Excellence In Services International Conference EISIC
Formerly Toulon-Verona Conference, founded in 1998

IMPROVING QUALITY OF FOLLOW-UP SERVICES FOR HEART TRANSPLANT RECEIVERS [*]

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Abstract

Medicine has made enormous progress, and today, many people with heart disease can hope for a new life thanks to a heart transplant. However, concerning the service design, there still seems to be a lot to do to improve the patients’ quality of life once their transplant has been successful. Our paper aims at investigating perceptions and needs characterizing the life of heart transplant patients, and it does so by adopting qualitative methodologies. Inspired by the human-centered approach, typical of Design Thinking, our paper offers insights to improve follow-up services. Its results feature the patients' needs, grouped in specific categories. Results also highlight the information asymmetry between the medical staff and the patients and some protection and organizational issues (working hours, fragmented processes). Our paper suggests some suitable solutions to improve the follow-up services in the specific context of the Veneto Region (specifically, the Centers for Heart Transplant of the Hospitals of Padua and Verona in northern Italy). Our analysis brings out the value of those solutions that meet the profound safety need experienced by the patients. The limitations of our research concern the specificity of the context investigated, the selection of the interviewees and the incomplete adoption of the Design Thinking approach during the Covid-19 emergency; its managerial implications concern the possibility of the practical implementation of one or more solutions, entering a closer link with the institutional stakeholders and the service providers.

Keywords
Health Care, Innovation, Design Thinking, Digital Healthcare, In-depth Interviews, Follow-up services

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[*] Authors declare that this paper is the result of joint work and that paragraphs 1, 2 and 3 are attributable to Nicola Cobelli, paragraphs 4 and 5 are attributable to Elisa Mazzucato, paragraphs 6 and 7 are attributable to Marta Maria Ugolini. This paper and research have been possible thanks to Francesco Calabrò, formerly thoracic surgeon and pioneer of transplantation in Italy, and suddenly a patient in urgent need of a heart transplant.

Dedicated to the dear memory of Mino Della Giustina

1. Design Thinking (DT) as a qualitative research innovative method

Like problem-solving, Design Thinking (DT) is a natural and ubiquitous human activity. Needs and dissatisfaction with the current state, combined with a determination that some action must be taken to solve the problem, is the start of a design process. In this view, many scientists have been designing as designers throughout their careers, albeit often not being aware of or recognizing that they are performing in a design process (Braha and Maimon, 1997).

In a 2013 interview with a well-known program dealing with innovation themes, David Kelley describes DT, i.e. an innovative approach that combines human behavior and design, whose distinctive characteristics can be summarized as follows: human-centered approach (a deep understanding of human behavior), interdisciplinarity and co-creation, creativity, and propensity for “crazy ideas” that allow going beyond the limits of knowledge (Razzouk and Shute, 2012).

The origins of DT are attributable to different contexts, such as the fine arts, the natural sciences, or even the more recent social sciences (Buchanan, 1992). The disparity of opinion on its derivations has led scholars to dig further thoroughly in the scientific method; in the 1960s, to understand its main aspects, an attempt was made to give it an exclusively scientific basis, aimed at understanding its influences and justifying its processes and methodologies (Cross, 2001). However, DT serves to define a holistic concept for which a system cannot be reduced to the simple mechanics of the elements that compose it. DT is therefore explained as a liberal art or as “a discipline of thought that can be shared, at a certain extent, by all men and women in their daily life, and is, in turn, mastered only by those who put it into practice using a different perspective and manage, in some cases, to advance it towards new areas of innovative application” (Buchanan, 1992).

The practice of DT is relatively recent, and it is only in the last twenty years that it has begun to attract some interest among national and international companies. To date, DT is widely applied both in the study programs of Engineering, Economics and Business Management schools. Compared to the traditional technocentric innovation approach and management philosophies, based solely on the use of existing strategies (eminently focused on the appearance and functionality of products), DT represents a design process that aims at finding new opportunities for the resolution of existing problems ("problem solving") and at redefining problems to find new innovative solutions ("problem finding") (Martin and Euchner, 2012). This process is conceived as a way of thinking that, thus, leads to transformation, evolution, innovation, new ways of living and new ways of managing the business (Lewrick, Link & Leifer, 2018). Not only is it an engine for innovation, but it offers new process models and tools, which contribute to the discovery and creation of value, which help to conceive the creative process differently and improve it, making it accessible to multidisciplinary teams (Kimbell, 2011). DT is, therefore, in all respects, a cognitive process, a mental attitude and an effective tool for every innovative process that connects the creative approach typical of design to traditional business thinking based on planning and rational problem solving (Kolko, 2018).

Tschimmel (2012) describes DT as a design method based on the ability of designers to consider at the same time: (a) human needs and new ways of life, (b) material availability and technical resources, and (c) limits and opportunities of a project or a business. The integration of these three factors requires designers to be both analytical and empathic, rational and emotional, methodical and intuitive, aware of planning and of the various limitations, but at the same time spontaneous. Design is therefore characterized by an open transformation process, in which information on the project and knowledge of the material is as important as creative thinking (Pombo and Tschimmel, 2005).

