Research Paper

Improving kNowledge Transfer to Efficaciously RAise the level of Contemporary Treatment in Heart Failure (INTERACT-in-HF): Study protocol of a mixed methods study

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Abstract

Heart failure 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 applying a multidisciplinary approach are recommended to improve heart failure care. However, there is a scarcity of research considering how disease management programme perform, in what form they should be offered, and what care and support patients and care providers would benefit most. Therefore, the Improving kNowledge Transfer to Efficaciously Raise the level of Contemporary Treatment in Heart Failure (INTERACT-in-HF) study aims to explore the current processes of heart failure care and to identify factors that may facilitate and factors that may hamper heart failure 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 in-depth interviews, patients were asked to complete three questionnaires: The Dutch Heart Failure Knowledge scale, The European Heart Failure Self-care Behaviour Scale and 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. All interviews were audiotaped and transcribed verbatim for analysis.

Keywords

Heart failure, organisation and administration, interviews, care providers, healthcare quality, access, and evaluation, mixed methods

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 multi-disciplinary approach to manage patients with HF and

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encompass different components as highlighted in recent guidelines.[9] If implemented comprehensively, DMPs offer accessible and efficient provision of care,[10] which may result in benefits on both quality and cost-effectiveness of care.[11–16] Therefore, guidelines[17] advice to organise HF care in multidisciplinary teams, including nurses, cardiologists and general practitioners (GPs).[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 healthcare systems, and the interplay of structure, process and outcomes may vary significantly between different regions.[21] In clinical practice, 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 disease,[26] 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 the 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

An HF network of three North-West European regions, Maastricht (the Netherlands; approximately 1,22,461 inhabitants) Aachen (Germany; approximately 2,43,336 inhabitants) and Noorder-Kempen (Belgium; approximately 2,46,021 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, GPs and (HF) nurses). A two-phase, cross-sectional, mixed methods design was used, encompassing both qualitative and quantitative methods (Figure 1).

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 design[28] 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[29,31–33] (Table 1).

Sample selection

Purposive sampling was used to include following stakeholders in HF care: patients, cardiologists, GPs 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 GPs.

Based on the protocol of the study, less care providers than patients were included (Figure 2). When interviews revealed additional care providers relevant to HF care of individual patients they were added to the study sample.
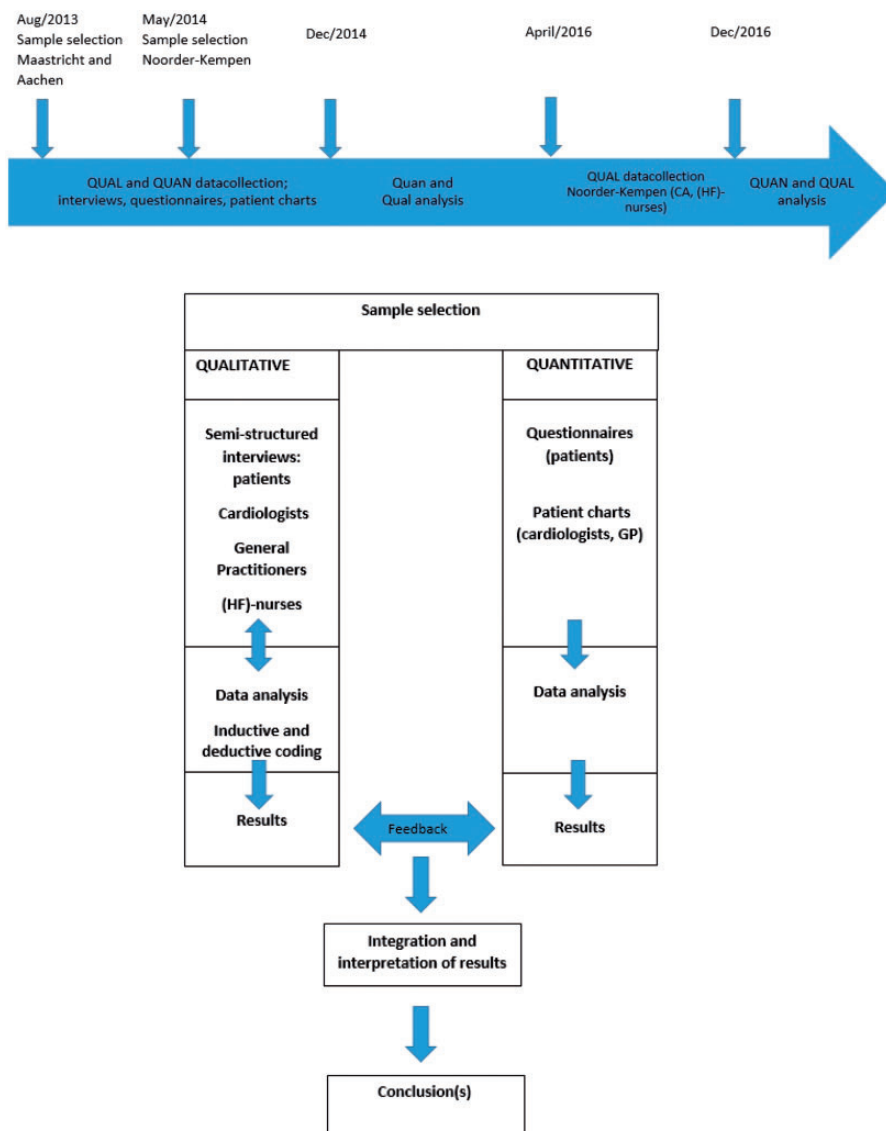
Figure 1. Study timeline and mixed methods study design.
HF: heart failure; QUAL: Qualitative; QUAN: quantitative.

