I-HARP in the routines of healthcare professionals

Integrating a tool to timely recognize palliative care needs in patients with advanced heart failure

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Abstract

Background: Patients with advanced heart failure have a high prevalence of physical and psychological complaints which has a negative impact on their quality of life. A tool called I-HARP was developed for healthcare professionals to facilitate timely recognition and direct personal palliative care needs for advanced heart failure to improve the quality of life. Feasibility research is needed to use I-HARP in hospital setting considering the roles of healthcare providers as part of the interdisciplinary context.
Aim: To explore the views of healthcare professionals in cardiology care regarding the use of I-HARP in practice by specialized cardiac nurses and heart failure nurses.
Method: This study used an exploratory single case study method. A non-probability sampling method was used to include cardiologists, specialized cardiac nurses and heart failure nurses from different hospitals in the Netherlands. Data was collected through focus groups and was coded inductively using conventional content analysis.
Results: Specialized cardiac nurses and heart failure nurses play a key role in the implementation and use of I-HARP due to more time with the patient and a more holistic view than cardiologists. I-HARP can already be used during diagnosis in the outpatient clinic and the inpatient clinic can serve as a place to mark the time to start using I-HARP. Barriers that healthcare professionals may face are lack of time, problems with communication, documentation, marking moments and creating awareness. However, the results also showed some practical solutions to these barriers. I-HARP can be used when medical and instinctive triggers have occurred, patients need to be prepared for the consultation and technical support is needed to document I-HARP. The use of I-HARP at an early stage will help raise awareness of palliative care among patients and healthcare professionals.
Conclusion: The insights gained from this study may be of assistance to support specialized cardiac nurses and heart failure nurses to incorporate I-HARP in their current routines. Starting I-HARP early in the disease trajectory will improve the quality of life of heart failure patients and will create more awareness about palliative care. To improve and extend the use of I-HARP in different working environments, an evaluation study on the use of I-HARP in practice is needed.

Table of content

1. Introduction

In 2019, nearly 240.000 people in the Netherlands were living with heart failure (HF), almost 38.000 people were diagnosed with HF for the first time and there were 32.687 hospital admissions for HF (de Boer, van Dis, Wimmers, Vaartjes & Bots, 2020). HF is a complex clinical syndrome which is defined as a pump function impairment of the heart with symptoms like tiredness, decreased exertion and shortness of breath. It is often accompanied by large disease burden, comorbidity, and a limited life expectancy (Ponikowski et al., 2016). HF mainly affects the elderly and because of the aging population and the improved medical treatment options, the prevalence of HF patients is expected to increase by 88% in the period of 2015 - 2040 (IKNL, 2018; Hilderink, Poos & Gommer, 2020). According to the New York Heart Association (NYHA), the severity of HF can be classified into four stages: (I) no limitations, (II) mild limitations, (III) major limitations in daily activity and (IV) severe limitations in any activity due to symptoms that may already be present at rest. Within five years after diagnosis 40-50% of HF patients die and after reaching stage NYHA III-IV 50% dies within one year (IKNL, 2018). In general, there is no cure for HF and most patients show rapid deterioration and are hospitalized at increasingly short intervals. However, patients can live a stable life for years due to medication. This unpredictable disease trajectory and poor prognosis makes it difficult for healthcare providers to talk to patients and family caregivers about the future of the disease trajectory, end of life scenarios, treatment goals and patient's wishes (IKNL, 2018).

Patients with NYHA III-IV heart failure (advanced HF) have a high prevalence of physical and psychological complaints which has a negative impact on their quality of life (QoL) (Blinderman, 2008; Janssen, 2008; Moens, 2014 & Alpert, 2016). Palliative care aims to improve the QoL for patients and their families facing any life-threatening illness (WHO, 2020). It consists of preventing and alleviating suffering, by means of early identification, careful assessment, and treatment of problems of a physical, psychological, social, and spiritual nature (IKNL, 2017). Palliative care can decrease physical and psychological complaints and leads to better documentation of patient's wishes and preferences. Furthermore, it can decrease medical consumption, hospitalization, and re-admissions, which can lead to reduced healthcare costs (IKNL, 2018). During the disease trajectory, palliative care considers maintaining the autonomy of the patient, the patients access to medical information and provides the patient with choice options (IKNL, 2017).

A palliative care team for HF can consist of a general practitioner, cardiologist, HF nurse, palliation specialist, psychologist/ psychotherapist, physiotherapist, and a

dietician. A palliative care team should work together to determine the patient's needs, goals and preferences, to manage pain and side-effects, provide medical and emotional support and to guide patients and their families through the healthcare system (van Staa, Visser & van der Zouwe, 2000). A Dutch randomized study showed that the combined deployment of a HF nurse and doctor at a HF outpatient clinic leads to a significant decrease in mortality and readmissions for HF patients (Bruggink-André de la Porte et al., 2007).

According to Goodlin (2004); McKinley (2004) and Metra (2007), palliative care should be an integral part of HF care. However, only a minority of people with HF across Europe receive palliative care. Merely 7% compared to 50% of cancer patients had their palliative care needs recognized (Sleeman et al., 2016). Also palliative care is often provided for a very short time, where the mean time from palliative care referral to death is less than 2 weeks (Beernaert et al., 2013). In contrast to other diseases, such as cancer, the separation between the curative phase and the palliative phase for HF is not very clear (IKNL, 2018). This is due to the fact that advanced HF can hardly ever be cured and the disease trajectory is unpredictable. Estimating life expectancy of patients with advanced HF, and therefore timely marking the last phase of life, is an important bottleneck in daily practice and often results in starting palliative care too late. Furthermore, practice shows that few consultations are requested by palliative teams in the Netherlands for HF patients. And if a consultation is requested, this often happens when life expectancy has decreased to one month or less (IKNL, 2018). Therefore, palliative care should be introduced early in patient's disease trajectory and expanded as the disease progresses. This could be accomplished by timely consulting advanced HF patients and by performing a needs and symptom assessment (Sobanski et al., 2020).

Several tools have been developed in the past decade to help healthcare providers identifying patients who have an increased risk of deterioration or death, and thus could benefit from the timely implementation of palliative care (IKNL, 2018). In a mixed-method study of Ament et al. (2020) a tool called I-HARP was developed for healthcare professionals to facilitate timely recognition and direct personal palliative care needs for advanced HF. Ament et al. (2020) suggests that feasibility research is needed for using I-HARP in hospital setting, general practice, and nursing homes. This feasibility research should include the healthcare provider's roles as part of the interdisciplinary context. As more evidence becomes available, arguments may be found to make the tool more usable for different disciplines. To address the next step of implementing I-HARP in hospital setting, this study proposes the following research question: How can a tool for healthcare professionals, to facilitate timely recognition of palliative care needs in patients with advanced heart failure, be used in the routines of specialized cardiac nurses

and heart failure nurses?

The aim of this study is to explore the views of healthcare professionals (HCPs) in cardiology care regarding the use of I-HARP by specialized cardiac nurses (SCNs) and heart failure nurses (HFNs) in practice. To achieve this, the following research objectives are proposed. First, the views on how and where to use I-HARP in the current routines of the SCNs and HFNs will be investigated. Secondly, the role of the SCNs and HFNs in using I-HARP as perceived by the HCPs will be explored. Finally, perceived recommendations of the HCPs on what is needed in hospital settings to use I-HARP in practice are identified. These research objectives will be approached using qualitative research. The views and experiences of the HCPs will be explored and used to gather in-depth insights into their perspectives. These views will generate recommendations for the successful implementation of I-HARP in the routines of SCNs and HFNs. The qualitative data will be collected through focus groups with cardiologists, SCNs and HFNs.

2. Theory and concept model

In this chapter the key concepts behind the problem statement and research objectives are defined and relationships between the concepts are explained. More background information about palliative care for HF patients, the importance of timely integrating palliative care and the tools that could be helpful are clarified in this section. Furthermore the roles of HCPs in palliative care are explained. Finally, the AACTT-framework used for this study is explained and converted to a conceptual framework.

2.1. Palliative care in heart failure

Palliative care is defined as care that improves the QoL of patients and loved ones who are dealing with a life-threatening condition or vulnerability. This type of care consists of preventing and alleviating suffering, by means of early identification, careful assessment, and treatment of problems of a physical, psychological, social, and spiritual nature (IKNL, 2017). The Dutch integral cancer center (IKNL) developed an evidence and consensus based guideline for palliative care that is intended to provide guidance to any healthcare professional involved in the care of people with advanced HF (IKNL, 2018). Palliative care regards dying as a normal process and intends neither to hasten nor postpone death, but offers a support system to help patients live as actively as possible until they die (Jaarsma et al., 2009). Palliative care uses a team approach and is applicable early in the disease trajectory, in combination with other therapies that are intended to prolong life (WHO, 2020). Jaarsma et al. (2009) identifies an old and new model for palliative care for HF patients (see figure 1) and three stages that are conceptualized to guide modelling of services for HF patients along their disease trajectory:

- Stage 1: Chronic disease management phase (NYHA I-III)
    - Goals of care: active monitoring, effective therapy to prolong survival, symptom control, patient and carer education and supported self-management.
- Stage 2: Supportive and palliative care phase (NYHA III-IV)
    - Goals of care: shift to maintaining optimal symptom control and QoL. A holistic, multidisciplinary assessment of patient and carer needs takes place. Opportunities to discuss prognosis and disease trajectory with professionals, including recommendation for completing an advance care plan can take place.
- Stage 3: Terminal care phase
    - Goals of care: symptom control is continued and resuscitation status is clarified. Increased practical and emotional support is provided, continuing to bereavement support.

