

Technology and doctor-patient relationships: an organizational change in chronic pediatric diseases

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Abstract. A challenge to be addressed in the coming years is the management of health in increasing population and needs, combining it with growing and demanding public spending. Technology, hardware or software, plays a fundamental role in the healthcare sector, but also related units, such as the first hospital wards or the follow-up centers. Among all the impacting innovations, this work focuses on the communication between patients and the health system, trying to understand the organizational model that focuses on ill persons, involves them, empowers them in the creation of the value, including their family entourage. Healthcare technologies changed existing relationships and paradigms, both for the hospital organization and for the roles of the system players. This new inclusive logic makes treatment more effective and efficient, especially in the case of chronic pediatric diseases, as the case of a public hospital in central Italy shows.

Keywords: e-health, doctor-patient relationships, patient-engagement, patient-centred, patient empowerment.

1 Introduction

Innovation is always fundamental for organizational competitiveness and effectiveness within the profit sectors but is often underestimated in the non-profit, public administration, and citizen services sectors.

In healthcare, innovation can be defined as an idea, practice, or material device perceived as new by the previous system. Technologies, hardware ones, with a physical content, or software ones with an impact only on procedural and organizational contents, play a pivotal role; in particular, this role is disruptive in the hospital sector, but also all the units around it, such as first emergencies or follow-up centers. Technological innovations are various and have different impacts.

This study focuses on the impact of technology on communication between patient and health systems to understand how can work a new organizational model of "person-focused care." This model involves patients, makes responsible, and includes, with their entourage, in the creation of value; it seems especially beneficial in chronic diseases.

More specifically, this paper aims to investigate how technologies in healthcare have changed the relationships between patients and physicians, doctors and caregivers, and existing organizational paradigms in chronic pediatric diseases.

This paper is structured as follows: firstly, it analyses how the technological changes, due to the introduction of ICT, contribute to innovation in the organizational processes of healthcare structures and how this corresponds to a different way of facing the challenges of our time. The second part opens describing the change in doctor-patient relationships; consequently, then explains the more active and central role of patients and caregivers in healthcare. In the third, we present a case study, aiming to observe this change and understand more deeply the impact of new technologies in its peculiarity, uniqueness, complexity in the specific context of chronic pediatric diseases. Finally, there are the authors' conclusions.

2 Technology and changes in healthcare: an overview

The organizational change in healthcare arises in a general context, and Italian, in particular, of profound social transformation. The biggest challenge to face in the next twenty years will be, on the one hand, the treatment of diseases in an aging population and, on the other, living with chronic illnesses at any age. [1]

Health is always a more critical need because society aims to wellbeing despite the lengthening of life, acute and chronic diseases, considering a growing and increasingly demanding public expenditure. [2]

Information technology (ICT) is more and more one of the main levers of change in all sectors; therefore, also in the health one. For example, its use is a priority for the management of chronic diseases through home monitoring [3].

Digital healthcare includes telemedicine but also e-health, e-care, remote technologies. Eysenbach [4] defines e-health as "an emerging field in the intersection of medical informatics, public health, and the health industry, about health services and information provided or improved through the Internet and related technologies." It has evolved from telemedicine, understood as a means of communication to integrate traditional services into real automation that provides decision-making tools that expand the scope and range of health services. This process creates unique health management and interaction [5] [6], which concerns the remote diagnosis and treatment of patients by telecommunication [7] and transform healthcare organizations.

Technological development is related to changing visions in the management of health systems and on the centrality of the patient [8]. In the beginning, it aimed to increase profitability, remotely monitoring, or cutting patient hospitalizations before and after interventions, thus reducing the time and costs of providing services; now, it is considered as a significant way to create value [9]. By involving the customer/patient through apps and sensors, new paradigms focused on him/her developed; we could speak about user innovation, referring to the fact that patients and caregivers, thanks to technological innovation, are part of this enhancement. They could check new instruments and processes but also being part and give feedback in real-time [10].

