

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

---

*MSH van Dieën<sup>1</sup>, LM Groen-van de Ven<sup>2</sup>, JM de Man-van Ginkel<sup>3</sup>, AS Olde Wolsink<sup>4</sup>, MJ Uitdehaag<sup>5</sup>.*

1. MSH (Milou) van Dieën, Nursing Sciences program in Clinical Health Sciences, University Medical Center Utrecht, Utrecht, The Netherlands. Registered nurse TriviumMeulenbeltZorg Twente, The Netherlands.
2. LM (Leontine) Groen-van de Ven, PhD, Research Group Innovating with Older Adults, Centre of Expertise in Health Care and Social Work, Windesheim University of Applied Sciences, Zwolle, The Netherlands.
3. JM (Janneke) de Man-van Ginkel, PhD, University Medical Center Utrecht, Department Julius Center for Health Sciences and Primary Care, UMC Utrecht, Utrecht University, The Netherlands.
4. AS (Annet) Olde Wolsink-van Harlingen, MSc, Research Center of Nursing, Saxion University of Applied Sciences, Deventer/Enschede, The Netherlands.
5. MJ (Madeleen) Uitdehaag, PhD, Research Center of Nursing, Saxion University of Applied Sciences, Deventer/Enschede, The Netherlands.

Student:	M.S.H. van Dieën
Student number:	3858294
Status:	Final Thesis
Date:	June 19, 2020
Lecturer:	Dr. JM (Janneke) de Man-van Ginkel
Supervisor:	Dr. MJ (Madeleen) Uitdehaag
Internship institution:	Saxion University of Applied Sciences, Deventer/Enschede
Journal:	Palliative Medicine
Words:	3785
Words abstract:	300
Words Dutch abstract:	300
Reporting guideline:	COREQ

Utrecht University, Master Program Nursing Sciences, Clinical Health Sciences, University Medical Center Utrecht, The Netherlands.

## **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 seem 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].

## **De ontwikkeling van een vragenlijst betreffende de communicatie van patiënt perspectieven in de palliatieve zorg: Een kwalitatieve studie**

### **SAMENVATTING**

**Achtergrond:** Aandacht voor het patiëntperspectief draagt bij aan de kwaliteit van leven en passende zorg. Desondanks brengt de minderheid van de hartfalen en COPD patiënten diens unieke perspectief naar voren in gesprekken met zorgverleners. Om de patiënt hierin te ondersteunen, is er een toolbox ontwikkeld in het EMpowerment van PATIËnten en hun naaste-project. Maar welke invloed heeft het gebruik van dergelijke interventies als deze toolbox? Momenteel is er geen Nederlands meetinstrument om in kaart te brengen in hoeverre patiënten hun voorkeuren en wensen identificeren, communiceren en documenteren. Om dit in kaart te brengen is een valide meetinstrument nodig.

**Doelstelling:** Het exploreren van topics die volgens hartfalen en COPD patiënten, naasten en zorgverleners opgenomen moeten worden in een vragenlijst, om zodoende te kunnen meten in hoeverre het patiëntperspectief aan bod komt in de communicatie tussen patiënt en zorgverlener.

**Methode:** Dit is een generieke, beschrijvende, kwalitatieve studie. Secundaire analyse van individueel semigestructureerde (n=30) interviews is gedaan volgens thematische analyse.

**Resultaten:** De gevonden topics zijn 1) wensen ten aanzien van levenseinde; 2) wensen ten aanzien van medische behandeling; 3) wensen ten aanzien van (dagelijks) leven; 4) behoefte aan autonomie; 5) behoefte aan informatie; 6) sociaal-emotionele behoeften; 7) behoefte aan identiteit. Daarnaast zijn belemmeringen en facilitatoren om wensen en behoeften te identificeren, communiceren en documenteren geïdentificeerd.

**Conclusie:** Indien deze topics worden opgenomen in de vragenlijst, zal deze ten volle het patiëntperspectief weergeven en meten welke interventies de patiënt ondersteunen bij het identificeren en communiceren van diens perspectief, om zodoende de kwaliteit van leven te bevorderen en een brug te slaan tussen voorkeuren van de patiënt en de ontvangen zorg.

**Aanbevelingen:** Het is aanbevolen om de juistheid en compleetheid van de topics te verifiëren bij alle doelgroepen, vanwege de generaliseerbaarheid van resultaten en validiteit van de vragenlijst.