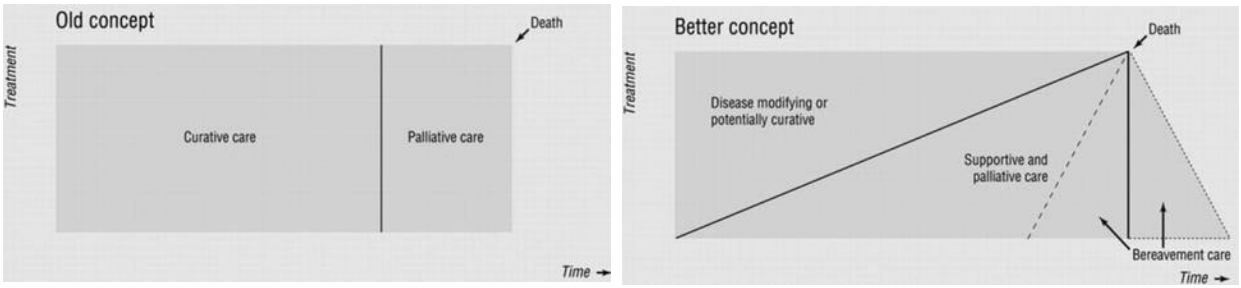

Figure 1: old and better concept for palliative care (Murray, Kendall & Boyd et al., 2005)

2.2. Integrating timely palliative care

In the past (see figure 1), palliative and curative care have been incorrectly regarded as contradictory options (Kavalieratos et al., 2014). It is no longer appropriate to think that palliative care should be initiated only in the end stage when HF care fails to fulfill patient's goals. Given the unpredictable disease trajectory of HF, waiting for a "trigger" event to initiate palliative care continues the false notion of palliative versus life-prolonging therapy. There are often multiple opportunities to consider integrating palliative care throughout the HF disease trajectory. Hospital admissions could be an opportunity to discuss goals of care and introduce possible palliative care, because the treatment routines of a HF patient may escalate in this situation (Kavalieratos et al., 2017). Furthermore, as the risk of mortality increases with each hospitalization, hospital discharge planning is an opportunity to discuss what is most important, what QoL means to the patient and family and under which circumstances they would and would not want life prolonging treatments (Yim et al., 2017). To facilitate optimal patient-centered care,

it is important that patient-reported outcomes, such as symptoms and QoL will be monitored regularly throughout the entire HF trajectory by primary care and/or cardiology care providers. But in practice, referral to palliative care is often done very late in the disease trajectory (Beernaert, 2013; Gadoud, 2014). There are several barriers to timely and adequately provide palliative care. For example, the misperception that palliative care should only be initiated at the end of life, prognostic uncertainty that results in avoiding discussions about future outcomes, and lack of training of HF clinicians in palliative care (Warraich & Meier, 2019). To facilitate the timely recognition of palliative care, an approach focusing on identifying palliative needs seems more appropriate than the recognition of a poor prognosis (Janssen, Johnson & Spruit, 2018 and Sobanski et al., 2020).

2.3. Tools to timely recognize palliative care needs

Several tools have been developed to support healthcare professionals in facilitating timely recognition of palliative care such as the Australian 'Needs Assessment Tool; Progressive Disease – Heart Failure' (Ament et al., 2021). The usefulness of this tool was limited for the Dutch healthcare setting and several disadvantages of the palliative care needs assessment were identified by HFNs. However, the HFNs recognized the value of a tool that meets the needs of Dutch patients, their families and health care professionals (Janssen et al., 2020). A mixed-method study of Ament et al. (2020) developed such a comprehensive tool called I-HARP (Identification of patients with HF with palliative care needs). This tool, approved by healthcare professionals, patients, and family members, is a promising guidance for healthcare professionals to timely recognize and direct palliative care needs in advanced HF (Ament et al., 2020). I-HARP contains an introduction with open questions to start the conversation, thirteen closed screening questions with additional follow-up questions and recommendations for action (see appendix 1). I-HARP is the first specific tool which is generally applicable and accessible to facilitate health care professionals from different disciplines. The needs-based and user-centered development of this tool may increase the chance for adoption in practice (Proctor et al., 2011).

2.4. AACTT framework

Designing implementation interventions to change the behaviour of healthcare providers requires a detailed specification of the behaviours that are targeted for change. This will ensure alignment between intervention components and measured outcomes (Presseau, McCleary & Lorencatto et al., 2019). Behaviour specification can help to clarify evidence-practice gaps and who needs to do what differently. In addition, it identifies barriers and

enablers and designs interventions. Ultimately, it provides an indicator to evaluate an intervention's effect on behaviour change. The AACTT framework can help to unpack the complexity and clarify the responsibility of all behaviours in organizational healthcare settings (Presseau, et al. 2019). AACTT is short for Action, Actor, Context, Target, and Time and allows for the allocation of 'who does what; to, for or with whom; when; where?' (see table 1). For example, the article of Versluis et al. (2020) provides a practical worksheet that incorporates the AACTT framework to effectively target barriers and enablers to facilitate healthcare professionals and researchers in the process of implementing an eHealth intervention. The AACTT framework will also be used in this study, which will be further explained by the conceptual framework.

Table 1: AACTT framework definitions (Francis et al., 2004)

AACTT domains	**Definition**
Action	A discrete observable behaviour
Actor	The individual or group of individuals who perform (or should/could) the Action
Context	The physical, emotional or social setting in which the Actor performs (or should/could) the Action
Target	The individual or group of individuals for/with/on behalf of whom the Actor performs the Action
Time	The time period and duration that the Actor performs the Action in the Context with/for the Target

2.5. Roles of healthcare professionals in palliative care

Many HF patients would benefit from the timely initiation of palliative care based on actual needs, which can be provided by all HF multidisciplinary team (MDT) members. However, the attention of healthcare professionals is often drawn to the prognostic indicators rather than the patient's needs (Hill et al., 2020). All healthcare professionals within the HF MDT are expected to be equipped, to some extent, in identifying clinical decline, initiating appropriate discussions, alleviating burdensome symptoms, negotiating supportive resources, and providing some elements of palliative care (Kavalieratos et al., 2017; Datla et al., 2019).

One of the most unique and essential aspects of palliative care is its interdisciplinary nature, that allows the team to deliver multidimensional care which addresses the complex care needs of patients (Hui, Hannon, Zimmermann & Bruera,

2018). The characteristics of an interdisciplinary palliative care approach are shared decision-making, responsibility, and leadership to support patients and their families. Figure 2 shows a layered model of team-based palliative care in the context of HF (Fendler, Swetz & Allen, 2015). This integrated and multidisciplinary model keeps the patient and caregivers central, while supported by layers of clinicians and healthcare providers. The main clinical team consist of primary care, cardiology, and palliative care. SCNs and HFNs play a key role in facilitating the provision of palliative care for patients with advanced HF (Johnson et al., 2012). SCNs and HFNs are central to effective HF care delivery as clinical navigators (Skrutkowski et al., 2008 & IKNL, 2018) and facilitate a patient-centered approach (Jaarsma et al., 2009).

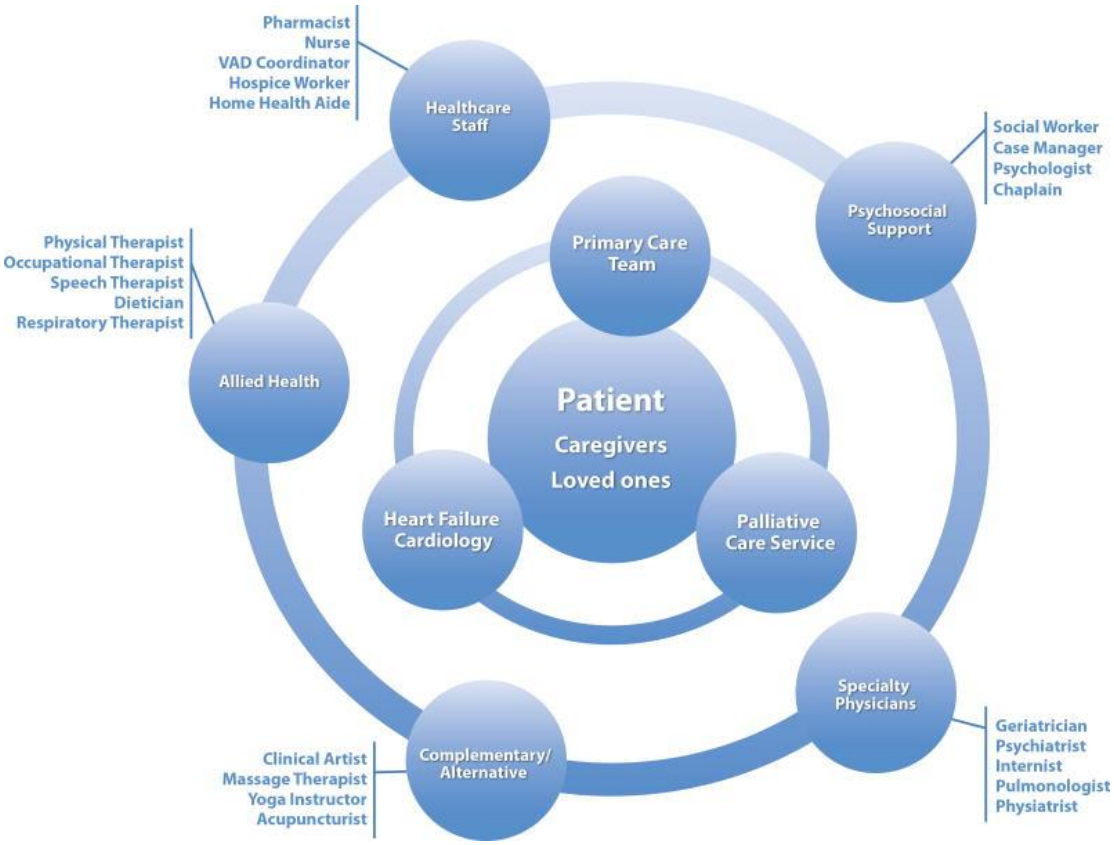

Figure 2: Layered model of team-based palliative care in heart failure

2.6. Conceptual framework

The following conceptual framework is developed to approach the research question of this study, using the above mentioned concepts (figure 3). The AACTT framework is the basis of this conceptual framework. It will specify the role of SNCs and HFNs (Actor) who need to change their behaviour in using I-HARP (Action) in their current routines (Context) during the disease trajectory (Time) of advanced HF patients and family members (Target) in a multidisciplinary context. By applying the AACTT framework, the

users of I-HARP and what could be changed in their current routines can be identified. Furthermore, the understanding of what is needed, what the challenges are and how to support the users of I-HARP can be explored. Applying this conceptual framework will help to achieve the research objectives of this study. This will eventually answer the question of how I-HARP can be integrated into the current routines of SCNs and HFNs and thus enable the timely identification of palliative care needs of HF patients.

