Tools and Technologies for Patients and Caregivers Engagement: A Qualitative Analysis of Health Professionals' Attitudes and Day-to-Day Practice

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Abstract. As patient engagement cannot be achieved without health professionals co-operation and agreement, attention to the clinicians' views and attitudes about patient engagement is essential in order to deepen potential enablers and barriers for its implementation. This qualitative study aimed to identify health professionals' attitudes towards patient engagement and the perceived hindrances and facilitators to the implementation of the patient engagement strategies in their routine practice with a particular focus of health information technologies for patient engagement. It identifies the dimensions underlying patient engagement realization, namely clinicians' "*Meanings and attitudes towards patient engagement", "practical experience of patient engagement"*, and "*being a health professional in the era of patient engagement"*, as well as highlights the fashion in which these dimensions operate will either activate or inhibit patient engagement innovation. Finally, the study highlighted the great potential of health technologies to support patient engagement if they are enablers of the patient-clinician relationship and not replace it.

Keywords: Patient engagement · Health professionals · Professional identity
Technologies

1 Introduction

Healthcare systems in Europe are currently confronted with the rising incidence of chronic illness. This epidemiological shift is challenging the traditional healthcare delivery models largely to provide acute care and manage infectious diseases [1, 2]. The paternalistic approach to healthcare, where health professionals make all of the decisions with little or no input from the patient, has evolved over the past 20 years towards a patient-centered care model that aims to personalize care according to individual patients' needs, values, and experiences [3–7].

As patient engagement cannot be achieved without health professionals co-operation and agreement, attention to the clinicians' attitudes about patient engagement is essential in order to deepen potential enablers and barriers for its implementation. Moreover, although patients gain skills from within and outside the healthcare system,

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their interaction with the health practitioners who have them in charge remains one of the main resource for encouraging their active engagement in the medical course [5, 6]. Without collecting the clinicians' perspective on this concept, interventions to optimize chronic patient engagement are at risk of being misdirected and achieving suboptimal clinical and quality improvement outcomes. Moreover, the last decades have assisted to an actual technological revolution that deeply restructured the ways people search and use information for healthcare purposes. For these reasons, new technologies are fundamental resources to fostering patient engagement in chronic care settings. At the same time, these tools need to be accepted and effectively used by both patients and their care providers [8, 9]. According to these premises, we performed an exploratory qualitative study, aimed to identify health professionals' belief and attitudes towards the concept of patient engagement and the perceived hindrances and facilitators to the implementation of the patient engagement strategies in their routine practice with a particular focus of health information technologies for patient engagement.

2 Methods

2.1 Study Design and Setting

We conducted an exploratory qualitative study between November 2015 and February 2016 analyzing data from focus groups and semi-structured individual interviews involving HCPs from a multi-disciplinary perspective. Participants provided written informed consent to participate in the study. The Ethics committee approved this consent procedure.

2.2 Population

In order to obtain a cross-section of health professionals operating in the chronic field, we sought a heterogeneous and multidisciplinary sample, stratified by clinical area (diabetes, cardiovascular disease, pulmonary disease, oncology, neurology), discipline (doctors, nurses, psychologists, physiotherapists), setting of clinical practice (hospital and private practice), age (<45 years versus >45 years), and gender. Finally, we purposively accessed health professionals of different level of experience.

2.3 Data Collection and Analysis

Focus groups took place interviews were conducted between March and June 2017. Before the conduction of focus groups and interviews, participants received an information sheet and signed an informed consent for being included in the study. Two researchers (SB and GG) conducted focus groups and interviews. Focus groups and interviews were audio-recorded and transcribed verbatim.

3 Results

3.1 Characteristics and Descriptions of Focus Groups and Interviews

Overall, N = 66 HCPs participated in the study. *Four* focus groups were conducted with a total of 38 participants: (a) physicians (N = 11); (b) nurses (N = 6); other healthcare professionals (N = 22, including 14 psychologist, 4 sociologists, 1 health educators, 1 physiotherapists). The mean duration of the focus groups was 117 min and the mean amount of female participants of the focus was 65%. Additionally, 28 interviews with a total of 24 physicians and 4 nurses were carried out. The mean duration of the interviews was 52 min. 39% participants were female.