This combination of skills can be summarized in what Pombo and Tschimmel (2005) called “dichotomy sapiens-demens”, or “knowing-not knowing”, and is in effect the key element of DT. While constructivist thinking is conceived as a “self-organized information system” that narrows the vision into pre-set schemes, design is conceived as an activity, an intuitive and emotional process, which combines with rational thinking and completes it. Other researchers call this type of dualism “abductive thinking” (Martin, 2009), or “perceptual cognition” (Tschimmel, 2010). Abductive thinking, which incorporates a term of Aristotelian origin, was coined in the 15th century by the American philosopher Charles Sanders Pierce. Abduction, according to Pierce, is the only form of reasoning capable of increasing our knowledge (Peirce, 1935). It allows us to hypothesize new ideas, guess, and foresee; Pierce also argues that no new ideas can be produced by deduction or induction using past data (Martin, 2009). Therefore, abductive thinking indicates a way of thinking about future possibilities that are not yet present in existing models according to new and different perspectives. Connected to the concept of abductive thinking is Tschimmel’s “perceptual cognition”, understood as the complex process of exploiting at the same time the input of stimuli and the reasoning on their characteristics, or more simply, the basic ability in the creation of new realities and new products (Tschimmel, 2010).

From these concepts, it can be understood that among the cardinal principles of DT, the so-called creative mindset stands out, which mixes reasoning with the creative side, pushing to think outside the box of reality as it is perceived and known. Creativity, therefore, must be an essential feature of every designer, who must feel free to overcome the limits imposed by their training and the setting of their thinking.

To let people understand the relevance and usefulness of the creative side in DT, Tschimmel (2012) also emphasizes the importance of sketching and prototyping. Referring to the studies of designers such as Lawson (2006), Goldschmidt (2003), and Cross (2001), Lawson suggests that designers frequently use sketching, drawings, and models to simultaneously explore the problem and the solution of the project (Lawson, 2006). In fact, sketching is defined as an extension of the mental imaginary (Goldschmidt, 2003); thoughts take shape and are visualized to expand the problem-space and discover new aspects. Similarly, building the first prototypes represents a method to visualize new solutions, and this makes it one of the main tools for applying DT. Therefore, transforming an idea into a testable model is an indispensable step in the creative process and, since the cost of the material is relatively low, it allows for errors and failures. Therefore, understanding and accepting errors is fundamental within these processes, and it is undoubtedly an element of differentiation that distinguishes DT from traditional managerial thinking (Tschimmel, 2012).

This way diversified and limitless exploration is favored, to the detriment of pursuing a path aimed at obtaining a pre-established result (IDEO, 2015, p. 3). Thus, the learning process of designers is fueled by a creative trust that leads to finding inspiration in the most unexpected places, promotes experimentation and embraces, with optimism, the failure of one’s ideas, making the path to the solution less insidious.

The second fundamental principle of DT is the so-called human-centered approach. The IDEO team defines this approach as follows: “Embracing the theory of human-centered design means believing that all problems, even the seemingly intractable ones such as poverty, gender equality and clean water, are solvable. Furthermore, it means believing that the people who face those problems every day are the ones who hold the key to their answer. Human-centered design offers all problem solvers the opportunity to design with communities, to deeply understand the people they are trying to serve, to dream dozens of ideas and to create new innovative solutions that lay their foundations on real needs of people” (IDEO, 2015, p. 9).

Therefore, the key ingredients for the success of a project are constituted not only by creativity but also by the deep understanding of people and the ability to create new solutions based on their true needs. Knowledge of behavioral psychology plays a crucial role in this design phase because it allows understanding how to extrapolate the unexpressed needs of the user (Brown, 2009). The human approach offers the opportunity to start a process where the user is not only the recipient but also, he/she plays an active role in the development phase of the project. In this regard, it is talked about participatory design (Lee, 2008), or co-creation and interdisciplinarity (Brown, 2009): designers develop innovative solutions by working in teams with colleagues (designers, engineers, marketing specialists), researchers, stakeholders and, increasingly, with end customers. Users are considered equal to experts in the design process because of their interaction with the project development context and their deep experience of products or services (Brown, 2009).

Building a multi-minded project is undoubtedly better than acting alone, but it also implies challenges. For example, filling a project of individuals with very different specializations and backgrounds requires knowing how to select people with great adaptability; on the other hand, the key to unlocking the creative power of every organization lies in the ability of everyone to become an integral part of the interdisciplinary environment, in which he/she is embedded, or to have a strong predisposition for collaboration among all disciplines. In the end, this is the ability to distinguish between a project carried out by a multidisciplinary team and a project that is instead the result of real collaboration.

This paper is organized as follows: the second section frames the topic of DT and digital opportunities in the context of health care industry; the third section briefly depicts the research model and methodology, providing some details on the circumstances that lead to adopting a more focused approach to DT. The fourth section summarizes the main findings, with three thematic nuclei and various categories of perceptions and needs (e.g., activities, health conditions, relationship with the transplant center…) resulting from the text analysis. The study's findings are critically discussed in the fifth section, while the final session summarizes the limitations and further opportunities of this project.