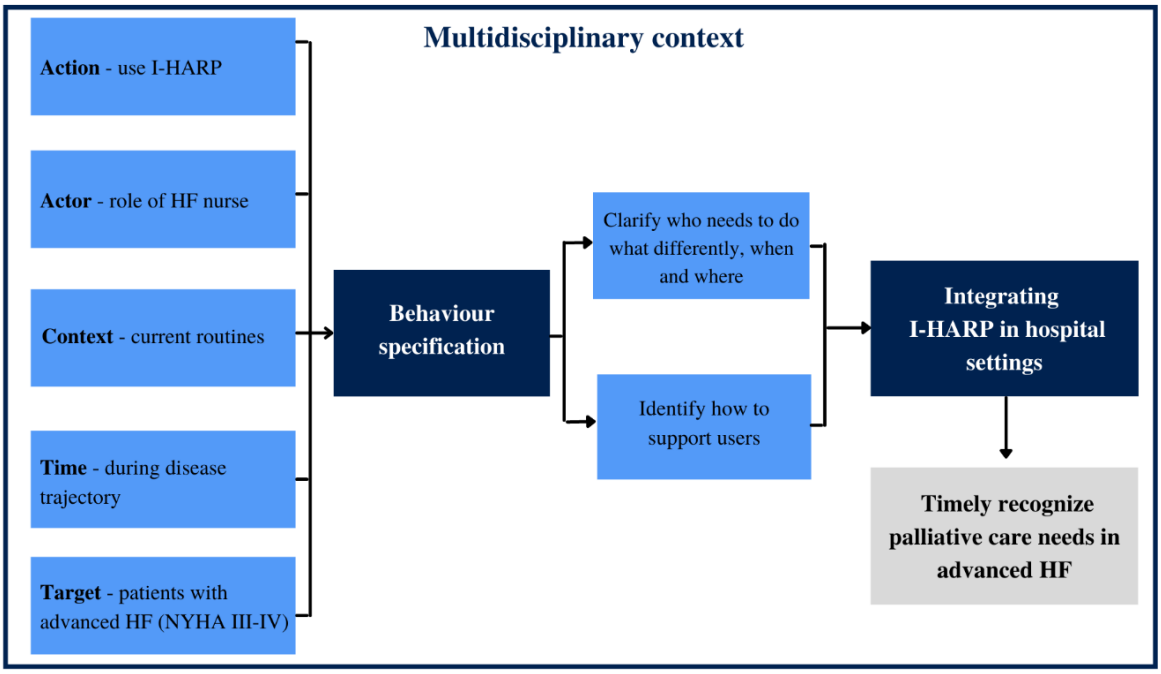

Figure 3: Conceptual framework

3. Methodology

The aim of this study was to explore the views of HCPs regarding the use of I-HARP by SCNs and HFNs in practice. To achieve this aim, this study used an exploratory single case study method to investigate the views of the HCPs in-depth and within its real-life context (Yin, 2003). In this chapter, the data collection, data analysis, trustworthiness and ethical considerations of this study are described.

3.1. Data collection

For this study, five focus groups with cardiologists, SCNs and HFNs from different hospitals in the Netherlands were conducted to collect data (see table 2). Focus groups were chosen to initiate discussion between the participants and to inspire each other. The focus groups were conducted in Dutch and online with Microsoft Teams, which was recommended by the University of Maastricht as a safe environment for online qualitative data collection (Autoriteit persoonsgegevens, 2020). If, based on the data analysis and

the level of data saturation, there was a need for more data, individual interviews would be conducted. However, this was not the case for this study.

A non-probability sampling method was used to only include healthcare providers from the cardiology departments of different hospitals (Summers, 1991). Therefore, purposive sampling was used as participants were selected based on the researchers' judgment of potential participants who were expected to be most informative (Moser & Korstjens, 2017). Each hospital was asked to inform cardiologists, SCNs and HFNs interested in palliative care about participating in this study. The participants would share experience in cardiology care but could have a different individual experience or view on how to use I-HARP in practice. When the dates and times for the focus groups were arranged, an invitation with a questionnaire about their background and an informed consent form was sent (see appendix 2 and 3).

A semi-structured topic list based on the conceptual framework was made to come up with open-ended questions to guide and start discussions in the focus groups (see appendix 4). During these focus groups, one researcher asked questions and led the discussions and another researcher kept track of time and made field notes. The focus groups were audio-recorded for data analysis purposes, for which prior informed consent was requested. To ensure that the focus groups ran smoothly and to prevent problems due to time constraints or problems with the questions, a pilot interview with a HFN was conducted. After each focus group the recordings were analyzed directly to identify and add topics that could be discussed more in depth for the next focus groups. By doing this, anonymously quotes from the previous focus groups and some more in-depth questions were discussed in the next focus groups. Also a summary of the discussed topics was sent to the participants after the focus groups. The participants were asked if the summary was correct or if it was still missing important topics. Participants could add things they forgot to mention and could indicate possible misinterpretations in the summary.

Table 2 Focus groups characteristics

Focus groups	**Participants**
Focus group 1	1 Cardiologist
	1 Physician assistant
	2 Specialized cardiac nurse
	3 Heart failure nurses
	2 Other*

Focus group 2	5 Specialized cardiac nurse
	1 Heart failure nurse
Focus group 3	3 Cardiologists
Focus group 4	4 Cardiologists
Focus group 5	3 Specialized cardiac nurse
	1 Heart failure nurse

*Management heart center

3.2. Data analysis

The qualitative data was analyzed by inductive coding to get a concise overview of the main points and common meanings that recured throughout the data. The data was coded inductively using conventional content analysis, where categories were created by breaking the data down into smaller units and coding and naming the units based on the content presented (Moser & Korstjens, 2017). This conventional approach provided direct information without imposing preconceived categories or theoretical perspectives and added new relevant codes to the coding framework (Hsieh & Shannon, 2005). During the analysis, missing analytical information was identified and used for data collection in subsequent focus groups until data saturation occurred.

First, the recorded focus groups were transcribed manually in a Microsoft Word document. Secondly, the data was coded independently by the researchers in NVivo 12 Pro [1] to examine the data for possible patterns or repeated ideas of the participants. Both researchers transcribed and coded half of the focus groups that corresponded to the professional perspective of their study. Although the transcripts were coded independently, the researchers used the same coding framework and checked and discussed each other's coded transcripts at the end. This coding framework was created by identifying various phrases and words that stood out as relevant or potentially interesting for answering the research objectives (see appendix 5). Going through the transcripts, new codes were added. After that, the researchers looked over the codes together, patterns among them were identified and codes were turned into themes that corresponded to the research objectives. In addition to the transcripts of the focus groups, the field notes were also coded. These were mainly used when non-verbal communication showed that other participants also agreed or disagreed with the person who was speaking at that time.

[1] NVivo 12 Pro is a qualitative data analysis software

3.3. Trustworthiness

The academic integrity of this study was maintained using the Dutch code of conduct for research integrity (VSNU, 2018). To prove the trustworthiness of this study, the following criteria were met: credibility and transferability.

To establish the credibility of this study, the following strategies were applied (Moser & Korstjens, 2017). Prolonged engagement was ensured by collecting data until saturation. Participants were therefor encouraged to support their statements with examples and follow-up questions were asked by the interviewer. Furthermore, data triangulation was assured by using multiple data sources from different professions (cardiologists, SCNs and HFNs) from different hospitals. To ensure method triangulation, data was gathered through focus groups and field notes. In addition, investigator triangulation was assured by including three researchers in the research team who conducted the focus groups together. The members of the research team consisted of two master students and one supervisor who is part of the I-HARP project. The two master students coded the data independently but checked each other's coded transcripts. The research team met regularly to reflect on the research process. The last strategy to establish credibility was a member check whereby a summary of the data from the focus groups was sent to the participants to check for authenticity, misinterpretations or missed information.

Transferability was assured by descriptive data such as the participants age, gender, profession, years of experience and experience with palliative care from the answers of the background questionnaire (Moser & Korstjens, 2017). In addition, the online setting, samples of different hospitals, the focus group procedure, the topic list and the data analysis method were provided to enable the reader to make a transferability judgement.

