



Caring for carers

A qualitative study to explore the facilitating and impeding factors for timely recognition of palliative care needs among family caregivers of patients with Chronic Heart Failure

“It’s supporting those closest to them and adding life to days, whether or not days can be added to lives.”

(World Hospice and Palliative Care Day, October 2006)

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Abstract

Background: The needs of family caregivers are not recognized or are recognized too late in the disease trajectory of patients with Chronic Heart Failure

Aim : The aim of this study is to explore which factors facilitate and impede a timely recognition of palliative care needs based on the experiences of family caregivers of patients with advanced heart failure and to identify the gap between these factors and the experiences of healthcare professionals.

Methods: Analysis of ten semi-structured interviews with family caregivers and two focus groups of healthcare professionals working in a hospital, are used to identify the gaps between family caregiver's experiences with regards to facilitating and impeding factors for timely recognition and the hospital perspective.

Results: Multiple factors have been identified by the family caregivers as either facilitating or impeding for a timely recognition of their needs. The lack of time, attention and education of healthcare professionals impede the timely recognition of family caregiver's needs. The fact that patients and family caregivers vary in the amount of information they wish to receive and the fact that family caregivers have to actively search for information are also identified as impeding factors. Having the same care provider and using the right timing and setting are identified as facilitating factors for a timely recognition of palliative care needs.

From the hospital perspective it became clear that the greatest gaps seem to lie in the lack of time, attention and expertise of healthcare professionals.

Conclusions/recommendations: Based on the results of the current study, some directions for timely recognition of palliative care needs in family caregivers can be provided. Firstly, healthcare professionals should get more time to pay attention to the family caregivers, since both groups mentioned that the lack of time impedes them in expressing and recognizing possible needs. This attention should focus on informing the family caregivers better in family conversations, since the results show a striking need for information among family caregivers. Besides that, healthcare professionals should get more education on communication techniques regarding palliative care since they mention they find it hard to determine when and how to start conversations with family caregivers.

Lastly, family caregivers should indicate with what healthcare professional they have the best care-relation, since they both mentioned the value of having a trust-relation for expressing and recognizing needs.

Acknowledgements

Dear reader,

Before you lies my thesis called: Caring for carers. This thesis was written to fulfil the graduation requirements of the Master's program Sociology: Contemporary Social Problems at Utrecht University. This thesis was commissioned by the Care and Public Research Institute (CAPHRI), that belongs to Maastricht University. I have written this thesis with great pleasure from February 2019 to June 2019.

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I hope you enjoy your reading,

Loeke Hameleers

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Table of contents

Abstract	2
1. Introduction.....	6
2. Theoretical framework.....	9
2.1 Factors influencing a timely recognition of family caregivers needs.....	9
2.1.1 Quantity and quality communication about information.....	9
2.1.2 Lack of expertise of health care professionals regarding palliative care	11
2.1.3 Continuity of care provision	12
3. Methodology	14
3.1 Ethics	14
3.2 Research design	14
3.3 Family caregivers interviews.....	14
3.3.1 Respondents	14
3.3.2 Data collection	16
3.3.3 Procedure	17
3.3.4 Analysis.....	17
3.4 Focus groups with healthcare professionals from the hospital.....	18
3.4.1 Respondents	18
3.4.2 Data collection	18
3.4.2 Procedure	18
3.4.3 Analysis.....	19
4. Results.....	20
4.1. Impeding factors for timely recognition.....	20
4.1.1 Variation in needs to access information about the condition across actors.....	20
4.1.2 Actively asking and searching for information.....	23
4.1.3 Lack of time and attention for family caregiver	23
4.1.4 Lack of expertise of healthcare professionals regarding palliative care	25
4.2 Facilitating factors for timely recognition	26
4.2.1 Having the same care provider.....	26
4.2.2 Timing and setting	27
5. Discussion	30
6. Future directions	33
7. References.....	38
8. Appendix.....	43
8.1 Information for respondents & Informed consent	43

8.2 Topic list 47

8.3 Coding scheme interviews 49

8.4 Coding scheme focus groups 50

1. Introduction

Chronic heart failure

The world is dealing with an aging population, meaning that the number of elderly people is rapidly increasing (Kennedy et al., 2014). This will result in more people with chronic diseases such as Chronic Heart Failure (CHF). Ten percent of the people of 70 years and older will have to deal with CHF, meaning that the number of people with CHF is likely to increase in the future (Ponikowski et al., 2016).

Chronic Heart Failure (CHF) is a major cause of morbidity worldwide (Janssen, Spruit, Uszko-Lencer, Schols & Wouters, 2011). Twenty-five percent of the patients that are diagnosed with CHF, can expect to pass away within three years (Martínez-Sellés et al., 2012). CHF is a progressive condition that affects the pumping power of the heart, resulting in various symptoms that decrease quality of life (Ramani, Uber & Mehra, 2010).

Palliative care

The rise in conditions such as CHF have led to an urgency in the development of the medical field, like developing curative techniques for life extension (De Meijer, Wouterse, Polder, & Koopmanschap, 2013). It has also led to a bigger need for palliative care. Palliative care is for patients with life threatening illnesses that cannot be cured anymore (Francke & Willems, 2000). Palliative care focusses on improving the quality of life of patients and their family members through the prevention and relief of suffering. Ideally this is done by an early recognition of physical (insomnia, stress), psychosocial (e.g. worries, anxiety, isolation) and informational (e.g. info about disease, care provision, prognosis) needs (WHO, 2018).

Due to decentralization, healthcare becomes increasingly driven by cost containment and competition, resulting in the fact that patients and their families are expected to longer life at home and rely on informal care instead of paid formal care (Wen & Gustafson, 2004; Collins & Swartz, 2011). Informal care is the care provided by a spouse, other relative or friends (Pickard et al., 2010). Because of these developments, the family caregiver's role becomes more important and gives them more responsibility (Collins & Swartz, 2011).

It is important to pay attention to the needs of family caregivers to reduce their burden, since a high experience of caregiver burden increases the need for formal, paid care. Besides that, patients more often have unmet needs if their caregiver has a high caregiver burden (Deeken et al., 2003). Paying attention to the needs of family caregivers is not only beneficial for the patients, but also for the family caregivers themselves (Bekelman et al., 2016). An

important aspect of the palliative care philosophy is therefore not only support for the patient, but also for the family (Hudson, Aranda & Kristjanson, 2004). Mainly for these reasons the world health organization emphasizes the role of the family caregiver as an important objective in palliative care (Deeken et al., 2003).

While fulfilling the informal care role may be satisfying, it can also cause physical and psychosocial burdens (Thomsen, Guldin, Nielsen, Ollars and Jensen, 2017). Family carers can take multiple roles varying from care provider, to expert on the life of the patient as loved one (Boddaert et al., 2017). Family caregivers need guidance, information, advice and support before and after the passing away of the patient. The quality framework for palliative care, states that paying specific attention to the individual values, wishes and needs of the family caregiver by healthcare practitioners, enables them to fulfil their role better and reduces stress on the caregiver (Boddaert et al., 2017). Ideally, healthcare providers pay special attention to the capacity, burden, values, wishes and needs of the family carer in his or her different roles, and offers support to prevent possible (physical, psychological, social and spiritual) overloads (Boddaert et al., 2017).

In contrast to other diseases (e.g. cancer), the separation between the curative phase and the palliative phase in CHF is not always clear (Collins & Swartz, 2011). Chronic heart failure is often incurable and the disease course is difficult to predict. The mortality rate in the end phase of CHF is 50 percent in the first year (Bellersen & Baltussen, 2018). This shows the difficulty of providing patients and their family with a clear prognosis about the life expectancy since it can vary between months and several years. During the end phase of CHF, the focus often shifts from curative care to palliative care. When the heart failure and its symptoms become more severe, CHF patients and their family carers usually have to seek acute care to receive treatment and symptom control. In hospitals, they are offered acute treatments for their illness and pain, but after discharge from hospital, the patients and their family return home without any specific follow-up or long-term care plan (Nordgren & Sørensen, 2003). Palliative care needs of patients with advanced CHF and their families are only recognized in the last months of a patient's life (Bakitas et al., 2013). Earlier recognition of palliative care needs by healthcare professionals might be more beneficial for the patients and their loved ones, because it helps people think about how they want to organize the palliative phase together with their loved one. A timely recognition of these palliative care needs have been proven effective, since it can reduce symptoms, improve mood and quality of life and promote the continuity of care (Pastor & Moore, 2013). However, important palliative care needs often remain unmet (Janssen et al., 2019).

Research aim

According to the literature, it can be stated that an early recognition of palliative needs is important for both patient and the family caregiver. The existing literature is unclear about the reasons why palliative care needs of family caregivers are recognized in a late stage of the disease. The Care and Public Health Research institute (CAPHRI), part of Maastricht University, is therefore conducting a research to develop a practical tool for healthcare providers to timely identify and meet palliative care needs in people with advanced CHF and their family carers. Multiple perspectives are taken into account in the development of this instrument; General Practitioners, hospital caregivers, patients and family caregivers (current and the bereaved). This research focusses on the perspective of the family caregivers and the bereaved since they have a unique informal view on the patient and palliative care. The aim of this study is to explore which factors facilitate and impede a timely recognition of palliative care needs based on the experiences of family caregivers of patients with advanced heart failure and to identify the gap between these factors and the experiences of healthcare professionals.

