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Patient Empowerment and Health online Community: two ways to give the new viability doctor-patient relationship

Cooperación y intercambio de conocimiento en la era de Internet: dos maneras de dar nueva viabilidad a la relación médico-paciente

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Abstract:

The purpose of this study is to analyze patient empowerment and point out how it affects new approach to physician-patient management. It is also examined the role of empowered patients and Health Communities in giving new viability to healthcare organizations. The paper is based on a literature review of empowerment and in particular of patient empowerment. The emerging results are enforced by the discussion of *RareConnect.org* explanatory case study. The study investigates new patient decision-making ability, which involves a radical shift in healthcare management and communication. It also contributes to the definition of a "viable" approach to organization-patient relationship management, based on cooperation and new resources acquiring. The paper represents a first attempt to examine physician-patient relationship according to the model of viability cycle.

Keywords: patient empowerment, viability cycle, online health community.

Resumen:

El objetivo de este trabajo es evaluar el empowerment del paciente y señalar cómo afecta el nuevo enfoque de gestión médico-paciente. También se examina la influencia que los pacientes y las comunidades de salud online tienen en la viabilidad de las organizaciones sanitarias. El presente artículo se basa en una revisión bibliográfica sobre el empowerment y, en particular, del empowerment del paciente. Los resultados emergentes son respaldados por el estudio de caso explicativo *RareConnect.org*.

El artículo investiga la nueva capacidad de decisión del paciente, lo que implica un cambio radical en la gestión de la asistencia y la comunicación sanitaria. También contribuye a la definición de un enfoque "viable" para la gestión de la relación médico-paciente, basa-

da en la cooperación y la adquisición de nuevos recursos. El artículo constituye un primer intento en la investigación sobre la relación médico-paciente de acuerdo con el modelo de ciclo de viabilidad.

Palabras clave: Empoderamiento del paciente, ciclo de viabilidad, comunidades de salud online.

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1. Introduction

The evolutionary pressures arising from recent developments in Information and Communication Technology (ICT) have encouraged healthcare renovation. In fact, the spread of social media technologies in association with the extensive growth of Web 2.0 have led to a revolution in healthcare management and in related problem solving (Johnston et al. 2013). In fact, the Internet represents a valuable source of information, which enables patients to deal with general or even chronic diseases, also thanks to the online sharing of experiences and results (Yang et al. 2011). Moreover, this process point to a real patient independence in decision-making, as well as they are able to express their own opinions that, sometimes, influence healthcare organizations management. The emerging role of patient in healthcare strategies is both the cause and the effect of the so called *patient empowerment*, a process that makes patient able to change their passive behavior and psychological dependence from medical staff, in a new awareness that also influences healthcare general strategies. Patients awareness enables them to express their own needs and to participate in healthcare decision-making (Buccoliero 2010; Bellio and Buccoliero 2009; Lemire et al. 2008; Salmon and Hall 2003).

With the spread of digital media, patients' interaction with healthcare providers has been drastically changed. In fact, these media contributed to the enforcement of patient power and its ability in knowledge sharing and co-creation process. In such context, the so-called Online Health Communities, which are virtual community dedicated to various medical issues, ensure closer relationships between people, organizations and institutions involved in healthcare debate and characterized by the same needs (Johnston et al. 2013). Consequently, this study aims to analyze patient empowerment according to the influence of ICT and systemic and/or sub-systemic stakeholder (i.e. patient, institution, ONG, families, medical provider etc.) on healthcare organization renewing.

2. From consumer to patient empowerment

In literature, *empowerment* has been widely discussed because it refers to the growing influence of clients on companies' strategies. In this stream of research, a

new concept is emerging, the so-called *patient empowerment*, which is focused on the renewed physician- patient relationship. Generally, the concept of empowerment refers to the emerging people and community’s influence on the surrounding environment and on its actors.

