Are ICT innovating doctor-patient relationships in chronic diseases? Two case studies before and during the pandemic

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Purpose. The paper aims to understand if digital healthcare can improve young and chronic patient engagement. The interpretation follows the doctor-patient relationship, investigating whether telemedicine fosters patients' engagement and, if they are young, also of their caregivers.

Methodology. The study analyses two Italian digital healthcare cases. A questionnaire and semi-structured interviews are administered to detect information on the new telemedicine service's satisfaction, utility, and usability.

Context. The study shows that e-health can answer the widespread need for well-being without space and time limits, before and during the pandemic, especially in Italy. It allows the humanization of a technology-driven system, which requires strong patient and community engagement to be built simultaneously.

Main findings. E-health can be a tool to improve the doctor-patient rela-

tionship and create a sense of community among patients. Moreover, patient engagement in a technology-driven healthcare environment is necessary to implement new treatments successfully.

Conclusion. We tested new digital healthcare services unique in Italy to understand the point of view of young and chronicle patients and their caregivers to contribute to a bottom-up harmonization process of e-health.

Keywords: digital healthcare, e-health, doctor-patient relationships, patient engagement, patient-centered, patient empowerment, pandemic.

Le ICT innovano il rapporto medico-paziente nelle malattie croniche? Due casi di studio prima e durante la pandemia

Obiettivi. Il paper mira a comprendere se la salute digitale possa migliorare il coinvolgimento dei pazienti giovani e cronici. L'interpretazione segue il rapporto medico-paziente, indagando se la telemedicina favorisca il coinvolgimento dei pazienti e, se sono giovani, anche dei loro caregiver. **Metodologia.** Lo studio analizza due casi italiani di salute digitale. Viene somSOMMARIO

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ministrato un questionario e vengono condotte interviste semistrutturate per raccogliere informazioni sulla soddisfazione, l'utilità e l'usabilità del nuovo servizio di telemedicina.

Contesto. Lo studio mostra che l'e-salute può rispondere alla diffusa esigenza di benessere senza limiti di spazio e tempo, prima e durante la pandemia, specialmente in Italia. Consente l'umanizzazione di un sistema guidato dalla tecnologia, che richiede un forte coinvolgimento di pazienti e comunità per essere costruito simultaneamente.

Principali risultati. L'e-salute può essere uno strumento per migliorare il rapporto medico-paziente e creare un senso di comunità tra i pazienti. Inoltre, il coinvolgimento del paziente in un ambiente sanitario guidato dalla tecnologia è necessario per implementare con successo nuovi trattamenti.

Conclusioni. Abbiamo testato nuovi servizi di salute digitale unici in Italia per comprendere il punto di vista dei pazienti giovani e cronici e dei loro caregiver, al fine di contribuire a un processo di armonizzazione ascendente dell'e-salute.

Parole chiave: sanità digitale, sanità elettronica, rapporto medico-paziente, coinvolgimento del paziente, centralità del paziente, responsabilizzazione del paziente, pandemia.

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1. Introduction

Technological innovation is fundamental for organizational competitiveness and effectiveness within the profit sectors but needs to be more recognized in the non-profit, public administration, and citizen services sectors. In healthcare, technological innovation can be defined as an idea, practice, or material device perceived as new by the previous system where technologies, hardware, physical content, or software that impact only procedural and organizational contents play a pivotal role. This role is particularly disruptive in the hospital sector and all its units, such as first emergencies or follow-up centers, especially during and after the Covid-19 pandemic. Technological innovations are various and have different impacts.