The study contributes to the current body of literature by addressing a few gaps: 1) exploring the underlying factors that facilitate or impede a timely recognition of needs according to family caregivers of patients with CHF 2) addressing the view of multiple actors regarding the aforementioned impeding and facilitating factors for timely recognition of palliative care needs.

This will be done by answering the following three research questions:

1. What stimulating and impeding factors for timely recognition of palliative care needs by healthcare professionals, do family caregivers of patients with CHF experience?
2. What are the experiences of health care professionals from the hospital regarding the facilitating and impeding factors for timely recognition of palliative care needs as identified by family caregivers and to what extent do these experiences align or diverge from each other?
3. What are future directions for healthcare professionals and policy makers to improve timely recognition of palliative care needs in family caregivers of patients with CHF?

2. Theoretical framework

Informal caregivers provide unpaid care to neighbours, friends or family. Family caregiver is a term that is used to describe the people who provide care for family members who are unable to take care for themselves (Noonan, Wingham & Taylor, 2018; Pickard et al., 2010). This care can consist of emotional or practical support. A family caregiver takes multiple roles to meet the needs of the patient. However, family caregivers have important needs themselves that often remain unmet. These needs have been identified in previous research and can be divided into three main categories; psychosocial, informational and physical (Hupcey, Fenstermacher, Kitko and Fogg, 2011).

It is known that these needs of family caregivers are recognized too late in the disease trajectory of the patient (Bakitas et al., 2013). The literature suggests that multiple factors influence the recognition of palliative care needs among family caregivers of patients suffering from CHF. This section uses insights from the existing literature to identify factors that possibly influence a timely recognition of palliative care needs. Additionally, the different needs of family caregivers will be linked to the factors to understand the importance of healthcare professionals recognizing them in time.

2.1 Factors influencing a timely recognition of family caregivers needs

A first factor that can influence the recognition of needs is the quality and quantity of communication between healthcare professional and family caregiver. If family caregivers do not know enough about the disease, process or opportunities, they cannot know what they need. Secondly, the lack of expertise of health care professionals can influence the recognition of palliative care needs. Healthcare professionals should have the proper training to recognize the needs of family caregivers. Lastly, the continuity of care provision is an important factor. Family caregivers see many different professionals and are not always able to build a trust relation with one of them that could recognize their needs. In the following section, these factors will be elaborated on.

2.1.1 Quantity and quality communication about information

Family caregivers of patients with CHF tend to have unmet informational needs (Hupcey, Fenstermacher, Kitko and Fogg, 2011). Informational needs can be described as the desire of family caregivers to gain more information about the care provision, prognosis and the disease course of the patient, throughout the illness trajectory of the patient (Noonan, Wingham & Taylor, 2018). They want more information on what to expect, when to be

concerned and what could change over time (Bekelman et al., 2016). Trigt, Dijkhoorn, van de Camp, Douma and Boddaert (2017), found that caregivers lack basic knowledge about the patient's condition and palliative care in general. To illustrate this lack of knowledge, Cherlin et al. (2005) found that family caregivers are often not told that CHF is incurable. A study of Doherty, Fitzsimons & McIlfatrick (2016) found that family caregivers also often do not know about the existence of a palliative phase.

The aforementioned lack of information among family caregivers results in a feeling of uncertainty. A feeling of uncertainty in turn comes along with physical and emotional burdens family caregiver's experience. The way family caregivers experience palliative care, is highly dependent on the quality of communication with health care professionals (Fitzsimons, 2019). Health care providers should involve family more and facilitate better communication and coordination, since the problem seems to lie in the communication field (Hudson, Aranda & Kristjanson, 2004).

A possible explanation for this lack of knowledge is the flaw in communication between family caregivers and healthcare professionals. Family caregivers sometimes are reluctant to talk about palliative care. They refrain from talking about the inevitable and do not disclose their needs to healthcare professionals. This could be caused by the thought that their needs for support and information are not important in contrast to the needs of the patient (Hudson, Aranda & Kristjanson, 2004). Family caregivers might also be reluctant to disclose, because they do not want to be judged inadequate as a carer or they think their issues are inevitable and cannot be improved (Bekelman et al., 2019; Hudson, Aranda & Kristjanson, 2004).

However, family caregivers feel that healthcare providers also have trouble in communicating about the end of life. Healthcare providers might be reluctant to tell about the prognosis of a patient because they do not want to give too much information too soon, afraid that they provide the wrong information about the prognosis (Hudson, Aranda & Kristjanson, 2004). This could be explained by the fact that doctors overestimate the survival of their patients or are afraid to take away patients' hope (Christakis, Smith, Parkes & Lamont, 2000).

However, not all family caregivers desire more information about the status of the disease of the patient (Cherlin et al., 2005). Some family caregivers just do not want to accept that the illness of the patient cannot be cured, and do not believe the doctors when they mention this (Cherlin et al., 2005).

So, it can be stated that the amount and quality of communication about information can be influenced by both the healthcare professionals as the family caregivers themselves.

The family caregiver's informational needs remain therefore too often unmet (Hupcey, Fenstermacher, Kitko and Fogg, 2011).

2.1.2 Lack of expertise of health care professionals regarding palliative care

Research shows that family caregivers are overall unsatisfied with the services they and their partners receive regarding palliative care (Fitzsimons et al., 2019). Van Trigt et al. (2017) report that this dissatisfaction among family caregivers is related to a lack of expertise in the field of palliative care among healthcare professionals. The palliative phase is not recognized by health providers, and if so, there seems to be no consensus about what palliative care is (Van Trigt et al., 2017). The fact that they do not know when to initiate palliative care, impedes the chances for healthcare professionals to recognize possible palliative care needs of family caregivers.

Adding to that, healthcare professionals do not pay enough attention to the needs of family caregivers. Research has shown that healthcare providers are not enough aware of the family caregiver in the current situation (Proot et al., 2003). Ignoring or not noticing the needs of family caregivers as an object of care, can lead to inadequate care provision (Proot et al., 2003). Family caregivers have important psychosocial needs that are not recognized enough because of this lack of expertise among healthcare professionals. Psychosocial needs can be either emotional, psychological or social and can be described as an internal or external conflict of emotion resulting in worries, anxiety and stress (Doherty, Fitzsimons & McIlfratrick, 2016; Noonan, Wingham & Taylor, 2018). The literature suggests that family caregivers miss attention and guidance from healthcare professionals because they feel like the burden of caregiving falls on them alone (van Trigt et al., 2017). Having the feeling that they have nowhere to turn to for support results in emotional burdens among family caregivers. These burdens in turn negatively affect the quality of life of caregivers.

Taking care of a family member comes with new tasks. These tasks affect the lives of the family caregivers. Family caregivers experience difficulties with combining their social and work-life with the new caring tasks. The caring role substitutes time that in the past was available for leisure (Noonan, Wingham & Taylor, 2018). Doherty, Fitzsimons & McIlfratrick, (2016) argue that it is important to support the family caregiver to maintain a sense of normality. Family caregiver need time for themselves and they need a social life. This support means that family caregivers need someone to talk to about their fears and provide companionship. When family caregivers do not receive enough social support, they will experience their role as a caregiver as more burdensome (Yeh & Bull, 2011).

Research shows that involving the family caregiver in the process by giving them attention and information, has positive effects on family caregiver's experiences (Hupcey, Fenstermacher, Kitko and Fogg, 2011). However, the literature suggests that family caregivers are being kept at a distance by the patient. This can possibly be explained by the fact that healthcare professionals avoid talking about it because they lack expertise (Hudson, Aranda & Kristjanson, 2004). Due to this lack of expertise, healthcare providers are not sensitive enough to recognize possible needs of family caregivers (Proot et al., 2003).

2.1.3 Continuity of care provision

Family caregivers experience a lack of continuity in the care they receive. They are exposed to many different health care providers, which hinders the development of trust between healthcare providers and family caregivers (Hudson, Aranda & Kristjanson, 2004).

This trust relation is important, because family caregivers are more likely to open up to a healthcare professional they know and trust. This is beneficial for the healthcare providers, since they have to assess the needs of family caregivers (Herder van der Eerden, 2017).

A trust relation can be achieved by providing continuity in care provision. Family caregivers tend to have a trust relation with a small number of healthcare professionals (Herder van der Eerden, 2017).

However, van Trigt et al, (2017) found that family caregivers are unsatisfied about the continuity in care provision. Meaning that they have to deal with many different healthcare providers without knowing who to turn to. Because they have trouble with trusting healthcare providers, they cannot express their needs. An example of family caregiver's needs that often remain unmet are physical needs (Hupcey, Fenstermacher, Kitko and Fogg, 2011).

