

From guideline to practise

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From guideline to practise

The organisation of multidisciplinary heart failure care in three European regions

The research presented in this dissertation was conducted at CARIM school for Cardiovascular Diseases, department of the faculty of Health, Medicine and Life sciences of Maastricht University and at Mobilab&Care, research center of Thomas More University of Applied sciences in Geel, Belgium.

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The organisation of multidisciplinary heart failure care in three European Regions

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From guideline to practise

The organisation of multidisciplinary heart failure care in three European regions

DISSERTATION

to obtain the degree of Doctor at Maastricht University,
on the authority of the Rector Magnificus, Prof. dr. Pamela Habibović
in accordance with the decision of the Board of Deans,
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Chapter **1**

General Introduction

Heart Failure

Why does Heart Failure matters?

With an estimated global prevalence of 37.7 million individuals, heart failure (HF) is an increasing challenge to health care systems and governments.¹ In developed countries 1 – 2% adults suffer from HF, increasing to $\geq 10\%$ among people older than 70.^{2,3} HF is the most common cause of hospitalisation in adults aged above 65 years with high costs and a negative impact on psychosocial well-being of patients and their families.^{4,5}

What is Heart Failure?

According to the European Society Cardiology (ESC), HF is a “clinical syndrome characterized by typical symptoms such as breathlessness, ankle swelling and fatigue. These symptoms may be accompanied by signs being e.g. elevated jugular venous pressure, pulmonary crackles and peripheral oedema caused by structural and/or functional cardiac abnormality, resulting in a reduced cardiac output and/or elevated intracardiac pressures at rest or during stress.”⁶ To describe severity of HF symptoms, the New York Heart Association (NYHA) has assessed 4 functional classifications which relates symptom burden to daily life activities (See table 1).⁷⁻⁹

Table 1. NYHA Functional Classification⁷⁻⁹	
Class I	No limitation of physical activity. Ordinary physical activity does not cause symptoms of HF.
Class II	Slight limitation of physical activity. Comfortable at rest, but ordinary physical activity results in symptoms of HF.
Class III	Marked limitation of physical activity. Comfortable at rest, but less than ordinary activity causes symptoms of HF.
Class IV	Unable to carry on any physical activities without symptoms of HF, or symptoms of HF at rest.

Heart failure is separated based on left-ventricular ejection fraction (EF), into HF with reduced EF (HFrEF), with mildly-reduced EF (HFmrEF) and with preserved EF (HFpEF).³ This is important as only in patients with HFrEF and likely HFmrEF, treatment is well defined, whereas best therapy in HFpEF is largely unknown. This is important as adherence to medical therapy - apart from diuretic therapy, which is important in all HF patients – mainly refers to those with HFrEF and HFmrEF. In addition, HF has a large variety of underlying aetiologies, many of them need specific treatment.³ Moreover, HF is mostly accompanied by a wide range of cardiac and non-cardiac comorbidities such as hypertension, atrial fibrillation, diabetes, COPD, renal dysfunctions, depression, and obesity.^{3, 6, 10, 11} These comorbidities have an impact on HF-progression, well-being as well as outcome and may negatively affect HF-treatment.¹⁰ For example, HF patients with concomitant COPD have more symptoms and worse quality of life as compared to those without COPD, despite similar severity of HF.¹²

How to manage Heart Failure?

HF-management is complex and challenging. On the one hand, patients have to undergo often extensive diagnostic tests. In addition, therapy contains multiple drugs and sometimes also device therapy. On the other hand, patients are exposed to significant lifestyle challenges and adherence to recommended treatment, particularly medication.¹³ Moreover, the average age of patients at diagnosis is 76 years and the presence of comorbidities often results in HF-management that is not limited to one sector of care.¹³ Therefore, it is of utmost importance that HF-management programmes provide seamless, patient-centred care, in which patients, community- and hospital care are equal partners.⁶

It has been showed that Disease Management Programmes (DMP's) are better equipped to address these critical challenges in HF-management.^{14, 15} Successful DMP-HF reduce among others (re)hospitalisation and costs, and improve QoL through structured follow-up, patient-education, medication up-titration and psychosocial support (Table 2).¹⁴⁻¹⁶

Table 2. Effects on outcomes of DMP-HF ¹⁴⁻¹⁶

Patient related	<ul style="list-style-type: none"> - Improved Quality of Life - Better symptom control and functional status - Improved patient knowledge and self-management ability - Improved survival rates
Service related	<ul style="list-style-type: none"> - Decrease of hospital (re)admissions - Reduced length of in hospital stay - More effective up-titration and prescription of evidence based treatment - Better care-coordination - Earlier patient identification
Resource related	<ul style="list-style-type: none"> - Reduced costs

Within the ESC-guidelines, essential components and characteristics of DMP-HF are described (Table 3). According to these guidelines, multidisciplinary care in combination with structured patient-education and self-care support are key elements within such a programme. ⁶

Table 3. Characteristics and components of HF-management programmes ^{3, 6, 13}

Characteristics	<ul style="list-style-type: none"> - Should employ a multidisciplinary approach - Should target high-risk symptomatic patients - Should include competent and professionally educated staff
Components	<ul style="list-style-type: none"> - Optimized medical and device management - Adequate patient education, with special emphasis on adherence and self-care - Patient involvement in symptom monitoring and flexible diuretic use - Follow-up after admission / discharge - Increased access to care - Assessment of unexplained change in weight, nutritional status, symptoms, functional status, QoL, and laboratory finding - Provision of psychosocial support

Multidisciplinary team management of Heart Failure

Multidisciplinary HF teams have the potential to improve quality, access, efficiency and equity of DMP-HF.¹⁷ However, a number of requirements must be met to achieve the best outcome:

First, an experienced, trained and multidisciplinary team is essential to tackle the challenges of HF.⁶ The ESC-guidelines identify HF-cardiologists, GP's and HF-nurses as key actors within this multidisciplinary team.^{6, 13} However to be successful, close collaboration with other experts such as pharmacists, physiotherapists, dieticians, social workers, surgeons, psychologists, is required.^{6, 13}

The combination of the unique skills of each team member addresses the challenges that patients and their families are facing, resulting in better outcome.^{15, 18} For example, it has been shown that close collaboration between cardiologists and general practitioners (GPs) reduces HF-mortality, and that nurse directed care reduces HF-(re)hospitalisation.^{18, 19}

Second, seamless communication between the members of the multidisciplinary team is of utmost importance to ensure continuity of care between the different care levels.^{20, 21} Patients are seen by different health care professionals in different care settings, which requires coordination and communication between e.g. cardiologists, HFN, GPs, primary care nurses, pharmacists, social workers,... and the patient self.²¹ A smooth transition from hospital to outpatient care is necessary to avoid hospital readmissions.¹⁹ When this transition is suboptimal, the risk for readmission rises significantly.²⁰

Third, the multidisciplinary team is a partnership between professional health care providers, the patient and their informal caregivers. They must develop a care and treatment plan together. This plan should also take into account patients goals and expectations.^{22, 23} This person-centred approach helps health care professionals to personalize their approach.²⁴ Moreover, it acknowledges that patients are more than their disease and has significant positive impact on QoL and other outcome.^{22, 23}

Fourth, the multidisciplinary team provides long-term follow-up. This means that the team remains present throughout the course of the disease.²⁵ This results in regular communication

between patients and health care providers but also among health care providers to assess if treatment- and patient goals are being met.^{19, 25} Moreover, they can act proactively and react in case of deterioration.²⁵

Fifth, shared electronic records with notes and reminders that are available for all professional HC-providers within the multidisciplinary team can support interprofessional cooperation and communication and facilitate continuity of care.²⁴

Patient education and self-care support

Adequate patient education with special emphasis on adherence and self-care is a key component of effective HF-management programmes.^{6, 26}

Self-care in HF can be defined as *'a process influencing the actions that maintain psychologic stability (maintenance), facilitate the perception of symptoms (symptom perception) and the response to the symptoms (management) when they occur. It is performed in both healthy and ill states.'*²⁷⁻²⁹

Engagement in self-care behaviour is essential to achieve long-term stability in HF.³⁰ It has been shown that patients who have high knowledge of the mechanisms of HF and their relation to its signs and symptoms are more likely to perform necessary self-care behaviour leading to an improved prognosis.^{31, 32} Moreover, effective self-care is associated with a number of positive outcomes such as QoL, prevention of (re)hospitalisation and maintaining physiologic stability in HF.^{29, 30, 32} However, self-care is complex for patient and their families. Optimal self-care requires understanding of the condition and skills to perform important self-care activities (Table 4).³²⁻³⁴

Table 4. Important Self-care activities ^{32, 34}

- Becoming knowledgeable about the condition
- Adherence to medication, diet and exercise
- Monitoring and self-management of symptoms
- Daily weighing to assess fluid retention
- Seeking assistance when symptoms occur
- Taking preventative activities: stop smoking, limit alcohol intake and receive immunisation
- The ability to move through the different levels of the health care system.

In order to support patients and their families to adapt to their chronic condition and to perform self-care, behaviour education about the nature and complexities of HF is essential ^{25, 27, 30, 33} Therefore, ESC-guidelines recommend that HC-providers provide comprehensive patient education, and defined 12 key topics and self-care skills that should be addressed (Table 5). ^{6, 34}

Table 5. Key topics to be included in patient education ⁶

Definition, aetiology and trajectory of HF (including prognosis)	<ul style="list-style-type: none"> - Understand the cause of HF, symptoms and disease trajectory - Make realistic decisions including decisions about treatment at end-of life
Symptom monitoring and self-care	<ul style="list-style-type: none"> - Monitor and recognize change in signs and symptoms - Know how and when to contact a HC-professional - In line with professional advice, know when to self-manage diuretic therapy and fluid intake
Pharmacological treatment	<ul style="list-style-type: none"> - Understand the indication, dosing and side effects of drugs - Recognize the common side effects and know when to notify a HC-professional - Recognize the benefits of taking medication as prescribed
Implanted devices and percutaneous/surgical interventions	<ul style="list-style-type: none"> - Understand the indications and aims of procedures/implanted devices - Recognize the common complications and know when to notify a HC-professional - Recognize the importance and benefits of procedures/implanted devices

Immunization	<ul style="list-style-type: none"> - Receive immunization against influenza and pneumococcal disease
Diet and alcohol	<ul style="list-style-type: none"> - Avoid excessive fluid intake - Recognize the need for altered fluid intake - Monitor body weight and prevent malnutrition - Eat healthy, avoid excessive salt intake (> 6g/day) and maintain a healthy body weight - Abstain from or avoid excessive alcohol intake, especially for alcohol induced cardiomyopathy
Smoking and recreational substance use	<ul style="list-style-type: none"> - Stop smoking and taking recreational substances
Exercise	<ul style="list-style-type: none"> - Undertake regular exercise sufficient to provoke mild or moderate breathlessness
Travel and leisure	<ul style="list-style-type: none"> - Prepare travel and leisure activities according to physical capacity - Monitor and adapt fluid intake according to humidity - Be aware of adverse reactions to sun exposure with certain medication - Consider effect of high altitude on oxygenation - Take medicine in cabin luggage in the plane, have a list with medical treatments and the dosage with the generic name
Sleep and breathing	<ul style="list-style-type: none"> - Recognize problems with sleeping, its relationship with HF and how to optimize sleep
Sexual activity	<ul style="list-style-type: none"> - Be reassured about engaging in sex, provided sexual activity does not provoke undue symptoms - Recognize problems with sexual activity, its relationship with HF and applied treatment and how to treat erectile dysfunction
Psychosocial aspects	<ul style="list-style-type: none"> - Understand that depressive symptoms and cognitive dysfunction are found more frequently in people with HF which may affect adherence - Recognize psychological problems which may occur in the course of disease, in relation to changed lifestyle, pharmacotherapy, implanted devices and other procedures

However, optimal patient education is more than knowledge transfer from HC-provider to patient. It is *'a process of improving skills and knowledge and influencing attitudes and behaviour with the aim to improve or maintain health.'*³⁵ Thus, patient education requires a tailored approach that takes into account education grade and health literacy of patients and their informal caregiver. Importantly, patient education should actively involve both patients and their informal caregivers.³ Moreover, in order to implement these principles, it is necessary that health care providers are sufficiently trained and supported.^{3, 36} Yet, most HF-health care providers have not received any training considering self-care support.³² This may lead to gaps in patients' knowledge, lack of recognition of HF-deterioration, limited self-motivation and poor knowledge of appropriate action plans.³¹

INTERACT-in-HF study

Although ESC-HF guidelines are the standard of care in many European countries, it has been shown that seamless integrated care has yet to be implemented throughout Europe.³⁷ Thus, it is often unclear how HF-care is organised in practice or to know which health care providers have which role. Moreover due to the complexity of HF, it is often difficult for individual health care providers to take all aspects of the disease into account and act accordingly. Also, the often passive role of the patient, who is not an active part of the multidisciplinary team, may result in low adherence and wrong expectations of care. Hence, the use of optimal (medical) therapy according to the guidelines is often lacking. Furthermore, it is unknown how HF practice differs between countries. Therefore, the Improving kNowledge to Efficaciously Raise the level of Contemporary Treatment in Heart Failure (INTERACT-in-HF) study aimed to explore the current processes of HF-care in three neighbouring ESC North-West European regions in the Netherlands, Germany and Belgium.

This study was part of the Regional Care Portals (RECAP) INTERREG NEW IVb project. The RECAP project aimed to stimulate the uptake and extended use of information and communication technology tools and systems in health care. To do so, research to identify transnational care models and the various organization and regulation frameworks in the three partner regions was needed.

AIMS and OUTLINES of the THESIS

Aims

The aim of this thesis was to gain better insight in the current organization and regulation frameworks in the three partner regions of the RECAP project: Maastricht, Aachen and Noorder-Kempen. More specifically, this thesis focusses on the organization of multidisciplinary care, patient education and self-care support.

Research^{38, 39} has shown that implementation of multidisciplinary-cooperation and self-care support remains challenging for health care organizations and -professionals. This thesis investigates how international guidelines considering multidisciplinary-care and self-care support are adopted and put into practice. Moreover, trained HF nurses (HFN) are considered by ESC-guidelines as an essential partner of the multidisciplinary team. Therefore, the Heart Failure Association (HFA) of the ESC has developed a core curriculum for HFN training. Within this thesis, we investigated how this European curriculum is implemented in the various HFN educations in Belgium, the Netherlands and Germany. Finally, we investigated how the different members of the multidisciplinary team implement guidelines considering self-care support.

The specific aims of this thesis were:

1. To investigate national and regional implementation of ESC-guidelines considering non-pharmacological- and multidisciplinary care both nationally and regionally;
2. To explore the extent to which cardiovascular education programmes in the Netherlands, Germany and Belgium correspond with the HFA-curriculum;
3. To describe non-pharmacological care in terms of patient education and self-care support from the perspective of different health care professionals.

Outline of the thesis

This thesis comprises 6 chapters. The current chapter presents the general introduction which provides the background, the aims and the outline of the thesis. **Chapter 2** describes the study protocol of the INTERACT-in-HF study. **Chapter 3** reports the level of which ESC-guidelines considering multidisciplinary care and patient education and self-care support are implemented both nationally as regionally. **Chapter 4** presents the results related of the comparison of national cardiovascular education programmes with the HFA HF-nurse curriculum. **Chapter 5** shows how ESC-guidelines in terms of patient education and self-care support are currently being implemented by Cardiologists, GPs and Heart Failure Nurses. **Chapter 6** puts the main findings of this thesis into perspective and discusses the main conclusions and limitations.

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Chapter 2

Investigating current Heart Failure care; The INTERACT-in-HF study, study protocol of a mixed methods study

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Abstract

Heart failure (HF) is a complex disease with poor outcome. This complexity may prevent care providers from covering all aspects of care. This could not only be relevant for individual patient care, but also for care organisation. Disease management programmes (DMP) applying a multidisciplinary approach are recommended to improve HF care. However, there is a scarcity of research considering how DMP perform, in what form they should be offered, and what care and support patients and care providers would benefit most. Therefore, the INTERACT-in-HF study aims to explore the current processes of HF-care and to identify factors that may facilitate and factors that may hamper HF care and guideline adherence. Within a cross-sectional mixed method design in three regions of the North-West part of Europe, patients (n=88) and their care providers (n=59) were interviewed. Prior to the semi-structured interviews, patients were asked to complete three questionnaires: The Dutch Heart Failure Knowledge scale, The European Heart Failure Self-care Behaviour Scale, The global health status and social economic status. In parallel, retrospective data based on records from these (n=88) and additional patients (n=82) are reviewed.

Introduction

Despite significant advances in therapy, heart failure (HF) is a highly prevalent chronic disorder with poor prognosis and high socio-economic impact.¹⁻⁴ This impact is likely to further increase as the prevalence of HF in North-West European countries is expected to further increase from approximately 2% at present to 3% by 2025.⁵

Because HF is a complex disease often accompanied by comorbidities, disease management programmes (DMPs) have been introduced.⁶⁻⁸ They include a multidisciplinary approach to manage patients with HF and encompass different components as highlighted in recent guidelines.⁹ If implemented comprehensively, DMPs offer accessible and efficient provision of care¹⁰, which may result in benefits on both quality and cost-effectiveness of care.¹¹⁻¹⁶ Therefore, guidelines¹⁷ advice to organise HF-care in multidisciplinary teams, including nurses, cardiologists and general practitioners (GP's).^{17, 18} In addition to healthcare providers, patient involvement is an important part of DMPs.^{12, 19, 20} However, DMPs are not uniformly implemented in Europe. In part, this may be related to the fact that DMPs do not refer to one single, clearly defined programme, but to an overall concept of delivering care. Thus, care is typically adapted to local needs and national health care systems and the interplay of structure, process and outcomes may vary significantly between different regions.²¹ In clinical practise, it is largely unknown how care is organised.²² In particular, the roles of care providers and inter-professional interactions are often indistinct^{17, 18, 23, 24} and patient perspectives regarding optimal HF-care have been hardly considered.²⁵ Moreover, care providers are sometimes not capable to consider all aspects of HF, given the complexity of the disease²⁶, resulting in inadequate guideline adherence.^{26, 27} Finally, it is unknown if the way how national healthcare is organised, may influence HF-care, and to what extent HF-care differs between countries.

Therefore, the INTERACT-in-HF (*Improving kNowledge Transfer to Efficaciously RAise level of Contemporary Treatment in Heart Failure*) study investigated current practice in chronic HF-care from perspectives of both patients and care providers. We hypothesised that there is variation regarding all aspects mentioned below between individuals, but also between the participating regions and between patients and care providers. The aim of the study was to

explore processes in HF-care to identify factors that may facilitate and factors that may hamper HF-care. For this purpose, a mixed methods study design was set up in three neighbouring regions in the North-West part of Europe. Particular attention was paid to organisational aspects of HF-care including the patients' perspective, the performance of DMPs if present, interaction between care providers and patients as well as interaction between care providers themselves, and the needs and experiences of both. More specifically, we investigated

- Applied diagnostics and therapeutics as compared to current guidelines;
- Reasons of not confirming to guidelines;
- Stakeholders and their role in HF-care from different perspectives;
- The patient flow, information transfer and communication between patients and care providers;
- Referrals and reasons for admission;
- The patients' and healthcare providers' view on quality of HF-care and factors that foster or hinder good HF-care;
- The impact of national healthcare in the Netherlands, Belgium and Germany on HF-care.

The present article presents the protocol of the INTERACT-in-HF study including some preliminary results to give a clear overview over the purpose of this trial, the methods used and the subjects included.