Our literature review found many studies about e-health, digital healthcare, patient-centered healthcare systems, communication, and patient engagement in chronic diseases. E-health (or "digital healthcare") and e-health management were born in response to the growing need to improve the quality, efficiency, and accessibility of healthcare using digital technologies. The concept of e-health began to spread in the 1990s (Cordero, 1990), when the rapid development of information and communication technologies created new opportunities to improve health data management, communication between health professionals, operator training healthcare, and patient access to health information. Analysing the spontaneous processes described, scholars searched for a definition of e-health as a patterning method to understand and describe innovation in the sanitary field. Many meanings of e-health have then been proposed in academic discussion, and in the first part of the literature debate, the idea needed to be more fully shared. Several systematic reviews of published definitions were analyzed to articulate the term clearly. The proposed definitions considered "e-health" as using information and communication technologies for health applications (Healey, 2007). However, the concept varies according to the context and institutions where it is used (Lewis, 2015) and is not yet mature across all healthcare disciplines (Al-Rimawi et al., 2016). Furthermore, e-health is not limited to the health domain but is used in many disciplines, such as education, insurance, and business (Cashen et al., 2004). Rodriguez et al. (2016) state that e-health technologies are tools created to improve the health process. The outcome is a new, efficient, fair way to improve accessibility to health services, which reduces response times, delivers cost savings, and provides the ability to distribute alerts.

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

In this case, there are some exciting aspects: patient's familiarity with technology, their responsibilities, and the engagement of their caregivers.

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 young patients' chronic diseases, in this person-focused care view; we observed also observed the change caused by the pandemic. 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 by describing the change in doctor-patient relationships; consequently, then explains the more active and central role of patients and caregivers in healthcare, especially during the pandemic. In the third, two case studies are presented, aiming to observe this change and understand the impact of new technologies in their peculiarity, uniqueness, and complexity in the specific context of chronic and degenerative diseases. Finally, there are the authors' conclusions.

2. Technology and changes in healthcare: an overview

The organizational change in healthcare and the Italian context of profound social transformation arise in general. 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. (Li, 2013).

Health is critical because society aims for well-being despite lengthening life and acute and chronic diseases, considering a growing and increasingly demanding public expenditure (Torre, 2017).

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 managing chronic diseases through home monitoring (European Commission, 2019).

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This scenario accelerated because of the Covid-19 pandemic: starting from virus diffusion, significant challenges for public healthcare systems were presented globally. The critical challenge for the public healthcare system is to provide adequate healthcare to patients while at the same time keeping frontline medical staff safe. Telemedicine has been affirmed as a fundamental service intervention for this purpose. Digital healthcare integrates technologies into medical practices to support the need for face-to-face interactions through video consultations (Leite *et al.*, 2022).

Digital healthcare includes telemedicine but also e-health, e-care, and remote technologies. Eysenbach, in 2001 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 (Gustke et al., 2000; Munos et al., 2016), which concerns the remote diagnosis and treatment of patients by telecommunication (Stanberry, 2000), transforming healthcare organizations. Technological development relates to changing visions in managing health systems and patient centrality (Robbins et al., 2013). By involving the customers/patients through apps, platforms, and sensors, new paradigms focused on them 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 and be part of and give realtime feedback (Prahalad *et al.*, 2004). In the beginning, telemedicine aimed to increase profitability, remotely monitoring or cutting patient hospitalizations before and after interventions, thus reducing the time and costs of providing services; after more than two years of the pandemic, this process induced a new step in value creation (Christensen *et al.*, 2009; Leite *et al.*, 2022).

The healthcare model is increasingly personalized: cures, patterns to follow, and follow-up are thought and organized based on the patient's needs, not only to improve results from a medical point of view but also as an organizational enhancement (Robbins et al., 2013). This innovation process is continuously evolving; artificial intelligence, for instance, while reducing human error and improving treatments and diagnostics (Meskò et al., 2018), 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 (Vitacca et al., 2009), and improve the clinical approach.

Patients and their families, especially those with chronic 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 (Hill *et al.*, 2015). As Franke studied in 2013, user innovation is innovation-driven or created by those who will benefit from it. This innovation is linked to the product, service, and process. The critical issues are data confidentiality and the perception of a workload increase without a significant counterpart (Vecchiato *et al.*, 2010; Bonomi *et al.*, 2015). Due to disseminating health information can depend on the excessive use of specialist services for fear of making a wrong assessment and for the unceasing request of people (Meskò *et al.*, 2018).

Organizational consequences are the horizontal setting of the flow and the adoption of multidisciplinary logic based on multi-stakeholder work teams. Integrating professionals and structures involved in e-health occurs at several levels, including patients. Their interactions are guided by specific team functions and processes, using the technological infrastructure as the basis of their work (Vecchiato et al., 2010). E-health transforms it into a "widespread hospital" and a place of integration of general services and customized solutions. It uses primary and advanced tools, from phones to smartphones, videos, electromedical devices, computers, wireless technologies, and the Internet (Munos et al., 2016).