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, GPs and HF nurses were interviewed after providing consent for participation. At the HF centre in Aachen, no specialised HF nurses were employed. To include HF patients exclusively treated in primary care, participating GPs 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 (Figures 1 and 2(a) and (b)).

Noorder-Kempen

Patients in Noorder-Kempen were initially selected at primary care level due to logistic reasons. GPs 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 (Figures 1 and 2(c)).

Table 1. Application of different types of triangulation.

Triangulation of data collection	Data triangulation	Triangulation of analysis method
• Semi-structured interviews • Patients medical charts • Questionnaires	• Three NWE regions: Maastricht, Aachen and Noorder-Kempen • Patients • Cardiologists • GPs • (HF) nurses	• Qualitative analysis of semi-structured interviews using inductive and deductive coding • Quantitative analysis of patient charts and questionnaires

GPs: general practitioners; HF: heart failure; NWE: North West European.

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, 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 was addressed to all patients to address the objectives of this study (Appendix 1).

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 2).

The topic list was developed after expert meetings with several HF-care stakeholders (patient organisation, GPs/GP networks, HF specialists, general cardiologists, internists, geriatrician, representatives of healthcare insurers and representatives of Dutch ministry of health). The topics were adjusted during the 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, 38 years, public health nurse, master in health sciences), RS (M, 40 years, Phsyiotherapist and Master of sience in Engenering Technology), MM (M, 50 years, Master of Sience in Engineering Technology and Post graduate in Relation and Communication Sciences), SB (F, 31 years, MD), ZS (M, 28 years, medical student), BON (F, 24 years, medical student), DR (F, 27 years, MD), CR (F; 25 years; MD student) and CH (F, 42 years, 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 min for care providers and patients, respectively.