In literature, we can find numerous and different empowerment definitions, related not only to their framework of origin, but also to their specific analysis perspective (Perkins and Zimmerman 1995; Wilkinson 1998; Wathieu et al. 2002). At first, this phenomenon has been discussed in social and behavioral sciences (Beckhard 1969; Neilsen 1986; Conger and Kanungo 1988; Bandura 1997), while also in a second time it was analyzed and defined in a managerial context, where it has been often related to the emerging client awareness about his own buying behavior, decision-making, and communicational capabilities (Wathieu et al.2002). Moreover, we have an empowered customer when he or she is able to participate to the construction, and monitoring of socio-economic dynamics (Warschausky and Zimmerman 1998).It is clear that consumer empowerment is strictly related to people ability in contents generation and management, even if these are fundamental for a product or a service evaluation (Pireset al. 2010).This peculiar process has been positively influenced by the spread of the Internet and its multimedia, which are at the root of the so-called “informative democracy” (Deshpande 2002; Sawahney et al. 2005). In another stream of research, scholars link empowerment to “social process through which it is possible to define, promote and emphasize the individual ability in their own need satisfying, and problem-solving, using all their abilities to control their own life” (Jones and Meleis 1993).

TABLE 1: Consumer Empowerment definitions

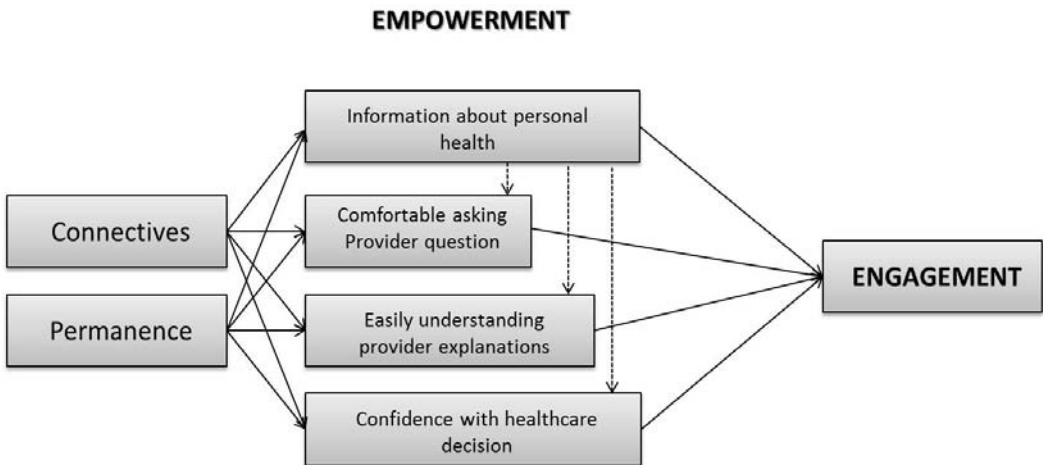
Consumer empowerment main definitions	
Jones and Meleis 1993	It is a social process that aims to define and promote individual capability in order to satisfy personal needs, solve personal issues, and control private life.
Zimmerman and Warschausky 1998	Consumers are <i>empowered</i> when they participate to comprehension, building, and control of socio-economic dynamic.
Wathieu et al. 2002	Phenomenon based on consumer growing control on product/ service information.
Pireset al. 2010	Phenomenon based on consumer ability in information creation and management, in order to evaluate the selected product/ service.

Source: our elaboration.

On the other hand, in healthcare has emerged a further declination of empowerment: the *patient empowerment*. This concept was originally defined and used by Skelton (1994), who highlighted patient growing ability in self-regulation and medi-

cal decision-making, in order to choose the best treatments for their diseases (Funnell et al. 1991). Therefore, the patient empowerment is considered a process of personal development, according to which patients can gain brand new knowledge, skills and awareness that led to more independent and self-consciousness attitudes. According to this process, practitioners can even act as facilitators who work within and for a physician-patient relationship (Bellio and Buccoliero 2009). Scholars have assumed that empowerment enables people (patients or not) to gain control over their health, needs, and lives. This process is based on knowledge sharing (*connectives*) and health information enforcement (*permanence*), which positively influences not only practitioners' information availability and understanding, but also patients' awareness and knowledge about treatment options.

FIGURE 1: Empowerment process in Healthcare



Source: adapted from Blue of California Foundation 2012: 8.

The empowerment of patient has contributed to management models changing and to a better distribution of power between who offers and benefits of healthcare services, in order to make them able to renew their capabilities and gain a growing self-awareness. In this context, it has been, recently, developed the notion of "informed consent", according to which when doctors have to choose between different treatments, they have also to explain them to patient, in order to make he or she able to be informed about all treatment's stages. Consequently, we have a shared decision-making only when doctor and patient cooperate in order to gain a shared decision about treatments' management. It is clear that medical practitioner have to share their medical and scientific skills, while patients have to express their preferences, doubts, and expectations.