Family caregivers are known to have physical needs since caring for an ill loved one can be physically demanding (Thomsen, Guldin, Nielsen, Ollars and Jensen, 2017). Often, patients with CHF are in need of constant care and support. Family caregivers are involved in this care by providing help in daily tasks, such as dressing and bathing the patient and important decision-making processes (Collins & Swartz, 2011; Dionne-Odom et al., 2015). This comes along with a high sense of responsibility, burden and stress for the caregiver. Family caregivers have to be alert and observing every moment of the day. They lay awake at night to check the patient's breathing. This results in a higher rates of insomnia and stress (Collins & Swartz, 2011; Noonan, Wingham & Taylor, 2018).

Family caregivers have to provide physical as well as emotional care for the patient, often neglecting their own health (Dirikkan, 2018). Family caregivers have trouble with;

keeping a healthy sleep rhythm, exercising regularly and eating healthy (Collins & Swartz, 2011). This neglect can be the cause of family caregivers' often becoming ill themselves.

Due to the fact that family caregivers do not know or trust the healthcare professional enough because of the lack of continuity in care, these physical needs are not expressed. Family caregivers need to spend a lot of energy in building new relationships and retelling their histories (Herder van der Eerden, 2017). This impedes the chances of healthcare professionals to recognize the physical needs of family caregivers.

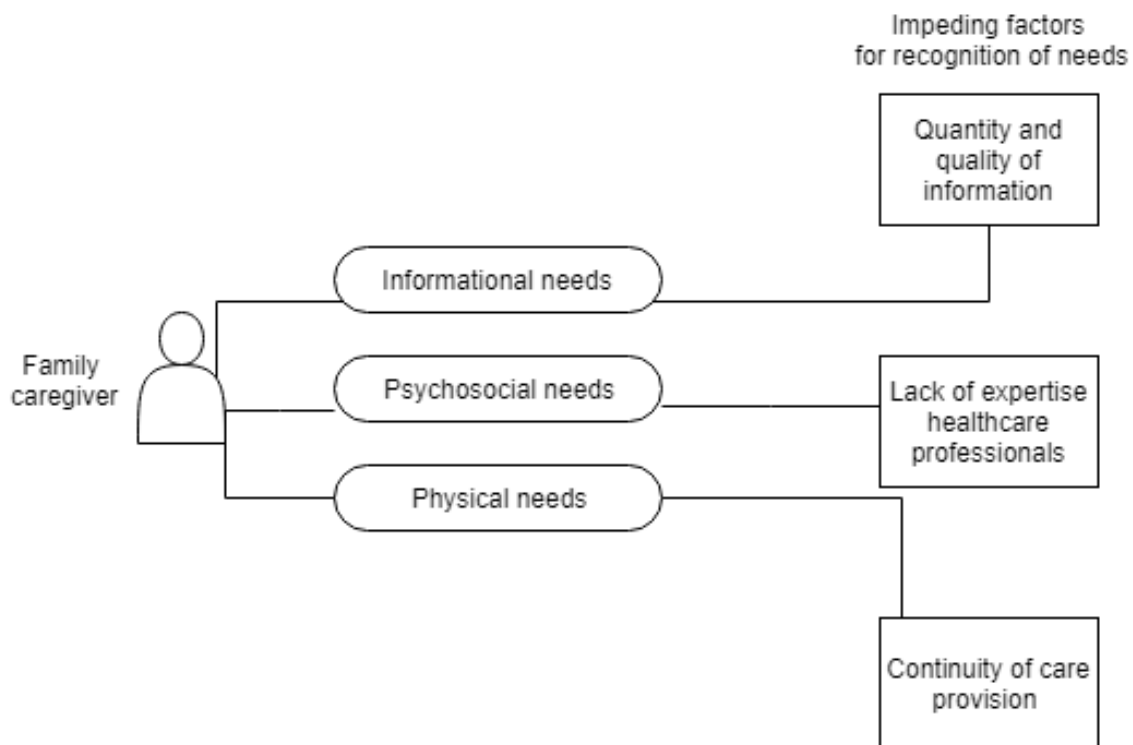


Figure 1. Visualisation of the link between the palliative care needs and impeding factors following the existing literature.

3. Methodology

3.1 Ethics

The ethical committee of Maastricht University and the Mumc+ (METC) approved the study since the interviews do not harm the respondents. The following steps were taken to ensure a high ethical standard. Every respondent was sent an informational letter in advance of the interview. This letter informed them about the content of the interview. At the beginning of each interview, the researcher verbally appoints the information letter and asks the respondent to fill out the consent form (See Appendix 8.1). By signing this form, the respondents agreed on the facts that they have had at least one week to think about their participation, the data will be saved for a period of 15 years and that they have the opportunity to withdrawal their participation at any given moment.

All data were handled confidential according to the privacy legislation. The transcriptions were pseudonymized in a way the data cannot be traced to a specific person. The audio files of the interviews and other personal information are stored on a secured folder of Maastricht University. Only the researchers involved in the I-HARP project have access to this folder.

3.2 Research design

To answer the research questions two methods were implemented. The first was, in-depth interviews with family caregivers. This research makes use of semi-structured interviews since the strength of qualitative research is the ability to explore descriptions of how people experience certain issues. Starks & Trinidad (2007) argue that respondents for qualitative interviews are selected on the fact that they have experienced the subject under study and therefore provide rich data. The second method used were secondary data of two focus groups with healthcare professionals in the hospital setting. This data was used to identify the gaps between the experiences of family caregivers and formal caregivers working in a hospital. The details off both methods will be addressed separately.

3.3 Family caregivers interviews

3.3.1 Respondents

Inclusion criteria were that the family caregiver or the bereaved has or had a family member suffering from advanced heart failure. The New York Heart Association (NYHA) conducted a

classification of four categories according to the severity of symptoms (Figure 1). Patients are placed in a category based on the limitations they encounter during physical activity. Classes I and II result in no or slight limitations on physical activity and are not addressed in this research. The focus will be on classes III and IV, which result in discomfort during any physical activity or even at rest (New York Heart Association, 1964; Ponikowski et al., 2016).

Class I	No limitation of physical activity. Ordinary physical activity does not cause undue breathlessness, fatigue, or palpitations.
Class II	Slight limitation of physical activity. Comfortable at rest, but ordinary physical activity results in undue breathlessness, fatigue, or palpitations.
Class III	Marked limitation of physical activity. Comfortable at rest, but less than ordinary physical activity results in undue breathlessness, fatigue, or palpitations.
Class IV	Unable to carry on any physical activity without discomfort. Symptoms at rest can be present. If any physical activity is undertaken, discomfort is increased.

Figure 2. New York Heart Association functional classification based on severity of symptoms and physical activity (Ponikowski et al., 2016).

A worsening in symptoms indicate higher chances of hospitalization and death, and is an indication to seek medical attention and treatment. Classes III and IV are also labelled as the end phase of heart failure. Family caregivers and the bereaved of CHF patients with NYHA classes III and IV are the population of this study. Semi-structured interviews are held with a sample of this population.

In nine cases, the respondents were the patient's partner. Five interviews were combined, meaning that the patient was also involved in the interview. One respondent was the daughter of a CHF patient. For an overview of demographics of the respondents, see Table 1.

<i>Interview</i>	<i>Sex</i>	<i>Relation</i>	<i>Age</i>	
<i>Respondent 1</i>	Female	Partner	81	Individual interview
<i>Respondent 2</i>	Female	Partner	-	Individual interview
<i>Respondent 3</i>	Female	Partner	68	Combined interview with patient
<i>Respondent 4</i>	Female	Partner	-	Combined interview with patient
<i>Respondent 5</i>	Female	Partner	-	Combined interview with patient
<i>Respondent 6</i>	Female	Bereaved partner	73	Individual interview
<i>Respondent 7</i>	Female	Bereaved partner	43	Individual interview
<i>Respondent 8</i>	Female	Bereaved partner	56	Individual interview
<i>Respondent 9</i>	Female	Partner	86	Combined interview with patient
<i>Respondent 10</i>	Female	Daughter	62	Combined interview with patient

Table 1. Demographics family caregiver respondents

3.3.2 Data collection

The respondents were recruited from general practitioners and nursing homes within the two consortia of Maastricht University Medical Center+ (MUMC+) and Radboudumc. The respondents are introduced to the research by their general practitioner or the heart failure nurse of the patient. Thereafter, the researcher contacts the respondent to further elaborate on the research and possibly plan an appointment for the interview. The interviews took place at a location of the participants' choice. This was for most participants their own home because this is a familiar environment. The interviews had a duration of at least 1 hour.

3.3.3 Procedure

The researcher used a topic list that is composed prior to the interviews and is the same for each respondent (See appendix 8.2). The question for the bereaved respondents were formulated in a slightly different way as with current caregivers (e.g. past tense). Directly after each interview, the researcher made field notes. This means that striking features about the interviewee, the setting and the interview were written down. No new participants were approached when data saturation appeared. This means that no new insights were provided in new interviews.