Today it is possible to receive and exchange information quickly to find treatments and respect the patient's needs (Frow et al., 2016). For example, electronic medical records (EMR) reduce hospital waiting times and costs and provide real-time information on updates regarding diagnosis and treatment (Bonomi et al., 2015; Bonomi et al., 2016). 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 better

inform patients and their families. Patients have reserved areas and can, for example, evaluate the structure, comment on their experience, deal with other people with the same disease, etc. (Prahalad *et al.*, 2004).

Five factors (Vitacca *et al.*, 2009) 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 and patient empowerment; however, ease of use and simplicity of approach is necessary. 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 (Prahalad et al., 2004). ICTs create an online intersection between users and service broadcasters, formal and informal associations, where comparing and exchanging experiences, the sense of belonging to the community, and the process, create precious, practical, and experiential knowledge (Prahalad et al., 2004).

Participation, even emotionally, overturns the approach to creating value, where the expectation of users

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is essential (Füller, 2010). In such a complex society, it is necessary to involve whoever is actively managing services (Fuchs et al., 2013). In public services, especially health ones, involvement invests the sense of citizenship and belonging to society. "Service" fits into "value co-creation" and "network:" it becomes a set of services in a system with a single logic and the enhancement of the concept of a network (Vargo et al., 2004). 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 (Lusch et al., 2006). Therefore, the organizational structure represents this co-creation, a new paradigm in which entities, people, information, and technologies become cornerstones.

The main barrier is the patients' concern about losing direct contact with their physician (Bonomi *et al.*, 2016), the security and protection of their physical integrity (avoiding contagion), and privacy management. The pandemic helped fight these fears because the virus was more potent. Teleconsulting in these years has represented an exciting application of telemedicine: video calls were, in many cases, the last care possibilities (Dubey and Tripathi, 2020). 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 have turned into systems that focus on the patient: this is what is called patient-centricity (Robbins *et al.*, 2013). 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 (Torre, 2017). It is an 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 giving the patient an organic and connected system assessed with efficiency indicators that serve as feedback and monitoring (Torre, 2017). 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 correct it, leading to patient empowerment

Tab. 1 - Some benefits and consequences of digital care - Authors' elaboration

Benefits of digital care include	Consequences of digital care include			
Remote controlling	Patients' houses are included in sanitary system			
Personalized monitoring	Tailored cures			
Reduction of management costs	More accessible sanitary system			

(European Patient Forum Strategic Planning, 2014).

2.1. A focus on the Italian context

Focusing on the Italian context, it 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 digital framework in which this revolution moves.

The Italian digital divide is profound (one family of three does not have a PC at home), 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 (Schiavone, 2020).

So many experiments, born to test the application of new technologies and devices in Italy, had significant participation with highly relevant results. Italian patients and patients' relatives are involved in helping care systems enhance innovation and sometimes are a way for new proposals and ideas. In this scenario, social communication in general and social media are a way to collect experiences, opinions, and testimonials and be part of the new approach (Schiavone, 2020). Their nature, chronic diseases of young people, are a primary playground to this new healthcare model; hat improves information collection through smartphones (Consolaro et al., 2016) and social networks.

3. Patients' engagement and empowerment

This term means 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" (European Patient Forum Strategic Planning, 2014). 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.

Personalization and co-creation (co-production or co-design) reshape healthcare models. Patients' clusters are now rich in several small niches, always an evolving configuration (Baldwin *et al.*, 2011). This revolution is the so-called customer mobilization that refers to customers' immediate identification and involvement in health systems and new health product development (King et al., 2013). At the heart of this study are the indications of care and information that must be complete and clear. This impacts the quality of care, the managerial process, and cost management (Torre, 2017). 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 and put themselves on the same level as patients without losing the sense of the role. Thus "the humanization of medicine and the treatment process" develops, and the communication system changes totally (Robbins et al., 2013).