The Healthcare model is increasingly personalized: cures, patterns to follow, follow up are thought and organized on patients' needs, not only to improve results as a medical point of view but also as an organizational enhancement [8]. This innovation process is continuously evolving; artificial intelligence, for instance, while reducing human error and improve treatments and diagnostics [11], allows doctors to meet patient needs.

They can implement interventions tailored to their patients, monitor their progress in real-time, be reached even at home [12], and improve the clinical approach.

Patients and their families, especially in cases of chronic or long-stay diseases, can avoid improper or redundant hospitalizations, reduce travel times and costs, and, above all, be integrated within the service, in so-called patient empowerment, be more serene and compliant [13]. As Franke [14] studied in 2013, user innovation is innovation-driven or created by those who will benefit from using it, and this innovation is linked to the product, to service, to process.

The critical issues are the data confidentiality and the perception of a workload increase without a significant counterpart [15] [16]. It can depend on excessive use of specialist services for fear of making a wrong assessment, and for the unceasing request of people, due to the dissemination of health information. [11].

Organizational consequences are the horizontal setting of the flow and the adoption of multidisciplinary logics, based on multi-stakeholder work teams. The integration between professionals and structures involved in e-health takes place at several levels, and, most of all, includes patients. Their interactions are guided by specific team functions and processes, using the technological infrastructure as the basis of their work [15]. E-health transforms it into a "widespread hospital" and a place of integration of general services and customized solutions. It uses basic and advanced tools, from phones to smartphones, videos, electromedical devices, computers, wireless technologies, and the Internet in general [6].

Today it is possible to receive and exchange information very quickly to find treatments and respect the needs of the patient [17]. Electronic medical records (EMR), for example, reduce waiting times, costs for the hospital, and above all, provide information on updates regarding diagnosis and treatment almost in real-time [16] [18]. Information impact on care, because of the greater efficiency of services, falls on the life of the patients and caregivers. The world of social communication is often an integral part of this system; a hospital today creates and updates its website, Facebook, or Instagram page to inform patients and their families better. Patients have reserved areas and can, for example, evaluate the structure, comment on their experience, deal with other people with the same disease, etc. [10].

Five factors [12] can facilitate this integration: information (direct patient access to data, conditions, diagnosis, treatment options, and facilities), patient planning (operator access to complete and targeted information), timeliness of care (data analysis to better plan personalized care), safety (information helps to reduce risks, potential injuries and damage to patients) and the effectiveness of the system (improvement of productivity and prevention waste, thanks to the optimal use of resources).

ICT plays a role in all factors, becoming fundamental in inclusive collaboration, the so-called patient empowerment; however, ease-of-use and simplicity of approach are necessary conditions. New forms of communication arise from the dialogue between institutions and patients and from users, and generate a continuous innovative process of forms of personalization and participation; listening is the new skill that produces a process between equals, between users, and between doctor and patient, reducing the asymmetry between institution and citizen [10]. ICTs create an online intersection space between users and service broadcasters, formal and informal associations, where the comparison and exchange of experiences, the sense of belonging to the community, and the process, create a precious, practical and experiential knowledge [10].

Participation, even emotionally, in the process, overturns the approach to creating value, where the expectation of users is essential [19]. In such a complex society, it is necessary to involve whoever is an active part of the management of services [20]. In public services, especially health ones, involvement invests the very sense of citizenship, of belonging to society. "Service" fits into "value co-creation" and also "network:" it becomes a set of services in a system, with a single logic and the enhancement of the concept of a network [21]. Service is not only a necessity to be fulfilled but a place where citizenship and institution converge in a new approach and sensitivity in which value is co-created and different actors belong to a network [22]. The organizational structure, therefore, becomes a representation of this co-creation, a sort of new paradigm in which entities, people, information, and technologies become cornerstones.