After each interview was fully transcribed, the researcher send out an summary of the interpretations of the interview to the respondents. This so-called member check gives the respondents the opportunity to agree or disagree on the interpretations.

3.3.4 Analysis

Two researchers were involved in the analysis of the transcripts. This was done to improve the intercoder-reliability. Intercoder-reliability refers to the process in which two independent researchers analyse the transcripts and compare their codes in order to get consensus (Lavrakas, 2008). Five interviews were coded on paper by two independent researchers. After the first interviews were analysed, the researchers came together in consensus meetings to discuss their findings. The researchers then agreed on a corresponding way of coding the interviews. For the analysis of the following interviews, one researcher coded the transcripts and the other researcher checked whether she agreed. If necessary, some additions were made.

For further analyses, Nvivo.12 was used. The research project of CAPHRI not only focuses on the family caregiver perspective, but also on the patient, general practitioner and hospital perspective. The project's aim was to be able to combine the patient and family caregiver perspective. To make sure these two perspectives could be placed under the same coding scheme, weekly meetings were held with the researcher of the patient perspective. After two meetings, it was decided to code for who should recognize the palliative care needs and when, where and how this should be done. This was done by using an interpretive analysis. The data were coded following an iterative, inductive process. The coding scheme was altered slightly after each meeting until the data of both perspectives could be placed in the coding scheme. For an overview of the coding scheme see Appendix 8.3 & 8.4, but reckon that not all codes were applicable for this thesis since it is also used for other research ends.

3.4 Focus groups with healthcare professionals from the hospital

3.4.1 Respondents

The focus groups were held with six to eight caregivers from the hospital. Details on the respondents can be found in Table 2.

Focus group 1	Position	Age	Focus group 2	Position	Age
<i>Respondent 1</i>	Nurse	63	<i>Respondent 1</i>	Unit leader nursing ward	45
<i>Respondent 2</i>	Employee cardiology	25	<i>Respondent 2</i>	Nurse and member palliative care team	55
<i>Respondent 3</i>	Cardiologist	66	<i>Respondent 3</i>	Specialized nurse	43
<i>Respondent 4</i>	Unit leader nursing ward		<i>Respondent 4</i>	Nurse	47
<i>Respondent 5</i>	Heart failure nurse	62	<i>Respondent 5</i>	Senior nurse and member palliative care team	30
<i>Respondent 6</i>	Cardiologist	33	<i>Respondent 6</i>	Cardiologist	
			<i>Respondent 7</i>	Cardiologist	56
			<i>Respondent 8</i>	Specialized nurse	46

Table 2. Demographics of respondents hospital focus groups

3.4.2 Data collection

The focus groups lasted approximately 2 hours and were held in the hospital setting.

3.4.2 Procedure

At the start of the focus group, the researcher leading the conversation posed a case to the respondents. This case was about a CHF patient and provided details on his symptoms and

mentioned his family caregiver that was struggling with his illness. The respondents were asked what palliative care needs they recognized. From this point, the conversation began and the respondents decided where they talked about. Sometimes the researcher intervened with a question.

3.4.3 Analysis

The secondary data of two focus groups were analysed by one researcher and coded in a separate Nvivo file. During the focus groups, the respondents talked about many other topics related to palliative care. Only the parts regarding family caregivers in the focus group were analysed. For the analysis, the same coding scheme as the family caregiver's data was used to identify whether the healthcare professionals addressed the same topics. One separate code was added, to show the fact that the healthcare professionals did not had consensus on what palliative care is.

4. Results

In the theoretical framework, some insights from the literature regarding factors that can influence the recognition of different palliative care needs were discussed. The results of this research, will provide more insight in several factors that influence the timely recognition of palliative care needs, with regards to recognizing and benefiting from palliative care, according to family caregivers. Based on the data, the factors will be divided in to impeding and facilitating factors for a timely recognition of palliative care needs. After each factor, the perspective of the hospital caregivers is mentioned to identify the gap between these two perspectives.

4.1. Impeding factors for timely recognition

4.1.1 Variation in needs to access information about the condition across actors

According to the data, respondents differ in the amount of information they would like to receive. The desire for information can be divided into two sub-categories; information about the disease and prognosis and information about palliative care and the end of life.

4.1.1.1. Information about the disease and prognosis

Respondents expressed a desire for more information about the disease of the patient with CHF. One respondent did not know what heart failure exactly was. Others needed more information on the disease course and prognosis. They desired information on the status of the patient and wanted to receive a clear and honest update from healthcare professionals. A 56-year old widow regretted the fact that she did not receive enough information. For her, a lot of things were unclear and uncertain. She said:

“I thought by myself... What is going on? And only in a simple context. I’m not a cardiologist or a nurse. No I’m not. I really missed that then, to be able to put in simple language what is going on with the heart. And in my case I wasn’t informed well enough about what was going on. That is why I thought it was important.”

Respondent 2, a current family caregiver expressed her wish to get more updates on the status of the patient.

“Just say, it does not have to be extensive, but just update us in 5 minutes about where we stand and what we can expect. That would be usefull every now and then.”

This respondent was dissatisfied about the fact that she sometimes did not hear anything from a healthcare professional during the time her partner was hospitalized.

4.1.1.2 Information about palliative care and the end of life

Next to the need for information about the disease and prognosis, there was also a shortage of knowledge regarding palliative care. Some respondents did not know what palliative care is.

They were not aware of a palliative phase in which you could have gotten support.

They wanted more clarity, because they often did not know what to expect in the future.

Respondent 3, a 68-year old current family caregiver said:

“I would have appreciated more explanation about how our lives would be affected and about which limitations we would have to face.”

So this respondent did not know about a palliative phase and what to expect in the future. Only one 43-year old bereaved caregiver was made aware of a palliative phase, but she was not offered guidance or support.

*“If I recall correctly *name cardiologist* said it’s just not going to get better. You are going to have to live with what you got now. We have to hope to maximize quality of life. But that conversation never led to an offer to talk to someone about this. To talk about it or anything. No.”*

From the data it became clear that almost all respondents desired more information and clarity. One exception was respondent 1, a 81 year old family caregiver who mentioned she does not want to know anything about the progress of the disease of the patient because that will cause her too much worries and stress.

The impeding factor connected to the need for information is the fact that it might vary between the family caregiver and the patient. In some cases, the family caregiver wanted to know more about the prognosis and status then the patient, or vice versa. Several respondents mentioned that their partner was very closed and did not talk about their illness or feelings. This can cause friction between the patient and family caregiver and impede on family

caregiver's expression of needs. The partner of respondent 8, a 56 year-old widow, was very closed. He did not want her to know anything to protect her from worrying. She said:

“It was so hard. My husband really did not want to talk about it. He also did not want me to have separate conversations with nurses or doctors to gather information about him. That made it really hard. I did it once, and he found out about it. He said to me: “I really do not want that you talk with them behind my back”.”

But I do know that the most important thing for him was that I was burdened as little as possible. I know that for sure.

Because this respondent was not allowed to talk about healthcare professionals about the disease of her husband, she did not talk to anyone about her own needs and feelings. Some patients do not want their family caregiver to collect a lot of information about the prognosis, just to protect their loved ones from worrying too much.

Hospital perspective

The respondents of the focus groups mentioned that the patient's wishes with regards of receiving information can differ from those of the family caregiver. This makes it hard for healthcare providers to recognize who wants to hear what. Family caregivers can for example take a dominant role and lead the conversation by deciding what the patients gets to know or vice versa. Resulting in the fact that healthcare professionals have to observe carefully what is being said by whom. A 66-year old cardiologist mentions that it can be difficult to include family in conversation.

“Sometimes you have a recalcitrant family member, that cannot accept the status of the patient. They go against everything I say and thereby deprive the patient of its opportunity to say something.”

Despite of the complexities family caregivers can bring, the respondents do see the benefit of involving them in conversations with the patient. A 25-year old cardiology employee mentioned:

“If they would join in more often they would have regular feedback and you would later on not have as much family conversations that people request. They would be more informed and that would unburden us too.”

4.1.2 Actively asking and searching for information

Family caregivers state they have to search and ask actively to gather any information because they are not satisfied with the amount of information they receive from healthcare professionals. Therefore, they mention their role of actively asking or searching for information. Respondent 3, a 68 year old woman who’s partner was also involved in the interview reports that:

“We’ve talked occasionally by my request, I insisted. Had I not asked it would not have happened. You really have to push to get some information especially when the kids are involved, I’d like them to hear it too. They should really provide this information by default. Not everybody asks.”

This role impedes them from expressing their needs in time, because they first have to make effort to get their desired information.

The hospital perspective

The respondents mentioned that most family conversations are done at request of the family caregiver. Next to that, they do not mention anything else about family caregivers having to search actively for information.

4.1.3 Lack of time and attention for family caregiver

The lack of time and attention of healthcare professionals are mentioned by the respondents as factors that impede them in expressing their needs.