**Trefwoorden:** Palliatieve zorg [MeSH], patiëntperspectief, vragenlijsten [MeSH].

## INTRODUCTION

Chronic Obstructive Pulmonary Disease (COPD) and Heart Failure (HF) are diseases with a high disease burden and which cause gradual decline<sup>1,2</sup>. COPD is characterized by persistent airflow limitation that is usually progressive<sup>3</sup>. It affects approximately 329 million people worldwide<sup>4</sup>. HF is also a major public health problem, affecting more than 23 million individuals globally<sup>5,6</sup>. Central to HF is a reduced exercise tolerance which results in symptoms of shortness of breath and fatigue due to a deficient pumping function of the heart<sup>7,8</sup>. A substantial increase in the number of people with HF is expected in the coming decades<sup>9</sup>.

Curative treatment is no longer possible in both diseases, which means that these patients are eligible for a palliative approach<sup>1,2</sup>. In palliative care the emphasis is on the quality of life (QoL) of patients and their relatives<sup>10,11</sup>. Quality of life is, according to the World Health Organization, '*an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns*'<sup>12</sup>. This perception is unique to each patient, meaning that exploration of patients' perspectives regarding QoL is essential for providing tailored care<sup>13</sup>. Conversations between the healthcare professional, patient and informal caregiver about the meanings of serious illness scenarios and identification of and prioritising of personal preferences for medical care are key factors in this exploration<sup>14-17</sup>. Paying attention to patients' perspectives can improve the concordance between patients' preferences and end-of-life care received, patient satisfaction, and QoL<sup>16,18-21</sup>.

Despite this, only a minority of HF and COPD patients convey their unique perspectives in conversations with healthcare professionals<sup>1,15</sup>. This is partly due to a lack of awareness among patients of the relevance of communicating their preferences and goals<sup>22</sup>. Therefore, in 2018, Dutch researchers started the EMpowerment of PATIEnts and their informal caregivers (EMPATIE) project<sup>23</sup>. The aim of this project is to support HF and COPD patients and informal caregivers to start an early conversation with their healthcare professional about what constitutes QoL and quality of care for them in a certain situation. A toolbox was developed by EMPATIE which contains tools to assist COPD and HF patients and their informal caregivers in identifying and communicating their unique perspectives during conversations about tailored care with their healthcare professional<sup>23</sup>.

But what influence does the use of interventions such as the EMPATIE toolbox have? Currently, there is no valid Dutch measurement instrument for charting to what extent patients identify, communicate and document their preferences and wishes. Therefore, the

development of the Communicating Patient Perspective Questionnaire (CPP-Questionnaire) for HF and COPD patients in palliative care is essential.

### **Aim**

This study aims to explore which items should be included in the CPP-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.

## **METHODS**

### **Design**

A qualitative, generic, descriptive study was conducted between January and June 2020<sup>24</sup>. Given the explorative nature of the aim of this study, a qualitative approach was considered most suitable to identify the perspectives of the involved patients, healthcare professionals and informal caregivers<sup>25-26</sup>.

Secondary data analysis of interviews previously conducted as part of the EMPATIE study was undertaken to identify items relevant for the CPP-Questionnaire. The research question of the EMPATIE study was: *“Which challenges are experienced by patients with COPD and HF and their informal caregivers in the palliative phase in identifying and communicating their unique perspectives during healthcare consultations?”*<sup>23</sup>.

This research question is closely related to the aim of the current study, making the EMPATIE interview data suitable to explore items for the CPP-Questionnaire. By making use of existing interview data, it was not necessary to query patients, informal caregivers, and healthcare professionals again.

The guidelines for reporting qualitative studies established by COREQ-32 were followed<sup>27</sup>.

### **Population and domain**

This study concerns patients diagnosed with HF and/or COPD and their informal caregivers. The sample of both the current study and the EMPATIE study consists of 8 COPD, 4 HF patients and 6 informal caregivers recruited from primary and secondary care institutions in the east of the Netherlands. In addition, nursing specialists in HF, COPD, and oncology, as well as a cardiologist, a pulmonary physician, a general practitioner, and HF and COPD nurses were included. No data were available for non-participation.