3.2 Qualitative Analysis

Three main themes were identified: *health professionals meanings and attitudes* towards chronic patient engagement, *practical experiences* with patient engagement and *being a health professional in the era of patient engagement.*

3.2.1 Meanings and Attitudes Towards Patient Engagement

HCPs' Perspective on Patient Engagement. There was almost unanimous agreement among the involved HCPs that patients should play an active role in their own healthcare. Generally, health professionals embraced the value and highlighted the ethical urgency of patient engagement policies because they felt patients themselves are more and more demanding for higher levels of engagement in their care. Participants underlined that, although doctors can manage the medical aspect of a chronic condition, patients need to have an active role in making lifestyle changes in order to reduce possible complications and to chose their preferred care pathway. Views on the extent to which patients should take responsibility over their healthcare process varied and suggested different underlying perspectives on the meaning attached to this concept. Notably, patient engagement in the health professionals' representations ranged from a more passivizing logic to a more empowering one. Particularly, HCPs referred to engaged patients as ones *"adhering to what they have been told to do"*, to *"openly communicating doubts and fears to clinicians", to "discussing with the healthcare team about care expectations and treatment decisions"*, to "*prompting HCPs about their care practices and identifying shared wellness goals*". This active engagement was termed as patients being a "*…partner in their healthcare*". Particularly, some HCPs described the concept of patient engagement as "*improving the patients' knowledge and self-efficacy and educating them so that they can take steps themselves*". This conceptualization mainly refer to the educative component of the therapeutic relationship which should aims to give patient the necessary skills and competences to become expert in their health and disease management. *"Patient engagement…what I understand about that is that there is the need to inform patients about their health condition and what we can do to manage it. Secondly we have to discuss these information with patients and check their understanding and if the therapeutic options might fits them". (Cardiologist, ambulatory practice).*

Many participants associated patient engagement with "*patients asking questions and acquiring knowledge*" about their care process. This conceptualization mainly refers to the patients' communicative behaviors during the medical encounter and to their level of proactivity in sharing concerns and actively search for information by the doctor. *"I think that people can be more involved if they get the opportunity to say something themselves, to ask questions they feel relevant. Not only about their medical problems but also about their quality of life. For this reason a HCP should make time to listen to them". (Neurologist, hospital).*

Although HCPs valued a paradigmatic shift towards an increased patient engagement in the care process, their comments suggested that this was not necessarily straightforward and it can take confidence to be able to share some of the control and responsibility with the patient. *"I think that there is a danger of putting too much responsibility on the patient to make clinical decisions about their condition without the adequate support...But, on the other hand, there a many patients that want to be told what to do and how. In some ways it is really difficult because we need to assess the individuals, you can't just do a change of rules and policies". (Cardiologist, hospital).*

Positive and Negative Outcomes of Patient Engagement

Participants generally agree on patients' adherence to medication as the most important expected positive outcome of patient engagement, along with significant improvements of doctor-patient relationship. Engaging patients allows improvements in "*honest and trust communication with patients"* who become, in their turn, increasingly confortable to question HCPs about their care and disease control. *"An engaged patient generally feels better and can do his/her life in a normal way...that's because he can adhere to medical prescriptions and – as a consequence – his/her quality of life improves". (pneumologist).* Engaged patients, in the HCPs perspectives, are more aware of their health conditions and are more able to search for relevant information and appropriately ask for medical support when needed. *"Engaging patients are a great resource for us (doctor) because they are more informed and they understand their health conditions and why I have to suggest them to do something or to avoid something else...they understand why certain drugs have to be taken or why they should follow a healthy diet...for these reason they can effectively self-manage "without" us..." (diabetologist).*

Many of the participants also reported patient engagement as a proxy of patient satisfaction with the received care; moreover, it would reduce patients' worries and litigation and increase patient's understanding of disease and treatment choices. Finally, one HCP refer that: *"I definitely think that engage patients is the best solution because when we should communicate that something is not going well they understand and they are much more open to redefine the therapeutic goals..." (oncologist).*

On the other hand, HCPs referred that their own job satisfaction would improve as well by engaging patients in the care process. They consider patient engagement as a continuing challenge and thought it would give them more background information about patients, which would enable them to collect patients' needs and preferences better. *"Engaging patients is just a satisfaction for us (doctors) because it allows to set the ground for an more satisfying relationship with them" (neurologist).*

Finally, patient engagement was perceived as a mean to make more equitable the consultation in terms of duties and responsibilities. *"People tend to get better control with their disease, probably a better regulation when they are engaged. And if they know what is going on and are in control over they health status, well…when the patient we have in front is really engaged we are in two to remember what is going to happen" (diabetologist).*

Concerning the potential negative outcomes of engaging patients, some HCPs referred anxiety about patient engagement, for example because consultation might become longer or people would ask too much questions. *"I think that engaging patients might have some dark sides…when patients are involved might require much more time because they are more aware and tend to ask a lot of questions…but we have really little time…just five minutes for each of them" (cardiologist).* Despite patient engagement being advocated by participants concerns was also expressed that this practice might results in patients becoming too much confident and avoid seeking help when necessary. Responses suggested that HCPs themselves needed to feel in control in order to fulfill their professional role and responsibilities.