They have the feeling that healthcare providers are too busy to make time for them and the patient. They report that they can feel the time pressure during an appointment. Because of this lack of time, the family caregivers feel that there is often no time to talk about their well-being or needs. This factor impedes the chances recognizing any palliative care needs since family caregivers will not open up if they have the feeling that there is no time available for them. Respondent 10, a 6-year old daughter of a CHF patient said was actively involved in the care her mother received in the nursing home and said:

“I think it goes for everyone in healthcare, not just my mother. The staff shortage causes the time for the patients to be minimal. Sometimes I notice they would like to make conversation, they tell me it happens. But it is so rare.”

Next to time, the lack of attention for the family caregiver is another impeding factor. Respondents state that they often feel alone and neglected by formal caregivers. They say that all the attention goes to the patient, and the family caregivers are forgotten. Several respondents mentioned that it is important to ask about the family caregiver as well because it makes them feel valuable and appreciated. An 81-year-old woman took care of her former partner who passed away and now she was taking care of her new partner with heart failure. She emphasized on the fact that the family caregivers get no attention of the healthcare professionals.

“Nobody ever asks about the person accompanying the patient. “How do you feel?” They never ask. I think the accompanying person also deserves some attention and care. But they don’t really provide this. “How do you feel madam?” No... They don’t have to do this all the time. Even if they say: “How are you feeling, Do you know how to handle this?” only once... But they never ask these questions. They only ask about the patient.”

Respondent 2, a current female family caregiver, also experienced this lack of attention of the healthcare professionals but also in her personal environment nobody asked about the well-being of the family caregiver:

“It doesn’t have to be every day of course. But once in a while it can be good to hear. Like for example: “He is doing such and such... But how are you feeling about this?” I don’t show anything. For him it is obvious, but not with me. Many people tend to forget that. I have mentioned this to several people.”

This family caregiver felt alone and isolated because no one asked about her.

Hospital perspective

The healthcare providers from the hospital agreed with each other on the fact that most of their attention goes to the patient. They all mention that they do not have enough time to focus

their attention on the family caregiver. Others state they should make time for it, because it is of great value that they involve the family caregiver in the process. A 66-year old cardiologist mentions that he does not have enough time to have elaborate conversations with family caregivers, because he has to see 23 patients in three hours' time.

“The atmosphere in the hospital was like: the less I ask, the less they have to answer, the faster I can walk by and go to the next room.”

Despite the fact that they almost all agree that they have too little time, some do mention the value of making time for the family because they then will be better informed.

4.1.4 Lack of expertise of healthcare professionals regarding palliative care

Family caregivers noticed that many formal caregivers do not want to talk about palliative care. They feel that healthcare professionals avoid giving clarity about the status of the patient because they lack expertise in having palliative care conversations. Others think that healthcare professionals too soon assume that everything they say is understood by the family. Respondent 7, a 43 year old bereaved caregiver had a similar experience during a family conversation with the children of her partner involved:

“When the conversation with the cardiologist ended I said: ‘Okay, let’s make one thing clear: It really isn’t looking good for him.’ She said: No, that is obvious. But I thought: it isn’t that obvious. I wonder whether she realised that it was not obvious at all for his children at that moment. Maybe she did realise it but she thought: If they do not specifically ask me, I do not have to say anything.”

The respondent expressed her discontent about this situation since she had wished for more clarity from the cardiologist. More expertise in these kinds of conversations may result in better communication skills of healthcare professionals regarding palliative care.

Hospital perspective

In both focus groups, the respondents asked themselves whether they know what or when the palliative phase is. In the second focus group, a 45-year-old unit leader of the heart ward in the hospital posed the following question:

“But, do we actually know, maybe you guys have the answer and I don’t. But when do we speak of the palliative phase? Is that at the time of the diagnosis? Because then we already know the patient is not getting better. Or is it somewhere later on in a so called, grey moment? Because we can all explain and mention the terminal phase, but do we talk about the palliative phase?”

They concluded that they did not had consensus, and that there is a grey area in which it is hard to determine what a patient and its family want to know.

The respondents mentioned that they, as professionals, find it hard to determine whether someone wants to talk about palliation or not. In one focus group, a respondent posed that healthcare providers use the fact that they do not have time as an excuse to talk about palliative care because they find this hard.

“Yes, those are real tough conversations. If we ask them: “Did you think about it already, what you want when the situation is getting worse?”. I think these are conversations many healthcare professionals avoid.”

They were aware of their lack of knowledge and experience in this field and requested more education or training in conversation techniques to recognize needs of patients and their families.

4.2 Facilitating factors for timely recognition

4.2.1 Having the same care provider

Respondents indicate that it is important that a healthcare provider knows them and the patient. Not only the physical, but also the mental part. It is important that healthcare professionals have the overall picture. They find trust and knowledge about the process important. If you trust your healthcare providers, family caregivers mention they would discuss their needs and thoughts sooner. Another benefit of having the same care provider is the fact that he/she knows you and can signal changes and needs. Having the same healthcare provider is a facilitating factor for recognizing the needs of family caregivers. Respondent 7, a 43 year old bereaved caregiver said:

“And we noticed that too, about the cardiologist. You see this person every month for six

years. A bond of trust forms naturally. They know so much more about you than just your heart disease. It influences your private life.”

She felt more comfortable to talk her feelings with this cardiologist and heart failure nurse because she trusted them throughout the years.

Hospital perspective

Respondents from both focus groups agree that they find it difficult to find a moment to start talking about palliative care. A 62-year-old heart failure nurse said:

“If I do not know these people, that keeps me from starting the conversation and sorting out their situation.”

Other respondents agreed on the fact that having a relationship with the patient and family is beneficial because conversations about palliative care are loaded. A 43 year old specialized heart nurse said:

“It depends on the relationship if someone visits the hospital for the first time or the second time. You are still feeling it out. If somebody visits you for years and they run into problems you know how to get a reaction from them or how to talk to them. At least I feel that way.”

When healthcare providers have a relationship with these people, they feel more comfortable to talk about it with them

4.2.2 Timing and setting

The respondents mentioned that the timing and setting of conversations can influence their willingness to express their needs to formal caregivers. Some respondents emphasized on the differences between the hospital setting when the patient is hospitalized and the home setting when the patient gets discharged from the hospital. In the hospital, all care for the patient is arranged, and at home, they have to do it all alone again. After discharge from the hospital, family report to be in greatest need of support. Respondent 2, a current female family caregiver said:

When he gets to go home, just ask me: ‘Can you deal with it? What can you do? What can’t you do?’ That would be helpful. Now they think: He is home, just figure it out.”

The moment after discharge could be the best moment to recognize possible needs of family caregivers.

Healthcare professionals should allow for the privacy of the patient and the family caregiver. Respondents expressed their displeasure with the fact that sensitive conversations were held in the hospital room with other people around. To the question whether the family caregiver should be involved in the conversation or not respondent 4 answered: ,

“Yes, certainly. But not in a room where other patients are. We, certainly I, was shocked at the way they asked it in the room.”

Hospital perspective

Respondents mention they find it hard to determine when to start talking about palliation. One focus group ends with a conclusive statement regarding the problem of timely recognition of needs of family caregivers by a 66 year old cardiologist:

“I find it very difficult to make clear what the biggest issue is. You see, I think that is very difficult. Because all kinds of things are involved: Lack of education, time pressure, lack of beds, irregular staff and management issues. You know, it is a combination of issues. That’s why I think it’s very hard to pinpoint the problem.

You mentioning all these issues, it’s all relevant. They can all be the cause of it not happening and you have to prioritize.”

This quote summarizes the findings of this research, since there are multiple factors at stake that can influence the timely recognition of palliative care needs among family caregivers.

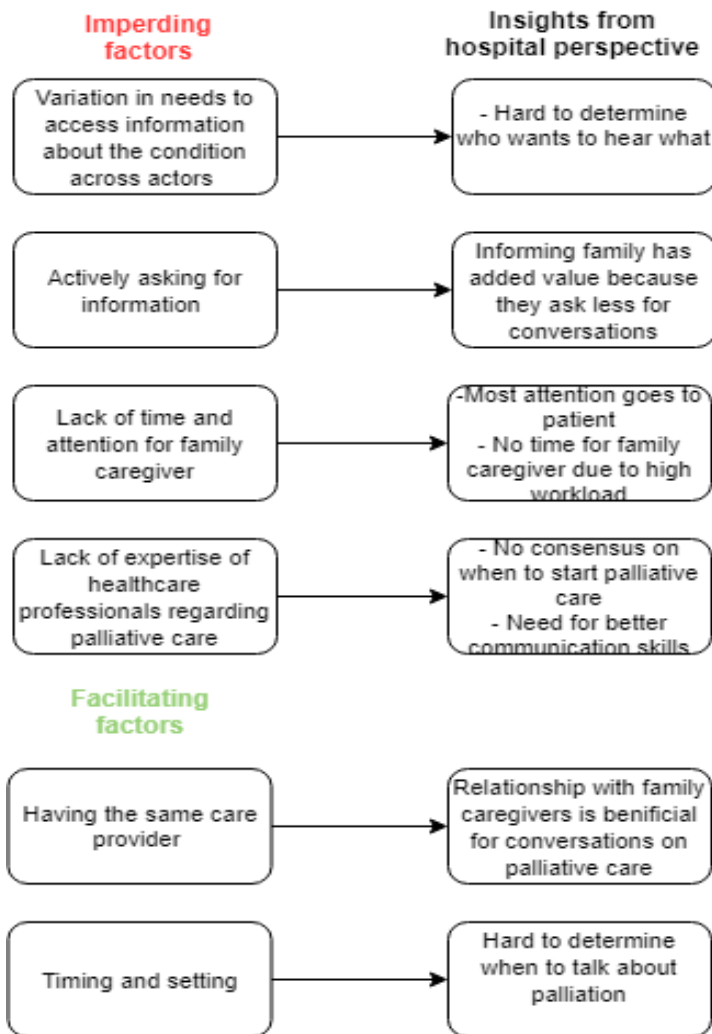


Figure 3. Overview of the impeding and facilitating factors for timely recognition of palliative care needs according to family caregivers and the experiences of healthcare professionals in the hospital.