For the EMPATIE study, eligible patients and informal caregivers were identified through gatekeepers for participation if 1) they were diagnosed with HF and/or COPD or provide care

to HF and COPD patients, 2) were able to speak and read the Dutch language, and 3) were 18 years or older.

Purposive sampling was used to achieve maximum variation in diagnosis, disease phase, health literacy, and cultural background due to expected variation in perspectives<sup>28-29</sup>. The purposively sampled professionals were recruited from different settings to ensure maximum variation and generalizability of the results<sup>30</sup>. Healthcare professionals had to provide daily care to HF and COPD patients and be able to speak and sufficiently understand Dutch. Diversity was sought in discipline, work setting, and years of experience in working with HF and COPD patients.

### **Procedures**

Thirty interviews were conducted and transcribed for the EMPATIE study. All these interviews have been included in the current study to explore the items from the perspective of patients (n = 12), informal caregivers (n = 6) and healthcare professionals (n = 12).

Participants of the EMPATIE study were asked for permission to reuse the data for additional research, and all participants agreed to this in writing. Patients and informal caregivers of the EMPATIE study were personally approached for participation in the EMPATIE project by their healthcare professionals. Nursing students who had internships in hospitals and practices with general practitioners recruited healthcare professionals for participation. If interested, they were fully informed about the study by a researcher. After consideration and agreement, an interview was planned.

### **Data collection**

The EMPATIE data was collected from November 2018 to December 2019. Semi-structured face-to-face interviews (approximately 70 minutes) were conducted to ensure the collection of in-depth insights into the perspectives of patients, informal caregivers, and healthcare professionals. Two experienced researchers (MJ and LM) and a PhD-student (AS) conducted the interviews using an interview guide based on the relevant literature<sup>9</sup>. At the start of the interview, the researcher provided the interviewee with adequate information about the intent of the study. Thereafter, socio-demographic data of the participants were collected. To stimulate an open and rich conversation, all patient and informal caregiver interviews were conducted in their homes, as in this safe environment participants were considered to be most comfortable<sup>31</sup>. Healthcare professionals were interviewed at their workplaces for their convenience.

The data were collected in four rounds, each round consisting of six interviews. After each round, the data were analysed and the interview guide adjusted if necessary. Participants

who indicated that they would like to read the transcripts, received the transcripts afterwards to check the interpretation and accuracy of their words<sup>30,32</sup>.

### **Data analysis**

All interviews from EMPATIE were digitally audio recorded and transcribed verbatim to reduce the risk of bias<sup>33</sup>.

Computer assisted qualitative data analysis systems contribute to validity and reliability in data management and analysis in qualitative research<sup>26</sup>. Therefore, analysis of this study was conducted using Atlas.ti version 8.4.24.

Secondary thematic analysis of the EMPATIE interviews was performed following the six steps of Braun & Clarke, which offer a method to guide the process of identifying, analysing and reporting patterns within qualitative data<sup>34</sup>. The researchers expected to find agreement in terms of items between all target groups. Yet, all fragments were coded in a way to make it clear from which target group the data originated.

Step 1 involved reading the transcripts to become familiar with the data. In addition, rough notes were made regarding early impressions (by MSH)<sup>35</sup>. In step 2, each segment of data relevant to the aim of the study was coded. Given the coding was done with the aim of the study in mind, a theoretical thematic analysis approach was used<sup>34</sup>. In step 3 the codes were examined by the researchers (MJ, LM and MSH) and preliminary categories and (sub)themes were identified. In step 4 the preliminary identified categories and themes were reviewed, modified and developed by re-reading the data associated with each theme. Since the final questionnaire will be used in practice by patients, the researchers found it important that all subthemes had at least partly emerged from data from the patients. The final refinement of the themes was carried out by drawing a thematic map in step 5. It became clear here that the codes of all three target groups coincided in the subthemes. Step 6 was the writing of the report.

The first interview was coded individually by two researchers to assert inter-rater reliability<sup>26</sup>. The coding and interpretation of fragments was largely similar. Difference of opinion was discussed until agreement was reached. The two researchers (MJ and LM) involved in this secondary data analyses were an integral part of the primary study and were involved in most of the data collection, facilitating data adequacy and congruency. To assert the credibility and confirmability of the interpretation, researcher triangulation during analysis was deployed<sup>26,36</sup>. Peer debriefing by discussions with the research team led to a broader view of the (sub)themes and more depth which enhanced accuracy<sup>36</sup>. Disconfirming data were identified in a few cases. By revising our code tree and themes, we are confident that our

interpretations derived from the data are valid and can also account for the alternative cases<sup>29</sup>. Reflections and feelings of the main researcher about the data were recorded in fieldnotes to stimulate theoretical thinking<sup>30</sup> To add transparency and trustworthiness to the findings, quotes from several participants have been added to this report<sup>34</sup>.

