

Chapter 7

Psycho-cognitive Factors Orienting eHealth Development and Evaluation



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1 The P5 and the Personomics Approach

“Individuality of human beings affects predisposition to disease and response to treatment” (Potter, 1988; Sykiotis, Kallioliias, & Papavassiliou, 2005), stated Hippocrates in the fifth century BC, becoming the first known physician mentioning the relevance of a personalized approach to diagnosis and treatment. Many centuries later, personalized medicine has gained increasing attention (Britten, Pope, Halford, & Richeldi, 2016; Brownell et al., 2016), applying the Hippocratic vision to the need of “delivering the right treatment to the right patient at the right time” (MRC, 2017) (cf. Chap. 4).

Starting from the individuality of human beings—and to further enrich the personalized medicine approach—that is mainly based on the biological characterization of each individual, some years ago we proposed the P5 approach (Gorini & Pravettoni, 2011; Pravettoni & Gorini, 2011). The fifth P (that followed the other four P’s: *predictive*, *personalized*, *preventive*, and *participatory* (Hood & Friend, 2011)) indicated the *psycho-cognitive* aspects that characterize a patient not only as a biological and genetic entity, but also as a person with specific needs and values, habits and behaviors, hopes and fears, beliefs, personality, and cognitive dispositions. Introducing the fifth P, we underlined the need of integrating all these aspects with biological and genetic information in order to empower the patient, increase

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his/her quality of life (QOL) and transform him/her from a passive recipient of care into an active decision-maker during the entire treatment process (Joseph-Williams, Elwyn & Edwards, 2014) (cfr. Chap. 1).

In line with this patient-centered approach, a few years later, the term “personomics” was introduced (Ziegelstein, 2015). Inspired by the other “-omics,” including genomics, proteomics, metabolomics, epigenomics, and pharmacogenomics, created to characterize patients by their biological uniqueness and to provide more precisely tailored diagnostics and therapeutics, personomics refers to the patient’s unique psychosocial situation and life circumstances that may alter disease behavior and response to treatment (Ziegelstein, 2015). In accordance with the previous P5 approach, personomics distinguishes individuals not only by their biological variability, but also by their psychological characteristics, health beliefs, social support networks, education, socioeconomic status, health literacy, and all the other life conditions and events that may have important consequences on when and how a certain health condition will manifest in that individual and how it will respond to treatment (Ziegelstein, 2015). As the other -omics, these individual characteristics are critical to patient care, being useful for a better understanding of the pathogenesis and treatment of disease and allowing a more personalized care that takes into account the patient’s internal world and external life circumstances.

By embracing the P5 and the personomics approaches, non-pharmacological interventions, including, among others, psychological support, a greater involvement of patients in shared decision making, and lifestyle coaching, appear to be relevant to reinforce the effects induced by traditional pharmacological treatments. Assessing the individual needs and perspectives, together with the patient’s psychological attitudes and preferences may be also relevant to improve his/her treatment adherence, satisfaction, and, overall, his or her short- and long-term quality of life. Moreover, since such personal characteristics can change over time, or because of the presence of an illness or, again, its progression or recovery, an iterative evaluation of the individual patient may become a key feature for an effective personalized disease management (cfr. Chap. 3).

In traditional care paradigms, patients are physically evaluated when the diagnosis is established, and, only when necessary, at one or more follow-ups. Sometimes, psychological and/or quality of life evaluations are also performed depending on the patient’s illness and local guidelines. Nevertheless, such evaluations, when present, are not sufficient to guarantee the right attention to the above individual factors and do not allow a long-term monitoring of the patient’s characteristics and evolution. Moreover, time and cost constraints, other than patients’ limitations and difficulties, prevent the application of the P5 approach in the actual clinical practice.

According to the P5 and the personomics approaches, collecting organized patient’s input throughout the entire disease course is important for different reasons:

- To correlate psychological variables and quality of life with physical events, clinical state, and clinical recurrences

- To better respect the patient's needs and preferences to not lose treatment adherence
- To provide better tailored treatments
- To maintain a contact with patients during and after recovery
- To empower patients in improving their understanding of their health conditions and in making them actively involved in the management of their own disease

2 The Key Elements for the P5-Personomics Approach

What are the key elements of the P5-personomics approach and how can they be collected? Which instruments can be used by physicians to understand the patient as an individual?