The main barrier seems the patients' concern of losing direct contact with their physician [18], as well as the security and protection of their integrity and privacy. Managing and analyzing a vast amount of data remotely, of which many are sensitive, is risky for all system stakeholders. The first organizational healthcare models focused on disease; today, they turned into systems that focus on the patient: this is what is called patient-centricity [8]. Physicians, healthcare staff, and management build the system around the patient, considering more the relational aspects, in a sort of joint "management of the service" according to a new communication paradigm.

There are several examples in this Copernican health revolution. One is the Diagnostic Therapeutic Assistance Paths, a health management tool that defines, concerning a disease, the best possible path within the organization [2]. It is a sort of on-demand approach, sewn on the patient, with a flexible structure around it, a mix of services within the hospital where the assessment and diagnostics process are suggested based on the needs of the case. The administrative system revolves around this approach giving the patient an organic and connected system assessed with efficiency indicators that serve as feedback and monitoring [2]. In this transformation, patients have also changed their approach. There is a great deal of information available to all. However, only attention from the institution and the patient, especially for social networks, can make it correct, leading to patient empowerment [23].

2.1 Technology and changes in healthcare: an Italian overview

The Italian context is, on the one hand, really influenced by new technologies constantly introduced in healthcare models; on the other hand, it is affected by the cultural and the digital framework in which this revolution moves.

Italian digital divide is profound (one family on three has not a PC at home), and this is an essential obstacle to telemedicine and digital healthcare diffusion. Still, at the same time, patients' and caregivers' participation in the healthcare process is robust, and the community of stakeholders is very present in the sanitary system [24].

So many experiments, born to test the application of new technologies devices in Italy, had significant participation with extremely relevant results. Italian patients and patients' relatives are involved in helping care systems to enhance innovation and sometimes are also a way for new proposals and ideas.

In this scenario, social communication in general and social media, in particular, are a way to collect experiences, opinions, testimonials, and be part of the new approach [24]. Chronic pediatric diseases are, for their nature, a primary playground to this new

model of healthcare, that improves information collection through smartphone (25) and social networks.

2.2 Patients engagement and empowerment

By this term is meant a process of social action through which individuals or communities acquire awareness and tools to improve the quality of their life. "*All patients must be supported and empowered to have a say in their care, according to their abilities and desires (...). If patients wish to delegate the decision to someone else, this must be respected*" [23]. The patient cannot always verify the information and, therefore, must be referred to in a mutual relationship with the doctor, on the climate of trust that allows patients to be more collaborative and responsible in a proactive way.

Nowadays, personalization and co-creation (also we can say co-production or co-design) are reshaping healthcare models. Patients' clusters are now rich in several small niches, always an evolving configuration. [26] This revolution is the so-called customer mobilization that refers to the immediate identification and involvement of customers in health systems and new health product development [27].

At the heart of this study are the indications of care, but also information that must be complete and clear. This impacts on the quality of the care itself, on the managerial process and cost management [2]. Some physicians choose the relationship based on sharing, stimulating the patient's active involvement in the treatment, and developing a new communication style focused on listening. Physicians then change perspective, put themselves on the same level as patients, without however losing the sense of the role. Thus "the humanization of medicine and the treatment process" develops, and the communication system changes totally [8].

Talk about "person at the "center; it means understanding the context in which he/she moves and assessing his/her centrality, regardless of the role of the patient [8]. Assistance focused on the person is based on accumulated knowledge for better recognition of health problems and needs over time and facilitates adequate aid; that is, it focuses specifically on the whole person and his story [28]. The differences in approach between patient-centered and person-focused care can be summarized [28] in Tab.1.

Table 1 - "Patient-centered care" vs. "person-focused care" [28]

<i>Patient-centered care (generally)</i>	<i>Person-focused care</i>
It is oriented to a single disease episode.	It considers the episodes as part of your life experiences with health
It refers to interactions during visits It is centered on disease management	It refers to the interrelationships over time Look at diseases as related phenomena
It considers co-morbidity as a sum of diseases	It considers morbidity as combinations of disease types (multi-morbidity)
It considers body systems as separated	It views related body systems
It uses coding systems that reflect professionally defined conditions	It uses coding systems that allow you to specify people's health problems
It is mainly interested in the evolution of patient diseases	It is interested in the evolution of problems of people's health and their diseases

The management of the relationship between physicians and patient overturns: the patients, first-hand, through their associations and caregivers ask for clarity, and the

physician invite us to involve patients, and those close to them, to improve dialogue. This process could lead to personalized protocols, to avoid waste and correct the therapeutic shot almost in real-time.