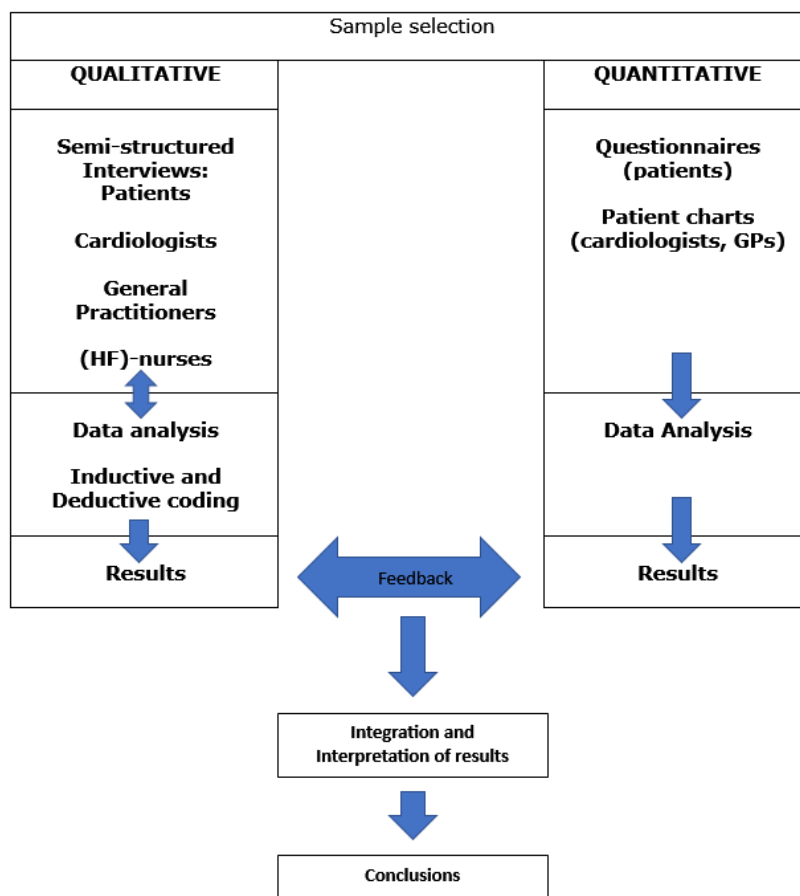
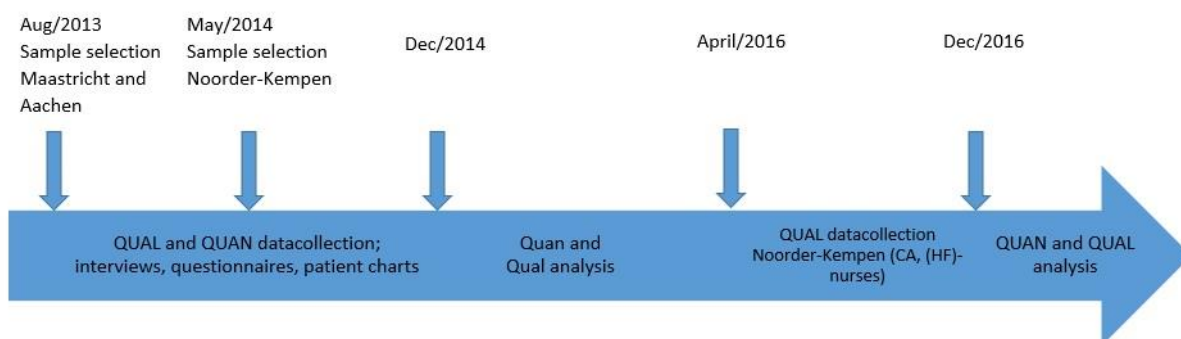
Methods

Study design

A HF-Network of three North-West European regions, Maastricht (the Netherlands; app. 122461 inhabitants) Aachen (Germany; app. 243336 inhabitants) and Noorder-Kempen (Belgium; app. 246021 inhabitants) was set up. Within this network, data were collected from 88 HF patients in primary and secondary care and their care providers (i.e. cardiologists, GP's and (HF-) nurses). A two phase, cross-sectional, mixed methods design was used, encompassing both qualitative and quantitative methods. (Figure 1)

Figure 1. Study timeline and Mixed methods study design:

Abbreviations: QUAL; Qualitative and QUAN; quantitative.



As depicted in figure 1, both quantitative (QUAN) and qualitative (QUAL) results were integrated and interpreted together. This approach is referred to as a triangulation design²⁸ and enables researchers to enhance strengths and to counter weaknesses of both methods (QUAL and QUAN). Triangulation refers to the use of multiple methods or data resources to enhance the methodology.^{29, 30} To meet the aims of this study and to develop a comprehensive understanding of the observations, data triangulation, triangulation of data collection and triangulation of analysis methods were applied (Table 6).^{29, 31-33}

Table 6. Application of different types of triangulation		
Triangulation of data collection	Data triangulation	Triangulation of analysis method
<ul style="list-style-type: none"> - Semi-structured interviews - Patients medical charts - Questionnaires 	<ul style="list-style-type: none"> - 3 NEW – regions: Maastricht, Aachen and Noorder-Kempen - Patients - Cardiologists - GP's - (HF) nurses 	<ul style="list-style-type: none"> - Qualitative analysis of semi-structured interviews using inductive and deductive coding - Quantitative analysis of patient charts and questionnaires

GP's: general practitioners; HF: heart failure.

Sample selection

Purposive sampling was used to include following stakeholders in HF-care: patients, cardiologists, GP's and HF-nurses. In order to avoid selection bias within the patient group, a selection of eligible patients was done by selecting the first, third, fifth, and seventh, patient with HF out of the patient database of the participating cardiologists and GP's.

Based on the protocol of the study, less care providers than patients were included (Figure 2). When interviews with patients or care providers revealed additional care provides relevant to HF care of individual patients that were initially not included in the study, they were added to the study sample.

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Maastricht and Aachen

Between August 2013 and December 2014, care providers from the outpatient HF-clinics of both Maastricht University Medical Centre (The Netherlands) and University Hospital Aachen (Germany) were approached for participation. All agreed to participate and patients were selected as described above. These patients were asked for consent to participate and to allow interviews with their care providers. Subsequently, patients' cardiologists, GP's and HF nurses were interviewed after providing consent for participation. At the HF-centre in Aachen, no specialized HF nurses were employed. To include HF-patients exclusively treated in primary care, participating GP's were asked to deliver a list of patients with the main diagnosis of HF that were treated only by them. From this list, the sample was selected as described (Figure 1 and 2 (a) and (b)).

Figure 2a. Sample selection Maastricht

Abbreviations; interview (I) and data (D)

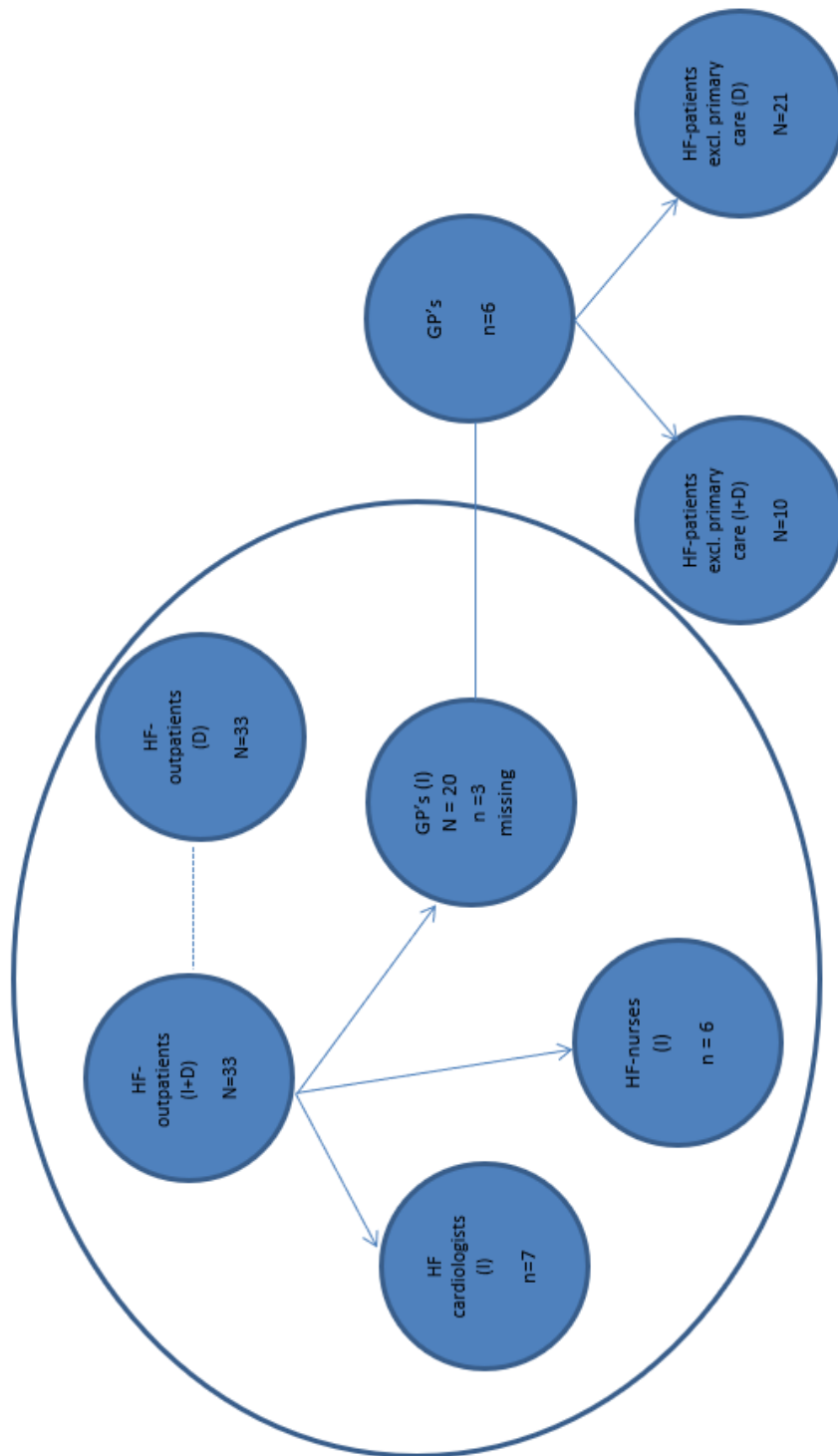
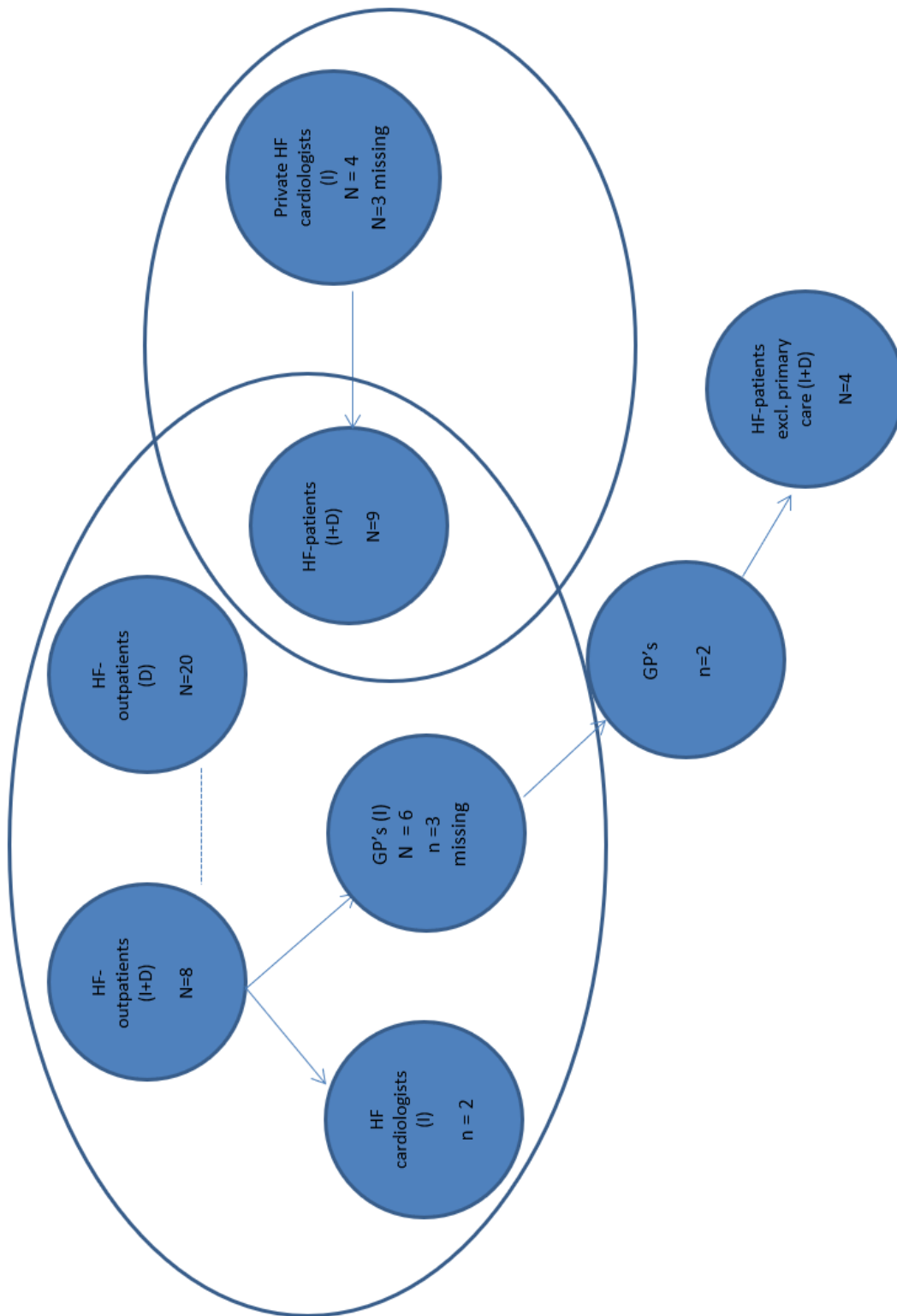


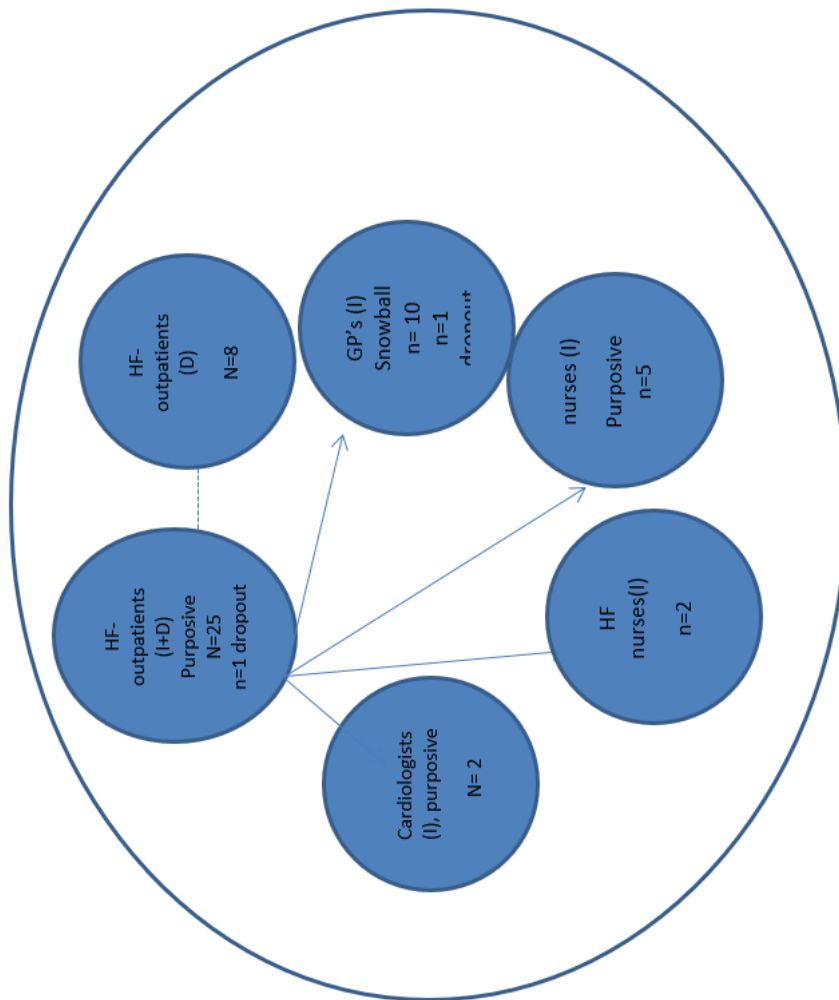
Figure 2b. Sample selection Aachen



Noorder-Kempen

Patients in Noorder-Kempen were initially selected at primary care level due to logistic reasons. GP's and members of the regional GP-association were approached for participation in this study. In order to have sufficient participation, the snowball sampling method was used.³³ Interviews with patients and GP's were preformed between May and November 2014. Cardiologists and (HF)-nurses have been interviewed between April and December 2016 (figure 1 and 2C).

Figure 2c. Sample selection Noorder-Kempen



Inclusion and exclusion

Patients were included if they fulfilled the following criteria: HF diagnosis due to left ventricular dysfunction, irrespective of underlying diagnosis and left ventricular ejection fraction (LVEF), age above 18 years, and being capable to understand instructions. Except for heart transplantation and lack of informed consent, no exclusion criteria were applied.

Ethical considerations

The protocol was approved by the Ethics Committees of Maastricht University Medical Centre, the University of Antwerp and the University of Aachen. Participating patients and care providers provided written informed consent after receiving oral and written information. The study followed the principles according to the Declaration of Helsinki.

Measurements and data collection

Qualitative part - Interviews

Patients underwent a semi-structured interview, starting with the open question: 'How did your heart problems start?' In response to this question, a number of upcoming issues in the patients' narrative were discussed. Alongside emerging topics, a set of predefined topics and questions were addressed to all patients to address the objectives of this study (Appendix 1a).

Care providers participated in semi-structured interviews about their experiences of HF care in general and in relation to their patient participating in the study. Interviews with care providers started with the open question: 'What does HF mean to you?' The interview topics addressed understanding and knowledge of HF, use of guidelines, roles of care providers in HF-care and communication (Appendix 1b).

The topic list was developed after expert meetings with several HF-care stakeholders (patient organisation, GP's/GP networks, HF-specialists, general cardiologists, internists, geriatrician, representatives of healthcare insurers, representatives of Dutch ministry of health). The topics were adjusted during progress of the interviews. This so called iterative approach allows emerging themes and ideas to be included in subsequent interviews, but also altering the

research methods and hypothesis as the study progresses.³³ Interviews were performed by trained research staff members (three male and six female) with different professional backgrounds. Interviews were performed by KB (F, 38y, public health nurse, master in health sciences), RS (M, 40y, physiotherapist), MM (M, 50y, post graduate relation and communication science), SB (F, 31y, MD), ZS (M, 28y, medical student), BON (F, 24y, medical student), DR (F, 27y, MD), CR (F; 25y; MD student), CH (F, 42y, MD). CR and CH interviewed all German participants. CR is a native German speaker (German parents) living in the Netherlands since childhood.

Interviewers did not have a patient-care provider relationship and had no contact with the patient prior to the interview. In Maastricht and Aachen, most patient interviews were performed in the outpatient clinic. Due to mobility problems or patients' preference, some interviews were performed at home. Because all Belgian patients were selected in primary care, interviews were conducted at home. In all participating countries, care providers were interviewed in their work environment. The average interview duration was 30 and 60 minutes for care providers and patients, respectively.

Dutch and Belgian interviews were coded separately. An attempt to merge the databases showed that there were too much codes, and that it was impossible to merge because of the different ways of coding. Subsequently, all interviews were re-coded and codes were restrained from 6090 to 670 distributed over 5 levels. In case of disagreement, analysts deliberated until consensus was reached. Primarily the Dutch and Belgian codebooks were merged. After consensus about the German codes, all databases were merged.

Quantitative part

Questionnaires

Prior to the interviews, patients completed three questionnaires:

- A. The Dutch Heart Failure Knowledge scale (DHFKS), a 15-item self-administered questionnaire (score 0-100), covers items concerning general HF knowledge, symptoms, symptom recognition, and HF treatment.³⁴ The non-validated German version was used in Aachen.³⁵
- B. The European Heart Failure Self-care Behaviour Scale (EHFScBS), a 12-item self-administered questionnaire (score 0-100), addresses several items concerning self-care in HF behaviour. Every item scores on a Likert scale from 1 (completely agree) to 5 (completely disagree).³⁶
- C. The global health status and social economic status (SES), a 20-item, self-developed global socio-demographic questionnaire, was used to evaluate general understanding of HF. This questionnaire includes self-reported general health status, educational level, smoking status, physical activity status, employment, knowledge about HF, and medication use.

Clinical characteristics

Data from patient charts were collected to determine patient characteristics. In addition, retrospective data of additional HF-patients were collected to test if diagnostic and therapeutic processes of the interviewed patients were representative. The following clinical characteristics were extracted from patient charts: age, gender, cause of HF, other cardiovascular diseases, comorbidities, cardiovascular risk factors (diabetes, hypertension, hypercholesterolemia, smoking), healthcare utilization within the last year, NYHA-class, weight and height, blood pressure, heart rate as well as diagnostics used: ECG (rhythm, QRS-duration), echocardiography, and laboratory findings. HF aetiology and comorbidities were only considered if registered in patient charts. Cardiac medication and changes over time were recorded. Medical charts were provided by the participating hospitals of Maastricht, Aachen and the GP's in Noorder-Kempen.

Analyses

Quantitative data are presented as frequencies (%), mean (SD), or median (IQR), as appropriate. The statistical programme SPSS v 20.0 (IBM) was used for data analysis.

All interviews were audiotaped (Smartpen, Livescribe, Oakland, California USA), transcribed verbatim and analysed by the qualitative analysis software programme NVivo 10. All interviews were coded independently by SB, LBD, KB and CR. An independent expert, MD, reviewed data extraction in NVivo. Areas upon which coding differed were reconsidered until consensus was achieved.³⁷

Results

Patient characteristics

Patient characteristics are given in table 7. Approximately 61 % of patients were male with a mean age of 77 years. Most common cause of HF in patient charts was coronary artery disease (CAD) followed by dilated cardiomyopathy (DCM). The cause was unknown in almost 30% of the cases. Cause of HF was less known in the group of Noorder-Kempen, where patients were recruited in primary care only. Patients included in Aachen were younger as the Aachen University Hospital is a tertiary referral centre, and prevalence of known cardiac risk factors was less common (Table 7).