2. DT and digital opportunities in the healthcare industry

To create a valuable solution for the recipients, it is important to know the environment in which they live, look at and experience it through their eyes, and listen to their stories. According to Brown (2009), "the mission of Design thinking is to translate observations into insights, and insights into products and services that will improve lives ". In this sense, the practice of DT enables creativity, enhances personal development, and prescribes deep immersion into the topic along with empathetic user research (Wölbling et al., 2012, pp. 121-136). Therefore, building empathy involves an exercise in careful observation of others, listening, collecting stories and points of view, and scrupulously studying people's behavior without personal judgement.

In the healthcare system, empathy plays a fundamental role in the application of DT and forms part of the main solution to relational barriers that often arise in environments in which 'power' relationships are established (Xu, 2019). Some scholars confirm that empathy and person-centered care are both increasingly seen as central to the delivery of good healthcare, with growing evidence that 'empathetic' healthcare professionals can improve patient outcomes, both pharmacologically and psychologically (Derksen et al.,2013); moreover, person-centered care provides the basic framework for many healthcare practices, particularly in primary care (Doug Hardman and Jeremy Howick, 2019).

Patient-centered care, a term popularized by the Institute of Medicine in 2001 (renamed in 2015 the National Academy of Medicine), initially described an approach to care that allows patients to guide their own clinical decisions. Today, its definition is broadened: it is seen as encompassing not only clinical care but also the patient experience, which includes comparing the course of encounters with the patient's expectations and, consequently, assessing the validity and effectiveness of care (Zhao et al., 2016).

Nowadays, patient-centered care has become a priority for healthcare organizations, which are adopting specific policies to achieve goals such as improving the health and well-being of citizens, but also economic goals such as reducing costs, more efficient use of resources and better performance of healthcare organizations (Cavacece et al., 2018). If the application of an approach such as patient-centered care is accompanied by a careful and deep understanding of the patient's needs (empathy), it might be possible to concur to the pursuit of the goal of health care sustainability. However, sustainability is increasingly threatened by factors such as ageing populations, the increase in multiple chronic diseases, the scarcity of financial resources and a growing lack of confidence and dissatisfaction on the part of citizens (Aquino et al., 2018) and which, therefore, needs to find new balances.

One solution to the current problems of health care sustainability is the active involvement of patients in health management through empowerment. Patient empowerment is a concept studied by different scientific disciplines, from medicine to public administration, from marketing to human sciences. The multiplicity of disciplines has not allowed the emergence of an unambiguous and standard definition. Despite the confusion about the meaning of this concept, it can be generally defined as a social process of recognizing, promoting and improving patients' abilities to meet their needs, solve their problems and feel in control of their lives (Aslani, 2013). Promoted by the “Health 2020” program of the WHO (World Health Organization) as the main objective to improve health outcomes, the concept of empowerment is a multidimensional construct with several facets: On the one hand, some scholars emphasize characteristics that relate to the strengthening of patient capacities, such as self-management, health literacy (Annarumma et al., 2017) self-efficacy, self-care and control over health status; on the other hand, the relationship between patients and health professionals is emphasized, whereby potentially improving aspects, such as the communication process, partnership, collaboration, patient-centered care and fair and egalitarian relationships, are highlighted (Cavacece et al. 2018).

The partnership between health professionals and patients at all these stages of development can transform the goals of care, health care delivery and communication systems (Israilov, 2017), allowing for a more agile and integrated system with better outcomes and fewer errors, enabling a focus on preventive intervention and facilitating increased patient autonomy and responsibility (Gummesson et al., 2015).

As an approach promoting disruptive solutions, the human-centered approach of DT constitutes a starting point for improving the sustainability of the health system. However, it is also reasonable to think that an important aid to implementing this process is offered by technology.

In general, the use of information and communication technologies for healthcare applications is considered eHealth (Healy, 2007). However, the concept varies according to the context and institutions in which it is used and is not yet mature in all health-related disciplines. Some scholars claim that eHealth technologies are tools created to improve the health process (Eysenbach, 2001). What would result from their use is, therefore, a new, efficient, and fair way to improve accessibility to health services, which reduces response times, guarantees cost savings, and offers the possibility of developing alerts, improving, ultimately, the therapeutic and diagnostic efficacy of the process itself (Cobelli, 2020, pp. 1-41).

As for the technological component of services, scholars such as Rodrigues et al. (2016) and Black et al. (2011) have identified the most relevant solutions among the applications put into practice at the health level. Furthermore, the classification of these technologies has highlighted the concept of Telemedicine, a term coined in the 1970s, which is used to designate a method of providing health services in situations where the health professional and the patient (or two health professionals) are not in the same geographical position. Telemedicine involves the secure transmission of medical data and health information and can provide good health assistance for activities such as secondary prevention (services dedicated to people classified as at-risk or already suffering from diseases that require constant monitoring, such as diabetes or heart disease) and procedures for diagnosis, treatment, and rehabilitation.

