

POSTER ABSTRACT

Nothing about me without me: Development of a questionnaire to evaluate experiences with co-creation.

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Introduction: Given the desirable move towards more personalized care management, new ways of involving patients and their caregivers in redesigning care are needed. One important tool is co-creation, which enables patients and their caregivers to play a key role in the design, development and implementation of health care innovations. Currently, health care innovations for improving care for Parkinson's Disease (PD) have been established that require the involvement of people with PD, informal and professional caregivers so that these innovations meet the needs, wishes and preferences of those who would benefit from the health care innovations. However, up to now there is no tool available that enables the evaluation of co-creation processes. Therefore, the aim of this study was to assess the core elements of co-creation and to develop a questionnaire together with people with PD, informal and professional caregivers allowing evaluation and more importantly, assessing the barriers and facilitators of co-creation.

Aims and methods: We aimed to identify the core elements of co-creation, in order to develop a questionnaire to evaluate the co-creation process and assess the experienced barriers and facilitators of the co-creation process. We collaborated with people with PD, informal and professional caregivers who have been participating in two projects for improving health care for people with PD and their caregivers at the neurology department of the Radboud University Medical Center in Nijmegen, the Netherlands. Firstly, we used focus group discussions to identify the core elements that members of the co-creation teams deemed important for successful collaboration within co-creation groups. Secondly, we designed a questionnaire in which barriers and facilitators were assessed regarding these core elements. Thirdly, we tested the questionnaires.

Results: Together with people with PD, informal and professional caregivers we succeed in identifying the seven core elements of co-creation: (1) Organisation, composition and communication; (2) Skills and equivalence; (3) Trust and security; (4) Feeling heard and appreciated; (5) Involvement; (6) Sustainable goals and processes; (7) Expectations and satisfaction. The questionnaire that we developed subsequently included 43 questions to evaluate the experiences of members of the co-creation teams and to assess the barriers and

experiences regarding these core elements. Testing the questionnaires in existing co-creation teams provided us with important starting points for improving the co-creation process within these teams.

Conclusion: The questionnaire we developed based on the seven core elements of co-creation that we identified in collaboration with people with PD, informal and professional caregivers provided us with important starting points for improving co-creation within existing co-creation teams.

Future implications: Co-creation is key to improve personalized care management, but to monitor the process and evaluate satisfaction of all involved stakeholders, it is important to have an instrument that assesses the core elements of co-creation and enables further improvement of the process. We present the first step in undertaking such an evaluation, which will be followed by qualitative assessments in the form of in-depth interviews that will help to deepen our understanding on what is needed to successfully implement co-creation of health care innovations.