Table 7. Patient characteristics per region

	Total N=170 (%)	Maastricht n=97 (57%)	Aachen n=41 (24%)	Noorder- Kempen n=32 (19%)
Demographics				
- Age, years [mean (range)]	77 (64-85)	79 (71-85)	61 (55-69)	88 (83-90)
- Gender, male [n,%]	104 (61)	52 (54)	37 (90)	15 (47)
Cause of HF [n,%]				
- CAD	55 (32)	30 (31)	22 (54)	3 (9)
- HHD	21 (12)	16 (16)	0 (0)	5 (15)
- DCM	45 (26)	28 (29)	15 (37)	2 (6)
- VHD	5 (3)	2 (2)	1 (2)	2 (6)
- Unknown	44 (26)	21 (22)	3 (7)	20 (63)
Comorbidities [n,%]				
- Diabetes Mellitus	31 (18)	21 (22)	8 (20)	2 (6)
- Hypertension	57 (34)	45 (46)	2 (5)	10 (31)
- Hypercholesterolemia	32 (19)	26 (27)	3 (7)	3 (9)

Abbreviations: HF, heart failure; CAD, coronary artery disease; HHD, hypertensive heart disease; DCM, dilated cardiomyopathy; VHD, valvular heart disease

Qualitative codebook

Prior to qualitative analyses, a framework was developed to enable efficient, consistent and in-depth analysis of data. This framework contains key aspects of HF-management experienced by patients, addressed by care providers and highlighted by guidelines. Emerging topics were arranged within one of these themes (Table 8) and registered in a codebook. Inductive analysis resulted in 6090 different codes. Thereafter, a deductive approach³³ was applied to these codes to reduce the number of codes by merging common themes, finally resulting in 684 codes.

Table 8. Framework of qualitative analyses

Definition of HF, signs and symptoms
Diagnosis
Treatment (invasive treatment + observed processes e.g. discussion making in treatment)
Treatment: medication
Lifestyle advice
Follow up and support
Communication
Roles of care-providers
Cooperation
Trajectory (evaluation)

Discussion

National and international guidelines are developed to define best practice in HF-management. In order to achieve this, a multidisciplinary-, patient centred approach organised in DMP is suggested.^{15, 17} Several initiatives have been initiated, yet implementation of DMP in Europe is still incomplete.²² Although DMP are structurally implemented in the Netherlands in most centres, this is not always the case in other European countries including Belgium and Germany. The INTERACT-in-HF study has been set up in three neighbouring North-West European regions because of these difference, but comparable demographic features of included patients. Also, national organisation of health care differs between the participating regions.^{38, 39} This allows us to get more insight into care processes, circumstances leading to successful implementation of guidelines, and bottlenecks hindering optimal organisation of HF-care.

This study included main stakeholders in the three regions in the North-West part of Europe. Underlying cause of HF was unknown in many patients suggesting differences in the diagnostic work-up of patients in primary and secondary care, highlighting the need for a study such as this one. The attempt of displaying a comprehensive picture of HF-management is crucial to understand current practice and its challenges. Several studies about HF-care organisation ignore the roles and responsibilities of different care providers possibly due to the fact that roles are not well defined in guidelines. This may, however, cause organisational and/or communicational uncertainties in daily practice.^{17, 18, 20, 23, 24, 40-42}

How to assess care process in chronic diseases?

Currently, there is no standardized approach to obtain a precise overview of the standard of HF-care.¹⁵ According to Bowling, 2002⁴³, “the most persuasive evidence comes through a triangulation of measurement processes, as well as through minimizing the error contained in each instrument.”⁴³⁻⁴⁵ Therefore, we used this mixed methods approach. This implies the use of multiple, complementary, measurement strategies to examine complex clinical problems.⁴⁴
⁴⁵ By using qualitative research, the study aims to gather an in-depth understanding of human behaviour and its governing reasons. More importantly, the qualitative method investigates the why and how of decision making, not just what, where and when. The combination with quantitative data improves validity as they provide information about the representativeness of patients included in the study.

During the initial coding process, we used an inductive approach to avoid relevant variables of interest remaining undetected. The most fundamental characteristic of an inductive approach is the holistic view. Thus, information provided in interviews was approached independently and without any prior knowledge of concepts, thus avoiding bias due to own experiences. Other characteristics of an inductive approach are purposive sampling and an iterative approach.⁴⁵⁻⁴⁹ Purposive sampling aims to include subjects with an additional value to answer the research question³³, whereas the iterative approach is useful to investigate processes. The inductive approach generates validity because its closeness to the truth.^{48, 50} Finally, intercoder-reliability is used to determine the coders’ consistency. Therefore, the approach used in this study will provide comprehensive insight into HF care in the three regions to test our hypothesis of significant variation in care between regions, but also between individuals.

To the best of our knowledge, this is the first study, using a selection of participants within the purposive sample of patients comparing three different countries. This combined approach providing a large amount of data, was used to achieve a representative description of HF-care in the investigated regions. In order to maintain the benefits of the inductive approach and ensure reliability^{48, 50}, the deductive codebook was based on the data gathered from the inductive approach. Deduction implies a focus on objective analysis of data and systemizes

qualitative research, thereby making it more reliable. The codebook was developed by three researchers with different professional backgrounds to eliminate selection of variables of interest; i.e. one MD and two nurses. One of the nurses was experienced in mixed methods studies, the MD had experience in heart failure and the other nurse in organisation of care. This allows objective description of important aspects of HF-care in the different regions, which is a prerequisite to define properly hindering and supporting factors of good quality care.

Altogether, this methodology is capable to provide a broad and reasonably unbiased insight into the organisation of HF-care.

Strengths and limitations

A strength of this study is the inclusion of a broad study population with sufficient number of both patients and care providers in primary and secondary care.

Compared with other studies, triangulation of data collection and analysis is an advantage. Although interviews took place in three different European regions, all interviews were peer-reviewed by the same investigators. Furthermore, they were coded independently and results were merged after coding. To minimise bias by interviewers, predefined questionnaires were used by means of a semi structured interview. To improve validity, the interview topic list was the same for all countries. Mastering of the German and Dutch language by the German interviewer prevented for bias due to translation. Thus, these measures may reduce the risk of bias significantly, whereas the combined use of inductive and deductive methodology improves reliability. Still, potential bias due to use of different interviewers, data-analysts, and languages cannot be completely excluded and needs to be considered when interpreting the results.

The patient centered approach focused primarily on the patients' perspective, which was similar in all three regions. This is important as care is often organised from the care providers' perspective which may not always address the patients' needs.

We acknowledge the limitation of retrospective quantitative data collection, but since we were interested in the least biased information obtained during interviews, we preferred the retrospective approach to collect quantitative data. Preliminary results demonstrate that

presence of comorbidities are not concordant to other evidence-based studies.⁵¹⁻⁵³ This suggests that some comorbidities may be undetected. Still, this supports the need of in-depth-studies on chronic diseases care such as this study.

Although guidelines state that DMP are necessary to address challenges of HF, the concrete content of DMP is not well defined and may vary significantly between individual centres. Therefore, results of this study might not be directly applicable to other centres using DMP. Also, we recognize the fact the selected regions might not be representative for all regions of the participating countries, i.e. the Netherlands, Belgium and Germany, and more differences between regions and countries is likely regarding Europe as a whole. Still, our study will give important insight into differences regarding many aspects of HF care that are useful and applicable not only to the investigated regions.

Finally, patient recruitment in the three regions differed considerably, which resulted in differences between patient groups. In particular, patients were recruited from primary care only in Belgium due to logistic reasons and mainly tertiary care patients were included in Aachen. The potential impact of this difference cannot yet be determined, but needs to be considered in further analyses.

Conclusion

This study will provide an in-depth insight into processes in chronic HF-care, patient and care providers' knowledge and preferences, the interaction and communication between stakeholders and the needs for improvements in HF-care. It will also define bottlenecks that may hinder good clinical practice, but also aspects that supports it. These results will help to understand the needs for providing well-organised excellent HF-care.

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APPENDIX 1A

Interview framework patient

- ☐ How did your heart problems start?
- ☐ Cardiac diagnosis
 - ☐ Cause of heart failure?
 - ☐ Definition heart failure?
 - ☐ How long do you know your diagnosis?
- ☐ Information about heart failure
 - ☐ What kind of information did you receive?
 - ☐ Oral or written information?
 - ☐ Who informed you?
 - ☐ Does the patient feel he received enough information?
- ☐ Diagnostics
 - ☐ What kind of diagnostics?
 - ☐ When/ Where?
 - ☐ Information (oral/written information)?
 - ☐ Own input?
- ☐ Interventions
 - ☐ Which interventions?
 - ☐ Waiting time?
 - ☐ Information (oral/written?)
 - ☐ Enough information?
 - ☐ Own input?
- ☐ Medication
 - ☐ Which medication?
 - ☐ How much medication?
 - ☐ Posology?
 - ☐ Compliance?
 - ☐ Information? (oral/written?)
 - ☐ Enough information?
 - ☐ How do you experience this medication?

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- ☐ Lifestyle changes
 - ☐ Which lifestyle advice?
 - ☐ By whom?
 - ☐ Compliance?
 - ☐ Impact on your ADL?
- ☐ Care provider
 - ☐ Who gave you your diagnosis?
 - ☐ What kind of care providers are involved in your heart failure care?
 - ☐ How do you experience communication between care providers?
- ☐ Other non-cardiac care providers?
- ☐ Living with heart failure
 - ☐ Changes in ADL?
 - ☐ Limitations?
 - ☐ Support from social network/care providers?
- ☐ Does the information you received confirms your own experience?
- ☐ Care organization
 - ☐ How do you experience care?
 - ☐ Room for improvement?

APPENDIX 1B

Interview care-provider

- ☐ What does heart-failure mean to you?
- ☐ Function in heart failure care?
- ☐ Number of heart failure patients you meet?
- ☐ Specific interest in heart failure?
- ☐ Which strategy used when confronted with a heart-failure patient?
 - ☐ Guidelines, evidence vs experience based
- ☐ Communication with other care-providers
 - ☐ Cardiologists, heart-failure nurses, general practitioners,....
 - ☐ Feedback?
 - ☐ Principal care provider?
- ☐ Referral
 - ☐ Do you refer?
 - ☐ What is the function of a heart failure nurse
- ☐ Patient contact
 - ☐ Frequency of consultation
 - ☐ Compliance?
- ☐ Diagnostics
 - ☐ Which diagnostic test?
 - ☐ Why
 - ☐ Patient information?
- ☐ Interventions
 - ☐ Which interventions
 - ☐ Why
 - ☐ Patient information?
- ☐ Prescription of medication
 - ☐ Which medication
 - ☐ Why
 - ☐ Patient information

APPENDIX 2

Questionnaire

Patient:

General information

Name: _____

Address: _____

Sex: _____

Birthdate and place: _____

Height and weight: _____

Marital Status: _____

Drivers license: _____

Education Level: _____

Date interview (dd-mm-yyyy): _____

Telephone Number(s): _____

Email address: _____

Risk factors

Do you smoke No
I used to: when did you stop smoking?

Yes, how many cigarettes per day?

Do you drink alcohol? No
I used to, when did you stop drinking?

Yes, how many units per week?

Are you obese? No
Yes, how do you know?

Are there cardiovascular diseases in your family? No
Yes, which ones?

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Do you have a high blood pressure?	No Yes
Do you have a high cholesterol level?	No Yes
Are you a diabetic?	No Yes
<u>Care data</u>	
Who is your main practitioner?	_____
What do you think heart failure is?	_____ _____ _____
Do you have heart failure?	_____
Which symptoms do you associate with heart failure?	_____ _____ _____
Do you still have a professional career?	No Yes, what kind of work: _____
Do you use medication?	No Yes, which one: _____
Do you still exercise?	No Yes, which one: _____
How many times a week do you exercise?	1 time per week 2-3 times per week 3-4 times per week more than 4 times per week
What is your general health status?	Excellent, because: _____ Good, because: _____ Moderate, because: _____ Poor, because: _____

Chapter **3**

From Guideline to Daily Practise, Implementation of ESC-guidelines considering Multidisciplinary and Non-pharmacological Care in Heart Failure

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Abstract

Introduction

To alleviate the burden of Heart Failure (HF), the European Society of cardiology developed guidelines (ESC-guidelines) to optimise HF-diagnosis and treatment. These guidelines state that optimal HF-care is organised in a multidisciplinary programme in which pharmacological and non-pharmacological treatment is offered. Research has proven that multidisciplinary programmes and effective self-care behaviour significantly reduce HF-mortality and (re)hospitalisation, yet little is known about implementation of these ESC-guidelines. Therefore, the INTERACT study investigated current HF-care processes and guideline adherence in three North-West European regions: Maastricht (the Netherlands), Aachen (Germany) and Noorder-Kempen (Belgium).

Methods

A case-study approach was adopted to study local implementation of ESC-guidelines considering non-pharmacological- and multidisciplinary care. National guidelines and local protocols were collected and studied to investigate the level of agreement with and implementation of ESC-guidelines. A matrix was developed to analyse the content of national and local guidelines and protocols in terms of non-pharmacological and multidisciplinary care.

Results

All national organisations promote ESC guidelines, and some developed additional national guidelines. In region A, B and C patients receive multidisciplinary care in hospital based HF-outpatient clinics. Moreover, region B and C patients can benefit from either structural (region B) or project based (region C) integrated care, where specialist- and primary care work together to provide seamless care for HF-patients. However, in region A this seamless integrated care remains to be implemented.

Conclusion

Although ESC-guidelines recommend clearly considering Multidisciplinary- and non-pharmacological care implementation may differ between regions.

Introduction

Heart Failure (HF) is a chronic and complex disease with poor prognosis and high socio-economic impact. ¹ To alleviate HF burden, the European Society of Cardiology (ESC) developed guidelines to optimise diagnosis and treatment of acute and chronic heart failure. ² These guidelines state that optimal HF-care should be organised in a multidisciplinary programme (MDisc-programme) and should contain a combination of both pharmacological and non-pharmacological treatment in terms of patient-education to promote self-care. ²

It has been proven that MDisc-programmes lead to an increase of evidence-based therapies. ³ Effective MDisc-programmes consist of a number of critical elements such as a well-trained seamlessly interacting multidisciplinary team ^{2,4} with low-threshold accessibility, the presence of HF-outpatient clinics, and guideline adherence. ^{2,5,6} Seamless HF-care throughout all levels of care is of utmost importance to tackle the challenges that HF imposes on patients, their caregivers and healthcare. ^{2,6}

Within ESC-guidelines, MDisc-management programmes receive a Class IA recommendation, meaning that there is ample evidence that these programmes have a significant impact on clinical outcome. ² Moreover according to these guidelines, successful MDisc-management programmes are designed to improve outcomes through structured follow-up with patient education, optimizing medication, psychosocial support and improved access to care. ² Furthermore, an overview of characteristics and components of MDisc-management programmes is provided. ²

Self-care support and education are considered key components of these MDisc-programmes. ² Effective self-care leads to a decrease in mortality, rehospitalisation, symptom burden and distress, and an increased quality of life (QoL). ⁷⁻⁹ In fact, effective self-care may be as beneficial as pharmacological therapy. ⁷

Therefore, ESC-guidelines formulate 12 key topics and self-care skills that patient education should include, but little is known about national and local implementation of these recommendations. Therefore, the Improving kNowledge Transfer to Efficaciously Raise the level

of Contemporary Treatment in Heart Failure study (INTERACT-in-HF study) investigated current processes of HF-care and guideline adherence in three North-West European regions in the Netherlands, Belgium and Germany.¹

Methods

The purpose of this study was to obtain an in-depth understanding of the implementation of ESC guidelines regarding MDisc-care and non-pharmacological therapy in HF-patients within the three INTERACT-regions. To do so, a case-study approach as method to explore, analyse and understand important issues related to this implementation was adopted.^{10, 11} In total six cases were selected. Each selected case had a close relation with the INTERACT-in-HF study.

Therefore, data was collected in two consecutive phases:

Firstly, we consulted representatives of national medical and nursing cardiovascular associations via e-mail to inquire about national HF-guidelines in terms of MDisc-care, patient education and self-care support.

Secondly, to study local implementation of ESC and/or national guidelines an internet search took place and researchers reached out to regional healthcare facilities and to HF-care professionals via e-mail. These professionals were asked to provide information and/or documents considering the organisation of HF-care in their organisation. The acquired documents were studied by two researchers (KB and JB) and screened for keywords and topics related to MDisc- and integrated care and non-pharmacological care (Appendix 3).

Consecutively, to verify online information researchers consulted project managers or staff members. If written care-protocols in terms of (non-pharmacological) HF-care were lacking this was discussed with local HF-specialists. These interviews took place in September 2020. Furthermore, an short interview guide was developed to discuss the organisation of non-pharmacological care (Appendix 3).

To analyse the content of all documents and interviews into detail, a matrix was developed. This matrix represents all MDisc- and non-pharmacological care topics explicitly addressed in the various investigated national documents or mentioned by local HF-specialists during their interview.

The INTERACT-study was approved by the Ethics committees of Maastricht University Medical Centre (reference number: 124074) of the University Medical Centre of Antwerp (reference number: UC UZA 14/6/54) and the University of Aachen (reference number: EK023/13) and complies with the Declaration of Helsinki.

Results

National guidelines

The search for national guidelines revealed that national cardiovascular organisations, national organisations for primary care physicians and national organisations of cardiovascular nurses promote ESC guidelines to their members. Additionally, as shown in table 9, several organisations provide their members with national guidelines based on either ESC 2016, ESC 2012 or ESC 2008 guidelines.

The content of these guidelines in terms of MDisc-care and patient education is summarized in table 10 showing differences between different guidelines and as compared with the ESC guidelines.

Table 9. HF-guidelines in the Netherlands, Belgium and Germany in relation to their importance

Guidelines			
	Belgium	the Netherlands	Germany
Cardiologist	ESC guidelines (2016)	ESC 2016 guidelines	ESC guidelines (2016)
		National Transmural Protocols (LTA) (2015)	ESC Pocket Guidelines (2016)
		Multidisciplinary Guideline Heart Failure (2010)	
		NHG-standard Heart Failure (2010)	
GP's	Guidelines Domus Medica/SSMG (2010)	NHG-standard Heart Failure (2010)	ESC Pocket Guidelines (2016)
		National Transmural Protocols (LTA) (2015)	National Health Care guideline Chronic Heart Failure (2019)
	ESC guidelines (2016)	ESC guidelines (2016)	ESC guidelines (2016)
HFN	ESC guidelines (2016)	National Transmural Protocols (LTA) (2015) ESC guidelines (2016)	ESC guidelines (2016)
		Multidisciplinary Guideline Heart Failure (2010)	
		NHG-standard Heart Failure (2010)	

Table 10. Content of national guidelines in terms of MDisc- and non-pharmacological care

		the Netherlands			Belgium	Germany	
	ESC HF-guidelines	National Trans-mural Protocols	Multidisciplinary Guideline HF	NHG standard HF	Chronic HF by Domus Medica	ESC pocket guidelines	National Health Care Guideline Chronic HF
Multidisciplinary HF-care							
	X	X	X	X	X	X	X
Topics of patient education and self-care support							
Definition, aetiology and trajectory of HF (including prognosis)	X	X	X				
Symptom monitoring and self-care	X	X	X			X	X
Pharmacological treatment	X	X	X	X	X	X	X
Implanted devices	X						X
Immunization	X		X	X	X		X
Fluid intake	X	X	X	X			X
Body weight	X	X	X	X	X		X
Healthy eating	X		X	X		X	X
Salt intake	X	X	X	X	X		X
Alcohol	X		X	X	X		X
Smoking and recreational substance use	X		X	X	X	X	X
Exercise	X	X	X	X	X	X	X
Travel and leisure	X		X	X			
Sleep and breathing	X		X				
Sexual activity	X		X		X		X
Psychosocial aspects	X	X	X		X	X	X
Driving			X	X			
Pregnancy			X				

MDisc-care and Non-pharmacological care in the Netherlands

All national HF-guidelines in the Netherlands provide a framework for MDisc-cooperation based on the characteristics and components of MDisc-programmes as defined in ESC guidelines. Furthermore, they discuss several key topics for patient education and self-care support described in ESC guidelines. However, education concerning implanted devices is not discussed and other topics such as sleep and sexual activity are discussed in one or two national guidelines. Moreover, one national guideline discusses driving and pregnancy, both of which are no topics in the ESC-guidelines (Table 10).

MDisc-care and Non-pharmacological care in Belgium

The Belgian organisation for primary care physicians has developed CHF-guidelines, in which the effectiveness of MDisc-programmes, the role of GP's in terms of HF and several of the key topics for patient-education and self-care support are discussed. Yet, these guidelines do not include topics concerning definition and aetiology of HF, symptom monitoring, implanted devices, travel and sleep (Table 10).

Moreover, no disease management programme for HF (DMP-HF) is yet in place in Belgium.¹²⁻¹⁴ Discussion with Belgian HF-professionals revealed that since September 2019 a learning HealthCare System HF has been established to facilitate implementation of multidisciplinary and transmurals HF-care in Belgium.¹⁵

MDisc-care and Non-pharmacological care in Germany

Both guidelines of the German Cardiovascular association and the German association for primary care physicians discuss MDisc-care and patient education in terms of lifestyle adjustments and self-care support. The guidelines of the German Cardiovascular association summarize ESC-recommendation. The guidelines of the German Association of Primary Care Physicians discuss MDisc-care in terms of revalidation, and most topics that should be included in patient education. Topics concerning definition and aetiology of HF, travel and sleep are not included (Table 10).