Furthermore, suppose the new needs created in conjunction with the current pandemic in progress are also taken into consideration. In such a scenario, technology, empowerment, and patient-centered care jointly represent the drivers of innovation in the healthcare industry.

3. The complete research model and the focused one: the impact of Covid-19 on the service re-design process

The human-centered approach typical of Design Thinking has inspired the present paper, albeit in a way that was unexpected at the beginning of the research. In December 2019, when the project started, a comprehensive roadmap was set out with a series of participative innovation workshops where patients, caregivers, health professionals and innovation experts had been invited, and specific techniques of active involvement were to be employed. More in details, 10 participative micro labs had to be held during 2020 in 10 Italian cities to collect viewpoints, best practices, actors, and resources, and develop solutions to improve efficacy, accessibility, and sustainability of follow-up services. The micro labs required presence in person and active participation.

Unfortunately, the development of the Covid-19 global crisis has hampered those participative micro labs and has forced us to focus on only one but a fundamental pillar of Design thinking: listening to patients' experiences. As a research team, we have consequently narrowed the scope of our work, but at the same time, we have deepened its analysis level. The focused research model we propose, indeed, has concentrated on the needs of patients and caregivers and has identified some starting research questions, as follows:

- What kind of role and involvement does the heart transplanted patient have within the existing system today?
- What are the problems that a heart-transplant person has to face following the surgery?
- What are the problems that the patient's family members face?
- What kind of relationship does the patient have with their transplant center, and how much do they feel bound to maintain this link?
- To what extent and how does the patient feel conditioned to lead a different lifestyle than the previous one?

To provide an answer to all the above questions and consider the historical moment we are going through, we tried to summarize them in a single - but central - question, which constituted the starting point for the development of the qualitative data collection. Therefore, the research question we tried to answer is the following:

- What does the heart transplant patient need today, considering that existing systems must also keep up with the times and, therefore, be able to provide timely answers to the needs of an ever-changing world?

In this sense, we focused on the follow-up of heart transplant patients in Veneto with a specific focus on the Transplant Centers of Padua and Verona. Our main objective is to investigate the perceptions and needs of patients who have undergone transplant, in order to understand better the context in which they live and interact, and then extrapolate insights that can provide a starting point for the development of innovative solutions, contributing to the implementation of patient-centered health services. To adopt an approach that allowed starting from the users, the investigation was carried out through the use of a qualitative research method. Thus, a collection of extracts of the postoperative experience of the patients was gathered employing semi-structured interviews. The choice to operate using a qualitative analysis methodology was dictated by the fact that qualitative data analysis, unlike the quantitative ones, allows researchers to collect information that describes a topic rather than measuring it (Winter, 2000). The decision to use the semi-structured interview as a means of data collection was, however, dictated by the purpose of use that characterizes it; this system allows the interviewer to keep a trace that shows the main issues that they want to touch during the interview, without however being bound to follow the questions' order. Specifically, the interview outline of the survey was constructed, under the supervision of the rapporteur, by identifying three main thematic nuclei: lifestyle, follow-up, family unit.

In addition to the interview outline, some proposals for innovative healthcare solutions have been included, such as the insertion of a new healthcare professional (referred to as Case Manager) and the use of eHealth technologies, potentially applicable to improve follow-up services.

4. Sampling and data analysis

The selection of the participants was based on two fundamental inclusion criteria: (a) being a heart-transplant subject and/or a relative of heart-transplant patients, and (b) having undergone the surgical operation in a transplant center within the Veneto region (in this case the only centers of reference are those of Padua and Verona). Ten were the subjects interviewed, six men and four women, aged between 38 and 69 years (see Table 1). All the interviews were anonymized to protect their privacy, and fictitious names were provided to the subjects involved in the project. The summary table of the participants' data is shown below, in Table 1.

Table 1 The sample investigated

Name	**Role**	**Age**	**Profession**	**Residence**	**Transplant Center of**
Tania	Patient	38	Employee	Veneto	Verona
Pietro	Patient	57	Employee	Veneto	Padova
Lilly	Patient	53	Employee	Veneto	Padova
Tullio	Patient	46	Freelance	Veneto	Padova
Lucio	Patient	47	Researcher	Veneto	Padova
Vincenzo	Patient	55	Freelance	Veneto	Padova
Giulio	Patient	58	Employee	Lombardy	Verona
Emanuele	Patient	69	Retired	Veneto	Padova
Laura	Relative	55	Employee	Veneto	-
Annalisa	Relative	50	Employee	Veneto	-

Source: our elaboration

Eight of them are transplant patients, including two women, and were interviewed thanks to the intervention of Professor Francesco Calabrò, ex-thoracic surgeon and a heart-transplant patient who acted as a link for the collection of contacts. The other two women in the group were family members of two of the eight patients – wife and sister respectively – and their contacts were collected after the meetings with the participants they relate to. All the interviewees are residents in Veneto, except for one who lives in Lombardy. Of the group of heart transplant recipients, six of them are being followed up by the transplant center of Padua and two, instead, by the center of Verona.

