CASE STUDY

Who Cares Where?

A Pivotal Ethnographic Study for Italian Hospital Homecare

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The case study presented is an in-depth view on the project "Casa nel Parco" (translated as "the House in the Park"), a three-year, European-funded project (ERDF Funds 2014-2020) in the Italian region of Piedmont that involves 4 hospitals, 2 large companies, 14 small-medium enterprises, 2 universities, and 2 private research centers. The goal is to research and innovate hospital-homecare services for elderly and ALS patients, as well as their caregivers, through the implementation of e-health solutions. The uniqueness of our case study lays on the fact that our ethnographic work was pivotal in shifting the narrative of closed hospital ecosystems (Goffman 1961); where those outside of the hospital environment are not viewed as credible or essential sources for improving the care system. In this study we share how we built trust and negotiated a complex network of stakeholders and technical systems to successfully influence the design of homecare services. Ethnography played a major role in identifying user requirements (patients, caregivers, healthcare professionals) and in building scenarios for product and service prototype development, technology adaptation, and testing. In this way, ethnography and design were used as holistic and critical approaches to addressing health challenges and change. Successful implementation could therefore be considered as a socio-technical design challenge, rather than a pure technological design challenge, emphasizing a non-conflationary approach in which the social and the material are held apart for the purpose of exploring their interplay (Mutch, 2013). The key success that ethnography brought was in identifying how technical systems that were designed in the abstract could be used for the very real and specific problems faced by the elderly and ALS patients needing homecare.

Keywords: hospitals, ethnography for technology, EU-funded project

WHY IS IT IMPORTANT TO SPEAK ABOUT HOSPITALS AND HOME CARE IN ITALY?

To begin, it is important to recognize the lack of existing literature regarding ethnographic work within funded hospital projects in Italy. The literature regarding ethnography in hospitals outside Italy (Goffman, 1961; King, 1962; Van der Geest & Finkler, 2004), identifies two main aspects, which are also relevant for the Italian context: 1) reluctance by the hospital to open space for observation and ethnographic research and the fact that 2) hospitals are closed institutions with no fluidity between the inside and the outside or among the stakeholders dealing with its particular setting. Using ethnography to

identify user requirements is *per se* innovative considering the Italian cultural context. The ethnography conducted focused on two different hospital departments that provide homecare services in the Piedmont Region: the geriatric department for acute care at the Molinette Hospital in Torino and the Regional Expert Center for ALS at the Maggiore Hospital in Novara (CRESLA). The patient services offered by these hospitals are unique in that care also takes place outside the hospital walls. They reflect a willingness to shift the model of care, made by the hierarchical doctor-patient relationships, by integrating important actors within the model, such as caregivers and the home setting (Milligan, Roberts, & Mort, 2011). However, despite the excellent results, this service still encounters major resistance in terms of transferability to other clinical settings. Indeed, literature shows that too often, older and more fragile patients are excluded from telecare system design and implementation is often wrongly seen as a one-off event (Delle Fave & Marsicano, 2004). In contrast, the project presented here aims at supporting safety, autonomy, and the independent living and welfare of frail, old and disabled people (Orlikowski & Robey, 2001). The current viral epidemic in Italy, which has hit the country's northern regions in particular, has demonstrated the need for good, alternative models of care that are able to change the health ecosystem.

HOW TO POSITION AND PRESENT ETHNOGRAPHY IN A WORLD THAT DOESN'T KNOW IT

Clinical settings and the field of medical device engineering are not comfortable dealing with qualitative research, due to their resistance in allowing outsiders to observe internal modes of working (Zaman, 2004). In order to perform ethnography in a medical setting and deal with diverse stakeholders who do not necessarily know what ethnography is, we had to build trust. We also had to educate people about our research methods, data analysis, and goals. This was primarily done by using a participatory and collaborative approach able to respond to any doubts, perplexities, and needs of the partners and stakeholders.

Diverse stakeholders may hold different assumptions, values, and worldviews. They may also 'talk past' one another and compete for recognition and resources. In order to achieve the project goals, a more effective inter-stakeholder dialogue was set up to establish an organizational vision that better accommodated competing discourses. Performing stakeholder interviews was the best way to engage with project partners—as said, there were many and not all of them were clear about our tasks for the project. The word *stakeholder* is here intended to refer to the 25 technology partners that were part of the project and the two hospital centers considered for the research. Secondly, interviews allowed us to understand the initial assumptions regarding users. This was very important because the different technologies considered for the project were born originally for different purposes and users. For example, we understood that most of the stakeholders were not clear with the idea that patients under the care of the geriatric department were in an acute state, meaning that they were heavily sick, most probably with Alzheimer's in a serious stage. They were expecting active elderlies, able to self-manage their care (Milligan, Roberts, & Mort, 2011).