### **Ethical issues (6 statements in CCMO)**

This study was conducted according to the principles of the Declaration of Helsinki (64<sup>th</sup> version, October 2013)<sup>37</sup>. The privacy of the participants is guaranteed according to the Dutch Act on Implementation of the General Data Protection Regulation<sup>38</sup>. The interview data and fieldnotes will be kept systematically and safe in the Saxion Research Repository.

Ethical approval for the EMPATIE study was obtained from the Medical Ethics Committee Twente (nr. K18-32).

## **RESULTS**

### **Participants**

The age of the patients ranged from 56 to 78 years and 5 of them were female. Most had been diagnosed more than 6 years previously with HF or COPD. The informal caregivers had a larger age range, from 40 to 78 years, and one of them was male. Participant characteristics are presented in Table 1. Theoretical saturation was achieved after analysis of 26 interviews (out of a total of 30), since no new concepts or dimensions for categories could be identified relevant to the items of the CPP-Questionnaire<sup>30</sup>.

[Table 1]

Based on the thematic analysis, key findings are described in three themes; wishes, needs and preconditions. An overview of resulting subthemes and categories within each theme is shown in Table 2.

### **Theme 1: Wishes**

Patients, informal caregivers and healthcare professionals indicated that the identification of wishes is essential in clarifying patients' perspectives. Three subthemes can be distinguished within the theme 'wishes'.

#### Wishes regarding the end of life

The first subtheme focuses on wishes regarding the end of life, such as a preference to die peacefully.



*“Well, we recently talked about how and what... when I die. Euthanasia or what... you can also just get an injection when you sleep. I like that best” (woman, 69, COPD).*

Several patients also indicated who they would prefer to have around their deathbed, where they would want to live before death and where they would prefer to die.

#### Wishes regarding medical treatment

With regard to medical wishes, treatment limitation was commonly mentioned. This included, according to the patients and informal caregivers, resuscitation, invasive ventilation and discontinuing life-prolonging treatment. In both subthemes it emerged from the interviews that there are essential elements to achieving this type of wish. A frequently discussed element was communicating wishes with family and healthcare professionals. Documenting these preferences regarding medical treatment was in particular mentioned by professionals as an important element. The medical wishes did not focus on extending life, but on quality of life and death:

*“At the moment, that's all I want in terms of medical treatment, some pills so that I sleep better... a good night's sleep” (woman, 69 COPD).*

#### Wishes regarding daily life

The third type of wish concerned daily life. In this subtheme it was made clear by both informal caregivers and patients that it is important for them to be able to continue to practice hobbies, to conduct daily activities and to go out. An 82-year-old woman said:

*“I found it so pleasant to spend an afternoon in the village. I went to the Hema and had coffee there.”*

### **Theme 2: Needs**

#### Need for autonomy

The first need identified in the interviews was the need for autonomy. Patients mentioned that they were afraid of ending up in a nursing home and being completely dependent. Informal caregivers wished to continue to care for their loved ones for as long as possible in order to prevent them losing control and freedom with regard to their daily schedules through deployment of district nursing. An informal caregiver of a woman with COPD said the following about this:

*“She can also be put in the shower by someone from eh... and all those things. But yes, then you depend on those people when they come. Well, we don't like that. See if we get up at 8 a.m. or want to get up once at 10 a.m. then we want to be able to do that at 10 a.m.”*

### Need for information

The majority of patients expressed a need for information, although there was some variation in this. Some patients ask for information about their life expectancy:

*“How long I have left, for example... He (the doctor) can give a direction” (COPD patient).*

A few patients indicated that they would prefer not to be informed about the course of their disease and life expectancy. One HF patient said:

*“We will see what the future brings”.*

Highly educated patients expressed a stronger need for information than low-skilled patients. The informal caregivers, on the other hand, were unanimous about their need for information. They all indicated that they want to know how the disease is characterized and what the prognosis is:

*“I have been searching for information for many hours. About the severity of the disease, the course, life expectancy. Whether you will be alone...” (informal caregiver of a woman with COPD).*

### Social-emotional needs

Patients reported that attention to social-emotional needs by healthcare professionals contributes to good conversations concerning patients' unique perspectives. An important topic within this subtheme according to both patients and informal caregivers was the need to have satisfying relationships with family, friends and people who have had or are having similar experiences. Patients and informal caregivers also indicated that they require attention from healthcare professionals concerning their wellbeing, emotions, fears, and concerns during consultation.

