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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.

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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

solutions in order to address such issues building on User Centered Design methods.

3. Patient engagement: what is and how to measure it

According to the Patient Health Engagement (PHE) Model, developed by Graffigna and colleagues [41] and to the more recent advancement in the psychological literature about the patient active role in healthcare, "patient engagement" has been defined as a "process-like and multi-dimensional experience, resulting from the conjoint cognitive (think), emotional (feel), and conative (act) enactment of individuals toward their health management" [42]. In other words, patient engagement is characterized by three interlaced aspects: a cognitive/informational aspect (what the patient knows and how he efficiently navigates across health information); a behavioral aspect (what the patient does concerning his/her disease and treatment management); an emotional aspect (how the patient feels when living with a disease). The articulation and the characteristic of these subjective dimensions contribute to determine how the patient succeeds in adjusting to (and elaborating) the onset of the disease and new life condition linked to it. Moreover, this meaning making process deeply affects the quality of the care experience and the role the patient is able to enact within the healthcare environment (from more dependent positions to more autonomous ones). According to the PHE model, patient engagement develops through four experiential phases (namely *blackout, arousal, adhesion, and eudaimonic project*, see [42]) which describe the process of patients' adjusting to his/her disease condition from being totally frozen due to the emotional disruption related to the diagnosis to a condition featured by having re-gained a satisfying balance between the illness condition and the other life spheres. According to this approach, the dynamicity of the patient's illness experience determines a fluidity of patients' needs and expectations along the care process. This is a crucial aspect that should be carefully considered in order to customize technological interventions above all when they occur within the daily environment of the patient. Indeed, patients may be differentially engaged in their healthcare according to their cognitive, emotional and behavioral approach toward the illness condition. Therefore, in order to develop and implement effective technological interventions, such devices should consider the patients' priorities and sustain their needs. Specifically, patient engagement studies suggest that the need for dealing with a chronic condition requires that the patient recovers the ability to re-adapt to multiple life domains, and finally learns how to realize his/her own potentialities and resources even in the presence of a long-life disease condition. As well as the patient engagement level is recognized to be unstable across time and across the clinical phases of the illness journey, measuring this aspect becomes more and more crucial in order to develop technological solutions really aligned with his/her needs and to assess their effect across time. In this aim, the scientific community has produced different tools aimed at measuring the patient ability to engage and be a proactive subject within the health care environment. These instruments differentiate among each other for their main focus in relation to the different aspect involved in determining patient engagement and might allow predicting patients' health risk [43]. For instance, the Patient Activation Measure, developed by Hibbard and colleagues [44] is a well-known instrument specifically aimed at assessing the patient behaviors when approaching his/her healthcare journey both in term of disease/treatment management and information seeking. Another scientifically accredited instrument is the Altarum Consumer Engagement (ACE) Measure™ [45] designed to assess the level of individuals' involvement in healthcare decisions and information management. Within the scientific literature, also the Patient Enablement Instrument [46] has been demonstrated to be a reliable measure for assessing patients' ability to understand the nature of their health condition and effectively cope with their illness. Recently, the Patient Health Engagement scale (PHE-s) [41] was developed as a measure of the patients' subjective experience of emotionally adjusting to the health condition. The specificity of this scale lays in the fact that it allows evaluators not only to assess the actual patient's attitude toward his/her health condition, but also to forecast the patient's risk for disengagement in health management and thus design preventive targeted intervention to optimize care pathways and technologies aimed at enabling them.

All these instruments can be applied along from the design to the concrete implementation of AmI solutions. These instruments might constitute a useful compass to orient the planning and delivery of technological interventions by effectively engaging people in disease management, keeping in mind a dynamic vision of the patient engagement experience. For example, in the first phases of the engagement process, AmI technologies should assist and scaffold patients – who are in a passive position for what concern the care process – in monitoring the health parameters and managing stressful consequences related to the disease onset. In the adhesion phase, patients should be empowered and supported in effectively following the medical regimen. Finally, when the patient is fully engaged (i.e., eudaimonic project phase), the main aim of technological interventions should be to support self-determination and the patient's autonomous choices related to the priority life goals; specifically, the adequate space should be left to patient's initiative, in that he/she is trying to recover life-projects and re-designing daily habits considering the presence of the chronic disease he/she has accepted in his/her own everyday life (see Fig. 1).