Focus on persons has led, in health policies, to the concept of "engagement," that is, of a patient an integral and active part of the treatment process and, more broadly, of taking charge. The patient becomes a promoter, commentator, and developer of the treatment process ("I take advantage, I recommend"), also enhancing the accessory service component; it is part of taking charge and impacts positively on health itself. For example, if the patient does not have waiting times, he/she has no difficulty in finding follow-up drugs outside the hospital, if he can easily book visits. So on, he/she has the possibility of better treatment [29].

The patient engagement highlights the two-way, privileged, and conscious relationship that develops between them and their healthcare system in chronic or reiterated illnesses; this partnership implements valuable information and changes the system step by step. It is necessary to take better care of both the interest of patients and of the health system, without waste, with feedback and using the users of the service themselves as privileged testimonials of the same [2]. Engage the patient makes him/her more compliant with the prescriptions of the health service, aware, proactive, able to contact the physician promptly and to quickly use all the necessary services [29], to obtain the maximum benefits that they have been and are paid to them [18]. Different definitions of "patient engagement" deal with the various aspects; Graffigna et al. [29] have, for example, exalted the emotional role it has in the treatment process and its therapeutic as well as organizational impact (Table 2).

Table 2 The characteristics of engagement (*Adaptation from [29]*)

Concept	Definition	Relation with the engagement
Empowerment	The <i>empowered</i> patients are informed, aware ones: have control over the treatment process, manages to correct the shot, and give critical feedback.	Mutual influence. It is a prerequisite for engagement and is strengthened throughout the engagement. They are synergistic but different concepts.
Activation	It indicates the patient's level of awareness, ability, and confidence in managing his / her illness and in moving within the health system.	It has different degrees of overlap with <i>engagement</i> , but the dyadic and institutional relationship between doctor and patient remains in the background.
Self-management	The ability to check the patient daily on his disease requires a knowledge of the therapies and their conditions.	In <i>engagement</i> , there is not a simple transfer of knowledge between doctor and patient.
Adherence	Ability to follow the recommended therapy: is a key factor in improving the quality of life of patients and reducing costs.	It refers to a particular context of care.
Compliance	Coincides with what the doctor wants the patient to do and what the patient does to satisfy this need.	<i>Engagement</i> overcomes compliance and becomes much more because it is a sort of involvement-testimony.
Shared decision-making	The cures are chosen together.	The patient is a negotiator of the cure (in relational and unscientific terms).
Involvement and participation	They describe the relationship between patient and healthcare professional in the clinical decision-making process	Idem

Consequently, patient engagement is a sort of transversal concept that includes the empowerment one, a strong collaboration for a constant update on one's health, the news search, the comparison between peers; the doctor-patient relationship completely changes appearance and becomes a real exchange relationship [30]. Patient engagement, therefore, improves the treatment processes and the health system in general [31]: it helps planning services and thus enhances the allocation of resources in health expenditure; allows that "therapeutic alliance" or the joint effort towards the best cure; will enable patients to adopt an informed lifestyle corresponding to their state of health; increases patient satisfaction; helps the culture of prevention; improves compliance; streamlines the information flow.

The best evidence of patient engagement results in the context of chronic diseases, partly because the therapeutic continuity gives time to develop more ongoing projects, partly because they are patients who need a well-rounded and investing approach and multiple areas connected [32]. Patient engagement can, therefore, be experienced in these areas and primarily in dedicated healthcare facilities. Examples are the structures in which traditional Departments leave space for organizations on the single complex disease and develop cross-sectional systems (for example, "rare diseases area").