5. Discussion

The aim of this research was to explore what factors impede or facilitate a timely recognition of palliative care needs among family caregivers and to identify the gap between the family caregiver's experiences and the current situation from a hospital perspective.

This study contributes to the existing knowledge regarding palliative care in the field of heart failure, since it was able to address the family caregivers point of view and combine it with the experiences of healthcare professionals in order to identify the gaps.

The findings show a clear link between the theoretical notions and the experiences of family caregivers. The healthcare professionals from the hospitals mostly had similar views on the cases. Some of the most noteworthy results will be discussed in the following.

Trigt, Dijkhoorn, van de Camp, Douma and Boddaert (2017), found that caregivers lack basic knowledge about the patient's condition and palliative care in general. This lack of knowledge among family caregivers was also a striking finding of the current research. Important in this finding is the fact that patients and family caregivers can differ in their needs for information, which makes it hard for healthcare professionals to recognize who wants to know what. The hospital perspective did mention the benefits of informed family members. Family caregivers that are informed properly, will request less family conversations with healthcare professionals and thus ask less time from healthcare professionals. This is valuable since healthcare professionals often lack time for their work.

This lack of time of healthcare professionals is experienced as impeding factors for recognizing needs by family caregivers. Not having the opportunity or time to open up to a healthcare professional, will impede the chances of expressing and thus recognizing the needs of family caregivers. Previous research did not mention the lack of time as an important factor. In the current research, both family caregivers and healthcare professionals mentioned the lack of time as a problem.

Another striking finding is that the family caregivers miss attention from healthcare professionals. Previous research of Proot et al. (2003), concluded that healthcare professionals are not sensitive enough to the family caregiver in the process of palliative care. The Healthcare professionals in the current study also mention that they predominantly focus their attention to the patient with heart failure, because they have no time for the family caregiver. The family caregivers stated that a simple question regarding their wellbeing would have been satisfactory. Asking someone how they are feeling, does not have to take a lot of time. Healthcare professionals should be aware of the fact that family caregiver are also an

object of care, and not only the patients (Proot et al, 2003). The findings of the current research are in line with previous findings by Boddaert et al. (2017) that show that healthcare professionals should ideally pay attention to the family caregiver in order to identify certain needs and wishes in order to prevent burdens. However, this research adds to the existing knowledge that healthcare professionals can use the lack of time as an excuse, since they find it hard to talk about palliative care because they lack expertise in the field of palliative care communication.

This lack of expertise is another impeding factor according to the family caregivers and is also mentioned by the healthcare professionals. Family caregivers noticed that healthcare professionals have trouble in talking about palliative care. The existing literature states that healthcare professionals do not like to talk about palliation and dying with patients and their family because they lack communication skills in this field (Christakis, Smith, Parkes & Lamont, 2000; Hudson, Aranda & Kristjanson, 2004). The current research showed that there is no consensus on when to start palliative care among healthcare professionals. They even requested education in communicating about palliation.

Another notable finding is the fact that family caregivers mentioned having the same care provider is a prerequisite for opening up towards a healthcare professional. The striking part is that healthcare professionals also mentioned this as an important factor. Previous research was unable to underpin these aligned experiences by both actors (Hudson, Aranda & Kristjanson, 2004).

From the hospital perspective it became clear that the greatest gaps seem to lie in the lack of time, attention and expertise of healthcare professionals.

While this study adds to the existing knowledge, a few limitations need to be addressed. A first limitation is that the current study has a sample size of family caregivers with little ethnic and gender diversity. All ten family caregivers in the sample are female. However, research of Collins and Swartz (2011) has shown that family caregivers are often women with an average age of 46 years old. Future studies should expand the study population, targeting also men and other ethnic groups. This will be beneficial for the generalizability to larger populations.

A second limitation is the fact that the focus group data was secondary. The coding scheme of the interviews with family caregivers was used to analyze the data of the focus groups, meaning that the focus groups did not sequentially follow the interviews. Even though, the data was rich enough to find many similarities between the facilitating and impeding factors that family caregivers had mentioned and the experiences of healthcare

professionals. Future research could focus on repeating the current research with a sequential design to explore whether this will provide richer data.

6. Future directions

The main goal of these future directions is to improve the timely recognition of palliative care needs in family caregivers of patients with CHF. To effectuate this goal, the impeding factors for recognition need to be limited and the facilitating factors should be enhanced. Based on the existing literature, examples from practice and the findings of the current research, some policy recommendations are composed that can contribute to a timely recognition of palliative care needs. Some future directions in this section will be divided in recommendations for healthcare professionals that can easily be implemented and recommendations for policymakers that need higher order changes to be accomplished.

6.1 Explore differences in information preferences between patient and family caregiver

Healthcare professionals

Family caregivers can have different preferences regarding gaining information about the prognosis of the disease than the patient has. The healthcare professional should be aware of this fact because he has to monitor who wants to know what. The healthcare professionals need to mention it if they notice that patients and family caregivers have different preferences. By doing this, healthcare professionals can start a conversation and explore what they can do about it. Maybe the patient and family caregiver are not aware of the fact that they are not on the same page. Maybe the family caregiver wants to have a separate conversation with his/her General practitioner.

Policy makers

Policy makers should focus on designing tools that can inform patients and family caregivers in a simple way. The University of Twente has conducted an online course for family caregivers of patients with cancer. This course is aimed at informing and supporting family caregivers in order to let them deal better with the situation they are in (Wiersma 2017). According to the existing literature, the amount of web-based healthcare is rapidly increasing. Nearly one-half of caregivers use some form of technology to improve the quality of the care they provide (Collins & Swartz, 2011).

Based on this knowledge, policy makers should advocate for the development of an online information platform specifically for family caregivers of patients with CHF.

6.2 Family conversations to provide family caregiver with information

Healthcare professionals

The family caregivers in the current research expressed their wish for a clear update on the patient status. However, physicians are not allowed to talk about the patient's status without the patient's knowledge. The request for these updates arises from the family caregiver's lack of information (Hudson, Aranda & Kristjanson, 2004). Therefore, healthcare professionals should have more conversations with both the patient and the family caregiver and provide them with information. Important for this conversations is that they take place in a separate room to ensure their privacy. Healthcare professionals should be aware of the fact that family caregivers are in greater need of information and support during care transitions and towards the patient's end of life (Collins & Swartz, 2011). This can be a moment to recognize possible needs in family caregivers.

Policy makers

In order to enable the healthcare professionals to have more conversations with family caregivers, they need more time. Family conversations are valuable for healthcare professionals since they provide a moment to recognize possible needs in family caregivers and give the opportunity to inform the family caregivers. Giving family caregivers more information will provide them with an improved feeling of control and less anxiety, which in turn will address their psychosocial needs (Dochterty et al., 2008). Besides that, patients more often have unmet needs if their caregiver has more unmet needs (Deeken et al., 2003). So it is also beneficial for the patient with CHF. More time is needed because family caregivers mention they cannot open up since they experience a lack of time. Healthcare professionals also mentioned the fact that they just do not have time for the family caregiver. Due to the positive effects on both patient and family caregiver, that having more time entails, it is valuable to invest more money in palliative care in heart failure.

6.3 Paying more attention to the family caregiver

Healthcare professionals

A third recommendation for healthcare providers is to acknowledge the family caregiver in the care provision.. Research shows that involving the family caregiver in the process by

giving them attention and information, has positive effects on family caregivers' experiences (Hupcey, Fenstermacher, Kitko and Fogg, 2011). Paying attention to the family caregiver requires that the health professionals are aware that family carers are also the object of care, to see if support is needed (Proot et al., 2003).

In America, attention for the family caregivers has already been recognized as a public health priority, since family caregivers provide 80 percent of the care for the chronically ill (Collins and Swartz, 2011). It is time that healthcare professionals in The Netherlands get more awareness on the fact that the family caregiver is also the object of care. This can be done on a small scale, by just asking how the family caregiver is doing.