In recent time, the patient empowerment has been defined as the power that enable patients to overturn traditional physician-patient hierarchy, turning it into a patient-physician relationship based on patients' experiences and knowledge (Broom 2005). In this context, the patient acts as an "expert" that is able to participate in diagnosis and treatments, in order to enrich their own expertise and prevent eventual health crises. Therefore, the patient empowerment according to the humanistic approach (Skinner 1953; Maslow 1967, 1998; Friedman 2008) highlights the self-realization and self-development tendency in human beings.

The understanding of patient empowerment process assumes a concrete perspective shift, which influence the evolution of traditional medicine in the so-called *participatory medicine* (Table 2).

TABLE 2: Perspective shift: from pending to active healthcare

Pending Healthcare versus Active Healthcare	
Disease-centered Based on hospital and specialist care People based Reactive, based on symptoms Treatment-based	Person-centered Based on primary care Communities based Proactive and planned Prevention-based

Source: adapted by Pan American Health Organization 2013: 28.

The gradual empowerment of patients is mainly due to their brand new ability in information generation, sharing, and finding, which they can use or not without any external restriction, according to informed consent principle. Although, sometimes patients can also decide to not exercise this power delegating any decisions about their diseases and treatments to medical staff.

3. Patient empowerment at Web 2.0 times

Conventionally, clinical information about medical treatments or diagnosis, prognosis and treatments were provided by medical practitioners, but then the Internet has contributed to change this process, opening medical communication to "*many to many*" paradigm, which is essential in online communication. In this context, medical communication is finally open to patients' contribution and cooperation through online tools such as websites, blogs, forums and social networks.

In literature, a lot of studies have investigated the role of social media communication in healthcare (Demiris 2006; Nambisan and Nambisan 2009; Doughty 2011; Caridà et al. 2013). In fact, in this specific sector, communication is considered an

intangible asset that positively affects real and perceived service quality. On the other hand, a limited number of contributions have investigated the influence of the web on value co-creation in health care.

In an online context, patients offer and gain an increasing number of information about common and rare diseases through web portal, social media, and virtual communities dedicated to healthcare issues. As some studies demonstrate, the emerging role of patient can be due to four different causes, such as (Anderson 2005):

1. *Therapeutic progress* occurred in recent years, especially in research, testing and treatment of rare diseases;
2. *Treatment specialization*, which led to new therapies and drugs;
3. *Patient satisfaction*, achieved thanks to clear and direct communication;
4. *Real-time online finding and/or disseminating of detailed information*, which sometimes are not so reliable.

These changes contribute to the shift from the traditional model of "biomedical treatment" to "empowerment of care" model (Gibson 1991), based on direct patients involvement in medical decision-making and on their ability to control their own health needs. Therefore, medical practitioners have to support patients' choices, in order to encourage their independence, collaboration and resources sharing.

The physician-patient cooperation can be based on three different approaches (Anderson 2005):

1. *Professional -centered*, whereby doctors' authoritarian attitude is based on the belief that they are the only reliable source of information and requirements;
2. *Patient -centered*, whereby physician-patient relationship can be improved thanks to information retrieved from patients online networks;
3. *Internet-prescription*, based on patients' information acceptance even by medical practitioners.

Other authors believe that patient empowerment contributes to the improvement of physician-patient relationship (McWilliams 1997) creating a positive mood based on dialogue and active listening; supporting and encouraging patient decision-making, providing information, personal recommendations, emotional support, and encouraging evaluation of changes occurred in patient self-representation.

The underlying innovations of patient empowerment promote a changing in role of actors that are involved in medical decision-making, encouraging their participation and autonomy. According to Eysenbach (2008), this change is based on the shifting from a decision-making "professional centered" to a "patient - centered professional guided", according to which patients themselves create, search, and chose

information, while doctors promote cooperation and a shared approach to treatment decision-making.

3.1. *Online Health Communities*

Recent studies revealed that patient empowerment is connected to the spread of online health communities created by NGOs, patient associations, or even health providers. In addition to private initiatives, it has been realized a great numbers of projects that aims to promote citizens active participation in medical processes.