An HF patient said:

*“Yes, I thought that was very nice... when there was an IC-nurse who had a night shift and then stayed even longer in the morning and stuff. She was very worried about me. When she was on duty, the first thing she did... she came to me.  
[Emotional] Yeah that was nice. Because she was personally interested.”*

### Need for identity

Patients cited respectful communication with healthcare professionals as important. They believe it is important for the healthcare professional to approach the patient as a human being and the healthcare professional should pay attention to the person behind the patient. This need for identity was expressed by a COPD patient:

*“Uh yes, I’m not the person I used to be. I was a wife who took care of my husband, mother of my children, grandmother of my grandchildren, uh I cannot uh... be the grandmother I want to be.”*

### **Theme 3: Preconditions**

The third identified theme concerns preconditions for conversations in which the patients’ perspective is central. A distinction was made between facilitating factors and aspects that impede patients to think about, communicate and document wishes and needs.

#### Facilitators of thinking about, communicating and documenting wishes and needs

According to the patients, a good relationship with the healthcare professional and a supportive informal caregiver contribute to having effective conversations about patients’ wishes and needs. In addition, a thorough preparation by the patient for the consultation adds to this:

*“But that’s the crucial thing, you just have to prepare. So if you want to have a decent conversation with a doctor nowadays, yes they are also short of time” (informal caregiver of a man with COPD).*

#### Barriers to thinking about, communicating and documenting wishes and needs

All participants agreed that a lack of time and the lack of a trusting relationship with the healthcare professional can be a barrier. In addition, professionals mentioned barriers such as patients attending the consultation unprepared and the inability of patients to communicate openly. One professional declared:

*“Euhm... well, a consult is scheduled for fifteen minutes so then... that is not the time for an in-depth conversation”.*

Finally, almost all patients indicated that wishes and needs must be identified and discussed during the consultation in order to provide tailored care. When asked which topics of conversation the patients and informal caregivers bring up, only medical topics such as medication use, treatments and results of medical examinations were mentioned. One informal caregiver stated:

*“Yes I don’t know if it’s really relevant to discuss hobbies, just because yes, he (the healthcare professional) is purely for the medical”.*

[Table 2]

## DISCUSSION

The focus of this study was to explore which items should be included in the CPP-Questionnaire according to patients, informal caregivers and healthcare professionals. The identified items were 1) wishes regarding the 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; and 7) the need for identity. In addition, facilitators and barriers to thinking about, communicating and documenting wishes and needs were identified.

The types of wishes regarding the end of life and treatment limitation are also reflected in a review by Dev<sup>39</sup>. This also applied to our found preference of patients for quality of life over quantity of life<sup>39</sup>. The findings regarding patients' needs are consistent with other studies as well. In particular the psycho-social needs, the need to have satisfying relationships and the need for autonomy are frequently expressed needs in palliative care<sup>5,13,40</sup>.

A contrasting finding in this study is the difference in what the patient says is important in a consultation with a healthcare professional and what the patient brings up during this consultation. Attention to the wishes and needs of the patient is seen as important by all participants, however, many interviews revealed that the patient considers a consultation as a medical check-up. For example, patients indicated that the professional must pay attention to the person behind the patient (need for identity) and pay attention to their wellbeing and concerns (social-emotional needs). Despite this, the majority of patients mentioned in the interviews that they only bring up medical subjects during consultation. All things considered, there is a significant discrepancy between what the patient considers to be essential and how the patient communicates during consultation. It is not remarkable in itself that wishes and needs are not discussed during consultation, since several studies have shown that the minority of HF and COPD patients discusses their unique perspective<sup>1,15,22</sup>. It is, however, noticeable that patients in this study indicated that they are aware of the importance of this, but still don't act to convey their wishes and needs during consultations.

