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*Feeling safe*

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### Development and pilot test of a telepalliation platform: Feeling safe

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**Background:** It is estimated that every year, more than 20 million people are in need of palliative care (PC) worldwide focuses on preventing and alleviating suffering through early diagnosis, assessment and treatment of pain and other physical, mental, psychosocial and existential problems confronting the patient with a serious, perhaps fatal illness. A 2019 report has shown that the majority of Danes (55%) wished to be cared for in their own home when dying, followed by 27% desiring hospice care, whereas only 5% wanted to die in hospital. The COVID-19 situation have called for technical solution for patients in palliative care. Telepalliation (TP) is defined as palliative effort using information and communication technologies such as video calls, websites with information on life in a terminal phase, phone calls and social media. The use and evidence of TP is limited internationally, and further research is necessary to identify possibilities and limitations. In collaboration with the Palliative Team Hospital Southwestern Jutland in Denmark we have performed a participatory design process to design and test a telepalliation platform. The aim of this study is twofold: Phase I: To identify challenges with PC viewed by patients, relatives, and palliative team. Phase II to develop and pilot test a telepalliation platform.

**Technical solution:** The Telepalliation portal consist of an information and communication module. In the informations module there is text in written and video about themes within palliative care (pain management, diet, psychological aspects, physical exercises, etc). The communication module consists of an email and video function to be used between patients, relatives and healthcare professionals.

**Methods:** Participatory design in two phases was applied. Phase I: Cultural probes from patients in palliative care (n=10), interviews with patients in palliative care (n=6) and relatives (n= 6), observation in patients' homes (n= 12 hours). Workshop with palliative team (4 hours). Phase II: Workshops with patients in palliative care and relatives (3 hours), interviews with patients in palliative care (n=3) and members of palliative team (n=4). A prototype of the telepalliation platform was developed and tested by patients (n=6) and relatives (n=4) for two weeks. Cultural probes and observations have been documented in a Word files and analyzed in NVivo 12.0. Interviews has been recorded, transcribed, and analyzed in NVivo 12.0. The project has followed the Helsinki Declaration and all participants have signed an informed consent.

**Results:** Phase I: Patients have experienced the following challenges: thoughts and worries about end of life, the body being changed, fragmentation in information flow, lack of individualised care and treatment. The relatives have expressed: fragmentation in information flow, need for more individualised care and contact with the palliative team. The palliative team experienced: High expectations, different needs for psychosocial support from patients and family, time and scheduling pressures for implementing individualized care, large amount of time used for travel, fragmentation in the coordination and communication in the overall patient care process due to different IT systems between hospitals, municipalities and general practitioners. Phase II: A telepalliation platform with a webpage with information on diet, physical, mental, psychosocial aspects within palliation and pain management has been developed and video communication was integrated. The telepalliation platform was evaluated user friendly by patients, relatives and the palliative team. The patients expressed that they felt safe using the platform.

**Discussion:** The introduction of TP can serve as a response to challenges experienced by patients in PC and their families, as well as the needs of palliative teams. Pros and cons using the telepalliation platform needs to be tested in a larger randomised controlled trial to demonstrate actual effects. The limitation of the study is that we have included few patients and relatives in the pilot study and only from one hospital in Denmark.

**Conclusion:** Pilot testing of the TelePalliation platform has demonstrated that the patients experienced the platform to be user-friendly and they expressed they felt safe using the Telepalliation platform that will be tested in larger scale.