Dutch and Belgian interviews were coded separately. An attempt to merge the databases showed that there were too many 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 684 distributed over five 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.
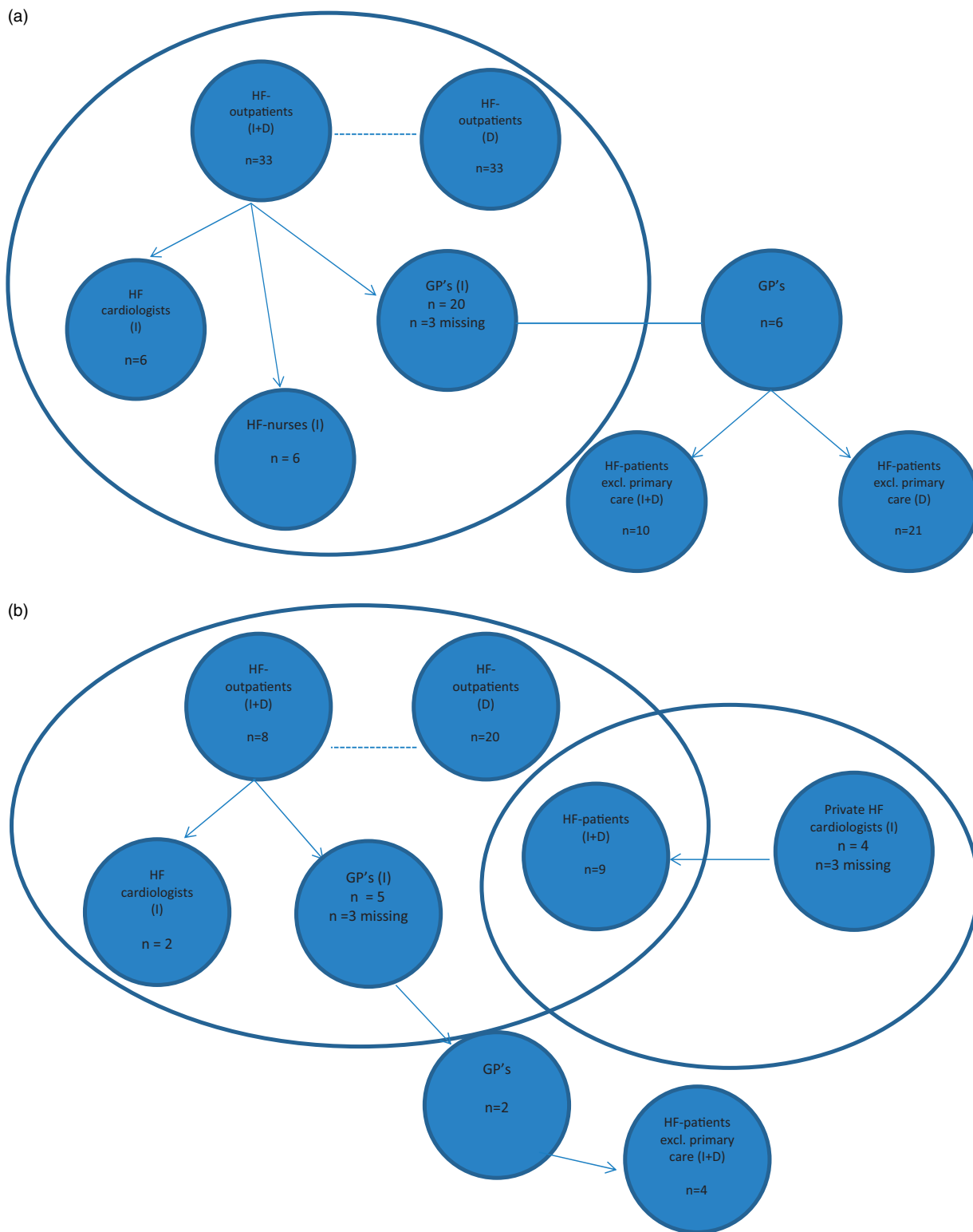
(a)

(b)

(c)

Figure 2. Sample selection. (a) Maastricht, (b) Aachen and (c) Noorder-Kempen. I: interview; D: data; GP: general practitioner; HF: heart failure.
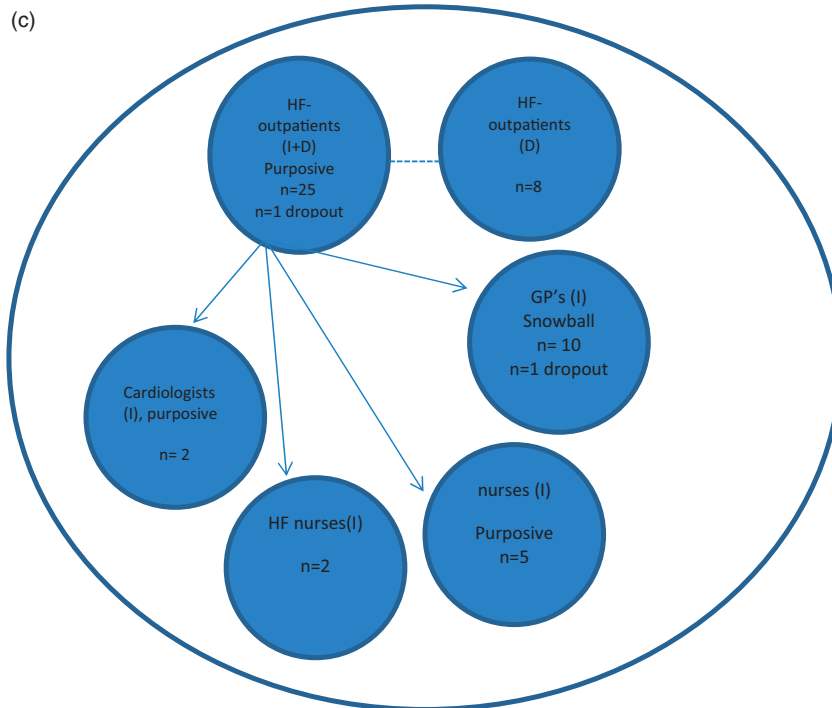
(c)

Figure 2. Continued.

