



UNIVERSITÀ DEGLI STUDI  
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A NEW DESIGN FOR THE SUPPORT OF  
COLLABORATIVE CARE WORK IN NURSING  
HOMES

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# Abstract

*Nursing homes are complex healthcare settings that take care of older adults with severe cognitive and physical impairments. Given the conditions of the patients, nursing homes can be considered end-of-life contexts. There, the care work that aims to mitigate and treat the conditions of the patients is the result of the collaboration between the care professionals and the relatives of the patients. Indeed, when the patients are very old adults in an end-of-life situation, the provision of care often involves a family caregiver as the main point of contact for the healthcare service. However, caring for institutionalized older adults is known to be a complex issue both for the families of the older adults and the care professionals. Over the last few years, there has been an increasing interest in this topic primarily due to a growing older population and, hence, a heightened need of research contributions in this area. Previous studies on caregiving for older adults living in nursing homes recognize the necessity to support professionals' work practices to ameliorate their working conditions, and decrease the risk of burnout and job dissatisfaction, as well as to relieve the families of the patients from the burden of caring for their loved ones. Yet, the literature shows a lack of solutions in terms of technologies for this kind of environments.*

*In this thesis we report an extensive study and analysis we performed within a network of six nursing homes located in the northern Italy. We investigated the practice of caregiving within the nursing homes. In particular, we focused on the work practices of care professionals, and on the relational issues between the care professionals and the families of the patients. We conducted, first, an exploratory study to comprehend the nature of our research context. Afterwards, we carried out a series of participatory design sessions and validation workshops to elicit the requirements for the development of a new technology platform to support the collaboration between care professionals and relatives of older patients.*

*The outcomes of this work shed new light on the opportunities of using ICT solutions to improve relations and information sharing among caregivers. Indeed, our findings state that the organizational and relational complexity of nursing homes emphasize how poor communication practices hinder the collaboration and the mutual understanding between the relatives of the patients and the care professional. As a result, we deliver a series of functional requirements for the development of a technology platform that aims to support relationships, communication, and coordination among care professionals, and between care professionals and families of the patients.*

**Keywords**[Technologies for healthcare; home-care; nursing homes; caregiving, CSCW, participatory design; information systems]

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# Chapter 1

## Introduction

The word “*healthcare*” defines the cluster of complex organizations that are intended to provide to individuals or community of people medical care in form of services, assistance, or counseling. Healthcare regards the assistance for the physical and psychological wellbeing of people.

Healthcare organizations provide services that cover the necessities of all people; from the youngest infants, to the oldest adults. Generally, services such as hospitals provide short-term care to the whole population. Nonetheless, the specificity of one’s condition may require the services of a particular organization. For instance, people in old age often experience a deterioration of their physical condition that can interfere with their autonomy [103]. Hence, the inability for an older adult to look after themselves requires the assistance of a care provider. In several cases, families look after their older loved ones for as long as they can. Yet, the hardness of assisting an older adult in severe conditions forces families to rely on an external support [201, 37]. Indeed, among the various services provided by healthcare organizations there are those dedicated to the oldest population.

In particular, nursing homes are long-terms healthcare organizations that furnish a constant assistance to older adults who require services on a daily base. However, nursing homes assist older adults, through a care process, or pathway - conceived as the management of patients’ conditions - rather than treating them, as it may be in the case of hospitals; nursing homes are residential facilities. In this sense, older adults move to live at the nursing homes to benefit from their services and, therefore, older adults are defined as residents rather than patients. Nursing homes host and look after older adults who lost their autonomy and require a 24-hours assistance. These institutions provide also a long-term care to older adults affected by severe condition or diseases. [105]

However, nursing homes are healthcare environments that are challenging not only from a medical perspective, but also under a social and emotional point of view [190, 205]. They provide assistance to people who typically experience an irrecoverable condition and,

therefore, they can be considered end-of-life contexts. Moreover, besides assisting their residents, nursing homes provide support to the families of the older adults. Given the residential nature of nursing homes, family members normally back up care professionals with additional assistance, but their personal involvement place them on a more intimate level within the care process [146, 191, 37]. In fact, in these contexts the difficulty to manage the care process is surpassed only by the difficulty to deal with the emotional involvement and distress of patients, family members, and care professionals [185].

After the experiences of domestic assistance for their loved ones, family members suffer the inevitable institutionalization of the older adults as a burden, which entails a sense of guilt for the “abandonment” of their loved ones, and causes a lack of trust towards the care professionals who work in the nursing homes. This distress negatively affect the personal lives of the family members and, subsequently, interferes on how they relate to the nursing homes’ staff. [135]

In addition, the literature suggests that the institutionalization of older adults does not decrease the amount of care work for the family members [135, 11]. If, on the one hand, it mitigates the difficulty to deal with medical procedures, on the other hand, since it does not release family members from the burden and the emotional distress, it drives them to keep acting as care providers for their loved ones. Indeed, given the residential context, family members often assist the residents almost in substitution to the work of the care professionals. This leads nursing homes’ staff to work, on the one hand, as care professionals for the care of the residents, on the other hand, on the management of the relationships with the family members [210].

Therefore, within the network of care providers that assist the residents rotate two types of caregivers [203, 95]: *i*) the *family* or *informal caregivers*, namely the family members or the relatives who belong to the family network of the residents; *ii*) the *professional* or *formal caregivers*, namely the care professionals of the healthcare institution that provides care and medical services to the residents. Both types of caregivers contribute to the care of the residents to different extents, but the duality of these roles requires for family and professional caregivers to build relationships based on the mutual collaboration onto the care process, and to build their collaboration on the mutual exchange of information on the residents. [37, 137]

Because of these dynamics, care professionals face challenging situations. Indeed, professional caregivers not only deal with older adults affected by degenerative conditions and severe impediments, but they have to work on the care process together with the family caregivers who, given their emotional involvement, are often even more challenging than the residents. As a consequence, formal caregivers may experience stress, job dissatisfaction and burnout, and this may effect the quality of the care they provide.



[11, 105, 210, 64, 135]

The peculiarities of these environments brought researchers to investigate new models for the coordination of the caregivers involved in a care process. The model *continuity of care* proposes the mutual integration of the work of family and professional caregivers thus to conduct a structured care process [29, 198], and the literature suggests Information and Communication Technologies (ICTs) as a way to enhance coordination and information exchange among caregivers, as well as to reduce workloads and costs [101, 104]. The continuity of care model emphasizes the role of ICTs in facilitating and supporting caregivers in the management of the care process on three levels [101]: 1) the *information continuity* that allows all caregivers the transmission and exchange of precise, coherent, and quick information; 2) the *management continuity* that aims to uniform all working protocols and tasks to carry out the care process; 3) the *relational continuity* that regards the establishment of solid relationships among caregivers, thus to create a network of mutual human support.

In fact, studies [104] affirm that there is a growing interest towards ICTs in healthcare environments, which is proven by the increasing adoption of technologies by several healthcare institutions [84]. Caregivers deem the possibility to rely on ICTs to decrease costs and workloads a great incentive [104, 101]. Several studies [117, 139, 31, 165] propose solutions that may serve these purposes. Researchers address the issues that affect both professional and family caregivers [104, 114, 170, 169]. Nonetheless, they fail to address those issues that pertain the emotional and relational side of “caregiving”, and that implicate emotional distress for family and professional caregivers.

Other studies [148, 48, 70, 118, 144, 160] investigated ICTs solutions able to mitigate the burden of the care pathway. Researchers focused not only on the managerial aspects of caregiving, but also on the relational and emotional issues that influence caregivers. However, research struggles to deepen the understanding of these issues. Healthcare environments are sensitive contexts, and investigating the intimacy of the caregivers’ experience in caregiving results challenging. Consequently, ICTs solutions are the outcome of a limited comprehension of healthcare contexts. Moreover, to our best knowledge, no available ICTs solution tackles managerial and social issues together. [150, 87]

## 1.1 Objectives of the Thesis

The focus of the thesis is the development, application and validation of an interdisciplinary approach to deepen the understanding of the problems that decrease the effectiveness of the care services provided by nursing homes. In particular, we have focused our attention first on a network of six nursing homes located in the province of Trento. Therefore, in

the end of our work, we discuss the generalization of our approach.

Hence, we aim to grasp the actual needs of the family and professional caregivers who belong to the network of the nursing homes, thus to comprehend how ICTs can support their care work [31, 86, 48, 137]. This research work took place within the framework of a research project - financed by the *Autonomous Province of Trento (PAT)* - called "*Collegamenti*". The project is ongoing at the time of writing, and it has been approved by the ethical committee of the University of Trento (protocol 2017-003) and, therefore, throughout our work we paid attention to anonymize all sensitive information and data. Our interdisciplinary approach relies on sociological methodologies, and design methods for the formulation of the requirements of a new technology platform.

Nowadays every individual can rely on ICTs that allow us to communicate with very little limitations. ICTs foster communications, social interactions, as well as the creation of communities and social groups beyond spatial barriers [174, 104, 114, 170]. Therefore, our work aims to exploit the potentials of ICTs in facilitating and supporting the members of care networks that rotate around residents of nursing homes to sustain the following activities: *a)* rapid, coherent, and clear communication to coordinate the care process; *b)* the establishment of solid relationships to increase mutual trust and, subsequently, an efficient collaboration; *c)* the exchange of medical information among caregivers upon which the care process and the work of caregivers should be built; *d)* the formulation of additional non-medical information from the unfolding of the care pathway (*data work*), in order to assist patients also on non-medical aspects; *e)* the possibility to institute relationships that go beyond the medical framework, thus to lower the impact of the care work on the emotional sphere of caregivers; *f)* channels of peer-to-peer support, in order to allow caregivers - especially informal ones - to cope with the burden of assisting their loved ones.

In this thesis, we study the care process as it is carried out by the caregivers of the six nursing homes. We engage in a qualitative and quantitative investigation on the dynamics that intervene on the daily practices of family and professional caregivers. In particular, to comprehend how ICTs should be designed to serve our target user group in conducting the six activities mentioned above, we investigate the following matters: *a)* The daily tasks that care professionals carry out; *b)* how families caregivers intervene and participate to the care process; *c)* how formal and informal caregivers jointly manage the care process; *d)* what is the nature of the relationship that caregivers establish and how it operates on the care pathway; *e)* which are the logistic and relational factors that hinder and/or facilitate the care process; *f)* the current use of ICTs of caregivers, and the role that technology plays in hindering or facilitating the care work; *g)* how emotional distress originates, and how it interferes on the care work *h)* which are the coping strategies that caregivers adopt

to deal with emotional distress. Therefore, our purpose is to keenly comprehend the issues that interfere on the care process of the residents, in order to formulate a series of technology requirements. The complete dataset of our study is available here: <https://drive.google.com/drive/folders/1uFYsgLPXc4rjT2mxFpfJOwdpkiQNo8Ui?usp=sharing>.

Our final goal is to define the prototype of a technology platform that support the care work of family and professional caregivers, while helping them to cope with the emotional distress of the care work; it will support users to conduct and sustain the care work as schematized through the six activities listed above. Our research poses the bases for the development, by an industrial partner involved in the Project *Collegamenti*, of a novel technology platform; the development of which is one of the future steps that will follow the research presented in this thesis.

## 1.2 Methodology

To answer the problem defined in the preceding section we built our study and its results on the following steps: *i)* literature review on the disciplines to design technologies for healthcare; *ii)* preliminary investigation within three nursing homes located in Trentino, in the northern Italy; *iii)* extended in-depth investigation within six nursing homes located in Trentino; *iv)* data examination; *v)* design of the solution; *vi)* iteration and validation.

*i) Literature review.* To contextualize our research we conducted an extensive literature review on the most used disciplines and methodologies for the design of technologies, in order to find which were the most appropriated for the matter of our study. In particular, we focused on those that were especially used for the design of technologies for healthcare contexts; specifically home care settings, which include also residential contexts like nursing homes. In our review, by synthesizing our results, we analyzed three main disciplines for the design of healthcare technologies: Computer Supported Cooperative Work; Participatory Design; Requirement Engineering. In doing so, we compared these disciplines with one another and we identified how their main characteristics can serve the design of healthcare technologies. Thus, we did not exclude one methodology over another, but we suggest as they can be jointly used upon the convenience of the research contexts, thus to obtain social requirements as refined as possible, and to avoid the clustering of disciplines that often affects the healthcare technology design.

*ii) Preliminary Investigation.* To contextualize our research framework we conducted a first preliminary investigation within three nursing homes located in the province of Trento; the study begun in the fall of 2015. The nursing homes were chosen among

a broader network of other structures. The three nursing homes we investigated were similar in terms of the services they provide and the characteristics of the residents they host, but they differed in terms of the structure of the facility, the number of patients they host, the number of care professionals they have, and the location they occupy. Therefore, we carried out a first series of short-term observations [129] in each facility. For each observation we explored the facilities, we observed how care professionals work and we interacted with them, and we informally interviewed the directors of the nursing homes. This first glance to the research context helped us to comprehend the nature of the research contexts we had to investigate, thus to design the proper research plan. Moreover, it helped us to establish a first contact with the personnel of the nursing homes. From this study we learned how delicate is the context of the nursing homes.

*iii) Extended in-depth investigation.* After the preliminary investigation, we designed a research plan built on a series of qualitative and quantitative methodologies. We included in our study other three nursing homes located in the same province. Given the delicacy of the contexts, once we designed our research plan, we coordinated the implementation of the research with the management of each nursing home. Therefore, we divided our study in three main parts. First, we enriched our data with additional short-term observations. Second, we relied on a questionnaire to draw a clearer picture of our research contexts; we investigated: the characteristic of our sample; how stakeholders deal with the care pathway and coordinate with one another; which are the issues that interfere with the provision of the care services; how stakeholders would ameliorate the provision of the care work; their use of ICTs; stressing factors. Third, we included almost thirty family caregivers and around twenty care professionals in interviews and focus groups, in order to comprehend - on a more individual level - the issues that interfered on the care work and the needs of the stakeholders. We conducted the study from the spring to the winter of 2016.

*iv) Data Examination.* After we accomplished our in-depth investigation we examined the data with the goal of abstracting the information necessary to design a first solution for our context of interest. Yet, before to design any solution, we carried out a comparison with a similar case study conducted within another end-of-life contexts: a pediatric palliative care network for children with incurable diseases. Our goal was to verify the consistency of our results with other healthcare contexts that deal with patients in a end-of-life situation. Both case studies displayed consistent results. We learned the necessity for the stakeholders to build the coordination of the care plan on relationships that do not rotate only around the exchange of mere medical information. In this, professional

and family caregivers need to be mutually involved in the planning and coordination of the care pathway, as well as in the information sharing on the patients' medical and non-medical situation, while building relationships that go beyond the medical framework. Therefore, since the care work in end-of-life contexts is highly time demanding and lacks the "space" to nourish the interactions among care professionals and family caregivers, we learned that a key role of technology is to allow care professionals and family caregivers to socialize through ICTs while coordinating the care pathway. These findings are also the outcome of a series of theoretical reflection built on a sociological analysis (for more details see Chapters 5 and 6).

*v) Design of the Solution* What we learned from our data allowed us to design a first solution. We conceived our solution as a technology platform to be implemented on portable devices such as tablets and smartphones, thus to allow users to rely on a technology detached from a specific location and able to support synchronous and asynchronous communications. We first designed a series of mock-ups that displayed the features and aesthetics of the technology platform in accordance with the following design guidelines: *(i)* shared information and transparency between care professionals and family caregivers with all the information on all patients; *(ii)* internal communication and coordination among all caregivers that allow also informal communication and friendly social interactions; *(iii)* data management of the communication conducted among caregivers; *(iv)* the possibility to rely on a referenced point - family navigator - within the care professional team for the family caregivers; *(v)* an overall view of the network of care that rotate around patients; *(vi)* spaces of peer-to-peer support for the family caregivers. This first prototype was designed to deliver a clear idea on the limitations and potentials in coordinating the care pathway. In other words, the mock-ups precisely displayed what users could view, share, exchange.

*vi) Iteration and Validation* We designed a first prototype. We, then, iterated on our results and the design guidelines. Afterwards, we verified the consistency between the mock-ups we produced and the needs we elicited from our data examination. At the end of the iteration we organized a series of workshops of validation with a total of thirty-three participants among care professionals and family caregivers. These workshops aimed to validate the users' needs the technology platform intent to fulfill, and the usability of the proposed solution. Eventually, the workshops helped us to refine some of the features. After the validation we redesigned the mock-ups in accordance with the suggestions received by the participants, and in accordance with the results of our analysis of the workshops.

## 1.3 Contributions and Results

To each step of our research corresponded a critic analysis of the process and of the results obtained and a publication. The contributions of this thesis can be summarized in four categories: *i)* the analysis of the state of the art and the consequent literature review on the most reliable disciplines that apply to design technologies for healthcare; *ii)* the empirical studies conducted to draw a clear understanding of the context of the nursing homes in the province of Trento, and the consequent validation of the needs of the stakeholders; *iii)* the increased theoretical understanding of the social issues that interfere within end-of-life contexts; *iv)* The delivery of the requirements for the development of the new technology platform, and a first prototype composed of interactive mock-ups. The dataset containing the data produced by our study is available at: <https://drive.google.com/drive/folders/1uFYsgLPXc4rjT2mxFpfJOWdpkiQNo8Ui?usp=sharing>.

### 1.3.1 State of the Art on Methodologies for Healthcare Technology Design

Our review and analysis of the most reliable disciplines for healthcare technology design (Computer Supported Cooperative Work, Participatory Design and Requirement Engineering) proposed an alternative view to technology design. The creation of ICT solutions for the healthcare sector can benefit from the use of various methodologies. The use of a mixed set of methodologies that belong to different disciplines may increase the understanding of the issues and necessities of healthcare contexts by opening up the spectrum of views [65]. In this sense, it would allow designers, developers, and researchers to have a greater understanding of users' actual needs, as different lenses of analysis may grant a different perspectives. With our study, we also opened a methodological discussion to stimulate the formulation of a new formalized methodology for healthcare technology design. For more details see Chapter 2.

### 1.3.2 The Empirical Study

In our in-depth investigation we thoroughly explored the nature of the contexts object of our study. On the one hand, our study validates several dynamics and problems emphasized by other researchers [185, 48, 137] that regard the context of nursing homes and healthcare contexts in general. On the other hand, our results shed new light on how these dynamics within healthcare contexts should be approached and analyzed, as well as how the needs of caregivers should be fulfilled (for more details see Chapters 3, 4 and 7). Moreover, our study discloses the specific needs of the caregivers working within the network of the six nursing homes, and it highlights the peculiarities of a relatively circumscribed context, as it is the province of Trento.

### **1.3.3 Methodological and Theoretical Contribution**

Given the delicacy of healthcare contexts, in particular end-of-life ones, researchers struggle to enter the intimacy of the actors involved into the care of patients suffering from severe impediments. Thus, several aspects of these environments are left out from the comprehension of what should be taken into account when designing technologies for healthcare. Therefore, it becomes important to find the right tool, methodologies, and research plan to investigate these environments to draw the right conclusions. In our study, we formulated a research plan built on a series of qualitative sociological methods that led to better disclose the issues that interfere with the care process, thus to better formulate the problems of the nursing homes. In our research we were able to tackle the problems from different perspectives that, eventually, led us to identify the requirements for the technology platform. Our research brought an increased theoretical understanding of the care work carried out within end-of-life healthcare contexts. For more details see Chapters 5, 6 and 7.

### **1.3.4 The Technology Platform Prototype**

The outcome of this research results in a set of requirements for a novel technology platform, which will be developed upon the results of the studies presented in this thesis. We propose an hybrid solution that it tackles medical, managerial, relational, and social issues; we also deliver a first prototype with interactive mock-ups of the new platform. Several studies [117, 139, 31, 165, 16, 19, 145, 60, 56, 112] propose technologies to support collaboration, information exchange, time and task management, and social interactions between family and professional caregivers and among care professionals. Nonetheless, to our best knowledge, there is no study, solution, or prototype that proposes a solution for all these issues with one technology. There are studies that focus either on the managerial factors of caregiving [31, 60, 116], or on the social issues of caregivers [98, 113, 112]. Therefore, although the literature offers several solutions, it appears that none of them proposes a technology that deals with the management of both managerial and social factors (for more details see Chapter 8).

## **1.4 Structure of the Thesis**

The contents presented in this thesis are mainly built on a series of research publications that discuss the topic presented in this manuscript. In other words, each chapter is based on a contribution - either published or accepted, or under submission - and it represents a segment of the whole research; all these segments correspond to a specific phase of the

whole research which was concluded with a publication. Therefore, all the chapters are presented in accordance with the chronological unfolding of our research work, which was conducted within two years. The chapters are connected to one another in a continuum that aims to deliver the whole picture of our study. However, due to the structure of this thesis, there are some repetition across chapters, such as state of the arts, description of the methodologies, sometimes common findings.

**Chapter 2. Open Issues in Designing Technologies for Healthcare** There are several methods and disciplines to the design of technologies for healthcare, such as Participatory Design. Each one follows a specific approach that is often inconsistent with other methods. In other words, each method focuses on a series of key points that are often left out by other approaches, and vice versa. In doing so, by relying on only one of these disciplines, designers may exclude from their design process issues that are worth to be taken into account. In this chapter, we analyse the features of three of the most reliable disciplines for the design of healthcare technologies - in particular home care and residential care - and we open a discussion on the possibility to rely on the methodologies they offer in a mixed fashion, thus to better tackle the social requirements for the healthcare technology design. This chapter is based on a book chapter published in the book “*Mobile e-Health*” edited by *Springer* [65].

**Chapter 3. Understanding How Software Can Support The Needs of Family Caregivers for Patients with Severe Conditions** In this chapter, we present a study carried out within two healthcare settings where the care relation between doctor and patients is mediated by the relatives of the patients: pediatric palliative care and nursing homes. Children or very old adults in a end-of-life condition, are patients that require the full involvement of a family caregivers as reference point for the health service. In these contexts the incurable condition of the patients leads family caregivers to experience strong emotional distress. In the chapter, we focus on information, coordination and social issues that emerge in such contexts. We also focus on how current technologies can help caregivers in dealing with this problems, and how software designers can fulfill the needs of the actors of these contexts. This research work has been published at *ICSE 2017 (International Conference on Software Engineering)* [67].

**Chapter 4. Design Considerations to Support Nursing Homes’ Communities** Caring for older adults living in nursing home is a complex matter for both families and professional caregivers. The increasing older population rose the attention towards this topic and the need for research contributions in this area. Several studies recognize the ne-



cessity to ameliorate the working conditions of professional caregivers in order to decrease the risk of burnout and job dissatisfaction. In this chapter, we present a study conducted within the network of nursing homes located in the province of Trento. We investigated the work practices of care professionals, by also focusing on the relational issues between care professionals and family caregivers. Our findings highlight the potentials in using ICTs to improve the working conditions of the care professionals working in the nursing homes. The results of this study have been published at *C&T 2017 (Communities & Technologies)* [68].