Although most patients reported a need for information, there were also patients who did not want to be informed about the disease and dying process. Being highly-educated seems to be associated with wanting more and detailed information about the disease course. These findings are consistent with the results of a systematic review on end-of-life communication<sup>41</sup>. Furthermore, both in the review of Parker and in our data, it emerged that there is a variation in information needs between patients and informal caregivers. Informal caregivers would like to receive information regarding the diagnosis, prognosis and aspects concerning end-of-

life care, specifically as the HF or COPD progresses, while patients do not always want to know what the future will bring<sup>1,41</sup>.

Based on our findings, the CPP-Questionnaire should consist of two parts, namely, a) questions regarding wishes and needs; b) questions regarding preconditions. For part a) it would also be valuable to be able to measure per item to what extent someone has identified, communicated and documented that kind of wish or need. In addition, we recommend including questions in the CPP-Questionnaire about preconditions.

Preconditions, such as thorough consultation preparation by the patient and healthcare professional and a relationship of trust between patient and professional, seem to influence the extent to which patients' perspectives are discussed during consultation<sup>1,19,41</sup>.

This study was strengthened by the use of a relatively large sample size. However, several limitations need to be considered. One limitation was the lack of control over the data collection, due to the secondary data analysis method. For example, there was no gender diversity among the group of professionals. This may have led to bias, given that gender is associated with variations in communication style<sup>42-43</sup>. Further, non-participants were present at four patient interviews, which may have led to less rich interview data.

It strengthens the study that although the focus was on the patient and informal caregiver, the perspective of the professional was also included. By including the perspectives of this group, it is more likely that the CPP-Questionnaire will actually be used in practice<sup>43</sup>.

To strengthen the findings and to verify the correctness and completeness of the items, we recommend to perform a member check, which will improve the construct validity of the questionnaire. Further, the results appear to be generally applicable in palliative care and not specific to HF and COPD patients. Further research should focus on the generalizability of these findings and the CPP-Questionnaire throughout the palliative setting.

## **Conclusion**

Much research has been done on the benefits of communicating patients' wishes, preferences and needs regarding quality of life and dying in order to receive tailored care. Less is known about to what extent patients identify, communicate and document their unique perspectives and what influence interventions have on this. Therefore, we explored which items fully reflect the unique patient perspective according to palliative HF and COPD patients. The CPP-Questionnaire should be developed on the basis of these items, so that it can be measured which interventions contribute to identifying and communicating patients' perspectives in order to bridge the gap between patients preferences and (end-of-life) care received.

## REFERENCES

1. Patel K, Janssen DJ, Curtis JR. Advance care planning in COPD. *Respirology* 2012; 17(1) : 72-8.
2. Murray SA, Kendall M, Boyd K, Sheikh A. Illness trajectories and palliative care. *Bmj* 2005; 330(7498): 1007-11.
3. Low J, Pattenden J, Candy B, Beattie JM, Jones L. Palliative care in advanced heart failure: an international review of the perspectives of recipients and health professionals on care provision. *Journal of cardiac failure* 2011; 17(3): 231-52.
4. Vos T, Flaxman AD, Naghavi M, Lozano R, Michaud C, Ezzati M, Shibuya K, Salomon JA, Abdalla S, Aboyans V, Abraham J. Years lived with disability (YLDs) for 1160 sequelae of 289 diseases and injuries 1990–2010: a systematic analysis for the Global Burden of Disease Study 2010. *The lancet* 2012; 380(9859): 2163-96.
5. Lowey SE. Palliative care in the management of patients with advanced heart failure. In *Heart Failure: From Research to Clinical Practice*. Springer, Cham; 2017.
6. Orso F, Fabbri G, Maggioni AP. Epidemiology of heart failure. In *Heart Failure*. Springer, Cham; 2016.
7. Tanai E, Frantz S. Pathophysiology of heart failure. *Comprehensive physiology* 2011; 6(1): 187-214.
8. Nederlandse Huisartsen Genootschap. Standaard hartfalen. [Internet]. Available from: <https://www.nhg.org/standaarden/volledig/nhg-standaard-hartfalen>. [cited 2019 Sep 3].
9. ZonMw. Passende zorg in de palliatieve fase door het bevorderen van de empowerment van patiënten en hun naasten: EMPATIE project [Internet] Available from: <https://www.zonmw.nl/nl/over-zonmw/onderwijs/programmas/project-detail/palliantie-meer-dan-zorg/passende-zorg-in-de-palliatieve-fase-door-het-bevorderen-van-de-empowerment-van-patienten-en-hun-na/>. [cited 2019 Nov 4].
10. Actiz. Waardering voor campagne VWS over palliatieve zorg. [Internet]. Available from: <https://www.actiz.nl/nieuws/ouderenzorg/actiz-waardering-voor-campagne-vws-over-palliatieve-zorg>. [cited 2019 Oct 14].
11. Sepúlveda C, Marlin A, Yoshida T, Ullrich A. Palliative care: the World Health Organization's global perspective. *Journal of pain and symptom management* 2002; 24(2): 91-6.
12. Whoqol Group. The World Health Organization quality of life assessment (WHOQOL): position paper from the World Health Organization. *Social science & medicine* 1995; 41(10): 1403-9.

