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INVITED COMMENTARY

Patient empowerment in the clinical encounter and beyond

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This invited commentary refers to 'Taking charge of your health: enabling patient empowerment in cardiovascular care', by M. Acuña Mora *et al.*, https://doi.org/10.1093/eurjcn/zvae015.

In their paper *Taking charge of your health: enabling patient empowerment in cardiovascular care*, Acuña Mora *et al.*[1] present an overview of the main challenges encountered by healthcare providers in relation to the valuable goal of empowering patients to take care of their health. The authors start by acknowledging an ambiguity often related to the term patient empowerment (PE), as this may be understood as either a process or an outcome, or both, with possibly different implications for the patient–provider relationship. By referring to Small *et al.*,[2] who defined PE as 'an enabling process or outcome arising from communication with the healthcare professional and a mutual sharing of resources over information relating to illness, which enhances the patients' feelings of control, self-efficacy, coping abilities and ability to achieve change over their condition', Acuña Mora *et al.*[1] point to the importance of collaboration, which is a key condition of an empowering patient–provider relationship.

The authors then present valuable strategies to enhance the healthcare providers' capacity to successfully engage in such an empowering relationship. The strategies presented include (i) the practice of motivational interviewing to support the patients' self-determination and self-efficacy towards health-related goals; (ii) the use of narratives as part of patient-centred care; (iii) the delivery of patient education to facilitate active learning; (iv) the use of health apps designed to support self-management; and (v) the promotion of peer support and networking. All of these strategies are evidence-based, may be enacted in the clinical encounter, and are congruent with the above-cited definition of PE. Taken together, they are likely to support the patients' motivation and skills to take care of their condition, hence their empowerment.

In addition to all of the valuable strategies recommended by Acuña Mora *et al.*,[1] it might be worth pointing to two additional types of interventions that healthcare providers might want to consider when aiming to support PE: one is emotion regulation and stress reduction to support psychological safety, as well as adjustment to illness,[3,4] and the second is personalized[5] and goal-oriented[6] healthcare planning to support self-regulation of agreed health behaviours.[7]

Going back to the duality of PE as both a process and an outcome, I would like to point to what seems to me a fundamental misunderstanding related to PE, either as a process or an outcome. Indeed, prevalent definitions of PE implicitly or explicitly convey the idea that PE primarily arises during the clinical encounter, as a result of an empowering communication and relationship with the healthcare providers. This may wrongly convey the idea that empowerment lies in the hands of the healthcare providers in the first place whereas these can actually only support a process that is grounded in the patients' unique life, health, and illness experiences, including their experiences of communicating with and relating to others, outside the clinical encounter. Thus, the patients' own role, i.e. their agency,[8,9] as they experience increased empowerment, is often underestimated. In the early 1980s, looking at how chronically ill patients would manage at home, Corbin and Strauss[10] evidenced that taking care of one's condition involves a number of intricated tasks that are related to three types of work: illness work, everyday life work, and identity work. As a result of this insight, PE may be best understood as a complex experience of personal change,[11] which may be supported or facilitated by the healthcare providers, but should not be seen as an outcome of the clinical encounter alone.[12]

Further, Acuña Mora *et al.*[1] rightly point to the fact that the different proposed strategies may not target all dimensions of PE. This points to another ambiguity often present in the literature on PE. Indeed, aiming to capture PE as an outcome with a single standardized measurement tool is in itself an ambiguous prospect, which may lead to a sense of failure, both in patients and in healthcare providers. As evidenced by Bravo *et al.*,[13] many different definitions of PE co-exist. These have led to the elaboration of many different tools that evaluate different constructs. The belief that a single measurement tool should be able to capture PE as a unique multi-dimensional outcome is implicitly associated with the belief that PE may be objectified and standardized, independently of people's environments, their living conditions, and their personal beliefs, preferences, and aspirations. This is contrary to the very purpose of patient-centred care, as it contradicts the valuable goal of personalizing and tailoring care to a person's unique needs and possibilities. If PE as a process or an outcome is to be measured, the object of measurement should always be defined in collaboration with the patients themselves, according to their own personal life goals, bearing in mind that these might change with evolving life events or condition- and treatment-related issues, thus challenging PE as a dynamic rather than a static construct. As Rappaport[14] put it, empowerment is difficult to define 'because it takes on a different form in different people and contexts… Understanding that H2O can be in liquid, gas or solid form and still be H2O is like the realization that empowerment for a

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poor, uneducated black woman can look very different than for a middle class college student or a thirty-nine year old business man, a white urban housewife or a single elderly person resisting placement in a nursing home' (p. 3).

