes and methodological dilemmas in sensitive design contexts, closing the circle of this research work.

11.2.4 Reflections

According to Mol (2008) "Care is an interactive open-ended process" (p.23), where we, as design researchers, should pay attention to its heterogeneous sociomaterialities to handle it *with care*. Working in sensitive care settings, my colleagues and I have been at the threshold of the lives of caregivers of dying patients. We often reflected together about our role in the design process that we were addressing, and about how we would have an impact on their lives. In taking care of end-of-life contexts, we were committed to supporting the continuous effort of caregivers in becoming part of their experiences.

In the light of the social complexities and conflicts that we found in the field, we have been engaged in respecting and valorizing the emancipatory values of design research (Bardzell, 2014; Teli, 2017). We tried to frame our role as enablers, openly listening to the voices of our participants, endorsing sharing of wishes, supporting mutual acknowledgement among caregivers, being *fellow journeyers* with our informants, and facilitating negotiations of collective meanings about caregiving (Light & Akama, 2014).

11.3 Limitations

During this PhD, I have to admit that I often was under pressure, collecting much data and collaborating in several research projects. Especially in the first two years, I spent a lot of time trying to grasp how to reframe my background as a sociologist in a computer science department, experiencing heteroglossia (the coexistence of different alterities, languages and viewpoints in a single discipline) and interdisciplinary contortionisms. In this way, I found it hard to take quality time to be

detached from my data and from my ideas about the phenomenon that I was studying, in order to come back to them after a while with a clear mind. This, sometimes, caused me to miss the *polyphony* of my work, which is conceived by Geertz as a way to study social realities by being open to the multiplicity (1987). However, I am firmly convinced that the interdisciplinary arrangements within my PhD path and writing in the fields of PPC and NHs have been good experiences, since they "inspired theory, shaped ideas and shifted conceptions" (Mol, 2008, p.10).

The findings of this PhD thesis present limitations related to the following areas.

- Despite the involvement in our study of eight end-of-life services and many participants, we found participation issues. Specifically, as researchers, we experienced the participation paradox (Tellioglu et al., 2014). We discovered how people who need to participate and to communicate their needs the most, are also those at higher risk of being excluded. Indeed, due to time and space constraints imposed by critical situation of the patients, both family and care professionals who participated in my research had limited time to dedicate to collaborate on the data collection. In this way, we dealt with caregivers who were willing to join a participatory design process but who had serious participation constraints related to the critical conditions of the patients. For example: in NHs the organization of validation workshops has been difficult, while, in PPC it has been just impossible.
- The involvement of family caregivers presented some issues. In NHs, the sample related to the family members had a self-selection bias, creating difficulties in reaching relatives who lived far away from the facilities, and who, as a consequence, needed an ICT service the most. In PPC, however, I had the chance to interview only two families due to the very dramatic

contingencies of the study, so I filled the gap left by the missing participants with ethnography observations.

- The involvement of professional caregivers also had some limitations. In NHs, the staff members had many time constraints that limited their participation, due to the fact they were understaffed and engaged in tight work schedules. In PPC, I managed to interview basically the entire population of care professionals of the service, but unfortunately I only reached the specialists in the care network through participant observations.
- The NHs project is still ongoing, therefore I did not have the opportunity to validate the adoption of the designed technology in NHs. In contrast, in PPC, my involvement had been limited only to the exploratory study due to organizational issues related to the project.

11.4 Future works

A design research is always unfinished, as suggested by Ehn (2008), Tonkiwise (2005), Karasti (2014) and Henderson & Kyng (1992) due to addressing the concepts of design-after-design, unfinished design unfinished things, continuing design, and continuing design-in-use, and so, obviously, is this thesis.

At this point in my career, my primary interest is to consolidate my research experience by continuing within multidisciplinary contexts, working on the topic of collaborative healthcare technologies to support continuity of care. In the months after the submission of my thesis, I am planning to finish writing and submit a paper that I am currently working on with my colleagues. It will present an intensive literature review on Participatory Design, analyzing the political agenda of Participatory Design itself. Moreover, I plan to work on a paper for CoDesign Journal that will present methodological reflections on the topic of the participation paradox in sensitive contexts. I also would like to continue my collaboration with my advisor Vincenzo D'Andrea and with Maurizio Teli on theoretical, empirical and methodological

reflections on how to address, nowadays, inequalities and experiences of the vulnerable in the political agenda of Participatory Design.

In relation to this, I will report a note that I took when I was supervising the thesis of a Master's student.