Moreover, the German Cardiovascular association has, together with the German association for thoracic and cardiovascular surgery and the German association of cardiologists in private practice, developed quality criteria for integrated care, in which three levels of HF-care are defined. For each level the criteria for accreditation in terms of facilities, equipment and staffing are determined. All accredited organisations in one region form a regional integrated HF care network.¹⁶

Additionally, German HF-professionals informed the principal investigator that in 2018, the German Government approved a national disease management programme (DMP) Heart Failure (DMP-HF) in which patients receive specialist- and MDisc-care and patient education. However, this DMP-HF has yet to be implemented.

Local implementation of guidelines

Table 11. Local guideline implementation in the different regions					
	Region A	Region B		Region C	
	outpatient clinic	outpatient clinic	integrated care	outpatient clinic	integrated care
Multidisciplinary HF-care	X	X	X	X	X
Topics of patient education and self-care support					
Definition and aetiology including prognosis		X	X	X	X
Symptom monitoring and self-care		X	X	X	X
Pharmacological treatment/ therapy adherence	X	X	X	X	X
Implanted devices				X	
Immunization		X	X	X	
Diet and alcohol					
- Weighing	X	X	X	X	X
- Salt intake	X	X	X	X	X
- Fluid intake		X	X	X	X
- Alcohol					
- Healthy eating		X	X	X	X
		X	X	X	
Smoking		X	X	X	X
Exercise		X	X	X	X
Travel and leisure		X	X	X	
Sleep		X	X		
Sexual activity			X	X	
Psychosocial aspects		X	X	X	X
Management of comorbidities		X	X		
Follow Up			X		X
Revalidation		X		X	

Region A

In region A, one hospital has been accredited as an interregional specialized HF-centre, meaning that it offers high level specialist and MDisc-care to HF-patients. An interview with a local HF-professional revealed that within the HF-outpatient clinic follow-up is provided by cardiologists and HFN. At the moment, no written protocol considering non-pharmacological treatment is agreed upon. However, cardiologists educate patients considering fluid, weight and salt-intake. If necessary, patients receive support in their pharmacological therapy adherence by HFN (Table 11). Since other healthcare facilities in the region have yet to be accredited as HF-centre, structural integrated care as described in the integrated care path is not yet part of HF-care in the entire region. Communication and exchange information considering patient cases takes place in direct contacts between GP's and cardiologists.

Region B

In region B, a working group consisting of representatives of the HF-team and of primary care caregivers developed the protocol about HF-treatment and collaboration. Within this protocol it is agreed that specialised care professionals treat newly diagnosed, unstable and high complex patients. Chronic, stable HF-patients are monitored by their GP and practise nurse, whereas both are able to seamlessly consult the HFN or cardiologist in case of problems. Allocation to the most appropriate professional occurs by means of a self-developed instrument. All investigated local protocols focus on ESC-guidelines considering patient education and self-care support (Table 11).

Region C

In region C, an in-hospital HF-programme both for patients who are admitted with HF as for outpatients has been set up. Within this programme, MDisc-care is provided by cardiologists and HFN in collaboration with other specialist disciplines involved in HF-care. Furthermore, an integrated care project for HF-patients has been established. This project is a partnership between the hospital based MDisc-programme and primary care. After HF-hospitalisation participating patients receive a follow-up home visit by a primary care nurse HF-manager. The

latter also coordinates primary care for HF-patients and supports them with their self-care. Within the project, no formal education manual exists yet. However, the European Heart Failure Self-care Behaviour scale-9 is used as a topic list.¹⁷ Additionally, medication i.e. adherence and self-medication, and wellbeing is assessed. Education is tailored according to the individual needs and questions of patients and their informal caregiver. Afterwards, a report is send to the primary care physician. Table 11 provides an overview of the topics discussed during these sessions.

Discussion

This study shows that ESC guidelines are widely adopted by national medical and nursing cardiovascular associations, and that most of them either adopt or translate these guidelines into national guidelines. Yet, the level of implementation of ESC-Guidelines in terms of MDisc-care and patient education differ among the investigated nations and regions.

On national level in Belgium, a general strategy for chronic diseases was adopted. However, experts deem this strategy too generic to have a significant impact on HF-care.¹² Moreover, the Belgian Board of cardiovascular Pathology recommends MDisc-programmes for HF as a collaboration between a cardiologists with special interest in HF and a HFN who provides education and follow-up.¹³ These programmes are not yet broadly implemented and no national DMP for HF exists in Belgium yet.^{13, 14} Moreover, the Belgian government does not recognise HF-specialist, nor provides reimbursement of HF-education or determining NT-pro-BNP.¹² This may, in part, explain that only a minority of Belgian hospitals developed a MDisc-programme for HF.¹³

Nevertheless, following the need for more integrated and MDisc-care, integrated care projects are currently being implemented throughout the country. Within each of these projects, hospital based specialist care cooperates with primary care. Unfortunately, no information was exchanged between the projects, which means that they all encountered the same problems without being able to learn from each other. To unite these different integrated care projects in the Flemish region in Belgium and work together towards a better HF-care, a learning

HealthCare Network HF was established.¹⁸ This network unites eight different regional integrated HF-projects in the Flemish region in Belgium. It aims to create an accessible, open and dynamic network in which knowledge and data can be exchanged to improve HF-care.¹⁸ Moreover, it aims to facilitate the implementation of an MDisc-programme for HF in primary care.¹⁸ This guideline driven bottom-up approach shows the urgent need to improve HF-care and HF-outcomes, yet it still has to be evaluated and scaled up.

In Germany, national criteria for integrated HF-care have been developed by the German Association of Cardiology. Healthcare facilities can apply for accreditation as HF-centre to take part in the integrated care network. In the whole of Germany 158 accredited HF-centres are in place.¹⁹ Moreover, a national DMP-HF has been developed. However, The German Federal office of Social Security assessed this DMP-HF and concluded the education programme was not yet sufficiently evaluated and implemented in the outpatient setting.^{20, 21} Moreover, it also remains unclear what kind of professionals need to be involved in the DMP-HF, and how the responsibilities among the team members should be distributed.²¹ The German association of Cardiology promotes physician directed care in which the physician a.o. educates patients in cooperation with specialised nurses, however, this is not according to ESC-guidelines and may limit the impact of patient education. Additionally within the DMP-HF, HFNs are not identified as key partners, which is in contrast to ESC-guidelines who identify HFN in addition to cardiologists and GP's as one of the primarily involved HF related care givers.²

All investigated DMP's, national guidelines and local protocols include patient-education and self-care support. Yet, it is noticed that none of them addresses all key topics defined by ESC-guidelines. Topics considering lifestyle adjustment, symptom monitoring and therapy adherence are widely implemented whereas topics such as sleep, travel and sexual activity are rarely included. Yet, these topics have a significant impact on the quality of life and the progression of HF, too.^{22, 23}

Patient education and self-care support are cornerstones of integrated care services, since both have the potential to improve patients' knowledge and self-care abilities.²⁴ Within region A and B, patient education is provided in the HF-outpatient setting by HFNs and in one by

primary care nurses in the primary care setting. In addition, in both regions, protocols for comprehensive patient-education and self-care support are in place. In region C, in the HF-outpatient setting, patient education is provided by cardiologists. Only patients whose therapy adherence is lacking, receive additional education and support by HFNs. However, whereas HFNs are specifically trained to educate and support patients, cardiologists receive little training on this topic, yet extensively on HF-treatment. This may, in part, explain the lack of local protocols on patient-education and self-care support and the limited patient education and self-care support reported by healthcare professionals (Table 11).

Finally in one region, the DMP was established as project and not (yet) fully integrated in the standard of care process. The project based nature of integrated care projects may have additional challenges: first and foremost is that these projects are limited in time, thus scaling-up is very important but also very difficult for individual projects. Therefore, implementation plans beyond the project should be an integral part.

Strengths and Limitations

To our knowledge this is the first study that investigates regional implementation of ESC guidelines considering MDisc- and non-pharmacological care in terms of patient-education and self-care support. As far as we are aware of, all national guidelines and local protocols concerning MDisc- and non-pharmacological treatment of HF have been included in this analysis. Yet, we cannot exclude that there may exist additional guidelines and particularly local protocols that are not included in this study. It is, however, unlikely they may provide other insights and therefore affect our conclusions.

This research focuses on three regions in three ESC-member states. Even within these countries, local and regional differences in HF-care are present but are not considered in this analysis. Also, significant differences between other ESC-member states not included in this study are likely, but not address so far. Therefore, it is recommendable to extend this research to other regions and countries to get broad insight into the implementation of the ESC-guidelines in Europe and the European 'real world' HF-care. The results of this study shows the urgent need for this.

Conclusion

This study shows that in all investigated nations national cardiovascular associations, national associations for primary care physicians and cardiovascular nurses endorse ESC-guidelines. However, structural barriers such as lack of a national strategy or of recognition of HF-professionals can hamper practical implementation of ESC-guidelines in general and in terms of patients education, SC-support and MDisc-care. However, in these countries and in the INTERACT-in-HF regions we have observed an increasing interest and commitment to implement multidisciplinary HF-care. This is shown by bottom-up initiatives leading to regional multidisciplinary HF-projects, national programmes and development of own quality criteria for HF-centres of expertise by national cardiovascular associations. Thus is it crucial that governments take on the challenges posed by HF and support the further scaling up and sustainability of these developments.

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APPENDIX 3: overview of topics used to screen national and regional protocols

Keywords and topics indicative for patient-education and self-care support
<ul style="list-style-type: none"> - Self-care - Self-management - Lifestyle - Topics that should be included in patient education such as: <ul style="list-style-type: none"> ○ information patients should receive concerning definition, aetiology and trajectory of Heart Failure, pharmacological treatment and implanted devices ○ symptom monitoring ○ therapy adherence ○ fluid intake ○ body weight ○ healthy eating ○ salt intake ○ alcohol ○ smoking ○ exercise ○ travel ○ sleep ○ sexual activity ○ psychosocial aspects - Other lifestyle topics <ul style="list-style-type: none"> ○ driving ○ pregnancy - Education as part of the role of a member of the multidisciplinary team

Chapter **4**

Unravelling Heart Failure nurses education: comparison of Heart Failure Nurses education in three ESC- states and the HFA Heart Failure curriculum

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Abstract

Aims

The European Society of Cardiology (ESC) guidelines state that heart failure (HF) nurse specialists (HF-nurses) with specific competences are essential for a successful HF-management programme. Thus, the Heart Failure Association (HFA) of the ESC developed the heart failure nurse curriculum (HFA-curriculum). Several ESC member states developed cardiovascular education programmes to enable nurses to deliver high specialist care, but little is known if these curricula are in line with the HFA-curriculum. Therefore, this paper describes the extent to which cardiovascular education programmes in Belgium, the Netherlands and Germany correspond to the HFA-curriculum.

Methods and results

A case study approach was adopted to obtain an in-depth understanding of the programme contents in relation to the HFA-curriculum. For this purpose, representatives of the educational programmes and/or delegates of the national cardiovascular nursing organisation shared their educational curricula.

All studied cardiovascular education programmes aim to provide HF- and/or cardiovascular nurses with essential competences for implementation of evidence based and guideline derived care. However, every cardiovascular education programme has a different focus/area of attention. Cardiovascular education in Belgium discusses aspects of all core-learning objectives of the HFA-curriculum and emphasizes mostly on knowledge aspects of these learning objectives. Cardiovascular education in the Netherlands focuses on chronic diseases in general and on learning objectives concerning patient education, support in self-care and management of device and pharmacological therapy. Cardiovascular education in Germany focusses on most learning objectives, however not every learning objective receives equal attention.

Conclusions

Although local cardiovascular education programmes adopt certain aspects of the HFA-curriculum, the curriculum as a whole is not adopted.

Introduction

Heart failure (HF) is a complex disease with poor prognosis inducing a high health care utilization.¹ Because the population is aging in Western countries, the prevalence of HF is rising, accompanied with increasing health care costs. Health care systems are challenged to maintain sustainability by minimizing costs while maintaining the quality of patient care.^{1,2}

In order to address these challenges, implementation of evidence-based and guideline-derived care is highly important.² Evidence demonstrates that a multidisciplinary approach reduces both HF mortality and hospitalization, and improves quality of life (QoL) which is poor in patients with HF.¹ Therefore, guidelines highly recommend multidisciplinary HF-management programmes as standard of care (class 1, level A).³

The European Society of Cardiology (ESC) states that the HF nurse specialist (HF-nurse) is essential for a successful HF-management programme, particularly to reduce hospitalizations.⁴ As part of the multidisciplinary team, HF-nurses may provide guideline-driven care in terms of education and self-care support.⁵ Additionally, HF-nurses may adapt medication in accordance with titration protocols, evaluate HF-status and treatment, refer patients to appropriate services, coordinate discharge management and communicate effectively with other team members.³⁻⁶ In order to deliver this highly specialized care, HF-nurses need specific competences. As basic nursing education insufficiently covers all required aspects, additional cardiovascular education is essential to provide guideline-derived care.^{2,4}

The Heart Failure Association (HFA) of the ESC recognises this need for education and competences, and developed the HF-nurse curriculum (HFA-curriculum).⁴ This curriculum provides a 'map' of key content with suggestions for learning and assessment. Additionally, the curriculum can be used as a tool to guide cardiovascular education and professional development of nurses working in cardiovascular settings across Europe.⁴ Recently, the ESC Education committee distributed an extensive online survey among National Cardiac Societies. Goal of this survey was to get insight into cardiology training with focus on knowledge and skills assessment, and was used as a starting point to develop a roadmap for cardiovascular education during the 4th ESC Education conference in Sophia Antipolis.⁷

However to the best of our knowledge, no systematic assessment has taken place for the professional education provided to HF/cardiovascular nurses in Europe so far. Furthermore, nothing is known regarding the level of agreement between the HFA-curriculum and cardiovascular education programmes in ESC member states. The INTERACT-in-HF study was set up to investigate the organisation and quality of HF-care in three neighbouring Northwest European regions: Maastricht (the Netherlands), Aachen (Germany) and Noorder-Kempen (Belgium).⁸ As part of this INTERACT-in-HF study, explored the extent to which cardiovascular education programmes in these three countries correspond with the HFA-curriculum was explored.

Methods

A case study approach⁹ according to the method of structured focused comparison¹⁰ by George and Bennett (2005) was used to obtain an in-depth understanding of the level of correspondence of the HFA-curriculum with cardiovascular education in three ESC member states: the Netherlands, Belgium, and Germany.

A search for accessible education programmes revealed one programme in the Netherlands and Belgium respectively, and two in Germany. Contact persons for collaboration were an employee of the Hogeschool Utrecht (the Netherlands), representatives of the nursing organisation (Belgium, Germany) and a representative of the Deutsches Zentrum für Herzinsuffizienz Würzburg (Germany). All representatives provided their curriculum and detailed information concerning the learning objectives (LO). These programmes were (i.e. LO) were compared with the HFA-curriculum to identify agreements and deviations. To compare the programmes with the HFA-curriculum a matrix was developed by two researchers (KB; age: 39, RN MSC/JB; age 64, RN MSC PhD) in which they indicated which aspects of each learning objectives of the HFA-curriculum explicitly correspond with the local programmes. Using this matrix, both researchers analysed the programmes separately. Hereafter results were compared and discussed between them. In case of disagreement or, when items were subject to multiple interpretations, the representatives of the programmes were consulted to provide clarity. To avoid interpretation only explicitly reported topics within the curricula were subject of investigation.

Appendix 1 shows the matrix that was used for this comparison. This matrix was shared with the respective contact persons for documented feedback and approval.

This study agrees with the principles outlined in the “Declaration of Helsinki”. ¹¹

Results

Description of cardiovascular education in the Netherlands, Belgium and Germany

The Netherlands: “Post HBO education, Heart and vessel nursing”, organised by Hogeschool Utrecht (HU) in cooperation with National Society of Heart and Vessel Nurses (NVHV). The Study load is, 1120 hours. In 2016-2017 and 2017-2018 this cardiovascular education educated 11 and 15 students respectively.

Belgium: “Post graduate education, HF-nursing”, organised by University College Leuven-Limburg (UCLL) in cooperation with the Belgian working group on cardiovascular nursing and “Ziekenhuis Oost Limburg”. The Study load is, 600 hours and In 2016-2017, this cardiovascular education educated 25 nurses. Eight nurses registered for the 2017-2018 programme, however the organisation needs a minimum of 12 students to organise this cardiovascular education.

Germany 1: Nursing expert for patients with HF, organised by "Deutsche Gesellschaft für Gesundheits- und Pflegewissenschaft". The study load is, 368 hours. In 2016-2017 11 nurses were educated, and 13 registered for the 2017-2018 programme.

Germany 2: Further HF-nurse education was organised by “Deutsches Zentrum für Herzinsuffizienz Würzburg”. This education comprises of 120 hours theoretical lessons and 80 hours practical education. No information considering study load was provided. In 2016-2017, 30 Nurses were educated and 39 registered for the 2017-2018 programme.

Table 12 depicts a global overview of the modules of the cardiovascular education in the three countries. Both the HFA-curriculum and cardiovascular education in Belgium and Germany aim to provide practicing HF-nurses with essential specialized knowledge, skills and professional behaviour to provide high quality care to HF-patients and their families. Due to the federal structure in Belgium, education is regionally organised. During the study, HF-nursing education was only available in Flanders, the Dutch speaking part of Belgium. Practicing HF-nurses are offered a five modules programme that covers all aspects of HF-care. This enables HF-nurses to optimize care for HF-patients and to support them in their self-care management.¹² In Germany, cardiovascular education in relation to HF is organised by the Deutsche Gesellschaft für Gesundheits- und Pflegewissenschaft and offers a five module programme combining both professional experiences and latest developments in HF-care. This enables HF-nurses to optimise quality of care for HF-patients and their families. cardiovascular education organised by the Deutsches Zentrum für Herzinsuffizienz Würzburg offers a six modules programme to nurses who have at least three years of professional experience in cardiology. The main aim of this education is 'to enable HF-nurses to detect early signs of decompensation and to provide telephone follow-up of HF-patients'.

In the Netherlands, cardiovascular education does not focus on heart failure specifically but on cardiovascular diseases and chronic illness in general. Dutch students are expected to acquire specific HF related knowledge, skills and professional behaviour within daily practice. The aim of educating Dutch nurses in chronic (non- and cardiovascular) diseases in general is to enable them to operate as independent professionals in the field of chronically ill and cardiovascular patients. Students are offered an eight modules training programme (Table 12). Every module entails specific LO required to practice effectively in chronic illness and cardiovascular health care.¹³

Table 12. Cardiovascular education in the Netherlands, Belgium and Germany

	The Netherlands	Belgium	Germany (DGGP)	Germany (DZHW)
	Cardiovascular education in relation to cardiovascular disease	Cardiovascular education in relation to HF	Cardiovascular education in relation to HF	Cardiovascular education in relation to HF
Module 1	<i>Clinical reasoning</i>	<i>Acute heart failure</i>	<i>Health care organization</i>	<i>Epidemiology, Definitions, pathophysiology</i>
<u>Class/practise hours</u>	unknown	32 hours	3 hours	16 hours
<u>Study load</u>	140 hours	120 hours	43 hours	unknown
Module 2	<i>Evidence based practice</i>	<i>Chronic heart failure In hospital</i>	<i>Medical and pharmacological principles</i>	<i>Diagnosis</i>
<u>Class/practise hours</u>	unknown	32 hours	24 hours	20 hours
<u>Study load</u>	140 hours	120 hours	104 hours	
Module 3	<i>Pharmaco-therapy</i>	<i>Chronic heart failure in outpatient care</i>	<i>Nursing HF patients</i>	<i>Pharmacological and non-pharmacological therapy</i>
<u>Class/practise hours</u>	unknown	32 hours	25 hours	42 hours
<u>Study load</u>	140 hours	120 hours	80 hours	unknown
Module 4	<i>Motivational interviewing</i>	<i>End stage heart failure</i>	<i>Patient education And self-management</i>	<i>Comorbidities</i>
<u>Class/practise hours</u>	unkown	32 hours	25	15 hours
<u>Study load</u>	140 hours	120 hours	105 hours	unknown
Module 5	<i>Nursing expert 1</i>	<i>Clinical heart failure practice</i>	<i>Evidence-based practice</i>	<i>Tele monitoring and coaching</i>
<u>Class/practise hours</u>	Unknown	32 hours	18 hours	25 hours
<u>Study load</u>	140 hours	120 hours	36 hours	Unknown

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Module 6	Nursing expert 2			Practical training and teamwork
<u>Class/practise hours</u>	unknown			14 hours
<u>Study load</u>	140 hours			Unknown
Module 7	Continuous care innovation and implementation			Framework for HF-patient care
<u>Class/practise hours</u>	unknown			8 hours
<u>Study load</u>	280 hours			Unknown
Module 8	Intervision			Telephone based monitoring
<u>Class/practise hours</u>	Unknown			80 hours
<u>Study load</u>	280 hours			

DGGP: Deutsche Gesellschaft für Gesundheits- und Pflegenwissenschaft mbH , DZHW: Deutsches Zentrum für Herzinsuffizienz Würzburg

Class/practise hours: The number of hours a student receives theoretical lessons/practise exclusive all other activities necessary to successfully complete the education.

Study load: contains all activities necessary to successfully complete an education incl. number of hours spend in class or in practise and hours spend on studying and/or assignments

Comparison with the HFA-Curriculum

As depicted in table 13, the HFA of the ESC formulates eight core and two optional learning objectives. Furthermore, knowledge, skills and professional behaviours required for competent practice within each learning objective are identified.