A virtual community dedicated to healthcare issues (Online Health Community) is generally made up of different people that share common interests (Brown and Duguid 2001; Wasko and Faraj 2005). These communities, thanks to their technological infrastructures, enable members' interaction, knowledge sharing (Brown and Duguid 2001; Chiu et al. 2006; Wasko and Faraj 2005), and a mutual emotional support (Wellman 1990).

In literature, reliable results about healthcare communities' impact on medical process are very limited. However, some researchers identified a number of health communities' benefits for patients and medical practitioners (Murray et al. 2003; Frost and Massagli 2008). Through these networks, users (patients, physicians, institutions, families, etc.) can share knowledge, experiences, and contents (Nambisan 2010), especially on rare diseases (Nambisan and Nambisan 2009).

In recent times, health communities are not only grown in number, but they are also oriented to a concrete specialization that can be defined according to three different principles (Caridà2013): *Customer- centered*; *Healthcare professional- centered*; *Customer- and- professional- centered* (Tab. 3).

TABLE 3: Healthcare communities' examples

Healthcare communities	
<i>Customer- centered</i>	Groups affected by same disease or under the same treatments, with the same problems and open to cooperation, information sharing, and empathy.
<i>Healthcare professional- centered</i>	Communities dedicated to messages, opinions, resources exchange, and mutual cooperation.
<i>Customer- and- professional- centered</i>	Communities that offer an alternative communication, which enforce physician - patient relationship.

Source: our elaboration.

The so-called health communities can be considered such as “environments” dedicated to information and experience sharing, which provide a direct access to unmediated information about common or rare diseases, treatments and related patients’ experiences (Thackeray et al. 2009). These communities are considered complex environments because of their topics, members’ involvement, and delivered information about medical innovation, peculiar treatments, and requested lifestyles’ changing (Alkhateeb et al. 2008). Health communities have also several problems due to information overload, a phenomenon arising from the information surplus (Yang and Tan 2010), whose reliability and value are not always evident.

4. Patient communities as viability source for healthcare organizations

Nowadays, healthcare organizations have been deeply changed their organizational and operational principles. In particular, patients’ empowerment and stakeholders participation has helped these organizations in development of competitive services in line with market’s needs (Berry and Bendapudi 2007; Mc-Coll- Kennedy et al. 2012).

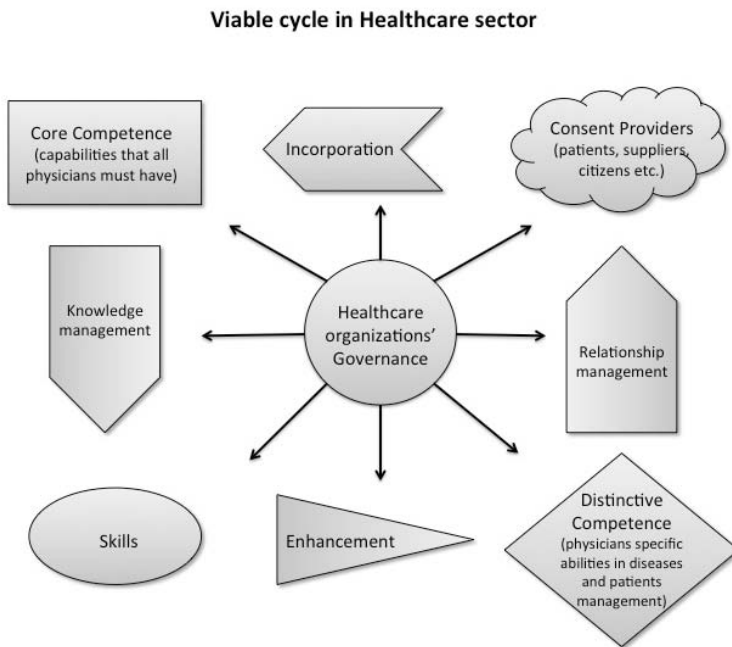
The growing involvement of healthcare environmental actors makes cooperation between providers and users not only possible, but even desired (Zeithaml and Bitner 2003). This cooperation is enhanced by online technologies such as social media and online communities, which make co-creation (Gummerson 2008) and even crowdsourcing relevant also for healthcare sector. These processes guarantee new viability to organizations, increasing their competitiveness thanks to the development of new skills, according to which they can offer highly competitive services in line with stakeholders’ expectations.