3.4. Ethical considerations and approval

As mentioned earlier, an informed consent form was included in the invitations for the online focus groups. In this form the participants indicated if they had been informed about the study and were aware and approved that the personal data will be used for this study in such way that it cannot be traced back to the participant and will be stored for 15 years. Also this form indicated if participants were aware and agreed that the data collection is fully anonymous, that the online focus groups were audio recorded for the data analysis and that withdrawing their participation at any time of this study is possible (see appendix 3).

To assure confidentiality, the collected and analyzed data of this research is stored

within the secure environment of the central IT system of Maastricht University. Furthermore, this study was not subject to the Medical Research Involving Human Subjects act and received a 'non-WMO' declaration from the medical ethical committee of the Maastricht University Medical Centre (MUMC+) (see appendix 6).

4. Results

This chapter presents the results of the data analysis based on the coded transcripts. First, the characteristics of the respondents are presented in a table. After that, the results of the focus groups related to the three research objectives are presented and supported by quotes from the focus groups.

4.1. Characteristics of the respondents

A total of 26 respondents from 9 different hospitals in the Netherlands participated in the five focus groups. Cardiologists, SCNs, HFNs and other professionals from different genders, age groups and experience levels participated in the five focus groups. Table 3 shows the characteristics of the participants. However, some values about age, years of experience and palliative care specialization are missing because these participants did not complete or return the background questionnaires. In addition, it became clear during the focus groups that there were 2 cardiologists and 2 SCNs who just started using I-HARP and already gained some experience with the tool. The other participants had not yet used I-HARP or did not even know of its existence before being invited to participate in this study.

Table 3 Characteristics of participants

Characteristics	**Number of participants (n = 26)**
Gender	
Female	22
Male	4
Age	
30 – 39	2
40 – 49	4
50 – 59	6
60 – 69	5
Profession	
Cardiologist	8

Physician assistant		1
Specialized cardiac nurse		10
Heart failure nurse		5
Other*		2
Years of experience		
1 – 10		5
11 – 20		7
21 – 30		4
31 – 40		1
Palliative care specialization		
No		16
Yes		1
Hospital	**Location**	
MUMC+	Maastricht	2
Zuyderland	Heerlen/ Sittard-Geleen	2
Laurentius	Roermond	2
Catharina	Eindhoven	2
Maxima MC	Veldhoven	2
Radboudumc	Nijmegen	2
Alrijne	Leiderdorp/ Alphen aan de Rijn	2
Dijklander	Purmerend	2
Isala	Meppel/Zwolle	10

* Management heart center

4.2. Use of I-HARP

This section will first explain in which hospital setting HCPs think I-HARP can be used. It will be discussed whether I-HARP can be used in the inpatient and/or outpatient clinic. This will be followed by a discussion on when SCNs and HFNs can use I-HARP and how these moments can be marked. Finally, this section will discuss how I-HARP can be integrated in the routines of SCNs and HFNs.

4.2.1. Hospital setting

Looking at the hospital setting, it was clear that application of I-HARP would be more efficient for SCNs and HFNs in an outpatient setting for three reasons. Firstly, because SCNs and HFNs can schedule more time for consultation. Secondly, the outpatient clinic

provides a private atmosphere where patients are more comfortable to speak. And third, the ability to start the conversation about palliative care earlier in the HF disease trajectory. However, SCNs and HFNs also indicated that there is added value in starting I-HARP already in an inpatient clinic because of two reasons. The inpatient clinic is a place to already discuss some options when patients are readmitted and some patients with NHYA III-IV are not classified in the outpatient clinic but only in the inpatient clinic. Although participants mentioned this added value of starting I-HARP in the inpatient clinic, SCNs and HFNs indicated that they do not have much time in this setting. Therefore, the possibility of training ward nurses was considered. Participants also mentioned that in an inpatient clinic more older and frail people are hospitalized. In this case, palliative care needs could be discussed too late or patients are not ready or able to talk about their needs at that moment. A participant mentioned that "*When a patient is readmitted, the inpatient clinic is a good place to already discuss some of the needs and gain experience with I-HARP. After that, the patient should come back to the outpatient clinic to apply I-HARP further.*" (Specialized cardiac nurse, 2021).

4.2.2. Moments to use I-HARP

When asked when I-HARP should be implemented and used in the routines of SCNs and HFNs, there were several answers. But it was clear that all participants agreed on the importance of starting earlier in the care process with identifying the palliative care needs of patients with advanced HF (Fieldnotes, all focus groups, 2021). Some participants indicated that I-HARP could already be helpful during the diagnosis of advanced HF. "*There are of course many questions that come up at a far earlier stage. That is where I could, of course, use the document as a thread throughout the treatment right from day one*." (Specialized cardiac nurse, 2021). According to a SCN the conversation about palliative care can become less loaded if this "loaded topic" could already be discussed during diagnosis and incorporated into the disease trajectory. However, a cardiologist reported that one should be careful about talking too much about palliative care needs already during the diagnosis. This is because patients who come in poorly can still recover well, so "*never be gloomy in early stages*" (Cardiologist, 2021).

4.2.3. Marking moments

The participants are aware that I-HARP should not be applied too late, but what has been mentioned several times is that the marking moment of using I-HARP is difficult and differs for each patient. Participants mentioned that it remains a complicated concept because some patients come in very badly but recover, and then do not see them again for a number of years. Furthermore, not all patients visit the outpatient clinic, which

makes it difficult for SCNS and HFNs to mark them. A participant mentioned that "*Someone will have to make a decision about it and this is different for every patient, it's just tailored care. When does palliation start for a heart failure patient? You say it. I don't know."* (Heart failure nurse, 2021). At that moment, many participants from this focus group shrug their shoulders which indicated that other participants also did not know (Fieldnotes, focus group 1, 2021). However, what was mentioned in determining when SCNs and HFNs can use I-HARP, is the deteriorating situation of the patient. Poor response to medications, low sodium level, decline in kidney function, but especially readmissions are prognostic markers to implement I-HARP.

"*A patient who has been readmitted many times, who responds poorly to diuretics, who has a low sodium, things like that are the medical markers and then you can check what the social situation is like. So that's the perfect time to start using I-HARP."*
(Specialized cardiac nurse, 2021)

Another trigger that was mentioned, which could be a reason to start using I-HARP, is the instinct of SCNs and HFNs. The longer SCNs and HFNs know or care for patients, the faster SCNs and HFNs pick up signals and sense whether the patient needs palliative care. *"And of course, I also think that we have to rely on our own knowledge and skills and I think that we can sense very well and also substantiate what stage of treatment a patient is in."* (Specialized cardiac nurse, 2021). Instincts of the SCNs and HFNs thus may play a role in marking the moment to apply I-HARP. However, participants indicated that medical markers give a better indication of the moment to apply I-HARP. Sometimes also patients themselves start the conversation about palliative care, or sometimes relatives give a signal to discuss the future care path in the outpatient clinic.

4.2.4. The integration of I-HARP

When the participants were asked how SCNs and HFNs should use I-HARP, there was often a moment of silence (Fieldnotes, focus group 1, 2 and 5, 2021). But after some discussion the participants indicated that I-HARP should definitely be integrated in the care pathways and the advance care planning[2] (ACP) of patients. It should be implemented in phases so that HCPs can provide much better tailored care for patients. "*I-HARP must become a phased process. It cannot be done all at once*." (Heart failure nurse, 2021).

[2] Advance care planning is the process of discussing and recording patient preferences concerning goals of care for patients who may lose capacity or communication ability in the future (Brinkman-Stoppelenburg, Rietjens & van der Heide, 2014).

4.3. The role of the SCNs and HFNs in using I-HARP

This section explains who is responsible for implementing I-HARP in practice and what the possible roles and cooperation between healthcare professionals are.

4.3.1. Key role for SCNs and HFNs

The focus groups showed that the question of "who is in charge?" is very important for the SNCs and HFNs. Participants mentioned that HF patients are treated by a lot of different healthcare professionals at the same time, so it is important to know who is in charge of the patient's palliative care, wishes and needs. Furthermore, one participant indicated that "*The ideal world for a heart failure patient is indeed to have a single contact person for this*" (Heart failure nurse, 2021). However, this is often not possible. When discussing who should take the lead, it quickly became apparent that the SCNs and HFNs have a key role to play in the implementation and use of I-HARP. "*I see myself almost as a kind of ambassador for this, to eventually spread the word*." (Specialized cardiac nurse, 2021). SCNs and HFNs have a good overview of the patient's disease trajectory and often know the patient best. SCNs and HFNs also have more time at the outpatient clinic to consult with the patient than cardiologists and have the ability and time to conduct ACP. In addition, SCNs and HFNs also see their role in bringing the option of no further treatment to the cardiologists' attention, were the use of I-HARP would be appropriate. The psychosocial aspects are something that SCNs and HFNs are particularly good at dealing with and a cardiologist is mainly involve to answer any medical questions or to substantiate SCNs' or HFNs' view on a case. The cardiologists in the focus groups also indicated that the key role should be with the SCNs and HFNs. Much of the preliminary work is done by SCNs and HFNs, they update and discuss results with cardiologists and make proposals. If possible, SCNs and HFNs also discuss with the cardiologists in advance whether a patient is a good candidate to have a conversation about palliative care. According to the cardiologists, SCNs and HFNs have a more holistic vision, more intensive contact with the patient, are more approachable and pay more attention to the patient. "*I think they have much more understanding than we do, much more feeling than we do. To look less at the organ and more at the whole person*". (Cardiologist, 2021).