#### **Chapter 5. Taking Care of Sensitive Milieus: a Story about Dialogical Interviews**

Dealing with design processes within healthcare settings often implies the management of sensitive scenarios and delicate emotional situations. This chapter addresses reflections on our research experience in adopting dialogical interviews in sensitive design contexts. Our reflections are the result of the field work carried out within the network of nursing homes. Here we conducted 27 dialogical interviews with family caregivers of patients in severe end-of-life conditions. In this chapter, we want to emphasize the importance of taking care of the human relationships with participants while investigating sensitive contexts, thus to better comprehend to which direction the design of a new technology platform should be driven. The results of this study have been published at *InfraHealth Conference 2017* [41].

**Chapter 6. Data Work as A Golem: Reflections on the End-of-Life Contexts** “Data work” plays an important role within healthcare contexts. Yet, this concept has unclear boundaries. In this chapter, we investigate the issues that characterize the data work within the two end-of-life healthcare contexts previously presented in Chapter 3: the network of six nursing homes and the pediatric palliative care network. We explore data work within both settings by analyzing how the practices to collect and share data are perceived by the caregivers. We then discuss the divergent opinions of family and professional caregivers on how data work should be done to enhance and support collaboration. This analysis helped us to shed new light on the understanding of the dynamics that exist between formal and informal caregivers. Hence, we deepened our comprehension on how the new technology platform had to be designed. This work is the base of a submitted article in *International Journal of Information Management* [42].

**Chapter 7. What is Appropriation Telling Us?** Healthcare end-of-life contexts are sensitive environment often difficult to investigate. The care work for caregivers is highly demanding, in terms of tasks and emotional involvement. In this chapter, we want to

assess the usefulness of observing *appropriation* to investigate how caregivers re-adapt the use of existing technologies to support their care work. The focus on appropriation allowed us to better comprehend the nature of the issues that interfere with the care work. Indeed, we learned that caregivers' struggles do not merely pertain matters related to the medical framework. Therefore, by analyzing appropriation we emphasize the use of a new methodological tool for technology design, and we draw the first requirements for the new technology platform. This work is the base of an accepted article in *First Monday Journal* [44].

**Chapter 8. Design and Validation of the Prototype** In this chapter, we bring together all the contributions presented in the preceding chapters, and we deliver the final contribution of this thesis. Firstly, after the summary of the whole research, we draw attention to the design process that led us to formulate the first requirements upon which we design a series of mock-ups of technology platform. Secondly, we explain the validation process that led us to reformulate the requirements. Thirdly, in the light of the results of the validation process, we illustrate how we reformulate the requirements for the development of the new technology platform. To validate the requirements, we conducted several participatory design sessions with the family and professional caregivers of the network of nursing homes. Our findings confirm the organizational and the relational complexity of the nursing homes, highlighting how cultural frictions and poor communication practices hinder collaboration and mutual understanding between family and professional caregivers. As outcomes of this chapter, we provide a new set of requirements accompanied by use cases, and we deliver the first prototype composed of interactive mock-ups of the new technology platform. The data pertaining this study is available here: <https://drive.google.com/drive/folders/1agSB38GcUoW3-nSYobW0Z-7wSqaymdTv?usp=sharing>. This work is the base of a submitted article in *Plos ONE* [43].

**Chapter 9. Conclusions** In this chapter we summarize the contributions of this thesis, stressing the importance of the methodologies we adopted in supporting the comprehension of our research setting. Afterwards, we draw attention to the lessons we learned throughout our research work, from both the outcomes and the research experience. We, then, highlight the limitations of our research. Finally, in the light of the limitation we highlight, we explain the future steps of this research work, and the possible paths that may be undertaken.

## 1.5 List of Publications

### 1.5.1 Published and Accepted

- Francesco Ceschel. “A Common Practice to Rise Older Adults’ Awareness of PD.” In Proceedings of the *COOP 2016* (pp 61-67). IISI Press. [45]
- Angela Di Fiore and Francesco Ceschel. “Open Issues in Designing Home Care Technologies.” In *Mobile e-Health*, 2017. (pp. 215-233). Springer, Cham. [65]
- Angela Di Fiore, Francesco Ceschel, Francesca Fiore, Marcos Baez, Fabio Casati, and Giampaolo Armellin. “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*. 2017, (pp. 33-36). IEEE Press. [67]
- Angela Di Fiore, Francesco Ceschel, Leysan Nurgalieva, Maurizio Marchese, Fabio Casati. “Design Considerations to Support Nursing Homes’ Communities.” In proceedings of the *8th International Conference on Communities and Technologies*. 2017, (pp. 64-67) ACM. [68]
- Francesco Ceschel, Angela Di Fiore, and Fabio Casati. “Taking care of sensitive milieus: a story about dialogical interviews.” *Infrahealth 2017-Proceedings of the 6th International Workshop on Infrastructure in Healthcare 2017*. 2017, (pp. 1-6). EUSSET. [41]

### 1.5.2 Under Revision

- Francesco Ceschel, Angela Di Fiore, Vincenzo D’Andrea, Maurizio Marchese and Fabio Casati. “What is Appropriation Telling Us? A study on collaborative end-of-life care work.” Under revision at *First Monday Journal* [44].
- Angela Di Fiore, Francesco Ceschel, Natalia Kolanowska, Vincenzo D’Andrea, Fabio Casati. “Social and Organizational Factors influencing the quality of care in Pediatric Palliative Care: a qualitative study.” Under revision at *Quality of Life Research by Springer* [66].
- Angela Di Fiore, Francesco Ceschel, Vincenzo D’Andrea, Maurizio Marchese. “Taking care of the Golem.” Reflection on the role of technologies and information sharing in complex care contexts.” Under revision at *International Journal of Information Management* [42].

- Francesco Ceschel, Angela Di Fiore, Vincenzo D'Andrea, Maurizio Marchese and Fabio Casati. “Designing a technology platform to support collaboration between professional and family caregivers in nursing homes: a study within sensitive health-care settings.” Under revision at *Plos ONE* [43]

## Chapter 2

# Open Issues in Designing Technologies for Healthcare

*with Angela Di Fiore*

In this chapter<sup>1</sup> we frame the research presented in this thesis. In particular, we draw attention to the methodological framework that lies behind our research work. Here, we explain “home care” as the management of the care pathway of patients within their residential settings. Nowadays, home care is being increasingly applied as it improves both the quality of life of the patient and the quality of care. This chapter aims to provide an overview concerning the recurring issues found while identifying requirements and users’ needs for home care technologies. We present a series of reflections from the literature to clarify the main factors that may support or hinder the design of effective solutions for this domain. Indeed, the design of such technologies often faces several complexities, such as social, communicational and organizational challenges. The goal of this chapter is to underline the relevance of the definition of appropriate social requirements, and to address the right key points of attention, in order to best manage the complexity of home care.

### 2.1 Introduction

The population of Europe is rapidly aging, and, according to the literature, in 20 years most of the citizens will be part of the over 65 cohorts [92, 85, 152]. Since aging may lead to physical impairments and since the aging population is increasing, there is a rising demand of home care and residential services for the older adult population [81, 62].

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<sup>1</sup>This chapter derives from [65].

This phenomenon is pushing the healthcare sector to enhance home care services within residential environments [51]. *Home care* is an umbrella concept that refers to “the care provided by professionals to a person in their own home with the ultimate goal being not only to contribute to patients’ life quality (...) but also to replace hospital care with care in the home” [192, p. 871].

Home care concerns the management of heterogeneous physical impairments, such as chronic and degenerative diseases [159]. Several studies recognized that home care has the potential to increase patients’ quality of life, to decrease costs of healthcare, and to leave patients in places they are emotionally attached to [29, 125, 159, 62]. Home care is a complex phenomenon, being characterized by a dynamic context that concerns a network of stakeholders with heterogeneous and conflicting needs [51, 199, 198, 153]. Indeed, home care engages several stakeholders in multisited 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 care.

Although home care appears to target only private dwellings as care sites, its peculiarities lead to involve into our discussion other type of residential healthcare settings. In particular, the non-medical nature of home care, its collaborative approach toward the care work of family caregivers and care professionals, and the need to fulfill the necessities of all the stakeholders involved, make home care the right framework of analysis also for other settings. Because of their residential nature, Nursing Homes (NHs) display the same dynamics of home settings: *a)* patients are hosted in a residential environments; *b)* family caregivers closely contribute to the care process; *c)* the care pathway requires a close and coordinated collaboration between family and professional caregivers; *d)* NHs are non-medical facilities that aim to create a comfortable and cozy environments for older adults; *e)* NHs do not “cure” patients, they rather assist them. Thus, home care and, therefore, home care technologies pertain all healthcare settings that involve all dynamics of residential care.

In this scenario, the technology is perceived as relevant asset, having a great potential in supporting the complexity of providing care at residential environments [62]. In particular, home care technologies have to deal with interrelations between places, healthcare providers, individuals’ needs and sensibilities and data and information exchange [136]. According to the literature, there is an emerging need of technologies that can support assisted living through home care services since “the existing systems are poorly aligned to the care that older populations require” [62, p. 5]. Due to the human and organizational complexity that characterizes this way of caring, there is a peculiar demand in solutions

that can support the residential care practices, backing coordination and communication [2]. The potentials of technology become a call for actions for designers and researchers, in particular in relation to mobile technologies [21]( 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 the reality through the definition of the requirements of a technology [76, 80, 9, 142]. If this problem is relevant in every design process, it is even more central in designing for a domain like residential care. Residential care contexts are generally known for being characterized by unpredictable events and an extreme micro-social variability [186, 57].

In the light of the issues described above, this chapter is an introduction to the issues in designing information technologies for residential care contexts. This work addresses some key points of attention in the definition of users' needs in the domain of home care. In particular, the identification of these key points of attentions has the goal to provide a shortlist of conceptual instruments that can inspire the designers while facing the complexity of the home care domain. This chapter aims to deliver a new perspective on how to tackle the issues that concern the care work within home care settings.

In the first section, we highlight the positive contribution of three computer science disciplines in the definition of the requirements of a technology. Requirements are the criteria that define the technical and social features of a future technology [197]. In this chapter, we focus specifically to social requirements. We go through the computer science disciplines that are related to the definition of the requirements, with particular attention to their contribution about dealing with dynamic human contexts and, specifically, residential care contexts.

In the second section, we discuss the features that characterized residential care settings, and we highlight some of the open issues that can be useful to consider when working in such contexts.

In the discussion, after we synthesize the argumentations presented in the preceding section, we draw attention to a shortlist of key points we believe fundamental to consider when designing technologies for home care.

## **2.2 Defining Social Requirements**

In this section, we discuss the disciplines in computer science that, to our best knowledge, can better inform the definition of requirements in dynamics and situated contexts, such as home care. We address specifically the concept of social requirement, which refers to requirements that focus on the reconciliation of the society and individuals' needs and not on technical – hardware and software – aspects [204]. Such concept “is centered around

knowing which (and how) social arrangements need to be satisfied” by a technology [4, p. 195]. We propose the concept of social requirements as an intellectual tool that can guide the design processes for home care technologies, informing the investigation of the users’ needs. It is an interesting resource in a design process, because it can be a bridge between different approaches in computer science that provide positive contributions 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 Computer-Supported Cooperative Work. In our opinion it can be a nexus between approaches that focus on the variability 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 positive contribution of these disciplines in defining social requirements and users’ needs in dynamic contexts, in order to assemble the potential of this intellectual tool.

### **2.2.1 CSCW (Computer-Supported Cooperative Work)**

CSCW investigates the role of technology in fostering interaction and collaboration among individuals within their working environment [76]. CSCW 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 [17, 171]. In the light of this peculiar attention, CSCW broadly focuses also on healthcare contexts [87].

One of the most relevant epistemological problems in CSCW concerns the definition of requirements and is known as the so called socio-technical gap. Socio-technical gap is a concept that refers to “the great divide between what we know we must support socially and what we can support technically” [4, p. 180]. This gap represents the main challenge of the field we are discussing here and highlights the complexity of the social dimension in relation to the intrinsic and ontological limits of technology. CSCW stresses the importance of the social requirements, because they allow for the evaluation of the boundaries within which technical solutions can fully address social needs. For this reason, this approach attributes considerable importance to the experience of professionals who work within a working environment; they can identify the limits of a technology and,



consequently, the socio-technical gap [17, 171, 4].

CSCW considers both the social and technological side, concerning a working environment as matters in co-evolution. Therefore, it ascribes much attention to the work practices and how these practices are shaped by the setting of the technologies in place [4, 17].

Studies on CSCW [17, 171] highlight how technology, in a few cases, lacks to support and satisfy the social complexity that characterizes the interactions among workers. According to Bannon and Schmidt [18, p. 360] “Computer Supported Cooperative Work should be conceived as an endeavour 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 users’ 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 [87]. Indeed, with regard to healthcare, CSCW stresses to investigate the influence of the technology on three levels, in order to better identify the socio-technical 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 [4].

Overall, CSCW appears to provide a useful framework to comprehend the social requirements. Therefore, it seems a suitable approach to investigate complex socio-technical environments, like healthcare contexts.

### 2.2.2 PD (Participatory Design)

PD is a democratic approach to design that aims to involve and commit users into the decision-making processes, as it will lead to the development of a new technology conceived to support the class of users involved in the design process itself [178]. The PD is a design-oriented approach that aims to empower users through proper techniques that support their participation and involvement. The PD – which is strongly linked to CSCW – mainly focuses on social requirements; it emphasizes that “human activities are carried out in cooperation with others and so new technologies need to be designed to support cooperation” [178, p. 8]. For this reason, the PD stresses the need to comprehend how to enhance commitment and foster cooperation and mutual support among future users. In other words, the PD calls for a deeper understanding of the needs of the future users.

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 [130]. 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 [80]. That is why, through the PD, designers aim to develop technologies in accordance with the user’s perspective, in order to improve their working and daily practices [178].

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. Conversely, the role of researchers and designers is limited to facilitating, validating, adjusting and monitoring the design path [177].

The strongest contribution of the PD is the enhancement of human relations through participation and mutual understanding, conceiving a design process as in becoming [9]. Indeed, the process primarily focuses on understanding the people involved (target user group), the relations they established within the group and in which context these relations take place. This helps to display the design and the subsequent development of technologies, as the co-evolution of services and human practices [187]. This is the reason why the PD community focuses on an approach centred on the human perspective, rather than drawing the attention on mere technical requirements.

The PD literature offers a wide variety of studies on the epistemological problem of empowering people, both with the technology and with the PD process itself [102]. Yet, the literature is also rich with empirical papers that illustrate the process and the most effective techniques used to engage users in order to grasp their needs [102]. 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. On the one hand, the peculiar attention of PD for situated contexts makes it particularly appropriate for healthcare contexts. On the other hand, this led to the avoidance of holistic models to guide the design processes. In PD 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 on participation, but limits the understanding of the macro level.

### **2.2.3 RE (Requirement Engineering)**

RE is a discipline originally established in the 1970s, with the aim to investigate which are the requirements that should lead the development of a software [208]. Differently from Software Engineering, which aims to design “things right”, the purpose of RE is to design the “right thing” by identifying and documenting specific requirements [30]. RE provides

models and taxonomies that use diagrams, mathematical analysis and UML notation to support the formalization of technical and social requirements [197]. RE investigates the reality from a macro perspective, focusing on the standardization and generalization of how a technology should be designed.

RE has a transformative rationale, and it encompasses the following main phases: (1) requirement elicitation, which refers to the gathering of requirements working with the future users; (2) requirement specification, in which the requirements are classified and defined; (3) and requirement validation, which is the phase in which the requirements are organized and tested. [179]

To keep the focus of this chapter on social requirements, here we draw attention to the phase of requirement elicitation. This phase aims to define the social requirements by understanding the context of use of a hypothetical technology and the consequent needs and constraints of potential users, in order to acquire the knowledge that will shape the technology [197]. 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 [15, 77, 91, 197].

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 [197, 91, 151]. These techniques aim to collect 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; (c) and information about the system as is – if any – that the stakeholders implemented to cope with the lack of available technologies to support their practices.

The requirement elicitation can be also divided into two subcategories: (1) models focused on 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 focus on assumptions on the domains to take into account during the elicitation [110].

The literature provides a few general examples. For instance, the most representative, the CoRea [91], suggests to use meetings and brainstorming sessions or contextual inquiry [197], which combines interviews and ethnographic observation to focus on the work activities of the users. Overall, these models are holistic, and they provide general guidelines, principles for elicitation, and techniques, without targeting specific domains. These models address activities on a macro level, and they may leave little space to the

definition of the social requirements. [136]

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 focuses on the role of the business analysts, which masters the techniques and enacts the requirements [110]. Hence, to valorise the role of the analyst and of the future users, is paramount to enrich the process with additional techniques for the understanding of complex contexts, such as home care [110].

To summarize, we may claim that RE furnishes a structured approach that supports the software development and should allow a generalization of the outcome. Nonetheless, differently from PD and CSCW, which focus on a deeper understanding of the practices in place, RE has lesser attention to the social dynamics that takes place within socio-technical environments. Yet, RE fulfills the needs of “generalization” and “rigor” that PD and CSCW lack.

### **2.3 Open Issues in Home Healthcare**

Home care is a discipline that seeks the best practices to carry the care pathway of patients in their house. This discipline aims to let patients live in their home as long as possible, a place to which they are emotionally attached [31]. Studies [192, 31, 2, 147, 51] suggest that patients would gain additional benefits from being “treated” within a familiar environment. The literature lists several benefits that home care may entail, fostering patients’ compliance to care plans, improving patients’ awareness about the care treatments, reducing hospitalizations, reducing costs of care and improving patients’ quality of life [164].

Yet, to better understand this perspective, we need to introduce a new concept. Home care is 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 home care system, which puts a regular and longitudinal path of care in the middle [26, 84]. This transition is perceived as a fundamental challenge that is changing the paradigm of the healthcare service organizations towards the engagement of a dense network of actors [26, 29].

Continuity of care was developed by focusing on the management of chronic conditions [199]. It deals with high organizational complexity, since home care involves a large number of care providers, and encompasses very diverse care medical locations [198]. These issues led to a greater demand of home care services in the developed countries, to allow families to deal with the care pathway within a “protected environment” [29, 125, 159]. Continuity of care aims to establish a solid network of all the caregivers involved

in the care pathway of a patient, by also ensuring the coordination among the caregivers [100]. The literature [101, 172] suggests that continuity of care enhances coordination among medical locations, such as central hospitals, local hospitals, specialist centers, clinics and patients' homes. Moreover, it provides a continuum of care, reshaping the care system by focusing on the needs of the individuals/patients.

Within this framework, Haggerty et al. [101] proposed an approach to better organize the continuity of care. The author suggested to work using three dimensions: (1) information continuity, which refers to the patients' sense of predictability, which is instilled by a coherent information sharing; (2) management continuity, which refers to the patients' sense of safety that derives from responsive protocols and clear interactions between providers; (3) and relational continuity, which refers to the sense of predictability and coherence among relationships with the professionals.

Home care technologies can be an important resource towards reducing the risk of care fragmentation in home care services [126, 141, 172]. Care fragmentation is a phenomenon that leads to a fragmented understanding of a care reality, and it may derive from underestimating the illness experience of a patient [180]. This may lead individual/patients 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 de-personalization [180].

Studies [198, 100, 180] 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" [147, 63, 21]. 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 [196]. In this sense, the design of proper technology would ease the independence, but, in the same way, it would 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 [196]. Similarly, the residential characteristics of NHs include them into the framework of home care. Within NHs, caregivers deal with the same dynamics that can be observed within home care settings.

### 2.3.1 Home Care and the Technology: An Opaque Topic

Technology has an important role in supporting home care works and the management of home-based disease care programmes [40]. However, there is an open issue on how the relation between technology and healthcare should be theoretically framed [84]. Therefore, this domain seems opaque because of 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 [26, 82, 84, 125, 175] delivers several examples of the terms that are generally used to describe the relation technology-healthcare: telemedicine, E-health, tele-health, tele-homecare, 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 telecommunication to transmit medical information [84, 175, 125]. 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 [82]. “Telehealth” is conceived as a way to promote health, in terms of medical education, to raise awareness among patients [40, 125]. “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 [40, 125]. “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 [125]. “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 [40]. 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” [31, p. 190]. To our best knowledge, 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, multi-modal and dynamic, since this domain needs *ad hoc* technologies to manage the interrelation between places, healthcare providers, individuals, needs, sensibilities, data and information [136].

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 [139].

Indeed, there seems to be a greater availability of papers concerning technical studies based on biological measurements and virtual visits [84, 175, 125] and cost reduction [164, 62], compared to the availability of research on the role the technology may have in managing the human relations within home care contexts, such as [148, 56]. 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 [26, 82, 84, 175], whereas the literature on telecare systems to support collaboration in complex networks of healthcare seems to receive a poorer attention [84, 175, 125, 164, 62]. Hence, telemedicine calls for a greater multidisciplinary effort to accurately define social requirements [40, 84, 175], and we believe that this literature deserves a greater attention in order to better comprehend how to define the social requirements [31].

In particular, Koch [125] identifies three common barriers related to home care services, which are the lack of standards and protocols, the lack of a shared framework of analysis and the lack of guidelines for the development of *ad hoc* solutions. In agreement with Koch [125], a lack of guidelines and frameworks to support the definition of social requirements for home care is affecting the quality of the existing home care technologies. In relation to the design of home care technologies, more work needs to be done, both with the requirement approaches and with the knowledge about the healthcare's complexity.

### 2.3.2 Home Care from a Social Perspective

As we anticipated in the preceding section, a greater focus on technical factors, rather than on social needs and humans' 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 care and that can hinder the design of effective technologies: (1) the coordination of caregivers involved in care delivery; (2) the communication issues within stakeholder networks; (3) and the complexity of the organizational setting of the healthcare sector.

#### Coordination among Caregivers

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 [29, p. 1064] suggests that "given this level of complexity, the coordination of care among multiple independent providers becomes an enormous challenge".

Several studies [186, 57, 35, 126, 164], carried with a peculiar attention to organizational issues, suggest that home 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 by an average of four doctors and as many nurses [172].

Within this framework, studies [203, 95] conceptualized care providers, distinguishing between formal and informal caregivers (or providers), but both perceived as co-producers of the care. The former are defined as experts, precisely healthcare professionals, whereas the latter are relatives who become “experts” through a *learning by doing*, 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 [186]). Indeed, as quoting Corbin and Strauss [57] 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 pathway 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 [29]; (b) it can affect the personal life of informal caregivers, who may face situations they are not formally prepared to [57, 186]. In fact, “each change in illness conditions not only brings about changes in trajectory management but also affects the management of everyday life” [57, p. 229].