Basically, the most important aspect emerging by taking into account the dynamics of patient engagement is that patient's priorities, intentions and needs tend to change over time. For this reason, AmI design should be centered on patient's experience including the ability to adapt its outcomes not only to basic needs emerging in habitual situations, but also to the overall user experience that is intrinsically characterized by dynamicity and complexity.

Basing on this concept, the next section will include an overview of possible issues that may emerge in the experience of AmI chronic patients users, in order to provide useful research/design tools to overcome them and increasing the probability of success for AmI implementations for healthcare.

4. Experiential issues in AmI implementation: solutions from User Centered Design

As previously explained, the patient engagement process highlights the inherently dynamic and complex patient's experience. AmI designers/engineers should be able to capture those aspects in order to produce technologies capable of adapting themselves not only to basic needs, but also to the evolving intentionality of patients who learn to manage their own health and everyday life issues over long periods of time.

Considering the evolving contexts related to health management and patient engagement, we maintain that some specific experiential issues related to AmI usage can be outlined in order to point out design precautions to be included in the AmI projects. Table 1 features these specific issues with related examples, consequences for implementation effectiveness, and schematic solutions. These are the experiential issues to be taken into account:

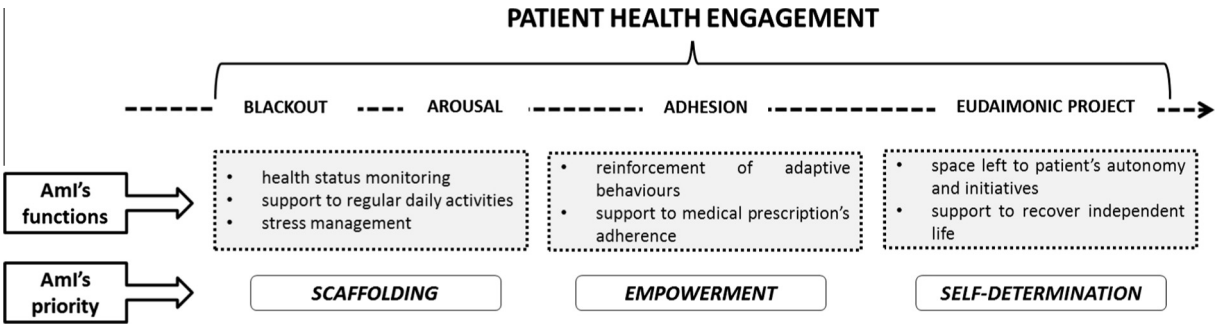

Fig. 1. Functions and priorities of AmI across the patient health engagement phases.

Table 1
User experience issues for developing AmI technologies and possible solutions.

User experience issue for AmI technologies	Example	Consequences	Possible solutions from patient engagement and experience design strategies
Privacy	Detection of patient's movement may reveal location of secret private property	Patient is stressed because of "big brother" effect	*User Profiling*: AmI design is informed by the accurate consideration of individual needs
Influence on behavior	Patient actively avoids to enjoy stimuli that he thinks may impact on physiological signals	(1) Detrimental effects on patient's well-being and (2) the behavior analyzed is not natural	*Contextual Inquiry*: AmI design benefits of analysis/observation of the individual patient's environment and related activities
Changes in patient's Quality of Life needs/priorities	Patient's needs moved from "*relieve my pain*" (first phases of illness experience) to "help me to recover my hobbies" (eudaimonic project)	AmI outcomes are not updated to users' emerging priorities	*Highly customizable and modular devices*: it should be possible to adapt AmI outcomes to emerging needs/objectives by the patients