The interviews were carried out remotely, specifically by making video calls via the Zoom platform or via WhatsApp, depending on the availability of the participants. In an attempt to provide a similar effect to interviewing person, all interviewees were asked to use their mobile phone or laptop camera during the calls – when possible, through the use of their own connection. This method was intended to allow better interaction and greater involvement of the participants, creating a less formal virtual environment. All the interviews were recorded, with the consent of the people involved, and subsequently transcribed and analyzed. With the desire to follow the line of thought of the human-centered approach, which is deeply oriented towards empathy and active listening to people, all participants were invited and stimulated to provide a story of their own experience autonomously. The average duration was ranging from a minimum of 60 minutes to a maximum of 120 minutes.

The analysis of the empirical documentation was carried out by dividing the information flow of each interview into segments (or extracts); each segment was analyzed and subsequently reconnected to a question belonging to one of the three thematic nuclei (or macro-categories) of the interview. In this way, it was possible to circumscribe the salient features of the participants' stories more precisely and to provide each unit of text analyzed with a label, thus allowing to build a table with a scheme of categories (Table 2) that can be grouped under the thematic nuclei (Lifestyle, Follow-up, Family). Therefore, with this approach, it was possible to identify numerous points that connect the thoughts and actions of the participants. However, not having followed a pre-established order in the construction of the dialogue, the narratives of the participants turned out to be rather heterogeneous; through the work of reading the documentation, some issues have also emerged which, although related to the guiding thread of the dialogue, cannot be grouped under the thematic nuclei of reference.

During the results discussion, all the categories and related sub-categories identified within the thematic groups will be analyzed; some quotes from the interviewees will be included as well. The reactions to the proposals for innovative healthcare solutions will also be included at the end of the discussion. In Table 2, a summary table of the thematic nuclei and of the categories identified by means of the qualitative analysis is shown.

Table 2 Thematic nuclei and categories emerged

Thematic nuclei	**Categories**
Lifestyle	Activities
	Health conditions
	Relationship with the Transplant Center
Follow-up	Examination process
	Criticalities of the follow-up
Family	Role of family and support
	Issues in follow-up management

Source: our elaboration

5. Thematic nuclei, categories and possible innovative solutions

5.1 The lifestyle

The consequences of heart transplantation can profoundly affect the lifestyle of a person or their family, and influences everyone differently. However, the interviews showed that all participants, especially patients, agreed that having received a new heart brought a great improvement in the quality of life and their physical condition. Confirmation of this change is given by Tania, who testifies:

"Sometimes I even forget that I am transplanted (laughs). I mean, sometimes I find myself doing things [...] like, for example, at work, to do something, I don't think twice about doing it. Obviously, if they tell me that I have to go and climb a mountain, I think about it for a moment, but I have no limits, let's say, I live my life even better, much better than before. On a physical level, everything has improved, absolutely everything: from circulation, to muscles, to breathing, from having breath to do things [...] (Tania).

However, many patients underline that the new lifestyle guidelines after the surgery are represented, first of all, by the directions that physicians give them. All patients try to pay close attention to these directions, to stay healthy and avoid physical repercussions for as long as possible. Only Annalisa reported that Lily, her sister, suffered a marked deterioration in the usual actions to be taken to maintain a healthy and proactive lifestyle. Regarding the lifestyle's macro-category, it was possible to identify three categories, which concern:

a. The activities
b. The health conditions
c. The relationship with the Transplant Center

a. The activities

The category of activities includes two sub-categories, which will be subsequently analyzed: the change of activities and lifestyle conditioning.

Regarding the change of activities, all the patients interviewed stated that, after the surgery, there was an overall increase in the number of the daily activities performed. According to the patients, additional activities include practicing sports, adopting a healthy diet and the addition of drug therapy, supported by a set of regular check-ups at the transplant center. The last two activities could appear to be limiting consequences of the transplant experience; however, for most patients, taking their medication and regular appointments with the hospital are seen as solutions to help maintain their health.

Although the transplant has allowed almost all patients to return to an almost completely normal life, it involves, or can involve, a series of all-round influences in the way of conducting their lifestyle; such conditionings tend to manifest on a physical, psychological, social, and economic-working level and can have both positive and negative implications. However, physical conditioning does not only lead to adverse outcomes; on the contrary, for some patients, it is defined as the end of a period of limitations previously imposed by their health conditions in the pre-transplant phase:

"No, on the contrary, my lifestyle has improved. Now I can do many more things that I couldn't do before. For example, I can go back to running, cycling, going to the mountains. By training, I could return, as I had already done, to Mont Blanc, but that is a matter of training. Instead,

before, I had to pay attention to the altitudes, even if they gave me a fairly high limit compared to many others, because I could reach 1800 m" (Emanuele).

Regarding psychological conditioning, however, there can be very different implications depending on the impact that this event has had on each individual. Nevertheless, most patients have successfully overcome the psychological trauma of the transplant.

b. The health conditions

The second category detected includes a different group of sub-categories that refer to the monitoring of specific parameters and health conditions, complications related to the management of these aspects and the frequency of check-ups at the transplant center.

