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Commentary

The quest for engaging AmI: Patient engagement and experience design tools to promote effective assisted living

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ABSTRACT

Recent research highlights that patient engagement, conceived as a patient's behavioral, cognitive and emotional commitment to his own care management, is a key issue while implementing new technologies in the healthcare process. Indeed, eHealth interventions may systematically fail when the patient's subjective experience has not been taken into consideration since the first steps of the technology design. In the present contribution, we argue that such an issue is more and more crucial as regarded to the field of Ambient Intelligence (AmI). Specifically, the exact concept of technologies embedded in the patients' surrounding environment implies a strong impact on their everyday life, which can be perceived as a limitation to autonomy and privacy, and therefore refused or even openly opposed by the final users. The present contribution tackles this issue directly, highlighting: (1) a theoretical framework to include patient engagement in the design of AmI technologies; (2) assessment measures for patient engagement while developing and testing the effectiveness of AmI prototypes for healthcare. Finally (3) this contribution provides an overview of the main issues emerging while implementing AmI technologies and suggests specific design solutions to address them.

1. Introduction

The aging society is today one of the major concerns for healthcare systems across Western countries because this sociological phenomenon is increasingly affecting the quality and quantity of the demand of care. Particularly, the increasing number of individuals suffering from chronic conditions and demanding for long-term treatments requires to identify sustainable solutions for providing cost-effective and high-quality care services. For these reasons, this has become part of the priorities' agenda for both clinicians and policymakers [1]. The implementation of technological solutions aimed at enabling continuity of care by systematically monitoring the patient along his/her healthcare journey is today recognized as a possible strategy to face this challenge. At the time the present contribution is been written, numerous reviews are available investigating the effectiveness of new technologies designed to improve assessment and rehabilitation, disease management, health information retrieval, medical consultation and treatment adherence [2–5]. Elbert and colleagues [6], who performed a systematic review of systematic reviews and meta-analyses, found that 23% of reviews reported positive results in terms of effectiveness and cost effectiveness, and other 43% concluded that the research results are appreciable and promising. Indeed, an important outcome of new technologies used in the context of healthcare is related to the improved possibility to continue analyzing and treating patients outside of the medical consultation, making home-based care possible [7,8]. In this sense, eHealth has proven to be an effective resource to extend care pathways from acute to chronic diseases, giving rise to healthcare scenarios in which the patient can be potentially assisted at any moment of his/her personal life. eHealth permits to develop integrated, sustainable and patient-centered services and promote effective exchanges among the actors involved in the care process [9].

However, coming closer to the focus of the present contribution, eHealth has been often considered able to promote *patient engagement* too [10–13], generally defined as patients' ability and availability to have a starring role in their healthcare [14–16]. This is today considered a key priority for healthcare. Indeed, "engaged" patients, or patients who actively participate in managing their own disease condition, are demonstrated to gain successful clinical outcomes more than patients who simply adhere to treatments in a passivizing logic [17,18]. This happens because engaged patients are more likely than others to enact preventive behaviors, self-manage their symptoms and treatments, actively seek health

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information, and become advisors of good health practices when approaching new patients and promoting peer support [19–22].

However, recent literature [23–25] suggests that patient engagement is not a direct outcome of eHealth implementation, rather patient engagement strategy should be considered in advance when designing the new technologies for healthcare. Otherwise, there is a widespread agreement about the fact that without considering the patient as an active agent in the healthcare environment, such solutions risk to be substantially ineffective in the end. Indeed, despite the rhetoric and trust for eHealth solutions, patients don't accept the use of health technologies as much as they could [26–28]. Indeed, when the personal commitment of patients to the healthcare process is at low levels, information technologies-based interventions may fail irrespectively of the effectiveness and technological advancement of the involved tools [25]. For example, therapeutic contents administered via computerized programs may lack of implicit emotional aspects which are fundamental elements for the establishment of a therapeutic alliance [29]. Only supporting this aspect, the patient will be able to enhance his/her disease management skills and would be more akin to accept technologies for managing his/her own health and care.

2. The case for Ambient Intelligence

As previously said, a strategic approach to the promotion of patient engagement is fundamental for the effective implementation of eHealth-based interventions. However, the web-based technologies that are usually included under the aegis of eHealth and related concepts require an active contribution on the patient's part. Indeed, patients involved in eHealth interventions typically interact with dedicated web portals, online social networks, or mobile apps that help them to enhance their own health literacy, disease management and the consultation with the health professionals.