"*I was explaining to Maria (a Master's student) the fetishism for gerunds that characterize the academic writing in Science and Technology Studies (STS). She looked at me astonished asking me how I knew these things. I didn't understand the question, because for me it was normal, doing research, to have a position about such topics. So I explained to her that it was my job and my passion to know these things, and that it is important to use a clear and consistent terminology to be understood and to understand others. She answered me: "Oh gosh, this (doing research) is not a simple job, this is a life philosophy!" Maybe, for me, this is the meaning of doing PD and design research, for me it is more of a mission than a job. I have colleagues, for instance Maurizio (Teli), who are engaged in research agendas that are more political than mine, but I am searching for my agenda in doing research and I am finding it by working in sensitive contexts. My research agenda is taking shape around the topic of design for taking care and for supporting kinship. What I love about what I am doing is to be at the disposal of the stories of the people and of the aspects of these stories that are more difficult to listen to. Listening, embracing stories, immersing myself in those stories… Engaging people in design processes to support collective change… this is what I love doing."*

Instead, defining the formal future works, the findings of this research provide contributions for future work, through the development of the streams that framed this research on designing collaborative technologies for end-of-life research settings. Possible research directions are described in this section.

In the light of the limitations of my PhD thesis, it would be interesting to expand this work in three interrelated ways:

- by working on methodological strategies in dealing with the participation paradox, where the willingness to participate is hindered by the effective possibility of participating. I would like to test the possibility of using multi-sited workshops in order to allow caregivers with time and space constraints to participate in codesign activities;
- by focusing more on the perspective of the family caregivers, especially in home care contexts, because they are those who were most difficult to reach during my study;
- by dedicating time to the investigation of the phenomenon of online peer-to-peer support communities, which emerged within my research but remained a side topic.

11.5 Final remarks

Since I was a child, I have always been passionate about stories, real stories. I was passionate about human narrations that communicate the deep beauty of everyday feats. Then, engaging in qualitative sociology I re-experienced the meaningfulness and the relevance of storytelling, which has also been recently highlighted by the inspiring Donna Haraway in the film: *Donna Haraway: storytelling for earthly survival* (Terranova, 2017).

Due to the paper-based format, this work sometimes flows less fluidly than that of a regular thesis, but I worked to reveal and to make visible the path that followed along with the stories and the streams that have grounded this work since its beginning. The projects in PPC and NHs are still ongoing, and I hope that with our intervention dedicated to taking care of these contexts, we planted the seed of listening and doing together, nurturing collaborative relationships and fellow becoming.

I hope you enjoyed this story,

Angela

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_ _ _ _ _ _ A P P E N D I X _ (A)

DOCTORAL PROGRAMME IN INFORMATION AND COMMUNICATION TECHNOLOGY

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Cycle	**30°**
Thesis	**Taking care of end-of-life settings**
Advisor	**Vincenzo D'Andrea (University of Trento, Italy)**
Co-advisor	**Fabio Casati University of Trento, Italy)**

1. List of publications

Peer-reviewed papers

Di Fiore, A., Ceschel, F., Nurgalieva, L., Marchese, M., & Casati, F. (2017, June). Design Considerations to Support Nursing Homes' Communities. In Proceedings of the 8th International Conference on Communities and Technologies (pp. 64-67). ACM.

Di Fiore, A., Ceschel, F., Fiore, F., Baez, M., Casati, F., & Armellin, G. (2017, May). Understanding how software can support the needs of family caregivers for patients with severe conditions. In Proceedings of the 39th International Conference on Software Engineering: Software Engineering in Society Track(pp. 33-36). IEEE Press.

Teli, M., Di Fiore, A., & D'Andrea, V. (2017). Computing and the common: a case of Participatory Design with think tanks. CoDesign, 13(2), 83-95.

Teli, M., Di Fiore, A., & D'Andrea, V. (2017). Computing and the common: a case of Participatory Design with think tanks. CoDesign, 13(2), 83-95.

Di Fiore, A., Fiore, F., & D'Andrea, V. (2014). The Emergence of E-Learning Needs in Participatory Re-Design of e-Service. *International Journal of Technology and Educational Marketing (IJTEM)*, *4*(2), 54-65.

Di Fiore, A., Chinkou, J. L. F., Fiore, F., & D'Andrea, V. (2013, September). The need of e-learning: Outcomes of a partecipatory process. In *e-Learning and e-Technologies in Education (ICEEE), 2013 Second International Conference* (pp. 318-322). IEEE.

Book Chapters

Di Fiore Di Fiore, A., & Ceschel, F. (2017). Open Issues in Designing Home Care Technologies. Book Chapter in Mobile e-Health (pp. 215-233). Springer.

