39.99 - Public Health and Health Economics, Other

90076

Co-designing an online support program for and with informal carers of people with heart failure

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Funding Acknowledgements: Type of funding sources: Public grant(s) – National budget only. Main funding source(s): Swedish research council for health, working life and welfare

Background: Informal care is increasing due to societal challenges such as ageing populations, more non-communicable diseases in combination with lack of health care personnel. Informal carers, namely family members, friends and neighbours, are important actors in the care and support of people with heart failure. To support them in their caring, information and communication technology has shown to be promising. The mentioned challenges have also put pressure on digitalising health care. The COVID 19 pandemic has further highlighted the need to provide and receive support through digital services. There is currently a lack of support interventions for carers of people with heart failure that are directly integrated within the health care system. To develop relevant support carers should be involved in the process.

Purpose: The aim of the study was to describe the co-design process in the development of an online support program for carers of people with heart failure.

Methods: Informal carers, researchers and practitioners were involved in the co-design process. In the first phase an assessment of carers' needs and preferences was performed based on a literature search, focus group interviews (n=23 carers), individual interviews and user group sessions (n= 7 carers). Phase two continued with the actual development of the support program prototype, based on the results of phase one. This phase included 13 carers and 18 researchers and practitioners. In the final phase, the program was reviewed and refined by carers, practitioners, and researchers. The project group coordinated the co-design process and took part in the development of the support program.

Results: The co-design process resulted in an online support program consisting of 15 modules with the aim to increase carers' preparedness to care for a person with heart failure. Each module focused on different topics such as "About heart failure" and "To be a carer". The support program was designed and integrated within the Swedish national e-health platform "1177" in a section called "support and treatment". During the co-design process, various challenges arose, which included the choice of platform itself which then influenced the further co-design process. This process involved balancing implementation and sustainability requirements, against carers' needs and preferences regarding the program itself.

Conclusions: To conduct a co-design process involving carers and other actors means to navigate diverse interests, goals and pay due attention to regulations. It is an explorative process in which researchers need to be flexible. The effects of the program will now be tested via a randomized controlled trial, and the results will also illuminate the co-design process further.