### **Communication Issues**

The second area concerns communication issues, which can be grouped into five main domains. Firstly, 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 a patient, and they need to share the information with the formal caregivers to coordinate the care. On the other hand, patients and their families do not always have the right expertise to deal with medical issues which would require the assistance of professionals [29, 126, 172]. Secondly, 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 [126]. Thirdly, there is a poor mutual involvement of primary and secondary physicians on the care plan



and discharge plan. Fourthly, the unpredictability of a medical situation often hinders the possibility to follow a strict schedule of treatments and medical appointments [58, 57]. Lastly, there is a the lack of universal data protocols to support information systems in communicating using the same standards.

Several studies [126, 175, 84] highlight the importance of these domains. In particular, poor communications and, consequently, a limited information flow lower the quality of healthcare services. As a consequence, this leads to discontinuity in the services and high rates of readmissions and relapses, creating the suspension of the care process.

### **Organizational Complexity**

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 of the professionals.

Healthcare contexts do not generally have a fully formalized structure. In particular, there are soft and hard aspects that need to be considered [122]. The former refers to the tangible aspects of an organization, such as the structure, the functions of each organizational level and the control protocols [35], whereas the latter refers to the intangible dimensions of an organization, such as the culture, the common “language” and “symbols” and the shared values [122]. These aspects are constantly renegotiated and readopted by the members of an organization [202]. Within these contexts, the individual skills and the organizational routines are conceived as the “building blocks of the organizational capability” [73, p. 5]. Accordingly, within healthcare contexts, individual skills and work practices are strongly related to soft aspects that are, by definition, difficult to handle [122, 35].

## **2.4 Discussion**

The healthcare contexts and, specifically, home 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 [4, 204], social requirements are the nexus of the design of a technology and, hence, inaccurate analysis of users’ needs and contexts may affect the overall design process and the efficacy of a technology.

For this reason, we explained the importance of understanding the needs of the potential users, and we stressed the significance of the key points of attention that would deliver the terrain from which to build a consistent design process. Therefore, we presented a

Table 2.1: Summary of The Approaches to Design Technologies For Healthcare

<b>Discipline</b>	<b>Characteristics</b>
<i>CSCW</i>	Focus on Healthcare
	Focus on work practices
	Wide empirical contribution
	Flexible and situated
<i>Participatory Design</i>	Attention to social requirements
	Flexible and situated
	Attention to work dynamics and engagement
	Wide knowledge on techniques and empirical work
<i>Requirement Engineering</i>	Focus on epistemological issues of participation
	Macro approach that tend to formalization
	Offers macromodels
	Contribution focused on technical requirements

series of disciplines that support the design of new technologies – CSCW, PD and RE – and we highlighted their characteristics (summarized in Table 2.1).

All these disciplines are of great importance. However, we believe that each one delivers contributions that can be enriched from one another. Therefore, one discipline should not be excluded over another. It is our belief that the techniques and methods made available by these disciplines should be joined accordingly to the convenience of the research context, to go beyond the circumscribed framework of PD, CSCW and RE, in order to obtain social requirements as refined as possible.

In particular, the great contribution of RE is to provide a groundwork for the definition of requirements useful for the development of a software. RE focuses, first, on how to employ the information that emerge during the requirement elicitation to later deliver them to the following phases of the requirement definition, which are more on technical requirements. This approach is particularly useful to create generalizable models and knowledge. Conversely, CSCW and PD mainly focus on social requirements by understanding the needs of the future users. In this sense, they intend to comprehend the relations that users establish, the practices that users carry out, and the contexts that users experience. These two disciplines draw attention to epistemological problems, ethical dilemmas, and empirical case studies, in order to address the main challenges in designing with and for users. 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. CSCW and PD rely on qualitative and narrative techniques and are less structured than RE. The effort of CSCW focuses more on collaborative technologies for working environments, and it draws particular attention to the care contexts. Whereas PD focuses more on design challenges and on the engagement of users through a participative approach.

In summary, on the one hand, RE provides a structured model, which allows for a formalized way to grasp the social requirements. On the other hand, CSCW and PD furnish the techniques to comprehend the social dynamics that take place within complex environments, and they provide the right methodologies to define the situated needs of target user groups.

To better understand the complexity of healthcare contexts, the literature we addressed in the previous paragraph highlights three types of issues that characterized the design of collaborative technologies for healthcare and, in particular, for home care: (1) the lack of data of the patients and lack of communication protocols among professionals, (2) the presence of coordination and organizational issues among the actors involved in the process of care, (3) and the fluctuating and erratic nature of the healthcare. As we observed in the previous paragraphs, the literature on technologies and home care shows a lack of attention to the social concerns that may emerge within these three levels of 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 issues that lie behind the home care framework.

Stange [180] suggests that the continuities of care and home care are an open challenge that “requires a deeper than surface understanding of the problem” [p. 100]. In fact, the network of home care is a mosaic where the caregivers co-produce together the care [203] 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 systems to allow for a transverse and continuous care [101].

Hence, we can affirm that the healthcare and home care domains face a series of challenges; they address issues on collaboration, heterogeneous actors, variability of the working practices and communication. These challenges limit the understanding of the social requirements. Therefore, the home care domain needs *ad hoc* guidelines and frameworks of analysis that can support the understanding of the social requirements, in order to address the interrelations among places, healthcare providers, individuals’ needs and expectations, as well as data and information delivery, which characterize healthcare.

## **2.5 Conclusions**

In this chapter, we introduced the key points of attention we believe are important to sustain how technologies for home care could be better addressed and designed. We tackled this issue by reviewing the main disciplines that, nowadays, provide the tools to design information technologies, and we furthered their exploration, in order to grasp the concepts that better served our scope. In addition, we suggested to transcend the intellectual boundaries of such disciplines to rely on the methods they offer upon the convenience of the research contexts. Finally, this whole introduction aimed to further the discussion on how to better address the challenges of designing technology for home care. We are aware about the vastness and complexity of this domain. Yet, we hope this discussion could open up the debate to other experts and professionals of the research fields we have taken into account, in order to bring together individuals with different backgrounds and, thus, to further the interdisciplinary discussion we wished by writing this chapter.

## Chapter 3

# Understanding How Software Can Support The Needs of Family Caregivers for Patients with Severe Conditions

*with Angela Di Fiore, Francesca Fiore, Marcos Baez, Fabio Casati, and Giampaolo Aremlin*

In this chapter<sup>1</sup>, we report our first study within two healthcare settings where the relation between care professionals and patients is mediated by the relatives of the patients. This first study posed the basis for our in-depth investigation and analysis (see Chapters 4, 5 and 6), and it led to the elicitation of the requirements for the new technology platform (see Chapter 7). The first setting is the network of the six nursing homes, object of this thesis. Whereas, the second setting is a pediatric palliative care network for children with incurable diseases. In both settings, patients - children or very old adults - experience an end-of-life condition, and the provision of care often involves a family caregiver as a reference point for the care professionals. The conditions of the patients together with the heavy careloads they require for the care professionals and the relatives turn these contexts into emotionally complex environments. In this chapter, we discuss how softwares can support the care work of relatives and care professionals by focusing: information, coordination and social challenges that arise by dealing with such contexts; the existing technology as it is appropriated today to cope with them; and what we, as software researchers, can do to develop the right solutions.

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<sup>1</sup>This chapter derives from [67].

### 3.1 Introduction

Pediatric Palliative Care (the end-of-life way of care for children with incurable diseases [137]) and care for elderly people in Nursing Homes are two areas of healthcare characterized by complex social and emotional challenges, in addition to medical ones [190, 205]. Although the patients and diseases are very different, the two scenarios present important similarities:

1. Patients are typically affected by a chronic condition. 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 for Italy, where we performed our studies). Cases of people leaving a NH 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 relation* 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.
3. Patients are restricted to live permanently in the same building until the end-of-life (this is obvious for NH but often the case also for PPC due to the illness).

An important difference is that in PPC the family also administers the care while in NH the patient is in charge of the NH staff and the family caregiver is mainly for support; although older adults are often in critical conditions and, therefore, the child take charge. 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 (also in NHs, where many admissions come from hospitals), and may provoke tensions within the family, marks the start of a progressive health deterioration<sup>2</sup>.

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 [203]. They are co-producers of care, and their collaboration and mutual trust are essential in the care of the patients [95]. However, several studies highlight gaps in communication between

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<sup>2</sup>On a personal note by the authors, this area is very emotionally draining for researchers as well [69]

formal and informal caregivers, revealing that often the family members have confusion and unanswered questions about the life expectancy of their relatives [172, 126].

Healthcare models such as *continuity of care* focus on integration between caregivers to provide a coherent, transparent and predictable care service [29]. 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 [198]. This model stresses the need to work on technologies to facilitate the dynamics among all caregivers for *information continuity* (the need of proper and coherent information), *management continuity* (the need for clear protocols) and *relational continuity* (the need of safe relations and human support) [101].

Most of the existing technology studies ([117, 139, 31, 165]) focus on solutions that foster coordination and information exchange issues (as we also stressed in Chapter 2). However, there is an emerging demand for technologies that help informal caregivers in both care and emotional concerns. Indeed, families caregivers are especially affected by above average burnout, depression, and stress [169]. The recognized lack in suitable technological solutions for supporting informal caregivers is a call for actions for software researchers [190].

## 3.2 Case Study

In this chapter we describe the results of analyses performed over the past two years to understand which role can software applications play in helping people cope with the challenges that these contexts present. We aim in particular at understanding *i)* which technologies are used today by the caregivers, why, and how effective they are, and *ii)* 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 (and we try to focus more on these aspects). We start by describing our analysis method and then report on our findings and recommendations.

### 3.2.1 Methods

To understand the needs we carried out several studies in two different contexts in northern Italy. We based our studies mainly on qualitative methodologies, although in the NH case we also developed a data warehouse to analyze populations and processes to the extent allowed by taking information from healthcare IT system, which are very detailed in NHs. In PPC, where patients are at home as long as possible, we studied the dynamics between formal and informal caregivers of a PPC network [31]. We interviewed 18 families, and performed observations in the houses of three families. Data have been collected from the

summer of 2015 to the spring of 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 of 2016, and all attended by at least three researchers, to collect different perspectives and reduce the chances of biases [188].

Specifically, we adopted the following research methods: *i*) we carried *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 places among all the subjects involved, by also creating moments of informal discussion on the emerging issues with our informants [129]; *ii*) we interviewed the caregivers - formal and informal - to focus on their emotional discomfort [127], and on the - technological - solutions they adopt to cope with their tasks and communication needs; *iii*) we involved several formal caregivers in some focus groups to have a deeper understanding of their perspective.

### 3.3 Findings

The analysis of the gathered data show that there are four main areas of problems where technology can be of help (See Table 3.1).

**1. Communication with the care professionals:** this emerged as a major issue in both PPC and NH. In PPC, formal and informal interactions (e.g., cute photos of 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 happen frequently and at any time) which results in the risk of losing important messages. In NH the interaction is by phone or face-to-face. The same problem of overload exists here, but in NH they complement much bigger problems which are: *i*) lack of trust in the abilities and willingness of NH staff to provide care, and *ii*) belief that the loved one may be mistreated, due to news of criminal behaviors in NH that is



sometimes reported in the national news. Furthermore, the family also feels a lack of clear and timely information.

The interesting, and for us unexpected aspect in NH is that the staff, 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 staff interacts differently with the families based on their classification of “personas”: with some family member they are more open and direct, with others there are more careful in the information they reveal, because of the perceived risk of over-reactions.

Finally, an important finding was that NHs already have an information system which they populate in great detail, every day for every resident. So most of the information needed to provide information and transparency is there, though not in the form that can be understood by relatives (and it may not always be wise to reveal them automatically).

**2. 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 in how to handle it. For example, in NH 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 foots the bills. We also observed frustration by 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 on the situation but in part also as a tool to make relatives feel a bit “guilty” because they are not visiting as much.

**3. Social support for the Family:** The transition to care for a relative in chronic 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 that 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 allover 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 NH the problems are more

“standardized” but the family caregivers are often relatively old themselves and do not use technology beyond, sometimes, email and chat.

**4. Education and Managing Expectations:** A huge source of problems and misunderstanding between family and professionals is the lack of knowledge and wrong assumptions on *i)* how the patient’s health will evolve and *ii)* what the healthcare system can do about it. Very often family believes the action of the professionals should be care or rehabilitation, but this is often impossible due to the medical conditions of the person or, in the NH case, to lack of staff for performing, for example, what would be a complex physical rehab program.

The problem of erroneous expectations is manifested by the fact that often the patient is not aware that their situation is permanent, even in the NH case. In this case, the technology used today is essentially web browsing and searching for information, but this is sometimes the cause of the problem which is indeed fostered by the use of diverse and inconsistent sources on the Internet. For example, in NH, because there are so many “types” of NH in different countries with very different population, one may find information on the internet that does not apply to the NH at hand, but mistakenly believe it does. The same is true for many aspects of care (such as prescriptions of medicine).

### **3.4 Opportunities for Technology Development and Adoption**

In this section, we summarize the first opportunities for a novel technology we elicited from our preliminary study for each problem category. We 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.

In family-staff interactions, by looking at the NH scenario it becomes apparent that a portal that allows relatives to view the status and activities of the relatives is both feasible and useful. It is feasible because NH staff already fills detailed information on the residents in an IT system, for internal reasons. This means that much of the information is already there. It is feasible also because the staff does want more transparency. And it is useful as relatives requested such information (and indeed they do so today, by phone).

Three key requirements emerged from the analysis:

- the staff segments the relatives into “personas” that react to news in different ways and with whom today they use different communication strategies, and so the software must support this
- 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 (e.g., the menu of the day, the wake up time, etc), some information requires explicit prior approval that it is “ok” to send, and other information needs to be edited/rewritten to avoid unnecessary concerns (The latter case also depends on the personas, and it may be different for new or “experienced” relatives);

- 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 the portal.

An additional observation that emerged is that NHs today do not really collect information about subjective wellbeing (of residents and relatives) while it would be important to do so given that quality of life is a key aspect of care.

In PPC, the opportunity lies more in taking the instant messaging paradigm and (semi-automatically) extracting messages related to coordination and administration of care. *Ad hoc* applications and a portal like in NH may also be proposed but it is unclear that they would be adopted, because the PPC care network is wide and *ad hoc* applications become effective if everybody uses them.

### 3.5 Conclusions

For interactions within the family, an opportunity that emerged is the obvious extension of the portal above, where the entire family can be given access to. But what appeared even more strongly is the need to involve the family members beyond the family caregiver using the instruments they already use. For example, 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 visit schedule to a calendar. In those PPC networks where a dedicated app is not be adopted for the reason stated above, a way to easily map WhatsApp exchanges into calendars would already be beneficial.

Opportunities for social support and education are instead more in terms of reusing existing technology but with better aggregation of content and people. For example, PPC would benefit for a single place that contains a set of forums, one for each rare disease, so that parents know where to go. Similarly for NH adults 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 same portal and app, though the challenges here are in terms of content organization.

Table 3.1 summarizes the common points for each scenario. In summary, there are several directions in which we as software researchers and engineers can contribute to make a difference in this difficult and stressful context, essentially by enabling easy access

to personalized information that provide transparency into care processes and information relevant to the physical and care conditions of our loved one.

These preliminary results opened up for further analysis and developments, as reported in Chapters 4 and 5. These findings pose the basis for the description of the final requirements reported in Chapter 7.

Table 3.1: Summary of problems, current practices and opportunities for the technology

Contextual problems	Opportunities for technology development
<b>Communications with the care professionals</b>	
<ul style="list-style-type: none"> <li>• Lack of transparency and traceability</li> <li>• Lack of clear and (timely) available information</li> <li>• No record of interactions</li> <li>• Overload of the communication channels.</li> <li>• Formal and informal exchanges going through the same channel.</li> <li>• Lack of mutual trust.</li> </ul> <p><b>Tech practices and limitations.</b></p> <ul style="list-style-type: none"> <li>• Care activities are scheduled and registered in EHR systems. Information collected is mostly focused on health-related data.</li> <li>• Communications are done face to face, via phone, WhatsApp or email (formal / informal with no trace and manually).</li> <li>• Facebook pages are used for events and general announcements.</li> </ul>	<ul style="list-style-type: none"> <li>• Integration of informal channels with EHR, to keep track of interactions and activities while making use of existing familiar channels.</li> <li>• (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.</li> <li>• Expand data collection to aspects of social and psychological well-being, and so accounting for this recurrent information need.</li> <li>• Personalization of information delivery to key indicators of the patient and preference of the final receiver.</li> <li>• Translation of the information to a format that is understandable in terms of its meaning, implications and course of action.</li> <li>• Structured interactions to account for type, priority, sensitivity of information and so facilitate retrieval and processing.</li> </ul>
<b>Communications within the family</b>	
<ul style="list-style-type: none"> <li>• Internal coordination issues, and different workload</li> <li>• Information not uniformly spread</li> </ul> <p><b>Tech practices and limitations.</b></p> <ul style="list-style-type: none"> <li>• Face to face coordination, no trace of performed activities and effort.</li> <li>• Sharing via WhatsApp and physical document by one person</li> </ul>	<ul style="list-style-type: none"> <li>• Traceability and visibility of family efforts.</li> <li>• Coordination tools that account for the care schedule, and activities of individuals and family as a whole.</li> <li>• Sharing tools that facilitate information flow among family members while still in control of the main responsible.</li> </ul>
<b>Social support for the family</b>	
<ul style="list-style-type: none"> <li>• Social isolation</li> <li>• Emotional distress</li> <li>• Need of feeling understood</li> </ul> <p><b>Tech practices and limitations.</b></p> <ul style="list-style-type: none"> <li>• Social support groups enabled via Whatsapp and Facebook private groups but problems finding relevant groups /peers.</li> <li>• Psychological consultations, though not available in all institutions.</li> </ul>	<ul style="list-style-type: none"> <li>• Widening the support network, facilitating the discoverability of relevant support groups.</li> <li>• Organizing online peer support networks with existing technology, (possibly) moderated by an expert.</li> <li>• (Self-)Coaching systems implementing existing successful programs to improve the psychological, emotional and social well-being.</li> <li>• Monitoring of the psychological well-being of the relatives</li> </ul>
<b>Education</b>	
<ul style="list-style-type: none"> <li>• Confusion in what to do and expect.</li> <li>• Lack of medical/care knowledge and medical language.</li> </ul> <p><b>Tech practices and limitations.</b></p> <ul style="list-style-type: none"> <li>• “Doctor google” and facebook groups leading to inconsistent info.</li> <li>• Exchanges with other caregivers, face-to-face though not optimal.</li> </ul>	<ul style="list-style-type: none"> <li>• Peer-to-peer networks that allow sharing of practices and experiences, (possibly) supported by the moderation of medical experts.</li> <li>• Facilitating access to portals with certified information.</li> <li>• Expert support systems to help family in care activities.</li> </ul>



## Chapter 4

# Design Considerations to Support Nursing Homes' Communities

*with Angela Di Fiore, Leysan Nurgalieva, Maurizio Marchese, and Fabio Casati*

In this chapter<sup>1</sup> we discuss the results of the study conducted within the network of six nursing homes from a new perspective. Differently from the preceding chapter, here we focus on the burden, for care professionals and relatives of the patients, of caring for institutionalized older adults. In our analysis, by focusing on the practices of caregiving, on a more sociological perspective, we deepen our understanding of the relational issues between professional and family caregivers. Thus, we comprehended the social context from which we derived some of the requirements upon which the new technology platform should have been built on. Our findings shed new light on the opportunities of using ICT solutions to improve relations and information sharing among caregivers.

### 4.1 Introduction

Nursing Homes (NHs) are long-terms care institutions that provide a 24-hour care to non-autonomous elderly “guests” with health conditions that vary from mild to severe impairments [105]. 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 professionals caregivers.

In this chapter we focus on the community dynamics among staff members and the guests' families of NHs. In particular, we investigate knowledge sharing among profes-

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<sup>1</sup>This chapter derives from [68].

sionals and between professionals and family members. In fact, knowledge sharing is a critical concept within healthcare communities [39]. 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 family 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 [101].

## **4.2 A Glance on Nursing Homes**

A number of studies [64, 135, 11, 210, 105] focused on work and physiological issues of NHs, emphasizing the impact of work shifts on job efficiency and satisfaction of the staff, health implications for the guest's family members and the staff of the NH. In fact, besides the guests, NHs encompass two main groups of actors: care professional (formal caregivers) and the family caregiver (informal caregivers) [203]. The former refers to the medical staff (social-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 [203], 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.

### **4.2.1 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 [105, 11, 210]. These hardships increase stress and, hence, higher chance of burnout, health problems, work dissatisfaction, and general decrease of the quality of care [105]. 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 [133]. 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" [57, p. 228]. According to Hertzberg et al. [109], 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" [109, 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 working routine [109]. The study suggests that, occasionally, professionals do not feel recognized, by peers or managers, in their effort with the relatives.

Matziou et al. [134] claim that an effective communication among professional caregivers is crucial for quality of care. Several studies [209, 134] 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 [78, 131] 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 into the care. Family caregivers often face problems that require social and physiological support [34]. Indeed, “it has been stated that communication problems are related to a lack of a shared framework and approach to communication” [133, p. 527]. Hence, improving inter-professional collaboration may boost knowledge translation and evidence-based care in health care workplaces [209].

Institutionalization of older adults becomes a source of burden for family caregivers. Sense of guilt and lack of trust towards professional caregivers interfere on the personal life of the family caregivers and, often, this distress is reflected on how the informal caregivers relate to formal caregivers [135]. Studies [11, 135] show that placing older adults in NHs 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 aging, but also play the role of a medium between guests and their families in a vulnerable situation [210]. This evokes ethical difficulties that create frustration in the working life of the personnel and negatively affects their quality of life [64].

#### **4.2.2 Opportunities for ICT.**

Recent studies [104, 114, 170] provide examples on 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 NH professionals. The literature provides three main reasons to 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 [170]. Nonetheless, Fatehi and Wootton [84] state that there is a growth of ICT usage in medicine and

caregiving. Recent studies [104] 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” [p. 54]. Possibilities of time and cost saving are seen as a motivation to use ICT tools by professional caregivers [104]. Therefore, addressing these issues may result in a better management of work practices to the benefit of the relational continuity [101]. To our best knowledge, these issues have not been fully addressed yet.

### 4.3 Case study

The study presented in this chapter was carried out within the six NHs object of this thesis. 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 NHs. The specific investigation that we discuss in this chapter took place from the spring to winter of 2016.