13. Jones PW, Watz H, Wouters EF, Cazzola M. COPD: the patient perspective. *International journal of chronic obstructive pulmonary disease* 2016; 11(Spec Iss): 13.
14. Thomas K. Overview and introduction to advance care planning. *Advance care planning in end of life care* 2011: 3-15.
15. Schichtel M, Wee B, Perera R, Onakpoya I. The Effect of Advance Care Planning on Heart Failure: a Systematic Review and Meta-analysis. *Journal of general internal medicine* 2019; 12 : 1-1.
16. Rietjens JA, Sudore RL, Connolly M, van Delden JJ, Drickamer MA, Droger M, van der Heide A, Heyland DK, Houttekier D, Janssen DJ, Orsi L. Definition and recommendations for advance care planning: an international consensus supported by the European Association for Palliative Care. *The Lancet Oncology* 2017; 18(9): e543-51.
17. Lum HD, Sudore RL, Bekelman DB. Advance care planning in the elderly. *Medical Clinics* 2015; 99(2): 391-403.
18. Houben CH, Spruit MA, Groenen MT, Wouters EF, Janssen DJ. Efficacy of advance care planning: a systematic review and meta-analysis. *Journal of the American Medical Directors Association* 2014; 15(7): 477-89.
19. Detering KM, Hancock AD, Reade MC, Silvester W. The impact of advance care planning on end of life care in elderly patients: randomised controlled trial. *Bmj* 2010; 340: c1345.
20. Kovacs AH, Landzberg MJ, Goodlin SJ. Advance care planning and end-of-life management of adult patients with congenital heart disease. *World Journal for Pediatric and Congenital Heart Surgery* 2013; 4(1): 62-9.
21. Cross SH, Kamal AH, Taylor Jr DH, Warraich HJ. Hospice Use Among Patients with Heart Failure. *Cardiac failure review* 2019; 5(2): 93.
22. Waldrop DP, Meeker MA. Communication and advanced care planning in palliative and end-of-life care. *Nursing Outlook* 2012; 60(6): 365-9.
23. Netwerk Palliatieve Zorg. EMPATIE. [Internet]. Available from: <https://www.netwerkpalliatievezorg.nl/achterhoek/Hulpverleners/EMPATIE>. [cited 2019 Sep 4].
24. Polit DF, Beck CT. *Nursing research: Principles and methods*. 7th ed. Philadelphia: Lippincott Williams & Wilkins; 2004.
25. Boeije H. *Analysis in qualitative research*. London: Sage publications; 2010.
26. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International journal for quality in health care* 2007; 19(6): 349-57.

