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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 ; Demirisi 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.

References

- AL DAHDAH M. (20219). Les mobiles du développement : le téléphone portable comme outil d’empowerment des femmes des Suds ? , *Terminal* [En ligne], 125-126 | 2019, mis en ligne le , consulté le 14 janvier 2022. URL : <http://journals.openedition.org/terminal/5013> ; DOI : <https://doi.org/10.4000/terminal.5013>
- ANDERSEN, T. (2010). The participatory patient. Proceeding of the 11th Biennial Participatory Design Conference. ACM, Sydney : Australia.
- ARKSEY, H. , O'MALLEY, L. (2005) Scoping studies: towards a methodological framework, *International Journal of Social Research Methodology*, 8, 1, 19-32.
- AUJOLAT, I., d’HOORE, W., DECCACHE, A. (2007), Patient empowerment in theory and practice: Polysemy or cacophony?, *Patient Education and Counseling*, Volume 66, Issue 1, 2007, Pages 13-20, ISSN 0738-3991, <https://doi.org/10.1016/j.pec.2006.09.008>.
- AZZOPARDI-LUSCAT, N., SORENSEN, K. (2019), Towards an equitable digital public health era: promoting equity through a health literacy perspective, *European Journal of Public Health*, Volume 29, Issue Supplement_3, October 2019, Pages 13–17, <https://doi.org/10.1093/eurpub/ckz166>
- BERNARD, F. (2014), « Imaginaire, participation, engagement et *empowerment* », *Communication et organisation* [En ligne], 45 | 2014, mis en ligne le 01 juin 2017, consulté le 13 janvier 2022. URL : <http://journals.openedition.org/communicationorganisation/4509> ; DOI : <https://doi.org/10.4000/communicationorganisation.4509>
- COULTER, A. (2011). Engaging patients in health care. Open University Press.

- DEMIRIS, G. ET AL., (2008). Patient-centered applications : use of information technology to promote disease management and wellness. A White Paper by the AMIA Knowledge in Motion Working Group. Journal of American Medical Informatics Association, 15(1), 8–13.
- EL HACHANI M, (2020). Reconfiguration des formes de médiation et transition numérique. Mémoire d'habilitation à diriger des recherches en SIC soutenue le 14 décembre 2020 à l'Université Bordeaux Montaigne .
- FORBAT, L., CAYLESS, S., KNIGHTING, K., CORNWELL, J., KEARNEY, N. (2009). Engaging patients in health care : an empirical study of the role of engagement on attitudes and action. Patient Education and Counseling, 74(1), 84–90.
- GROSJEAN, S., BONNEVILLE, L., REDPATH, C. (2019). Le patient comme acteur du design en e-santé : design participatif d'une application mobile pour patients cardiaques. *Sciences du Design*, 9(1), 65-83. doi:10.3917/sdd.009.0065.
- GROSJEAN, S., BONNEVILLE, L. (2007). Logiques d'implantation des TIC dans le secteur de la santé. *Revue française de gestion*, 172, 145–158.
- HARDYMAN, W., DAUNT, K.L., KITCHENER, M. (2015). Value co-creation through patient engagement in healthcare : a micro-level approach and research agenda. *Public Management Review*, 17, 90–107.
- KUSHNIRUK, A., NØHR, C. (2016). Participatory design, user involvement and health IT evaluation. *Study Health Technology Informatics*, 222, 139–151
- LABARTHE F. TRAINOIR, M. (2019). Explorer les déclinaisons de l'empowerment en régime numérique , *Terminal* [En ligne], 125-126 | 2019, mis en ligne le , consulté le 14 janvier 2022. URL : <http://journals.openedition.org/terminal/5570> ; DOI : <https://doi.org/10.4000/terminal.5570>
- LEVAC et al.(2010). Scoping studies: advancing the methodology. *Implementation Science* 2010, 5:69
- MCCORMACK, L.; THOMAS, V.; LEWIS, M.A.; RUDD R.(2017). Improving low health literacy and patient engagement: A social ecological approach, *Patient Education and Counseling*, 100 (1), 8-13.<https://doi.org/10.1016/j.pec.2016.07.007>.
- SCHULZ, P. J., NAKAMOTO, K. (2013), Health literacy and patient empowerment in health communication: The importance of separating conjoined twins, *Patient Education and Counseling*, Volume 90, Issue 1, 2013, Pages 4-11, ISSN 0738-3991, <https://doi.org/10.1016/j.pec.2012.09.006>.
- SORENSEN & al.: (2012) Health literacy and public health: A systematic review and integration of definitions and models. *BMC Public Health*
- VERBEEK, P.P. (2016). 'Toward a Theory of Technological Mediation: A Program for Postphenomenological Research'. In: J.K. Berg O. Friis and Robert C. Crease, *Technoscience and Postphenomenology: The Manhattan Papers*. London: Lexington Books.189-204