#### 4.3.1 Methods

During our investigation we conducted 27 semi-structured interviews [176] with the family caregivers. The interviews were based on a interview guideline we used to explore the following topics: *i)* why they drew on the NH; *ii)* frequency of visits; *iii)* their relation with the staff; *iv)* their relation with other family caregivers; *v)* the management of medical information; *vi)* ICT literacy; *vii)* what would they change of the NH. The guideline was presented as a flexible list of topics we used to let family members free to 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 included if willing to participate and able to provide the informative consent. We paid peculiar attention towards the people involved, avoiding any questions or situations that could cause distress to the participants, in order to guaranty an efficient and respectful data collection. Moreover, three audio-recorded Focus Group Discussions (FGD) [176] 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 FDG 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 hour and a half. The data from the interviews and focus groups has been enriched with *in situ* visits. Due to logistical limitations, we conducted one-day visit for 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.

### 4.3.2 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 on 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. Yet, 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*, *understaffed*, *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. Whereas, a minority of the guests were receiving palliative treatments because 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 [96]. Crisis tasks occur randomly and are linked to the delicate health conditions of the guests, such as deceases, 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 to dedicate 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 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: care professional).

**Understaffed.** A common problem that affects the overall coordination and quality of care in NHs are understaffed professionals. 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. Whereas, those who are not autonomous 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 this things, not me.”* (Interview: daughter of a resident).

*“My mother walked, (...) she wanted to go to the toilet in autonomy, 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 social-health operators (SHOs) work on 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 in wards that generally encompass guests with similar conditions, and the professionals are grouped in work units that are assigned to each floors. The units are usually formed by 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 structure have an important impact on how communication practices are carried among professional caregivers, and between family and professional caregivers. Specifically, SHOs can communicate every type of information but 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 that this information arrives to 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 put in between the work tasks.

#### 4.4 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 relations. 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 with limited resources. Conversely, the absence of a reference point among staff members - due to frequent work shifts - often leads them to frustration.

We can claim that the majority of problems emerged from our study can be linked to the division of labor in NHs. Staff reductions and overwhelming workloads appear to

result in fragmented care. Staff members constantly rotate, working across planned and unplanned tasks, which 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. However, in terms of social requirements, it emerges the need 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 on the guests' situation.

We thus provide some issues that we believe technology designer should consider in supporting the relations between staff and relatives in NH contexts: *i)* professional caregivers should be supported in sharing both medical and social knowledge on all patients among colleagues; *ii)* professional caregivers should be constantly informed respectively on the family network and the care team of the guest; *iii)* 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; *iv)* the technology should provide an always up-to-date calendar to ease appointments between family caregivers and care professional; *v)* the technology should provide a “space” of informal interaction among all caregivers to nourish informal interaction, and exchange of thoughts and information about the guests.

## 4.5 Conclusions

Our study is a call for action to design technologies for the realm of NHs, by providing a better micro-sociological understanding of the limits of the current care practices, knowledge distribution, and information communication. Designers should focus on supporting communities in the creation of technologies to address collective sense-making and to support relations. Whereas, the design process itself should enhance community building and support a mutual understanding among actors, revealing also the unfairness of the work dynamics that lie at the foundation of collective actions.

This chapter, together with the following one, opens up our analysis to a greater sociological understanding, which leads us - in Chapter 7 - to better frame and comprehend the requirements (also “social”) defined for the new technology platform.

## Chapter 5

# Taking Care of Sensitive Milieus: a Story about Dialogical Interviews

*with Angela Di Fiore and Fabio Casati*

In this chapter<sup>1</sup> we discuss our experience in conducting the twenty-seven dialogical interviews with the family caregivers of the residents of the six nursing homes. This experience led us to formulate a series of theoretical reflections that helped our design process, and enriched the comprehension of the social issues - from the side of the family caregivers - upon which the requirements for the new technology platform had to be formulated. In particular, we noticed that, during the interviews, by focusing on the human relations we were establishing with the interviewees, we were creating the interaction space that should have been integrated into the new technology platform.

### 5.1 Introduction

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

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<sup>1</sup>This chapter derives from [41].

## 5.2 Case Study

The work presented in this chapter represents only a part of the broader research presented in this thesis (for more details see the Chapters 3, 4 and 7), which aims provide a picture of the relational issues that occur between the care professionals and the relatives of the residents of the six NHs, in order to deliver the requirements and, subsequently, the prototype for a new technology platform to support the *continuity of care* between the professionals and family caregivers.

Our initial idea was to comprehend how technologies could tear down the boundaries that often hinder the communication between family and professional caregivers. As we previously mentioned in Chapter 4, NHs, as healthcare contexts, were conceived as based on a mere exchange of medical information [183] and, therefore, the quality of the communication was considered correlated to the ability to deliver reliable and rapid medical information to relatives. Hence, we assumed that a better communication would have been allowed by an improved way of transmitting medical information to the relatives; this would have helped to improve the quality of the human relations between professionals and families. In addition, it was expected that a clearer understanding of the medical situation of a resident would have decreased the level of emotional distress that the relatives often experience [135]. Conversely, a system that allows users to automatically deliver real-time medical information, was expected to help care professionals to better concentrate on their tasks and decrease their level of stress, while informing relatives on what is necessary to know [105].

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 [127]. Our interviews aimed to explore the reality and the daily routine within the NHs, and also to comprehend the logistical and communication problems experienced by professional caregivers and family caregivers. The interviews also served to understand to which extents, if really needed, a technology could solve the relational issues within the NHs.

Our preliminary study led us to comprehend the nature of the issues that affect the relations between the care professionals and the relatives. Differently from what initially



expected, 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, 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. Thus, we deepened the understanding of a social requirement that was actually implicit in the way we were conducting the interviews.

### **5.3 Experiencing Dialogical Interviews in Sensitive Contexts**

Working within delicate contexts like NHs, we encountered several difficulties that challenged our capabilities as researchers, as well as human beings. On the one hand, we faced a strong emotional attachment to many interlocutors and to their stories. On the other hand, we often questioned the possibility to gather concrete data that could inform our research and support our design process.

As mentioned above, we conducted 27 dialogical interviews as part of an exploratory study to evaluate the feasibility of the design process we aimed to accomplish. The interviews were built on a guideline that focused on investigating the communication and relational issues that the family caregivers experienced in relating with the staff members. In particular - as explained in the preceding chapter - the guideline considered how the family members approached and dealt with the transition from being the primary caregivers of their loved ones, to visit them in the NH, sharing the care activities with the staff members.

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

From the interviews, we understood that the detachment from the loved-ones creates a deep distress [135, 67, 68] in the family caregivers, hindering also the possibilities to establish positive relations with the staff members.

During our research experience, we somehow let the context drag us into the overwhelming nature of feelings and sentiments that the family caregivers experience. Although the interview guideline focused on communication issues, most of the interviewees displayed a need to talk about the experience of detachment from their loved ones, talking with us about their sense of guilt and burden. Despite our research purposes, we experimented the willingness of the interviewees to open up to us, due to their need of personal space where to be listened. The interviewees approached the interview almost

as a way to open themselves on matters they could not discuss elsewhere. Because of this, we experienced role issues, struggling to be researchers and empathetic humans at the same time. Sometimes we even felt inappropriate to extrapolate cold data from their stories. As researchers, we had to approach the “talk” as a way to gain new information, but as human beings we were reconsidering our “role”. Hence, we needed to create a safe place within which we could safely interact; the relation between us and the interviewees was approached as a human-to-human dialogue, rather than a hierarchical interaction researcher-interviewee. The interviewees who participated welcomed us within their private lives and shared their experiences, their feelings, and fears with us; we received the privilege to be considered worthy and trustworthy listeners. Conversely, we had the responsibility to comprehend, accept and keep these information as our own, and we could not avoid to be shocked by the often-difficult experiences interviewees shared with us.

We took the side [20] of the interviewees, having a dialogue with them, without passively receiving their information. We understood that to better comprehend what they were trying to share, we had to put ourselves in their position with a reciprocal sharing process. We delivered something back that could correspond, and shared our own care experiences in a way that they could perceive our being human before researchers.

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

## **5.4 Taking Care of Sensitive Milieus**

With this chapter we attempted to restructure, as researchers, what we experienced and comprehend as human beings. Previous works on using qualitative methods in sensitive contexts already cover a wide range of topics, such as managing emotions [160], and detachment from the field [143]. Yet, we tried to convey the necessity to reconsider healthcare contexts as rich of information that cannot be treated as source of cold data. Contrarily to what the rationalizing trends are telling us [195], as researchers and human being we have to keep in our minds how doing research, especially in sensitive healthcare

contexts, is all about taking care of others' stories. In this scenario, in accordance with Light & Akama [130], we understood our engagement in sensitive milieus as a form of care work. We distinguished the concept of care from a paternalistic sense of caring, conceiving it as a way to entangling our experiences with others, or using Puig de la Bellacasa's words [61], as a way to do sustainable actions by engaging "with the inescapable troubles of interdependent existences" [p. 199].

Researchers involved into healthcare milieus, are likely to deal with sensitive research settings. Since sensitive milieus are emotionally powerful, they can bring aftermaths that shake both the participants and the researchers themselves [118]. Sensitive contexts can be hard to approach, especially in absence of previous experiences in such contexts. Indeed, Dickson-Swift et al. [70] highlight the need of care professionals to deal themselves with these sensitive contexts. The authors explain that, often, care professionals develop their own strategy to cope with the emotional distress that sensitive contexts may bring; care professionals protect themselves by becoming insensitive to certain situations, perceiving them as bizarrely ordinary. On the opposite, as outsider in these contexts, we were emotionally thrown into them, absorbing - sometimes too much - the distress and discomfort of the family caregivers.

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

This approach allowed us to take care of this sensitive context by fulfilling the need of being listened of the interviewees, and by using their narrations to adjust the rationale of our project. In particular, throughout the interviews, we had the possibility to comprehend the hidden needs of the family caregivers to establish better relations and more sensitive communications with the professional caregivers of the NHs. Specifically, the main social requirement that the new technology platform had to encompass was hidden within the framework of the interviews, and by the idea that the information within the

dialogues would have given us the requirements. Yet, in reality, the interviews themselves and the experiences that the interviewees had with us were the “social requirement”: a place to talk, interact, and relate on a more “human” level.

## 5.5 Conclusions

Our reflections want to be memorabilia for both the novices that are facing such contexts, for those who are working there for some time and that need to remember the privilege of entering such unique others’ lives, and also for us, the authors, grasping thoughts on our present experience and leaving a memento for our future ones. Indeed, “we are engaged in important, difficult research, but we must keep the purpose of our work in mind. What we do is significant and makes a difference for those who follow” [144, p. 1005].

Our experience in using dialogical interviews, shed a light on what was needed within the NHs context. The interviews made us comprehend that family caregivers lack a “listening space” rather than a better strategy to be kept aware on the health situation of their loved ones. What we learned is that to take care of sensitive milieus it is fundamental to create open dialogical spaces, providing a place [52] where the participants can feel listened and accepted, and where we, as design researcher, can take care of their stories by shaping the design processing that will affect them. In our case study, this opened up to greater potentials for the new design. Indeed, we understood that the new technology should support the family caregivers in having better communication with the staff members through a dialogical experience, as the one we experienced with them. This led us to better frame and refine the requirements presented in Chapter 7.

## Chapter 6

# Data Work as A Golem: Reflections on the End-of-Life Contexts

*with Angela Di Fiore, Vincenzo D'Andra and Maurizio Marchese*

In this chapter<sup>1</sup> we analyze and compare the data work that family and professional caregivers carry out within the network of six nursing homes (object of our study) and the pediatric palliative care network we previously examined in Chapter 3. Our findings emphasize the importance that data work has in determining the management of the care pathway of the patients. Hence, we explain how data work should be investigated and interpreted within healthcare contexts, in order to comprehend to which extents technologies should support the exchange of medical information between care professionals and relatives.

### 6.1 Introduction

The concept of data work does not have clear boundaries because is still in a defining stage. In this work, we observe arising issues related to data work within the two end-of-life healthcare contexts object of this thesis; previously examined in Chapter 3. In particular, we explore the contrasting opinions of caregivers on how data work should be carried out to enhance collaboration. In both settings, we explore data work by analyzing how the practices related to collecting and sharing data are perceived, using as a lens the logic chain that connects data, information and knowledge.

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<sup>1</sup>This chapter derives from [42]

## 6.2 Related Work

Data and information flow through all the levels of an organization and allow: support, coordination and sense making by influencing how actors relate and articulate their practices.

In particular, within the healthcare sector there are heterogeneous actors who articulate their work according to shared understandings and distributed knowledge [24], routing their *care work* on collaboration and coordination [37]. Many studies about care work are built on the concept of *trajectory of work*, which refers “to the total organization of work done over that course [of patients’ conditions], plus the impact on those involved with that work and its organization” [185, (p. 8)]. Trajectory of work is also related to the *articulation work* among caregivers [184], which is the “work that gets things back ‘on track’ in the face of the unexpected, and modifies action to accommodate unanticipated contingencies.” [181, (p. 10)]. Trajectory of work and articulation of work are intertwined. 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 invisible coordination efforts in managing unpredictable care pathways. These concepts focus on the importance of coordination and support among caregivers because within healthcare contexts heterogeneous care practices mutually intersect [185]. They highlight the importance of having aligned, coordinated, and aware caregivers, to deliver quality care [58].

In this chapter, we explore the perception of data work within two end-of life context where family and professional caregivers collaborate to deliver care. Indeed, in the study about Pediatric Palliative Care (PPC), we explore the role of data work in the articulation of care of incurable children at home. Whereas, in the study on the Nursing Homes (NHs) (see previous Chapters: 3, 4 and 5), we investigate the data work and relational issues between care professionals and relatives of residents affected by severe impairments. Within both settings, we explore data work by analyzing how the practices related to collecting and sharing data are perceived, using as a lens the logic chain that connects data, information and knowledge.

Managerial studies provided a clarification on how data, information and knowledge are rooted within organizations and we believe that this view can enrich our analysis on data work. In particular, Ackoff [6] distinguishes between *data*, *information*, *knowledge*, and *wisdom*, describing these concepts as connected through a logic chain [8]. Ackoff [6] 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 [79] 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* [6]. 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[23].

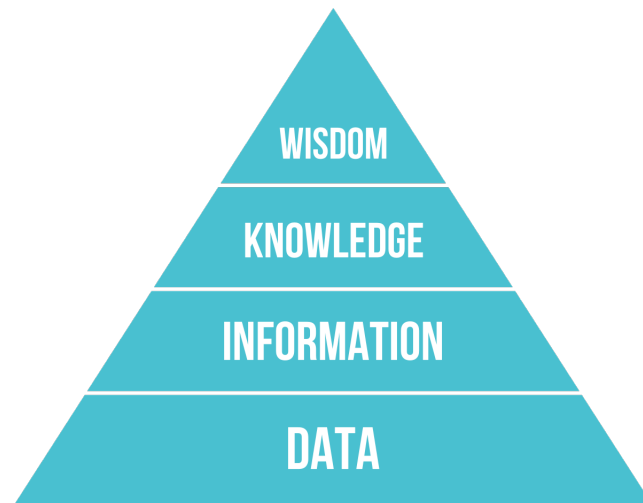


Figure 6.1: The DIKW hierarchy

In our opinion, these principles can enrich the understanding of healthcare contexts as well. The chain of sense-making that links data, information, knowledge, and wisdom lies also on the intersections among the situated practices of caregivers. The shift from data, up to knowledge, passes through the ability of caregivers to articulate their work according to its trajectory. In other words, caregivers share and collect all information on records that, regardless being digital or on-paper, allow information sharing. Yet, the knowledge that derives from this is always situated and, hence, comprehensible only through the understanding of the situated practices.

Over the last years, the literature 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 [24, 207, 156]. Studies (i.e. [156]) discuss *the dual role of EMR*, stressing its coordinating and accounting roles. On the one hand, EMRs are described as artifacts that embodied policies, making care contexts compliant to laws. On the other hand, they are understood as information tools that support care work coordination. In this sense, data work entails both transparency and articulation of care work, which support coordination as well as the creation of accounts of work process, revealing the erratic nature of this phenomenon.

The literature suggests that according to various policies and governmental institu-

tions the EMR would increase the efficiency of healthcare contexts by making them more integrated, cheaper, safer, coordinated and documented [156, 99]. 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 [50, 156]. Indeed, EMRs are increasingly used to standardize information on patients and, subsequently, practices and knowledge in healthcare settings [24, 50, 156]. However, other authors depict a different scenario, describing this view as a *technological utopia* [99]. Care professionals may misinterpret what this standardization entails, since their sense-making depends on the intersection between their situated practices [155], rather than on the accountability provided by the EMR [207]. In this sense, Pine and Mazmanian [156] observed that the EMR may create negative organizational outcomes that interfere with the coordination, and it may also entail inaccurate accounts of work. Similarly, Greenhalgh et al. [99] stress a series of paradoxes. The EMR is often described as a container of information that can increase the effectiveness of the care work, sharing as much information as its distribution is larger. However, the authors emphasize that EMR is an organizer rather than a container of information, which often cannot be integrated with the care work, because the constant need of human work to re-contextualize the knowledge *in-situ*.

These paradoxes are also evident in a series of studies [50, 86, 24, 99, 156, 13]. Christensen and Ellingsen [50] 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 [50, (p. 11)].

The same issues are investigated by Osterlund [154], noting that the distributed knowledge does not lie on how documents spread the knowledge across boundaries, rather on how actors share their knowledge within their shared practices.

Likewise, Fitzpartick [86] highlights the constant manipulation of 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 [13] analyzed the potential of coordinative artifacts 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.

In the light of the various contributions in the state of the art that attempt to frame the concept of data work, we can argue that this concept is still unresolved and that its boundaries are blurred. In this context, 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. However, the knowledge that derives from this data is always indexical and, hence, comprehensible only through the sense-making deriving from situated practices. Giddens [94] 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, collective understanding frames the organizational knowledge, determining articulation of work and collaborative dynamics.

In the following sections, we report the contrasting cases of PPC and NHs in experiencing collective knowledge from data work. In the PPC study emerged that the data work was perceived as a paramount collaborative activity that enabled the overall care work. Whereas, within the NHs, care professionals rose many resistances to data work, being reluctant to share too much information with the family caregivers. In the last section, we compare the two studies, addressing theoretical reflections.

### 6.3 Case Studies

Our work was built on the two case studies firstly presented in Chapter 3. Both contexts are characterized by the centrality of the relationships between formal and informal caregivers, and by a low technological adoption. End-of-life care services aim to take care of patients affected by severe diseases who are living the last months or years of their lives [146]. This approach supports patients on a medical, pain-management, emotional, social and psychological perspective; it also supports the care environments by backing up the families [191].

Given the severe conditions of the patients, a part of the care work in end-of-life environments is dedicated to *sentimental work* [185] and relational work. Sentimental work refers to the effort of care professionals of creating a trustful and good relationship with the patients, knowing their human history, respecting their attitude, and disclosing information they need to be aware of. Whereas, relational work includes also collaborating and making kinship with the relatives of the patients in order to deliver quality care.

We explored the end-of-life contexts by conducting an in-depth qualitative investigation (previously mentioned in Chapters 3 and 4). Therefore, we relied on semi-structured interviews, focus groups, and observations (see Table 6.1) [176, 157, 97, 124].

Table 6.1: Summary of the Methods

<b>Paediatric Palliative Care</b>		
<b>Method</b>	<b>Sample/Duration</b>	<b>Object/Contexts</b>
<i>Interviews</i>	18 interviews with head physicians, medical doctors, nurses, psychologists, social workers	We investigated how they 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
<i>Observations</i>	Several short-term sessions of observations for a total of 34 days of observation	We focused on the network of actors involved into the care process, the variability of the care work, the daily routine of the caregivers, the communication practices, the factors that either facilitate or hinder the home care work.
<b>Nursing Homes</b>		
<b>Method</b>	<b>Sample/Duration</b>	<b>Object/Contexts</b>
<i>Interviews</i>	27 interviews with the relatives of the residents of the six nursing homes	We investigated why they chose to rely on the NH, how frequently they visit their loved ones, their relation with the relatives of other residents and with the staff members, their use of technology, what they wish to change within the NH
<i>Focus Groups</i>	3 focus groups with the care professionals working in the nursing homes	We investigated their daily routine, 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 categorise the relatives

## 6.4 Findings

**Nursing Homes.** The *Collegamenti Project* - upon which the research presented in this thesis was built - 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 residents.

The NHs we investigated provide residential care, and work on creating a cozy environment for older adults with severe cognitive and physical impairments. The staff members are social-health operators, nurses and doctors, 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.

Over the last years, the NHs adopted and implemented an EMR system, 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 data recording work increased their workload with no perceived advantages comparing to the old paper records. In the NHs, the family members of the residents are 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”*.

The family members are involved in the care pathway for the residents, they usually attend 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”* [a nurse]. However, some staff members stated, *“if we want to tackle the situation the right way receiving the family caregivers may interfere”*. 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 family caregivers. 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, and because, 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 the information necessary to understand the condition of their loved ones, but are not given enough information to develop their own knowledge. During a focus group, we asked professionals what they thought of a greater involvement of the families into the care work, and a nurse provocatively answered that relatives would excessively control the staff by holding them to ransom “*This would be like ISIS!*”.

It appears that care professionals choose to which extents family caregivers can be involved and informed, as a form of resilience 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 pathway. In this way, they displayed a strong resistance to the development of the new technological platform. 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 re-shape our intervention within the NHs.

**Pediatric Palliative Care.** This study was based on a research project that aims to explore the potentials of collaborative technologies in home care settings. Differently from the preceding case, the project had a bottom-up rationale. At the beginning, we, as design researchers, were contacted by a member of a home care network that provides Pediatric Palliative services. She 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 codesign a digital platform tailored to their needs and context. This revealed their awareness of the issues that were affecting their communication practices, and of the importance of sharing data and information between family and professional caregivers.

In our study, we relied on *Participatory Design* approach to study their context and their care practices. Thus, we elicited the requirements for a collaborative technology

platform.

The Pediatric Palliative Care 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 are usually 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 care specialists. The specialists visit the patients occasionally and provide 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 assisted by PPC team. Normally, the family members take care of the little patients autonomously at home, since they are usually visited by the 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, thus to monitor the frail conditions of the little patients, and in order to take care of their care pathway from a human and medical perspective. For instance, a doctor said: *“We work with the families, we support them and they support us”*.

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 the consequent low quality of the information and data flows among caregiver may interfere with the care work. Moreover, the severe conditions of the little patients are often unstable and may lead to unpredictable exacerbation or unexpected events in handling medical devices and medications.

