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Digital Health Communication: Issues and Perspectives

ICA Preconference 2022

Issues of therapeutic education for connected heart failure patients

RealWorld4Clinic is a research project funded by the EIT Health. It aims at developing a connected implantable medical device, which will record and transmit cardiorespiratory data [1]. This device could be used in a remote monitoring program to optimize heart failure treatment and prevent acute cardiac decompensation, a severe complication which generally requires hospitalization if it is not detected early enough [2].

In order to involve heart failure patients in the development of the information materials concerning this future connected implant, we started in 2021 a co-designed study. We recruited a team of 4 patient collaborators motivated to participate in the conception and development of this project. These patients helped us to design the hypotheses of a study aiming at better understanding the experience of heart failure patients and their perspectives on implants and remote monitoring. These hypotheses were then strengthened by 26 additional interviews.

The detailed methodology of this study as well as its preliminary results will be published by ISTE Editions in a collective book in 2022. In this communication for the ICA preconference, we would like to go deeper into one aspect of this study, namely therapeutic connected patient education. This is an important issue in the case of heart failure, because, according to a study by the French Society of Cardiology, one third of patients leave the hospital after acute cardiac decompensation without being able to name their condition [3].

The need for therapeutic education appeared both in co-design sessions and in individual interviews. Indeed, the participants admire the healthcare professionals who are able to support them in the discovery and understanding of their illness, whereas they judge harshly those who only act as prescribers or who are not able to take into consideration their perspectives and personal situation.

Moreover, heart failure patients represent a particularly connected population. Most of them have access to the Internet and if they search information about heart failure, they might find false medical information, but also raw and anxiety-provoking information which does not necessarily match with their actual situation. Social networks and patient associations give them an opportunity to share with their peers, which help them to find a moral support and access practical information to live better with their illness. They frequently wear cardiac implants, such as pacemakers or implantable defibrillators, which have been able of remote communication for decades [4]. However, they have almost no control over these implants, while at the same time participating actively in their maintenance [5]. Lastly they may benefit from remote monitoring tools, such as connected watches or scales, which are sometimes part of hospital programs [6-8]. While these tools enable patients to be involved directly in their follow-up, they also represent an additional work for them [9, 10].

Addressing the question of therapeutic education will allow us to analyze under what conditions a connected implantable device could empower heart failure patients, in other words, enable them to take a more active role in decision-making regarding their health [11]. Our hypothesis is that this empowerment requires a cooperation framework, integrating both therapeutic patient education and healthcare professional training in a new approach to patient-doctor relationship.

References

- [1] RealWorld4Clinic : <https://eithealth.eu/project/realworld4clinic/>
- [2] The Heart Failure Policy Network, *The Handbook of Multidisciplinary and Integrated Heart Failure Care*, 2018.
- [3] Beauvais F., Tartière L., Pezel T., Motet C., Aumont M. C., Baudry G., ... Damy T., First symptoms and health care pathways in hospitalized patients with acute heart failure: ICPS2 survey, A report from the Heart Failure Working Group (GICC) of the French Society of Cardiology, *Clinical cardiology*, 44(8), 1144-1150, 2021.
- [4] Slotwiner D., Varma N., Akar J. G., Annas G., Beardsall M., Fogel R. I., ... & Yu C. M., HRS Expert Consensus Statement on remote interrogation and monitoring for cardiovascular implantable electronic devices, *Heart rhythm*, 12(7), e69-e100, 2015
- [5] Oudshoorn N., Sustaining cyborgs: Sensing and tuning agencies of pacemakers and implantable cardioverter defibrillators, *Social studies of science*, 45(1), 56-76, 2015.
- [6] DeVore A. D., Wosik J., Hernandez A. F., The future of wearables in heart failure patients, *JACC: Heart Failure*, 7(11), 922-932, 2019.
- [7] De la Torre Díez I., Garcia-Zapirain B., Méndez-Zorrilla A., López-Coronado M., Monitoring and follow-up of chronic heart failure: a literature review of eHealth applications and systems, *Journal of medical systems*, 40(7), 1-9, 2016.
- [8] Desnos M., Jourdain P., Télémédecine: une solution d'avenir pour l'insuffisance cardiaque ?, *Bulletin de l'Académie Nationale de Médecine*, 2020.
- [9] Mayère A. Patients projetés et patients en pratique dans un dispositif de suivi à distance, *Reseaux*, (1), 197-225, 2018.
- [10] Andersen T. O., Langstrup H., Lomborg S., Experiences with wearable activity data during self-care by chronic heart patients: qualitative study, *Journal of Medical Internet Research*, 22(7), e15873, 2020.
- [11] Anderson R. M., Funnell M. M., Patient empowerment: myths and misconceptions, *Patient education and counseling*, 79(3), 277-282, 2010.