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Listening to the patients: User Involvement in Palliative Care Research

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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.