The tautological statement that in home care the care is provided at home stresses how unusual the care setting is. The home is an informal place that belongs to those who live in it, differently from formalized medical environments, such as hospitals. Home care requires a continuous negotiation of boundaries between family and professional caregivers who jointly take care of the patients. Home care is a care context where care professionals are engaged in both relational and medical practices spread through several informal care settings. *“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”*.

Our findings show that the caregivers used data and information sharing to make

sense of their collective care practices, seeking for meaningfulness, and to cope with the uncertainty of the care conditions of the patients. Specifically, they adopted commercial mobile instant messaging applications to share medical data, communicate updates, ask advice, and provide human support to each other.

In this context, to properly take care of the patients, caregivers need to be aligned on the information and data they have and share. Indeed, information and data flows laid the foundations for the collaborative practices of the actors involved in the PPC networks, allowing remote articulation of work. The data work supports the articulation of crisis tasks and routine care tasks among places and care providers, becoming a factor that enables the management of the unpredictable health conditions of the little patients. Hence, information and data flow within PPC network is paramount.

This multi-sited setting is 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 all caregivers perceive data work fundamental to provide an efficient care, embedding collective sense-making into the care practices.

## **6.5 Reflections on Data Work**

The concept of data work is still in the defining stage, and this can be perceived also through the state of the art that is a mosaic of contributions. Most of the literature refers to studies on EMRs, revealing a polarization between its coordinating and accounting role [156]. Yet, efforts in reconciling this view are emerging [155]. Other empirical studies [86, 13, 50] emphasis issues related to standardization of medical data, showing how data work in healthcare context concerns the articulation of situated practices according to the intrinsic contingencies of the care work.

In the light of the literature, we focused on 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. Thus, the work on sharing data and information have the dual role of distributing things that are meaningful, but also the role of aligning meanings, allowing collective knowledge.

In this chapter, we discussed how data work is perceived and integrated into the care routines that intersect the efforts of family and professional caregivers.

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 data work 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

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 fear the possibility for the data to become information and knowledge that relatives could use to interfere with the care relationship. The staff members developed aversion towards a joint data work with the relatives, in order to protect their autonomy and care work against interference. This study displayed resistances to data work in order to maintain an information asymmetry based on *nonknowledge* [25].

Differently from the preceding case, 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 considers 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 data work.

## 6.6 Conclusions

Within care settings the efforts toward formalization often come into conflict with the situatedness of the contexts themselves. There, the quality of the relationships among caregivers is paramount in allowing an alignment of meanings among data, information, and knowledge. The two studies yielded opposite results on data work dynamics, highlighting the relevance of relational work. These cases show a link between data work and relational work, since the data to support articulation of work need to become information and knowledge by acquiring sense and aligning collective meaning. In this sense, as Giddens [94] mentions, relationships are needed in care work to contextualize and make sense of data and practices of data work itself.

Data work is a social, organizational and technological phenomenon that need to be handled in a situated way. Speaking with the words of Collins and Pinch [54, (p. I)], in our two studies data work *seems to be either all good or all bad. For some, data work increased the amount of work without advantages, and the information that can emerge from it can be dangerous. For some, data work is an integral part of quality care, supporting collective knowledge and coordination. Both of these ideas are wrong and dangerous. The personality of [data work] is neither that of a chivalrous knight nor that of a pitiless juggernaut. Data work 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 [data work] is not to be blamed for its mistakes; they are our mistakes.* [54, (p. I)]



## Chapter 7

# What is Appropriation Telling Us?

*With Angela Di Fiore, Vincenzo D’Andrea, Maurizio Marchese and Fabio Casati*

The research presented in this thesis reaches its cornerstone in this chapter <sup>1</sup>. Here, we discuss the practical benefits of using *appropriation*: a “theoretical instrument” that helped us to investigate the use of current technologies of family and professional caregivers of the six nursing homes object of this thesis. The use of appropriation empathized the actual problems that the caregivers experienced, and it led us to formulate the requirements upon which a first prototype of the platform will be developed (for more details see Chapter 8).

### 7.1 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 [146, 191]). 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 [184]. 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. [147]). 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 [48]. In addition, the research struggles to approach [70, 118,

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<sup>1</sup>This chapter derives from [44]

144, 160] 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 category of actors, providing only partial views of healthcare contexts [150].

The objective of this chapter is to study technology appropriation and evaluate 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, thus we also discuss how appropriation informed the design process for our new technology platform.

The goal of this chapter has been shaped by the first case study we present here, 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 the two studies previously presented in the Chapters 3 and 6. The first is based on the 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 PPC network, we decided to investigate and evaluate the potentials of studying appropriation also within the network of six Nursing Homes (NHs).

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.

PPC and NHs 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 patients.

Exploring appropriation helped us to understand how people use technology in their own ways in order to fulfill their needs [71]. For this reason, in this chapter we observe 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 requirements that a designer should embed into the 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.

The chapter starts in Section 7.2 with the state of the art: it first addresses studies on collaborative care technologies (7.2.1); then, it frames the concept of appropriation (7.2.2); afterwards, it delivers an overview of the results presented by other studies on technology appropriation (7.2.3). In Section 7.3, we introduce our studies and the methodologies we used. In Section 7.4, 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 7.5 provide design and empirical considerations on our studies, by also providing a series of requirements and some hints on how we investigate and conceive appropriation. We conclude in Section 7.6 by summarizing our results and explaining the future steps of our work.

## 7.2 Framing Appropriation in the CSCW and care contexts

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

We present (section 7.2.1) the current literature on empirical studies on collaborative technologies for healthcare contexts to frame the specificity of care organizations and care technologies. Then (section 7.2.2), we discuss the state of the art on appropriation of technologies, framing this concept from a broad theoretical point of view. Afterwards (section 7.2.3), 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.

### 7.2.1 Framing Care Technologies

Some healthcare contexts, like NHs and PCC, are based on the *carework* of both family caregivers and professional caregivers [36, 193, 68].

As we previously explained in the preceding chapters, 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" [184, p. 8]. This concept is strictly related to the *articulation work* [184], 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" [181, 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 articulating their work [184].

Traditionally, part of the CSCW community studies the collaboration of caregivers [36, 173]. In the context of this thesis, Strauss' 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 [184, 181]. Indeed, the collaborative nature of the care work requires for responsibility and information to be shared in defined flows [47, 36].

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 [116], and there is a novel need to focus on collectives and their forms of collaboration to overcome the issues in care technologies [150]. 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 [13].

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 [137]. 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 [48, 55]. 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 [31]. Indeed, studies highlight the effectiveness of collaborative technologies that focus on caregivers' relationships [112], acknowledging the paramount role of family caregivers [13, 173, 193], the potential in decreasing their level of stress, while increasing their quality of life and supporting the management of the care tasks [60].

In this sense, the contribution of Nunes and Fitzpatrick [150] 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.

### 7.2.2 The Concept of Appropriation

A broadly used definition of appropriation can be found in Dourish [74]. 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” [22, 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 [167], 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 [89] 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* [161], which refers to the intersection between the possible uses of an artifact and the aesthetic capabilities of the individuals [93]. Indeed, Flint and Turner [88] 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 [158]. It can be described as a collaborative effort that individuals undertake collectively to make sense of a technology within their environment. Ackerman et al. [5] 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 [163]. Similarly, it can be conceived as a process of collective discovery [16] that is the result of shared practices [75]. Thus, the communities of practice are significant in the appropriation process [80], since they enhance the *alignment*

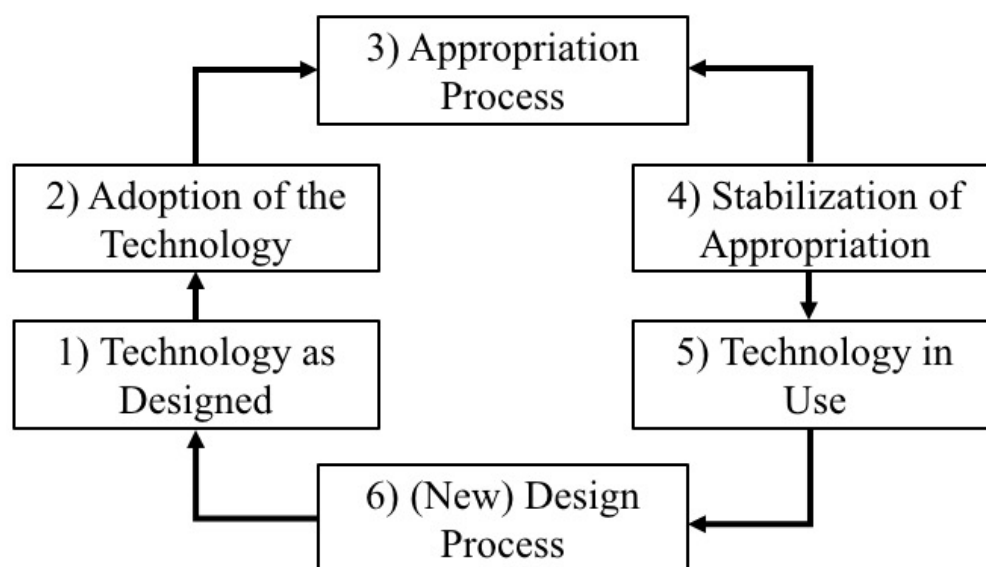


Figure 7.1: The Technology Appropriation Cycle

of *agency* around the technology. Indeed, studies on appropriation [74, 88, 16] have a strong focus on the socio-technical environment within which a design process takes place.

Dourish [75] 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 [75]. By focusing on appropriation, “we know the technology has become the users’ own [and not simply what the designer gave to them]” [71, p. 27].

To grasp appropriation from a temporal perspective, Carroll [38] developed a model that displays appropriation as part of a cyclic process involving users and technologies: The Technology Appropriation Cycle (TAC) (see Figure 7.1). 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* [38], focusing on the real-use in place of the technology [178]. The author describes the ap-

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 [38]. In particular, both Carroll [38] and Dix [71] 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 [71]. 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 [80]. Whereas, design from appropriation [38], 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” [120, 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” [74, 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 [74] 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. [88] 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 “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 [120]. Many design studies are combined through a common denominator (i.e. [161, 74, 80, 178, 17]: 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* [74]. From a theoretical point of view, it is widely accepted that when we observe the *real-use* in place of a technology [178] there are often frictions between the expected *use-through-design* and its actual *use-through-use* [161]. 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* [10]. Whereas, the *use through use* [161] refers to the definition of the meanings of a certain artifact through the way in which this 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* [80], *unfinished things* [194], *continuing design* [120], and *continuing design-in-use* [106], which conceive design as an *open-ended process*, aiming for “seeing every use situation as a potential design situation” [80, 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 with Storni [183], 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 chapter, 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.

### 7.2.3 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 and Wagner [16] 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 and Bossen [19] 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. [145] 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 [183] 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 “technological determinism” in the care pathway of the chronic patients.

Lastly, Aarhus and Ballegaard [1] 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 of 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 [98, 149]. They found that such technologies help patients and informal caregivers in having emotional support, information sharing, and a sense of community [98].

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 [113].

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

### 7.3 Research Context and Methods

In this chapter, we deepen the analysis of the two studies carried out in within the two end-of-life contexts previously presented in the Chapters 3 and 4: *i)* the PPC network, and *ii)* the network of six NHs. The studies are based on two independent projects, which were conducted respectively within the *InterAction Lab* and the *Life Participation* research group of the University of Trento.

The study within the PPC network was conceived to 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 study carried out within the six NHs aimed (similar to the preceding case) to investigate 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 NHs 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.

In the following Sections (7.3.1 and 7.3.2), differently from the preceding Chapters, we explain the methodologies we used more in details.

### **7.3.1 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 [31]. 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 an exploratory project, which had the goal of supporting the development 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 [189] to study the care practices, organizational dynamics and the collaborative relationships within the PPC service we investigated. Doing ethnography [27] 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 [129]. We used sensitizing concepts [28] 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; 4) 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: 5) 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 [157]. 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 [127].

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; *v)* what the information and communication gaps between family and professional caregivers are; *vi)* appropriation, and what the role of technologies and social media is in supporting the home care provision; *vii)* the collaborative care dynamics among caregivers; *viii)* 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.

### 7.3.2 Exploring Nursing Homes

The study conducted within the framework of the project *CollegaMenti* aimed to develop a new information system to support the collaboration and the communication among professional caregivers and between professional and family caregivers of the NHs. The field investigation was carried out in six NHs located within the Province of Trento from March 2016 to January 2017.

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 they 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 27 in-depth interviews with family caregivers. We designed a semi-structured interview guideline [176] configured in line with the concept of a topic guide as proposed by Arthur and Nazroo [14]. The guideline covered the following topics: *i*) what led the family caregivers to rely on the NHs; *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 NHs; *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 NH.

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” [14, p. 115] and, therefore, is very suitable for our exploratory research design. Together with the staff of the NHs, we randomly selected the interviewees. Those willing to participate were recruited by the staff members of the NHs. 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 NHs 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 NHs, since several studies [123, 124, 97] 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 [115]. The focus groups aimed to understand the context of the NH 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

Table 7.1: Summary of the Methods

<b>Paediatric Palliative Care</b>		
<b>Method</b>	<b>Sample/Duration</b>	<b>Object/Contexts</b>
<i>Interviews</i>	18 interviews with doctors, nurses, psychologists, social workers and head physician	We investigated: how they perceive the care context; their relationships, what interfere with their care work; their daily practices, their technology usage; their collaborative dynamics.
<i>Observations</i>	Several short-term sessions of about 4 days each, for a total of 34 days of observation	Observations focused on: network of actors; variability of collaborative work practices; daily practices of caregivers; communication practices, the impeding and facilitating factors of the home care practices.
<b>Nursing Homes</b>		
<b>Method</b>	<b>Sample/Duration</b>	<b>Object/Contexts</b>
<i>Interviews</i>	27 interviews with the family caregivers of the residents of 6 NHs	We investigated: why they relied on the NHs; how frequently they visit the NH; their relations with other families and the staff; how they manage the communication with the staff; their ICTs usage; what they would change in the NH.
<i>Focus Groups</i>	3 focus groups with the professional caregivers from the NHs	We focused on: their daily schedule; the frequency of unexpected events; what worries families; what families are eager to know; which topics are important to communicate to the families; their channels of communication; how they would categorize the relatives.



of the NHs, in accordance with their willingness to participate and their availability, since the focus groups had to be held in the NHs during working time. We tried to involve at least one staff member for each professional role, including nurses, social-health operators, doctors and office workers.

Focus groups were scheduled based on the availability of the NHs and the care professionals, and conducted within the NHs 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.

### **7.3.3 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 [33]. 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 NH 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.

## **7.4 Findings**

The following subsections explore the findings that emerged from the two healthcare studies that we conducted.

The findings stress the importance for caregivers in PPC and NHs 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

### 7.4.1 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 Medical 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 fulfill 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.

Secondly, *“It is [WhatsApp] a great tool, since we started using it we communicate more and we are closer”*. 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 empathetic 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.”*

#### 7.4.2 The Nursing Homes

The six NHs 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 NHs provide similar services but with different approaches, and each NH is structured differently. Yet, the work practices and the mission are the same. The NHs 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 NH 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 NHs 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 NH, 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 NHs 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 NHs, 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 NHs 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 NHs 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. The NHs involve both groups of caregivers in a perpetual negotiation. Differently from the PPC, in NHs 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 NH 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!”*

### 7.4.3 Final Remarks: Arising Issues

Although PPC and NHs differ under several aspects, there are many common organizational issues that unite them. (i) We noticed that PPC and NHs 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 [173]. (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 NHs are health-care contexts that may be perceived as built upon the need to exchange merely medical information [183], 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 NHs 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 NHs 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 attempt 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.

## 7.5 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 [120]. Similarly, to other studies presented in the literature [36, 193, 173], our studies were 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 [150]. 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 NHs.

With this chapter, 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 [161] 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* [38] 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, to our best knowledge, 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 requirements; 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* [9] of relations, practices, understandings and appropriations (itself) that can arise also before the formal design process. Yet, to better comprehend how our focus on appropriation opened up 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 closer 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 care professionals 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 NHs, 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 NHs - turning them into places [52] - 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 setting, 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 requirements that arose from our studies.

### **7.5.1 What is appropriation telling us? Design opportunities**

The work presented in this chapter conceived appropriation as a *collective effort* [16] 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*” [181, 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 four domains, which are presented in the following paragraphs. From the domains we elicited the product parameters of the technology platform, which will be defined as “system” from now on; the system is conceived as an application for mobile devices (such as smartphones and tablets). The domains are preceded by the explanation of the actors and users of the system, and are followed by the functional requirements of the system [111, 206, 3]. Non-functional requirements and process parameters are left out, as they do not pertain the scope of this chapter. All parameters which are not settled yet are followed by “TBD” (To Be Decided).

The six domains 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 and coordination, and data management; (c) family navigator support and network awareness; (d) peer-to-peer communication.

### **Actors and Users of the system**

Users of the system: the system is conceived to be used to manage the care pathway of patients and, hence, the users are the network of actors that assist a patient.

- *Family caregivers*: the system is conceived to be used only by the primary caregiver, the relative legally appointed to decide on behalf of the patient; the primary caregivers is entitled to grant the access to other family caregivers.
- *Professional caregivers*: the care professionals of the nursing home are entitled to access and edit the system according to their professional role and, therefore, according to the legal limitation that are applied to the EMR as well.

Actors of the system:

- *EMR*: the system is conceived to be linked to the EMR and, therefore, the medical information contained in the EMR will be displayed in the system as well; yet, family

caregivers as well as care professional will have a limited access to the information (however, this issue will require additional studies).

- *Administration*: the system will be administrated by the company in charge of the development (*CBA Group*).

**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 displays 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. [48, 145]) 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 Medical Records (EMR), 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. [31], 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. [31], the calendar should support the information needs of different caregiver roles, such as doctor, nurse, social-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, and data management.** 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 NHs 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 what they know on habits, tastes, attitude and medical history of their loved ones in a narrative fashion.

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 EMRs. 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.

***C. Family navigator support and network awareness*** 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 com-

municate, 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 direct communication when routing information.

We observed that within NHs and PPC there are large networks of care professionals - among doctors, nurses, specialists, social-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.

***D. 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.

## Functional Requirements

A) *Shared information transparency*: these requirements are mandatory.

- The system shall require sign-in credentials:
  - sign-in will be permitted with email address;
  - sign-in will be permitted to primary family caregivers and care professionals entitled by law.
- The system shall permit limited actions (see Section 7.5.1) to each user according to their role (i.e. doctor, nurse, family caregiver etc.)
- The system shall permit to interact (TBD) only among users that belong to the same care network (family and professional caregivers who assist the same patient).
- The system shall provide a Patient Profile (PP) containing the medical and social information (TBD) of a patient.
  - The PP shall display a profile of a patient.
  - The PP will be edited and updated by the family and professional caregivers who assist the patient.
  - The PP shall contain a chronology of the updates and changes made by the users.
  - The PP shall contain the demographic data (TBD) of the patient.
  - The PP shall contain the electronic medical tests' results (all those required for the specific patient) of the patients.
  - The PP shall contain the chronology of the medical events (TBD) that pertains to the patients.
  - The PP shall be linked to the EMR.
- The system shall provide a calendar.
  - The calendar shall be read and updated by the users.
  - The calendar will display the “done” and “to be done” medical tests (all the medical tests and visits planned by the care professionals) of a patient.
  - The calendar will display the appointments (TBD) of the users signed-in, and the appointments (medical tests, medical visits, participation to social activities) of the patient.

- The calendar will display all the social events, for patients and their relatives, organized by the NHs
- The calendar shall be linked to the PP.

*B) Internal communication and coordination, and data management:* these requirements are mandatory.

- The system shall provide two Real Time Messaging subsystems (RTM).
  - The first RTM shall permit real time messaging among care professionals only.
  - The second RTM shall permit real time messaging between family and professional caregivers who assist the same patient.
  - The second RTM shall be linked to the calendar:
    - \* users will request appointments to other caregivers through the RTM;
    - \* upon approval of the appointment request, the event will be saved in the calendar
  - Both RTM shall save the history of the messages exchanged among users.
  - If medical and social information (TBD) are exchanged, both the RTM shall allow users to save the information into the PP.

*C) Family navigator support, and network awareness:* these requirements are highly desirable.

- The system shall provide two Care Networks description (CN) of the family and professional caregivers who assist the same patient, for which the system is intended.
  - The CN shall contain the following information on the relatives and care professionals of a patient:
    - \* demographic information;
    - \* role information (primary caregiver, kinship, professional role);
    - \* contact (phone number, email, receiving hours in the case of doctors).
  - The CN shall graphically display the networks of care professionals and relatives.
  - The CN will permit users to update their own information, included a picture.
  - The CN shall be linked to the calendar:
    - \* users will request appointments to other caregivers displayed in the CN;
    - \* upon approval of the appointment request, the event will be saved in the calendar.



- The system shall permit to assign the reference points among the networks of family and professional points who assist the same patient.

*D) Peer-two-peer support:* these requirements are desirable.

- The system shall provide a subsystem in the form of a forum platform.
  - The subsystem will include only caregivers of the same NH.

## 7.6 Conclusions

In our research we focused on the communication, relational, and coordination issues that interfere with the care work within PPC and NHs contexts. We studied appropriation to focus on how the actors, within the two research contexts, adapted technologies and spaces, and redefined the boundaries of their roles. Our contribution aimed to enrich the current state of the art on how studying technology appropriation can nourish, support and integrate a design process, highlighting the necessity to focus more on social aspects and collaborative practices within healthcare contexts.

We observed that healthcare contexts cannot be comprehended as merely related to medical information. Studying appropriation helped us to grasp the needs of the sensitive participants without overloading them, and by drawing attention to the practices that they consolidated. This moved the focus toward the necessity to investigate how caregivers re-created their socio-technical environment through the adaptation of technologies. The appropriation that occurred within the two contexts, defines a first step of a design process that, in this sense, does not remain isolated as a side-phase. Moreover, it helped us to draw a first series of requirements for the development of the technology platform.

This chapter anticipates the work presented in Chapter 8, which describe the process that led to refine the requirements for the development the technology platform aimed at supporting family and professional caregivers of the network of NHs object of this thesis.



## Chapter 8

# Validation of the Final Requirements

*with Angela Di Fiore, Vincenzo D'Andrea, Maurizio Marchese and Fabio Casati*

In the light of the studies presented in the previous Chapters, here we describe the validation of the requirements for the new technology platform. Our findings confirm the organizational and the relational complexity of the nursing homes, highlighting how cultural frictions and poor communication practices hinder collaboration and mutual understanding between family and professional caregivers. Therefore, we provide a new set requirements for the development of the new technology platform for the support of the care work of family and professional caregivers.