- **Privacy:** privacy concerns probably constitute the most renowned issue for AmI technologies implementations [47]. As Cook and Colleagues [31] say, almost any form of data gathering about users can be regarded as a potential violation of privacy. For example, cameras filming users may present privacy issues for both registration of personal information (e.g., password digit), and private/embarrassing situations (e.g., nudity). Solutions have been proposed limiting cameras registration to information devoted at the sole localization of users in space obscuring bodies [48], but these do not exclude the possibility for potential spectators of inferring private information from videos; for example, the exact location of secret private property the user habitually reaches. Indeed, privacy is a multidimensional construct [49,50] which encompasses aspects related to personal dignity, individual freedom and control over information. Moreover, consistently with the patient engagement evolutionary phases, also user's subjective privacy concerns may evolve over time. A patient may passively accept that his physiological correlates will be monitored at the time physicians and caregivers are worried for his safety because of a new diagnosis; but, when the patient is finally learning how to manage his own health condition and want to recover different activities (leisure, personal relationships), such analyses may suddenly become invasive. In general, it is probably inadvisable to base AmI projects on absolute/generalized ideas of privacy rights.
- **Influence on Behavior:** consider the example above, about a user who is aware of AmI technologies registering his own location and movement inside the house, and who wants to reach a personal property; he may decide to not do it in order to avoid the property location being registered. Similarly, a user aware that wearable devices are monitoring his own physiological state may decide to not enjoy stimuli (e.g., eating certain foods, watching emotional movies, ...) to avoid that physiological responses will be erroneously elaborated by the monitoring technologies. Such examples highlight that the presence of AmI technologies around a patient, independently of his more or less exact knowledge of their functioning, may lead users to modify their own behavior because of a "big brother syndrome" [51], namely the negative feeling emerging from the impression of being observed by technologies. This issue has two major consequences: first, the user may feel stressed; second, the observed behavior will be not natural and maybe scarcely informative.
- **Changes in Quality of Life Priorities:** In addition to sustain health promotion, AmI technologies should be able to not putting at risk, or better to actively promote, positive quality of life of their users [52,53]. However, the well-being of a person with a chronic disease, who has to learn how to deal existentially and day-by-day with his own disease, could not be conceptualized as some list of features/requisites to be simply satisfied [54]. Quality of life priorities tend to change over time, especially in the case of chronic patients. For instance, in the first periods after receiving the diagnosis (the "blackout" phase according to the PHE model), patients may have to deal with depression symptoms, and could have the necessity of being monitored also in respect to the emotionally disrupting experience they are carrying on. Diversely, when patient engagement is at the highest possible level (i.e., the PHE model's "eudaimonic project" phase), patients have accepted their chronic disease condition, and try to recover their ability to manage daily life, redefining everyday activity, leisure, personal relationships and of course the disease management. In such a condition, their quality of life priorities moved to a general need of recovering a sense of freedom in their own life, and they deserve to be helped in goal setting and high level sense making of their personal life.

These aspects constitute just some of the possible experiential issues emerging from AmI technologies, which are not adequately focused on the user subjective experience throughout the healthcare journey. However, such issues may be countered by means

of including research strategies in the design. User Centered Design (UCD) is a type of design whose goal consists in ensuring that no aspects of the user experience take place in the interaction without the designer's knowledge [55]. The only way to achieve this is to *actively involve the user in all the steps of the generation of the product*, rather than only in the evaluation phase as in the classical Usability approach [56]. In this sense, the term UCD can be used when referring to any design process that is deeply influenced by the engagement of end-users. [57]. In general, the user involvement in the design process goes from a merely-consultative to an active decision making/participatory role [58].

In order to implement a UCD, the first step is to identify all the different stakeholders who are involved with the technologies and who may benefit from their implementation. This entails those who manually interact whit it, but also those who or are affected at some level of its products/results [59]. Then, users become active contributors in every step of the design process.

UCD methods have been already considered in the field of new technology for healthcare and patient-centered medicine [24,60,61], even in the field of AmI [62,63]. Indeed, some of these research methods come to the aid of AmI designers when trying to overcome issues related to adequate implementation.