6.4 Education and training for healthcare professionals regarding palliative care (communication)

Healthcare professionals

Education and practical tools may make professionals more sensitive for the vulnerable position of family caregivers, even when these caregivers do not show their vulnerability. (Proot et al., 2003).

There is one well known tool for the assessment of needs of both patient and family caregiver in CHF. This so called: Need Assessment Tool: Progressive Disease- Heart Failure (NAT: PD-HF) is a one-page assessment tool that can be completed by health professionals in order to assess the palliative care needs of both patients and their primary family caregiver (Janssen et al., 2019). This tool was originally designed in Australia, but is widely implemented in other countries. Healthcare professionals should use this assessment tool more often, keeping the importance of the informational needs in mind.

Policy makers

As mentioned earlier, CHF can be characterized by a disease course that is hard to predict because life expectancies can vary between months and several years (Bellersen & Baltussen, 2018). Family caregivers have trouble in adjusting to this uncertain prognosis of the disease. Fitzsimons et al. (2019) argue that healthcare professionals should give sufficient information and support to family caregivers, despite the uncertainty of the disease. Since the healthcare professionals express that they find this difficult, more education is needed. Healthcare

professionals have to be trained better to have palliative care conversations. By doing this, all other future directions will profit.

6.5 Letting the family caregiver mention with whom they have the best care-relation.

Previous literature (Hudson, Aranda & Kristjanson, 2004), and the current research find that a good relationship between the healthcare provider and the family caregiver is beneficial for the expression of needs. People find it hard to open up to someone they do not know. Therefore, it can be helpful to let the family caregiver mention the healthcare provider in their network with whom they have the best relationship. Research of Herder-van der Eerden (2017), found that family caregivers have a trusted relationships with a small number of key health care professionals. A heart failure nurse can ask this for example during one of the first meetings after the patient is diagnosed with heart failure.

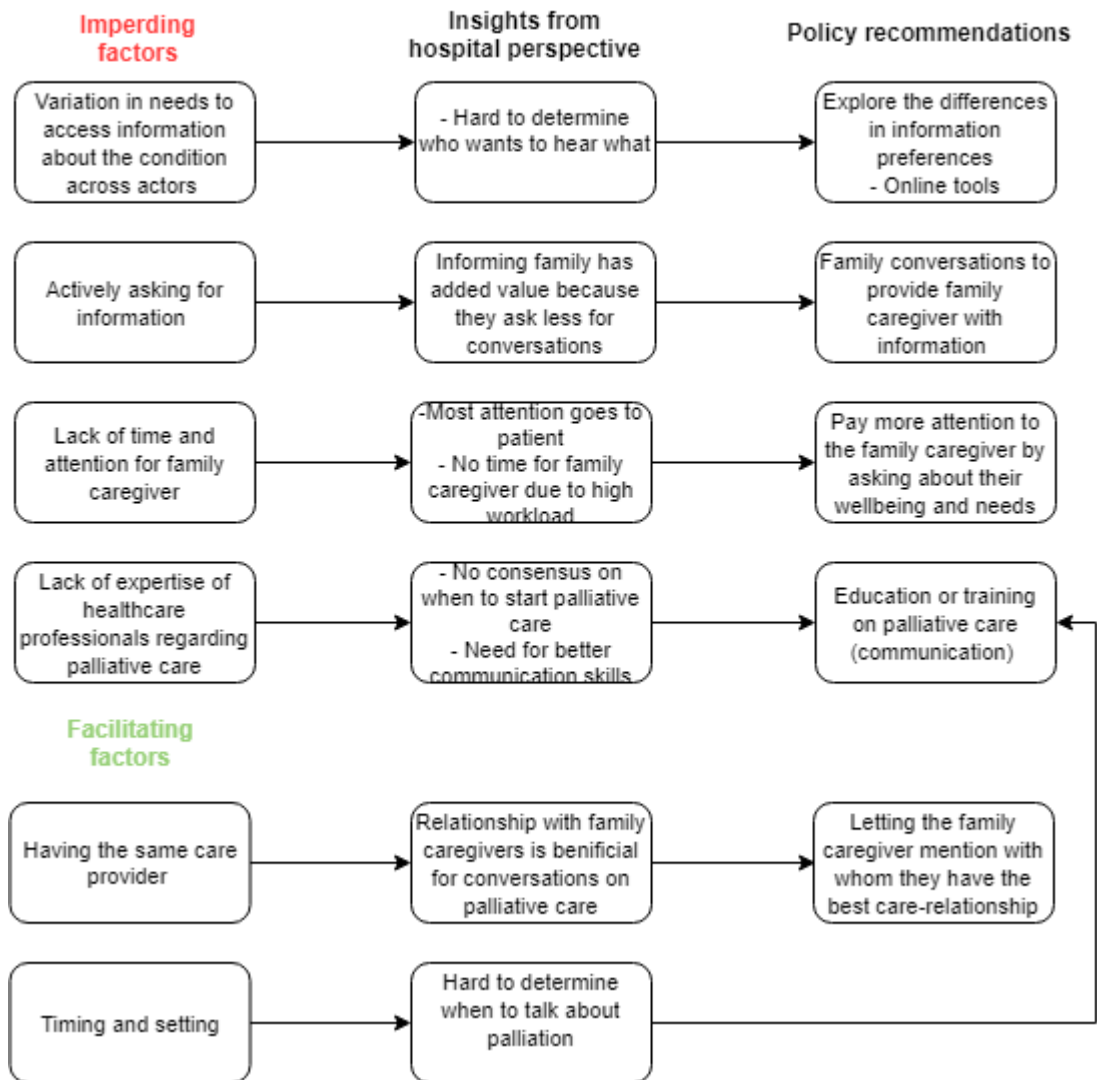


Figure 4. Overview of policy recommendations based on the results

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8. Appendix

8.1 Information for respondents & Informed consent

Geachte mevrouw / meneer,

U heeft bij uw zorgverlener aangegeven geïnteresseerd te zijn om deel te nemen aan een wetenschappelijk onderzoek. Allereerst danken wij u voor uw interesse. Voordat u de beslissing neemt om deel te nemen, is het belangrijk om meer te weten over het onderzoek. Lees daarom eerst deze informatiebrief rustig door en bespreek het eventueel met uw partner, vrienden of familie.

Het onderzoek gaat over het herkennen en beter tegemoetkomen aan zorgbehoeften van mensen met ernstig hartfalen

Palliatieve zorg is gericht op het verbeteren van kwaliteit van leven in de fase dat het hartfalen steeds moeilijker te behandelen wordt. Deze vorm van zorg heeft als doel symptomen te verlichten. Door palliatieve zorg eerder in het ziekteproces in te zetten kunnen symptomen worden verminderd en wordt de kwaliteit van leven verbeterd.

Zorgbehoeften zijn persoonlijk en het is dus per persoon verschillend wanneer palliatieve zorg gewenst is. Een instrument zal zorgverleners helpen bij het tijdig herkennen van palliatieve zorgbehoeften waardoor mensen met hartfalen betere zorg krijgen.

Het doel van het onderzoek is het maken van een instrument om zorgverleners te ondersteunen bij het herkennen van palliatieve zorgbehoeften

Het instrument zal zorgverleners helpen bij het tijdig herkennen van zorgbehoeften en het inzetten van passende palliatieve zorg bij mensen met hartfalen. Om dit instrument te maken willen we graag weten hoe een zorgverlener dit volgens u het beste kan doen. In een latere fase van het project gaan we het instrument inzetten in de dagelijkse praktijk.

De onderzoeker wil graag met u in gesprek over uw ervaringen en ideeën

De onderzoeker zal naar u toekomen voor een gesprek. Door ons over uw ervaringen te vertellen, kunt u meehelpen de toekomstige zorg te verbeteren. Er zijn geen goede of foute antwoorden. We willen juist graag van u leren. Het gesprek duurt een uur.

U beslist zelf of u wilt meedoen aan het interview

Uw deelname is geheel vrijwillig en u kunt op elk moment besluiten dat u wilt stoppen. U hoeft daarvoor geen reden te geven.

U kunt voorafgaande het interview uiteraard vragen stellen. Als u de informatie heeft begrepen en hiermee akkoord gaat, vragen we u op de dag van het interview de bijgevoegde formulieren te ondertekenen. Eén exemplaar mag u zelf houden.

Mogelijke voor- en nadelen

Uw verhaal draagt bij aan onze kennis en daarom is uw deelname heel waardevol. We vragen hiervoor wel een moment van uw tijd (ongeveer 1 uur). Ook kunt u altijd aangeven als u pauze nodig heeft tijdens het interview. Vertellen over (bepaalde onderwerpen van) de zorg kan lastig of vervelend zijn. Geef u daarom gerust aan als u ergens niet over wilt praten. Door uw deelname kunnen we de toekomstige zorg voor mensen met ernstig hartfalen en hun naasten verbeteren.