From the analysis of the interviews, some recurring elements emerged concerning the pharmacological treatments to which transplant patients are subject; in particular, the interviewees declared to know (or to have already suffered for some time) the consequences that such a therapy entails in the long term and therefore provide for the consistent implementation of preventive or monitoring actions aimed at maintaining good health.

Expressly, all patients declared they were carrying out regular follow-ups at the transplant center to check the condition of the organ received and evaluate a change in therapy, if necessary. Each of them frequently monitors, individually or through the Center, a different number of parameters such as cholesterol, blood pressure, heartbeat, blood sugar, creatinine and uric acid. If they do not comply with the standard, these values often constitute an alarm bell relating to the state of health and require prevention actions to be carried out to avoid the appearance of serious diseases such as diabetes or kidney failure. Therefore, the attention of patients is mainly aimed at monitoring and preventing the onset of chronic diseases, but not only. Being particularly at risk, they also carry out practical prevention actions against infections by limiting direct contact with possible sources of contagion (such as closed and crowded places) and by carrying out regular prophylaxis of infectious diseases.

c. The relationship with the Transplant Center

With the results analyzed in the previous paragraphs, it was possible to ascertain that the consequences of the transplant are of a different nature and embrace many aspects of patients' daily life and health. Therefore, the transplant event leads the transplanted subjects to begin a path of care and check-ups that will last for the rest of their life. For this reason, in formulating the research question, we asked ourselves how patients perceived the relationship established with the health system. The last category identified within the first thematic core concerns the perception that patients have towards their connection with the transplant center and the way it affects certain aspects of their life.

What emerges from the interviews shows, in general, that the relationship is not perceived as binding by patients but is seen from a positive perspective:

"It is not a burden to carry out the check-ups, quite the contrary. It is good for us. First, because being monitored is always good, since some viruses may suddenly wake up; therefore, it is better to be controlled" (Lucio).

5.2 The follow-up

Therefore, the analysis of the previous nucleus shows that, after the surgery, a long-term relationship is established between the patient and the healthcare system. To better understand what this relationship entails, respondents were asked to describe the typical process of a follow-up day at their Center of reference. They were asked to describe the types of check-ups, the methods of access and execution and any steps, timing and difficulties they had to face to carry out the procedure mentioned above. Furthermore, interviewees were asked to express their opinion regarding possible improvements that could provide a valuable contribution to the structure and organization of the transplant center.

Some interesting observations emerged from the interviews, which can be divided into two sub-categories, that concern respectively: (a) the examinations process and (b) the criticalities of the follow-up.

a. The examinations process

In the first sub-category surveyed, some aspects related to the examinations and the influence of the pandemic on the follow-up process were investigated. First, patients initially provided an overview of the examinations that take place during a typical follow-up day:

"I'm going, consider, well [...] the first thing you do is run a blood test. You have to run one blood test in the morning and then, you have to run one after two hours, to see the reaction. I take the test, then, I take the immunosuppressants and, after two hours, based on the reactions that they provoke, I take another test to see the changes in blood values. In the interval between the first and second test, you go to do the x-rays and then, you wait. I, then, in short, I repeat, I don't sit there waiting in the hospital, I usually go to the bar to get a croissant, to have breakfast, then I come back. When you go back you do the electrocardiogram and the doctor visits you, asks you how you are doing, you have a chat and then it ends like this. Alternately, I have an echocardiogram, which is the visit with the gel. We have it to the heart, but it is basically an ultrasound that you can do to all the other organs. And this is the normal process. During the first months, on the other hand, in the first weeks after you are discharged, the process is a bit more complex because in any case you must also do the biopsy. However, that is only, in short, for the first months. Every 2 years, we do coronary angiography" (Tullio).

b. Criticalities of the follow-up

Therefore, the second sub-category detected through qualitative analysis summarizes the set of criticalities detected by patients within the follow-up system. Deepening and analyzing the process of check-ups at the two hospitals in the Veneto Region, the inefficiencies of this system emerged, along with the most pressing desires and needs patients want to be satisfied.

In summary, what emerges from the interviews shows that the follow-up gaps are many, but they can all be traced back to two essential needs:

- the need to implement a system that allows to communicate adequately and more often with the Center, and
- the need for a dedicated physical space for transplant patients.

According to the interviewees, it emerged that the need for communication with the Center appears to be the most predominant, the triggering reasons for which can be summarized in the following points:

- lack of security and sense of abandonment: the patient is unable to establish a direct relationship with the doctor for clarification and reassurance on his state of health and on the management of therapy,

- the patient does not have an autonomously manageable information system regarding the dosages and ranges of therapies,
- lack of direct contact for emergencies: patients complain of not being able to have direct contact with a doctor in case of need or emergency, especially due to the presence of limited hours for telephone calls to the Center - which consequently causes a blockage of the line and the occurrence of problems related to the delay in sending replies, and
- lack of communication between the Center and external figures or structures: among the obstacles inherent in communication, there is a problem related to the lack of dialogue between hospitals or professionals operating outside the company of reference for transplant recipients. Therefore, the problem of communication does not exist only between doctor and patient but also among professionals.