Extended abstracts

Ceschel, F., Di Fiore, A., & Casati, F. (2017). Taking care of sensitive milieus: a story about dialogical interviews. In Infrahealth 2017-Proceedings of the 6th International Workshop on Infrastructure in Healthcare 2017.

Di Fiore, A., D'Andrea, V. (2016). "We are human." Coping strategies in sensitive settings. Workshop paper at CHI '16 Conference on Human Factors in Computing Systems
https://ethicalencountershci.files.wordpress.com/2016/03/we-are-human-angela-di-fiore.pdf

Macchia, T., D'Andrea, V., Mazzini, R., Di Fiore, A., & Cozza, M. (2016, August). Exploring theater of the oppressed for participatory design. In Proceedings of the 14th Participatory Design Conference: Short Papers, Interactive Exhibitions, Workshops-Volume 2 (pp. 125-126). ACM.

Under review

What is Appropriation Telling Us? A study on collaborative end-of-life care work.
Submitted to: ECSCW 2018 - Conference

Factors influencing the quality of care in Pediatric Palliative Care: a qualitative study.
Submitted to: Quality of Life Research – Springer Journal

Taking care of the Golem: reflections on the role of technologies and information sharing in complex care contexts.
Submitted to: Science, Technology and Human Values – SAGE Journals

Designing a technology platform to support collaboration between family and professional caregivers in nursing homes
Submitted to: PeerJ computer science

2. Research/study activities

Training abroad:

- 2014, Winter school "Action research in IT studies" – Aalborg University (DK)
- 2015, Summer school "Designing Human Technologies 3.0" – Roskilde University (DK)

Mobility:

- 2017 (from February to July) mobility period spent at Technical University of Munich (DE) - Infrastructuring Participation research group of the Munich Center for Technology in Society, led by prof. Ignatio Farias
- 2107 (from October to November), mobility period spent at Technical University of Vienna – Multidisciplinary Design & User Research lab. led by Prof. Hilda Tellioglu

Projects:

- Miuchi project, supporting the redesign of a technology for pediatric palliative home care
- Collegamenti project, design a technology platform to enhance relationships between formal and informal caregivers in nursing homes
- ThinkDigiTank project, using participatory design to support a network of Italian leftist think tanks
- EIT program, european ICT innovation program focused on innovation and entrepreneurship

Teaching:

- **@ University of Trento, Italy**

  Assistant professor
  2015: Quantitative methods and software STATA (BA - Department of Sociology and Social Research)
  2015 - 2017: Course in Participatory Design (MA - Department of Computer Science)
  2017: Laboratory of the course of Privacy and intellectual property rights (MA - Department of Computer Science)

  Master's thesis tutoring
  2014 - 2018: (Department of Sociology and Social Research, 5 students)
  Thesis topics: collaborative technologies for home healthcare, impact of open data on IT work

environments, collaborative dynamics in open data communities, role of IT in enabling change management and CRM, role of culture in CRM projects

- **@ Technical University of Munich, Germany**
  2017: Class (4 hours) on Participatory Technology Design (Department of Architecture)

- **@ Fondazione Lelio and Lisli Basso, Italy**
  2015: Course on Participatory Design and Qualitative Data Analysis within the Think-Digi-Tank project

Conferences attended:
- Participatory Design Conference (PDC), 2016
- Conference on Human Factors in Computing Systems (CHI), 2016
- Community & Technologies (C&T), 2017
- Alpis - symposium on infrastructuring for the common good, 2015
- Alpis – beyond creativity toward collaboration in practice, 2016

Other:
- student volunteer during COOP conference 2016
- reviewer for CSCW 2016 conference
- organization of the Summer School: “Designing Human Technologies 4.0”, to be held in Trento, June 2018

_ _ _ _ _ _ A P P E N D I X _ (B)

Ethical approval MIUCHI (v.1)

Azienda Provinciale per i Servizi Sanitari
Provincia Autonoma di Trento

COMITATO ETICO PER LE SPERIMENTAZIONI CLINICHE

Rep. Int. 11287 del 21/07/2016
Class. ii.12

VERBALE N.5

RIUNIONE DEL 7 luglio 2016

Il giorno 7 luglio 2016 alle ore 14.00 il Comitato etico per le Sperimentazioni Cliniche si riunisce nella sede dell'Azienda Provinciale per i Servizi Sanitari.

(omissis)

Con la nota di convocazione è stato inviato ai componenti del Comitato etico la documentazione relativa agli argomenti all'ordine del giorno.