Hospitals and centers were both stakeholders and final users of the technologies in place. We performed stakeholder interviews as exploratory research to set expectations and to establish rapport. After that we started working closely with doctors and nurses in the design of the research protocol. This collaboration changed our initial idea of ethnographic

research. From a methodological point of view, we had planned an ethnography based on shadowing in both hospital and home environments, interviewing selected caregivers and patients according to a rigid scheme of inclusion criteria. With shadowing, our idea was to spend some time at the hospital to observe nurses' work, a typical workday, and documenting patients' households with pictures. We had to redefine our methodology in order to be more flexible on recruitment and to find a way to observe nurses' work and spend time with caregivers. We also had to conduct interviews with the counselor of the hospital homecare service as a representative of the hospital.

We also experienced more reluctance from one hospital department, which was supposed to be the third field where we planned to conduct our research. But unfortunately, we haven't been able to present our methodology and negotiate ways to overcome their fear of letting us in. So, we never performed research in that department. Finally, we had the chance to interview 5 caregivers and 2 patients, and 5 healthcare professionals from the OAD service and 6 families and 10 people of the clinical staff from CRESLA.

The opportunity to create a bridge between the hospital staff and our team has allowed us to enter the field more easily and perform research while accompanied by a representative of the hospital who could witness and understand our methodology firsthand. We were in dialogue with both the public and the private sector but as our main work was about users, we felt engaged in creating a good relationship with hospitals and their staff.

Performing ethnography has required clear explanations and formal approvals, especially when accessing the patients and caregivers at their homes when under the care of the hospital. Negotiating and communicating the approach has been an important part of our contribution to the project. It has also allowed us to improve our understanding of how to interact with healthcare institutions, healthcare professionals, and cross-sector partners. The designers, anthropologists, and ethnographers learned this while conducting the research itself, aided by their unique position: liaising between healthcare professionals and project partners; entering patients' homes and aligning mutual expectations and needs. Of course we had to adapt our design-anthropological language, trying to translate it in a more scientific way avoiding any misunderstandings about our objective and methods. During a meeting with doctors, we faced some challenges with their understanding of the reasons for a certain approach, more qualitatively, instead of the usage of tools like surveys. Fortunately, in the same room was the radiologist, a very empathetic professional, who had encountered qualitative methods in his career, and he helped us to translate, by making comparison with the clinical study language.

Adopting a human-centric approach means advocating for a scientific methodological *apparatus* able to understand and properly represent the life conditions of the final users, negotiating expectations with partners and adapting research methods to be as non-intrusive as possible. The final goal is to provide evidence and support evidence-driven innovations that can make a difference for healthcare ecosystems. The research focus, therefore, was to consider how homecare can support patients while contributing to a reshaping of place and the care experience. This was done by addressing the ways in which remote care systems can act:

to change the experience of the home;

to re-order the place of care-work, as new actors become enrolled within the care
    network and existing caregivers take on different roles and responsibilities.

LOOKING TO THE PRESENT TO IMAGINE THE FUTURE OF ALTERNATIVE HEALTHCARE SERVICES

Many of the companies that develop medical devices are engineering based, yet they do not integrate a user centered or participatory design approach in their development process. Most of the devices that were tested as part of the pivotal project study have a unique genealogy that considers a different kind of user than those at the center of the two homecare services we researched. For example, they might ignore the role of caregivers, or fail to consider chronic patients who are not experiencing acute episodes, or dismiss the delicate relationship between doctors, nurses, and their patients. Perhaps the technology employed was originally created for nephrological patients able to self-manage their treatments. It may not, therefore, think about elderly people with dementia. Or, it may assume caregivers are young people and not daughters and sons in their 60s who are not used to technology, or anyone who is a non-native Italian speaker. Ethnography was conducted to collect and understand user requirements, which were then shared during participatory workshops attended by the partners of the project, including representatives of the two hospital homecare services involved in the study. More than ethnography itself, these workshops gave us the chance to present the analysis derived from it, under the form of user requirements.

We began by organizing a participatory stakeholder workshop, which was an excellent opportunity to bring together key players to discuss relevant topics and engage with new ways and tools to research homecare effectively. The success of the workshop was determined by two key aspects:

1. For the first time, partners could have a clear picture of the homecare service provided by the geriatric department thus understanding the different roles and needs of healthcare professionals, caregivers, and patients.

2. The 25 partners involved could align themselves with each other's functions and devices (for the first time) and define where to locate their solution within the services process.