Table 13: Core and optional Learning Objectives HFA-curriculum ⁴
Recognize patients with suspected heart failure and have critical awareness of triggers for clinical deterioration
Assess and monitor common symptoms and signs
Apply education theory to develop, implement and evaluate effective patient and family heart failure education
Provide self-care and lifestyle advice (including diet, exercise and travel)
Manage the effective use of pharmacological and device therapies
Competently and rapidly assess need and deliver care to the patient with acute HF
Identify the need for, coordinate and provide care at the end of life to patient and family
Recognize the importance of co-morbidities in heart failure and plan and deliver individualized patient care
Optional learning objectives
Identify the need for, and understand novel strategies in the management of advanced heart failure, such as mechanical circulatory support and heart transplantation (optional for nurses who wish to provide and manage the care of patients with advanced end-stage HF)
Leadership in HF-nursing (optional for nurses who wish to develop leadership skills)

Table 14 summarises which learning objective of the HFA-curriculum are completely, partly or not addressed into the cardiovascular education training programmes in the participating countries. Further details concerning the individual content of these learning objectives can be found in appendix 1. Cardiovascular education in Belgium discusses aspects of all core learning objectives, but not every aspect receives equal attention: most attention is paid to knowledge, and less on skills or professional behaviour. Cardiovascular education in the Netherlands discusses patient education, support in self-care and management of the use of pharmacological and device therapies. Regarding the German education programmes, cardiovascular education provided by the Deutsche Gesellschaft für Gesundheits- und Pflegewissenschaft includes: recognition of patients with suspected HF, support in self-care, management of the effective use of pharmacological and device therapies, palliative care and the importance of comorbidities. cardiovascular education provided by the Deutsches Zentrum

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für Herzinsuffizienz Würzburg discusses aspects of all core learning objectives however, most attention is paid to: recognition of patients with suspected HF, patient education, self-care support, management of the effective use of pharmacological and device therapies, comorbidities, additional learning objectives considering novel strategies in the management of advanced HF.

Table 14: Summary of which learning objective of the HFA-curriculum is covered fully (green), in part (orange) or not at all (red) in the cardiovascular education in each of the three countries.

1.	Recognize patients with suspected heart failure and have critical awareness of triggers for clinical deterioration	BE	NL	D (DGGP)	D (DZHW)
1.1	Knowledge				
1.2	Skills				
1.3	Professional behaviors				
2.	Assess and monitor common symptoms and signs	BE	NL	D (DGGP)	D (DZHW)
2.1	Knowledge				
2.2	Skills				
2.3	Professional behaviors				
3.	Apply education theory to develop, implement and evaluate effective patient and family heart failure education	BE	NL	D (DGGP)	D (DZHW)
3.1	Knowledge				
3.2	Skills				
3.3	Professional behaviors				
4.	Provide self-care and lifestyle advice (including diet, exercise and travel)	BE	NL	D (DGGP)	D (DZHW)
4.1	Knowledge				
4.2	Skills				
4.3	Professional behaviors				
5.	Manage the effective use of pharmacological and device therapies	BE	NL	D (DGGP)	D (DZHW)
5.1	Knowledge				
5.1.1	- Pharmacological				
5.1.2	- Implantable cardiac resynchronization therapy (CRT)/implantable cardioverter defibrillator (ICD) devices				
5.1.3	- Respiratory support				

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5.2	Skills				
5.2.1	- Pharmacological				
5.2.2	- CRT/ICD				
5.2.3	- Respiratory support				
5.3	Professional behaviors				
5.3.1	- Pharmacological				
5.3.2	- CRT/ICD				
5.3.3	- Respiratory support				
6.	Competently and rapidly assess need and deliver care to the patient with acute HF	BE	NL	D (DGGP)	D (DZHW)
6.1	Knowledge				
6.2	Skills				
6.3	Professional behaviors				
7.	Identify the need for, coordinate and provide care at the end of life to the patient and their family	BE	NL	D (DGGP)	D (DZHW)
7.1	Knowledge				
7.2	Skills				
7.3	Professional behaviors				
8.	Recognize the importance of co-morbidity in heart failure and plan and deliver individualized patient care	BE	NL	D (DGGP)	D (DZHW)
8.1	Knowledge				
8.2	Skills				
8.3	Professional behaviors				
9.	Identify the need for and understand novel strategies in the management of advanced heart failure, such as mechanical circulatory support and heart transplantation (optional for nurses who wish to provide and manage the care of patients with advanced end-stage HF)	BE	NL	D (DGGP)	D (DZHW)
9.1	Knowledge				
9.2	Skills				
9.3	Professional behaviors				
10.	Leadership in HF-nursing (optional for nurses who wish to develop leadership skills)	BE	NL	D (DGGP)	D (DZHW)
10.1	Knowledge				
10.2	Skills				
10.3	Professional behaviors				

BE: Belgium, NL: the Netherlands, D: Germany, DGGP: Deutsche Gesellschaft für Gesundheits- und Pflegenwissenschaft mbH, DZHW: Deutsches Zentrum für Herzinsuffizienz Würzburg

Discussion

As a result of this comparison, none of the four programmes fulfils all requirements defined by the HFA. However, all representatives of the curricula highlighted that all competencies as described in the HFA-curriculum were integrated into the cardiovascular education programme. Thus, this integration remained only partly visible.

Furthermore, all local curricula include some content not explicitly mentioned by the HFA-curriculum. This could be explained by the fact that basic education of nurses in Europe differs between countries leading to variation in additional education and that one cardiovascular education was already well established (the Netherlands) before the HFA-curriculum was developed. These findings stress the need for a better alignment between local education programmes and the HFA-curriculum. The items below may be helpful in order to give a structure at this alignment.

Structure and organisation of local cardiovascular education

Structure and organization in relation to European legislation

All studied cardiovascular educations aim to provide HF- or cardiovascular nurses with essential knowledge, skills and professional behaviour to enable them to implement guideline derived care. Therefore, all local cardiovascular educations discuss pathophysiology and most cardiovascular educations (Belgium, the Netherlands, Deutsche Gesellschaft für Gesundheits- und Pflegewissenschaft) cover competences considering evidence-based care. More specifically, evidence-based practice and/or pathophysiology is discussed throughout one or more modules (Belgium, Deutsches Zentrum für Herzinsuffizienz Würzburg) or organised into separate modules (the Netherlands, Deutsche Gesellschaft für Gesundheits- und Pflegewissenschaft). This is inconsistent with the HFA-curriculum in which evidence based practice and pathophysiology are integrated into the modules and not mentioned separately. When discussed with an author of the curriculum, it became evident that the HFA considers students being fully educated about cardio-pathophysiology and evidence based practice prior to inclusion in the programme, and thus no specific attention has been paid on this topic. The

HFA-curriculum states that nature of educational preparation of nurses in Europe varies and that learning objectives must be interpreted locally.⁴ Therefore regular reviewing of the curricula, either exchange of programmes, and harmonisation of cardiovascular educations between countries and HFA are required to obtain education equality of HF nurses in Europe.

Knowledge, skills or professional behavior?

In contrast to the Netherlands and Germany, cardiovascular education in Belgium focuses more on knowledge regarding HF-care and less on skills and professional behaviour in comparison to the HFA-curriculum. Although HF-nurses should have sufficient knowledge considering all aspects of HF-care, research shows that competent nursing reflects how a nurse manages a specific task, using knowledge, but also skills and attitudes.¹⁴ This means that both professional behaviour and skills are equally important as knowledge to deliver high quality care. Therefore, the HFA-curriculum advises to include all aspects of competent nursing more explicitly and equally in educational programmes.

Similarities and differences in relation to roles of HF-nurses

In providing guideline-driven care, HF-nurses may adopt tasks or roles more related to the organization of the health care system in which they participate than to these of the HFA-curriculum.

Patient education

When managing chronic diseases such as HF, adherence to treatment i.e. medication, diet, exercise are an important part of HF-self-care.³ Therefore, the HF-guidelines of the ESC identify “Adequate patient education, with special emphasis on adherence and self-care”³ as an essential component of management programmes for patients with HF. In addition, the HF-guidelines of the ESC identify key topics that should be included in patient education. Notwithstanding the importance of all of these topics few of them, i.e. diet, pharmacological treatment, implanted devices and percutaneous/surgical interventions, fluid intake and physical activity, are explicitly discussed within the HFA-curriculum. This is reflected in curricula of local cardiovascular education. In Germany, cardiovascular education either discuss key topics

considering self-care and CRT/ICD (Deutsche Gesellschaft für Gesundheits- und Pflegewissenschaft) or diet, medication, CRT/ICD and physical activity (Deutsches Zentrum für Herzinsuffizienz Würzburg). cardiovascular education in Belgium discusses salt intake, diet and physical activity and state that HF-nurses should know all key-topics considering patient education. cardiovascular education in the Netherlands states that nurses should know suitable patient education. However, education considering medication and CRT/ICD is included. Education considering psychosocial aspects is missing within local cardiovascular education. Research ^{15, 16} demonstrates that HF-nurses are most comfortable in educating patients about physical aspects of HF and least comfortable on psychosocial aspects, prognosis and spiritual topics. Therefore, a more explicit inclusion of a broader range of psychosocial aspects is advisable.

Psychosocial and palliative care

Patients and their families may need psychosocial support in dealing with the significant impact of HF on all aspects of their lives. Patients not only experience physical signs and symptoms but also psychological and social problems, which may hinder them in performing normal activities of daily living. ¹⁷ They also have to face mental distress due to changing roles, feeling superfluous and lack of income. ¹⁸ Accordingly, the HF-guidelines of the ESC (2016) stipulate that “*provision of psychosocial support to patients and family and/or caregivers*” is a key component of disease management programmes (DMP) for patients with HF. ³ Within the HFA-curriculum, psychosocial aspects are mentioned in the context of end of life care and self-care and life-style advice. Cardiovascular education in Belgium and Germany address palliative care and psychosocial aspects of HF. In Germany (DDGP), additional attention is paid to assess living conditions and quality of life.

Although palliative care is discussed within local cardiovascular education, evidence shows that only 4% of patients are referred to a specialist of palliative care. ²⁰ This means that a significant number of patients that could benefit from palliative care, are denied from this service. ²⁰

Lifestyle factors

Lifestyle factors, such as limited physical activity, not only play a significant role in developing coronary disease but also HF.²¹ Contrary to guidelines for coronary diseases, primary prevention is not mentioned in the HF-guidelines of the ESC.²² Both the guidelines and the majority of the investigated curricula mainly focus on secondary and tertiary prevention of HF.

Nevertheless, Belgian cardiovascular education also considers primary prevention of HF as an important topic. Students are expected to know the most important preventive measures to prevent HF. Indeed, dealing with the challenges of HF requires attention for all levels of prevention²² therefore consensus is needed whether HF-nurses should not only play a role in disease management, but also in primary prevention of HF.

Vocational support

Being able to work is one of the activities of normal life, which may be compromised by HF. About 10% of patients with HF are younger than 60, and being able to resume work is often highly important to them. Employment offers not only financial independence and higher levels of self-confidence and self-esteem, it is also an indicator for better survival chances.^{23, 24} However, many patients with HF are unable to work for longer periods of time, leading them to claim for disability pension.²⁵ Little attention has been paid to patient employment in the HFA-curriculum and national programmes in both the Netherlands and Germany. In Belgium, supporting patients to return to the workforce is an integral part of the cardiovascular education .

The multidisciplinary team

When cooperating within a multidisciplinary team (MD-team), it is important that every team member knows and plays their designated role. This is an important attitude of professional HF-nurses since being aware of and respect for own competences, is necessary for multidisciplinary cooperation. Whereas cardiovascular education in the Netherlands addresses this attitude in relation to pharmacotherapy, neither the HFA-curriculum nor cardiovascular educations in Belgium and Germany explicitly address this competence in their curricula.

Additionally integrated care models combining both hospital and primary care more effectively reduce morbidity and mortality of HF. ^{1, 3, 26, 27} Therefore, primary care providers are an essential part of the MD-team. ^{1, 3, 26, 27} HF-guidelines of the ESC allocate specific roles to primary care providers concerning monitoring of the clinical status of patients discharged after being hospitalized due to acute HF, for long-term follow up of stable HF-patients and end of life care. ³

As HF-nurses are expected to refer patients to the appropriate services, coordinate discharge management and communicate effectively with other team members ^{3-5, 28} an extended knowledge of the care processes, willingness to cooperate, and communication skills are very important. Whereas cooperation with primary care is part of cardiovascular education in Belgium and of Deutsches Zentrum für Herzinsuffizienz Würzburg, the HFA-curriculum and cardiovascular education in the Netherlands and of Deutsche Gesellschaft für Gesundheits- und Pflegewissenschaft do not pay special attention to this aspect of multidisciplinary care. Differences in national health care organizations, e.g. health care financing, may possibly contribute to these discrepancy, but the exact reasons and how to address them remain to be elucidated.

Assessment of needs and deliver care to patients with acute HF

Acute HF is not a major focus of all local cardiovascular education programmes. Although cardiovascular education includes knowledge aspects considering acute HF in Belgium, this is limited and does not contain skills and behavioural changes. In Germany and the Netherlands, cardiovascular education programmes pay limited attention to this learning objective. This may be related to the fact that HF-nurses are usually not part of the acute HF teams in hospitals in these countries. In addition, the cardiovascular education programme in the Netherlands aims to educate cardiovascular and chronic illness nurses rather than specific HF-nurses only.

Strengths and limitations.

As far as we know these are all cardiovascular education programmes in the three countries. However, we cannot exclude that there are additional cardiovascular education programmes that were not included in this survey. Though unlikely, this would result in an incomplete overview over the cardiovascular education programmes in these three countries. Still, given the differences between the HFA-curriculum and the investigated cardiovascular education programmes, it is unlikely that such programmes might cover a significantly larger part of the HFA-curriculum. Therefore, our conclusions are unlikely to be affected by additional cardiovascular education programmes.

The purpose of the study was to investigate the frameworks on which professors and teachers rely to shape and form the education they provide to nurses. This research did not analyse all documents and teaching forms used within the investigated educations. We are aware this limits the exploration of how curricula and topics are integrated.

While collecting the data it became apparent that some representatives had difficulties to make the distinction between a learning objective and content of the cardiovascular education. It also became evident that certain aspects of the HFA-curriculums' learning objectives are an implicit part of the education programmes without explicit registration in the curricula.

Finally, this research focuses on four Cardiovascular Education programmes in three ESC member states, meaning that only a small proportion of the ESC member states have been included. It may be expected that comparable differences can also be found in other countries. Nevertheless, this needs to be investigated in further studies.

Conclusion

Cardiovascular education programmes of Germany, Belgium and the Netherlands correspond only partly with the HFA-curriculum and none covers all of the proposed aspects. Furthermore, the results show (internal) variation among local programmes in terms of content and study load. In addition, local education programmes include aspects not explicitly covered by the HFA-curriculum and a few aspects of managed care showing to improve outcome are included in none of the local cardiovascular education programmes. Therefore, these discrepancies indicate the need to open up the discussion between national committees and the HFA considering the content of education programmes for HF-nurses in order to acquire a uniform European nursing education, covering all necessary aspects of HF-care.

Implications for practise

- None of the four investigated programmes corresponds completely with the HFA-curriculum, demonstrating the need for more discussion between national organisations and the HFA considering development and/or adjustment of curricula.
- (inter)National cooperation and exchange between cardiovascular education can be beneficial in further improving HF-nurse education.

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APPENDIX 4A

1.	Recognize patients with suspected heart failure and have critical awareness of triggers for clinical deterioration	BE	NL	D (DGGP)	D (DZHW)
1.1	Knowledge	x			
1.1.1	Define HF, using ESC criteria	x	x		x
1.1.2	Knowledge of the epidemiology and aetiology of HF in general and in the local area of clinical practice	x	x	x	x
1.1.3	Understand that HF frequently develops as a consequence of the treatment of other illnesses or of other health conditions	x	x		x
1.1.4	Knowledge of the strengths and limitations of common diagnostic tests including intracardiac and pulmonary pressures	x	x	x	x
1.2	Skills				
1.2.1	Monitor and document the presenting symptoms and signs using objective assessment tools where possible	x			x
1.2.2	Undertake a focused clinical history and examination and identify probable causes and triggers for the symptoms and signs, take family history where appropriate	x			x
1.2.3	Explore and take action on simple diagnostic test (ECG, chest X-ray, echocardiography, vital signs and HF biomarkers)	x		x	x
1.3	Professional behaviors				
1.3.1	Recognize the importance of an accurate diagnosis at the basis for further investigation and treatment			x	
1.3.2	Recognize the impact of a HF diagnosis on the patient and their family	x		x	x
1.3.3	Respect patient choice around prognostic information				
1.3.4	Work within scope of role, own limitations and refer appropriately to the multidisciplinary HF team and wider health-care teams	x		x	x

APPENDIX 4B

2.	Assess and monitor common symptoms and signs	BE	NL	D (DGGP)	D (DZHW)
2.1	Knowledge				
2.1.1	- Knowledge of the causes of common symptoms		X		X
2.1.2	- Detailed knowledge of the monitoring and follow-up necessary for optimal treatment and symptom management	X			
2.1.3	- Knowledge of the advantages and limitations of different methods of monitoring including: face-to-face, remote with external equipment, and remote using implantable devices	X			
2.2	Skills				
2.2.1	- Use objective monitoring tools (where available) to monitor effectiveness and side-effects of symptom management	X			
2.2.2	- Accurately interpret and manage monitoring data and escalate appropriately to a more senior member of the HF team	X			X
2.2.3	- Gain patient acceptance of advanced health-care technology (such as remote monitoring devices) and teach the patient and family how to effectively use it				
2.3	Professional behaviors				
2.3.1	- Understand that patients interpret and express symptoms differently	X			
2.3.2	- Understand that a variety of factors affect individual attitudes to health-care technology	X			
2.3.3	- Understand the need to closely integrate monitoring data from implantable devices with HF management	X			
2.3.4	- Appreciate that devices are being developed that monitor surrogate markers of HF severity.	X			

APPENDIX 4C

3.	Apply education theory to develop, implement and evaluate effective patient and family heart failure education	BE	NL	D (DGGP)	D (DZWH)
3.1	Knowledge				
3.1.1	- Have a detailed knowledge of education theories that inform adult learning	x	X	X	X
3.1.2	- Define the term health literacy and have a critical awareness of its impact on learning.		X	x	
3.2	Skills				
3.2.1	- Assess for and identify barriers to patient learning		X	X	
3.2.2	- Develop an individualized patient education plan.	x	X	x	X
3.3	Professional behaviors				
3.3.1	- Adopt an inclusive approach to patient education that includes communicating with the family and the multidisciplinary team.		X	X	X

APPENDIX 4D

4.	Provide self-care and lifestyle advice (including diet, exercise and travel)	BE	NL	D (DGGP)	D (DZHW)
4.1	Knowledge				
4.1.1	- Knowledge of the key topics for effective self-care	x	x		
4.1.2	- Knowledge of the common barriers and facilitators to effective self-care	x	x	x	
4.1.3	- Knowledge of strategies for self-care support including telehealth and remote monitoring	x		x	x
4.1.4	- Understand the physiological and clinical benefits of exercise in HF	x	x		x
4.1.5	- Detailed knowledge of advice on diet and fluid intake	x	x		x
4.1.6	- Knowledge of key safety issues related to travel.				
4.2	Skills				
4.2.1	- Undertake a formal assessment of key self-care barriers using validated assessment tools where available (such as for assessment of cognitive function, anxiety, depression)			x	x
4.2.2	- Provide individualized self-care support and advice to the patient and family	x	x	x	x
4.2.3	- Evaluate the effectiveness of self-care supportive interventions	x			x
4.2.4	- Demonstrate use of Ratings of Perceived Exertion (RPE) scales with patients				
4.2.5	- Provide individualized patient support for an exercise regimen.	x	x	x	x
4.3	Professional behaviors				
4.3.1	- Recognize that the patient is central to self-monitoring of symptoms		x		
4.3.2	- Recognize the impact of symptoms on self-care ability		x		
4.3.3	- Appreciate the availability and usual practice of exercise training and/or cardiac rehabilitation in HF in locality	x	x	x	
4.3.4	- Be aware of need to provide culturally sensitive information around diet and fluid intake	x	x		
4.3.5	- Appreciate the country-specific legislation regarding driving regulations.	x		x	