5.3 The family

a. Role of family and support

The transplant experience can also involve the closest people to the patients. During the interviews, the participants were asked to talk about their families, to tell whether and how their relatives participated in their clinical experience, as well as to express what kind of support they feel they have received (if any) during recovery. Both family members and patients were also asked to tell whether any problems concerning follow-up management had been addressed.

Analyzing the results that emerged, it was clear that, for all patients, the family unit played an almost fundamental role in helping them overcome difficulties; in fact, all confirm that they have received, where possible, all kinds of support from their relatives and friends. Mainly, the patients' families were able to offer strong emotional and psychological support, which provided them with the initial input for physical, mental, and professional recovery, along with the hope of a new chance for life.

In addition, the offer of support from families has also come from the economic aspect. Although only one patient, Pietro, eventually declared he had received financial support from the family, for the other patients, there was nevertheless the possibility of receiving help to support expenses, especially in the early postoperative period.

b. Issues in follow-up management

If, for a group of receivers, the transplant has positively influenced both the lifestyle and the relationships with their relatives, for some patients the event has unfortunately led to the interruption of the emotional bond - or the marriage bond - with their respective partner. These are the cases of Tania and Lucio, who have highlighted the negative implications of their path. Their partners perceived the post-effects of the transplant as a continuation of the disease, and this reaction led to a lack of processing and acceptance of the change, irreparably damaging the relationship. Therefore, these observations bring out what could be defined as the 'psychological difficulties related to the psychic-emotional management of a transplanted person. Although for the rest of the participants, the transplant experience did not lead to excessive psychological complications, through the reading and analysis of their stories, it was possible to identify other aspects of the follow-up that were difficult to manage, especially for the families. These aspects can be traced back under the label of 'practical-organizational difficulties' and involve issues related to the management of a transplant person who is not entirely self-sufficient, for which relatives must be able to conciliate both work and family at the same time. In other words, following a transplant patient in his rehabilitation process, can weigh on other aspects of the life of family members, who find themselves taking on commitments and responsibilities that lead to neglecting their consort, or their children, or even having to raise a family alone. Caregivers can find it difficult to reconcile everything with work - for example, to obtain permits to accompany the person they are following to medical examinations.

5.4 Possible innovative solutions

At the end of the interview, researchers discussed some proposals for potential innovative solutions with the interviewees. The intention was to investigate the propensity to apply these solutions. To this end, people were asked to identify which solutions could be adopted, motivating their answer by highlighting advantages and disadvantages. The proposals concerned two E-Health technology-based solutions and one organizational solution, as follows:

a. teleconsultation,
b. the use of wearable devices for telemonitoring,
c. the insertion of a new health figure (Case Manager) at the transplant center.

a. Teleconsultation

Most of the interviewees expressed themselves in favor of the use of teleconsultation, seen as a tool to recover direct contact between patient and doctor, skipping any intermediaries. According to the patients, live interaction during video calls would enable the doctor to see the patient's face and gain a clearer understanding. There would be the possibility of clarifying doubts immediately, a circumstance that could make the patient feel safe. In addition, there would be a reduction in the necessity to travel for those who live far away or have mobility difficulties. A further advance is economic saving in implementing the video call. On the other hand, there are the difficulties of the older generations concerning new technology, the risk of hasty and superficiality in the calls, the fragmentation of the diagnostic process (which the remote medical consultation does not solve).

b. Wearable devices for telemonitoring

Patients were both favorable and skeptical about the use of wearable devices useful for telemonitoring. The use of this technology would undoubtedly enhance remote surveillance. Still, some patients have doubts about the adequacy of connections and hospital staff digital skills. They also fear the intrusiveness of these devices in their daily lives.

c. Case Manager

The inclusion of a case manager seems to find the approval of all the interviewees. He/she would be an intermediary, a clinical figure who knows the patient's entire history and can provide answers and immediate support. Furthermore, the case manager would also play a facilitator role, especially in emergencies; finally, he/she would favor a less depersonalized relationship with the Transplant Center.

6. Discussion and Conclusions

The aim of this paper was to investigate a series of aspects that characterize the life of heart-transplant patients within the Veneto Region, to identify the physical, psychological, and economic consequences of the intervention on the lifestyle of the subjects and grasp their perception of the relationship with the hospital developed in the postoperative phase. The aim of the study was to understand and identify the deepest needs of patients, drawing inspiration from the human-centered approach, typical of DT and to propose some potentially applicable solutions, aimed at improving follow-up services.

As for the consequences of the transplant on lifestyle, the results show, in general, a marked improvement in the health conditions of patients from a cardiac point of view, which in turn is reflected in the performance of daily activities, allowing to finally return to lead a 'normal' and mainly healthy and active life. However, despite the evident positive effects of the transplant, the rehabilitation path of each of the patients developed in a diversified way and influenced the physical and psychological state of the interviewees subjectively. In addition, the consequences of the transplant have caused some influences that affect the social aspect and the professional profile: the first is deeply influenced by the fact that patients are immunosuppressed and, therefore, more likely to expose themselves to the risk of contracting infections and viruses; the second is mostly related to the need to reduce stress and lead a moderate lifestyle, taking better care of health and prioritizing the family. By observing the results of the analysis, it is possible to ascertain that the physical and character predisposition of the patients, the attitude and emotional support of the family members and the indications of the doctors have proved to be decisive factors for the pursuit and achievement of a stable living condition after the transplant, affecting everyone differently.

