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CONFERENCE ABSTRACT

Development of remote person-centred care based on participatory design for people with chronic obstructive pulmonary disease and chronic heart failure -A Randomized Controlled trial.

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Background: Person-centred care (PCC) is an approach based on ethical principles. To support operationalization of person-centred ethics in clinical practice a framework was developed by the Gothenburg Centre for Person Centred Care (GPCC). Both chronic obstructive pulmonary disease (COPD) and chronic heart failure (CHF) are known for their high mortality and severe impact on activities in daily living. Therefore, self-management strategies are crucial to optimize care. Digital solutions have been suggested as a safe option to promote self-management of chronic conditions such as COPD and CHF. However, most digital solutions seem to be lacking the user-perspective in the development of the platform. The project aimed to develop and evaluate a remote PCC based on a participatory design for people with chronic obstructive pulmonary disease and chronic heart failure.

Method: Public involvement is a cornerstone in PCC. Therefore, this study incorporates a participatory design that assumes that all users; patients, relatives and healthcare professionals (HCPs) are involved in the study design and development of the intervention (remote PCC). Extensive iterative consultations with the users took place during the development and design of the digital platform (7). An advisory group consisting of patient representatives, relatives, HCPs, system-developers and researchers was formed to provide advice and co-design all of the major elements of the study design. This study was a multicenter randomized trial conducted from 2018 through 2020. In total, 222 patients were recruited from nine primary care centers. Patients with a diagnosis of COPD and CHF were eligible. Participants were randomized into either usual care

(n=112) or PCC on top of usual care (n=110). The primary endpoint was a composite score of change in general self-efficacy (GSE) and hospitalization or death 6 months after randomization, which was dichotomized into improved and deteriorated/unchanged. In addition, data from the 3-month follow-up were analyzed and a per-protocol analysis of those participants that used the intervention were conducted.

Results: The patient representatives suggested that the platform should include functionalities such as the possibility of a two-way communication and reliable user-friendly information about their condition. The HCPs contributed with input concerning layout and technical functionalities. The effect study showed no significant between-group differences in the composite score at the 3- and 6 months follow-ups. There was, however, a significant difference between the study groups in the per-protocol analysis at three months (p=0.047). This effect was driven by a change in General Self Efficacy from baseline.

Conclusion: The participatory designed remote PCC resulted in a generic digital platform in this study, the end-user input in the development process is probably mirrored in the increase in self-efficacy among those that used the platform. PCC by a combined digital platform and structured telephone support seems to be a safe option to support people with CHF and COPD to increase their self-efficacy. This study adds to the knowledge of involving users in the design and development process of interventions. Further research is needed in order to explore how to tailor different components in digital interventions and PCC to each unique patient.