3.2.2 Practical Experiences with Patient Engagement

Facilitators and barriers towards patient engagement. Barriers to the implementation of patient engagement were mentioned at different levels. Key barriers were grouped under three analytical categories: (a) *How the healthcare organization functions?* (b) *What happens during the patient-clinician relationship*? (c) *Who is the patient*?

(a) *How does the healthcare organization function?*

With regard to *organizational aspect of clinical practice*, HCPs reported that in their perceptions they have *too limited time* to effectively engage patients. This lack of time for consultation would limit the possibility of clinicians to adequately inform patients and also to give them the right space and time to ask questions, raise concerns and discuss issues with their clinicians. Conversely, adequate time for discussion can facilitate patient engagement in making shared treatment plans and can afford opportunities for high quality relationship building and more patient-centered communication. *"We have problems of timing…if you have 15 min for each visit and in this 15 min you have to discuss the clinical exams, set the therapeutic plan, write down the drugs prescriptions…12 min have just gone away…and only 3 min are available to speak with the patient…" (diabetologist).*

Another important theme belonging to the organizational aspects is the *continuity of care*: HCPs refers that poor continuity of care is a major barriers to patient engagement as chronic care requires strong coordination among health services and providers who have in charge the patients' management. Many clinicians, in this regards, expressed concerns that care is becoming more and more fragmented, thus threatening their own ability to make sense of the patients' needs and develop a partnership relationship. HPSs, in this regard, advocate the need for a case manager that helps the care team to guarantee to the patient the needed care coordination. *"How can patients take the most benefit from their healthcare if they don't perceive a fil rouge along their care process? If they feel that each HP is an interlocutor completely detached from the others?" (cardiologist).*

(b) *What happens during the patient-clinician relationship?*

Generally, participants agreed that the way in which health care professionals interact and communicate with patients could affect patient engagement in health care. Health care professionals who respond positively to patients' needs and views and who provide feedbacks to patients concerns can increase patient engagement. Conversely, health care professionals who are dismissive towards the patients' concerns can decrease the level of patient engagement. *"It (patient engagement) strongly depends on the doctor…if he/she is not available to listen to the patient…engagement can't occur…" (oncologist); "You should be open and available to give the patient the space…communication is fundamental" (cardiologist).*

A major barrier relates to the traditional presumptions and expectations about the patient role in the care process where normal patients are passive and expect clinicians to make decisions. HCPs often report that explicit encouragement to be involved in the clinical process could be a facilitator for patient to take an active role in their care; some patients, indeed, might feel they do not have the right to be involved in their healthcare. *"Some people need to be stimulated more. By nature they can be inclined not to ask to much to their doctors, to agree always what the doctor says. They are not used to be interactive with us…" (doctor, oncologist, hospital).*

Another factor frequently discussed by HCPs was the presence or absence of trust within the clinical relationship. A trusting relationship is considered by the majority of clinicians as one of the most powerful precursor of patient engagement: trust makes patients more willing to ask questions, report their concerns or troubles with the disease management. *"When you succeed to build a relationship based on mutual trust you have won the match with that patient. Without trust nothing will happen…you risk to lose the patient…." (doctor, cardiologist, ambulatory).* Also the use of the medical lexicon could be a barrier to patient engagement. Patients feel that clinicians are taking "another language" and may misinterpret the content of the communication. Conversely, "layman terms" might facilitate the patient understanding and also allows them to intervene in the conversation. *"Clinician should speak the language of their patients. The use of medical terms protect ourselves from the patients' questions and fears…but it is not useful in the long term" (doctors oncologist, hospital).* Most factors related to interpersonal characteristics of the patient-doctor relation could be modifiable by supporting positive attitudes towards patient engagement among both patients and clinicians. In this sense, both medical and patient education on this topic is reported by the clinician involved in the study as a fundamental strategy to promote a cultural shift towards the value of engaging patients in their medical course and emphasizing their role and responsibilities over their health management. *"I think that not only technical education is needed by clinicians. We should be trained in how to relate with different patients and how to adapt our communication to them" (doctor, private setting, cardiology).*

c) *Who is the patient?*

The key barriers to patients being engaged their own healthcare, according to practitioners involved in the study, were mostly related to some patient attitudes and a lack of willingness to get involved. *"Patients should be aware of the diagnosis and what it means …but if a person is not interested in their own health, nothing can help.' (Nurse, hospital, surgery).*