The National Institute for Health and Clinical Excellence (NICE) has proposed a guideline document ((UK), 2012) that outlines 5 areas containing the elements of knowing the (adult) patient as an individual (p. 48). These areas include the consideration of:

1. How clinical conditions affect the person and how the person's situations and experiences affect his/her condition and treatment.
2. How the patient's life circumstances affect his/her treatment involvement and experiences, and his/her lifestyle choices.
3. How the patient's concerns, values, and preferences affect the way he/she engages with the treatment experience.
4. How the patient's psychological, social, spiritual needs affect his/her condition and treatment.
5. They also include an admonition to clinicians not to make assumptions about the patient based on appearance.

To answer the second question as to how such information can be collected, the most intuitive solution would be to interview each patient for as much time as possible. Unfortunately, this is not a feasible solution in the everyday clinical practice for the following reasons:

- Physicians have not enough time to investigate such aspects.
- Collecting this information requires different methods compared to those used to investigate medical symptoms.
- One single interview is not sufficient to implement a new model of cure based on the P5 approach.

3 Solutions Come from the eHealth Apps

A very promising approach to solve the above limitations and to collect as much data as possible involving patients in managing their health comes from eHealth. eHealth solutions have been considered in the last two decades as the “holy grail,” able (if properly implemented and scaled up) to reduce healthcare costs (cfr. Chap. 1), and improve patient experience while maintaining adequate levels of care (Tang and Lansky 2005; Bradford & Palmer 2016) (cfr. Chap. 4). In particular, eHealth solutions provide the basis for “participatory health” (cfr. Chap. 6), in which active involvement of all the involved parties—the patient, caregivers, and healthcare professionals alike—is encouraged. This assumes particular importance in the context of searching for innovative ways of supporting chronic patients, where it is fundamental to keep under control the underlying pathology and detect as early as possible the signs of worsening in order to anticipate countermeasures and prevent possible hospitalization. Thanks to the developments in the field of information and communication technology (ICT) observed in the last years, in particular with the large penetration of mobile cellular phone technology in the global market and its ubiquitous access to the World Wide Web, a large proportion of the world population has now access to and uses the Internet in their daily lives (via, e.g., a PC, tablet, wearables, and/or smartphone), thus finally providing the tools for the “holy grail” to exploit its potentials within healthcare (Internet World Stats, 2018; Kay et al., 2011).

This technologically permeated background, if properly utilized in the context of clinical medicine, has the potential to switch the way healthcare is provided from a paternalistic model to a collaborative approach, by means of self-management, shared decision making, and a coaching relation between the physician and the patient (Mead and Bower, 2000; Bacigalupe & Askari, 2013) (cfr. Chap. 4). In this way, the focus of healthcare could be moved from management of acute episodes to secondary prevention, and also to primary prevention (cfr. Chap. 3), physical fitness, nutrition, mental health, end-of-life care, home-care, and other fields related to an individual’s health.

4 Digital Health in the Patient’s Journey

Indeed, the use of technology for health is already permeating the patient journey, from prevention to treatment: while there are no diseases, access to specific tools such as mobile applications (or “apps”) could increase knowledge about possible risks associated to incorrect lifestyle behaviors and help in increasing levels of wellness through self-monitoring of exercise and fitness, diet and nutrition, alcohol moderation, and smoking cessation.

Once symptoms of a disease are manifested, a plethora of patient experience tools are available: searching related keywords on the web, specific apps for symp-

tom checking, social media to share concerns, and tools to find specialized centers if necessary.

In the process of clinical decision making, the physician could base the diagnosis on data acquired directly by the patient using smartphone embedded sensors or connected medical devices that have the potential to record possible pathologic phenomena when they manifested, if symptomatic (e.g., for atrial fibrillation (Halcox et al., 2017), thus overcoming some existing limitations of well-established diagnostic Holter ECG technology).

Once the diagnosis has been established, the physician may recommend digital tools for condition monitoring, such as app-supported disease management programs, connected sensors for remote monitoring and rehabilitation programs, or apps for psychological and cognitive profiling, and for any use case across the patient journey. In addition, patients could share their experiences, success and failure stories in patient's forum groups specific for the underlying pathology. In the context of treatment, medication management and adherence could be improved by utilizing digital tools, from simple reminders activated through the smartphone to more advanced electronic medication packaging (EMP), or solutions based on active patient involvement and artificial intelligence.