APPENDIX 4E

5.	Manage the effective use of pharmacological and device therapies	BE	NL	D (DGGP)	D (DZHW)
5.1	Knowledge				
5.1.1	- Pharmacological				
5.1.1.1	o Knowledge of the indications, contraindications, action and potential side-effects of common drugs	X	X	X	X
5.1.1.2	o Knowledge of the optimal dose of common HF medication and factors influencing individual susceptibility to side-effects	X	X	X	X
5.1.1.3	o Knowledge of how patients develop their beliefs in their medication and how these beliefs influence adherence.		X		
5.1.2	- Implantable cardiac resynchronization therapy (CRT)/implantable cardioverter defibrillator (ICD) devices	X	X	X	X
5.1.2.1	o Knowledge of the effective use of devices (including CRT and ICD), their actions and potential risk	X	X	X	X
5.1.2.2	o Knowledge of the follow-up required for optimal device functioning (including remote monitoring).	X	X	X	X
5.1.3	- Respiratory support				
5.1.3.1	o Knowledge of the effective use of respiratory support [to include oxygen therapy and continuous positive airway pressure (CPAP)], their side-effects and contraindications.	X	X		X
5.1.3.2	o Be aware of the different devices available for delivering oxygen and ventilator support.	X	X	X	
5.2	Skills				
5.2.1	- Pharmacological				
5.2.1.1	o Record and take appropriate action on altered monitoring data		X		X
5.2.1.2	o Effectively discuss with the patient their medication, the action plan for optimizing dose, side-effects of medication, and important interactions with other medication, herbal remedies, or foods		X		X
5.2.1.3	o Identify individual patient's barriers and facilitators to medication self-care and adapt information		X		X
5.2.2	- CRT/ICD				
5.2.2.1	o Monitor for effectiveness and side-effects/adverse events related to ICD/CRT function in immediate phase and in the longer-term		X	X	X
5.2.2.2	o Integrate monitoring (including data from remote monitoring) for optimal device functioning with HF follow-up		X	X	X
5.2.2.3	o Provide education around specific therapies that includes issues such as effects of electromagnetic fields, ICD shocks, infection		X	X	X
5.2.2.4	o Identify changes in physical and emotional functioning resulting from ICD implantation. Take appropriate action to optimize quality of life.		X	X	
5.2.3	- Respiratory support				
5.2.3.1	o Accurately and promptly administer oxygen and non-invasive respiratory support within the scope of practice		X	X	
5.2.3.2	o Facilitate the effective use of such therapies, including gaining patient acceptance		X	X	

5.3	Professional behaviors						
5.3.1	- Pharmacological						
5.3.1.1	o Ensure prompt communication of medication and action plan to patients and care providers (such as primarycare)			X		X	
5.3.1.2	o Be aware of individual patient factors affecting the optimal medication dose for maximum effect and that minimizes risk			X			
5.3.1.3	o Work within the legislation for safe medication prescription and titration in country of practice	X		X		X	
5.3.1.4	o Recognize and respect patient choice regarding their medicine management.			X			
5.3.2	- CRT/ICD			X			
5.3.2.1	o Recognize the role of remote monitoring			X		X	X
5.3.2.2	o Recognize the potential effect of inappropriate shocks from an ICD device			X		X	X
5.3.2.3	o Be aware of e regulations regarding fitness to drive in country of practice and recognize the potential impact of driving restrictions.	X		X			X
5.3.3	- Respiratory support						
5.3.3.1	o Recognize the need for appropriate community services to ensure ongoing use of oxygen and respiratory support following discharge home.			X		X	

APPENDIX 4F

6.	Competently and rapidly assess need and deliver care to the patient with acute HF	BE	NL	D (DGGP)	D (DZHW)
6.1	Knowledge				
6.1.1	- Knowledge of the different clinical manifestations of acute HF, their signs, and symptoms	X			X
6.1.2	- Detailed knowledge of the common triggers and different trajectories	X	X		X
6.1.3	- Knowledge of pharmacological therapy specifically used in the management of acute HF	X	X		X
6.1.4	- Have an understanding of the non-pharmacological treatment such as non-invasive and invasive ventilation, intra-aortic balloon pump and ventricular assist device.	X			X
6.2	Skills				
6.2.1	- Undertake a focused clinical history and examination to identify potential causes/triggers of acute HF				
6.2.2	- Assess the severity of symptoms (using validated tools where appropriate)				X
6.2.3	- Monitor and interpret patient data, including vital signs, level of consciousness, serum electrolytes, ECG, echo, chest X-ray, and biomarkers	X			X
6.2.4	- Triage to appropriate level of care				
6.2.5	- Safely administer medication in response to vital signs, blood chemistry, and response to treatment				
6.2.6	- Monitor and manage the care of the patient using non-invasive respiratory support.			X	
6.3	Professional behaviors				
6.3.1	- Arrange safe yet rapid transfer of the patient to the appropriate clinical setting.			X	

APPENDIX 4G

7.	Identify the need for, coordinate and provide care at the end of life to the patient and their family	BE	NL	D (DGGP)	D (DZHW)
7.1	Knowledge				
7.1.1	- Knowledge of trajectory of HF and prognostic signs	X			X
7.1.2	- Knowledge of the emerging evidence for pharmacological and non-pharmacological management of symptoms specific to the end of life	X			X
7.1.3	- Understand the need for the active management of device therapy at the end of life	X			X
7.1.4	- Understand that a palliative care approach addresses the physical, psychological, social, and spiritual needs of patients and families.	X		X	X
7.2	Skills				
7.2.1	- Respond honestly to questions about prognosis and refer to other professionals when appropriate			X	
7.2.2	- Develop a management plan that includes preference for place of death			X	
7.2.3	- Administer medication for symptom control and use objective assessment tools to monitor for symptom relief			X	
7.2.4	- Assess emotional need and refer appropriately for specialist psychological, social, and spiritual support.			X	
7.3	Professional behaviors				
7.3.1	- Communicate management plan to all health-care sectors and charitable organizations (where appropriate)			X	X
7.3.2	- Be aware of local and country-specific issues necessary to ensure smooth patient path and liaise appropriately across health and social care, including palliative care specialists	X			
7.3.3	- Communicate effectively with specialists to provide psychological and spiritual care according to need			X	X
7.3.4	- Recognize country-specific regulations regarding the deactivation of devices at the end of life.	X		X	

APPENDIX 4H

8.	Recognize the importance of co-morbidity in heart failure and plan and deliver individualized patient care	BE	NL	D (DGGP)	D (DZHW)
8.1	Knowledge				
8.1.1	- Knowledge of the prevalence of common non-cardiac comorbidities in general and in the local area of practice	X		X	X
8.1.2	- Knowledge of the impact of common comorbidities and their management on HF management and outcome	X		X	X
8.1.3	- Understand the challenges for diagnosis, clinical management, and patient self-care	X			X
8.1.4	- Have an awareness of the increased risk associated with common HF medications in the presence of common comorbidities and their clinical presentation.	X			
8.2	Skills				
8.2.1	- Undertake a comprehensive assessment of comorbidities such as frailty, mental functioning, and emotional state using objective measurement tools (where appropriate)			X	X
8.2.2	- Use the patient's interpretation of HF within the context of their overall health to inform their management plan				
8.2.3	- Identify changes in cognitive and physical functioning indicative of electrolyte disturbance or dehydration.				
8.3	Professional behaviors				
8.3.1	- Recognize the importance of integrated care of comorbidities within the specialist HF setting			X	
8.3.2	- Be aware of altered medication prescribing practices in the presence of comorbidities				
8.3.3	- Understand the impact of comorbidities on how the patient understands HF and on their self-care behaviors.			X	

APPENDIX 4I

9.	Identify the need for and understand novel strategies in the management of advanced heart failure, such as mechanical circulatory support and heart transplantation (optional for nurses who wish to provide and manage the care of patients with advanced end-stage HF)	BE	NL	D (DGGP)	D2 (DZHW)
9.1	Knowledge				
9.1.1	- Knowledge of indications and contraindications of heart transplantation	X			X
9.1.2	- An awareness of key drugs used specifically in managing adverse effects of transplantation	X			X
9.1.3	- Knowledge of MCS as destination therapy or bridge to trans plant	X		X	
9.1.4	- Have an awareness of current research into novel treatments for end-stage HF				
9.1.5	- Have a detailed knowledge of the psychological impact of advanced HF treatments on the patient and family.			X	
9.2	Skills				
9.2.1	- Monitor and take appropriate action on signs and symptoms of rejection in the immediate postoperative period and over the longer term	X			X
9.2.2	- Provide individualized patient education around the safety issues involved in living with a MCS or heart transplant				
9.2.3	- Provide psychosocial support in the pre and post-operative period.				
9.3	Professional behaviors				
9.3.1	- Recognize the social and psychological impact of MCS or transplant assessment			X	
9.3.2	- Work collaboratively with and refer to specialists in the multidisciplinary team when necessary.	X		X	X

APPENDIX 4J

10.	Leadership in HF-nursing (optional for nurses who wish to develop leadership skills)	BE	NL	D (DGGP)	D (DZHW)
10.1	Knowledge				
10.1.1	- Knowledge of the key components of effective HF nursing service	X			
10.1.2	- Discuss different methods of health services evaluation (including audit)				
10.1.3	- Understand the key issues in quality improvement	X	X		
10.1.4	- Have an awareness of different methods and measures for patient-centered outcomes that include patient-reported outcomes, patient experience and satisfaction, and how to include these in research and quality improvement. ²⁶				
10.2	Skills				
10.2.1	- Contribute to the collection of data for national and/or inter- national HF audit databases ²⁷				
10.2.2	- Write a business case for the development of an effective multidisciplinary HF service				X
10.2.3	- Select appropriate outcome measures including patient-centered outcomes for a defined patient population				
10.2.4	- Design and undertake an audit.				
10.3	Professional behaviors				
10.3.1	- Recognize the roles of other members of the multidisciplinary HF team such as doctor, cardiac physiologist, general practitioner, care of the elderly team, manager, and the impact of any change in service delivery.	X	X		

Chapter 5

What Kind of Patient Education and Self-Care Support do Patients with Heart Failure Receive, and by Whom? Implementation of the ESC Guidelines for Heart Failure in Three European Regions

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Abstract

Background

In order to manage Heart Failure (HF) properly, both pharmacological and non-pharmacological interventions including patient education and self-care (SC) support are important. Appropriate health care (HC) professional support is necessary to improve patient SC-skills. However, little is known which HC-professionals deliver specific education and support in daily HF-care.

Objectives

To describe patient-education and SC-support as perceived by different HC-professionals in three neighboring North-West European regions: Maastricht (the Netherlands), Noorder-Kempfen (Belgium), Aachen (Germany).

Methods

Semi-structured interviews with cardiologists, HF-nurses and general practitioners (GPs) were performed, followed by qualitative content analysis with a five-step approach: 1) familiarization with data, 2) initial coding with an a-priori code manual, 3) structuring of data in main themes, 4) revision and recoding of initial codes and 5) synthesizing codes in main themes.

Results

The sample consisted of 15 cardiologists, 35 GPs and 8 HF-nurses. All interviewed HC-professionals provide HF patient-education, yet, the extent differs between them. Whereas HF-nurses identify patient-education and SC-support as one of their main tasks, physicians report that they provide little education. Moreover, little patient education takes place in primary care; with almost none of the GPs reporting to educate patients about SC. GPs in Maastricht refer HF-patients to their practice nurse for education and SC-support. None of the HC-professionals reported to provide patients with all key-topics for patient education and SC-support as defined by the ESC.

Conclusion

HF nurses consider patient-education and SC-support as one of their main tasks, whereas physicians pay limited attention to education. In none of the three regions, all recommended topics are addressed.

Highlights

- HF-patient education and self-care support are not a priority for physicians;
- If nurses are not available little self-care support takes place;
- HF-education and self-care support in primary care is lacking.

Introduction

Heart Failure (HF) is a chronic and debilitating disease. Therefore, maintaining quality of life (QoL) and prevention of rehospitalization by both pharmacological and non-pharmacological interventions are highly important.^{1,2} Non-pharmacological interventions include therapy adherence and self-care behavior in which patients themselves play a vital role in relation to the long-term management of their disease.³ Effective self-care behavior may improve QoL and reduce hospitalization and mortality rates.^{1,4,5} Important reasons for re-admission are low therapy adherence related to medication and diet, and poor self-care such as not seeking medical support when symptoms escalate.^{3,4} In order to improve patients' knowledge and skills, and to influence their attitude and behavior, it is necessary to provide them with adequate Health Care (HC-) professional support.^{3,6}

Multidisciplinary management programmes (DMP's) are considered as a key element to improve both the clinical management and patient outcome in HF-patients.⁷⁻¹⁰ According to ESC-guidelines, these programmes should include patient education and self-care support for both patients and informal caregivers.^{7,8} Therefore, self-care skills and 12 key topics have been defined which should be included into patient education.⁷

Although ESC-guidelines emphasize the importance of patient education and self-care support, the most appropriate professional to provide this education is not indicated. HF-patients meet different HC-professionals during their treatment who each provide patient education and self-care support, including general practitioners (GPs), cardiologists and, if available, HF-nurses. Providing adequate education regarding lifestyle and self-care is inextricably linked to a tailored, individual approach, which makes promoting self-care highly challenging.^{4,5}

Although ample literature is available regarding the importance of self-care and patient-education,¹⁻⁵ little is known about who delivers specific education and self-care support in daily HF-care. Therefore, the aim of this study was to describe which HF professionals provide which part of patient education and self-care support in three neighboring Northwest European countries (the Netherlands, Belgium and Germany).

Methods

This study is part of the INTERACT-in-HF study, a mixed methods study designed to explore the current process of HF-care in three Northwest European Regions: Maastricht (the Netherlands), Noorder-Kempen (Belgium) and Aachen (Germany).

The study was approved by the ethical boards of Maastricht University M.C, Antwerp University and the University of Aachen and confirmed to the principles of the declaration of Helsinki.

The detailed methods used are described elsewhere.¹¹ In summary, data were collected by semi-structured interviews with GPs, HF-nurses, cardiologists and patients between August 2013 and April 2016. Inclusion of participants occurred by purposive sampling.¹¹

The research team consisted of 10 members: RS (physiotherapist, MSC. ING), MM (MSC ING), SB (MD), ZS (Medical student), BON (Medical student), DR (MD), CR (Medical student), KB (RN, MSC), CH (MD), LDB (RN, MSC, PhD). The interviews were conducted by RS, MM, KB (Noorder-Kempen), SB, ZS, BON, DR (Maastricht), CR and CH (Aachen). Subsequently the data were analysed by SB, KB, CR and LDB, supervised by MD. Two participants decided to withdraw from the study and were not included in the analysis.¹¹

Credibility was maintained by starting the semi-structured interviews with an open-ended question: all HC-professionals were asked what HF meant to them. Subsequently, different topics regarding their understanding and knowledge of HF, the use of guidelines, their role in terms of HF and communication were discussed. If necessary, topics were clarified, and additional questions were asked in order to gain a better understanding.¹¹

All interviews were transcribed ad verbatim and triangulation of data collection was applied as different stakeholders (patients, cardiologists, GPs and HF-nurses) in three different regions were interviewed. All interviews were coded independently by four members of the research team (SB, KB, LDB, CR) and supervised by an expert (MD). Inter-coder reliability (Kappa) was $K = 0,73$.

Qualitative content analysis was completed with a five step approach. ¹² First, the interviews were read as a whole to familiarize ourselves with the data. Second, initial coding was done based on an a-priori code manual containing key aspects of HF-management as defined by patients and HF-caregivers in expert meetings and by HF-guidelines. ¹¹ Third, this conceptual framework was used to support the organization of the data within main themes. Fourth, the main themes were reviewed, and data was recoded. In case of disagreement, researchers deliberated until consensus was reached. Fifth, synthesizing the themes identified in phase 3 and 4 resulted in definitive main themes. Native language speaking researchers translated participants' quotes into English.

The software programme NVivo v. 10.0 was used to organise the dataset.

Results

The sample consisted of 15 cardiologists, 35 GPs and 8 HF-nurses (Table 15).

Table 15. Sample selection			
	Maastricht	Aachen	Noorder-Kempen
General Practitioners (n)	20	9	6
Cardiologists			
- Private (n)	0	4	0
- In hospital (n)	7	2	2
Heart Failure Nurses (n)	6	0	2

n = the number of participants

During qualitative content analysis, 2 themes and 11 subthemes were identified. Consecutively the experiences of HC-professionals as addressed in their interviews were recorded within each of these (sub)theme's (Table 16).

Table 16. lists HC-professionals experiences according to subthemes

	Maastricht			Noorder-Kempen			Aachen	
	CA	HFN	GP	CA	HFN	GP	CA	GP
Theme 1: Extent of patient education reported by different HC-professional/ role as educator								
Theme 2: topics of patient education and self-care advice								
Subtheme 2.1: aetiology and trajectory								
Subtheme 2.2: symptom monitoring and self-care								
Subtheme 2.3: pharmacological treatment								
Subtheme 2.4: implanted devices								
Subtheme 2.5: salt-intake								
Subtheme 2.6: fluid-intake and weighing								
Subtheme 2.7: maintaining a healthy body weight								
Subtheme 2.8: alcohol								
Subtheme 2.9: smoking								
Subtheme 2.10: exercise								
Subtheme 2.11: psychosocial aspects								
Immunization								
Travel and leisure								
Sleep and breathing								
Sexual activity								

CA: Cardiologists, HFN: Heart Failure Nurses, GP: General Practitioners –

Red: not addressed by any HC-professional, yellow addressed by some HC-professionals, green addressed by most HC-professionals

PATIENT EDUCATION AND SELF-CARE SUPPORT

Theme 1: Extent of patient education reported by different HC-professionals/role as educator

As shown in table 16, cardiologists, GPs and HF-nurses reported that they provide patient education and self-care support to patients. However, the extent differed between HC-professionals and geographical regions.

Cardiologists in regions Maastricht and Noorder-Kempen reported to provide some patient-education and information; yet they mainly referred to HF-nurses when it came to patient education in terms of self-care. Three cardiologists in Aachen reported that they educate patients, one of them emphasized the importance to provide tailored education. Furthermore, their patients were advised to implement life-style changes and were referred to heart support groups.

HF-nurses in Maastricht and Noorder-Kempen reported that tailored patient education and self-care support are two of their main tasks. Moreover, patients were encouraged to call them if they experienced symptoms of HF exacerbation.

General practitioners provided little patient education and life-style advice to patients. Most GPs in Noorder-Kempen reported that they considered this someone else's responsibility e.g., HF-nurses/cardiologist or practice assistant. Some GPs in Maastricht indicated that time management was an issue and some GPs in Noorder-Kempen that patients were either too old or had too complex conditions to provide education. Other GPs did not elaborate on the reasons for the lack of patient education and self-care support.

Yes, most of the time consultations are already full of all the medical stuff. Maybe it (patient education, AN) is given a bit too little attention. (GP, male, Noorder-Kempen)

Theme 2: Topics of patient education and self-care advice

The second main theme consisted of 11 subthemes relating to life-style advice and self-care support as defined by ESC guidelines: education considering definition, etiology and trajectory of HF, symptom monitoring and self-care, pharmacological treatment, implanted devices, diet and alcohol, smoking, physical activity and psychosocial aspects (Table 16).⁷

PATIENT EDUCATION AND SELF-CARE SUPPORT

Subtheme 2.1: etiology and trajectory of HF

In all regions, cardiologists and GPs informed patients about their diagnosis and prognosis. However, they were often confronted with patients who did not understand their condition or forgot what had been told. Therefore, some cardiologists in Maastricht reported that they referred these patients to HF-nurses to further inform them regarding their diagnosis.

*“I think, the most important task of a nurse is to inform patients about their diagnosis of heart failure, which we also do, but they explain it once more in simpler language.”
(Cardiologist, Female, Maastricht)*

All HF-nurses in Noorder-Kempen, and one in Maastricht felt that it is the cardiologist’s responsibility to inform patients about their diagnosis and prognosis.

“Experience helps me to interpret things, but the final responsibility lies with the physician.” (HF-nurse, Female, Maastricht)

However, most HF-nurses in Maastricht reported that they inform patients regarding their diagnosis and prognosis. Moreover, they stressed that it is important to regularly repeat information to facilitate better understanding of their disease.

Subtheme 2.2: Symptom monitoring and self-care

Cardiologists in Maastricht and Noorder-Kempen did not report discussing symptom monitoring and self-care with their patients. One cardiologist in Aachen mentioned telemedicine to monitor symptoms.

Both HF-nurses in Noorder-Kempen and most in Maastricht reported that they educate patients about symptom monitoring and self-care e.g., in terms of fluid intake and weight.

It is important that they know what to check in terms of signs of exacerbations. To know when to call: if they gain a lot of weight in a few days, all that sort of thing. If they start retaining fluid, if clothes start to get tighter. (HF-nurse, Female, Maastricht)

Almost none of the GPs reported educating patients about symptom monitoring and self-care. One GP in Aachen mentioned that it is important to discuss what patients themselves can do to manage their disease.

Subtheme 2.3: Pharmacological treatment

Cardiologists in all regions reported that they inform patients about their pharmacological treatment to improve therapy adherence. They were responsive to patients and reflected on the benefits of therapy adherence that patients may experience. Moreover, cardiologists in Maastricht and Noorder-Kempen recognized HF-nurses as an essential partner and referred patients to them to recapitulate education concerning pharmacological treatment and to support therapy adherence. HF-nurses similarly reported that they educate patients regarding pharmacological treatment.

“I think it helps to explain what they should expect....” (Cardiologist, Female, Maastricht)

As cardiologists, HF-nurses, and most GPs informed patients concerning pharmacological therapy. They were responsive to patients and provided tailored information regarding medication.

Subtheme 2.4: Implanted devices

All cardiologists reported that implanted devices are part of treatment. Two cardiologists in Noorder-Kempen also reported that they informed patients regarding implanted devices/procedures. HF-nurses and GPs reported that they did not educate patients about these interventions.

Subtheme 2.5: Salt-intake

Cardiologists in Maastricht and Noorder-Kempen referred to HF-nurses to educate patients about diet and restriction of salt-intake. All cardiologists in Noorder-Kempen, two cardiologists in Maastricht and none in Aachen reported discussing salt-intake with patients. Moreover, all HF-nurses in Maastricht and Noorder-Kempen mentioned that they educate patients considering salt-intake. Some GPs in Maastricht and in Noorder-Kempen informed their

patients to moderate their salt-intake; GPs in Aachen did not report advising their patients about salt-intake.