Quantitative part: Questionnaires. Prior to the interviews, patients completed three questionnaires:

1. 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]
2. 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]
3. The global health status and social economic status (SES), a 20-item, self-developed, global, and sociodemographic 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 and smoking), healthcare utilisation within the last year, New York Heart Association class, weight and height, blood pressure, heart rate and diagnostics used: electrocardiogram (rhythm and 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 GPs in Noorder-Kempen.

Analyses

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

All interviews were audiotaped (Smartpen, Livescribe, Oakland, CA, USA), transcribed verbatim and analysed by the qualitative analysis software program 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]

Table 2. Patient characteristics per region.

	Total	Maastricht	Aachen	Noorder-Kempen
	N = 170 (%)	n = 97 (57%)	n = 41 (24%)	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)

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

Results

Patient characteristics

Patient characteristics are given in Table 2. 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 followed by dilated cardiomyopathy. 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 2).

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 3) and registered in a codebook. Inductive analysis resulted in 6090 different codes. Thereafter, a deductive approach[33] was applied to these codes to reduce the number of codes by merging common themes, finally resulting in 684 codes.

Discussion

National and international guidelines are developed to define best practice in HF management. In order to

Table 3. 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)

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 DMPs are structurally implemented in most centres in the Netherlands, 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 different, but comparable demographic features of included patients. Also, national organisation of healthcare 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 workup 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 standardised approach to obtain a precise overview of the standard of HF care.[15] According to Bowling,[43] "the most persuasive evidence comes through a triangulation of measurement processes, as well as through minimising 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 question,[33] whereas the iterative approach is useful to investigate processes. The inductive approach generates validity because of 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, and 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 systemises 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 HF 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

The 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-centred 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 the presence of comorbidities is 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 recognise the fact that 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 are 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, patients' 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, and also aspects that support it. These results will help to understand the needs for providing well-organised, excellent HF care.

References

1. Schou M, Gustafsson F, Videbaek L, et al. Extended heart failure clinic follow-up in low-risk patients: a randomized clinical trial (NorthStar). *Eur Heart J* 2013; 34: 432–442.
2. Allen LA, Yager JE, Funk MJ, et al. Discordance between patient-predicted and model-predicted life expectancy among ambulatory patients with heart failure. *JAMA* 2008; 299: 2533–2542.
3. Jhund PS, Macintyre K, Simpson CR, et al. Long-term trends in first hospitalization for heart failure and subsequent survival between 1986 and 2003: a population study of 5.1 million people. *Circulation* 2009; 119: 515–523.
4. Ko DT, Alter DA, Austin PC, et al. Life expectancy after an index hospitalization for patients with heart failure: a population-based study. *Am Heart J* 2008; 155: 324–331.
5. Braunschweig F, Cowie MR and Auricchio A. What are the costs of heart failure? *Europace* 2011; 13(Suppl 2): ii13–ii17.
6. Krum H and Gilbert RE. Demographics and concomitant disorders in heart failure. *Lancet* 2003; 362: 147–158.
7. Lang CC and Mancini DM. Non-cardiac comorbidities in chronic heart failure. *Heart* 2007; 93: 665–671.
8. Metra M, Zaca V, Parati G, et al. Cardiovascular and noncardiovascular comorbidities in patients with chronic heart failure. *J Cardiovasc Med (Hagerstown)* 2011; 12: 76–84.
9. Ponikowski P, Voors AA, Anker SD, et al. 2016 ESC guidelines for the diagnosis and treatment of acute and chronic heart failure: the Task Force for the diagnosis and treatment of acute and chronic heart failure of the European Society of Cardiology (ESC) developed with the special contribution of the Heart Failure Association (HFA) of the ESC. *Eur Heart J* 2016; 37: 2129–2200.
10. Davidson PM, Newton PJ, Tankumpuan T, et al. Multidisciplinary management of chronic heart failure: principles and future trends. *Clin Ther* 2015; 37: 2225–33.
11. Kimmelstiel C, Levine D, Perry K, et al. Randomized, controlled evaluation of short- and long-term benefits of heart failure disease management within a diverse provider network: the SPAN-CHF trial. *Circulation* 2004; 110: 1450–1455.
12. McDonagh TA, Blue L, Clark AL, et al. European Society of Cardiology Heart Failure Association Standards for delivering heart failure care. *Eur J Heart Fail* 2011; 13: 235–241.
13. Whellan DJ, Hasselblad V, Peterson E, et al. Metaanalysis and review of heart failure disease management randomized controlled clinical trials. *Am Heart J* 2005; 149: 722–729.