Sono presenti alla seduta, quali membri del Comitato etico:

Nome e qualifica	Ruolo secondo D.M. 8 febbraio 2013	Presenza
dott. Giovanni Tognoni, presidente, Istituto Mario Negri	Farmacologo	X
dott.ssa Marina Ferri, vicepresidente, Servizio farmaceutico, Area sistemi di governance	Farmacista del servizio sanitario regionale	X
dott.ssa Vittoria Cauvin, U.O. di pediatria, Ospedale di Trento	Pediatra	X
dott. Flavio Corradini, Comitato Difesa dei Consumatori	Rappresentante del volontariato o dell'associazionismo di tutela dei pazienti	X
Prof. Enrico Arosio, U.O.C. di angiologia, Azienda ospedaliera universitaria integrata di Verona	Clinico	X
dott. Renzo Girardello, U.O. di geriatria, Ospedale di Rovereto	Clinico	X
dott.ssa Carla Sartori, U.O. di farmacia, Ospedale di Rovereto	Esperto in dispositivi medici	X
dott. Pierantonio Scappini, Direzione medica, Presidi ospedalieri di Cavalese e di Borgo Valsugana	Altro	X
dott. Giovanni Guarrera, Servizio di governance clinica, Area sistemi di governance	Sostituto permanente del direttore sanitario	Assente
prof.ssa Maria Elisabetta Zanolin, Dipartimento di sanità pubblica e medicina di comunità, Università degli studi di Verona	Biostatistico	X
prof. Carlo Casonato, Facoltà di Giurisprudenza, Università degli Studi di Trento	Esperto di bioetica	Assente

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dott.ssa Giuseppina Ciraolo, U.O. di medicina legale	Medico legale	Assente
dott. Enzo Galligioni, U.O. di oncologia medica, Ospedale di Trento	Clinico	Assente
sig.ra Roberta Iori, U.O. di cardiologia, Ospedale di Trento	Rappresentante dell'area delle professioni sanitarie	Assente
dott. Daniele Ortolani, Medico di medicina generale	Medico di medicina generale territoriale	X
dott. Armando Toniolatti, Servizio affari generali e legali	Esperto in materia giuridica e assicurativa	Assente

Sono, inoltre, presenti alla seduta, quali membri aggiuntivi del Comitato etico:

Nome e qualifica	Ruolo secondo DM 8 febbraio 2013	Pres.
ing. Walter Mattei, Servizio Ingegneria clinica	Ingegnere clinico (in relazione all'area medico-chirurgica oggetto dell'indagine con il dispositivo medico in studio)	X
dott. Antonio Costa, Servizio dietetica e nutrizione clinica, Ospedale di Trento	Esperto in nutrizione (in relazione allo studio di prodotti alimentari sull'uomo)	Assente
prof. Pierluigi De Bastiani, Dipartimento di psicologia e scienze cognitive, Università degli studi di Trento	Esperto clinico (in relazione allo studio di nuove procedure tecniche, diagnostiche e terapeutiche, invasive e semi invasive)	X
prof. Alberto Turco, Dipartimento di scienze della vita e della riproduzione, Università degli studi di Verona	Esperto di genetica (in relazione allo studio di genetica)	

Segreteria tecnico – scientifica

- dott. ssa Francesca Spadaro, farmacista del Servizio farmaceutico

Segreteria amministrativa

- dott.ssa Paola Zanetti, collaboratore amministrativo dell'Area sistemi di governance

Preso atto della presenza del numero legale dei componenti, alle ore 14:00 il Presidente dichiara aperta la seduta del Comitato Etico.

I componenti del Comitato Etico dichiarano che si asterranno dal pronunciarsi su quegli studi per i quali possa sussistere un conflitto di interessi di tipo diretto o indiretto.

(Omissis)

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0.1 NOTIFICHE

Codice protocollo	**MIUCHI** n.a.
Titolo del protocollo	la tecnologia al servizio della domiciliarità pediatrica – (Fase 1: Analisi esplorativa della realtà organizzativa)
Tipo di studio	Sociologico
Promotore	Vincenzo D'Andrea, professore (Dipartimento di Ingegneria e Scienze dell'Informazione (DISI), Univ. di Trento) Milena di Camillo (Fondazione Hospice Trentino Onlus) Giampaolo Albertini (No pain for children- Onlus)
Sperimentatore principale locale	Angela Di Fiore , dottoranda (Dipartimento di Ingegneria e Scienze dell'Informazione (DISI), Univ. di Trento)
Unità Operativa	Servizio di cure palliative pediatriche-APSS
Responsabile U.O.	Gino Gobber

E' disponibile per la discussione il materiale di cui si riportano i seguenti dati sintetici:

