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Digital health technologies and the patient's role : empowerment or engagement ? A critical review of literature from the perspective of Information and Communication Sciences

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As part of a European project on the H2020 call SC1-DTH-02-2020, we have explored the notions of empowerment and health literacy in connection with digital health technologies. As a continuation of this work, we offer here a conceptual analysis of these notions through a review of the literature on the notion of commitment, freedom of action and social equality in digital health from the perspective of Information and Communication Sciences (El Hachani, 2020 ; Labarthe, Trainoir, 2019 ; Bernard, 2014).

The existing solutions on the digital health market promise, among other things, greater involvement of individuals in the management of their own health through coaching approaches or by allowing them to adopt a healthier lifestyle, as well as better communication and coordination between the patient and the various health professionals (Andersen, 2010 ; Demiris et al., 2008). However, they also pose ethical considerations, including extra responsibilities assigned to patients to tasks which were traditionally carried out by healthcare professionals (Lucivero and Jongsma, 2018). In fact, collaboration between patients and health professionals presupposes on the part of professionals the responsibility to inform, but also more importantly to maintain a learning relationship with their patients, so that it can give meaning to their illness (or even suffering). This understanding allows patients to become progressively autonomous and active in the care dynamic (Coulter, 2011; Forbat et al., 2009) with the continued support of their healthcare provider. However, Al Dahdah, (2019) explains that the empowerment of patients can be limited by technical barriers due to design flaws in the modalities of application interactivity for the patient. She associates this observation with disempowerment of a use context.

Scientific literature that analyze digital health technologies underline their potential (à la carte medicine with the possibility of benefiting from appropriate diagnosis and treatment, predictive, precision medicine, participatory and preventive, based on the use of big data or big data), but also the difficulties linked to the appropriation of these technologies by users (Aujolat et al ., 2017, Ruckenstein et Schüll, 2017). In fact, the patient's role in the care pathway is correlated with their level of involvement in health literacy (Sørensen et al. 2012 ; McCormack et al., 2017 ; Schulz et al., 2013). Several researchers emphasize the need to develop such

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technologies with patients in user-centered approaches, with their needs and constraints taken into account (Grosjean, Bonneville, 2007; Hardyman et al., 2015 ; Grosjean, Bonneville, Redpath, 2019). They also highlight the need for participatory approaches such as co-type design or participatory design (Sanders et al., 2008 ; Kushiruk et al., 2016).

The purpose of the literature review revolved around the use of health technologies. While the focal point of the existing researches is mainly centered around the empowerment of patients by or with technology, we will focus on “people, not technology”. The research protocol was inspired by the scoping studies framework (Arksey & O’Malley 2005; Levac et al. 2010). The choice of a scoping study was made on the basis of the emergence of the subject, and the uncertainty as to the number of existing publications reporting initiatives linked to empowerment and patient engagement and not through the prism of health education heavily invested in by the medical community.

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