“Eat less salt’, yes I do say. I usually ask about that, because here in the Kempen most of these old people like to eat bacon in the morning. So yes, I do pay attention to the salt.”
(GP, Female, Noorder-Kempen)

Subtheme 2.6: Fluid intake and weighing

In general, cardiologists did not educate patients about fluid-intake and the importance of weighing. One cardiologist in Aachen reported that he/she did not have the time to provide nutritional advice and another reported that telemedicine can be helpful in monitoring congestion.

“But I don't have the time, of course, to give nutritional advice. To monitor him, that is even more important.” (Cardiologist, Male, Aachen)

In Maastricht and Noorder-Kempen, HF-nurses reported that they educate patients about fluid intake and weighing. None of the GPs in Aachen and few in Maastricht and Noorder-Kempen reported addressing fluid intake and weighing.

“For example, weighing, so many people do not make the connection between fluid retention and weight gain. If I ask them about their weight they answer: ‘yes, I’m eating a lot less’ but that is not why I ask. There are people who keep missing that connection, and then you try to explain that if you gain weight from eating, it happens gradually. You don’t eat in one week 3 or 4 kilos’ extra. With fluid that can happen.” (HF-nurse, Female, Maastricht)

Subtheme 2.7: Other dietary advice

In general, few HC-professionals reported addressing weight issues and a healthy diet with their patients. One cardiologist in Aachen and Maastricht reported addressing a healthy body weight. One HF-nurse in Maastricht and two in Noorder-Kempen reported discussing a balanced diet with patients and referring them to a dietician when indicated. Moreover, some GPs in

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Noorder-Kempen and Maastricht reported discussing a healthy diet and weight reduction with patients. None of the GPs in Aachen reported discussing these themes.

Subtheme 2.8: Alcohol intake

None of the cardiologists in Maastricht and Noorder-Kempen reported educating patients about alcohol intake. In Aachen, one of the cardiologists reported that patients receive information by a leaflet. None of the HF-nurses reported educating patients about alcohol intake, whereas one GP, in Noorder-Kempen reported giving information about alcohol intake.

“He knows that too, and he also knows that alcohol is actually out of the question for him. Or at least that he should limit it as much as possible.” (GP, Female, Noorder-Kempen)

Subtheme 2.9: Smoking and recreational substance use

In instances where patients smoked, all cardiologists, HF-nurses and GPs advised to stop smoking.

Subtheme 2.10: Exercise

Both cardiologists in Maastricht and Noorder-Kempen reported that they advise patients to remain or to become physically active. If necessary, patients were referred to a cardiac rehabilitation programme. One cardiologist in Aachen reported referring patients to a physical exercise programme. HF-nurses reported that they advise patients to remain or become physically active or refer patients to rehabilitation. In Maastricht and Noorder-Kempen, GPs also discussed physical activity and provided their patients with advice. In Maastricht, GPs referred patients to a cardiac rehabilitation programme. In Aachen, GPs in general did not report discussing physical activity with patients. One GP mentioned that the physical activity of one of his patients is improved after attending a rehabilitation programme.

I must say, for this patient, the rehabilitation resulted in more Quality of Life. (GP, Male, Aachen)

Subtheme 2.11: Psychosocial aspects

Most HC-professionals reflected on the impact of HF on the lives and wellbeing of HF-patients; yet patient counselling was mostly provided by GPs and/or HF-nurses. The latter expressed explicitly that patient counselling is one of their designated tasks.

“It is the nurse’s task to look at the psycho-social side of the patient and to respond to it.” (HF-nurse, Female, Maastricht)

Other subthemes that are part of the guidelines were not mentioned by any participants. Including immunization, sexuality, travel and leisure and sleep.

Discussion

HF education and who provides it differs between the investigated geographical regions. This is shown by the fact that HF-nurses incur the main part of HF-education in two regions only (Maastricht and Noorder-Kempfen) where they are part of the HF care pathway, but not in Aachen. Although physicians provide some HF-education, it is the HF-nurse who mainly educates HF-patients. This follows the conception that HF-education and self-care management support are essential components of HF-nurse care.^{6,13} Our study elucidated relevant differences between HC professionals in terms of guideline adherence regarding patient management and education. The absence of HF-nurses in Aachen (only established in 2019 after completion of the interviews) leads to distinct pattern of task distribution within the framework of HF-care.

Usually, HF-nurses are mainly part of specialist HF-care and not involved in primary care. General practitioners consider diagnosis, referral and follow-up patient-education as their specific tasks in HF-care; still in daily patient care, this is often lacking.¹⁴ Thus, patient-education is not well established in primary care. As shown in our study and previous research, time-management can be an issue for GPs, with the result that education is not a priority for them.¹⁴ This may, in part, explain the education gap between primary and specialist care. In the Maastricht, this gap is reduced by practice assistants working in primary health care facilities. These practice assistants are trained to educate patients with chronic conditions such as HF.¹⁵

To our knowledge, no such trained PCNs or practice assistants are involved in primary care facilities at the other two regions, whereas in Noorder-Kempen GPs consider PCNs as preferred partners to delegate tasks such as patient-education and self-care support.¹⁴ Therefore, a local Multidisciplinary Care pathway has been developed in which a PCN HF-coordinator visits HF-patients after discharge from hospital has been established. However, this multidisciplinary care pathway is not yet a structural part of the general health care system. (Personal communication)

There is little research on the role of a PCN in HF-care in general, and in terms of patient education and self-care support. The fact that ESC-guidelines do not identify PCN, unlike HF-nurses, as stakeholders in HF-care may explain why most research and interventions in primary care focuses on the role of the GPs and implementation of education and follow-up by specialist HF-nurses, which usually are not available in primary care. Therefore, PCNs can make a substantial contribution to seamless HF-care.^{14,16} In order to enable PCNs to adopt this role, appropriate training and resources are required.^{16,17} This is of particular importance, as a shift from secondary to primary care is advocated for care of chronic diseases including HF in many countries.

In addition to the heterogeneity between the different HC professionals regarding topics discussed with patients, this study also shows that some of the topics, such as immunization, travel and leisure, sleep, sexual activity and alcohol intake, identified as important by ESC-

guidelines, are rarely or not addressed by any HC-professional. However, it is possible that some of these topics have been discussed by other HC-professionals such as pharmacists or physiotherapists who have not participated in this study. Moreover, these professionals are more often and more regularly involved in the care process of HF-patients in some countries as compared to the regions involved in this study.^{18,19} Moreover, education is often tailored and individualized to fit patients characteristics and beliefs.²⁰ This may, in part, explain that some education topics are less prominent than others. Additionally, literature shows that HC-professionals may feel uncomfortable discussing some topics with patients, such as sexuality.^{21,22} Furthermore, involvement of different HC professionals and appropriate allocation of tasks may help to improve patient education. In this regard, appropriate communication among involved HC professionals is crucial but often not the case.

It is also remarkable that none of the HC-professionals reported advice about immunization. It is possible that HC-professionals have their own beliefs concerning immunization, do not see this advice as part of lifestyle or self-care support, or lack of awareness and therefore, do not report it as part of their strategy or feel that it is not their responsibility to discuss this topic with patients.

Limitations

It cannot be excluded that some healthcare professionals discuss more topics in terms of patient education and self-care support with patients than they report during the interviews. However, results are coherent within each of the professional groups independent of the region. Therefore, it is unlikely that this has a significant impact on the results. Similarly, the results might not be fully representative for the entire countries as a limited number of HC professionals have been included. This is inherent to qualitative research that provides in-depth but no quantitative insight into the topic.

Moreover, HF-nurses were not yet part of the multidisciplinary team in Aachen at the time of this study. This may have influenced the results.

Finally, this study focused on the HF-practitioners as defined by the ESC: however, there could be many other HC-professionals who deliver HF-education and self-care support not captured in our sample. For example, it is shown that PCNs can play an important role in non-pharmacological care for HF-patients; yet, this study did not investigate PCN experiences, nor was the level of their training known in terms of patient-education and self-care support. Therefore, the training and role of PCN in non-pharmacological care for patients with chronic conditions such as HF needs to be further investigated. Moreover, multidisciplinary teams may additionally include other HC professionals such as pharmacists, physiotherapist, dietician, geriatrician or specialists of co-morbidities who have not been considered, but this was beyond the scope of this study and it is less likely that they addressed the topics significantly more often than the HC professionals involved in this study, at least regarding the HF specific topics. Therefore, it is unlikely that the results would differ in a meaningful way.

Conclusion

All interviewed HC-professionals report that they provide patient-education to HF-patients, but the degree and extent varies significantly between and within the different regions and among the interviewed HC- professionals. None covered all topics recommended by the guidelines. Whereas HF-nurses consider patient education and self-care support as one of their core tasks, physicians practice other interventions.

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Chapter **6**

General Discussion

The main aim of the project, summarised in this thesis, was to gain more insight in the current status of organisation of multidisciplinary HF-care focussing on patient education and self-care support, in the three partner regions of the RECAP project: Maastricht, Noorder-Kempen and Aachen. This resulted in a detailed picture of the practical implementation of European and national HF-guidelines on patient education and self-care support in the three regions and the differences in between.

Main Findings of this Thesis

- The implementation of ESC-guidelines in terms of multidisciplinary care and patient education is suboptimal;
- National education programmes for HF-nurses correspond only partly with the HFA-curriculum and differ from one country to the other one;
- Nevertheless, there is a growing interest and commitment of individual HC-providers to implement multidisciplinary care.

It is remarkable that national implementation of these guidelines is often suboptimal although international guidelines on HF promote patient centred multidisciplinary care and patient education. Some of the investigated countries do not have a national disease management programme (DMP) in place, others do have a theoretical plan but implementation is lacking (**Chapter 3**). This results into limited patient education and a lack of transparency among health care providers considering tasks and responsibilities within the multidisciplinary team.

Guideline derived multidisciplinary care, patient education and self-care support.

Multidisciplinary Care

National HF-organisations, organisation for cardiovascular nursing and primary care physicians have all their own HF-guidelines. Yet, some are currently outdated (**Chapter 3**), as the new ESC guidelines for the diagnosis and treatment of acute and chronic heart failure were published in August 2021. ¹ Within these 2021 guidelines, changes have been made to recommendations regarding medical and device treatment but also related to multidisciplinary care and patient education. Multidisciplinary care additionally has gained in importance as the new ESC

guidelines have a strong focus on co-morbidities, which are very common in patients with heart failure. This urgently requires an update of existing national guidelines. In the Netherlands, the national primary care HF-guidelines were updated in May 2021 but do not consider the latest ESC-guidelines ², in Belgium, a partial update of the 2012 guidelines has yet to be completed and in Germany, the 2019 guideline was updated concerning pharmacological treatment in September 2021. ²⁻⁴

The 2021 guidelines also state that multidisciplinary HF-management programmes are essential to reduce the risk of HF-hospitalisations and mortality. ¹ These programmes should be patient centred, multidisciplinary, and provide follow-up after discharge. ¹ Yet, structural barriers such as lack of a national DMP-HF or lack of reimbursement of patient empowerment activities hamper implementation of HF-programmes (**Chapter 3**).

In the Netherlands, a national transmural agreement on the management of Heart Failure is present. ⁵ This DMP has been developed by cardiologists, GPs, HF-nurses, a patient representative and a representative of the national health insurance agencies. ⁵ The agreement describes the responsibilities of the different team members in terms of care for HF-patients. For example, it describes when patients have to be referred to primary or secondary care, which follow-up activities are needed and when HF-rehabilitation, lifestyle support and advice is required. The implementation of this agreement is organised regionally and is established in 22 regions. Despite of this, there are still significant differences between the different regions. ^{6, 7}

In Belgium, no DMP-HF or national HF care pathway has been implemented. Moreover, HF-cardiologists and HF-nurses are not recognized by the Belgian government and patient empowerment activities are not reimbursed. ⁸ This may explain why only 10% of Belgian hospitals have established an in hospital DMP-HF and why transition between care settings is suboptimal. ⁸⁻¹¹ Moreover, efforts to integrate care are often undermined by the fragmentation of decisive power. ¹² To overcome this fragmentation, a learning health care network, HeartsConnect, was established in 2019. ^{9, 13, 14} It unifies 8 local, project based HF-DMPs to bundle collective knowledge and to learn from each other. Moreover, this network developed

HF- training for primary care professionals such as GPs, pharmacists and primary care nurses and collaborates with the Belgian Working Group on Heart Failure (BWGHF) to develop a uniform Belgian DMP-HF. ⁹ It is expected that both the DMP and the updated national guideline will be published simultaneous in the autumn 2023.

In Germany, a national DMP-HF has been developed as early as in 2018. However, implementation is lacking. One of the reasons is that the German Federal Office of social security has not yet approved the education programme included in the DMP-HF. ¹⁵ Moreover, no progress has been in terms of developing and agreeing on an education programme **(Chapter 3)**. ¹⁶ Additionally, an update is needed since the publication of the 2021 ESC-guidelines. However, a swift and broad implementation of the DMP-HF may have more impact than the update. ¹⁵

As in Belgium, some German hospitals have an in hospital disease management programme HF, but this is not yet standard practise of HF care. Moreover, despite the fact that hospitals are required to offer structured discharge planning for every patient, transition to outpatient care is often hampered since patients must provide written consent in order to participate in discharge planning programmes. This leads to suboptimal communication across settings.

In our case study, we found some patients receive multidisciplinary care in hospital based outpatient clinics in all investigated regions. Still, seamless integrated care including both hospital and primary care was only in place in the Maastricht region. However, due to the GPs' own choice to participate, not all GPs of this region participate in the multidisciplinary programme. In Noorder-Kempfen, a project based integrated care pathway including hospital and primary care was developed and implemented until 2021, but then funding ended. Further implementation is unfortunately lacking as in other regions in Belgium. Thus, there is an abundance of projects, yet sustainment is lacking. ¹² In Aachen such an integrated care path that includes primary care is still lacking **(Chapter 3)**. Moreover, the majority of patients remain within specialist care after discharge. This might be explained by the fact that GPs are not considered to up- or down titrate medication. ¹⁷

Taken together, our results show delayed and/or incomplete implementation of a DMP-HF in two of the three regions, which seem to be representative for other regions in these countries. This may lead to suboptimal HF-care in general. However, it is also shown that although authorities may be slow to adopt integrated guideline derived care, national organisations, individual care providers and care organisations rise to the occasion and step in to fill the gap.

Patient education within the multidisciplinary team

Patient education, with special emphasis on symptom management and self-care, is a key component of a HF-management programme.¹ Therefore, the ESC guidelines provide a list of 16 educational topics that should be addressed during consultation. Additionally, they emphasize the importance of tailored education, which enables patients and their families to gain a more in-depth understanding of their HF, symptoms and treatment and facilitates patient centred care (PCC).^{1, 18}

In-depth understanding of HF symptoms and treatment is essential to improve patient outcomes, as a result of better self-care behaviour and self-management activities.^{19, 20} Moreover, poor self-care such as lack of therapy adherence to medication or diet, or not being able to recognise symptoms of HF exacerbation and thus to seek medical support when needed, are among the most common reasons for rehospitalisation.²¹ Consequently, promoting effective self-care through tailored patient education is essential. This is, however, challenging and time consuming since tailoring of education requires an individual and dynamic approach that assesses patient's health literacy, life goals, motivation and skills. Consequently, interventions need to be customized to the outcomes of the assessment of these aspects.²²

The thesis shows that all professional health care providers acknowledge the importance of patient education and self-care support. However, the extent to which the different key topics are discussed, differs significantly between the different professions. Whereas cardiologists generally focus on treatment and little on patient education, patient education is one of the key roles for HF-nurses. Cardiologists in Maastricht and Noorder-Kempen refer to HF-nurses in order to educate patients. These nurses educate most topics considered as important by the ESC with the exception of implanted devices, which is mostly discussed by cardiologists **(Chapter 5)**.

Our results confirm earlier research showing that patient education is a designated role of HF-nurses.^{23, 24} However, this is not yet the case in every investigated European region. In Aachen, patient education is considered to be the responsibility of cardiologists, whereas HF-nurses are only consulted when therapy adherence is lacking. Yet, most cardiologists in Aachen mainly focus on education considering diagnosis, medication and smoking only, resulting in a gap between guidelines and actual practise **(Chapter 3)**.

The majority of HF-patients in Europe are managed by GPs in primary care practises²⁵, yet HF-management in primary care is often suboptimal. GPs are confronted with several barriers such as lack of knowledge of guidelines considering diagnosis and pharmacological treatment of HF, lack of experience and/or lack of confidence.²⁶⁻²⁸ Unfortunately, there is, to the best of our knowledge, no literature that investigates knowledge of HF-education principles by GPs. This leads to a gap in evidence.

Time-management issues are another barrier for optimal HF-care. GPs would like to take on patient-education and self-care support but are confronted with limited consultation time.²⁹⁻³² In our study, GPs were also confronted with time-management issues in terms of patient-education and self-care support **(Chapter 5)**. If they provide patient education, they mainly focus on medical aspects such as diagnosis, medication, smoking and exercise. Most also focus on psychosocial aspects and impact of HF **(Chapter 5)**. Other aspects are usually not addressed.

Generally speaking, GPs would also like to be able to delegate patient-education and self-care support to trained nurses or practise assistants^{29, 30}, however, this is not the standard of care

throughout Europe.^{33, 34} Additionally, complicating the situation is that most European countries are facing with a shortfall on specialized and primary-care professionals.³⁵

Nevertheless, several European regions have introduced interventions to close the gap between daily practise and guideline adhered care. For example, in some regions in the Netherlands, trained primary care nurses or practise assistants educate HF patients.^{5, 36} In Sweden and the UK, HF-nurse led clinics in primary care have been established.^{23, 37} In other European regions such as in Germany and Belgium, such actions have yet to be taken. The following paragraph describes these observations in more detail.

Bridging the gap between guidelines and practise

Role of nurses

In Maastricht and Noorder-Kempen, in-hospital patient education and self-care support is provided by HF-nurses (**Chapter 5**). These observations are in line with ESC-guidelines who state that HF-nurses are essential members of the multidisciplinary team.¹ It has to be mentioned that nurses need to be trained and educated to enable them to take on their specialist role. In order to gain an overview of the education levels of HF-nurses, we investigated HF-nurse education in the Netherlands, Belgium and Germany. We found that most HF-nurse education is provided at post-graduate level. Although the HFA-curriculum for the continuing education of HF-nurses was the basis of all trainings, they were all adapted concerning the national needs and status of HF-nurses (**Chapter 4**).

In the Netherlands, students are generally trained on cardiovascular and chronic diseases and not on HF specifically. They need to acquire HF-specific competences while working as HF-nurses (**Chapter 4**). Moreover, HF-nurses are well established as part of the multidisciplinary team in the Netherlands (**Chapter 3**). Their role is defined within the national HF-DMP, the “*transmural agreement on HF*”.⁵ According to this agreement, HF-nurses play a central and coordinating role in the patient journey. They are often the first point of contact when patients experience HF-related signs and symptoms or when primary care healthcare or other professionals have HF-specific questions. Their main focus is on patient education, supporting self-management and therapy adherence but also on up-titration of HF-medication.⁵

This “*transmural agreement on HF*”⁵ also includes a role for all involved professionals, also for practice assistants in primary care practices. The latter are trained primary care nurses or physicians assistants who support patients with chronic diseases such as HF. They follow up patients with stable HF, report to the GP, and provide patient education and practical support.

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In Belgium, HF-nursing is still in its early stage. Most of them are trained by the HF-nurse education programme described in **chapter 4**. Unfortunately, HF-nurses in Belgium have no legal status and their interventions are not covered by national health insurance. This means that either individual healthcare organisations or cardiologists themselves must provide funding to engage HF-nurses.⁸ This may explain why there are only few HF-nurses and why most of them work in hospital and why their responsibilities are not defined and may differ between hospitals.⁸ However, once HF-nurses are present, their main focus is on patient empowerment and -education (**Chapter 5**).

Belgian GPs feel that a trained primary care nurse could play a pivotal role both in providing patient education and as sentinel in case of HF-exacerbations.²⁹ However, the lack of insurance coverage for patient empowerment activities by primary care nurses limits their role in this regard significantly.^{8,29} In primary care in Belgium, there is only insurance coverage for diabetes education by accredited diabetes educators to patients enrolled in the type 2 diabetes care pathway but for no other chronic diseases.³⁹

In Germany, HF-specialists recognize the importance of HF-nurses in order to enhance quality of care, but reality is different (**Chapter 3**). Most patient education is done by cardiologists with only an assisting role for HF-nurses due to the lack of a national DMP-HF and insurance covering. Particularly the latter hinders HF-nurses in taking up their role.¹⁶ Additionally, some trained HF-nurses may not be able to continue to work as HF-nurse, as regional health care organisations have the power to accept or ignore their certificate.¹⁶

This uncertainty and lack of standardization might explain why in Germany two HF-nurse educations are present with slightly different objectives. Both trainings enable HF-nurses to optimize quality of care but with a different perspective. Whereas the focus of the

Cardiovascular education offered by the Deutsches Gesellschaft für Gesundheit- und Pflegewissenschaft (DGGP) lies on nursing and patient- and self-management education, the education offered by the Deutsches Zentrum für Herzinsuffizienz Würzburg focusses on patient support via telemonitoring (**Chapter 4**).