In 2017, Graffigna [29] called this an "engagement ecosystem" because not only does the internal organizational paradigm change but it develops towards the outside, the company, the other communities, the socio-assistance area that often becomes one with therapy and which allows sensitizing those who are outside the hospital but in close contact. The advantages of involving the patient in the treatment process are numerous, from therapeutic to managerial ones, through cost-benefit analysis. Graffigna [29] identifies eight priorities useful for this discussion:

- 1) Complex, systemic, and "multi-stakeholder" vision, in a model that sees the health system as a sort of ecosystem of cellular organisms.
- 2) Evaluation strategies of patient engagement to impact strongly on organizational models and health expenditure in virtuous terms
- 3) Counseling tools, psychological and educational support aimed at the patient to support his engagement, which is also influenced by peer associations (e.g., the protection of certain diseases), positively impacting the new process.
- 4) Involvement, training, support, awareness of health professionals who must be willing to change their role in terms of involvement, no longer normative.
- 5) Enhancement of caregivers and patients' families, promoting their engagement through specific training, information, and involvement interventions.
- 6) Information and involvement of civil society favoring the birth of networks and informing about the prevention and involvement of associations; the social action, websites, online news, for example, allows reaching an increasingly widespread and decisive target.
- 7) Support and enhance the third sector as a crucial catalyst for the engagement process, e.g., in information about a disease
- 8) Promotion of active involvement also through technologies, which can build an engagement ecosystem. The role of new technologies is fundamental in the

engagement and its constant expansion. They can be in presence as at a distance or in social terms, but each one develops its role.

An important role in recent years, especially in chronic diseases, is the unpaid caregivers: people who are next to the patient in the treatment process, family members in most cases, but also friends, or in a broad sense, even the associations of patients. [33]

2.3.1 The pediatric context

It is crucial to analyze the difference between a children's hospital (considered here) and a standard hospital. Physicians must face the relationship with patients and caregivers in the pediatric hospital from two different perspectives; first of all, the psychological/ clinical one, towards the patient (that is in pediatric age), proposing and foreseeing a solution to the clinical problem, also if it generates psychological consequence. Then, there is a doctor/caregiver perspective that must also be approached from a clinical and psychological point of view but in a different way: in the case of chronic diseases, the physician establishes a relationship of trust with the caregivers, such as if it were a path, because they, unlike the patient, is more conscious. It's essential to establish this path to collaborate overtime for the solution of the clinical problem that generates the psychological problem.

This involvement cannot be left to chance or the initiative of the doctor or ward but must be systemic. Measuring engagement allows quantifying the risk level of clinical populations (or social groups). This way improves the identification of the targets of the care intervention, customizes health services, and intervention programs to respond to previous evaluations in a continuous improvement process that manages investments to structure it. Finally, it strengthens the social and health area with the awareness that welfare networks have a strong influence on engagement models [32].

In this specific intersection space between the engagement and empowerment of patients/caregivers, and the context of chronic pediatric diseases, our work fits.

3 The case of the Emme (M) Paediatric Hospital.

3.1 Method

This paper aims to investigate how technologies in healthcare have changed the relationships and existing organizational paradigms in chronic pediatric diseases.

The case study methodology allows us to correctly answer the "how" and "why" specific phenomena are found in a particular context [27] and was considered appropriate for answering the research question of this work, which is a "how question."

The case was chosen as particularly significant to confirm or refute the theory outlined so far and to support the answer to the research question. In the case of diabetic patients, that are chronically ill, technology is a fundamental monitoring and communication tool, and the difference between the doctor/patient relationship and the doctor/caregiver one becomes even more critical. Patients in pediatric age, do not have an immediate and visual confirmation of the damage caused by improper management of

the disease. For this, they are interested only in the psychological repercussions of having to cure themselves. Caregivers can understand that the treatment is a perspective to live well not only in the present but in a long view; the only way to tackle is seeing the management of the disease as a project to be pursued with the help of the physician.