In healthcare context, organizations can “survive” (Golinelli 2010; Pellicano and Ciasullo 2010; Barile et al. 2012) achieving a good agreement based on positive relationship with entities (patients, families, institutions, NGOs, etc.) that populate the related context. In fact, relationships are able to connect organizations to their internal and external stakeholders, in order to develop good “consonance” with environment (Pellicano and Ciasullo 2010).

In healthcare, organization must achieve a good consonance with the surrounding environment (Pellicano and Ciasullo 2010) in order to get new skills through which gaining the attitude at surviving even in complex scenarios. Gaining new resources is an important process, even for healthcare organizations, because it represents a fundamental step of “viability cycle model” (Pellicano 2004). The main purpose of this model is achieving a concrete “distinctive consent” that can be obtained when the “resources’ keepers”, after the acceptance of a specific value proposition, decide to “release” them to organization. It is clear, that an organization is viable if it is able to evolve, and renew its structure, acquiring new resources through which develop new skills and competencies.

In the healthcare sector, the purpose of viability cycle model is the “regeneration” of organizations, which goes from resources acquisition to new skills’ development. This process aims to gain stakeholders consent and a new competitiveness, thanks to new knowledge acquiring (knowledge management) and the development of stable relationships (relationship management) (Figure 2).

Figure 2: The Viable Cycle in Healthcare sector



Source: our elaboration.

This process is fundamental even for healthcare organization, because it enables them to answer to patients’ emerging needs, offering interesting value proposition, according to which they can preserve stakeholders’ loyalty (i.e. patients, families, online and offline communities etc.). In this scenario, patients are no longer a passive element of physician-patient relationship, but they participate to value co-creation (Bendapudi and Leone 2003), contributing to make services much more competitive. The active role of patient in healthcare service creation is facilitated also by web technologies (McColl-Kennedy et al. 2009) such as social media, communities, healthcare networks, and mobile applications, which represent the natural substrate on which it is possible to build a concrete collaboration and co-creation (Caridà et al. 2012, 2013).

5. RareConnect.org Case Study

5.1. Methodology

The study is based on a qualitative research method to increase the knowledge in the particular domain of patient empowerment and its peculiar tools, such as health communities.

The present research is based on the explorative case study of health community named *RareConnect.org* and dedicated to management and care of different rare diseases. The case study method is a valuable tool for investigating the patient empowerment ??(Eisenhardt 1989) and the not predictable changes emerging in physician-patient relationship. This method provides a deep analysis of context-dependent knowledge, because it is focused on the reason why certain phenomena occur and on research aims description (Yin 2003). The Rare Connect case study is based on "within-case" method (Eisenhardt 1989), which provides a better understanding of patient empowerment, it's influence on doctor-patient relationship and healthcare organization viability, and of course their consistency with the assumptions highlighted by previous literature review.

5.2. *RareConnect.org*

Rare Connect.org is a network of several online communities dedicated to rare diseases that enables patients, families and groups to interact, learn and deal with those diseases that often cause isolation and relational difficulties.

RareConnect.org is a *EURORDIS* project based on cooperation between the European Organization for Rare Diseases and NORD. It aims to facilitate patients' interaction and experiences' sharing through a safe and moderated online forum and some social networks (e.g. Facebook and Twitter).

Patient empowerment approach

RareConnet promotes patient awareness about rare disease thanks to experiences and knowledge sharing. The web site has also some pages dedicated to patients' evidences, resource sharing (e.g. Photos, videos, texts etc.), interaction with healthcare organizations, and with social and/or patients' groups. The web site is also accessible to healthcare providers in order to increase the quality of published resources. The community advantages are related to rare diseases impact on patients' mobility and their ability in information seeking. Consequently, RareConnect aims to reduce not only physical and geographical boundaries, but also time constraints, in order to make information accessible without any logistical effort. It is clear that this web site acts as real

facilitator for doctor-patient relationship creation. Patient empowerment, enhanced by RareConnect, passes through three stages: understanding, sharing, and learning.