Talking about the "persons at the center" means understanding the context

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in which they move and assessing their centrality, regardless of the role of the patient (Robbins *et al.*, 2013). Assistance focused on the person is based on accumulated knowledge to recognize health problems better and needs over time and facilitates adequate aid. It focuses on the whole person and his story (Starfield, 2011). The differences in approach between patient-centered and person-focused care can be summarized (Starfield, 2011) in Tab. 1.

The management of the relationship between physicians and patient overturns: the patients, first-hand, through their associations and caregivers, especially if patients are young, ask for clarity, and the physician invites them 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.

In health policies, focus on persons has led to the concept of "engagement," an integral and active part of the treatment process and, more broadly, of taking charge, especially during the pandemic. The patient becomes a promoter, commentator, and developer of the treatment process ("I take advantage, I recommend"), enhancing the accessory service component. This is part of taking charge and positively impacts health; for example, patients can easily find follow-up drugs outside the hospital and quickly book visits if they do not have waiting times. So they have the possibility of better treatment (Graffigna *et al.*, 2017).

In chronic or reiterated illnesses, patient engagement highlights the two-way, privileged, and conscious relationship between them and their healthcare system; 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 the health system, without waste, with feedback and using the service users themselves as privileged testimonials (Torre, 2017). Engage patients makes them 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 (Graffigna et al.,

Tab. 2 – "Patient-centered care	″ vs.	"person-focused c	care"	(Starfield,	2011)
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Patient-centered care (generally)	Person-focused care
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

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2017) to obtain the maximum benefits that they have and are paid to them (Bonomi *et al.*, 2016). Different definitions of "patient engagement" deal with the various aspects; Graffigna *et al.*, in 2017, have, for example, exalted its emotional role in the treatment process and its therapeutic and organizational impact (Tab. 2).

Consequently, patient engagement is a sort of transversal concept that includes empowerment, a strong collaboration for a constant update on one's health, the news search, and the comparison between peers; the doctor-patient relationship completely changes appearance and becomes a real exchange relationship (Palumbo et al., 2016). Patient engagement, therefore, improves the treatment processes and the health system in general (Fischer et al., 2016): it helps planning services and thus enhances the allocation of resources in health expenditure, allowing that "therapeutic alliance" or the joint effort toward 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 wellrounded and investing approach and multiple areas connected (Domecq *et al.*, 2014). 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 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 identifies eight priorities helpful for this discussion:

- 1) Complex, systemic, and "multi-stakeholder" vision in a model that sees the health system as an ecosystem of cellular organisms.
- 2) Evaluation strategies of patient engagement to impact strongly on organizational models and health expenditure in virtuous terms.
- Counseling tools and psychological and educational support are 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, and awareness of health professionals willing to change their role in terms of involvement are no longer normative.
- 5) Enhancement of caregivers and patients' families, promoting their engagement through specific training, information, and involvement interventions.

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Tab. 3	_	The characteristics of	engagement	(Authors'	adaptation	from	Graffiana	et al.	2017)
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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 engagement, 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.	Engagement 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

- 6) Information and involvement of civil society favoring the birth of networks and informing about the prevention and involvement of associations; social action, websites, and online news, for example, allow 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 can build an engagement ecosystem. The role of new technologies is fundamental in engagement and its constant expansion. They can be present 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 (Collins *et al.*, 2011)

3.1. The chronic disease context

It is crucial in this work to analyze the difference between a chronic disease context and a standard hospital. Physicians must face the relationship with patients and caregivers with the awareness that patients will always be under therapy and control. For this reason, they feel part of the healthcare ecosystem and the disease community engagement. Then, a doctor/caregiver perspective must also be approached from a clinical and psychological point of view but differently. In the case of chronic diseases, the physician establishes a relationship of trust: developing a path to collaborating over time to solve the clinical problem that generates the psychological one is essential. This involvement cannot be left to chance or the doctor's or ward's initiative 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 and customizes health services and intervention programs to respond to previous evaluations in a continuous improvement process that manages investments to structure it. Finally, engagement strengthens the social and health area with the awareness that welfare networks strongly influence the related models (Domecq *et al.*, 2014).