4.1 A Possible Scenario

Taking into account the P5 approach, such tools could be perhaps structured on the basis of the NICE guidelines, to be used by the patient both during the acute and the chronic phase of the illness. Organized in different areas, they can be used to:

1. Fill health journal, allowing users to record their clinical parameters directly or from remote monitoring tools.
2. Write diaries of life events that can have a significant impact on the individual well-being and quality of life. They include negative or stressful events occurring in everyday working or personal life, health-related events, illness recurrences, and any kind of event that is perceived as negative by the individual.
3. Collect the patient's concerns about the treatment experience, such as treatment side effects, or patient's complaints including physical or behavioral aspects induced by treatments.
4. Regularly collect information about the patient's social conditions and psychological status. Individual characteristics, such as personality traits, decision-making style, emotional profile, as well psychological dimensions, such as the presence of stress, anxiety, depression, etc, and the presence of protective or negative social conditions (social support or social isolation, etc.) are collected in this area.

All this information may be collected through monitoring tools and periodic remote administrations of specific questionnaires starting from the acute phase of

the illness (if possible) for as long a time as possible in order to provide long-term monitoring of the patient, from the acute to the chronic phase.

Specific algorithms are then needed to put together information obtained from the different areas in order to integrate physical, environmental, and psychological factors into explanatory and possibly predictive models.

At the same time, periodic reports for patients and physicians may be created by the system in order to make the patient aware of his/her condition and to alert the physicians when unexpected or worrying events or health changes occur.

A comprehensive monitoring program, consisting of an eHealth app collecting different patient information may have the potential to improve trial design, enhance self-management, allow for early treatment adaption to minimize side effects, reduce hospital admissions, and, in general, improve personalized management and long-term QOL. Only by integrating biological information with patient-reported and patient-collected information, will we be able to realize truly personalized treatment, preventing clinicians from making assumptions about the patient based on appearance, as suggested by the fifth point of the NICE guidelines.

5 The Importance of Patient Education

Due to the availability of medical information through an incredible number of sources, a deep cultural change has been manifested, and described by the term of apomediation (Eysenbach, 2008) that is the process of disintermediation, where previous intermediaries (e.g., healthcare professionals) are functionally bypassed by new apomediarities (i.e., the web, online groups, GoogleSearch, etc.) in guiding the citizens' access to health information.

To appreciate the relevance of this phenomenon, this open access to information through technology could be compared to what happened after the introduction of movable-type printing press by Gutenberg in 1439, which led later to the era of mass communication in Renaissance Europe. This invention, by increasing literacy, permanently altered the structure of the society by the relatively unrestricted circulation of information and revolutionary ideas, thus threatening the power of political and religious authorities and breaking the education and learning monopoly of the literate elite, thereby bolstering the emerging middle class.

In the medical information context, while increasing patient literacy is a positive factor, the chief ethical concern regarding apomediation is that incorrect ideas or potentially dangerous practices will take hold. As observed previously, patient education is a lifelong program, where technology can enhance the learning process, but reliable content is the key. Examples of possible consequences related to these cultural changes are represented by the information overload while searching information through Internet (e.g., 770 million results are returned by Google when searching for "cancer" and 389 million when searching for "diabetes"), or by the incredible proliferation of apps in the "Medical" and "Health & Fitness" categories in the app stores: the patient is potentially left alone in the process of choosing

which information to rely on, or which app to adopt that best suits her/his needs, with the risk of trusting unreliable sources or using apps with claims not supported by validation for accuracy and efficacy.

In the process of patient empowerment, defined as the acquisition of motivation and ability that patients might use to be involved or participate in decision making (Fumagalli et al., 2015), patient education becomes a critical goal for patient enablement, that is, the acquisition of knowledge and skills for meaningful self-management.

Patient education aims to increase the level of health literacy, defined as the ability of the patient to obtain, read, understand, and use healthcare information to make appropriate health decisions and follow instructions for treatment and self-care (Sørensen, et al., 2012; Mårtensson and Hensing, 2012). Indeed, patient literacy constitutes the first step to properly understand health concepts, and it has been indicated by the World Health Organization as one of the social and economic factors impacting on adherence, defined as the extent to which the persons' behavior corresponds with agreed recommendations from a healthcare provider (Adherence to long-term therapies. Evidence for action, WHO 2003). To effectively utilize mHealth technology, health literacy is not enough, as digital literacy, that is, the ability to locate, organize, understand, evaluate, and analyze information using digital technology, needs to be ensured. These two abilities have been lately summarized in the concept of digital health (eHealth) literacy as the ability to seek, find, understand, and appraise health information from electronic sources and apply the knowledge gained to addressing or solving a health problem (Norman and Skinner, 2006). As a recent EU-funded project (Health Literacy Europe) has highlighted, health literacy cannot be taken for granted as, of the eight countries (Austria, Bulgaria, Germany, Greece, Ireland, the Netherlands, Poland, Spain) surveyed, only the Netherlands showed less than 40% of the studied population with inadequate or problematic levels, while the other countries had higher values, with extremes found in Spain (58.5%) and Bulgaria (62.1%).

