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641. Co-Designing The Future Of The Cancer Ambulatory Care Shift: An Exploratory Study Of Stakeholder Needs

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ABSTRACT Today, as a result of the political will to reduce congestion in hospital and the recent move toward outpatient care, an increasingly number of people with cancer are receiving care at home. This paper discusses a participatory project that entailed the conceptualization of an innovative healthcare concept for persons concerned by the French ambulatory care shift. Starting from the idea that the traditional home care services fail to anticipate the needs and wishes of this growing group, the goal of this project was to involve care receivers, relatives and other stakeholders (caregivers, policy makers, social workers, private medical practitioners, etc.) in defining and developing such a concept for the near future.

Rooted in the principles of participatory design, the project consisted of a 2-year period of observation, workshops and participation in activities with more than 50 stakeholders in 3 French regions, in order to deepen the understanding of living with cancer, gain sensibility toward working with this population, and to learn how they are engaged in activities in non-institutional environments. Furthermore, this study aimed to inspire tools and design services through identifying aspects considered to be relevant for a subsequent design process.

Preliminary findings revealed that the combined methods used in this study were fundamental to notice various details regarding the everyday life of care receivers, relatives and non-institutional practitioners, while ensuring that a design perspective was kept. Also, experiencing how a participatory project is structured (the project was led by 2 patient associations), and how people with varying abilities engage in several stages of the project raised important insights into the inclusion of people with chronic diseases in the design process.

Keywords: Participatory design, co design, design methods, design for care, design for health, home healthcare concept, cancer



Introduction

Over the last 20 years, health research has been impacted by defining transformations in care (chronification of acute pathologies, ambulatory care, predictive medicine, gene therapy, etc.). This paradigm shift allowed designers to play a key role in the conception of objects and services supporting the technological innovations and societal changes (Jones 2013). It appears that the introduction of design in healthcare institutions and laboratories fosters a freedom to imagine, create, manufacture, and overall improves the ability of researchers and clinicians to tackle the challenges facing healthcare (Carmel-Gilfilen and Portillo 2016).

Nevertheless, the structuring of healthcare systems and institutions remains difficult to fully apprehend, and working in that field is a challenge (Jones 2013). For those reasons, the literature suggests that it is best for designers willing to work in the health sector that they use a “participatory” approach (also called co-design), whilst collaborating with multidisciplinary and pluri-professional teams (Bate and Glenn 2007; Reay et al. 2016).

This paper presents our design research project called “CancerAdom”, that enables every individual involved in cancer ambulatory care in France to participate to the elaboration of a patients care that is of high quality, safe and suited to patients’ needs. First, we will have a look at the French context of home care for chronic and severe illnesses that increases inequalities and disparities. Secondly, we will present the methods we used during our project to highlight our work of co-design in the making. Lastly, we will try to answer the following questions: what is made possible with the use of mixed approaches between co-design and anthropological methods in the making of research design projects in the health sector? How can co-design tools help foster pluri-professional and multidisciplinary collaboration? How can they help empower the sick and vulnerable people?

Context

In 2017, in France, there was an estimated 400,000 new diagnosed cancer cases. Over the same period, over a million people were hospitalized in relation to the diagnosis, treatment or surveillance of their cancer (INCA 2017).

The significant developments in cancer care imply a paradigm shift from healthcare to ambulatory and home care. This evolution raises hopes in terms of system improvement and quality of life of patients. But it is also a cause of concern for professionals in the field (general practitioners, pharmacists, nurses, physiotherapists, etc.) given the specificity of some pathologies and the emergence of complex and poorly known therapies. This concern is aggravated by challenging working conditions, due in part to a declining medical demography and in another part to a problematic coordination with hospitals. The situation is made worse by the vulnerability of some patients facing financial difficulties, or even in extremely precarious situations. There is an increase of social and territorial inequalities in home care (unequal geographical distribution of care, heterogeneity of housing, family situations, incomes, etc.).