4.3.2. Collaborations with other healthcare professionals

During the focus groups also collaborations with other healthcare professionals were discussed. Working together with the general practitioners (GPs) and home care to implement I-HARP and the communication with them was mentioned. SCNs and HFNs

mentioned that some GPs are very willing to take up the gauntlet with them, but there are also GPs who say "*no, you are in charge because you are with the outpatient HF clinic so that's your deal*" (Specialized cardiac nurse, 2021). SCNs and HFNs indicated that I-HARP could also be used to support GPs and home care with their patients. "*And I think that it is also certainly very good to have agreements with GPs, possibly practice support physicians or home care/ district nurses, that you divide those tasks*." (Specialized cardiac nurse, 2021). Efficient communication with the person primarily responsible for the patient is very important in this case to avoid duplication of I-HARP questions.

4.4. Challenges of I-HARP and their solutions

In this section, some barriers, but also solutions to these barriers will be discussed. This section will discuss the barriers that SCNs and HFNs believe may arise when applying I-HARP in their current routines. After each barrier, the possible solution or ideas that emerged from the focus groups will be described. Barriers and solutions around awareness, communication and documentation, expertise and time will be discussed below.

4.4.1. Create awareness

SCNs and HFNs mentioned that it is difficult to talk about palliative care with patients due to the lack of awareness among patients but also among healthcare professionals. Using I-HARP in an early stage could be helpful to make palliative care less loaded and create more awareness. Another thing that SCNs and HFNs mentioned is the need for a dedicated HF cardiologists who is aware that just continuing treatment is not always the best option and that not treating and starting palliative care is certainly an option as well.

"*That's where perhaps such an I-HARP can be very helpful. So that you discuss it, that you have given it a perspective, that it may not be for now. But if the situation deteriorates, you can pick it up again. Then you have mentioned it, and perhaps the sharp edges will have been removed, and it may be easier to say, "Well, hey, when the time comes, how would you see it?"*
(Specialized cardiac nurse, 2021)

4.4.2. Communication with healthcare professionals

Communication with other healthcare professionals about I-HARP and how to document I-HARP was a barrier faced by many participants. It is unclear for the participants how I-HARP should be documented correctly, how to communicate this to primary care and how to deal with the issue of time during documenting. SCNs and HFNs also face difficulty

with planning a multidisciplinary team meeting [3] (MDTM) with cardiologists due to time limitations. A participant mentioned that a lot of patients do not always come back to the same nurse and doctor, which indicates the difficulty of coordinating I-HARP in a multidisciplinary setting. During that discussion, other SCNs and HFNS also agreed with this difficulty (Fieldnotes, focus group 2, 2021).

"*I notice this in our nursing department as well. That it has already been discussed, but it has not been documented in the patient file. So the next time the patient is hospitalized, you will find that there is a different practitioner and that it cannot be traced back*."
(Specialized cardiac nurse, 2021)

To improve communication between healthcare professionals and documentation around I-HARP, several possible solutions were discussed by the participants. For example, technical support is needed to be able to briefly and clearly document I-HARP in the patient's ACP to prevent duplicated questions. According to participants, it is important that all patient's caregivers involved can access this information and that there should be "*universal reporting across disciplines*" (Specialized cardiac nurse, 2021). In addition, SCNs and HFNs often discussed the added value of a MDTM with a "dedicated" heart failure cardiologist, which is seen as a solution to ensure efficient communication around I-HARP.

"*But it would be so nice if you had an MDTM where you could have cardiologists and Specialized cardiac nurses discussing a case with each other while cross-pollinating*."
(Specialized cardiac nurse, 2021)

4.4.3. Communication with the patient

Another discussed topic about communication was the communication with the patient. Patients may have very different expectations and perceptions, making it difficult to discuss palliative care and apply I-HARP. Patients might also be surprised by the I-HARP questions for which patients were totally unprepared. A participant mentioned that "*Sometimes patients are still on such a different track that they almost fool you. They almost take you with them, making it difficult to look at the situation objectively*." (Specialized cardiac nurse, 2021). Another participant mentioned that having an own patient group promotes bonding with patients and makes it easier to communicate with the patient. But having this own patient group is not possible for every hospital.

[3] Multidisciplinary Team Meetings (MDTMs) aim at uniting care professionals from different disciplines to decide upon the best possible treatment plan for the patients based on the available scientific evidence.

Informing the patient in advance of the consultation about the future options was considered very important in order to prepare the patients and not to overwhelm them. It also gives the patient a chance to think about the different palliative care options, which can only benefit the efficiency of the next consultation. A SCN mentioned that it would be a good idea to include this patient information in a kind of folder or questionnaire. Furthermore, consciously setting the agenda for the use of I-HARP in the outpatient clinic could also help to avoid overwhelming the patient. SCNs and HFNs should consciously plan the consultation to discuss "the future" of the patient.

"*It's really about planning such a conversation. Someone comes to the outpatient clinic, you signal that I-HARP is applicable, you give them information and then invite them back after a few weeks to follow up.*"
(Specialized cardiac nurse, 2021)

4.4.4. Experience with palliative care conversations

The third barrier discussed by the SCNs and HFNs was the lack of experience with palliative care, especially for young nurses who experience a threshold in starting the conversation. However, I-HARP might be a good tool to use as a "cheat sheet". That is why the SNCs and HFNs stated that I-HARP should be integrated into the standard outpatient consult preparation. "*The more often you do this, the more often this is discussed, the more automatic it becomes in my opinion*." (Specialized cardiac nurse, 2021).

4.4.5. Time limitations

The last barrier discussed by the participant included the issue of time limitations. I-HARP contains a lot of questions and during a consult in the outpatient clinic many other areas of concern need to be discussed. A participant mentioned that "*If I do it once in a while, I really need an hour*." (Specialized cardiac nurse, 2021). Also the limited time of the cardiologist is seen as problematic for SCNs and HFNs to discuss cases in a MDTM.

"*I hope that when people are admitted for the second or third time that there is a good discussion in the ward, but that very often does not happen. Because of the time pressure, the patient is fixed up and goes home again. Then I think: missed opportunity*."
(Specialized cardiac nurse, 2021)

Time constraints will always be a challenge, but during the focus groups, SCNs and HFNs indicated that informing the patient with possible folders or questionnaires could make it easier to handle the barrier of time constraints. After all, if patients are informed

in advance and had time to think about the questions, patients are better prepared which will prevent longer consultations than necessary. SCNs and HFNs would also be able to pick up the I-HARP questions more quickly, which would allow I-HARP to be embedded in daily practice more quickly.

5. Discussion

The aim of this study was to explore the views of HCPs in cardiology care regarding the use of I-HARP by SCNs and HFNs in practice. To reach this aim, the following three research objectives were formulated. First, the views on how and where to use I-HARP in the current routines of the SCNs and HFNs were investigated. Secondly, the role of the SCNs and HFNs in using I-HARP as perceived by the HCPs was explored. Finally, perceived recommendations of the HCPs on what is needed in hospital settings to use I-HARP in practice was identified. This chapter will discuss the most important findings from the results, the strengths and weaknesses of this study and will give recommendations for practical implications and future research.

5.1. Most important findings

With regard to the first research objective, the results show that SCNs and HFNs are better able to use I-HARP in the outpatient clinic because of more time and privacy for a comprehensive consultation than in an inpatient clinic. A similar study of HCPs discussing end-of-life (EOL) issues with patients also found that both nurses and doctors experienced lack of time and privacy in the inpatient clinic as a problem (Bergenholtz, Timm & Missel, 2019). However, findings from this study indicated that the inpatient clinic can serve as a place to mark the time to start using I-HARP. Furthermore, the conversation about palliative care should start earlier in the disease trajectory to make this topic less loaded. Therefore the SCNs and HFNs mentioned the possibility of starting I-HARP already during diagnosis. Hill et al. (2020) also recommends considering palliative care throughout the whole HF trajectory, regardless of the stage of the patients illness.

Participants indicated their difficulty with marking the moment to start I-HARP. It became clear that the instinct of SCNs and HFNs, but especially the medical markers are triggers to start using I-HARP. These triggers are also supported by the guidelines for palliative care in heart failure (IKNL, 2018), which state that there are a number of markers to identify patients with poor life expectancy. For example, frequent readmissions, persistent symptoms despite treatment and answering the question of whether HCPs are surprised if a patient dies within 12 months. These triggers may indicate that it is time to start using I-HARP. Also the study of Bergenholtz et al. (2019)

support the timing of EOL conversations determined by health status and partly by an intuitive attitude. As the risk for mortality increases with each hospitalization, hospital discharge planning is an opportunity to discuss palliative care and thus apply I-HARP (Yim et al., 2017).

With regard to the second research objective, the results showed that SCNs and HFNs play a key role in the implementation and use of I-HARP due to their holistic view and more time for the patient. This outcome is to some extent contrary to that of Bergenholtz et al. (2019), who found that all HCPs saw the doctor as the main character in initiating the EOL conversation, whereas the role of the general nurse was less explicit and was seen as a kind of "pick up on things" afterwards. Their findings indicated that general nurses were afraid to answer questions from patients that they could not answer and did not know how to cope with patient reactions. However, the SCNs and HFNs in this study did not express this fear and mentioned that a cardiologist could easily be consulted for difficult medical-related questions.

What was surprising from the results was that although the role of primary care was not included in the topic list, SCNs and HFNs indicated that it is important to work together to use I-HARP. According to the participants, I-HARP could also support GPs and home care with their patients. However, SCNs, HFNs, GPs and home care should communicate efficiently with each other about the palliative care needs of the patient to avoid duplication of I-HARP questions. A study about EOL communication between primary and secondary care agrees on the importance of improving palliative care in hospital setting through active communication with primary care (Boland et al., 2015).