Wat u tijdens het gesprek met de onderzoeker deelt, wordt vertrouwelijk verwerkt

We vragen u of we het interview mogen opnemen (geluidsopname). Ten behoeve van het onderzoek zullen uw gegevens gecodeerd worden en niet herleidbaar zijn tot uw persoon. Enkel het onderzoeksteam heeft inzage in de gegevens. De verzamelde gegevens zullen na afloop van de studie gedurende een periode van 15 jaar bewaard blijven. Wilt u uiteindelijk niet deelnemen, dan kunt u de toestemming voor gebruik van de gegevens altijd weer intrekken.

Mocht u nog vragen, opmerkingen of ideeën hebben bel of mail dan gerust

U kunt ons op werkdagen telefonisch bereiken op het nummer (0)43 38 81731 of u kunt een email sturen naar s.ament@maastrichtuniversity.nl.

Met vriendelijke groet en alvast hartelijk dank voor uw tijd.

Stephanie Ament (onderzoeker)

Department of Health Services Research
Focusing on Value-based Care and Ageing

Toestemmingsformulier (deelnemersexemplaar)**I-HARP project: – fase 1: ontwikkeling (interview naasten)****Een onderzoek over hoe zorgverleners palliatieve zorgbehoeften bij mensen met hartfalen tijdig kunnen herkennen en hieraan tegemoet kunnen komen**

Ik (ondergetekende) verklaar naar tevredenheid mondeling en schriftelijk (informatiebrief) geïnformeerd te zijn en geef hierbij toestemming om deel te nemen aan een interview voor het onderzoek naar hoe palliatieve zorgbehoeften bij mensen met hartfalen door zorgverleners herkend kunnen worden.

Ik ben in de gelegenheid gesteld om vragen over het onderzoek te stellen. Mijn vragen zijn naar tevredenheid beantwoord. Ik heb een week de tijd gehad om over deelname aan het onderzoek te kunnen nadenken. Het staat mij vrij om deze toestemming op ieder door mij gewenst moment (schriftelijk) in te trekken.

Ik ben me bewust dat deelname aan de studie betekent dat gegevens zullen worden verzameld en geregistreerd, en zullen worden bewaard gedurende 15 jaar na afloop van de studie. Alle gegevens zullen vertrouwelijk worden behandeld zoals vastgelegd in de geldende privacywetgeving.

Tekent u a.u.b. elk hokje apart na het lezen van de tekst, omcirkel wat van toepassing is.

1	Ik geef toestemming voor het verwerken van mijn gegevens in het kader van het I-HARP project. Mijn verwerkte gegevens worden na afloop van het onderzoek 15 jaar vertrouwelijk bewaard in een dossier.	JA / NEE Paraaf:
2	Ik geef toestemming voor het delen van mijn onderzoeksgegevens met derden, zoals onderzoekers of overheidsinstellingen voor wetenschappelijk onderzoek. Het onderzoeksteam van het I-HARP project zorgt ervoor dat de onderzoeksgegevens niet tot mij herleidbaar zijn.	JA / NEE Paraaf:
3	Ik geef toestemming om in de toekomst benaderd te worden voor de volgende onderzoekronde van het I-HARP project of een daaraan gekoppeld project/onderzoek.	JA / NEE Paraaf:
4	Ik geef toestemming om in de toekomst benaderd te mogen worden voor het verstrekken van extra gegevens ten behoeve van het I-HARP project.	JA / NEE Paraaf:

Achternaam en voorletter(s):

Handtekening deelnemer:

Datum: __/__/__

Handtekening onderzoeker:

Datum: __/__/__

8.2 Topic list

Introductie

Het onderzoek gaat over het herkennen en beter tegemoetkomen aan zorgbehoeften van patiënten met ernstig hartfalen. Bij ernstig hartfalen zal het op een gegeven moment moeilijker worden om de ziekte te behandelen (bijvoorbeeld door medicatie of een operatie) maar kan wel worden gekeken naar hoe symptomen kunnen worden bestreden. Dit heet ook wel palliatieve zorg, palliatieve zorg hoeft niet het einde van het leven te betekenen. Zorgbehoeften zijn persoonlijk en afhankelijk van wat er in uw leven toe doet, wat u echt belangrijk vindt.

- Interview duurt ongeveer een uur
 - Opgenomen
 - Geen goede /foute antwoorden
 - Ieder moment stoppen
-
- *Wat is op dit moment belangrijk in uw leven?*
 - *Besteden uw zorgverleners aandacht aan wat voor u belangrijk is in uw leven? (Of: weten uw zorgverleners wat voor u belangrijk is in uw leven?).*
 - *Wie zijn de zorgverleners voor u?*
 - *Wat vindt u **de belangrijkste vraag** die zorgverleners aan u moeten stellen?*
 - *Welke zorgverlener zou deze vraag moeten stellen?*
 - *Wat maakt dat u uw vragen wil stellen aan deze zorgverlener?*
 - *Waar wordt nooit naar gevraagd maar vindt u belangrijk?*
 - *Wat zou u weerhouden om te bespreken wat u nodig heeft?*
 - *Wat is uw grootste frustratie bij gesprekken over hoe het met u gaat?*
 - *Wanneer in uw leven als hartfalenpatiënt zouden deze gesprekken gevoerd moeten worden?*
 - *Waar wilt u dat deze gesprekken gevoerd worden (bijv. bij u thuis, op de poli in het ziekenhuis, in de huisartspraktijk, tijdens een ziekenhuisopname op de afdeling)*
 - *Is er een andere manier waarop u zou willen aangeven hoe het met u gaat?*
 - *In hoeverre heeft u mantelzorgers en familie om u heen? Maken zij zich zorgen om u? Maakt u zich zorgen om hen (indien niet eerder aan bod gekomen)*
 - *Als u aan uw toekomst denkt met uw hartfalen: maakt u zich ergens **zorgen** over?*
 - *Hebt u deze zorgen besproken met uw zorgverleners? (of kennen uw zorgverleners uw zorgen?)*
 - *Met wie zou u deze zorgen willen bespreken?*
 - *Als u deze vragen nog niet hebt gesteld, wat weerhoudt u dan daarvan?*

- *Wat is de belangrijkste tip die u voor uw zorgverlener heeft?*
- *Heeft u vragen of onderwerpen gemist tijdens dit gesprek?*
- *Hoe heeft u het gesprek ervaren?*

8.3 Coding scheme interviews

Name
1. Methoden en type vragen om te signaleren
1.1 Gesprek met patient
1.2 Gesprek met naaste
1.3 Virtueel, digitaal instrument
1.4 Observatie
1.5 Voorbeeldvragen
2. Factoren signaleren
2.1 Zorgnetwerk, rollen en signaleren
2.1.1 De HF VP
2.1.2 De huisarts
2.1.3 De cardioloog
2.1.4 Naasten
2.1.4.1 Signalerende rol naasten
2.1.4.2 Zorgrol naasten
2.1.4.3 Zelf actief vragen om gesprek, info
2.1.5 Wijkverpleging, thuiszorg
2.1.6 POH
2.1.7 WMO-consulent
2.1.8 Diverse
2.3 Wanneer, levensloop en triggers
2.3.1 Patient hoort dat hij, zij HF heeft
2.3.2 Patient heeft zorgen, groeien in symptomen, grijze gebied
2.3.3 Patient wordt vaker opgenomen, acute verergering status
2.3.4 Patient krijgt ICD, PM
2.3.5 Patient beseft dat die in een nieuwe HF-fase zit, moet inleveren
2.3.6 Patient gaat naar terminale fase
2.3.7 Patient is overleden
2.4 Tijd, aandacht, empathie van zorgverleners en privacy
2.5 Dezelfde zorgverlener - relatie, totaalbeeld
2.6 Deskundigheid van zorgverleners en complexiteit HF
2.7 Continuïteit en vangnet
2.8 Type patient, naaste
3. Patienten en naastenbehoeften
3.1 Behoeften van patient en middelen
3.2 Behoeften van naasten en middelen
3.2.1 Behoeftte aan informatie
3.2.1.1 Behoeftte aan informatie over ziekte, prognose, management, zorgverlening
3.2.1.2 Behoeftte aan informatie over PZ, zorgverlening en EOL
3.2.1.3 Informatievoorkeuren
3.2.2 Behoeftte aan psychologische ondersteuning
3.2.3 Behoeftte aan sociale steun
3.2.4 Lichamelijke (onder)steun(ing) en behoeften in dagelijks leven

8.4 Coding scheme focus groups

Name
1. Hoe. Methoden en type vragen
1.1 Gesprek met naaste
1.2 Observatie
1.3 Voorbeeldvragen
2. Factoren signaleren
2.1 Zorgnetwerk, rollen en signaleren
2.2 Setting en behoefte, waar
2.3 Wanneer, levensloop en triggers
2.4 Tijd, aandacht, empathie van zorgverleners, privacy
2.5 Dezelfde zorgverlener - relatie, totaalbeeld
2.6 Deskundigheid van zorgverleners en complexiteit hartfalen
2.7 Continuïteit en vangnet
2.8 Type patient, naaste
2.9 Type zorgverlener
3. Wat is Palliatieve zorg