### 8.1 Introduction

Studies [85] state that an aging population is a phenomenon that has been prominent in recent years. The latest “World Report on Ageing and Health” [153] 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 [7, 182, 200, 201]. In particular, Nursing Homes (NHs) are healthcare settings that provide assistance and support to older adults (residents) with severe physical conditions. NHs also assist the relatives of their residents and these relatives often rely on NHs following on from experiences of having provided home care to their loved ones. As a consequence, feelings of guilt and lack of trust towards care professionals can develop. Therefore, NHs 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 [135, 210].

In this context, care professionals and relatives need to coordinate with one another, in order to mutually participate in the care of the residents. Studies [104, 117, 139, 31, 165]

suggest that ICTs are a possible solution for improving the coordination between care professionals and family caregivers. Yet, healthcare environments and, specifically, NHs, are sensitive contexts 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 [150].

In this chapter<sup>1</sup>, we discuss the design process of the technology platform that aims to enhance coordination, collaboration and information sharing among caregivers within the network of NHs object of this thesis. 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 NHs, and the formal caregivers, which are medical professionals.

This study focuses on how ICTs can enhance communication, coordination, 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 professional caregivers and the family caregivers of the residents of the six NHs. After we summarize the preceding studies we conducted (see Chapters 3 and 4), and we present the first requirements we formulated (see Chapter 7), we explain the validation<sup>2</sup> of the requirements through the use of (static) mock-ups, which, subsequently, led us to reformulate the requirements and produce a first interactive prototype<sup>3</sup>.

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 new set pf requirements.

The chapter is structured as follows: in the next section we discuss the state of the art on collaborative healthcare technologies, and NH contexts; in Section 8.3, we present our research setting, the methodologies we used, and how we applied them in more details; we then present the findings of our study; finally, in Section 8.5 and, in the light of our

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<sup>1</sup>This chapter derives from [43]

<sup>2</sup>The data concerning our validation is available here: <https://drive.google.com/drive/folders/1agSB38GcUoW3-nSYobW0Z-7wSqaymdTv?usp=sharing>

<sup>3</sup>The interactive prototype is available here: [https://drive.google.com/drive/folders/1UFL4JlvWCRdlgQjZm8quZN60-W\\_22gaA?usp=sharing](https://drive.google.com/drive/folders/1UFL4JlvWCRdlgQjZm8quZN60-W_22gaA?usp=sharing)

results, we deliver suggestions on how to design collaborative cross-cultural technologies for healthcare settings, and we deliver the final requirements for the new technology platform. We also present a set of use cases, and a first interactive prototype of the platform.

## 8.2 Related Work

In this section, we present the state of the art concerning NH environments and collaborative care technologies. We start by discussing the existing literature on the relationship between family and professional caregivers and NHs, 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 [90]. According to Gaugler and Kane [90], 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 NHs [108, 109]. Family caregivers are seen as a useful source of information when attempting to settle new residents joining the facility [162], helping to frame their temperament and special needs [109, 108, 166]. However, usually, this information is informally gathered and is often lost because there is no dedicated space for such information on the NHs’ formal records [162]. There are not recognized processes or protocols to define the involvement of family caregivers in NHs. As a result, the inclusion of informal caregivers in partaking in the care of residents depends on the sensitivity of the care professionals [128], who are often committed to tight work schedules based on performance parameters [32]. In this context, 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 [166]. 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 towards the staff [166].

Conversely, the care professionals trust their technical knowledge, underestimating

the sentimental care work of the relatives [83]. Usually, medical professionals do not appreciate the intrusion of relatives in their care tasks [166, 72].

In NHs, 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 coexist, joining their effort in caring for the older adults [48, 47, 49, 46]. Within this environment, there is an emerging need to enhance communication exchange, empathy [109, 108], and mutual understanding between caregivers [166], with this being the basis of quality care delivery.

In NH 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 aging at home, but not within institutionalized facilities such as NHs [31, 60, 56, 112]. 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 by supporting the independence of older adults. Their contributions highlight the need to focus on how professional and family caregivers collaborate, in order to comprehend how to develop IT systems able to foster and support their practices. In this sense, Miller et al. [137] and Miller [138] 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. [48] argue for attention to be given to the social and logistical needs of caregivers when designing information systems. Nunes and Fitzpatrick [150], 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 [12, 13] worked on a management system to support coordination between a broad network of medical professionals, 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 provides 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 coexist. 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 summarize and complete the research work we conducted within the framework of the project *CollegaMenti*. Initially, the purpose of the project was to use a data warehouse on the medical data of the residents of the NHs, 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) [24] 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). Eventually, we reached the elicitation of a new set of requirements that differ from those expected by the partners of *CollegaMenti* at the beginning of the project. In other words, the project was built on the assumption that the efficiency of healthcare settings should have been built on an effective exchange of medical data. Yet, the outcome of our research emphasized the necessity to move the from a platform for real-time monitoring to a collaborative information “space”.

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 NHs, and to validate the requirements for the platform. Overall, the study was conducted from the spring of 2016 to the summer of 2017. We divided our whole research into two phases: an exploratory phase (see Chapters 3, 4 and 6), and a design phase (see Chapter7).

To summarize, 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 NHs. Once we arrived at the theoretical saturation [168], we started Phase 2, which aimed to deliver and validate the requirements for the development of the new technology platform.

### 8.3.1 Phase 1

Here we recapitulate the studies we conducted, previously presented in Chapters 3 and 4, and partially Chapter 7. In particular, we draw attention to the methodologies we used.

#### Focus Groups

The study begun with three Focus Group Discussions (FGDs) [176, 124, 123] 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 [33].

### 8.3.2 Interviews

After the FGDs were completed we interviewed [176] 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 [127]. 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 [33]. The interviews were carried out individually by three researchers who participated in this project.

### 8.3.3 Questionnaire

We also designed a questionnaire [121] 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.

### 8.3.4 Phase 2

In the second phase, through the creation of personas and scenarios, we designed a series of (static) mock-ups upon the first requirements we elicited (see Chapter 7). Then, we validated the requirements - through the use of the mock-ups - using participatory workshops. In these activities, we included both family and professional caregivers to validate the concept of the technology, its features and the requirements.

#### Personas & scenarios

In the light of the outcomes of Phase 1, we developed eight personas and four scenarios. The personas depicted five family caregivers and three care professionals. We created them by using part of the guidelines provided by Hensely-Schinkinger et al. [107] for the development of technologies for caregivers, including: age, gender, living situation, care situation, care received, care receiver, social environment and technical skills. We also added to the personas their emotional situation medical skills<sup>4</sup>. Eventually, for the workshops we used 4 personas (two professional caregivers, and 2 family caregivers).

#### Validation Workshops

In the course of Phase 2 we held six validation workshops (see Figure 8.1), in order to verify the consistency between the requirements we elicited and the results of our studies. We carried out 3 workshops with family caregivers, and 3 workshops with professional caregivers. Overall, 33 people participated to the workshops. The workshops followed a participatory approach [120, 177, 79]. Participants reviewed the requirements through the mock-ups we designed. The mock-ups were divided in two versions, 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

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<sup>4</sup>The personas we designed are available here: <https://drive.google.com/drive/folders/1qGc-8JFXoIEaeEFLOI98c2ySyY4i7GqQ?usp=sharing>

mock-ups while discussing the requirements with the other participants<sup>5</sup>. The mock-ups



Figure 8.1: Picture of a Validation Workshop.

were grouped according to the domains we formulated in Chapter 7, which resulted in six categories that represented the features of the technology platform. We presented regular “prototypes” and also some *provotypes*. Provotypes [140] 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 a half hours, and were facilitated by two researchers. The workshops were recorded and analyzed with thematic analysis [33].

**Prioritization.** Once participants finished reviewing all the requirements represented with the mock-ups, they were asked to perform a prioritization of the 6 features embedded into the mock-ups. 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.

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<sup>5</sup>The data of the workshops is available here: <https://drive.google.com/drive/folders/1agSB38GcUoW3-nSYobW0Z-7wSqaymdTv?usp=sharing>

**Validation Questionnaire.** At the end of the workshops, we asked to the participants to fill out a validation questionnaire we adopted because already used and validated by other researchers [60, 121, 119]. We adopted a validation questionnaire to collect quantitative data on the satisfaction of the participants with the mock-ups and, therefore, the requirements that represent 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) usefulness in supporting 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. Therefore, we first recapitulate the results presented in the preceding Chapters.

### 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 [65]. 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 relationship 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 [41]. In particular, the interviews rotate around the personal experience of the interviewees and their relation with the NH 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 NHs because they are unable to continue to provide adequate home care;
  - Relying on the NHs 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 NHs, 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 NHs;
- They suggest that care work should focus more on the humans behind the patients.

2. The relationship and information sharing with the NHs' staff:

- Since they regularly visit the NHs, 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 positive 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<sup>6</sup> 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 NH;
- 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.

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<sup>6</sup>The data of the survey is available here: [https://drive.google.com/drive/folders/1NNivaXU-JaVaFsw3xKnuPX\\_g1UgNkcHI?usp=sharing](https://drive.google.com/drive/folders/1NNivaXU-JaVaFsw3xKnuPX_g1UgNkcHI?usp=sharing)

Concerning the importance 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 NHs;
- these data suggest that the relatives do not rely on the staff members of the NHs 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 a series of mock-ups we used to validate the requirements for 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 NH 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 [68], in order to re-frame the goal of the technology, using the results of Phase 1 we defined a series of requirements upon which we designed the mock-ups. Then, we created personas and scenarios upon the results of the exploratory study in order to represent the contexts of the NHs 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 requirements we elicited into a series of (static) mock-ups. In light of the friction between the initial aim of the project and the needs of the caregivers, we decided to include some provotypes during the workshops. 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 mock-ups 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. This “simulation” of the platform 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 8.2 and 8.3), including the prototypes. We accompanied the explanation of the mock-ups and, therefore, of the requirements through the use of personas and scenarios, presented in slides and videos<sup>7</sup>.

**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. The main areas of the platform that are used by family caregivers consist of the following (see Figure 8.2a):

- *Health Status*:
  - *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 prototype 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

<sup>7</sup>The videos are available here <https://drive.google.com/drive/folders/1luq9-PH6Ji-O1NtzBbg0BnSubzui8MJ5?usp=sharing>

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.

- *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 8.3b).

*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 (prototype) on their sleeping habits, meals consumed, and the toilet necessities (see Figure 8.2b).

*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 8.2c). 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 8.3a).

*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 NH events, because they stressed the will to participate in turning the NHs 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 duplication.

**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 platform displayed the list of all the residents grouped in

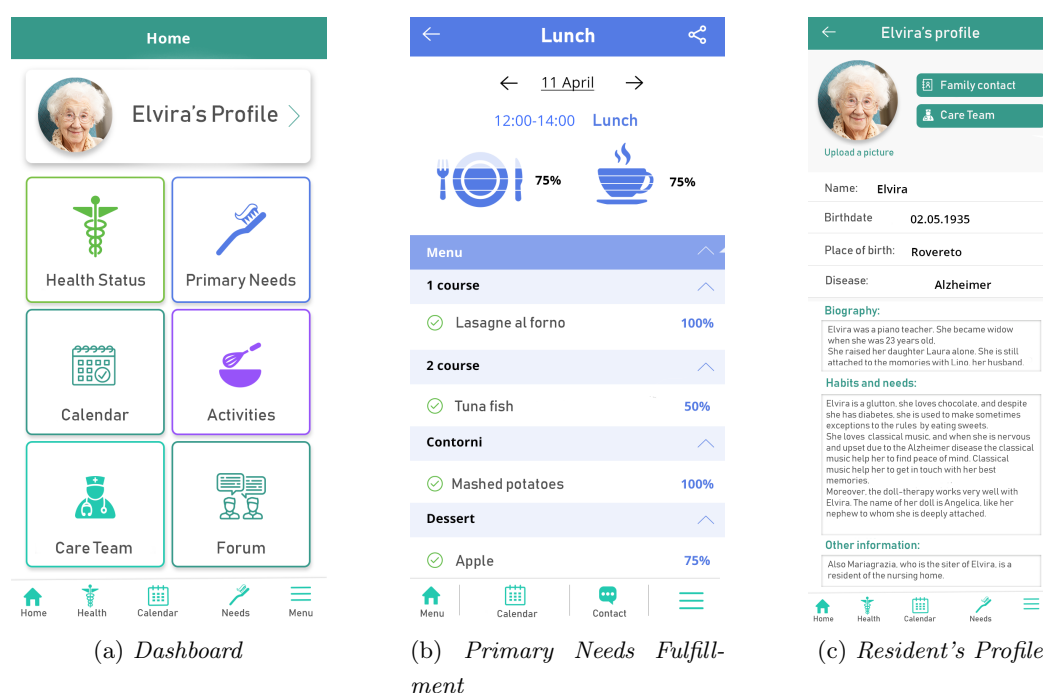


Figure 8.2: Examples of The Mock-Ups (1)

wards and alphabetical order (see Figure 8.3c). 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. 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 (prototype), and the narrative reports related to health status and therapies (see Figure 8.3b).  
*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 (prototype) 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 NH 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 8.3a). 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 organogram 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.

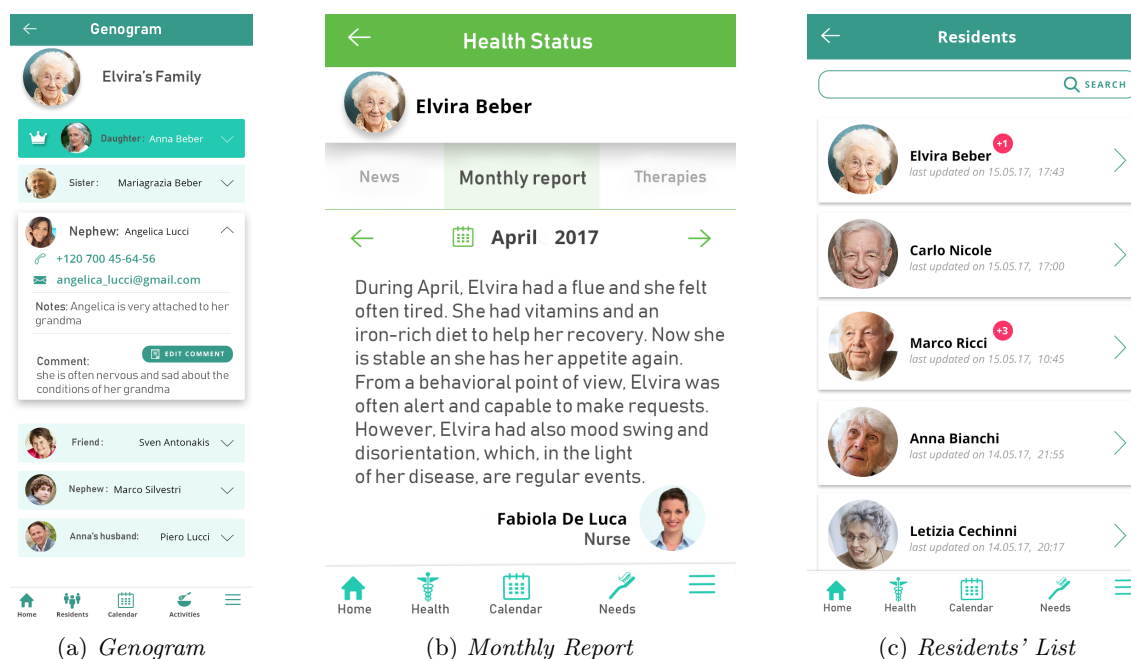


Figure 8.3: Examples of The Mock-Ups (2)

- *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 version 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 Fulfillment; 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 Fulfillment (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 8.1: Prioritization (mean of a scale 1 to 6)

<b>Levels</b>	<b>Family Members</b>	<b>Levels</b>	<b>Care Professionals</b>
<i>1. Health Status</i>	1.1 (SD 0.3)	<i>1. Health Status</i>	2.1 (SD 1.6)
<i>2. Primary Needs Fulfillment</i>	2.6 (SD 0.7)	<i>2. Primary Needs Fulfillment</i>	2.5 (SD 1.1)
<i>2. Relational Areas</i>	2.6 (SD 1.0)	<i>3. Relational Areas</i>	2.8 (SD 1.2)
<i>3. Activities</i>	4.4 (SD 1.2)	<i>4. Activities</i>	3.7 (SD 1.0)
<i>4. Forum</i>	4.7 (SD 0.8)	<i>5. Calendar</i>	4.4 (SD 1.3)
<i>5. Calendar</i>	5.5 (SD 0.7)	<i>6. Forum</i>	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 8.2. Family and professional caregivers found the platform useful (relatives 100%; care professionals 65%). They would mainly use the platform to:

Both respondents stated that the main benefits of the technology are related to the possibility of: a) involving the family caregivers in taking care of their loved-ones (relatives 81%; care professionals 65%); and b) checking the overall situation of the residents (relatives 87%; care professionals 82%).

a) Schedule meetings and communicate among caregivers (relatives 81%; care pro-



fessionals 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 NHs (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 8.2: Validation Questionnaire (N=32)

Question	Family Members		Care Professionals	
<i>The platform would be useful for the care work</i>	100% answered “yes”		65% answered “yes”	
<i>The platform would allow me to schedule meetings with the other caregivers</i>	81%	agreed/totally agreed	70%	agreed/totally agreed
<i>The platform would allow me to have shared data with the other caregivers</i>	100%	agreed/totally agreed	82%	agreed/totally agreed
<i>The platform would allow me to check the overall situation of the residents</i>	87%	agreed/totally agreed	82%	agreed/totally agreed
<i>I am worried that the platform could hinder face-to-face relations</i>	56%	agreed/totally agreed	18%	agreed/totally agreed

## **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 (described also in Chapters 3 and 4) allowed us to identify the issues that interfered with the care work of the care professionals and the relatives. We noticed that the NHs, 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 NHs, 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 artifact 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 mock-ups we designed represented a digital space within which caregivers could build relationships and coordinate their care work, while increasing their mutual understanding. The mock-ups 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” (see Chapter 6), 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 requirements and, subsequently, the new interactive mock-ups<sup>8</sup> representing 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 requirements upon which the prototype should be developed. We are aware about the necessity of achieving a full development of the platform, in

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<sup>8</sup>The interactive mock-ups are accessible here [https://drive.google.com/drive/folders/1UFL4JlvWCRdlgQjZm8quZN60-W\\_22gaA?usp=sharing](https://drive.google.com/drive/folders/1UFL4JlvWCRdlgQjZm8quZN60-W_22gaA?usp=sharing)

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:

- 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;
- Raw medical data are not necessarily meaningful for family caregivers if they are not contextualized;
- 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;
- 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;
- Medical and sensitive information is more effective if it is contextualized, being exchanged face-to-face, or in a “narrative” way;
- The care work of both family and professional caregivers should rotate around the comprehension of each other’s work and contribution;
- 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 [16]. Therefore, iterations and validation processes are fundamental to refining the requirements upon which a technology is designed [65], especially if there are social issues, organizational problems, and relational issues to solve [67]. 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.

### 8.5.1 Requirements

In this section we present the new set of functional requirements (to be all conceived as mandatory) [111, 206, 3], the use cases [59, 132, 53] for the new technology platform, and a first interactive prototype of the platform. The requirements are grouped according to the domains we used during the validation workshops (see Section 8.4.2). Each domain is conceived as a sub-function of the system. The explanation of the requirements is preceded by the definition of “users” and “actors” of the system. After the requirements we present the use case diagrams; the explanation for each use case can be found in Appendix A.

#### Users and Actors:

As we explained in the preceding Chapter (7), the system is conceived to be used to manage the care pathway of patients and, hence, the users are the network of actors that assist a patient. Yet, according to our analysis and the validation, the system should be delivered in two versions: one for each class of users. Therefore, the following are the two class of users:

- *Family caregivers.* The system is conceived to be used by the Relative (R) who is in charge of the care of a patient. Namely, the relative who is legally appointed to decide on behalf of the patient.
- *Professional caregivers.* As we explained earlier, the roles of care professionals are hierarchically organized, and upon their roles they are legally entitled or not entitled to conduct certain practices, or communicate sensitive information to the relatives. For this reason, they will read and edit the system according to the legal limitations that apply to their professional roles. These are the professionals roles and their permissions on the system:
  - Doctors and Nurses (D&N) will have a complete access (edit and read), they will:
    - \* visualize all the contents;
    - \* receive notifications if changes are applied to the system;
    - \* edit the system;
    - \* edit and update medical information;
    - \* edit the calendar: request and receive appointment notifications, edit the calendar of patients.
  - Social-Health Operators (SHO) will:

- \* visualize all the contents;
- \* receive notifications if changes are applied to the system;
- \* edit the system;
- \* cannot edit and update medical information;
- \* can only read the calendar.

Actors of the system:

- *EMR*: the system will be linked to the EMR, which already contains the information for the *Health Status* and the *Primary Needs Fulfillment*, but this information will be displayed on the version for the R upon the approval of the D&N. Still, the specific requirements for this cannot be drawn yet.
- *Administration*: as we previously state, the system will be administrated by the company in charge of the development (*CBA Group*).

### **Version of the system for Family Caregivers:**

#### *Access*

- The system shall require sign-in credentials:
  - Sign-in will be permitted with username and password provided to the R of a patient by the administrator.
- The access to the system will permit R to read content only related to the patient they assist.
- The system shall display notification once any user (connected to the same patient) edits the system.
- Upon sign-in, the system shall display a home page with direct access to the sub-functions (“domains”) of the system presented below.

#### *Health Status*

- The system shall contain an Event History (EH):
  - The EH shall contain the history of all the past events of a patient (medical and physiological events, medical tests, vitals);
  - The EH shall display events that already happened and that R is already aware of.

- The system shall contain a Monthly Report (MR):
  - The MR shall display an abstract (edited by the D&N) that describes - in a narrative fashion - the overall physical and social situation of a patient (description of the therapy, description of the physiological state, description of the psychological state);
  - The MR shall be available every 15 days.
- The system shall contain a Primary Needs Fulfillment (PNF):
  - The PNF shall contain the history of the physiological situation of the patient (hours slept, meals consumed, drinks consumed, use of the toilette);
  - The PNF shall update the information weekly.
- The EH, MR, and PNF will be only read by R.
- The EH and MR will be edited by D&N.
- The PNF will be edited by D&N and SHO.