Social media

RareConnect network brings together 40 virtual communities, each of them dedicated to a specific disease, and the related medical treatment. Most of information and resources are available through social media, in particular through Facebook and Twitter.

The Facebook page is a consolidated tool with a great number of supporters (2573 Likes) and content sharing, in order to ensure detailed information about specific diseases and their related treatment, and/or psychological assistance. On the other hand, Twitter page counts 2.106 followers and 2.102 tweets, and it is also connected to others 25 accounts (Table 4).

TABLE 4: Rare Connect Twitter account

Company	Features	Type
RareConnect	It is designed for connecting rare disease patients globally. It is a social network for rare disease patients, families and patient groups.	Patient group
EURORDIS	It is a non-governmental European alliance of patient organizations and individuals, dedicated to improving the lives of people living with rare diseases.	Patient group
NORD	National Organization for Rare Disorders (NORD) is the voice of the rare disease community.	Patient group
NIH for Health NPR Health News European Cancer Patient Coalition	Turning Discovery Into Health. Health coverage from the NPR Science Desk. The European Cancer Coalition that gives more than 300 cancer patients organizations a voice in the EU – from the major to the rarer cancers. Turning Discovery Into Health	Government Journalism Patient group
Francis Collins European Medicines Agency Andrew Jack	Latest news from the European Medicines Agency.	Government Government
Faster Cures Rare Disease UK	Andrew Jack writes for the Financial Times on pharmaceuticals and health. Other interests: UK, Russia, France, Africa, non-profits and culture. It guarantees a fast access to cure information. It is the national alliance for people with rare diseases and all who support them.	Journalism Non-Profit Patient group
Genetic Alliance UK	It is the national charity of patient organizations with a membership of over 150 charities supporting all those affected by genetic conditions.	Patient group
NIH Office for Rare Disease Research Fondazione Telethon Italia Kate Bushby	Office of Rare Diseases Research (ORDR) rarediseases.info.nih.gov Since 1990, it collects found for supporting the research on rare genetic diseases.	Government Foundation
RD-Connect	Clinical Professor at Newcastle University interested in translational research/care for rare diseases, especially muscular dystrophies. An integrated platform connecting databases, registries, bio-banks and clinical bioinformatics for rare disease research.	Non-profit/Individual Project
European Patients' Academy on Therapeutic Innovation Téléthon France	It is the patient-led collaborative project to educate patients & the public about medicines R&D patientsacademy.eu	Project Foundation
Jan Geissler	It collects found for supporting the research on rare genetic diseases. Committed patient advocate and social media geek.	Non-profit/Individual
Rare Disease Day	28 February 2014 is Rare Disease Day. Raising awareness for patients, families and cares living affected by rare diseases worldwide.	EURORDIS

Source: adapted from "RareDisease Patient Advocates: Follow These 25 Twitter Accounts"

Finally, RareConnect.org relational network is based on an ambitious project that involves different subjects, such as volunteers, patients, families, researchers, and practitioners in order to gain new competences necessary in a high value service creation.

6. Conclusion

The spread of ICT and social media technologies enhanced healthcare organization to gain new viability and a strong relationship with their stakeholders. The literature review focused on patient empowerment has highlighted the emerging need for a more autonomous and participative patient. In fact, through social media communication, they can be considered as resources holders and/or providers, who can help healthcare organizations in gaining new viability. However, the basic features of these media affect physician-patient relationship and healthcare co-creation process (Gustafsson et al. 2012).

The development of patients empowerment and their emerging influence not only on offline and online communication, but also on organizations viability, has been deeply analyzed through the discussion of RareConnect.org case study, the virtual communities network dedicated to patient, families and even practitioners interested in rare diseases. The network seems to be focused on patient enhancement, possible sharing experiences, innovative healthcare solutions, and result of research conducted to defeat these diseases. Furthermore, patient seems to be the focal point of institutions and companies that aim to launch new alliances for promoting National Health System innovation. Therefore, organizations should be the first partner for patients, and society, because of they have a set of moral obligation to stakeholder and community.

According to previous statements, patient empowerment goes beyond the simple information sharing, because it aims to a real patient commitment in healthcare process (Caridà et al. 2013), in order to enable the transition from the traditional professional-centric perspective to a patient-centric perspective.

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