**Development of a questionnaire regarding the communication of patients’ perspectives in palliative care: A qualitative study**

**ABSTRACT**

**Background:** Paying attention to patients’ perspectives improves quality of life and tailored care. Despite this, only a minority of Heart Failure (HF) and Chronic Obstructive Pulmonary Disease (COPD) patients effectively convey their preferences and wishes in conversations with healthcare professionals. In order to empower HF and COPD patients in communicating their perspectives during consultation, a toolbox has been developed in the EMpowerment of PATIEnts and their informal caregivers project. But what influence does the use of interventions such as this toolbox have? A valid Dutch measurement instrument is required to measure to what extent patients identify, communicate and document their preferences and wishes.
**Aim:** This study aims to explore which items should be included in a questionnaire according to HF and COPD patients, informal caregivers and healthcare professionals to measure the extent to which the patient perspective is addressed in the communication between patients and healthcare professionals.
**Method:** This is a generic, descriptive qualitative study. Secondary analysis of individual semi-structured interviews (n=30) was performed using thematic analysis.
**Results:** The identified items were: 1) wishes regarding end of life; 2) wishes regarding medical treatment; 3) wishes regarding daily life; 4) the need for autonomy; 5) the need for information; 6) social-emotional needs; 7) the need for identity. In addition, facilitators and barriers to identifying, communicating and documenting wishes and needs were indicated.
**Conclusion:** By including these items, the questionnaire will fully reflect patients’ perspectives and will give insight into which interventions seems to support the patient in communicating their unique perspectives in order to provide tailored care.
**Recommendations:** It is recommended to check the correctness and completeness of the items identified among the target groups with a view to the generalizability of the results and the validity of the questionnaire.

**Keywords:** Palliative care [MeSH],patients’ perspectives, surveys and questionnaires [MeSH].