In this specific intersection between the engagement and empowerment of patients/caregivers, and the context of chronic diseases of young people, our work fits, comparing both scenarios before and after the pandemic.

3.2. The scenario after the pandemic

Also, due to the recent pandemic, public services are simultaneously experiencing challenges and opportunities (Lent & Studdert, 2019; Liu *et al.*, 2020; Giannopoulou & Tsobanoglou, 2020).

The challenge concerns the increase in demand, and it is catalyzed by profound structural changes, including demographic ones (Dall *et al.*, 2013; Beard & Bloom, 2015) and the increase in chronic diseases (Dall *et al.*, 2013). These diverse and interdependent trends challenge the longterm sustainability of public services as they are currently organized.

The opportunity, on the other hand, concerns the desire of the population to have a more significant influence on the public context, this trend, defined as "Community Building" (Lent & Studdert, 2019), represents an opportunity to bridge the gap between the increase in supply and demand for health services. New technologies are then also a trigger for the development of community building.

There is extensive international literature on community initiatives to promote health. The interventions in which the community is involved to achieve health objectives can be organized with different approaches according to the characteristics of each intervention and the various degrees of community involvement, which may depend on the range of action of the public administration. The main strands identified in the literature can be summarized as community participation, community development, community empowerment, community-centered approaches, community building, community organizing, community-based initiatives, and community engagement (Longo & Barsanti, 2021).

Community engagement is a generic term encompassing a continuum of approaches to engage local communities and interest in improving population health and reducing health inequalities (Popay *et al.*, 2007). Patient engagement as part of community engagement can be explained as how much information flows between a patient and a provider, how active a role the patient has in care decisions, and how involved the patient or patient organization is in health orga-

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nization decisions and policy-making (Carman *et al.*, 2013).

To be involved, patients need to feel at the center of the process (Wheat *et al.*, 2018). To have comprehensive health care, it is essential to focus on the quality, effectiveness, and timeliness of the service; from this perspective, technology can play a crucial role in health care widespread to all (Graffigna *et al.*, 2017; Graffigna *et al.*, 2020; Longo & Barsanti, 2021).

During and after the pandemic, this patient-centric culture permitted to help people affected by Covid-19 and people that could not go to hospitals for contagion to feel ongoing monitored and psychologically safe (Majid and Wasim, 2020).

This process of participation and involvement allows including in the chain of co-creation of the value of the health service a series of "other" actors: caregivers, social assistance systems, and reference communities (associations on specific diseases) and to obtain new practices that can then be transformed into protocols (Botti and Monda, 2020).

As Graffigna (2017) explained, the "engagement ecosystem" changes the internal managerial paradigm, and the assistance model develops towards the outside, society, neighboring communities, and the socio-welfare area. Often the associations for chronic diseases, for example, become testers of therapies with their members and allow to sensitize those who are physically outside the hospital but in contact with the disease (George and Bucatariu, 2020).

In this perspective, the concept of involvement plays a role close to that of "corporate social responsibility" and "long-term sustainability" of the health service (Testa *et al.*, 2017; AlDossary, 2017) in an attempt to understand and explain the type of relationship that exists between an organization and its stakeholders. From an even broader perspective, we can speak of sustainable health service development where stakeholders' involvement mediates conflicts arising from different expectations (Pereno *et al.*, 2020).

Therefore, value co-creation among service participants includes external stakeholders as another piece of the co-creation process. We could speak of general management because a new path is defined between the actors of the care and management process (Lo Presti et al., 2019). Caregivers become, in the evolution of the healthcare ecosystem, more and more one with the community of the healthcare facility, changing the relationship between internal (doctors, nurses, patients) and external (caregivers, caregiver associations, patient associations, stakeholders) in hospital (Spagnoletti et al., 2015).

4. The case of two Italian places of care

4.1. Method

This paper aims to investigate how technologies in healthcare have changed the relationships and existing organizational paradigms in chronic diseases of young people before and during the pandemic.

The case study methodology allows us to correctly answer the "how" and "why" specific phenomena are found in a particular context (King *et al.*, 2013) and was considered appropriate for answering the research question of this work, which is a "how question."