With regard to the last research objective, the results presented the solutions to the barriers that SCNs and HFNs may face when using I-HARP. First of all, using I-HARP in an early stage could be helpful to make palliative care less loaded and create more awareness. What SCNs and HFNs also expressed was their need for a "dedicated" HF cardiologist who is aware of the possibility to timely integrate palliative care and who does not only look at life-sustaining treatment.

Secondly, the problem of adequately communicating with other HCPs involved with the patient is supported by several studies (Bergenholtz et al., 2019; Wotton, Borbasi and Redden, 2005). Therefore, the results of this study show the importance for HCPs to have a MDTM to discuss the situation of the patient and to indicate if I-HARP is applicable. In addition, SCNs and HFNs reported the importance of efficient communications with GPs and home care. For the implementation of I-HARP, technical support is needed to clearly and briefly document I-HARP in the patient's ACP to communicate efficiently across disciplines. The Palliation programme of ZonMw (2020) indicated that hospital and transmural care coordination can be improved for the ACP of

HF patients. Therefore, a care pathway for HF is being developed, which will give hospitals a better idea of what has been discussed with the HF patient in transmural care (ZonMw, 2020). A cardiologists who participated in this ZonMw Palliation programme also sees an important role for the SCNs and HFNs in indicating when ACP is necessary.

Thirdly, the importance of consciously setting the agenda for the use of I-HARP in the outpatient clinic by SCNs and HFNs was supported by many participants. Doctors in the study of Bergenholtz et al. (2019) endorsed that this planning should be part of the role of the nurses. However, consciously agenda-setting also contradicts the study by Bergenholtz et al. (2019), who found that the EOL conversation often occurred spontaneously when the patient was receiving personal care and it felt natural for the nurses to talk about it. General nurses in the study of Bergenholtz et al. (2019) indicated that when the EOL conversation was planned and formal, patient reluctance was expressed. The difference in profession and tasks of general nurses compared to SCNs and HFNs in this study could explain this contradiction. However, it should be kept in mind that it is possible that some patients feel less comfortable answering the I-HARP questions in a planned and formal setting. This shows that patient-tailored care is important if SCNs and HFNs want to use I-HARP.

Finally, lack of time to use I-HARP and the concern of overwhelming an unprepared patient with the I-HARP questions was seen as one of the biggest barriers. Lack of time has been described as a well-known barrier to conducting palliative care conversations in hospital settings by other studies as well (Gardiner et al., 2011; Wotton et al., 2005). To limit the time and to avoid overwhelming the patient during the outpatient consultation, the patient should be informed and prepared in advance. According to the findings, this can make patients feel more comfortable to speak and avoids longer consultations than necessary. Furthermore, a prepared patient makes it easier for SCNs and HFNs to use I-HARP during the consultation, which helps to embed this tool in daily practice. The Palliation programme of ZonMw (2020) also indicates the importance of informing and preparing the patient before conversations about palliative care.

5.2. Strengths and limitations of this study

This study has several strengths concerning the research method, analysis method and conceptual framework. Firstly, a strength of this study is the exploratory single case method used, which produced a detailed qualitative report. This report not only helped to explore and describe data in its real-life environment, but also helped to explain the complexity of the real-life situations participants faced (Yin, 2003). This research method enabled the researcher to understand the behavioural conditions through the participants

perspective and therefore gives a much richer and deeper understanding of the data than can be found through other experimental designs (Yin, 2003). Furthermore, this research method offered new and unexpected insights and generated ideas to use I-HARP in the current routines of SCNs and HFNs. Secondly, the conventional content analysis approach used in this study enabled the researcher to collect direct information from the participants without imposing preconceived categories or theoretical perspectives (Hsieh & Shannon, 2005). Thirdly, the conceptual framework developed increased the construct validity of this study (Strauss and Smith, 2009). For the data collection, it provided a theoretical foundation for the topic list, which provided structure during the focus groups. Moreover, the conceptual framework was useful for the data analysis. Construct validity was verified as no new themes emerged from the inductive analysis.

However, this study also has some limitations. First of all, The data collected in this study cannot necessarily be generalized to the wider population, which affects the external validity of this study (Yin, 2003). The views of the participants in this study might differ from those of other healthcare professionals in hospitals from other countries or might be different in other settings such as primary care. Secondly, there may have been researcher bias in this study due to subjective feelings and personal interpretation of the data, which could have intrude the assessment of what the data actually meant (Willis, 2015). This could affect the reliability and validity of the results and conclusion of this study. However, this may have been prevented because of the collaboration with another involved researcher who checked the data analysis and results of this study. Thirdly, there might have been selection bias in this study, as participants were included based on their interest in the timely integration of palliative care. These HCPs were motivated to participate, which may have influenced their view about the use of I-HARP, that might be different for those who declined to participate.

Prolonged engagements is to some extent established in this study by collecting data until saturation (Moser & Korstjens, 2017). The five focus groups provided sufficient information to identify differences and similarities in frequently discussed topics. However, the views of HCPs on how to work together to integrate I-HARP in practice was not discussed in detail. This was due to the fact that most focus groups were homogenous, including only SCNs and HFNs or cardiologists, which made discussion about their collaboration difficult. Another limitation of this study was the online setting of the focus groups that sometimes caused internet connection and audio troubles, which took up time and caused some missing transcribed data. Furthermore, this online setting also sometimes caused people to talk at the same time and not everyone felt compelled to speak up. Lastly, the size of some focus groups might be a limitation of this study. The researchers experienced that a focus group with four participants worked much better

than a focus group of more participants. This is because with only four participants everyone gets a chance to speak up and we noticed that participants felt more obliged to respond and share their views. In this study only two focus groups included four participants, one included three and two included more than four participants.

5.3. Recommendations

The results of this study showed that there are many topics to consider when implementing and using I-HARP in the routines of SCNs and HFNs. These findings resulted in three practical implications. First of all, a major effort is needed to create more awareness for the timely integration of palliative care. The integration of I-HARP in the outpatient clinic by SCNs and HFNs and starting to use I-HARP when medical and instinctive markers have occurred can already be a first step. The results reported that HCPs should simply start using I-HARP to gain experience with the tool. This is also shown in the results of ZonMw's Palliation programme, where is stated that conducting palliative care conversations takes practice and HCPs should do it regularly to become more skilled at finding the right formulations (ZonMw, 2020). Secondly, to use I-HARP efficiently, patients should be prepared for the consultation in advance through folders and questionnaires about their options for the future. The Palliation programme of ZonMw (2020) developed various tools to better prepare the patient for conversations about treatment wishes. This document contains 11 questions in which patients can write down, for example, what they consider important in life and how they feel about being permanently hospitalized (Van der Plas, 2019). This document also helps HCPs to reach patients who are reluctant to discuss such matters. Thirdly, technical support is needed to document I-HARP in the patients ACP to communicate efficiently across disciplines. It should become possible to document I-HARP in electronic patient files, which will remind HCPs to use I-HARP when necessary and will improve communication between the different disciplines involved with the HF patient (Derikx, Erdkamp and Hoofwijk, 2013).

Besides practical recommendations, there are also a number of recommendations for future research. Findings indicated that having a MDTM with a dedicated HF cardiologist is important for SCNs and HFNs, which is often not possible because of time constraints. This challenge of time constraints and the cooperation between HCPs in the use of I-HARP could be further explored. It would be interesting to conduct another focus group with HCPs of different professions to explore this cooperation in more depth. Communication between HCPs and primary care about the I-HARP questions addressed could also be further investigated. These two topics were beyond the scope of this study, but insights into conducting MDTMs and communication between HCPs would support a successful implementation of I-HARP. Moreover, a general evaluation study on the

implementation of I-HARP is recommended. As participants of this study had little to no experience with the use of I-HARP in practice. By conducting an evaluation study, after a certain period of time with multiple HCPs from different hospitals, it is possible to evaluate the barriers, facilitators and points of improvement for the efficient use of I-HARP in practice. If online focus groups are planned it is advised to organize these with a maximum of 4 HCPs to ensure an efficient discussion were all participants can share their views. The resulting feedback could be used to further modify I-HARP and/or working environments in hospital settings.

6. Conclusion

The aim of this qualitative study was to examine the views of HCPs on how to use I-HARP in the current routines of SCNs and HFNs. It is recommended to use I-HARP in the outpatient clinic already during diagnosis, with SCNs and HFNs playing a key role in the implementation and use of I-HARP. SCNs and HFNs should start using I-HARP when medical and instinctive triggers have occurred early in the disease trajectory. In order to use I-HARP successful in practice, patients have to be informed in advance about their future options and prepared for the consultation so that SCNs and HFNs can use the I-HARP questions efficiently. In addition, SCNs and HFNs should document I-HARP in the patient's ACP to communicate efficiently across disciplines about the palliative care needs of patients.

The insights gained from this study may be of assistance to support SCNs, HFNs and other HCPs to incorporate I-HARP in their current routines. The exploratory single case method used in this study helped the researchers to explore in-depth and detailed insights into the views of different HCPs. However, there were some minor limitations in this study that could have affected the reliability and validity of this study. The focus on Dutch hospital settings may indicate that the results cannot be generalized to other countries or to other healthcare settings. Moreover, some focus groups had too many participants or did not include participants from different professions, which may have resulted in a lack of relevant information.

This study has also raised a number of questions in need of further research. A greater focus on the role of different professions and settings could produce interesting findings that may identify the possible collaboration between HCPs in the use of I-HARP. In addition, an evaluation study of the implementation and use of I-HARP by hospitals is required to obtain feedback that could improve and expand the use of I-HARP in the Netherlands.