14. Rich MW, Beckham V, Wittenberg C, et al. A multidisciplinary intervention to prevent the readmission of elderly patients with congestive heart failure. *N Engl J Med* 1995; 333: 1190–1195.

15. McAlister FA, Stewart S, Ferrua S, et al. Multidisciplinary strategies for the management of heart failure patients at high risk for admission: a systematic review of randomized trials. *J Am Coll Cardiol* 2004; 44: 810–819.

16. Duchenne J, Verbrugge FH, Dupont M, et al. Implementation of transmural disease management in patients admitted with advanced heart failure. *Acta Cardiol* 2014; 69: 145–154.

17. McMurray JJ, Adamopoulos S, Anker SD, et al. ESC guidelines for the diagnosis and treatment of acute and chronic heart failure 2012: the Task Force for the Diagnosis and Treatment of Acute and Chronic Heart Failure 2012 of the European Society of Cardiology. Developed in collaboration with the Heart Failure Association (HFA) of the ESC. *Eur J Heart Fail* 2012; 14: 803–869.

18. Voors AA, Walma EP, Twickler TB, et al. Multidisciplinary guideline "Heart failure 2010". *Ned Tijdschr Geneeskd* 2011; 155: A2957.

19. Katon W, Von Korff M, Lin E, et al. Rethinking practitioner roles in chronic illness: the specialist, primary care physician, and the practice nurse. *Gen Hosp Psychiatry* 2001; 23: 138–144.

20. Luttik ML, Brons M, Jaarsma T, et al. Design and methodology of the COACH-2 (Comparative study on guideline adherence and patient compliance in heart failure patients) study: HF clinics versus primary care in stable patients on optimal therapy. *Neth Heart J* 2012; 20: 307–312.

21. Donabedian A. The quality of care How can it be assessed? *JAMA* 1988; 260: 1743–1748.

22. Jaarsma T, Stromberg A, De Geest S, et al. Heart failure management programmes in Europe. *Eur J Cardiovasc Nurs* 2006; 5: 197–205.

23. Feltner C, Jones CD, Cene CW, et al. Transitional care interventions to prevent readmissions for persons with heart failure: a systematic review and meta-analysis. *Ann Intern Med* 2014; 160: 774–784.

24. Savard LA, Thompson DR and Clark AM. A meta-review of evidence on heart failure disease management programs: the challenges of describing and synthesizing evidence on complex interventions. *Trials* 2011; 12: 194.

25. Nordgren L, Asp M and Fagerberg I. An exploration of the phenomenon of formal care from the perspective of middle-aged heart failure patients. *Eur J Cardiovasc Nurs* 2007; 6: 121–129.

26. Cleland JG. Contemporary management of heart failure in clinical practice. *Heart* 2002; 88 Suppl 2: ii5–ii8.

27. Bosch M, van der Weijden T, Grol R, et al. Structured chronic primary care and health-related quality of life in chronic heart failure. *BMC Health Serv Res* 2009; 9: 104.

28. Creswell JW and Clark VLP. *Designing and conducting mixed methods research*. Thousand Oaks: SAGE, 2007.

29. Patton MQ. Enhancing the quality and credibility of qualitative analysis. *Health Serv Res* 1999; 34: 1189–1208.

30. Denzin N. *Sociological methods*. New York: McGraw-Hill, 1970, pp.19260–19265.

31. Hale ED, Treharne GJ and Kitas GD. Qualitative methodologies II: a brief guide to applying interpretative phenomenological analysis in musculoskeletal care. *Musculoskeletal Care* 2008; 6: 86–96.

32. Carter N, Bryant-Lukosius D, DiCenso A, et al. The use of triangulation in qualitative research. *Oncol Nurs Forum* 2014; 41: 545–547.