The Plan Cancer 3 (2014-2019)¹ has identified as a priority to reinforce the coordination between hospitals and local caregivers, in urban and rural communities alike. The current discussion around the new organization of home care seems to include the point of views of all stakeholders. Nevertheless, one may wonder what importance is being given to the needs and preferences of patients in this scheme that is going to impact their journey. Institutional action plans have addressed numerous areas of improvement, but they are yet to put users' expectations as a priority. Yet, the valorization of their insight is still a lever for improvement to promote.

In this context, the CancerAdom project was launched and driven by two cancer patient organizations (2) and myself (a design researcher) from February 2016 until September 2017. It was funded by the French Ministry of Health and Solidarity. Its primary goal was to identify the existing and future needs and expectations of home care users in accordance with the patients and their family life project.

In view of the developments in the procedures of care, the working team on the CancerAdom project intended to put the whole spectrum of people affected central to its reflection on the care pathway for patients and their families: i.e. patients, carers, practitioners, hospital and medico social professionals.

Method

In order to focus on the experience of patients, carers and caregivers, we committed to a multidisciplinary approach by mobilising skills from participatory design and anthropology. The method of qualitative data collection, modelled on participatory design tools, meets two essential requirements: on one hand, it highlights propositions emanating from the people directly affected by home care and cancer, and on the other hand, it applies the principles of direct democracy in healthcare, namely to work “with” instead of working “for”. It is embodied in four steps.

Step 1: Immersions

The goals of this first step were the following: working on the ground, at the patients' homes, within their living and care environment, and with their family. Meet with the healthcare professionals in existing structures. Experience the daily life of those people for a given time, immerse oneself in their everyday practices, develop empathy in different contexts, build the mutual trust that is essential to any participatory approach.

Immersion, consisting of observations and exploratory talks, allow the researcher to understand the representation each user has formed of the care pathway, and also of the home care experience (Figure 1). For each instance, we modelled the users' journeys with the help of specific tools (with patients' course charts).

The immersions took place in three regions: Ile-de-France, Auvergne Rhône-Alpes and Hauts-de-France. Within those three different territories, we met with some fifty individuals of different age, socio-professional background, pathology and profile.



Figure 1: Working on the ground, at the patients' homes, within their living and care environment, and with their family.

Step 2: Co-design workshops

The goals of this second step were the following:

- to work “with” instead of “for”.
- to identify innovation levers and obstacles, bringing together a variety of competences by associating patients, health professionals (hospital and local), caregivers and experts.
- to combine points of views for a greater richness and cross-over in the solutions, and gradually change perceptions.

Co-design workshops brought together multidisciplinary teams mentored by a designer who put participants in an active and participative frame (Figure 2). This process stimulated creativity and helped the emergence of fresh ideas in response to questions and issues, using tools created by designers such as a card game, or a bank of ideas to develop (Figure 3).

The workshops allowed us to validate and invalidate propositions all along the unfolding of the project; by submitting them to discussion on one hand, and by imagining the conditions

of their deployment on the territory on the other. Finally, they enabled the ranking of those propositions according to various criteria such as the innovative character of the idea, its relevance in regard of its potential of declination, its implementation, etc.

Three co-design workshops took place in the presence of about fifteen participants in Paris, Lyon and Lille.



Figure 2: Co-design workshops in Lyon with patients, relatives and healthcare professionals.