Moreover, **chapter 5** shows that both German cardiologists and GPs mainly focus on more technical education topics such as aetiology and trajectory of HF and pharmacological treatment. This may lead to suboptimal HF-care. Additionally, as in Belgium, primary care nurses are not yet considered as part of the multidisciplinary team and thus not involved in follow-up and HF education. A representative of the German association of chronic disease (DSCK) revealed that in Germany, as in the rest of Europe, primary care nurses are confronted with many chronic diseases. Thus, training in chronic diseases for primary care nurses should cover many topics. According to the representative of the DSCK, this is difficult to organise.⁴⁰

It is indeed true that primary care nurses need to be able to navigate in the field of chronic disease, particularly as co-morbidities are a common problem in patients with chronic diseases. It has been already shown that primary care nurses may contribute to the management of chronic diseases such as diabetes and HF.⁴¹⁻⁴⁴ They can provide ongoing education and self-management support to patients in order to improve patient outcomes.^{41, 42, 44} Moreover, collaborative primary care nurse case-management interventions have shown to reduce rehospitalisation rates, the total number of hospitalisations and bed days in chronically ill patients.⁴³ Therefore, it is important to train and educate primary care nurses that they are able to provide patient education and self-care support, to clinically assess patients and to take their role as partner in HF-care.^{33, 44}

Therefore, HeartsConnect, together with the Belgian Heart Failure Nurses Association, has developed a HF training for nurses in primary care. This three day training provides basic knowledge on HF, HF-medication, sign and symptoms of HF-exacerbations, self-management support and patient education.⁴⁵

However, international guidelines including 2021 ESC-guidelines¹ do not identify primary care nurses as members of the multidisciplinary team, nor do they describe the role of each team

member in primary care specifically, which may be seen as shortcoming. National DMP-HF may help to close this gap if they are developed and implemented to cover the entire spectrum from specialised to primary care. Within these DMPs, it is necessary to identify all members of the multidisciplinary team including primary care nurses, their roles and their responsibilities.

Role of technology

Obviously, professional caregivers are not continuously available. Moreover, some patients may be reluctant to approach healthcare professionals if needed, e.g. in case of deterioration of HF. This is even true if patients are explicitly instructed to approach them. Technology support using eHealth and mHealth, may be a mean to provide patients with additional digital support in order to optimize adherence and follow-up. It may even enhance patients engagement in treatment and thus also improve patient outcomes.^{1, 46-49} At professionals' side, technology may play a role to improve guideline adherence and treatment support, resulting in a reduced workload.⁴⁹ However, implementation of technology support in the care work processes and pathways is required to achieve positive impact on patients' outcome and use of healthcare resources.

Implications for practice

According to ESC guidelines, self-care behaviour and thus self-care support are important elements of treatment together with multidisciplinary care and medication.¹ This thesis shows that implementation of self-care support and multidisciplinary care hampers in daily practice, especially in regions and countries where there is no DMP-HF implemented. In two of the investigated three regions and countries, there are few HF-nurses or they have limited authority, and self-care support and patient education is mostly hospital related. As most HF-patients are followed-up in primary care⁵⁰, where GP's are confronted with time-management issues and primary care nurses are generally not trained in HF nor considered to be part of the multidisciplinary team, HF-care is not optimal for the majority of patients with HF, with a gap between in-hospital and primary care.

Patient education and self-care support by professionals interacting with HF-patients is a strategy to improve guideline adherence.⁵¹ Although HF-nurse training is organised at

postgraduate level in all investigated countries, it fully corresponds to the HFA- curriculum in none of the countries. This demonstrates the need for more information exchange between national committees and the HFA considering the content and/or adjustment of the curricula. Moreover, (inter)national cooperation and exchange between cardiovascular educations can be beneficial in further improving HF-nurse education.

As healthcare providers including HF-nurses and trained primary care nurses are not continuously available, it is important to provide patients with tools to support self-care and to enable them to respond appropriately to clinical signs and symptoms of deterioration.^{49, 52} The digital era is growing rapidly providing new opportunities and technologies that are potentially helpful to support patients and make them, at least in part, independent of their care professionals. Therefore, the PASSION-in-HF consortium (Patient Self-care uSing eHealth in chronic Heart Failure) was established with financial support from Interreg NWE. This consortium has committed to develop an AI (artificial intelligence) based digital and interactive physician avatar combining a digital support engine, serious gaming, a self-learning feedback system and patient coaching in order to create a “doctor at home” system. This system aims to support patient’s self-care and self-management activities finally including self-prescription of treatment according to HF-guidelines.⁴⁹ Intermediate steps may include improved patient monitoring and adherence as well as decision support to health care professionals including those in primary care. Implementing such a system in current healthcare has the potential to enhance guideline adherence both by patients and professional health professionals.

Recommendations for further research

Based on our study findings, some recommendations for further research on implementation of HF-guidelines in practise can be made. First, we encourage to further investigate implementation of ESC-guidelines in terms of multidisciplinary and both pharmacological and non-pharmacological care in other European countries. This is, in particular, to gain a broader and in-depth view on implementation of ESC-guidelines throughout Europe and the real-world HF-care. Second, further research on HF-nurse education in Europe is needed since it can be expected that similar or even larger differences may be found in other countries. This can be

helpful to investigate the role of HF-nurses throughout Europe. Third, little research has been done on the position of primary care nurses within the multidisciplinary team. Existing research suggests they may play an essential role within this team. In some European countries, they are already part of the team. Therefore, it is essential to study their training, knowledge and role in order to develop recommendations. Fourth, we have investigated the role of GPs, cardiologists and HF-nurses in terms of patient education. However, it may be that other healthcare providers such as pharmacists and physiotherapists also educate and support patients in their self-care and self-management which are currently not included in this study. Thus, it is recommended to explore which other health care providers are essential within a DMP-HF and what kind of education they provide to patients. Fifth, the impact of specific aspects of DMPs and their implementation in clinical practice has not yet been investigated, which may be a reason for the differences between the countries. Such investigation may help to define the most important aspects to focus on, where most needs and effects are expected. Finally, as technology can be helpful to alleviate the burden of HF on patients and care systems, further research on validation of user-friendly technology in order to continues support patients is advised.

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Chapter **7**

Summary

Samenvatting

Valorisation Addendum

Dankwoord

About the author

Publications

SUMMARY

Heart Failure (HF) is an example of a high prevalent, complex and debilitating chronic disease. In order to alleviate the burden of HF, the European Society of Cardiology (ESC) has developed guidelines for the diagnosis and treatment of HF. This thesis examines the implementation of these guidelines in three European regions: Maastricht (the Netherlands), Noorder-Kempen (Belgium) and Aachen (Germany). More specifically, it focuses on implementation of guidelines concerning multidisciplinary care and self-care support.

The **introduction** provides general insights in HF and HF-management in terms of multidisciplinary care and patient education. Multidisciplinary team management has the potential to improve quality, access, efficiency and equity of HF-care. Moreover, patient education and self-care support are much needed in order to achieve required lifestyle changes. Prior to the INTERACT-in-HF study, it was largely unknown how these recommendations were implemented within the ESC-member states. Thus, the primary aim of this thesis was to gain better insight in the current organization and regulation frameworks in three ESC-member states.

Chapter 2 presents the design of the main study. The aim of this study was to explore the current processes of HF-care and to identify factors that may facilitate and factors that might hamper HF-care and guideline adherence. The study population consisted of HF-patients and their professional caregivers: cardiologists, HF-nurses and GPs in three European (Maastricht, Noorder-Kempen and Aachen) regions. Within a cross-sectional mixed methods design, these patients and caregivers participated in semi-structured interviews. Prior to these interviews, patients were asked to complete three questionnaires: The Dutch Heart Failure Knowledge Scale, The European Heart Failure Self-Care Behaviour Scale and a global health and social economic status. In parallel, retrospective data based on records from these and additional HF-patients was collected.

Chapter 3 investigated local implementation of ESC-guidelines considering non-pharmacological and multidisciplinary care. A case-study approach was used to collect national Guidelines and local protocols in order to examine the extent of national and regional implementation of ESC-guidelines. We concluded that although all national organizations promote ESC-guidelines, the level of implementation differs significantly between nations and regions.

Chapter 4 explored the level of agreement of national curricula for the training of HF-nurses in the Netherlands, Belgium and Germany with the Heart Failure Association (HFA) of the ESC curriculum for the continuous education of HF-nurses. A case study approach was used to obtain an in-depth understanding of the programme contents in relation to the HFA-curriculum. All investigated programmes aim to provide HF- or cardiovascular nurses with essential competences for implementation of evidence based, guideline derived care. However, every education has different areas of attention and corresponds only partly with the HFA-curriculum. None of them covers all of the proposed aspects. Moreover, the results show variation among local programmes in terms of content and study load. Additionally, local programmes include topics not explicitly covered by the HFA-curriculum.

Chapter 5, focusses on patient education and self-care support provided by different professional health care providers in Maastricht, Noorder-Kempen and Aachen. Semi-structured interviews followed by qualitative content analyses revealed that all health care professionals provide patient education and self-care support. However, the extent differs between them. While patient education and self-care support is a core task for HF-nurses it is not for physicians. Cardiologists in Maastricht and Noorder-Kempen refer patients to HF-nurses for education, and GPs in Maastricht refer patients to their practise assistant. Yet, when no nurses or practise assistants are present, patients receive little education. This is true in all three regions studied but obviously most striking when no DMPs are in place.

The final chapter (**Chapter 6**) concerns the general discussion in which the main findings are situated within the new 2021 ESC HF-guidelines. A special focus of the discussion is on structural barriers for implementation such as lack of a DMP-HF or insurance coverage. Finally, several facilitators for implementation such as training and education of nurses in order to become HF-nurse or HF-educator in primary care and the use of technology are presented. Still, there remain many open questions requiring future investigation, that are addressed in the discussion.

SAMENVATTING

Hartfalen (HF) is een veel voorkomende, chronische en invaliderende aandoening. Om de impact van HF te verminderen heeft de Europese Vereniging voor Cardiologie (ESC) richtlijnen voor de diagnose en behandeling van HF ontwikkeld. Deze thesis onderzoekt de implementatie van deze richtlijnen in drie Europese regio's: Maastricht (Nederland) Noorderkempen (België) en Aken (Duitsland). Meer specifiek focust ze op de implementatie van richtlijnen met betrekking tot multidisciplinaire zorg en patiënten educatie.

De **introdunctie** biedt algemene inzichten in HF en HF-management in termen van multidisciplinaire zorg en patiënten educatie. Multidisciplinaire zorg kan de kwaliteit, toegankelijkheid en gelijkheid van HF-zorg verbeteren. Daarnaast zijn zelfzorg ondersteuning en patiënten educatie nodig om te komen tot de nodige levensstijlveranderingen. Voor de INTERACT-in-HF studie, was het niet geweten hoe deze aanbevelingen geïmplementeerd werden in de ESC lidstaten. Daarom was het algemene doel van deze thesis: een beter inzicht krijgen in de huidige organisatie en regelgeving van HF-zorg in drie ESC lidstaten.

Hoofdstuk 2 stelt het opzet van de INTERACT-in-HF studie voor. Het doel was om de huidige processen van HF-zorg te verkennen en de factoren te identificeren die richtlijn gebaseerde HF-zorg vergemakkelijken of juist belemmeren. De studiepopulatie bestond uit HF-patiënten en hun professionele zorgverleners: cardiologen, HF-verpleegkundigen en huisartsen in drie Europese regio's (Maastricht, Noorder-Kempen en Aken). Binnen een cross-sectioneel mixed methods onderzoeksdesign namen de respondenten deel aan semigestructureerde interviews. Aan patiënten werd voorafgaand aan deze interviews gevraagd om drie vragenlijsten in te vullen: de Dutch Heart Failure Knowledge Scale, de Europese Heart Failure Self-Care Behaviour Scale en een globale gezondheids- en sociale economische vragenlijst. Tegelijkertijd werden er retrospectieve gegevens verzameld op basis van de dossiers van deze maar ook van andere HF-patiënten.

In **Hoofdstuk 3** werd de lokale implementatie van ESC-richtlijnen met betrekking tot patiënten educatie en zelfzorgondersteuning en multidisciplinaire zorg onderzocht. Door middel van een casestudy werden nationale richtlijnen en lokale protocollen verzameld. Hierna werd de mate van nationale en regionale implementatie van ESC-richtlijnen bestudeerd. Hoewel dat alle nationale organisaties de ESC-richtlijnen promoten verschilt de implementatie significant tussen ESC-lidstaten en regio's onderling.

In **Hoofdstuk 4** werd onderzocht in hoeverre de nationale curricula voor de opleiding van HF-verpleegkundigen in Nederland, België en Duitsland overeenkomen met het curriculum voor de permanente educatie van HF-verpleegkundigen van de hartfalen associatie (HFA) van de ESC. Via een case study is er een diepgaand inzicht gekregen in de inhoud van deze programma's in relatie tot het HFA-curriculum. Alle onderzochte opleidingen hebben tot doel om HF- of cardiovasculaire verpleegkundigen te voorzien van de nodige competenties voor de implementatie van evidence based zorg. Elke opleiding heeft echter verschillende aandachtsgebieden en geen enkele komt volledig overeen met het HFA-curriculum. Bovendien is er variatie tussen de verschillende opleidingen wat betreft studielast en inhoud. Daarenboven worden er in elke opleiding topics behandeld die niet expliciet tot het HFA-curriculum behoren.

Hoofdstuk 5 richt zich op patiënten educatie en zelfzorgondersteuning door verschillende professionele zorgverleners in Maastricht, Noorder-Kempen en Aken. Uit semigestructureerde interviews en na kwalitatieve content analyse bleek dat alle zorgverleners patiënten educatie en zelfzorg ondersteuning bieden. De mate waarin verschilt wel tussen zorgverleners. Terwijl patiënten educatie en zelfzorg ondersteuning een kerntaak is voor HF-verpleegkundigen geldt dit niet voor artsen. Cardiologen in Maastricht en Noorder-Kempen verwijzen patiënten door naar de HF-verpleegkundigen. In Maastricht verwijzen huisartsen hun patiënten door naar de praktijkverpleegkundige of praktijk assistent. Maar als er geen verpleegkundigen of praktijkassistenten aanwezig zijn, krijgen patiënten weinig educatie en zelfzorg ondersteuning. Dit geldt voor alle drie de bestudeerde regio's, maar is uiteraard het meest uitgesproken in regio's waar geen DMP-HF is.

Het laatste hoofdstuk (**hoofdstuk 6**) betreft de algemene discussie. Hierin worden de belangrijkste bevindingen gesitueerd binnen de nieuwe hartfalenrichtlijn van de ESC (2021). Deze discussie focust voornamelijk op structurele barrières voor implementatie zoals het ontbreken van een HF-zorgpad of verzekeringsdekking. Ten slotte, worden verschillende facilitators voor implementatie zoals training en inzet van HF-verpleegkundigen en HF-educatoren in de eerste lijn en het gebruik van technologie als ondersteuning van zowel de HF-patiënt als de zorgprofessional besproken. Toch blijven er nog veel open vragen die verder onderzoek vereisen en die besproken worden in de discussie.

VALORISATION ADDENDUM

In this chapter, the valorisation and the societal value of this thesis: *‘Between guideline and practice: the organisation of multidisciplinary heart failure care in three European regions’* are addressed. In particular, the relevance of heart failure (HF) for health care organisation and members and training of the multidisciplinary team, more specifically the role of HF-nurses and primary care nurses within this team are addressed. This includes the training as a mean to improve HF-care in primary care and the use of technology as mean to support both health care providers and patients.

Currently, the prevalence of known HF in the developed countries is estimated at 1% to 2% of the adult population, and up to 10% of the elderly population over 75. It is expected that this number will further grow since the baby boom generation born between 1945 and 1965 is ageing fast. Moreover, the treatment options for HF have improved significantly, resulting in more patients surviving with HF. This also leads to an increased use and the complexity of care and an increasing burden on an already congested health care system. Due to the increasing complexity of HF care, the risk of suboptimal treatment is substantial. The European HF-Guidelines are developed to improve care, but also to alleviate the challenges of HF care for the health care systems, the health care providers and the HF-patients. However, notwithstanding these guidelines and better treatment options, HF-care remains suboptimal. It is therefore important to get more insight into the implementation of the HF-guidelines in daily practice in order to identify barriers and facilitators for guideline adhered care.

One of the main findings of this thesis is that HF-care remains to be improved in participating centres. To some extent, the differences in health care organisation contribute to different implementation of recommendations and differences in the way how HF-care is delivered. For example, in Belgium and Germany, HF-nurses are not considered to be part of the multidisciplinary team by government and by health care insurance companies. This leads to a limited number of HF-nurses in both countries although the European guidelines strongly advises the multidisciplinary approach of HF-care. Our study also showed that national HF-nurse education does not necessarily correspond to a significant extent with the Heart Failure

Association curriculum for the continuous education of HF-nurses and that the focus varies between countries. Nevertheless, it may prepare nurses to act within the limitations of their own health care system to provide optimal care within the possibilities of each system.

Despite the fact that HF is a complex disease, in which diagnosis and treatment are usually initiated in hospital, most patients receive their follow-up and treatment in primary care. Unfortunately, primary health care providers have limited knowledge of HF, its detection and management and HF-education principles, leading to missing early diagnosis of HF, inadequate up- or down titration of HF-medication, missing early deterioration of symptoms, and lacking of HF-education to patients and self-care support. Primary care HF-clinics, in which a combination of HF-nurse and HF-cardiologist provide follow-up and treatment in primary care, can be a means to manage this shortcoming. However, this thesis shows that in none of the investigated regions such primary care HF-clinics are present. Therefore, it is important to increase the awareness of primary care health care providers with respect to HF and its management, highlighting the large impact on outcome if done properly. GPs should be trained to diagnose and treat HF in order to acquire sufficient knowledge and confidence to start, up- or down titrate HF medication if required, but also to seek contact with HF specialists (both physicians and nurses) in case of uncertainties. Realistic estimation of what is possible but also what is not possible in the primary care setting should be made. The local agreements on collaboration between primary and secondary care including also patients need to be made. Although guidelines do not consider primary care nurses to be part of the multidisciplinary team, in fact they are and should be. Consequently, they should be trained to enable them to provide evidence based HF education, to monitor patients during their follow-up and to recognise early HF signs and symptoms in order to timely refer patients to the GP or HFN. This training can be included in regular training programmes for GPs and nurses, yet this education can also be organised in continuing education programmes.

The congested health care system as a result of too many patients and a shortness of professionals is a challenge where patient empowerment may help to reduce professionals' interference. The results of this thesis contributed to design the digital 'DoctorME' application

developed within the INTERREG-NWE PASSION-HF project. This application interacts regularly with patients about their wellbeing, symptoms and vital signs on a regular basis or when it is needed. The patients input will be combined with clinical data such as echocardiography and lab results to formulate an individualized therapy recommendation. Currently, a prototype of this app is being evaluated in 4 academic centres: Maastricht University Medical Centre, Uniklinik RWTH Aachen, Queens University Belfast and University College Dublin.

DISSIMINATION

In addition to the scientific value of this thesis of which all chapters are published in international peer reviewed journals, the results are also of societal value. Thus, the results of this thesis have been used to develop education in HF for primary care nurses in Flanders, the Dutch speaking part of Belgium. Additionally, they are currently being used for the update of the Belgian primary care HF-guideline and to develop a national transmural care path.

The results of the thesis also show the need for harmonisation of education programmes for HF nurses, and probably also other health care professionals involved in the management of HF. The results have been well perceived by the patient care working group of the HFA to take action to improve HF nurse training in Europe.

Finally, these results can also be used to create awareness in (inter)national organisations and among health care providers that more attention is required for the involvement and training of health care providers in primary care and that this involvement should not be limited to GPs but also include nurses and physician assistants. They may significantly contribute to the improvement in HF-care along the entire health care chain.

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Karolien Baldewijns was born in Beringen, Belgium, on 6th of December 1978. After graduating from secondary school at Zusters der Voorzienigheid Diest, she started her nursing studies at Katholieke Hogeschool Kempen in Lier. Karolien obtained her nursing degree Cum Laude in 1999. In 2002 she completed her master's degree Medische en Sociale Wetenschappen in Health Promotion Cum Laude at the University of Ghent. In the early years of her career Karolien worked as professor/lecturer at the nursing department at the Katholieke Hogeschool Kempen in Lier. She combined her teaching assignment with applied research, coordinated the social nurse education and further developed internationalisation for staff and students. Since 2013 she works full-time as researcher at Mobilab&Care, a multidisciplinary research centre at Thomas More University of applied sciences. She focuses on Heart Failure and Health Literacy. In 2019 she became member of the Learning Health Care Network Heart Failure that unites eight transmural heart failure projects but also local hospitals, health care professionals and heart failure patients to scale-up guideline adhered heart failure care in Belgium. Within the Learning Health care Network she developed, implemented and evaluated Heart Failure training for primary care nurses in Belgium. She is also a member of the guideline development committee that partially updates the Heart Failure guidelines for primary care in Belgium. Karolien lives in Tessenderlo with her husband Bjorn Claes and their daughters Maaïke and Imke (born in 2007 and 2010).

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