As the solutions provided by the different partners were already developed, our role was mostly to escalate some of the functions, bearing in mind that most of the devices were originally developed for other kinds of patients or clinical contexts. Most of the companies partnering on the project saw user and ethnographic research as new concepts that could be integrated in their work. Our research found that caregivers desired to have more self-reliance and assurance that they were performing care tasks correctly, and so our recommendations focused on identifying ways that these systems could provide safety mechanisms and instill confidence. Some examples of user requirements we shared with partners were: in case of wounds, it could be beneficial for both caregivers and nurses to share pictures from a distance in order to monitor the correct procedure of medication and keeping as an archive, in order to avoid loss of record keeping information between nurses. Another example was for the caregiver to consult video tutorials or other toolkits in order to manage unexpected situations as many caregivers avoid calling nurses for fear of disturbing

them. Additionally, having the possibility to communicate with CRESLA from home, through video-calling, especially when the patient is in the first phase of adaptation to the ventilator and the caregiver might not be completely comfortable with the self-management of the device. Sometimes technology has to respond to apparently small needs where the level of innovation is not on the technical aspect but on the impact on the quality of life and well-being of users.

As a result, we had two main successes during the research—three if we consider the challenging path to gain the hospitals' trust. The first success was related to the partnership between two companies: Celi, an AI and language technology company, and Panacea, a Società Cooperativa Sociale (*social cooperative organization*). The two companies decided, based on our research, to collaborate and create a virtual assistant which will be integrated into educational material for caregivers' support. This can be considered a success because their solution was specifically designed for the context of the project, personalized on the relationship between nurses and their patients, and the training sessions with caregivers.

The second success was the design of a prototype concept as a solution aimed at meeting the user requirements identified during UX research activities. A hi-fi prototype platform named GoCare was finalized, taking into consideration major pain-points and user needs—especially those regarding the management of the hospitalization at a homecare service, and the logistics planning required for its delivery. GoCare is software that enables medical staff to monitor the status of patients, schedule the home visit calendar, and manage logistics, and medical teams. It is important to understand that in homecare services, there is an externalization of hospital services to home, meaning that a complex number of people and resources are moving around the city. This means that thoughtful organization and communication is a must. Currently everything is done manually, so there is a lot of paperwork that moves in and out from the hospital. The main objective of the platform is to support organizational tasks, allowing more efficiency but also more time with patients.

Informed by ethnographic research, the digital platform is meant for doctors and nurses and is integrated with the needs expressed by the caregivers. It was presented to the medical staff and usability testing is currently in progress. The platform is receiving positive feedback considering the high value of optimizing and simplifying daily work. While it can relieve the staff from paperwork and workarounds in their flow, it is important to note that the platform is based on a highly significant element that was identified and understood only due to the research: the intimate and trusting relationship between the medical staff and their patients and caregivers. Indeed, this aspect is at the center of the homecare service and still represents the most valuable characteristic that enables hospitals to provide good (e-)care. In a world of increasingly heterogeneous and interconnected contexts, and domains of design, production and use, the aim is not merely 'getting closer' to final users (healthcare practitioners, doctors, patients, caregivers) and real-life contexts, through familiarization, mediation, and facilitation. The aim is also to create a critical and theoretically-informed distance from which to perceive and reflect upon complex and situated relations between people, technology, and design.

CONCLUSION

The Casa nel Parco project is ongoing and will be closed by the end of the 2020 calendar year. The devices developed during the project are part of a trial, including testing their

efficiency in adapting to homecare service and reducing caregivers' stress by implementing the service. Before concluding, we want to share the most important lesson learned, which is related to how difficult it could be to enter the field and perform ethnography in hospitals. Hospital institutions are closed and very protective environments that do not speak our same language. Involving them in the research and partnering with them during the work has been the key action to create trust and collaboration. Human-centricity and participatory design are often buzzwords, especially for medical devices that may show a one-size-fits-all mentality. Ethnographic data is actionable, but deserves to be explained via workshops and participation. Ethnography has the enormous value of bringing people together. When ethnography is told, the audience is allowed to see beyond their algorithms and measurements. It helps in designing functionalities that can leverage on the strengths of human relationships. Homecare services provided by hospitals are based on the idea that they can be effective when the entire care ecosystem is human centered. These kinds of services change the relationships between doctors and patients, allow caregivers to perform an active role and delete the hostility of the clinical environment. These are all elements that can only be seen and told through the ethnography and every future technology should consider taking this lesson into account in order to start from there. In the next phases of the project we will look at caregivers' and healthcare practitioners' experiences with the devices, for new narratives to emerge. Ethnography actively contributed to conceptual debates around institution and ex-titution—that is, the de-territorialization of the physical structure of the institution and its re-manifestation through new spaces and times that seek to end interior and exterior distinctions.

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