- Richiesta di notifica pervenuta in data 30/06/2016
- Protocollo pervenuto in data 30/06/2016
- dichiarazione relativa a conflitti di interesse e dichiarazione di responsabilità del prof. Vincenzo d'Andrea responsabile del progetto di ricerca
- dichiarazione sulla natura osservazionale dello studio di data 30/06/2016
- lettera di invito di data 24 luglio 2014
- foglio informativo e consenso allo studio
- informativa sul trattamento dati sensibili
- traccia di intervista per gli operatori del servizio cure palliative
- traccia intervista per genitori
- moduli 1/Indip (domanda) 2 (dichiarazione di ricerca indipendente) e 3 (dich. natura osservazionale)
- parere del CE dell'Università del 16 luglio 2015

Il Comitato etico prende atto che si tratta di uno studio preliminare di tipo sociologico, rivolto sia ai professionisti e personale volontario che operano nel Servizio Cure palliative pediatriche, che ai genitori dei bambini seguiti dal Servizio stesso.
Data la tipologia dello studio, il Comitato etico ritiene di propria competenza unicamente gli aspetti inerenti il coinvolgimento dei genitori, particolarmente rilevanti vista la situazione delicata in cui si trovano i bambini e le loro famiglie.
Il Comitato etico raccomanda quindi uno stretto coordinamento e supervisione dello studio da parte dei clinici del Servizio cure palliative.
In particolare, raccomanda che la proposta della partecipazione ai genitori /care giver e le informazioni sullo studio vengano fornite dai medici curanti, che hanno conseguentemente la responsabilità dell'informazione in maniera adeguata non dimenticando gli aspetti riguardanti la privacy dei minori e delle loro famiglie, in quando lo studio viene condotto da personale esterno.

(Omissis)

Scritto, letto e confermato,

Il Presidente del Comitato Etico
dott. Gianni Tognoni

La verbalizzante
dott.ssa Francesca Spadaro

Francesca Spadaro

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Ethical approval MIUCHI (v.2)

UNIVERSITÀ DEGLI STUDI DI TRENTO

COMITATO ETICO
PER LA SPERIMENTAZIONE CON L'ESSERE UMANO

DATA	**16 luglio 2015**
SEDE	**Sala degli Stucchi - Rettorato - Via Calepina, 14 – Trento**
N. ordine del giorno	**4**
PROTOCOLLO N°	**2015-012**

Sono presenti alla deliberazione:

BRANZ Fabio	Componente	**P**
BONFIGLIOLI Claudia	Componente	**AG**
CASONATO Carlo	Vice-presidente	**P**
CORRADINI Flavio	Componente	**P**
DENTI Michela Alessandra	Componente	**AG**
GHIA Francesco	Componente	**P**
MARSICO Gaia	Componente	**P**
ROCCHETTI Loreta	Presidente che presiede	**P**
ZAPPATERRA Fabrizio	Componente	**P**

Protocollo 2015-012
Titolo: **"MIUCHI - Technology as an enabler of collaboration in pediatric palliative home care services"**
Responsabile: **Vincenzo D'Andrea**

Il Comitato Etico per la sperimentazione con l'essere umano, dopo aver esaminato la documentazione relativa allo studio in oggetto, esprime all'unanimità il seguente parere:

parere di approvazione, fatte salve le eventuali autorizzazioni da parte degli organismi competenti del territorio dove avrà luogo la sperimentazione.

Il Presidente _____ Il Segretario _____

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Ethical approval *Collegamenti*

UNIVERSITÀ DEGLI STUDI
DI TRENTO

Comitato Etico per la Sperimentazione con l'essere umano

Trento, 15 marzo 2017

Al prof. Fabio Casati
Dipartimento di Ingegneria e Scienza
dell'Informazione
Università degli Studi di Trento

e p.c.

Al prof. Niculae Sebe
Direttore del Dipartimento di Ingegneria e
Scienza dell'Informazione
Università degli Studi di Trento

Loro sedi

Oggetto: parere conclusivo del Comitato Etico su protocollo 2017-003

Preso atto che le integrazioni e modifiche richieste in calce al parere espresso nella seduta del 16 febbraio 2017 sono state compiutamente apportate, il Comitato Etico per la Sperimentazione con l'essere umano autorizza l'avvio della sperimentazione relativa alla ricerca:

"CollegaMenti, la tecnologia al servizio delle relazioni in casa di riposo".

Si ricorda di inviare formale comunicazione della data effettiva di inizio della sperimentazione e, al termine della ricerca, un rapporto sullo studio completato.

Cordiali saluti

Il presidente del Comitato
dott. Fabrizio Zappaterra

Via Calepina, 14, 38122 Trento, Italy -Tel. +39 0461/281245 - SegreteriaComitatoEtico@unitn.it