33. Devillé A. *Schuilen in de Schaduw. Mensen zonder wettig verblijf in de Belgische samenleving*. Mechelen: Wolters Kluwer, 2008.

34. van der Wal MH, Jaarsma T, Moser DK, et al. Development and testing of the Dutch Heart Failure Knowledge Scale. *Eur J Cardiovasc Nurs* 2005; 4: 273–277.

35. Koberich S, Suhonen R, Feuchtinger J, et al. The German version of the Individualized Care Scale—assessing validity and reliability. *Patient Prefer Adherence* 2015; 9: 483–494.

36. Jaarsma T, Stromberg A, Martensson J, et al. Development and testing of the European Heart Failure Self-Care Behaviour Scale. *Eur J Heart Fail* 2003; 5: 363–370.

37. Pope C, Ziebland S and Mays N. Analysing qualitative data. In: Pope C and Mays N (eds) *Qualitative research in health care*, 3rd ed. Oxford, UK: Blackwell Publishing, 2006, pp.63–81.

38. De Bleser L, Baldewijns K, Decock W, et al. *Beleid, organisatie en kwaliteit in de gezondheidszorg*. Antwerp: Uitgeverij De Boeck, 2015.

39. Thomson S, Osborn R, Squires D, et al. International profiles of health care systems 2012: Australia, Canada, Denmark, England, France, Germany, Iceland, Italy, Japan, the Netherlands, New Zealand, Norway, Sweden, Switzerland, and the United States, http://www.commonwealthfund.org/˜/media/Files/Publications/Fund%20Report/2012/Nov/1645_Squires_intl_profiles_hlt_care_systems_2012.pdf (2012, accessed 2 August 2017).

40. Rutten FH, Grobbee DE and Hoes AW. Diagnosis and management of heart failure: a questionnaire among general practitioners and cardiologists. *Eur J Heart Fail* 2003; 5: 345–348.

41. Philbin EF, Weil HF, Erb TA, et al. Cardiology or primary care for heart failure in the community setting: process of care and clinical outcomes. *Chest* 1999; 116: 346–354.

42. Ukena C and Bohm M. Management of heart failure: are specialists really needed? *Eur Heart J* 2013; 34: 416–418.

43. Bowling A. *Research methods in health*, 2nd ed. Buckingham: Open University Press, 2002, p.202.

44. Happ MB, Dabbs AD, Tate J, et al. Exemplars of mixed methods data combination and analysis. *Nurs Res* 2006; 55: S43–S49.

45. Wyrwich KW, Metz SM, Kroenke K, et al. Triangulating patient and clinician perspectives on clinically important differences in health-related quality of life among patients with heart disease. *Health Serv Res* 2007; 42: 2257–2274; discussion 94-323.

46. Eisenhardt KM. Building theories from case-study research. *Acad Manage Rev* 1989; 14: 532–550.
47. Whitehead D and Yin R. Case study research design and methods, 3rd edition. *J Adv Nurs* 2003; 44: 108.
48. Greenhalgh T and Taylor R. Papers that go beyond numbers (qualitative research). *BMJ* 1997; 315: 740–743.
49. Schotter A and Beamish PW. Performance effects of MNC headquarters-subsidiary conflict and the role of boundary spanners: the case of headquarter initiative rejection. *J Int Manag* 2011; 17: 243–259.
50. Hausen B, Demertzis S, Schafers HJ, et al. The impact of early postoperative cyclosporine serum levels on the incidence of cardiac allograft rejection. *Eur J Cardiothorac Surg* 1993; 7: 257–262.
51. McMurray JJ and Stewart S. Epidemiology, aetiology, and prognosis of heart failure. *Heart* 2000; 83: 596–602.
52. Braunstein JB, Anderson GF, Gerstenblith G, et al. Noncardiac comorbidity increases preventable hospitalizations and mortality among Medicare beneficiaries with chronic heart failure. *J Am Coll Cardiol* 2003; 42: 1226–1233.
53. Ather S, Chan W, Bozkurt B, et al. Impact of noncardiac comorbidities on morbidity and mortality in a predominantly male population with heart failure and preserved versus reduced ejection fraction. *J Am Coll Cardiol* 2012; 59: 998–1005.

Appendix 1

Interview framework patient

- How did it all begin?

- 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 diagnostic?
  - 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

- 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 organisation
  - How do you experience care?
  - Room for improvement?
  - Thing you miss?

Appendix 2

Interview care provider

- Definition of heart failure?
- 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