The case with one of the most advanced incarnation of communication technologies for healthcare, namely *Ambient Intelligence*, is quite different. The term Ambient Intelligence refers to monitoring and assistive technologies embedded in the everyday objects, which already affect the everyday activities of the target users. Specifically, the embedding of micro-computers and different kinds of sensors (pressure/strain, image processing, sound, motion, physiological signals, ...) allows a distributed system to recognize, analyze and monitor people present in the environment and their activities; then, integrated computational elaboration permits to understand their needs and to respond accordingly with online modifications of the environment itself. According to literature [30–32] an Ambient Intelligence application is recognizable on the bases of some distinctive characteristics: it is **context aware** (it makes use of information drawn on the here-and-now situation); **personalized** (it is tailored on the individual user's needs); **anticipatory** (it develops the capacity of predicting user's needs); **adaptive** (it is able to modify its own functions/behavior on the basis of the user's habits); **ubiquitous** (it is embedded and distributed among the environment); **transparent** (it is able to function without direct action, nor perception, nor knowledge by the human user). Indeed, health is one of the main application fields for AmI technologies [33], so that Ami (considered in terms of ubiquitous sensors; pervasive care; artificial intelligence, and automation) can be considered the gold standard for eHealth professionals to achieve [34,35].

However, if we consider the characteristics of AmI as outlined above (the latter in particular), one could say that patient engagement would be less important in the context of AmI. Indeed, AmI users can be even unaware that a given technological system is working around them, analyzing their physiological status and behaviors in order to automatically-provide assistive outcomes. In this sense, a chronic patient (or secondary users, such as his caregivers) could be involved in the AmI implementation process at the level of authorization only. Then, when the patient is placed within an intelligent environment, he has nothing to do apart from behaving as he normally does. Around him, the AmI system will proceed with its analysis patterns and will provide the programmed positive/assistive outcomes such as (for instance) facilitating tasks by means of online modifications of tools' affordances [36,37]; activating alarms in case of detection of health emergencies [38,39]; satisfying anticipated user's needs because of having identified habitual behavior [31,40]; and so on.

Actually, this cannot be the whole story when we consider the complexity of the subjective point of view of the patient/user. Even if we talk about "transparent" technologies, that the user does not interact with for most of the time, at least two obstacles can get in the way of acceptance and successful implementation. The first obstacle is related to **authorization** by the target patient and/or the caregivers. Authorization to AmI implementation may be given by patients basing on misconceptions and/or partial representations of the system and its functioning, resulting in the patient later opposing usage because of having experienced an impact on everyday life he had not correctly estimate previously. The second obstacle, that is strongly related to the first one, regards **integration at the level of everyday life**. The implementation of web-based eHealth tools usually encounters this issue at a significantly lower level in that the patient is asked to complete tasks that require limited time (e.g., report medication adherence on the web platform). On the contrary, AmI refers to a technology that is potentially *omnipresent* and observing specific portions of the environment continuously. From the point of view of the patient, it is almost impossible to prefigure any possible event/situation in his everyday life and what will be his own personal reaction to being monitored without interruption in specific cases. This makes difficult for the patient to (1) give authorization to more-or-less complex AmI implementation in his house, without proper knowledge of what this would mean for his everyday life, and for peculiar occasions and (2) feel comfortable with AmI working during specific situations in which he would like to enjoy privacy, autonomy, or solitude.

In other words, some aspects related to patients/users should always be taken into account when designing AmI technologies:

- the patient is not an object of analysis, but a subject with his/her own perception of AmI itself;
- as a subject, patient is not monolithic; his/her own perception of AmI can *change* over time or depending on specific situations; so can attitudes, behavior and overall acceptance;
- according to literature, the patient assumes different roles in his own relation with the integral care system over time; these roles are associated with peculiar needs, objectives and behavioral profiles.

The subsequent sections of the present contribution will explore these aspects in detail, in order to provide methodological and operative guidelines about how to deal with possible obstacles for AmI effective implementation. Specifically, the next section will present the construct of patient engagement, outlining the evolutionary phases of the patient's healthcare journey, the associated psychosocial states with peculiar needs and objectives, along with the presentation of assessment tools able to capture patient's healthcare experience. According to the specific needs emerging from the patient engagement dynamicity, the main issues for AmI technologies implementation will be outlined. Finally, this contribution will suggest actionable