#### *Relational Areas*

- The system shall contain a Patient Profile (PP):
  - The PP shall display a profile of a patient (in form of social network page).
  - The PP will be edited and updated by R.
    - \* The PP shall contain the demographic data of the patient.
    - \* The PP shall contain the bibliography of the patient.
    - \* The PP shall contain the description of the patient (attitude, habits, tastes, hobbies).
    - \* The PP shall contain the information of the network of relatives of the patient (picture, kinship, contacts).
  - The PP shall contain a chronology of the updates and changes made by R.
  - The PP shall be only read by professional caregivers from their version of the system.
  - The PP shall be linked to the “Health Status”.
- The system shall provide the Care Team description (CT)
  - The CT shall contain the following information on Doctor, Nurses and chief SHO (the main medical roles) who assist the patient:



- \* Name and Surname;
- \* Role information (head physician, head nurse, physician, nurse);
- \* Contact (phone number, email, receiving hours).
- The CT shall be graphically displayed.
- The CT can only be read by R.
- The CN shall be linked to the calendar (see below):
  - \* R will request appointments to the caregivers displayed in the CT;
  - \* upon approval of the appointment request, the event will be saved in the calendar.
- The system shall provide a subsystem in the form of a forum platform.
  - The subsystem will include only caregivers of the same NH.

### *Activities*

- The system shall contain a Bulletin Board (BB).
  - The BB shall display the list of events, for residents only, organized by the NHs.
  - The BB shall permit R to apply to volunteer to the events to help the NHs' staff.
  - The BB shall display important information (TBD) provided by the NH.
  - R can only read the BB
  - The BB will be edited by D&N and SHO.
- The system shall provide a calendar.
  - The calendar shall be read and updated by the R.
  - The calendar will display the “done” and “to be done” medical tests (all the medical tests and visits planned by the care professionals) of the patient.
  - The calendar will display the appointments of the R signed-in.
  - The calendar will display all the social events organized by the NHs (see preceding point)
  - The calendar shall be linked to the CT.
  - The calendar shall display the events of the EH.

**Version of the system for Professional Caregivers:***Access*

- The system shall require sign-in credentials:
  - sign-in will be permitted with username and password provided to the care professional of a NH by the administrator.
- The access to the system will permit D&N and SHO to read and edit (upon role permission) content on all patients of a NH.
- The system shall display notification once any user (connected to the same patient) edits the system.
- Upon sign-in, the system shall display a home page with the list of residents of the NH.
- Upon the access to a patient on the list, the system shall grant access to the following sub-functions.

*Health Status*

- The system shall contain an Event History (EH):
  - The EH shall contain the history of all the past events of the patient (medical and physiological events, medical tests, vitals);
  - The EH shall be linked to the EMR.
  - The EH will be edited by D&N.
  - SHO will only read the EH.
- The system shall contain a Monthly Report (MR):
  - The MR shall display an abstract that describes - in a narrative fashion - the overall physical and social situation of the patient (description of the therapy, description of the physiological state);
  - The MR shall be available every 15 days.
  - The MR will be edited by D&N.
  - SHO will only read the MR.
- The system shall contain a Primary Needs Fulfillment (PNF):

- The PNF shall contain the history of the physiological situation of the patient (hours slept, meals consumed, drinks consumed, use of the toilette);
- The PNF shall update the information weekly.
- D&N and SHO will edit and update the PNF.

### *Relational Areas*

- The system shall contain a Patient Profile (PP):
  - The PP shall display a profile of a patient (in form of social network page).
  - D&N and SHO will only read the PP.
    - \* The PP shall display the demographic data of the patient.
    - \* The PP shall display the bibliography of the patient.
    - \* The PP shall display the description of the patient (attitude, habits, tastes, hobbies).
    - \* The PP shall display the information of the network of relatives of the patient (picture, kinship, contacts).
  - The PP shall contain a chronology of the updates and changes made by R.
  - The PP shall be linked to the “Health Status”
- The system shall provide the Care Team description (CT)
  - The CT shall contain the following information on Doctor and Nurses chief SHO (the main medical roles) who assist the patient:
    - \* Name and Surname;
    - \* Role information (head physician, head nurse, physician, nurse);
    - \* Contact (phone number, email, receiving hours).
  - The CT shall be graphically displayed.

### *Activities*

- The system shall contain a Bulletin Board (BB).
  - The BB will be edited by D&N and SHO.
  - The BB shall display the list of events, for residents only, organized by the NHs.
  - The BB shall display the R that apply to volunteer to the events to help the NHs’ staff.
  - The BB shall display important information (TBD) provided by the NH.

- The system shall provide a calendar.
  - The calendar shall be read and updated by the D&N and SHO.
  - The calendar will display the “done” and “to be done” medical tests (all the medical tests and visits planned by the care professionals) of the patient.
  - The calendar will display the appointments of the D&N and SHO signed-in.
  - The calendar will display all the social events organized by the NHs (see preceding point)
  - The calendar shall be linked to the CT.
  - The calendar shall display the events of the EH.
  - The calendar shall display notifications when appointment requests are forwarded by R.

### **Use Cases and Prototype**

The use cases are summarized in the diagrams presented in the Figures 8.4, 8.5 and 8.6. There is one diagram for each class of user: Relative (R); Social-Health Operator (SHO); Doctor and Nurse (D&N). The specific explanation of the use cases for each diagram are presented in Appendix A. The interactive prototype we produced from the elicitation of the new requirements we drew is available here: [https://drive.google.com/drive/folders/1UFL4JlvWCRdlgQjZm8quZN60-W\\_22gaA?usp=sharing](https://drive.google.com/drive/folders/1UFL4JlvWCRdlgQjZm8quZN60-W_22gaA?usp=sharing). However, the prototype slightly differ from the specifications defined in the requirements and use cases because the necessary negotiation we had with the designer who draw the mock-ups.

## **8.6 Conclusion**

Studies on cross-cultural collaboration in healthcare settings 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, NH settings. With our work, we proposed a study that shows how technology should support caregivers in dealing with managerial issues, while nourishing social relationships. We presented the design process we conducted by using mixed methods, highlighting how the iterative procedure allowed us to deepen the social and collaborative complexity that lies at the relationship between professional and family caregivers. Such complexity led us to re-frame our research project focused on real-time sharing of medical data, toward the participatory design of a wider collaborative solution to share information, support relationships, and enhance mutual understanding and collective sense

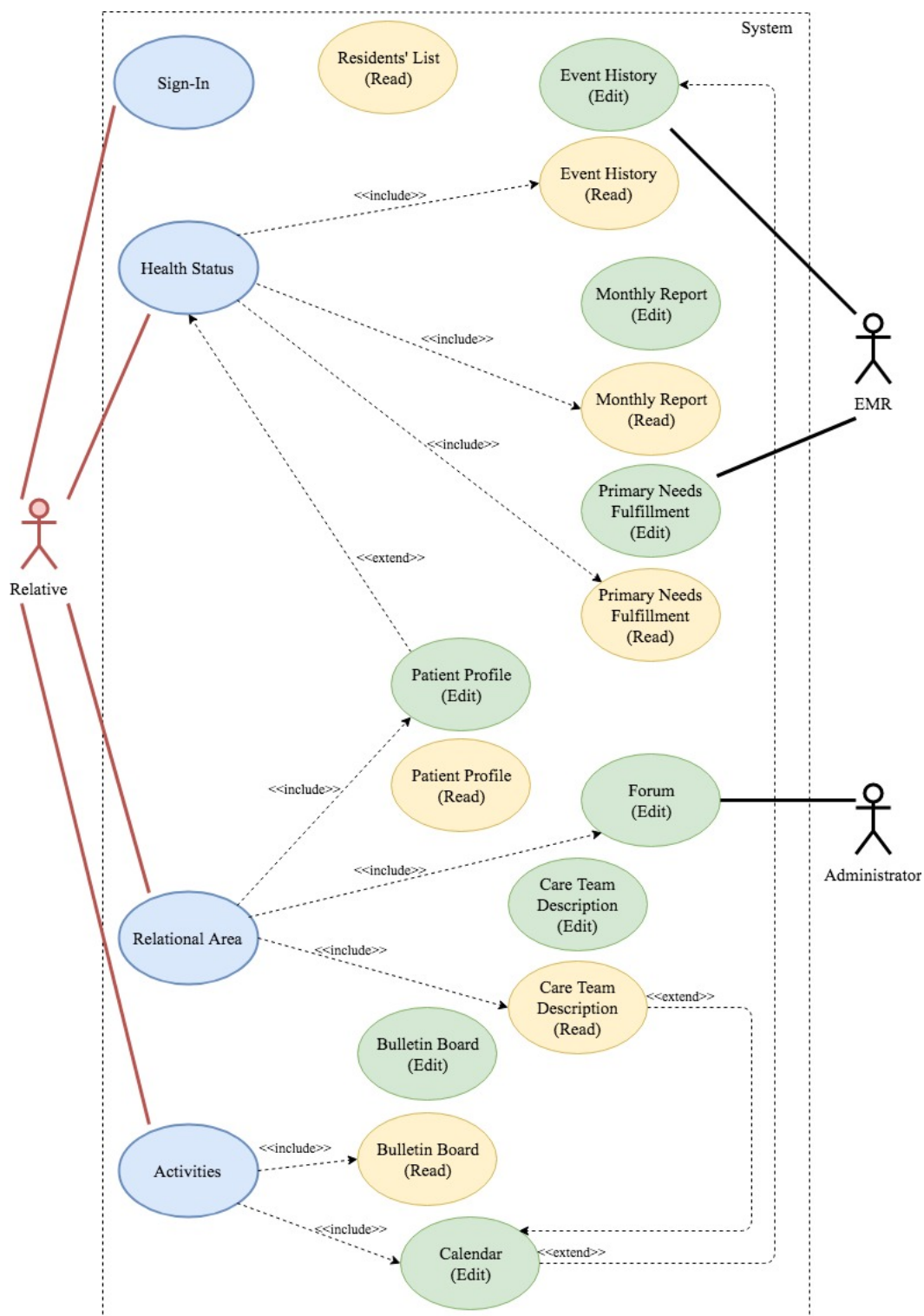


Figure 8.4: Relative - Use Case Diagram

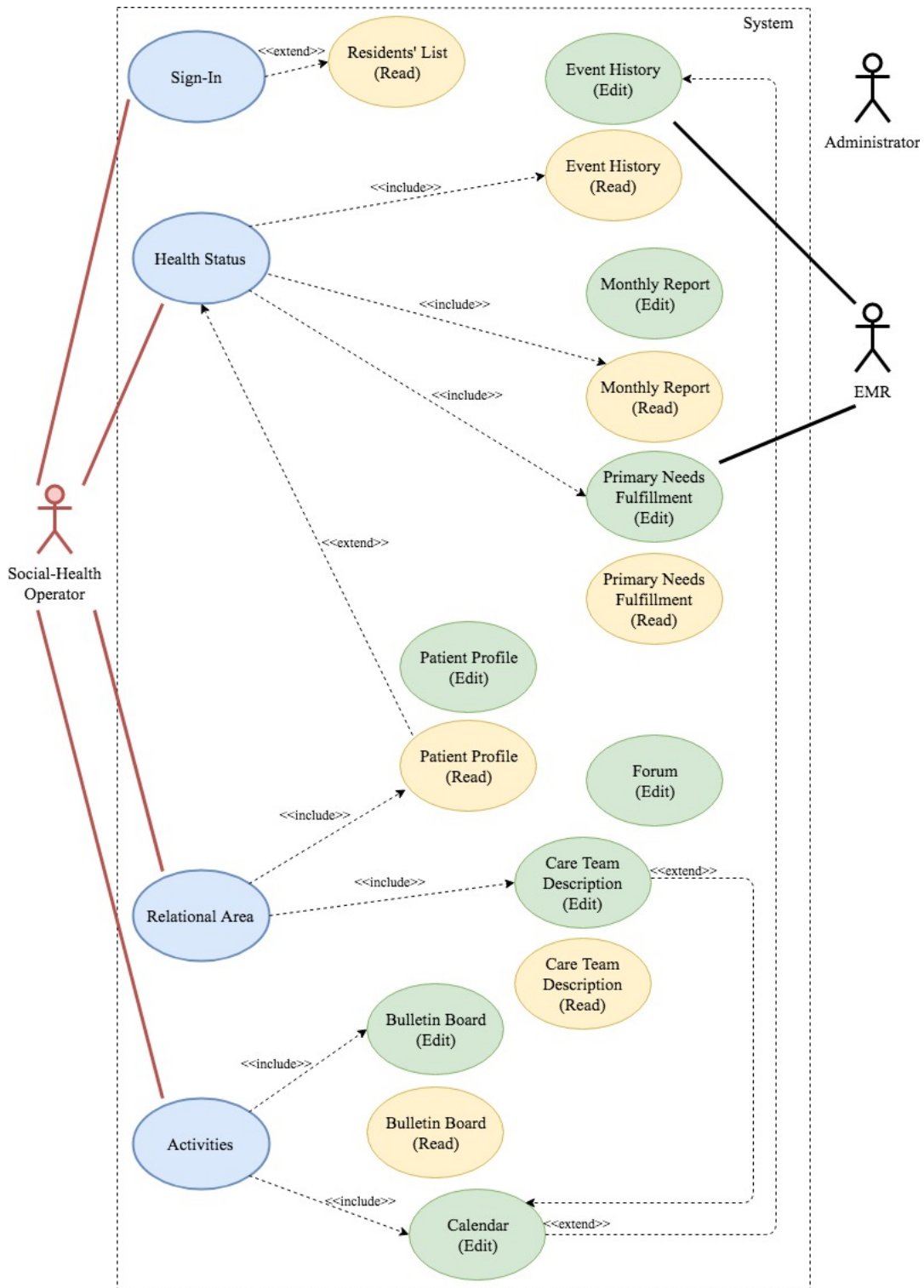


Figure 8.5: Social-Health Operator - Use Case Diagram

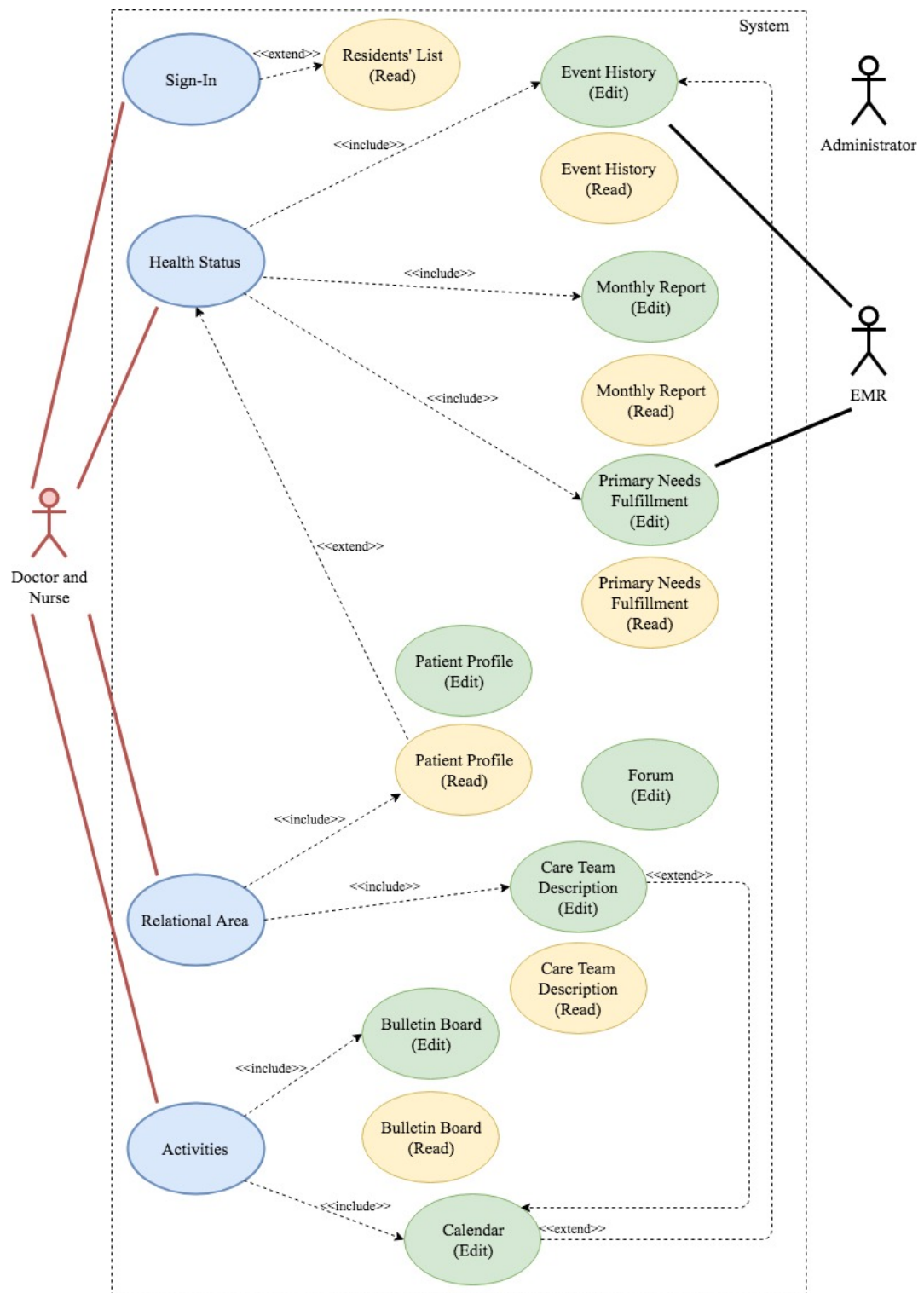


Figure 8.6: Doctor and Nurse - Use Case Diagram

making between caregivers. Eventually, we were able to define a new set of requirements for the development of the new platform, and to produce a first interactive prototype of the platform.



## Chapter 9

# Conclusions

This thesis addresses the problems of enhancing better communication, coordination, information exchange, and relationships within healthcare settings, and it is based on a number of studies carried out within a network of six nursing homes located in the northern Italy. We built our study on a research project that was aimed at building a technology platform for the delivery of medical information, in a real-time fashion, to the family caregivers of the residents of the nursing homes. However, our investigation revealed a scenario that differed from that upon which the research project was written. In particular, we observed that - accordingly to Storni [183] - the care work within healthcare contexts do not merely rely on the exchange and communication of medical information. On the contrary, healthcare settings and, in particular, the network of nursing homes object of this thesis, require the establishment of better social relations among the caregivers involved into the care of the patients, rather than a mere exchange of medical information. Therefore, in this thesis, after an in-depth study aimed at validating our understanding of our research context, we propose a set of requirements upon which a new technology platform should be developed. The technology should foster family and professional caregivers in establishing better interactions, thus enhancing mutual involvement and collaboration into the care pathways of the patients, while building social relationships. In this chapter we summarize the contributions, discuss the outcomes of our work, discuss the limitations of our study, and present the possible directions for future work.

### 9.1 Summary of the Contributions

In this thesis we presented a series of in-depth studies that led us to comprehend which are the real needs of the family and professional caregivers of six nursing homes located in Trentino. Consequently, in our work, we investigated how these needs could be better supported by technologies and, in particular, how a new technology platform should

have been designed in order to fulfill the caregivers' needs. To this end, we actualized a series of requirements we later validated. From the validation we elicited a new series of requirements upon which the technology platform should be designed. We also produced a first interactive prototype of the new platform. The specific contribution of this thesis are:

- A study on the most reliable disciplines for the design of technologies for health-care settings that led us to suggest to exploit their respective methodologies, thus deepening the comprehension of healthcare settings;
- An in-depth study that sheds new light on the issues that affect nursing home settings and, specifically, the management of the care pathways of the residents;
- Evidences that prove the unwillingness of our target user group to build the care pathways on issues merely related to the medical framework;
- Evidences that support the impossibility to design technologies for collaborations - on the care pathways of patients - based on the exclusive exchange of medical data;
- A generalizable theoretical and methodological contributions on how other health-care settings - like nursing homes - should be approached and investigated, in order to protect the sensitivity of their actors (patients, relatives and care professionals), while eliciting requirements;
- A validated set of requirements for the development of the new technology platform, and a first interactive prototype of the platform.

## 9.2 Lessons Learned

From the study presented in this thesis we learned the following lessons.

- *Caring for the patient is caring for their families as well.* During our study we closely observed all the dynamics related to the care work in healthcare settings. We investigated all mechanism that regard the management of the care pathways from the perspective of both family and professional caregivers. We learned that, although a care pathway concerns the management of the physical conditions of a patient, the work of professional caregivers also regards the management of the psychological and emotional state of the relatives of the patients. Hence, care professionals have to “look after” the relatives as well. Conversely, family caregivers seek the support and the understanding of the care professionals.

- *Raw medical data is “not useful” unless it is delivered face-to-face.* During our study we found a strong consistency between the opinions of the care professionals and the relatives of the residents on the usefulness of medical data. Both groups deemed raw medical data “not useful” and, in some cases, dangerous. Specifically, medical data require to be filtered, interpreted and contextualized in order to become information (see Chapter 6) and, subsequently, to be keenly comprehended. Medical data, even if translated into information, are far from being generalizable because they pertain the specific situation of each single patient. Both family and professional caregivers stated that sensitive data and medical information can only be conveyed face-to-face to be effective.
- *Medical information can become a “weapon”.* Given the nature of the research project, we thoroughly investigated the possibility to deploy a system able to support the exchange of medical information in a real-time fashion. Nonetheless, we always found the obstruction of both our target user groups - in particular of care professionals - for several reasons. Among all reasons, we observed that care professionals feared the possibility for family caregivers to use medical information as a “weapon”. We learned that, although medical information are data filtered and contextualized, family caregivers can draw on them to gain new knowledge that they can use to negotiate their roles within the nursing homes to take charge of the care pathways, which should be primarily managed by the care professionals (see chapter 6).
- *The families of the residents put many efforts into the care of their loved ones and, therefore, they want to be recognized as “caregivers”.* We observed that the relatives of the residents are normally regular at the nursing homes; they sacrifice their private lives to stay close to their loved ones. We noticed that the attitude of the family caregivers towards the care professionals it is not merely determined by the need to take control over the care pathway, rather, it is driven by the expectation of the relatives of being recognized as caregivers, as well as of being better included into the care pathway.
- *Often family and professional caregivers do not have the time and the space to nourish their mutual understanding.* The care work is time demanding for both relatives and care professionals. Our data show that both target user groups struggle to nourish their relationships and mutual understanding. In this sense, we learned that we could rely on technologies to create an additional space for the interaction of family and professional caregivers that could allow both synchronous and asynchronous communications. Moreover, we comprehended that the technology could

be used to enhance and manage the mutual involvement into the care pathways of the caregivers.