The cases were chosen as particularly significant to confirm or refute the

theory outlined so far and support the research question's answer because they are two essential structures dedicated to young chronic patients where we could observe through a privileged access route, as caregivers, the various phenomena (Siggelkow, 2007) indagated. We chose a multiple case study because the data collected seemed more reliable and gave greater rigor to the study of the observed phenomenon (Concoran et al., 2004); their different nature (one profit and one non-profit organization) can show is the phenomena are the same, regardless of the context.

In the first case of diabetic pediatric 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 of pediatric age do not have an immediate and visual confirmation of the damage caused by improper disease management. They are interested only in the psychological repercussions of "having to" cure themselves.

In the second case of degenerative diseases, the situation is similar because young people gradually lose their autonomy and are aware of the consequences of their actions, especially of appropriate care. The IT monitoring and communication between physicians and caregivers become fundamental for targeted and timely interventions.

In both cases, caregivers can understand that the treatment is a perspective to live well not only in the present but in the long view; the only way to tackle it is to see the disease's management 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 because this study revolves around a 'how' question. The scientific research in this field in addressing healthcare challenges is still in its infancy (Edmondson *et al.*, 1994).

Structured questionnaires and semi-structured interviews are frequently applied in mixed-method studies to produce confirmatory results despite differences in data collection, analysis, and interpretation methods. In aligning data from the two different ways, we found a lack of variability in participant responses, greater sensitivity to context, and seemingly emotive responses (Harris and Brown, 2010)

We did 28 semi-structured surveys lasting 40 minutes and recorded and transcribed them. We interviewed ten young patients and five kinds of their family caregivers: two fathers (public employees and an entrepreneur), six mothers (four managers, a housewife, and one physician), four grandmothers (retired), two brothers (an IT consultant and a sustainability consultant), and one sister (student at university), three volunteer assistant (Starfield, 2011). Those caring all involved in a chronic process for years could understand the evolution of the technological impact on the ward's life and have been available for collaboration.

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

- the person-focused care and the doctor-patient/caregivers' relationships (Which episodes of your life experience with health made you feel more understood and welcome by physicians or health workers in

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general, or considered as a person before than an ill person; or aware, to reduce your anxiety and so on)

- the relationship with technology of patients and caregivers, and connections with their engagement and empowerment (which e-health tools improved your relationship with physicians, and made you feel more responsible or involved and so on);
- the empowerment developed by patients and caregivers (which is your contribution to improving the quality of care, monitoring the illness, reducing hospitalizations, ...);
- the engagement shown by patients and caregivers themselves (do you participate in training done in the hospital, or in associations or online community to be more informed and to testify your experience, or other...).

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

At a later time, we also sent 135 questionnaires (response rate 64,4%, i.e., 87 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 improving communication and services.

More specifically, four questions were about the competencies, professionality, sensitivity, privacy, and quality of care to indagate the person-focused care and the doctor-patient/caregivers relationships; five questions regarded the different kinds of tools of telemedicine and their use in communication about the state of health, monitoring of patients' conditions and to foster the management of care in health structures to indagate the relationship with technology of patients and caregivers, and connections with their engagement and empowerment; four questions indagated the training and knowledge transfer to patients and caregiver for control over the treatment process and the management of care at home and the mutual influence to verify the empowerment; finally, five questions regarded the patients'/caregivers' ability to check daily on disease requires the associations of patients and caregivers for mutual help, and the testimony to other, to understand the engagement shown by patients and caregivers themselves.

The collection of data takes place through participant observation (Brius, 2007; Corbetta, 1999), the technique most used to study the interaction between two or more subjects within a context such as a hospital (Graffigna et al., 2017), with the first-person intervention of one of the researchers, who is a family caregiver, and another, ex family caregiver and, now, volunteer. This method allowed us to see the real situations and activities and subjective characteristics, accompanying the criterion of objectivity with the sensations and emotions felt. The process is based on what people said and reported but also pays attention to non-verbal language, alongside the careful analysis of 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.

4.2. A brief description

The X hospital is a sanitary structure and a university clinic dedicated exclusively to children. The hospital has accommodation facilities connected to care, places for patients and caregivers, but also social places. With a portal that contains and shows the stories of children and their families, even Facebook pages, Instagram, and Twitter accounts are essential 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 has a lively stakeholders' involvement; in this way, the hospital can test its policies and understand how to monitor process innovation and implementation.

