Listening to the patients
Hansen, Mette Maria Stampe; Andersen, Stine Østergaard; Nielsen, Sophia Kromann Bøgehøj; Dinesen, Birthe Irene; Sigaard, Jarl Voss

Publication date: 2018

Document Version
Publisher's PDF, also known as Version of record

Link to publication from Aalborg University

Citation for published version (APA):

General rights
Copyright and moral rights for the publications made accessible in the public portal are retained by the authors and/or other copyright owners and it is a condition of accessing publications that users recognise and abide by the legal requirements associated with these rights.

- Users may download and print one copy of any publication from the public portal for the purpose of private study or research.
- You may not further distribute the material or use it for any profit-making activity or commercial gain
- You may freely distribute the URL identifying the publication in the public portal

Take down policy
If you believe that this document breaches copyright please contact us at vbn@aub.aau.dk providing details, and we will remove access to the work immediately and investigate your claim.

Downloaded from vbn.aau.dk on: oktober 23, 2018
Listening to the patients: User Involvement in Palliative Care Research

Mette Stampe MSc1, Stine Ø. Andersen MSc1, Sophia Bøgehøj MSc, Birthe I. Dinesen MSc, PhD.1, Jarl V. Sigaard MD1,2
1 Laboratory of Welfare Technologies – Telehealth & Telerehabilitation, SMI, Department of Health Science and Technology, Faculty of Medicine, Aalborg University, Denmark
2 Specialized Palliative Care Team, Southwest Jutland Hospital, Esbjerg, Denmark

BACKGROUND
A report by the World Health Organization and The Worldwide Hospice Palliative Care Alliance estimates that annually at least 40 million people need palliative care. The majority of these are patients suffering from cancer, cardiovascular and respiratory diseases. In Denmark approx. 58% of all deaths are related to one of these diseases. The aim of this abstract is to explore the advantages and challenges when including palliative patients and their relatives in a user-driven innovation process.

METHODS
In collaboration with the Specialized Palliative Care Team in South West Jutland, Esbjerg a user-driven innovation process was designed and implemented in spring 2018. A total of eight patients and eight relatives were included in the innovation process. The following data collection techniques with both patients and their relatives were: Individual interviews (N=3) and follow-up telephone interviews (N=3), Cultural probes consisting of postcards aiming to identify their everyday challenges (N=10), a three-hour workshop with three different sessions (N=6) and usability tests performed using questionnaires, interviews and observation (N=12). Furthermore, data were collected during three observation days with the palliative team and a focus group interview (N=9). Data were analysed within the project group using NVivo 11.0.

FINDINGS
The analyses of our data showed that user-driven innovation with palliative patients and their relatives is associated with both advantages and challenges.

Advantages:
- The patients and their relatives were enthusiastic, motivated and had the energy to complete all the different activities.
- The project gave the participants a purpose and another focus than the illness.
- All the members of the project group have a professional background as nurses and physiotherapist, which has provided a trustful relation and an open dialogue with the participants.

Challenges:
- Planning of the activities must be agile due to the rapid progression of the patients’ diseases.
- Due to the patients’ physical conditions, it can be a necessity to include their relatives to help the patients fulfilling the different activities.

CONCLUSION
Based on the findings, we conclude that the advantages outweigh the challenges when conducting user-driven innovation with palliative patients and thus, it is beneficial to include the patients and their relatives in a user-driven innovation process. The patients were motivated to be a part of the project but their conditions must be taken into consideration when planning the process. Further research is required.