Considering that the main cause of medical errors have been attributed to communication-related origins (Hughes and Ortiz, 2005), the ability of the patient to fully understand medical recommendations given by the physician during the consultation appears crucial: in Kessels (2003) it was reported that from the given medical information, 40–80% is immediately forgotten, while half retained is incorrect. To improve physician–patient communication, the teach-back assessment has been proposed as a method to confirm patient's understanding of medication and treatment recommendations (Porter et al., 2016). In this context, digital technologies provide new opportunities also for physicians to get used to this approach, with online learning modules freely available through the Internet (Abrams et al., 2012) or for the patient, with video recorded outpatient clinic sessions accessible for the patient via patient portal, as recently implemented at the Erasmus Medical Center in Rotterdam.

In order to define the baseline level for comparison after exposure to the educational interventions to determine its effectiveness, it is important to assess patient health literacy. In literature, different assessment tools have been proposed; for example, the Rapid Estimate of Adult Literacy in Medicine (REALM) (Davis et al.,

1993), or the Test of Functional Health Literacy in Adults (TOHFLA) (Parker et al., 1995), designed to measure both reading comprehension and numeracy to assess adult literacy in the healthcare setting. In the context of eHealth and health informatics for patients or for the public, it is crucial to be aware of who the final user really is and what characteristics he/she has that might impact on eHealth design and implementation: digital health (eHealth) literacy needs to be assessed. The foundations of the eHealth literacy concept are based in part on social cognitive and self-efficacy theories, which promote competencies and confidence as precursors to behavior change and skill development. eHealth literacy includes six core skills, or literacies: (1) traditional literacy; (2) health literacy; (3) information literacy; (4) scientific literacy; (5) media literacy; (6) computer literacy. The eHealth Literacy Scale (eHEALS) is a self-report tool composed of eight questions that can be administered by a health professional and is based on an individual's perception of his/her own skills and knowledge within each measured domain (Norman and Skinner, 2006).

6 Persuasive Design Technology

Research has proven that by means of technology, it is possible to help people to change their thoughts, improve their behavior and gain better health and well-being. Cognitive behavior psychology aims to explain, predict, and change our behavior using processes that are going on in the mind. In 1958, Albert Ellis developed one of the first cognitive behavior theories explaining how and what kind of cognitions (i.e., beliefs and thoughts) can change behavior. Since then, several theories for behavior change have been developed, thus prescribing what factors must be first influenced.

Behavior change is about persuasion, therefore behavior change techniques are often persuasive strategies as well. In the last decades, technology is used more and more as a vehicle for persuasion, because of its interactivity and adaptability. Compared to human persuasion, technology solutions present several advantages:

- Persistence: technology does not get tired of trying to persuade someone, and it can continue indefinitely.
- Anonymity: when talking to a human persuader, it is impossible to stay anonymous, while with technology this is easier, thus representing a huge advantage for sensitive subjects (i.e., psychological problems or substance abuse).
- Ability to manage large volumes of data: technology's ability to process huge volumes of data in a short time gives more persuasive power, as technology can back up a certain message with the data that supports it.
- Scalability: people can only reach a limited number of other people; using technology, many more people can be reached without a large increase in cost.

- Ubiquity: technology can be everywhere, even in places where a human persuader cannot be allowed to be. As for many behavior change techniques, effective timing of message delivering is crucial, so ubiquity represents a pivotal characteristic to modify existing behaviours;
- Multimodality: technology can present information in many different ways, including text, audio, and video, thus matching each person's individual preferences to the persuasive methods it uses.

In the late 1990s, the use of technology to persuade the users to change their behavior was first defined by Fogg (2002), and more recently persuasive systems were defined as “computerized software or information systems designed to reinforce, change or shape attitudes or behaviours or both without using coercion or deception” (Oinas-Kukkonen and Harjumaa 2018).