In other words, PE as an objective of care or an object of evaluation should not be normalized and prescribed but needs to be always situated instead and re-evaluated by and with the patients themselves. Moreover, PE should be seen as a life-long journey where patients and their significant others struggle for balance and meaning and not only for choice and control.[15] In this perspective, the fact that some aspects of one's illness experience and life are out of control and may not be changed needs to be acknowledged and accepted, both by the patients and the healthcare providers.[16,17] This brings us back to the importance of emotion regulation and stress management which we believe are central, not only in the patients' journey but also in that of the healthcare providers, who need to unlearn being in control as they engage with their patients in 'mutual creating'[18] through collaborative and personalized processes of care. This also calls for a greater attention to the role and needs of the patients' significant others in relation to PE. In their article, Acuña Mora *et al.*[1] contain that the patients' significant others mostly come to play a role in situations where the patients lack the necessary autonomy to decide and act by and for themselves. Implicitly, this means that significant others are addressed as tutors for incapacitated patients. At best, they would receive the necessary information and education to act as intermediaries between the healthcare providers and the patients. However, being a partner, a parent, a child, or a sibling of a chronically ill person entails a personal process of transformation, and thereby of empowerment, that deserves to be supported by the healthcare system as well, for the significant others' own sake and not only as a way to contribute to the patients' care. Indeed, the experience of illness is demanding and may be disempowering not only for the patients, but for their significant others as well, as the caregiving tasks put them at risk of exhaustion.[19]

As Acuña Mora *et al.*[1] well explain at the end of their article, in order for healthcare providers to engage in such processes that are conducive not only to better health and quality of life outcomes for the patients but also to greater satisfaction and self-efficacy for themselves, they need to be in turn sufficiently supported by the healthcare system in which they operate. This is, unfortunately, still insufficiently the case, as modern healthcare systems are still striving very much for performance, thus undermining the healthcare providers' capacity to work collaboratively and to be truly patient-centred.[20]

Last, health apps were cited by Acuña Mora *et al.*[1] as a recommended strategy to support PE. The authors cited Thomas *et al.*[21] to point to five important characteristics to bear in mind when using apps to support PE. As a strategy to enhance their effectiveness, it might be worth adding to the already cited features that such apps need to be theory-based and co-designed in constant dialogue with the end-users, i.e. patient representatives and healthcare providers. Moreover, whereas health apps do have the potential to enhance adherence to agreed self-management behaviours, possible negative impacts in terms of increasing health inequities need to be carefully assessed as well. As has become even more obvious during the recent COVID-19 crisis worldwide, a significant proportion of people lack the necessary health literacy and numerical literacy to successfully access and process health-related information. Therefore, the feasibility and relevance of using health apps should be carefully assessed, and the patients' need to be prepared to use them should receive sufficient attention. Indeed, whereas such apps, and other health technologies (e.g. closed loop system in type 1 diabetes management), may usefully contribute to a better control of the disease, it is important to keep in mind that disease control does not equal PE. In particular, the risk that such apps contribute to a normalization and objectifying of self, which is contrary to the very purpose of PE and the ethics of autonomy, should not be ignored.[22,23] Looking at autonomy, it should be stressed that whereas in most theorizations of PE, autonomy is implicitly or explicitly associated with self-determination, a relational autonomy approach is sometimes preferred, as this acknowledges the patients' vulnerability and legitimates the role of others, including the clinicians, in the decision-making process.[24,25]

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