27. Lovell A, Yates P. Advance care planning in palliative care: a systematic literature review of the contextual factors influencing its uptake 2008–2012. *Palliative medicine* 2014; 28(8): 1026-35.
28. Davidson PM, Phillips JL, Dennison-Himmelfarb C, Thompson SC, Lockett T, Currow DC. Providing palliative care for cardiovascular disease from a perspective of sociocultural diversity: a global view. *Current opinion in supportive and palliative care* 2016; 10(1): 11-7.
29. Holloway I, Galvin K. *Qualitative research in nursing and healthcare*. 4th ed. West Sussex: John Wiley & Sons; 2016.
30. Mason J. *Qualitative researching*. 3th ed. London: Sage Publications Ltd; 2017.
31. Sandelowski M. Rigor or rigor mortis: the problem of rigor in qualitative research. *Advances in nursing science* 1993; 16(2): 1-8.
32. McLellan E, MacQueen KM, Neidig JL. Beyond the qualitative interview: Data preparation and transcription. *Field methods* 2003; 15(1): 63-84.
33. Braun V, Clarke V. Using thematic analysis in psychology. *Qualitative research in psychology* 2006; 3(2): 77-101.
34. Maguire M, Delahunt B. Doing a thematic analysis: A practical, step-by-step guide for learning and teaching scholars. *AISHE-J: The All Ireland Journal of Teaching and Learning in Higher Education* 2017; 9(3).
35. Lincoln YS, Guba EG. Establishing trustworthiness. *Naturalistic inquiry* 1985; 289(331): 289-327.
36. World Medical Association (WMA). WMA Declaration of Helsinki Ethical principles for medical research involving human subjects. [Internet] Available from: <https://www.wma.net/policies-post/wma-declaration-of-helsinki-ethical-principles-for-medical-research-involving-human-subjects/> [cited 2019 Oct 28].
37. Autoriteit Persoonsgegevens. Introductie AVG. [Internet] Available from: <https://autoriteitpersoonsgegevens.nl/nl/onderwerpen/algemene-informatie-avg/algemene-informatie-avg> [cited 2019 Nov 4].
38. Dev S, Abernethy AP, Rogers JG, O'Connor CM. Preferences of people with advanced heart failure—a structured narrative literature review to inform decision making in the palliative care setting. *American heart journal* 2012; 164(3): 313-9.
39. Gardener AC, Ewing G, Kuhn I, Farquhar M. Support needs of patients with COPD: a systematic literature search and narrative review. *International journal of chronic obstructive pulmonary disease* 2018; 13: 1021.
40. Parker SM, Clayton JM, Hancock K, Walder S, Butow PN, Carrick S, Currow D, Ghera D, Glare P, Hagerty R, Tattersall MH. A systematic review of prognostic/end-of-life communication with adults in the advanced stages of a life-limiting illness:



patient/caregiver preferences for the content, style, and timing of information. *Journal of pain and symptom management* 2007; 34(1): 81-93.

41. Hall JA. *Nonverbal sex differences: Accuracy of communication and expressive style*. Johns Hopkins University Press; 1990.
42. Roter DL, Hall JA. Physician gender and patient-centered communication: a critical review of empirical research. *Annu. Rev. Public Health* 2004; 25: 497-519.
43. Meinel C, Leifer L, Plattner, H. *Design thinking research, building innovators*. Springer, Cham; 2015.

**Table 1.** Demographic data

Characteristic		Patients	Informal caregivers	Professionals
Participants (N*)		12	6	12
	COPD (N)	8	3	-
	HF (N)	4	3	-
Sex, (N)	Female	5	5	12
Age, median (IQR**) (years)		66 (62-68.5)	67 (63-69)	52.5 (43-55.5)
Duration of disease (N)	<1 year	2	2	-
	1-2 year(s)	1	-	-
	2-5 years	1	1	-
	6-10 years	4	2	-
	>10 years	4	1	-
Education (N)	Low	6	3	-
	Median	-	3	-
	High	5	-	-
	Missing	1	-	-
Patients per month, median (IQR)		-	-	40 [33-60]

\*Number

\*\*InterQuartile Range

**Table 2.** Results

<b>Themes</b>	<b>Subthemes</b>	<b>Categories</b>
Wishes	Wishes regarding end of life	Type of Wish regarding end of life Prerequisites/essential elements for this type of wish
	Wishes regarding medical treatment	Type of wish regarding treatment limitation Important/essential elements for this type of wish
	Wishes regarding daily life	Type of wish regarding daily life
Needs	Need for autonomy	Decreased sense of self-determination Including patients' expertise as part of decision making
	Need for information	Information about life expectancy Information about disease course Information regarding medical treatment
	Social-emotional needs	Having satisfying relationships Attention to patients' wellbeing and concerns
	Need for identity	Attention to the patient as a person Approaching the patient as a human being
Preconditions	Facilitators to thinking about, communicating and documenting wishes and needs	Satisfying relationship with healthcare professional Preparation for consultation Facilitating influence of informal caregiver
	Barriers to thinking about, communicating and documenting wishes and needs	No need for information Presence of informal caregiver No preparation for consultation Lack of a trusted relationship with the healthcare professional Too little time