The Y structure is a residential, rehabilitation, and health facility for young people with the degenerative disease in the Northeast of Italy.

This structure is the evolution of a non-profit organization's project, working on sport and rehabilitation for disabled young people, to give hospitality to chronically sick people, first on weekends and then continuously. Usually, the primary purpose of the activities is to encourage encounters among illness young people and between them with health workers, to improve the quality of life and health, physical and mental, as much as possible, thanks to the care provided. During the pandemic, most of the activities should have been interrupted. Still, a mix of different telemedicine tools for visits and rehabilitation allowed everybody to continue health care and community management while preserving protection from Covid-19 infections.

 $4.3.\ {\mbox{Patient-focus}}$ care and communication

In the last ten years, there has been an evolution of the structure and the development due to new technologies and the new approach to communication between doctors, patients, and caregivers to include all of them in a dedicated community; it developed projects for treatments, research, and person-focus care. This world wants to be a physical and social community for sharing paths, experiences, and values

Tab. 4 –	- Patient	centricity	in X	and Y	' cases	(Our	elaboration	I)
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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

Part of the system is the world of associations.

Technology is at the service of the centrality of the person.

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to bring together internal and external stakeholders around projects and develop awareness, empowerment, and testimony until a decisive engagement. Some non-profit associations contribute daily to this ecosystem. The following table underlines the path of patients' centralization, which has developed in recent years, taking up what the literature highlighted.

Technologies are a crucial point in the evolution of patient innovation. This analysis notes two strands: remote technologies, appropriate telemedicine devices, and communication systems. Using devices in patient care is a way of controlling data in therapy and developing a different communication relationship. Speaking, for instance, about diabetes, with a new application, insulin pumps for treatment have been connected to an application that continually monitors parameters for a few years. Another example is the case of psychiatric or neurological therapies, which require regular dosages and schedules; the application warns the patient or family members of which drug to

Tab. 5 – Characteristics of patient engagement in the two case studies. (Authors' elaboration)

Concept	Definition X	Definition Y	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 website, social media, but also the seminars, courses, and workshops organized by ASL, associations of the network, and the structure itself are a source of particularly important awareness and a way of learning.	The great synergy between empowerment and engagement, also thanks to storytelling and the institutional Facebook page.
Activation	Through remote management, micro-infused patients are activated continuously as well as their caregivers.	Through a simple app, patients are activated continuously as well as their caregivers about their therapies	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).	The entire rehabilitative 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.	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.	A differentiated structure for rehabilitation, entertainment and temporary hospitality 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.	It is also important in degenerative and long-term illness care. For example, all programs are proposed and applied with awareness.	The choice of the device involves shared decision making.
Involvement and participation	Idem (see previous)	ldem (see previous)	Idem (see previous)

administer and how to ask for care to remember when the drug is running out, and it is necessary to obtain the prescription. So, the doctor-patient-caregivers 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 and network integration between patients, caregivers, doctors, nursing staff, pharmaceutical companies, and device manufacturers. It is possible to use a 24-hour cell phone number, which doctors or operators manage, as a handy help desk for these diseases. Next to direct interaction, another important communication system born in recent years, developed on social media and the web. The X 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, in both cases, the Facebook page, Instagram, and Twitter accounts provide training, culture, information exchange, and empowerment for patients already treated by the hospital and the entire activated community.

4.4. Patient engagement: testimonials and associations

Based on the model in Tab. 2, the level of engagement developed by X and Y cases' organizational and communication strategies were analyzed. Tab. 4 shows the parameters identified as an index of the Patient level Engagement set. Finally, voluntary and protection associations work among hospital patients to support care, associations, foundations of parents, donators of blood and marrow, operators, and teachers. Their presence is significant.