- *Technology can be more effective if it used as a space for socialization rather than a tool to communicate.* We designed our study to comprehend how a new technology platform could be used to enhance communication between family and professional caregivers. Throughout our investigation, we observed that several caregivers relied on social networks to find peer-to-peer support, as well as to socialize with people who experience the same situation. These factors are missing within the nursing home contexts. Therefore, we understood that a new technology platform should become a space for socialization between the two groups of caregivers, rather than being a mere tool for the exchange of information.
- *Care professionals and relatives fear the risk for the technology to become a factor that hinders the interactions face-to-face.* Despite our expectations, our study revealed that caregivers are not willing to sacrifice the interactions face-to-face, even though they struggle to find the time to dedicate to each other. In fact, our interviewees declared that they would not substitute the relations face-to-face with digital interactions. Hence, we comprehended that the technology should have embedded features that stimulate face-to-face interactions. The technology should make caregivers able to organize their care work thus to save time they can dedicate to interact with each other.
- *The technology has the potentials to bring people together.* The frequent use of social networks among family caregivers emphasized the potential of technologies in bringing people together, even if they do not know each other and are far apart. In other words, we observed that several people prefer to rely on social networks to find peer-to-peer interactions, even though family caregivers are often in the nursing home in proximity of people who share their same experience. Therefore, we learned that the technology, as a “free zone”, stimulates people in seeking these interactions. Moreover, we comprehended that we had to exploit this peculiarity of the technology to make people build those social relationships, which - for the lack of time and space - cannot be built within the nursing homes.

### 9.3 Limitations

We are aware that the results we presented are limited for the following reasons:

- The overall investigation was built on both qualitative and quantitative method-

ologies we used to comprehend the nature of our research contexts. However, we understand that the data we gathered and analyzed can be interpreted only within the framework of our research context.

- Although Italy is a relatively small country, there are several regions and provinces that, despite being in proximity, widely differ from each other. For instance, Italy has five “Autonomous Regions”. Hence, there are cultural, geographical, administrative and legal differences that intervene on how the care pathways could be managed within different regions or provinces. The peculiarities of northern Italy render our research context, somehow, “unique”. Therefore, our study did not consider peculiarities that may be of interest elsewhere.
- We are aware that the study misses a deeper understanding of which may be the incentives for our target user groups to adopt the new technology platform. For instance, we know that there may be economic implications for which the caregivers would not adopt the technology. Therefore, this research requires a deeper comprehension of what would encourage our target user groups to adopt the platform.
- The prototype we designed and the requirements we reformulated after the validation, define a system that also stores medical information accessible by both family and professional caregivers. Yet, nursing homes already rely on the Electronic Medical Records (EMR) to collect the medical data - available only to the care professionals - of all the residents. In this sense, we did not investigate how to link the existing EMR with the new technology platform.
- Our study was conducted within sensitive healthcare contexts. There, we constantly negotiated our access to the research settings. Care professionals and family caregivers could be approached, met, and interviewed only within the nursing homes. Therefore, we often re-adapted our research plan according to their necessities, and according to the delicacy that required the nursing homes. This inevitably prolonged the time we needed for our study.
- Even though we carried out the validation process that consolidated and refined the requirements we formulated, we are aware that a relevant implementation work needs still to be done to deliver the tangible platform. Such development work is the natural continuation and follow up of this thesis work.
- We believe that this thesis delivers solid evidences for the understanding of our research contexts. We also believe that our findings deliver a concrete contribution on how technology should serve the family and professional caregivers in establishing

better relationships, communications practices, as well as in socializing, exchange information and manage the care pathway. However, without the actual technology platform we cannot fully validate its requirements, aesthetic and usability. Hence, we are aware that our analysis and conclusions remain partially circumscribed within a software engineering, requirements elicitation and validation framework.

## 9.4 Future Work

In the preceding section we highlighted a series of limitations that were determined by the difficulty to coordinate a large number of stakeholders, and by our impossibility to complete the development of the technology. Here we explain the next steps that our research will undertake to “repair” its limitations.

In the future we plan to extend our research in other contexts. As part of the project upon which the research on this thesis was based, we work together with an industrial partner, the *CBS Group*. Together with the partner we already widened our sample of nursing homes. Thus, we will be able to replicate the research we presented in this thesis within other nursing homes. We targeted facilities located also outside the province of Trento. This will allow us to consider also logistic, managerial, and administrative factors that in the province of Trento are already uniformed among the nursing home we investigated.

The project’s purpose is also to deploy the technology platform within the network of nursing homes included in our study. Therefore, we plan to complete the development of the technology platform according to the findings of our research, and enriched with the data we will gathered form the new studies. Still, once the development is completed, we intend to carry out a new series of validation workshops of the actual platform with a new sample of family and professional caregivers. In this sense, we will be able to consolidate our findings, but we will also test the usability of the platform. These steps will require several iteration to consolidate the product of our research.

Together with the industrial partner, we also plan to investigate how the new platform can be integrated with the EMR already deployed within the nursing homes. The platform should be able to communicate with the EMR. Indeed, we aim to make the platform able to extract the medical information from the EMR and automatically update it into the application that family and professional caregiver will use.

# Appendix A

## Appendix

Table A.1: Relative - Description of Uses Cases

<b>Use Case</b>	Sign-In
<i>Description</i>	To access the system, a user should be provided with username and password. The access to the system through username and password will grant the user to read and edit the system in accordance with their permissions.
<i>Actor(s)</i>	Relative (R).
<i>Assumptions</i>	The relative should be provided with the username and password by the administrator of the system. The username and password will protect the system, thus to protect the data regarding the patient.
<i>Steps</i>	The user will open the system, the system will ask username and password. The user will enter username and password and by clicking a “sing-in” button, the user will access the system, which will display a “home page” with all the sub-functions of the system (see following use cases)
<b>Use Case</b>	Health Status
<i>Description</i>	From the home page the user will access the “Health Status”. The access to the health status will permit the user to read the <i>Event History</i> , <i>Monthly Report</i> and <i>Primary needs Fulfillment</i> of the patient.
<i>Actor(s)</i>	Relative (R).
<i>Assumptions</i>	The health status will contain the information as specified in the Chapter 8, Section 8.5.1
<i>Steps</i>	The user will access the health status by clicking on the corresponding button on the home page. Afterwards, the system will display three other icons. Each icon will correspond respectively to <i>Event History</i> , <i>Monthly Report</i> and <i>Primary needs Fulfillment</i> . By clicking either one of the icon the user will access and read the content of the corresponding page.

<b>Use Case</b>	Relational Area - Patient Profile
<i>Description</i>	From the homepage the user will access the “Relational Area”. The access to the relational area will permit the user to read and edit the <i>Patient Profile</i> , namely the page that contains all the information they have on the patient they assist, to make them available to the professional caregivers.
<i>Actor(s)</i>	Relative (R).
<i>Assumptions</i>	The <i>Patient Profile</i> will contain the information as specified in Chapter 8, Section 8.5.1.
<i>Steps</i>	The user will access the “Relational Area” by clicking on the corresponding button on the home page. Afterwards, the system will display three other icons. Each icon will correspond respectively to <i>Patient Profile</i> , <i>Forum</i> and <i>Care Team Description</i> . By clicking on the one corresponding to the <i>Patient Profile</i> , the user will access the profile of the patient they assist. There the user will apply to “edit” the profile description. From there the user will also have direct access to the health status.
<b>Use Case</b>	Relational Area - Forum
<i>Description</i>	From the homepage the user will access the “Relational Area”. The access to the relational area will permit the user to read and edit the <i>Forum</i> .
<i>Actor(s)</i>	Relative (R), Administrator.
<i>Assumptions</i>	The <i>Forum</i> will embed the same features of a Forum Platform. The Administrator of the system will be the facilitator of the forum.
<i>Steps</i>	The user will access the “Relational Area” by clicking on the corresponding button on the home page. Afterwards, the system will display three other icons. Each icon will correspond respectively to <i>Patient Profile</i> , <i>Forum</i> and <i>Care Team Description</i> . By clicking on the one corresponding to the <i>Forum</i> , the user will access the “forum”. There the user will apply to “edit” new messages and participate to other “conversations”.
<b>Use Case</b>	Relational Area - Care Team Description
<i>Description</i>	From the homepage the user will access the “Relational Area”. The access to the relational area will permit the user to read the <i>Care Team Description</i> , namely the page that contains the information on the primary caregivers that assist the patient.
<i>Actor(s)</i>	Relative (R).
<i>Assumptions</i>	The <i>Care Team Description</i> will contain the information as specified in Chapter 8, Section 8.5.1.



<i>Steps</i>	The user will access the “Relational Area” by clicking on the corresponding button on the home page. Afterwards, the system will display three other icons. Each icon will correspond respectively to <i>Patient Profile</i> , <i>Forum</i> and <i>Care Team Description</i> . By clicking on the one corresponding to the <i>Care Team Description</i> , the user will access the list of the primary care professionals who assist the patient. By clicking on any “name” on the list, the user will access the information (see Chapter 8, Section 8.5.1) on that specific professional figure. From there, the user will apply to request an appointment with the professional figure in object.
<b>Use Case</b>	Activities - Bulletin Board
<i>Description</i>	From the homepage the user will access the “Activities”. The access to the activities will permit the user to read and edit the <i>Bulletin Board</i> , namely the page that contains the information on the events and important information on the nursing homes.
<i>Actor(s)</i>	Relative (R).
<i>Assumptions</i>	The <i>Bulletin Board</i> will contain the information as specified in Chapter 8, Section 8.5.1.
<i>Steps</i>	The user will access the “Activities” by clicking on the corresponding button on the home page. Afterwards, the system will display two other icons. Each icon will correspond respectively to <i>Bulletin Board</i> and <i>Calendar</i> . By clicking on the one corresponding to the <i>Care Team Description</i> , the user will access the “board” listing, in chronological fashion, the information made available by the nursing home. There the user will apply to to volunteer the events opened (by the professional caregivers) to volunteers.
<b>Use Case</b>	Activities - Calendar
<i>Description</i>	From the homepage the user will access the “Activities”. The access to the activities will permit the user to read and edit the <i>Calendar</i> , namely the page that contains the appointments, and events of respectively the patient and the nursing homes.
<i>Actor(s)</i>	Relative (R).
<i>Assumptions</i>	The <i>Calendar</i> will contain the information as specified in Chapter 8, Section 8.5.1.
<i>Steps</i>	The user will access the “Activities” by clicking on the corresponding button on the home page. Afterwards, the system will display two other icons. Each icon will correspond respectively to <i>Bulletin Board</i> and <i>Calendar</i> . By clicking on the one corresponding to the <i>Calendar</i> , the user will access the “calendar”. There the user will read and edit events.

Table A.2: Social-Health Operator - Description of Uses Cases

<b>Use Case</b>	Sign-In
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<i>Description</i>	To access the system, a user should be provided with username and password. The access to the system through username and password will grant the user to read and edit the system in accordance with their permissions.
<i>Actor(s)</i>	Social-Health Operator (SHO).
<i>Assumptions</i>	The social-health operator should be provided with the username and password by the administrator of the system. The username and password will protect the system, thus to protect the data regarding the patient.
<i>Steps</i>	The user will open the system, the system will ask username and password. The user will enter username and password and by clicking a “sing-in” button, the user will access the system, which will display a list of all the residents of the nursing home. By clicking the name of any patient, the user will access a “home page” with all the sub-functions of the system (see following use cases) that concern the patient in object.
<b>Use Case</b>	Health Status - Event History
<i>Description</i>	From the home page the user will access the “Health Status”. The access to the health status will permit the user to read the <i>Event History</i> .
<i>Actor(s)</i>	Social-Health Operator (SHO).
<i>Assumptions</i>	The <i>Event History</i> will contain the information as specified in the Chapter 8, Section 8.5.1
<i>Steps</i>	The user will access the health status by clicking on the corresponding button on the home page. Afterwards, the system will display three other icons. Each icon will correspond respectively to <i>Event History</i> , <i>Monthly Report</i> and <i>Primary needs Fulfillment</i> . By clicking on the one corresponding to the <i>Event History</i> , the user will access and read the content of the page.
<b>Use Case</b>	Health Status - Monthly Report
<i>Description</i>	From the home page the user will access the “Health Status”. The access to the health status will permit the user to read the <i>Monthly Report</i> .
<i>Actor(s)</i>	Social-Health Operator (SHO).
<i>Assumptions</i>	The <i>Monthly Report</i> will contain the information as specified in the Chapter 8, Section 8.5.1
<i>Steps</i>	The user will access the health status by clicking on the corresponding button on the home page. Afterwards, the system will display three other icons. Each icon will correspond respectively to <i>Event History</i> , <i>Monthly Report</i> and <i>Primary needs Fulfillment</i> . By clicking on the one corresponding to the <i>Monthly Report</i> , the user will access and read the content of the page.
<b>Use Case</b>	Health Status - Primary Needs Fulfillment
<i>Description</i>	From the home page the user will access the “Health Status”. The access to the health status will permit the user to read and edit the <i>Primary needs Fulfillment</i> .

<i>Actor(s)</i>	Social-Health Operator (SHO).
<i>Assumptions</i>	The <i>Primary needs Fulfillment</i> will contain the information as specified in the Chapter 8, Section 8.5.1
<i>Steps</i>	The user will access the health status by clicking on the corresponding button on the home page. Afterwards, the system will display three other icons. Each icon will correspond respectively to <i>Event History</i> , <i>Monthly Report</i> and <i>Primary needs Fulfillment</i> . By clicking on the one corresponding to the <i>Primary needs Fulfillment</i> , the user will access and read the content of the page. From there, the user will apply to edit changes.
<b>Use Case</b>	Relational Area - Patient Profile
<i>Description</i>	From the homepage the user will access the “Relational Area”. The access to the relational area will permit the user to read the <i>Patient Profile</i> .
<i>Actor(s)</i>	Social-Health Operator (SHO).
<i>Assumptions</i>	The <i>Patient Profile</i> will contain the information as specified in Chapter 8, Section 8.5.1.
<i>Steps</i>	The user will access the “Relational Area” by clicking on the corresponding button on the home page. Afterwards, the system will display two other icons. Each icon will correspond respectively to <i>Patient Profile</i> and <i>Care Team Description</i> . By clicking on the one corresponding to the <i>Patient Profile</i> , the user will access and read the contents of the profile of the patient in object. From there the user will also have direct access to the health status.
<b>Use Case</b>	Relational Area - Care Team Description
<i>Description</i>	From the homepage the user will access the “Relational Area”. The access to the relational area will permit the user to read and edit the <i>Care Team Description</i> , namely the page that contains the information on the primary caregivers that assist the patient.
<i>Actor(s)</i>	Social-Health Operator (SHO).
<i>Assumptions</i>	The <i>Care Team Description</i> will contain the information as specified in Chapter 8, Section 8.5.1.
<i>Steps</i>	The user will access the “Relational Area” by clicking on the corresponding button on the home page. Afterwards, the system will display three other icons. Each icon will correspond respectively to <i>Patient Profile</i> and <i>Care Team Description</i> . By clicking on the one corresponding to the <i>Care Team Description</i> , the user will access the list of the primary care professionals who assist the patient. By clicking on either “name” on the list, the user will access the information (see Chapter 8, Section 8.5.1) on that specific professional figure. From there, the user will apply to edit changes.
<b>Use Case</b>	Activities - Bulletin Board

<i>Description</i>	From the homepage the user will access the “Activities”. The access to the activities will permit the user to read and edit the <i>Bulletin Board</i> , namely the page that contains the information on the events and important information on the nursing homes.
<i>Actor(s)</i>	Social-Health Operator (SHO).
<i>Assumptions</i>	The <i>Bulletin Board</i> will contain the information as specified in Chapter 8, Section 8.5.1.
<i>Steps</i>	The user will access the “Activities” by clicking on the corresponding button on the home page. Afterwards, the system will display two other icons. Each icon will correspond respectively to <i>Bulletin Board</i> and <i>Calendar</i> . By clicking on the one corresponding to the <i>Care Team Description</i> , the user will access the “board” listing, in chronological fashion, the information made available by the nursing home. From there, the user will apply to edit changes, in order to add and delete events and information.
<b>Use Case</b>	Activities - Calendar
<i>Description</i>	From the homepage the user will access the “Activities”. The access to the activities will permit the user to read and edit the <i>Calendar</i> , namely the page that contains the appointments, and events of respectively the patient and the nursing homes.
<i>Actor(s)</i>	Social-Health Operator (SHO).
<i>Assumptions</i>	The <i>Calendar</i> will contain the information as specified in Chapter 8, Section 8.5.1.
<i>Steps</i>	The user will access the “Activities” by clicking on the corresponding button on the home page. Afterwards, the system will display two other icons. Each icon will correspond respectively to <i>Bulletin Board</i> and <i>Calendar</i> . By clicking on the one corresponding to the <i>Calendar</i> , the user will access the “calendar”. There the user will read and edit events.

Table A.3: Doctor and Nurse - Description of Uses Cases

<b>Use Case</b>	Sign-In
<i>Description</i>	To access the system, a user should be provided with username and password. The access to the system through username and password will grant the user to read and edit the system in accordance with their permissions.
<i>Actor(s)</i>	Doctor and Nurse (D&N).
<i>Assumptions</i>	The doctor and nurse should be provided with the username and password by the administrator of the system. The username and password will protect the system, thus to protect the data regarding the patient.

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<i>Steps</i>	The user will open the system, the system will ask username and password. The user will enter username and password and by clicking a “sing-in” button, the user will access the system, which will display a list of all the residents of the nursing home. By clicking the name of any patient, the user will access a “home page” with all the sub-functions of the system (see following use cases) that concern the patient in object.
<b>Use Case</b>	Health Status - Event History
<i>Description</i>	From the home page the user will access the “Health Status”. The access to the health status will permit the user to read and edit the <i>Event History</i> .
<i>Actor(s)</i>	Doctor and Nurse (D&N).
<i>Assumptions</i>	The <i>Event History</i> will contain the information as specified in the Chapter 8, Section 8.5.1
<i>Steps</i>	The user will access the health status by clicking on the corresponding button on the home page. Afterwards, the system will display three other icons. Each icon will correspond respectively to <i>Event History</i> , <i>Monthly Report</i> and <i>Primary needs Fulfillment</i> . By clicking on the one corresponding to the <i>Event History</i> , the user will access and read the content of the page. From there, the user will apply to edit changes.
<b>Use Case</b>	Health Status - Monthly Report
<i>Description</i>	From the home page the user will access the “Health Status”. The access to the health status will permit the user to read and edit the <i>Monthly Report</i> .
<i>Actor(s)</i>	Doctor and Nurse (D&N).
<i>Assumptions</i>	The <i>Monthly Report</i> will contain the information as specified in the Chapter 8, Section 8.5.1
<i>Steps</i>	The user will access the health status by clicking on the corresponding button on the home page. Afterwards, the system will display three other icons. Each icon will correspond respectively to <i>Event History</i> , <i>Monthly Report</i> and <i>Primary needs Fulfillment</i> . By clicking on the one corresponding to the <i>Monthly Report</i> , the user will access and read the content of the page. From there, the user will apply to edit changes.
<b>Use Case</b>	Health Status - Primary Needs Fulfillment
<i>Description</i>	From the home page the user will access the “Health Status”. The access to the health status will permit the user to read and edit the <i>Primary needs Fulfillment</i> .
<i>Actor(s)</i>	Doctor and Nurse (D&N).
<i>Assumptions</i>	The <i>Primary needs Fulfillment</i> will contain the information as specified in the Chapter 8, Section 8.5.1

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<i>Steps</i>	The user will access the health status by clicking on the corresponding button on the home page. Afterwards, the system will display three other icons. Each icon will correspond respectively to <i>Event History</i> , <i>Monthly Report</i> and <i>Primary needs Fulfillment</i> . By clicking on the one corresponding to the <i>Primary needs Fulfillment</i> , the user will access and read the content of the page. From there, the user will apply to edit changes.
<b>Use Case</b>	Relational Area - Patient Profile
<i>Description</i>	From the homepage the user will access the “Relational Area”. The access to the relational area will permit the user to read the <i>Patient Profile</i> .
<i>Actor(s)</i>	Doctor and Nurse (D&N).
<i>Assumptions</i>	The <i>Patient Profile</i> will contain the information as specified in Chapter 8, Section 8.5.1.
<i>Steps</i>	The user will access the “Relational Area” by clicking on the corresponding button on the home page. Afterwards, the system will display two other icons. Each icon will correspond respectively to <i>Patient Profile</i> and <i>Care Team Description</i> . By clicking on the one corresponding to the <i>Patient Profile</i> , the user will access and read the contents of the profile of the patient in object. From there the user will also have direct access to the health status.
<b>Use Case</b>	Relational Area - Care Team Description
<i>Description</i>	From the homepage the user will access the “Relational Area”. The access to the relational area will permit the user to read and edit the <i>Care Team Description</i> , namely the page that contains the information on the primary caregivers that assist the patient.
<i>Actor(s)</i>	Doctor and Nurse (D&N).
<i>Assumptions</i>	The <i>Care Team Description</i> will contain the information as specified in Chapter 8, Section 8.5.1.
<i>Steps</i>	The user will access the “Relational Area” by clicking on the corresponding button on the home page. Afterwards, the system will display three other icons. Each icon will correspond respectively to <i>Patient Profile</i> and <i>Care Team Description</i> . By clicking on the one corresponding to the <i>Care Team Description</i> , the user will access the list of the primary care professionals who assist the patient. By clicking on either “name” on the list, the user will access the information (see Chapter 8, Section 8.5.1) on that specific professional figure. From there, the user will apply to edit changes.
<b>Use Case</b>	Activities - Bulletin Board
<i>Description</i>	From the homepage the user will access the “Activities”. The access to the activities will permit the user to read and edit the <i>Bulletin Board</i> , namely the page that contains the information on the events and important information on the nursing homes.

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<i>Actor(s)</i>	Doctor and Nurse (D&N).
<i>Assumptions</i>	The <i>Bulletin Board</i> will contain the information as specified in Chapter 8, Section 8.5.1.
<i>Steps</i>	The user will access the “Activities” by clicking on the corresponding button on the home page. Afterwards, the system will display two other icons. Each icon will correspond respectively to <i>Bulletin Board</i> and <i>Calendar</i> . By clicking on the one corresponding to the <i>Care Team Description</i> , the user will access the “board” listing, in chronological fashion, the information made available by the nursing home. From there, the user will apply to edit changes, in order to add and delete events and information.
<b>Use Case</b>	Activities - Calendar
<i>Description</i>	From the homepage the user will access the “Activities”. The access to the activities will permit the user to read and edit the <i>Calendar</i> , namely the page that contains the appointments, and events of respectively the patient and the nursing homes.
<i>Actor(s)</i>	Doctor and Nurse (D&N).
<i>Assumptions</i>	The <i>Calendar</i> will contain the information as specified in Chapter 8, Section 8.5.1.
<i>Steps</i>	The user will access the “Activities” by clicking on the corresponding button on the home page. Afterwards, the system will display two other icons. Each icon will correspond respectively to <i>Bulletin Board</i> and <i>Calendar</i> . By clicking on the one corresponding to the <i>Calendar</i> , the user will access the “calendar”. There the user will read and edit events.

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