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General palliative care to the heart failure patient based on their personal narratives

Background: For many, living with life-threatening heart failure means to live with insecurity in everyday life. This is due to both mental, social and clinical problems and symptoms. Palliative care aims at supporting people's quality of life by alleviating physical, mental, psychosocial and spiritual problems arising from life-threatening disease. So far, palliative care in Denmark have primarily been implemented for cancer patients and research have concentrated on the late phases of palliation. Consequently, we lack knowledge about palliative care in connection with heart failure. Furthermore, healthcare professionals in cardiology lack palliative skills.

This PhD study will investigate the importance of an early-integrated general palliative care approach developed in collaboration with patients, relatives and health professionals.

Purpose: The purpose of this project is to develop, test and evaluate a general palliative care intervention through the following objectives:

- I. To investigate how life with heart failure is experienced, and what needs and wishes for palliative support the person with heart failure has.
- II. To increase palliative care skills at a general level.
- III. To operationalize the WHO's definition of palliative care with inspiration from the S-approach which uses the narrative method to include the psychological, psychosocial and spiritual problems.
- IV. To evaluate the importance of the palliative care model developed in collaboration with patients, relatives and interdisciplinary staff.

Method: 1) Through a systematic review, I will gather research knowledge on the use of personal narratives in palliative care in the hospital. 2) Through semi structured interviews with people affected by heart failure, I will explore their wishes and need for support. 3) This will guide the further process of developing and implementing the general palliative care model. An educational program for health professionals with elements of interdisciplinary teaching, knowledge sharing and workshops will be carried out along side the palliative care model development. 5) A qualitative case study with newly diagnosed heart failure patients with an aim of identifying the importance of the integrated general palliative care will be carried out.

Implications for practice: Heart failure is a life-threatening condition with a 5-year mortality rate of 45-60% and there is a great need for a palliative care approach. The idea is that this newly developed palliative care model that uses personal narratives and is based on the patient's lived lives and desires for the future, will strengthen the patient's experience of quality of life as well as strengthen cooperation with the professionals on planning a continuously supported patient care.

Schedule: Literature study and baseline interview: July 2017- March 2018

Main study: April 2018 - June 2020

Supervisors: Professor Helle Timm (SDU and REHPA); Postdoc Charlotte Simonö (SDU, NSR Hospitals); Chief physician, MSc. Henrik Ryde (NSR Hospitals)