A qualitative research approach is the most suited to handle this type of inquiry not only because this study revolves around a 'how' question, but also because the scientific research on this field in addressing healthcare challenges, is still in its infancy.[34][35]

We did ten semi-structured surveys, lasting 40 minutes, and recorded and transcribed them. We interviewed 5 kind of family caregivers: a father (public employee), 4 mothers (2 managers, an housewife, one physician), 2 grandmothers (retired), a brother (IT consultant), and one sister (student at University), a volunteer assistant [28]. The carers, all involved in a chronic process for years, could understand the evolution of the technological impact on the life of the ward and have been available for collaboration.

We focused our questions on the four topics found in literature:

- the person-focused care and the doctor-patient/carers relationships;
- the relationship with technology of patients and caregivers, and connections with their engagement and empowerment;
- the empowerment developed by patients and caregivers;
- the engagement showed by patients and caregivers themselves.

Then we analyzed data using computer-assisted qualitative analysis software, Atlas.ti, to code and summarize the gathered data.

Consequently, we also sent 45 questionnaires (37 feedbacks), with 4 or 5 questions for each topic on a Likert scale to patients and other caregivers, on the issues of engagement and empowerment of ICT-based patients, doctors, nurses, volunteers, and family members. The aim was to understand their correlation with the improvement of communication and services deeply.

The collection of data takes place through participant observation [36][37], the technique most used to study the interaction between two or more subjects within a context such as a hospital [29], with the first-person intervention of one of the researchers, who is a family caregiver. This method allowed us to see not only the real situations and activities but also subjective characteristics, accompanying the criterion of objectivity with the sensations and emotions felt. The method is based on what people said and reported, but also paying attention to non-verbal language, alongside the careful analysis of the place where researchers are. This condition, therefore, leads to much more specific results than just the interviews. We also collected relevant documents, web pages, reports, and press clips to triangulate the data.

3.2 A brief description

The M hospital is a sanitary structure, and a University clinic was founded in Tuscany more than one century ago and dedicated exclusively to children. This was a particular attitude because pediatric specialization was not common in the past. The hospital was born from a donation with this specific aim. It was an anticipation of a concept of the field that will spread throughout Europe later. The company is now integrated with the University and the research and is a highly specialized pediatric hospital and national

reference center for high pediatric complexity and includes all specialties. It is a national and international point of reference. It has become such not only for the treatment but also for everything that revolves around it that becomes a cure itself.

This mission develops thank services and projects that want to include patients and caregivers in a dedicated community. During the years, new tools and organizations were born for this purpose. In a recent development, new programs structured using modern concepts of involvement community: M + Program, for instance, is a container created to develop fundraising, of everything that means going beyond the traditional idea of the hospital. It is a space where personal storytelling of patients and caregiver could point the attention to a specific problem. Then, ad hoc projects are developed both for treatments, for research, and for person-focus care. This whole world wants to be a physical and social community for sharing paths, experiences, and values to bring together internal and external stakeholders around projects, develop awareness, empowerment, and testimony, until a decisive engagement.

The hospital has accommodation facilities connected to care, places for patients and caregivers, but also social places. Together with M + sub-portal, which contains and shows the stories of children and their families, even Facebook page, Instagram one, and the Twitter account are an essential reference for the community.

Furthermore, the voluntaries' Associations and Foundations for parents or the protection of diseases cover a virtual and official space. This space is both physical and conceptual and a lively stakeholder's involvement; in this way, the hospital can test its policies and understand how to monitor process innovation and implementation.

3.3 Patient-focus care and communication

In the last ten years, there was an evolution of the structure and the development due to new technologies and the new approach to communication between doctors, patients, and caregivers in general. Some non-profit associations contribute daily to this ecosystem. The following table underline the path of patients' centralization, which has developed in recent years, taking up what literature highlighted.