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I-HARP IDENTIFYING

PATIENT INTRODUCTION

I would like to talk to you about your wishes and concerns about your heart failure, so that we can look at what you need together. I would therefore like to ask you a number of questions.

POSSIBLE QUESTIONS FOR STARTING THE CONVERSATION

- What is mainly keeping you busy at present?
- What do you enjoy?
- How have you been doing the last few days?

IDENTIFICATION QUESTIONS		YES	NO
1	Do you have physical complaints that make it more difficult for you to do normal activities?		
2	Do you need help or more help with washing yourself, getting dressed, doing shopping or doing housework?		
3	Do you have any questions about heart failure or your treatment?		
4	Heart failure can considerably affect your daily life. Do you find it difficult to cope with?		
5	Many people with heart failure experience psychological complaints. Does this also apply to you?		
6	Do you sometimes feel misunderstood by important people who are close to you?		
7	Would you like to talk to someone about questions about life, or 'why' questions?		
8	Is there something that I should know about your cultural background or religion in order to provide you with proper care?		
9	Are you worried about money matters as a result of your condition?		
10	Do you have any questions or concerns about your future with your condition (heart failure)?		
11	Would you like to talk to your doctor about the treatment and care you would like to receive if your condition continues to deteriorate?		
12	We have often found that informal caregivers would like to receive more help from others. Does that also apply to you?		
13A	(Question for patient, if next of kin is not present). Would your next of kin like to receive a further explanation about heart failure or about the treatment?		
13B	(Question for next of kin, if present). Would you like to receive a further explanation about heart failure or about the treatment?		

I-HARP FURTHER QUESTIONS

SUGGESTED FURTHER QUESTIONS PER ITEM FOR POSSIBLE CARE NEEDS

1	• Do you suffer from shortness of breath, tiredness, pain or loss of appetite, for example? • What complaint affects you the most? • Is it more difficult for you to do activities such as washing the dishes and cleaning as a result of your heart failure?
2	• What do you need help with? • Do you need help doing housework or when washing yourself and getting dressed? • Who is helping you now? • What kind of help would you like to receive? • How do you feel about having to ask for help?
3	• What questions do you have about heart failure? • What questions do you have about your treatment? • What questions do you have about medication?
4	• Does it make you sad or angry when you find that you can no longer do activities the way you used to? • Do you have periods in which you are angry or sad since you have had heart failure? • Do you find it difficult to accept that you can no longer do things the way you used to? • Do you need help in this area?
5	• Do you suffer from sadness, tension, worry or loneliness? • Does heart failure make you feel anxious quickly? • Do you think about heart failure a lot?
6	• Who are the most important people to you? • In what areas do you feel misunderstood? • What should the most important people to you know so that you do feel understood? • What would help you?
7	• Are there certain questions about life, or 'why' questions that you have been asking yourself? • Is there something that is always on your mind? • Would you like to talk to someone about it? • With whom would you like to talk about it? • Who or what do you need to make life worthwhile? How can I (or another person) help you do that?
8	• What should I know so that I can provide you with good care? • To what extent does your cultural background or religion influence your wishes in this stage of your life?
9	• Do you need any help with your money matters? • Would you like to know more about receiving help with your money matters?
10	• What questions do you have about your future with your condition, heart failure? • What are you worried about? • Would you like to know more about what heart failure means for your future?
11	• What would you like to discuss? • Would you like to know more about the care you can receive if your condition deteriorates? • Do you have an advance directive?
12	• What are the heaviest tasks for you (or your next of kin)? • What would you like assistance with? • Can you talk about it together? • How do you feel about having to ask for help?
13A	***Questions for the patient about next of kin, if next of kin is not present*** • Do your next of kin have any questions? • Do your children have any questions about heart failure or the treatment? • What would your next of kin like to receive more information about?
13B	***Question for next of kin, if present*** • What would you like to receive more information about?

8.2. Appendix 2: Background questionnaire

Question	Answer
Background information	
1. What is your gender (male/female)	
2. What is your age?	
3. What is your profession?	
4. Years of experience in profession	
5. Specialization in palliative care (yes/no) If yes, which course/education?	

8.3. Appendix 3: Informed consent form

Toestemmingsformulier (deelnemersexemplaar)

I-HARP project

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 geheel vrijwillig toestemming om de focusgroepdata ter beschikking te stellen voor het onderzoek 'Tijdige herkenning van palliatieve zorgbehoeften bij patiënten met gevorderd chronisch hartfalen: I-HARP'.

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 zonder verdere opgaaf van redenen.

Intrekking van mijn toestemming heeft geen gevolgen voor de rechtmatigheid van de verwerking van mijn gegevens voorafgaand aan de intrekking (geen terugwerkende kracht).

Ik ben me bewust dat deelname aan de studie betekent dat verzamelde gegevens 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 -HARP project.	JA / NEE Paraaf:

Achternaam en voorletter(s):

Handtekening deelnemer: Datum: __ / __ / __

Handtekening onderzoeker: Datum: __ / __ / __

8.4. Appendix 4: Topic list

Topic	Question
Topic 1 – Use of I-HARP in practice	What is your first impression of I-HARP?
	When would I-HARP be most appropriate to use? In which setting?
	How do you think I-HARP can be used in practice by the heart failure nurses?
Topic 2 - Division of roles between cardiologists and nurses	What is the role of the heart failure nurse in the use of I-HARP? In what setting do you envision that (parts of) I-HARP could be applicable to you?
	Is there a role for the cardiologist in using I-HARP and what would that be?
	Multidisciplinary cooperation: How could cardiologists and heart failure nurses work together in the best possible way to use I-HARP?
Topic 3 – What is needed to use I-HARP in practice	What do you think you will need in order to make the best use of I-HARP in your practice?

	Statement: As a heart failure nurse, if you were expected to start using I-HARP tomorrow, how would you approach it and what do you think you would need to do?
	What do you think you need together in order to make the best use of I-HARP in practice? From who and what do you need from another? What information would you want to receive from the cardiologist?

8.5. Appendix 5: coding framework

Name	Files	References
Gebruik van I-HARP	0	0
• Integratie in het zorgpad	4	12
• Setting	3	3
○ Kliniek	5	19
○ Polikliniek	4	19
• Wanneer I-HARP gebruiken	3	10
○ Aanvoelen	3	6
○ Eerder in het zorgtraject	3	11
○ Seintje van naasten	1	1
○ Tijdens diagnose	3	4
○ Verslechterde toestand	5	7
▪ Achteruitgang nierfunctie	2	2
▪ Na ICD voorschrijven	4	7
▪ Na opname	3	3
▪ Na eerste opname	0	0
▪ Na heropname	3	5
▪ Niet of slecht reageren op medicatie	2	2
Rolverdeling	1	5
• Rol cardioloog	3	8
○ Medische aspecten	3	7
○ Terughoudend	4	12
○ Toewijding	5	12
• Rol palliatief team	3	12
• Rol van andere zorgverleners	0	0
○ Huisarts	5	12

○ Overige zorgverleners	1	1
○ Thuiszorg of buurtzorg	3	8
• Rol verpleegkundige	5	30
○ Psychosociale aspecten	3	7
○ Signalerende functie	5	12
Wat nodig	1	1
• Barrière	4	8
○ Communicatie	0	0
▪ Naar patiënt toe	2	7
▪ Tussen arts en verpleegkundige	3	4
▪ Documentatie I-HARP	3	12
▪ Mondelinge overdracht	1	2
○ Markeermoment is lastig	4	18
○ Meer ervaring nodig	3	4
○ Tijd	5	25
• Oplossing	1	1
○ Bewustwording	4	6
▪ Bewustwording arts	4	14
▪ Bewustwording patiënt	1	2
○ Communciatie	3	7
▪ Naar patiënt toe	3	6
▪ Informatievoorziening patiënt	3	11
• Brochure	3	4
• Filmpje	1	2
• Vragenlijst	1	4
▪ Inleiden gesprek	4	19
▪ Tussen arts en verpleegkundige	3	7
▪ Documentatie I-HARP	6	13
▪ Mondelinge overdracht	4	7
○ Ervaring opdoen en oefenen	4	9
▪ Trainingen	2	3
○ Standaardisatie	4	6
○ Tijd	3	8
○ Zakkaart I-HARP	2	4

8.6. Appendix 6: FHMLREC form

FHMLREC: Ethics Review of niet-WMO-plichtig research with human participants
Programme: MSc Healthcare policy, innovation and management

Student Name: Pien Eras
email: p.eras@student.maastrichtuniversity.nl
Supervisor Name: Stephanie Ament
email: s.ament@maastrichtuniversity.nl

Project Title: Using I-HARP in practice to timely recognize palliative care needs of heart failure patients.

The following list presents the key characteristics of a high-risk study. Please indicate which of these characteristics (if any) apply to the study that you will conduct for your master thesis project.

- ☐ own data collection among population below 18 years of age
- ☐ own data collection among patients or persons placed in long-term care institutions
- ☐ own data collection among persons with limited decision-making capacities or disabilities
- ☐ own data collection among persons with a specific disease, e.g. diabetes, HIV, dementia, etc.
- ☐ own data collection among other vulnerable groups, e.g. migrants, minorities, etc.
- ☐ own data collection among former patients or clients of long-term care institutions
- ☐ own data collection on a sensitive topic, e.g. deviance, informality, taboo subject, etc.
- ☐ own data collection using invasive research instrument(s), e.g. medical intervention, etc.
- ☐ use dataset with (former-)patient data or data of clients of long-term care institutions

Please complete the following in a free style with a high level of detail. FHMLREC is looking to see that you have identified ethical issues and addressed them satisfactorily; and, that you are thinking about undertaking your research in an ethical manner, and can communicate this to your research participants and other people in society generally.