- *User profiling:* users' needs in terms of privacy and healthcare management should be accurately understood in order to guide design decisions. Moreover, such a research process could be iteratively reproduced at given times, in order to account for possible changes in patient's priorities. First, the creation of *personas* can come in handy in the first phases of design. Personas are fictitious, specific, concrete representations of target users of a given product/technology [64] that designers use as objects of reference while developing the product features. First introduced by Cooper [65], the creating personas technique became a widespread tool for UCD. Miaskiewicz and Kozar [66] used a Delphi methodology to identify benefits of personas for design, and identified 22 of them, ranging from improved focus on the target audience, to correct priority setting, and enhanced innovativeness and evaluation. In general, personas may be sharpened over time thanks to the conduction of UCD interviews with target users [67], devoted to the identification of the actual needs of the patients at a given time period. In the end, UCD usually includes user tests such as the ones typical of Usability, but the first phases entailing user research are to be considered more important in influencing the product development [55].
- *Contextual inquiry* [68] consists in an interview of ethnographic inspiration which should be conducted with the target user in the expected context of use of the product/technology, the UC Designer and the interviewee deepening together the (physical and cultural) obstacles and opportunities for the implementation. In the case of AmI, preventive contextual inquiries conducted within the environment that is supposed to become "intelligent" thanks to the technological implementations (e.g., the patient's house) could be extraordinarily useful in order to understand users' needs but also habits and behaviors. Indeed, contextual inquiry differs from a typical interview that is conducted outside of the environment of interest. Being "contextual", this method allows both the designer and the target user to observe and notice aspects of everyday activities that the patient himself could not be able to recall while thinking of it in abstract terms, and without the specific competences of the designer who knows which kind of modifications AmI technologies could cause in the environment.
- *Customizable and modular devices* should be probably preferred, in general, for any healthcare AmI design. Since patients' needs, intentions and priorities could change over time, and quality of life requisites could change as well, AmI should be conceived as easily modifiable in its functioning and constitutive elements. Doing so, possible unpredictable changes in patients' needs can be accounted for in design, in order to provide AmI technologies that can be (1) customized by users, possibly with little help from the professionals, accordingly to emerging needs and changes in habits and (2) really able to adapt themselves even to more or less sudden transformations in user experience toward the everyday management of illness and disease.

5. Conclusion and future research challenges

This paper discussed the current issues of building AmI technologies for promoting effective assisted living interventions. We have observed the research efforts of building pervasive home-care environments with advanced Ambient Intelligence, which promises to provide safe environments for chronic patients in their own houses. AmI technologies may be a useful instrument to make patients active health consumers by controlling their own health status, assisting everyday tasks and activities, monitoring and enhancing their quality of life.

However, we also foresee some challenges of such solutions: we discussed that, despite AmI's undoubtable potentialities, they may fail in their aims if designers don't consider the evolving experience of health engagement the patient goes through. Not taking into account the dynamicity of the patients' health needs and expectations along the care process – indeed – puts at risk the beneficial effect technologies could have on the patients' health outcomes. To address these issues, we deem that the use of UCD methods could help to meet the challenges of building an efficient and effective AmI system.

Qualitative research may constitute a valuable resource to capture the complexity of behavioral, cognitive and emotional correlates of chronic patients using prototypes of sophisticated AmI technologies, in order to provide information about the characteristics of AmI as subjectively experienced daily: for instance, are AmI technologies truly transparent? Or, could they be experienced as omnipresent/intrusive depending on different situations? Could the assistive ubiquitous technologies be perceived as a dehumanized/artificial figure included in the care process, causing negative feelings in the patient? Such questions deserve to be properly investigated in order to identify possible acceptance issues related to the AmI technologies of the future.

Moreover, customizing technologies on the bases of the patient engagement position – i.e., to the level of patient's adaptation to the disease condition – makes it possible to diversify/tailor the service functionalities and to fully explore the potential of the assistive devices, this way providing patients with chances to keep living actively. As a final suggestion, future research might test the discussed design methodologies and the customization potentialities in controlled trials aimed at systematically evaluate engagement-sensitive AmI technologies and their effects on the patient health outcomes.

Statement of conflict of interest

The authors declare that there are no conflicts of interest.

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