Table 3 Patient centricity in Emme case (*Our elaboration*)

Summary from interviews and observations
-The course of care and the doctor-patient relationship and doctor-caregivers is structured over time. Each visit is part of a path. It is seen in its entirety.
-The path of life with the disease is seen as part of a lifestyle to follow. A demonstration is the attention paid to therapy, pharmacology and food, and related wellbeing.
- Chronic illness is compounded by consequences related to other specialties. The patient is taken care of on a path between multiple departments. The booking system and follow up are automatic.
- The system considers caregivers an active part and not only as accompanying patients.
- Part of the system is the world of associations.
- Technology is at the service of the centrality of the person.

Technologies are a crucial point in the evolution of patient innovation. In this analysis, there are two strands to be noted: the use of remote technologies and appropriate telemedicine devices, and the use of communication systems.

The use of devices in patients care is not only a way of controlling data in therapy but develops a different communication relationship. Speaking, for instance, about diabetes, with a new application, for a few years, insulin pumps for treatment have been connected to an application that continually monitors parameters. So, the doctor-patient-carers relationship is mediated by technology through constant data. In support, seminars are regularly held for device management and data analysis, and there are in-depth online courses on the lifestyle of patients.

Technologies allow a better quality of life as well as the integration of the network between patients, carers, doctors, nursing staff, pharmaceutical companies, and device manufacturers. It is possible to use an available 24-hour cell phone number that doctors manage in turn, a sort of help desk, very useful for these types of diseases.

Next to a direct interaction, there is another important communication system born in recent years, which is developed on social media and on the web in general. This structure responds to the guidelines of the Agency for Digital Italy on some critical parameters: institutional information, generally available actions, accessibility/usability, administration 2.0, services, peer to peer channels. This contributes to the empowerment of its current and potential users. Similarly, the Facebook page, Instagram, and the Twitter account provide training, culture, information exchange, empowerment for patients already treated by the hospital but also for the whole activated community.

3.4 Patient engagement: testimonials and associations

Based on the model in table 2, the level of engagement developed by the organizational and communication strategy of the Complex Operational Unit of case M was analyzed. Table 4 shows the parameters identified as an index of the Patient level Engagement developed. Reference covers the use of insulin pump technology, which is important in the treatment of diabetes.

Table 4 Characteristics of patient engagement in the Emme case. *(Our elaboration)*

Concept	Definition	Relation with engagement
Empowerment	The website, social media, but also the seminars, courses, and workshops organized by Diabetology, pharmaceutical companies, associations present in the facility, and the hospital itself are a source of particularly important awareness and a way of learning.	The great synergy between empowerment and engagement, also thanks to M storytelling and the institutional Facebook page.
Activation	Through remote management, micro-infused patients are activated continuously as well as their caregivers.	The dyadic and institutional relationship between doctor and patient or caregivers is an incredibly important aspect of the excellent management of telemedicine activated in the ward.
Self-management	The entire diabetes management program is aimed at self-management (from courses to seminars, to workshops).	In engagement, there is not a simple transfer of knowledge between doctor and patient but a real involvement.
Adherence	implemented by apps, data management, and comparison with parameters.	The context helps PE.

Compliance	Extraordinarily complex since it is a pediatric hospital, but it is helped by sharing with caregivers.	The testimony of some patients, also thanks to the associations present, is instrumental.
Shared decision-making	It is also important in chronic pediatric care. For example, in diabetes treatment, the use of the micro-infusion pump is chosen only with awareness.	The choice of the device involves shared decision making.
Involvement and participation	Idem (see previous)	Idem (see previous)

Finally, eight voluntary and protection associations actively work among hospital patients in support of care, twenty-two associations and foundations of parents, and seven of donators of blood and marrow. Their presence is incredibly important.

3.6 Main findings

Regarding the humanization of healthcare, all the interviewees think that doctors and the healthcare professional are excellent and work in full respect of privacy, even if for three people this is less important; the 80% check-ups booked by other specialists are punctual and efficient.

Everyone appreciates the human qualities of the medical and health personnel, regarding competence and sensitivity, since they are young patients, the issue of protecting their relationships with other children is a priority. Sometimes it seemed that putting children at ease in a family atmosphere, and the guarantee of confidentiality, was challenging to manage. An equal relationship is not always easy to coordinate with the secrecy that children deserve; however, the almost game-like dimension developed in the ward and throughout the hospital helps to create an atmosphere of humanity.