1. The Study

1.1 What is the nature of the study? What are the key questions that you are seeking to address?

The aim of this study is to explore the views of HF nurses and cardiologists regarding the use of I-HARP by HF nurses in practice by conduction qualitative research using focus groups and interviews.

Research question: How can a tool for healthcare professionals, to facilitate timely recognition of palliative care needs in patients with advanced heart failure, be used in the routines of the HF nurse?

Research objectives:

1) The views of HF nurses and the cardiologists on how to use I-HARP in the current routines of the HF nurse will be investigated.
2) The role of the HF nurse in using I-HARP as perceived by the HF nurses and cardiologists will be investigated.
3) Perceived recommendations of the HF nurses and the cardiologists on what is needed in hospital settings to use I-HARP by HF nurses are identified.

1.2 What are the methodologies that you will employ in the study?

Study design: This study uses a qualitative case study method to investigate the views of the health professionals in depth and within its real-life context.

Data collection: The methods that will be used to collect data for this research are focus groups with cardiologists and HF nurses and if necessary additional semi-structured interviews. The non-probability sampling method that is used for this study is purposive sampling.

Data analysis: The qualitative data will be analyzed by a content analysis approach to identify and interpret patterns and themes in the collected data. The data will be analysed using an inductive and deductive approach with the software Nvivo 12 Pro.

1.3 How will humans be participants in the study (either directly or indirectly, for example, through the use of their personal data)?

Humans will participate in an online focus groups with several others. And if necessary they will individually participate in an online interview. This will be done online because of the COVID-19 pandemic and because cardiologists and heart failure nurses of different hospitals in the Netherlands are invited for the focus groups.

1.4 Does your study re-use data that has already been gathered for another project or purpose? If so, do you have permission to re-use that data, and was there the relevant consent for this re-use in the first study? (Please explain, with reference to, for example, previous ethics committee decisions and informed consent protocols.) If your thesis project is a part of a larger project, please also indicate if the larger project has received an ethical approval and is your thesis project is covered by this ethical approval (please consult the supervisor).

No.

1.5 What sort of people will be involved? (For example, professionals in the course of their profession, members of the general public.)

Healthcare professionals in cardiology care: cardiologists and heart failure nurses of different (academic) hospitals in the Netherlands.

1. 6 On what grounds did you determine the number of participants needed for the study?

On the ground of the availability of multiple cardiologists and heart failure nurses of different hospitals.

1.7 On what grounds did you determine that this is a useful study?

On the grounds of a mixed-method study of Ament et al. (2020), where a tool called I-HARP was developed for healthcare professionals to facilitate timely recognition and directing of personal palliative care needs in advanced heart failure. The state that the next step is to implement I-HARP in different healthcare organizations. Ament et al. (2020) suggests that feasibility research is needed for using I-HARP in hospital setting. This study will fill in the gap of the needed feasibility research to implement I-HARP in practice.

Ament, S., van den Beuken-Everdingen, M., Maessen, J., Boyne, J., Schols, J., Stoffers, H., Bellersen, L., Brunner-La Rocca, H. P., Engels, Y., & Janssen, D. (2020). Professionals guidance about palliative medicine in chronic heart failure: a mixed-method study. BMJ supportive & palliative care, bmjspcare-2020-002580. Advance online publication. https://doi.org/10.1136/bmjspcare-2020-002580

1.8 Is this a 'one-off'/ 'stand-alone' project, or do you foresee that you will want to re-use the data in future (different) research, or to share the data with other researchers for their future research? How have you ensured consent for this from your participants?

This is a stand-alone project. The participants have to agree on this in the informed consent form that will be sent with the invitation of the focus groups and interviews.

1.9 If relevant, what is your publication strategy?

Not applicable at the moment.

1.10 If the work is not going to be undertaken (solely) in The Netherlands, is local Ethics Review required in the country/countries where the research is to be undertaken? How will this be achieved?

The work is going to be undertaken in the Netherlands.

2. Identifying Harms

2.1 What are the possible harms that participation in your study could bring for the human participants? (These could be, for example, physical, psychological, economic, harms, harms relating to privacy, etc.)

None, because all the data collection will be performed anonymously and stored in a confidential and secure environment of the central IT system of the University of Maastricht.

2.2 How will you ensure integrity in the use of other researchers' data and published work?

All the literature that is used in this study will be of scientific relevance and will be included in the reference list and referred in the text using an APA referring style. This literature will be searched for in databases for scientific (medical) literature like PubMed and Google Scholar.

2.3 How will you ensure within your team that the highest standards of academic integrity are maintained, and that there are mechanisms to raise and discuss concerns within the team (and to the University Integrity Officer)?

The academic integrity of this study is maintained using the Dutch code of conduct for research integrity (VSNU, 2018). To prove the trustworthiness of this study, the following criteria should be met: credibility and transferability. For credibility, the following strategies are applied: prolonged engagement, data-, method- and investigator triangulation and member check. For transferability, thick description of the participants and research approach is applied.

VSNU (2018). Nederlandse gedragscode wetenschappelijke integriteit. Retrieved from: https://www.vsnu.nl/files/documenten/Nederlandse%20gedragscode%20wetenschappelijke%20integriteit%202018.pdf

3. Safeguards

3.1 How will you inform participants about their participation in your study? (Please also comment on any re-use of data issues.)

To participate in the focus groups and possible interviews, the participants are invited by an e-mail with information about the study, an informed consent form and a background questionnaire.

3.2 Will individuals be invited to participate in your study through informed consent, or are you appealing to, for example, the public interest in undertaking the work (for example, you might be undertaking a participant observation)?
Please supply details (and, where appropriate, drafts of any forms) of your informed consent process (i.e. both how you will gain informed consent from your participants e.g. on paper, online or orally, and how you will evidence that consent), and the information sheets that you will use. Please note that the inform consent form and the information sheet should explain the objectives and the nature of the study if there is a reward and what will happen with the data during and after the study. It is also necessary to state that participation is voluntary, and participants can withdraw any time without having to give a reason. Example informed consent form can be found at: https://www.who.int/ethics/review-committee/informed_consent/en/

Individuals will be invited to participate in the study through informed consent and participation information. After receiving the participant information, the participants have one week to consider their participation. In this informed consent, information about the goals and process of this study, I-HARP itself and the collected and stored data is provided. Furthermore the participants will have to give consent for processing the data in the context of this study, agree on storing the data for 15 years, consent on sharing research data with third parties, agree to be approached in the future for the provision of extra data for the I-HARP project. Participants can withdraw their participation at any time for any reason.

3.3 How will you process any personal data in the project? (You should explain the safeguards in place throughout the processing of the data from gathering the data, analysing the data, storing the data, and destroying the data at the end of the period.)

The Student uses existing data provided by a researcher who works at the FHML

- Property: original data and modified data files remain the property of FHML.
- An agreement has to be made between the student and the researcher who provides that data about safe use of the data, i.e. that:
    - Data cannot be taken out of the given FHML building or only anonymous data can be taken out of the building
    - Precautions are taken by the student to prevent the loss of the data (e.g., not travelling around with the data unnecessarily, being careful not losing the external hard drive, USB stick or laptop with the data during travel), having a password protection on the external hard drive, USB stick or laptop, when not using the external hard drive, USB stick or laptop, keeping these in a cupboard that is locked).
    - Precautions are taken by the student to prevent that the data can be viewed or used by others (e.g., prevent access to laptop with data by housemates; remove data from laptop after finishing the research).
- Storage: At the end of the thesis period, the student has to return the original data and all copies of the (modified) data file(s) to the researcher who has provided the data, as well as all documents from which the data can be retrieved. After that, the student has to delete the original data and all copies of the (modified) data file(s), and all documents from which the data can be retrieved, that the student has. The data are stored by the researcher who has provided the data.

The data will be gathered by online focus groups and interviews using Microsoft Teams, which is recommended as a safe environment to collect data by the University of Maastricht (UM). Data will be video recorded with Microsoft Teams and stored within the secure environment of the central IT system of the UM. The data will be transcribed from the recorded video's in a word-document and analysed within Nvivo 12 Pro. Again, all these files will be stored and saved within the secure environment of the central IT system of the UM. All this data will be stored in the IT system of the UM for 15 years.

3.4 Who will have access to the personal data? In particular, will you use de-identification methods (coding, anonymising, etc.) as a protection? Will there be an identification key and where/how it will be stored and who will have access? Will you engage in "open data" methods of data sharing for integrity issues? Under what conditions will they have access?

Only members of the research team will have access with an identification key to the data that is stored in the secure environment of the central IT system of the UM.

3.5 Will there be any reimbursement, remuneration or reward for participation? If so, what is your reasoning for this and is it proportionate and appropriate?

No.

3.6 Are there any further safeguards that you have put in place?

No.

3.7 In what circumstances and to what extent will your participants have the opportunity to withdraw their participation? How will this be communicated to them?

See 3.2.

3.8 Is participation in the study confidential? In particular, will participants be identifiable in any publications or other dissemination of research results? If so, will you have a specific consent for this use of the data? If participants will be unidentifiable, how will you ensure this in your publications?

Participation will be confidential and anonymous and the scripts will be pseudonymised. The raw data will not be published for open access. Each participant will get a number after the data collection, which will be used through the whole study process so that no names will be used.

3.9 How will the data be stored, and for how long will it be stored? Please indicate which data storage plan you will use (please copy here one of the data storage plans describe below). If you are not proposing to use this, why not?

See 3.4 for the storage of the data. The data will be stored for 15 years.

4. Any other ethics observations that you wish to make.

No.