4.5. Main findings

Following the results of the combined research are listed:

 Regarding the humanization of healthcare, all the interviewees think that doctors and healthcare professionals are excellent and work in full respect of privacy, even if for five people, this is less important; the 80% of 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 or disabled patients, the issue of protecting their relationships with others is a priority. Sometimes it seemed that putting young patients 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 young deserve; however, the almost game-like dimension developed in the ward and throughout the hospital helps to create an atmosphere of humanity. In the patients' and caregivers' opinion, the activity of the Y structure is based on the same values and cares.

 As far as technology is concerned, most interviewees are fundamental in the treatment process. 85% positively evaluate remote monitoring, although five people think it needs more real following. Elderly rela-

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tives have trouble following the technological evolution of care; however, telemedicine can significantly help everyone because technology replaces the knowledge necessary for managing the disease and makes everyone feel more monitored and calmer. The first empowerment process engages the family caregivers in a community. For twothirds, the relationship between the technology made available by the institutional website and the department's communication is not attractive; 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) are almost considered "discounted" for caregivers. However, upon specific request, they greatly appreciate them (93,5%). Especially during and after the pandemic, all the interviewed people, patients, and caregivers highlighted that they couldn't have been cured without ICT and would lose contact with their community. The community is considered fundamental to addressing the course of disease better.

3) As far as empowerment is concerned, the attention of doctors and operators is indeed projected on young chronic and disabled patients, their needs, and their difficulties; therefore, the process of information to parents may not always prove helpful. However, the placement of caregivers in the care process is considered a priority for the well-being of patients and family members. There is a strong commitment from the department, both doctors and non-doctors, including associations, to raise awareness militaries of the sick on care and support paths. First aid maneuvers and general rules for dealing with the daily life of the disease are explained. The condition's chronicity and long-term care require the necessary independence and shared and ongoing management of these paths. Only three people declare that "they do not contribute to doctors with a personalized treatment plan for optimizing patient care."

4) For 33 caregivers, who filled out the questionnaires, the association is necessary for sharing and belonging; for 21, it is fundamentals, and for 21, particularly significant. Even those who have not personally supported themselves consider the service a source of growth for relatives-patients.

As far as engagement is concerned, analyzing the interviews, 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. In addition, the Covid emergency has evidenced a new protocol of communication between physicians and patients/caregivers: an overarching possibility of telemedicine enriches wider healthcare delivery (Leite et al., 2021).

5. 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 chronic and degenerative diseases, especially of young patients, also during the pandemic.

The literature analysis found that the intersection among the relationships between doctors-patients/caregivers and chronic diseases needed to be explored. Comparing the theories with the case studies, the organizational change, and the doctor-patient (and caregiver) relationship in a person-focus oriented, the so-called 'humanization of healthcare' in chronic diseases seems deeply tied to health technology. This model was incredibly accelerated because of the pandemic and the new use of telemedicine (teleconsulting, first of all). This creates links and increases trust and safety, empowering patients, and caregivers. It develops through the information and courses organized by the hospital to raise their awareness, and the engagement shown by the patients and caregivers towards the community, enhancing the effectiveness and efficiency of care.

From the semi-structured interviews conducted live with all types of caregivers on the humanization of the ward, the doctor-patient connection, the relationship of the caregivers 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 place of care and the engagement shown by the caregivers in witnessing their experience at the facility, it was easy to analyze this commitment. Based on the Likert scale, patients' and caregivers' evaluations also confirmed these elements.

The main implications of our study regard the increase of telemedicine as an integrated system in the treatment process. The specific and disruptive case of the Covid-19 emergency, with the consequent lack of normality, showed that it is possible. Remote check-ups and monitoring, and knowledge transfer, in fact, make patients and caregivers feel safer. They can be trained, made more responsible, and stimulated to organize themselves in communities of mutual-help to reduce hospitalization.

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. Consequently, it facilitates the economic management of the health system thanks to the implementation of awareness by patients and caregivers and the creation of independence in the practical management of the disease. A different healthcare delivery means a more democratic approach to sanitary systems. This is preliminary research, aware that two cases, although significant as those analyzed, may not be sufficient; it is, however, believed that they constitute a good starting point for subsequent studies: telemedicine, especially in chronic disease, is one of the most significant parts of European agenda, so an essential pattern of examination is needed. A qualitative analysis will be followed by quantitative research thanks to the diffusion of these new services.

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