

Understanding needs and expectations of heart failure patients and their caregivers regarding digital health - the PASSION-HF project

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Background/Introduction

Current heart failure (HF) healthcare provision is not sufficient. Due to demographic changes and subsequent increases in comorbidities, along with unequal distribution of medical care in rural areas, alternative approaches need be sought. The use of eHealth applications has potential to enable patients to become more self-sufficient. The "PASSION-HF" project aims to develop an interactive decision-making system – a virtual doctor – that provides solutions based on current guidelines and artificial intelligence. Patient independence is maximized through 24/7 access to personalized HF-management. Furthermore, the application defines decision points, where medical professionals need to be included.

Purpose: To understand needs and expectations of HF patients and their informal caregivers in regard to a virtual doctor.

Methods: We conducted an exploratory mixed-methods study within the Netherlands, UK, Ireland and Germany. Semi-structured qualitative interviews were supplemented by a standardized questionnaire. The interviews focused on i) acceptance and motivation to use a virtual doctor and ii) experience and perception of current health care provision. The interviews were analysed using the content analysis according to Mayring (2010) with the help of "ATLAS.TI" software. Additional information about the role of informal caregivers, technology acceptance and decision-making processes was collected via questionnaires.

Results: A total of 49 patients and 33 informal caregivers were interviewed. Most patients were male (76%), aged between 60 and 69 years (43%). Three key themes were identified in regard to an interactive decision-making system: 1) Reassurance, because patients felt uncertain about their condition and their symptoms, they had a strong desire for an application that could monitor their health 24/7, was able to spot deteriorations, before they occurred and gave them instant feedback about their current health status; 2) Personalized advice, e.g. patients wanted the virtual doctor to adapt medication, sport activities and food recommendations to their current health status; and 3) Transparency, e.g. patients wanted to know, where the recommendations are coming from and justifications for management modifications. Interview findings also identified that the HF-nurses play a significant role in the care and management of the condition. Across all countries with HF-nurses, they were the primary point of contact, when patients had any HF related concerns.

Conclusion: The findings provide valuable information for the development and implementation of eHealth solutions. Patients want reassurance, independently of the availability of healthcare services, combined with personalized advice regarding day-to-day management of their HF. For the next step, we are planning a multicentre clinical trial to test the prototype of the application. Here all decisions are examined by a clinical committee and benefits are evaluated.