In general, therefore, transplantation guarantees patients to achieve good health conditions and excellent physical recovery, but in the long run, complications can arise due to the assumption of massive drug therapy. Therefore, the patients' activities change after the transplant and are mostly oriented towards maintaining a good state of health and constantly monitoring a series of parameters that act as indicators of their body's changes following the operation and when adding therapy. Precisely because of these two factors, patients must undergo a series of periodic checks (follow-up) that are used to detect the functionality of the new organ and identify the possible presence of rejections or malfunctions of other body systems. Contrary to what was assumed at the beginning of the research, these checks, carried out at the transplant center to which each of them refers (in this study, Padua or Verona) do not constitute a constraint. On the contrary, patients consider checks as a security for most cardio-transplant recipients, who feel the need to receive constant updates and reassurance on their state of health. However, taking many medications and maintaining these appointments with the hospital are activities that are seen in a positive light only by those who have had a pathological background before the transplant and, therefore, see the postoperative phase as the possibility of a return to normal. The case of Lily, on the other hand, is the only one to highlight the impatience perceived by those people who find themselves facing a sudden and total upheaval in their lives, both for the effects that this event causes on a physical level and for the psychological shock and the consequent difficulties in accepting one's condition.

Although having established a lasting bond with one's transplant center is seen as a positive factor for health, the general perception of this relationship is instead negative in two main aspects: the organizational difficulties that entail maintaining a connection with a distant center from their home and the general lack of continuity of care for patients after the operation, even in emergencies. While the first limit is linked to practical factors that patients have to face - such as the distances, times and costs used to reach the Center - the second limit refers, instead, to organizational aspects of the transplant center - such as, for example, the fragmentation and incompleteness of the visits or the unavailability of staff during the hours set aside for telephone consultation. These observations highlight the inconsistency of a system design which, on the one hand, requires the patient to establish a relationship of exclusivity with the Center in terms of controls, evaluation of parameters and treatments. At the same time, the system design neglects a series of highly relevant issues in terms of information and communication, generating a strong sense of abandonment in most transplant recipients.

In general, our analysis highlights the profound need of safety experienced by all the patients.

In the last year, these circumstances have been further aggravated by the arrival of the Covid-19 pandemic, which has seen patients forced into isolation and Transplant Centers to drastically decrease, if not even interrupt the follow-up activity, to avoid exposing transplant recipients to the risk of exposure to the virus. It follows that, to ensure remote control, patients were required to carry out exams outside the Center and to communicate the results electronically. Occasionally, video calls were made for investigations. However, the implementation of this system remains a temporary solution, with obvious unresolved problems. Although it allows transplant recipients to avoid complications at a practical and organizational level, it does not avoid the exposure of these subjects to the risk of getting sick, since to carry out the tests, they must go to a multitude of widely frequented health facilities; in addition, the evaluation parameters differ from those used at the transplant center and the patient's medical history is not known outside the hospital; therefore, the resulting evaluation is not always appropriate.

From the interviews, it has emerged that patients' propensity to adopt innovative solutions is good, also for high tech innovations. If properly implemented and used, E-health technologies would support the work of healthcare personnel. They would constitute a practical and safe method to obtain, share, and monitor relevant information on patients' state of health, thus opening the doors to the possibility of implementing preventive interventions, where necessary.

7. Limitations and further opportunities of research

The undisputed value of DT is given by its flexibility, since it allows to constantly readjust the methodology of approach to the context and the resources available and, above all, it does not require to follow a pre-established order in the design phase. For the project in question, if on the one hand only the insights of the interested parties were collected and identified, on the other hand, actions were taken directly, with a launch of proposals which, if applicable, will be integrated from time to time by further information collected in the field and revisited according to the feedback received. The study of the context and the adoption of an empathic approach to the subjects interviewed - supported by careful listening to their opinions and needs - were of fundamental importance in order to formulate, step by step, further questions which, in some cases, allowed to delve into very private aspects of their lives. This goal could not have been achieved by developing a simple questionnaire or by the collection of quantitative systems, which are certainly more immediate but lack a human-centered approach.

The results presented here have the limit of being based on only two transplant centers; only 10 people were involved. In addition, the Covid 19 emergence hindered the application of the comprehensive DT methodology.

Despite the recognized limitations, these results could prove useful for carrying out further investigations, by applying methods consistent with DT such as brainstorming and prototyping, by carrying out live participatory seminars with all relevant actors, or concrete activities of immersion in the environment in which patients live and work, allowing to highlight the points of view of all stakeholders, as well as to actively involve them in this process of creation, which sees in Telemedicine and the emergence of integrated systems the possibility of implementing a new way of doing healthcare.

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