This is often associated with a general lack of knowledge and awareness amongst patients in relation to their own healthcare and to their own possible involvement in that overall process. This was often described by practitioners in terms of a lack of motivation, lack of interest and passivity denial of illness and lack of commitment to enact a healthy lifestyle. *"The level of education and health literacy is basically one of the most important barrier to effective patient engagement...when the patient is less educated or belong to a disadvantaged socio-cultural environment-...well, in this case it is very difficult to engage him/her..." (nurse, hospital, pneumology).*

Clinicians also considered potential modifiable barriers to patient engagement such as dealing with individuals with poor health literacy or belonging to vulnerable populations; or having some physical impairment. Whilst age and ethnicity are not modifiable factors, the barriers reported by the involved clinicians in relation to the patients' characteristics are linked more to their prejudices that could be managed by sensitizing them or providing educational interventions. For example, some older patients believe that the patients' role should be passive, thus accepting the authority of clinicians, which could be not questioned. *There are some patients – generally the elderly – that prefer to be guided by their doctors. Well, the younger patients are more available to be active in our relationship, but the older ones prefer prescription on what to do or not to do because they think that I am the doctor and I know what they have to do..." (doctor, hospital, oncology).* Similarly, unless other reported barriers (i.e. level of education) are relatively non-modifiable, their influence on patient engagement could be mitigated if health professionals provide alternative ways to support patients' change and their active role. Again, also in this case, the strategy for promoting patient engagement could be to act on attitudinal change towards the possibility to act a starring role in the health management.

Regarding the psychological dynamics that occur when patients have to deal with a disease, clinicians underlined that not having time to come to adjust to a diagnosis is a barrier to effective patient engagement. Timing barriers are potentially modifiable barriers for most situations, if we reconsider where active patient engagement might fit in the patients' illness trajectory and if we adopt a processual vision of his/her engagement experience. *"Not all patient should be engaged always. It depends on the moment of their illness...we should identify the best moment to engage them" (nurse, hospital, oncology).*

Strategies to Promote Patient Engagement. HCPs also referred that there are some key areas of interventions particularly recommendable to promote patient engagement in healthcare.

- *Improving patient doctor relationship and shared decision making.* Clinicians strongly highlighted the need to engage patients in a high-quality relationship with them in order to shared care plan which are satisfying for both parts. This kind of partnership approach is recognized by clinicians as a boost for patient engagement. *"Patients, sometimes, need some help to understand the treatment options, and the clinician must communicate risks effectively and elicit and respect patients' preferences and values" (nurse, hospital, cardiology).*
- *Promoting multidisciplinary care approach.* Patient engagement programs that also transform practice organizational culture have been recognized by the involved

clinicians to have greater impact than those requiring the patients to do all the changing. Collaborative multidisciplinary care teams within a practice and care coordination with inpatient, emergency, and specialty services beyond primary care practice walls are particularly important for improving chronic patient engagement in their healthcare journey. *"Taking care of complex patients and assuring their engagement means to strongly support multidisciplinary team that are able to understand them in a holistic way" (nurse, hospital, cardiology).*

- *Using technologies to enhance the patients' active role in the care course.* Interventions adopting some technological components to support the delivery of care, might enhance the engagement experience of chronic patients in the healthcare practitioners' perspective. Health professionals particularly sustained disease self-monitoring tools that encompass the use of devices, audio, video, and other telecommunication technologies to monitor patient status. Health information technologies are considered effective when they "augment" and support, rather then replace, interactions between patients/caregivers and professionals. "*Technologies could be a very relevant tool for empowering and engaging patients in the clinical path…however, to effectively adopt new technologies, the most important thing is the medical staff's awareness of benefits of technological innovation adoption*"; "*Technologies are relevant but they should not be a alternative of the patient-doctor relationship*!" *(diabetologist, hospital).*