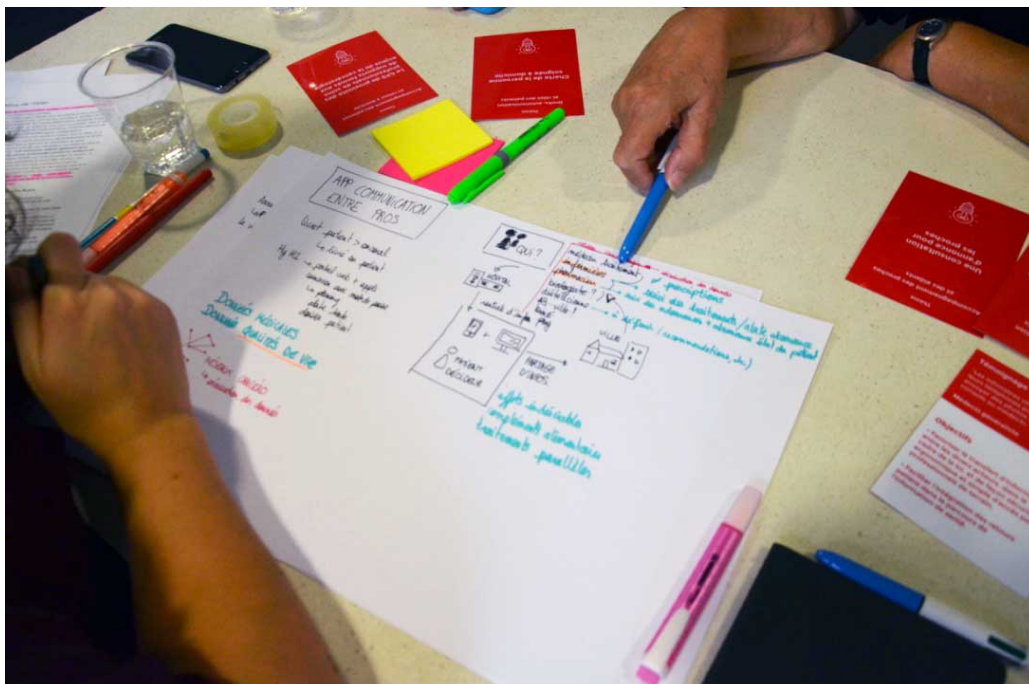


Figure 3: Workshops' tools: card game of ideas to develop.

Step 3: Discussion panels

The goals of this third step were the following:

- to raise awareness among the largest number of people on the issues related to home care and cancer.
- to debate and exchange with all citizens.
- to meet with as many people as possible and disseminate topics usually perceived as anxiety-inducing.

For this third step, we developed a tool for raising awareness called “discussion panel”, a public event with several objectives (Figure 4). First, it is used to raise awareness of citizens on a topic; in this instance home care for cancer patients. It also aims to present topics, ideas and projects from fieldwork through communication tools and ideas presented on tables (mapping, itineraries, thematic trestles, card games, etc.). It allows participants to meet in a dynamic process of exchanges and discussions. It also expands the scope of the propositions.

The discussion panels took place in a media library in Lyon, a community centre in Lille and a school in Paris.



Figure 4: Discussion panel in a community centre in Lille.

Step 4: Output

The goals of this fourth step were the following: using a collective and exploratory approach, it was crucial to track accurately and present in an attractive format the scope of the experiences carried out during the project. In fact, the different steps of this work are as important as the results. It should therefore include two types of schemes.

Firstly, develop communication tools that enable documentation to recount how the project was conducted, and to highlight all the steps taken in real time (photos, videos, articles, summaries, etc.) on a dedicated website (www.canceradom.fr). All documents have free access.

Secondly, to come up with an original output method for the project and its propositions that summarises them in order to continue to raise awareness with citizens. The bottom-up methodology we used on the course of this project is exemplified by the variety of output supports.

Results

The key objectives of this project were:

- Allow all stakeholders to have a say in the making of a new model of home care, and bring democracy (both representative and participatory) in cancer care.
- Come up with solutions aimed at improving home care, based on methodologies grounded in meetings, talks and workshops of co-design that involve all aspects of the healthcare sector.
- Deliver knowledge, education and proposals to be widely shared with patients and carers' current uses, and on innovative care experiences led by patients, carers and healthcare professionals.
- Establish devices that are modelling and reproducible to other chronic pathologies.