As far as technology is concerned, most of the interviewees are fundamental in the treatment process. The 85% positively evaluate the remote monitoring, although five people think that it needs more real following. Elderly relatives have trouble following the technological evolution of care; however, telemedicine can be a great help by everyone because technology replaces the knowledge necessary for the management of the disease and makes everyone feel more monitored and calmer. It is a process of first empowerment, which engages the family caregivers in a community. For two thirds, the relationship with the technology made available by the institutional website and the department's communication is not interesting; for the third, social media is the most important, thanks to Facebook groups that were born freely on the network and integrated into the institutional page of the hospital. Some technologies available in the ward (telephone H24), an integral part of the care, are almost considered "discounted" for carers. However, upon specific request, greatly appreciate them all (93,5%).

As far as empowerment is concerned, the attention of doctors is indeed projected on children, their needs, and their difficulties; therefore, the process of information to parents may not always prove useful. However, the placement of the carers in the care process is considered a priority for the wellbeing of patients and family members, and there is a strong commitment from the department, both doctors and non-doctors, including associations, to raise awareness militaries of the sick on care paths. First aid maneuvers and general rules for dealing with the daily life of the disease are explained.

The chronicity of the disease requires the necessary independence and shared and ongoing management of these paths. Only one person declares that "they do not contribute to doctors with a personalized treatment plan for the optimization of patient care."

For 13 carers, who filled the questionnaires, the association is fundamental; for 7 particularly significant, for sharing and belonging; even those who have not personally supported themselves, consider the service as a source of growth for relatives-patients. As far as engagement is concerned, analyzing the interviews, it is clear that they are all witnesses, albeit with different degrees of involvement, of the proposed care, also thanks to the paths of participation: for some, the involvement aimed at the community and associations oriented to a social communication; for others, to extra care activities; for still others it is the sharing of the experience of private use of telemedicine.

4 Conclusions

This work aimed to investigate the change generated by technologies in healthcare, especially in the relationships between physicians, patients, and caregivers (paid or not, familiar or not) and the structures themselves in case of pediatric chronic diseases.

From the analysis of the literature, we found that the intersection among the change of relationships doctors - patient/caregiver and the pediatric chronic diseases was unexplored. Comparing the theories with the M case study, it emerged that the organizational change and the doctor-patient (and caregiver) relationship in a person-focus oriented, the so-called 'humanization of healthcare,' in pediatric chronic diseases seems deeply tied on health technology. This, indeed, creates links and increases trust and safety, on the empowerment of patients and caregivers. It develops through the information and courses organized by the hospital to raise their awareness, and on the engagement shown by the patients and caregivers themselves towards the community, enhancing the effectiveness and efficiency of care.

From the semi-structured interviews conducted live to all types of carers on the humanization of the ward, the doctor-patient connection, the relationship of the carers with the infrastructures offered (in particular technological), and engagement and empowerment of patients/caregivers, we found numerous common elements. Through the information and courses organized by the hospital and on the engagement shown by the carers themselves in witnessing their experience at the facility was easy to analyze this commitment. Patients and carers evaluations, based on the Likert scale, also confirmed these elements.

What emerges from our study is that telemedicine is an increasingly essential and integrated system in the treatment process also in the specific and disruptive case of the COVID 19 emergency, with the consequent lack of normality. Remote check-ups and monitoring make patients and caregivers feel safer.

So, in the emergency case, as in everyday routine, the management of chronic diseases occurs very often with the help of hospitalizations for targeted control. The use of telemedicine reduces the need for hospitalizations and consequently also reduces the economic management of the health system thanks to the implementation of awareness by patients and caregivers and creating independence in the practical management of the disease. Aware that a single case, although significant as that analyzed, may not be

sufficient, it is however, believed that it constitutes a good starting point for subsequent studies.

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