Technology can act in persuading throughout several different techniques:

- Informing: individuals have to learn the presented information, in order for this information to be remembered.
- Reinforcement: desired behaviour should be rewarded/reinforced as quickly as possible upon its performance.
- Discussing: individuals share their thinking processes and beliefs among each other.
- Social comparison: individuals are stimulated to compare themselves with individuals from other groups that perform the desirable behavior.
- Fear appeal: materials (i.e., images or texts that elicit fear) are presented and should appeal fear to individuals of the target group; typically, fear appeals are effective to a certain extent only, because, when reaching a high level of elicited fear, target users could avoid the issue instead of considering it.
- Skills training: individuals learn from practicing behavior by themselves, and practice improves their confidence.

In the context of the P5 approach, by using the persuasive power of technology, eHealth solutions can be made more effective, as people are more adherent to eHealth interventions when more persuasive elements are used (Kelders & Van Gemert-Pijnen, 2013). The Persuasive System Design (PSD) model (Oinas-Kukkonen and Harjumaa 2018) represents a state-of-the-art approach for designing and evaluating persuasive systems. It is applicable to systems that are designed to form, alter, or reinforce attitudes, behaviors, or an act of compliance without using deception, coercion, or inducements, that is, it is well suited for the design of eHealth technologies.

The PSD model assumes several principles common to all persuasive systems, as regards the ways that people can be persuaded by means of technology:

- Technology is never neutral, but has always an intention.
- People like their views and behavior to be organized and consistent: if systems support the making of commitments, then users are more likely to be persuaded to follow these commitments.

- Persuasion is often incremental: behavior change never takes place at once, but in small steps.
- Direct and indirect routes: paying attention (consciously or unconsciously) is very important when changing behavior.

As regards the characteristics that a technology should have in order to effectively persuade people, these can be listed as:

- Unobtrusive, to fit into our daily lives without requiring a big change in our daily routines.
- Open, to allow a person that starts using a system to clearly know its purpose from the beginning.
- User-friendly, as a system is more effective when it is appealing and easy-to-use; however, recent approaches partially challenged this assumption, because even tools difficult to use could generate emotions and affection that influence both their usage and their persuasive power (cfr. Chap. 9).

The PSD model defines four categories of elements, or software features, based on what technology can do to persuade its users into changing their attitude or behavior: (1) primary task support; (2) dialogue support; (3) credibility support; (4) social support. Accordingly, different software features based on psychological theories can be chosen and implemented to reach the aim of supporting the user's primary activities, to facilitate the information flow between the computer and the user, to increase credibility about the presented information, or to leverage social influence.

In recent years, the PSD has been used both to better understand the impact of persuasive eHealth technology, as well as to evaluate which features are implemented in an eHealth solution, and their effects on adherence and outcome. It represents a promising field in the aim of changing behavior in the domain of health and well-being, but more studies are needed to get more insight into which features and subjective factors could predict the effectiveness of eHealth technology.

Once these aspects are better defined, it will be possible to define an optimal intervention for each individual, based on the selection of only those software features able to highly engage the subject. This could then be described by extending the P5 approach with a sixth "p" relevant to "persuasive," to describe the personalized process of defining a specific persuasive technology approach that could optimize the desired change in behavior, paving the way for a P6 approach conceptualization.

7 Conclusion

In this chapter, we have seen how eHealth could be based on a more accurate and systematic consideration of the psycho-cognitive uniqueness of individuals (and patients). Specifically, we have presented *persuasive technology* as a possible

resource for designing technologies able to promote treatment adherence and healthy activities (e.g., behavioral change regarding lifestyle); however, we have to consider that medicine in general is a still evolving field. Although we have discussed that a consideration of psychological aspects is fundamental for the health-care context to evolve toward patient centeredness, the research is still open to a complete understanding of the psycho-cognitive aspects to be included in the design and evaluation of technologies.

Future studies may focus on how technologies can help patients to perform decisions toward their healthcare process, by identifying the influence of biases and misconceptions that could lead patients toward making disadvantageous choices toward their own health management; such technologies could be used not only to aid medical practice (Lucchiari, Folgieri & Pravettoni, 2014), but also to empower patients (Woltmann et al., 2011); moreover, cognitive psychology would be included, in the form of theory-based prescriptions, in user-centered design approaches toward the development of health technologies, in order to take into consideration patients' mindset and cognitive abilities.

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