The main deliverable of the project is a notebook of citizens' ideas called "Building ambulatory care in cancerology, 10 propositions for a considerate and innovative home care" (Royer and Huguet 2017) that compiles an array of practical measures, enforceable mechanisms and desirable experimentations that could be applied to the territory as a whole.

It is designed to be used as a toolkit for any person interested in improving home care, by introducing ten propositions aimed at bettering cancer patients' home care experiences (Figure 5). These propositions are represented by a variety of new and concrete ideas that can be implemented in the territory (services, tools, communication, professions, legislation aimed to implement in-depth changes to the ambulatory cancer care). The propositions are backed by verbatim, reflecting the realities shared and lived by the people encountered (patients, caregivers, healthcare professionals, etc.). The notebook is completed by inspiring initiatives existing on the territory.



The citizens' ideas notebook has been presented to numerous healthcare institutions, patients and practitioners organizations, as well as public authorities. The stakes of these presentations were to allow local actors to embrace those ideas and develop them locally. The second part of the project that will begin soon will allow designers to assist those actors in developing some of the ideas from the notebook.

Discussion and conclusion

Benefits of a combined approach between co-design and anthropology

The main objective of CancerAdom was a thorough and precise review of what is existing: how are home cancer patients living today? What are their needs and challenges with the new practices in ambulatory care? Anthropological studies are crucial in the healthcare sector that has been impacted by major transformations over the past 20 years and is yet a largely unknown reality (Royer 2015).

Design anthropology is a recent attempt to integrate anthropological research to the process of conception to generate new knowledge as design projects progress (Gatt and Ingold 2013, 139-58). In the case of CancerAdom, it was a two-fold objective:

- On one hand, give a clear picture of the existing situation to account for the experience of patients and their families;
- On the other hand, being able to provide ideas of services, innovations, professions or even new legislation to protect the rights of at home patients, built on analysis of what already exists.

According to Gunn and Donovan (2012, 1-16) who suggest three ways to frame the relation between design and anthropology in a context of project making, we are situated in the "Design Anthropology (DA)" classification, a balanced research method where both disciplines are learning from the other. The anthropologist and the designer work hand in hand exchanging mutual knowledge.

Co-design tools, shared visions of a projects as well as empowerment levers

It's a well-admitted fact that collaboration fosters people's ability to go beyond their partialities and allows a group to expand their ways of thinking, but multi-professional collaboration also enables new and unexpected ideas that enhances the potential for innovation, which can be called the "collaborative advantage" (Kanter 1994).

The novelty aspect in CancerAdom is the introduction of co-design methods as structural elements of the approach, for members of the operational team made of two patients' organizations (about ten patients and former patients), professionals of the healthcare sector (one hospital pharmacist, one doctor, one public health doctor) and four designers and one researcher in design coordinating the methodological component. The creation of tools to facilitate discussion (cards game to relaunch debates, charts of user's course, etc.) was a powerful resource to bring consensus and come up with a shared vision, and help create a

common representation of the project's future (Sanders 2013). It proved particularly useful for the stakeholders who were emotionally distant (including healthcare professionals) who acquired a better comprehension of the topic.

Furthermore, the use of co-design tools assisted patients and their families in their supportive role on the project. Whereas they are considered as “resources people” in anthropological research, they are at the centre of the work in co-design. An example is the creation of charts of users' courses, that proved very useful for patients to describe precisely the different steps, actors and problems encountered. Another example is the card game that was designed for one of the workshops and that contributed to an engaging and friendly atmosphere, allowing participants to overcome their fear of speaking in public. All these objects are reliable mediation objects between the team and participants, and helped create an environment conducive to qualitative data collection, as well as enriching research, both in anthropology and in design.²

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¹ 1. The Cancer Plans are a series of plans launched by the French government in 2003. The goal is the fight against cancer and improving the care of patients.

² 2. The association Cancer Contribution and the French Association of Multiple Myeloma Patients (AF3M).