3.2.3 Being a Health Professional in the Era of Patient Engagement: A Matter of Identity Change

Reflecting upon patient engagement stimulated HCPs to report about changes that this approach to the patient care has implied for their professional identity. HCPs refers that, unless the value of engaging patients is almost clear, this shift of paradigm is hard to be incorporated in routine practice because HCPs are trained and socialized in an approach to care based on the treatment of the symptoms – often in acute settings. This approach is based on the view that the problem is linked to the patient's behavior rather than the HCPs approach to care, which has been seldom considered. Moreover, HCPs referred a substantial gap between the medical training curriculum devoted to promote a highly specialized education and the requirements from the field that implies to adopt a wider and systemic vision of the patient care. Sharing the patient engagement paradigms implies to have wider visions of the patients' care pathway where the presence of multiple professionals is required to reach successful outcomes. *"I had trainings in caring the disease, the organic problem…It is difficult to put into practice a totally different approach where you have to relate with persons and not with organs" (doctor, hospital, surgery).* Adopting a patient engagement view means to "*redefine the power dynamics that occurs in the therapeutic relationship with the patients".* To engage patients means to recognize that in the medical encounters two experts meet each other: one (i.e. the doctor) is the technical expert and the other (i.e. the patient) is the illness experience expert. According to this perspective, the therapeutic relationship should be acknowledged as partnership where patients and clinicians are co-author of the patients' health trajectory. *"In this perspective, we can say that doctors and patients* *should sit on the same side of the desk looking at the same directions" (doctor, hospital, oncology); "In my opinion, speaking about patient engagement is like being together (patient and clinicians) on the same boat…rowing in the same direction" (nurse, hospital, diabetology).* Moreover, the patient engagement visions need a process of re*framing of the boundaries among disciplines and professions*. Engaging chronic patients in the clinical workflow means to activate collaboration and partnership among all the professionals involved in the patients care, to redistribute duties and promote task shift. *"Engaging patients needs to have a complex vision of his/her clinical course. This means to overcome a fragmented vision of the clinical interventions and to promote multidisciplinary care team, inside and outside the hospital walls" (doctor, hospital, cardiology).*

4 Discussion

This research provides insights into the HCPs' variety of representations linked to patient engagement, their perceived barriers and enablers for its concrete implementation in the clinical practice, and their expectations towards the outcomes of engaging patients. Moreover, the findings also highlighted the effect of the patient engagement paradigm on the health professionals' work identity and the implications for their perceived role.

Firstly, HCPs' representations and meanings related to the concept of patient engagement varied greatly among the involved clinicians. This huge variation is particularly evident when discussing the definition of patient engagement and the contexts in which patient engagement takes place. This finding, on one side confirmed the fragmentation of definitions of patient engagement suggested by other studies that showed how patient engagement is a nuanced concept that include a wide range of patient's activities or behaviors [10–12]. Moreover, this wide spectrum of visions and meanings linked to the concept of patient engagement appears to concern the degree to which patients might (or not) take part in the clinical process. Particularly, it connotes different levels of power transfer from health professionals to patients in the form of increased knowledge and responsibility on health outcomes and illness trajectories. This result confirmed previous studies that highlighted different professional-determined forms of patient participation in their healthcare disposed along a power continuum from information-giving to shared decision making [13–15]. To conceive patient engagement as promoting patient adherence and compliance to treatment underlines a still passivizing logic in the patient-health provider relationship where the doctor took a dominant role and made decisions on behalf of the patient, a 'passive' recipient in the process [16]. Then, when professionals were asked about their perceived benefit of engaging patient in their healthcare they overall refereed a generally positive attitude towards patient engagement because it would lead to improvements in the patients' ability to adequately follow treatments and care prescriptions, along with augmenting the patient's satisfactions and trust towards the relationship with the providers and the healthcare services. This result in aligned with other empirical studies that demonstrated the impact of the patient engagement on a great variety of patients' outcomes [17, 18]. On the other side, results emerged from this study suggested that, although an increasing valorization of patient engagement in healthcare conceived by health professionals as an opportunity to build value both for patients and health organization, this is not necessarily prioritized. This because this practice might fight with other relevant professional values such as responsibility as well as contextual or cultural factors featuring the current medical practice. Moreover, clinicians referred they had little training in how to support patient engagement. This result confirm previous studies that highlighted the lack of medical training devoted to educate clinicians in this area [19, 20]. Clearly, more patient engagement support training for clinicians is needed. Particularly, healthcare professionals recognized new technologies as a promising tool to support greater patient engagement. Yet open questions remain about how they can encourage their adoption and what factors might contribute to sustain their use by patients and caregivers. Furthermore, participants referred a complex system of barriers that might hinder the realization of patient engagement in the medical practice. These barriers are at different levels and mainly refer to: specific patients' characteristics; dynamics occurring in relationship between the patients and the health providers; organizational aspects of the healthcare services. These barriers are coherent with recent frameworks discussed in the literature that suggest to consider elements at different level of complexity to promote patient engagement where technologies are crucial enablers of its implementation [22]. Future work is needed to directly elicit the patients and caregivers' perspectives on strategies to build real patient engagement in healthcare and to test the impact of these strategies on clinical and psychological outcomes.

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