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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-Kempen(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 region 2 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.

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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

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influence their attitude and behavior, it is necessary to provide them with adequate Health Care (HC-) professional support.^{3,6}

Multidisciplinary management programs (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 programs 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.²² 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. (Source deleted for blinded review)

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 (region 1), SB, ZS, BON, DR. (region 2), CR and CH (region 3). Subsequently the data were analyzed by SB, KB, CR and LDB, supervised by MD. Two participants decided to withdraw from the study and were not included in the analysis.²²

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.²²

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). Intercoder reliability (Kappa) was $K = 0,73$.

Qualitative content analysis was completed with a five step approach.¹¹ 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.²² 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 program NVivo v. 10.0 was used to organize the dataset.

Results

The sample consisted of 15 cardiologists, 35 GPs and 8 HF-nurses (Table 1).

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 2)

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

As shown in Table 2, 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 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 Maastricht reported that they considered this someone else's responsibility e.g., HF-nurses/cardiologist or practice assistant. Some GPs in Noorder-Kempen indicated that time management was an issue and some GPs - in Maastricht 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.⁷ (Table 1)

Subtheme 2.1 etiology and trajectory of HF

Table 1.
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.

Table 2.
Lists HC-professionals experiences according to subthemes.

	Region 2			Region 1			Region 3	
	CA	HFN	GP	CA	HFN	GP	CA	GP
Theme 1: Extent of patient education reported by different HC-professional/ role as educator	Yellow	Green	Yellow	Yellow	Green	Yellow	Yellow	Yellow
Theme 2: topics of patient education and self-care advice								
Subtheme 2.1: aetiology and trajectory	Green	Green	Green	Green	Green	Green	Green	Green
Subtheme 2.2: symptom monitoring and self-care	Red	Green	Red	Red	Green	Red	Yellow	Red
Subtheme 2.3: pharmacological treatment	Green	Green	Green	Green	Green	Green	Green	Green
Subtheme 2.4: implanted devices	Green	Red	Red	Green	Red	Red	Green	Red
Subtheme 2.5: salt-intake	Yellow	Green	Red	Yellow	Green	Red	Red	Red
Subtheme 2.6: fluid-intake and weighing	Red	Green	Red	Red	Green	Red	Red	Red
Subtheme 2.7: maintaining a healthy body weight	Green	Green	Green	Red	Green	Green	Yellow	Red
Subtheme 2.8: alcohol	Red	Red	Red	Red	Red	Yellow	Yellow	Yellow
Subtheme 2.9: smoking	Green	Green	Green	Green	Green	Green	Green	Green
Subtheme 2.10: exercise	Green	Green	Green	Green	Green	Green	Yellow	Yellow
Subtheme 2.11: psychosocial aspects	Yellow	Green	Green	Yellow	Green	Green	Yellow	Green
Immunization	Red	Red	Red	Red	Red	Red	Red	Red
Travel and leisure	Red	Red	Red	Red	Red	Red	Red	Red
Sleep and breathing	Red	Red	Red	Red	Red	Red	Red	Red
Sexual activity	Red	Red	Red	Red	Red	Red	Red	Red

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.

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 region 2 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)

We explain how patients should take their medication, why they should take the medication and what the medication is for (HF-nurse, 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 Maastricht 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 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 Noorder-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 kgs' 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 Maastricht and Noorder-Kempen 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 program. One cardiologist in Aachen reported referring patients to a physical exercise program. 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 program. 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 program.

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-Kempen) 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.^{6,12} 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.¹³ 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.¹³ This may, in part, explain the education gap between primary and specialist care. In the Maastricht, this gap is reduced by primary care nurses (PCNs) working in primary health care facilities. These nurses are trained to educate patients with chronic conditions such as HF.¹⁴

To our knowledge, no such trained PCNs 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.¹³ 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.^{13,15} In order to enable PCNs to adopt this role, appropriate training and resources are required.^{15,16} 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.^{17,18} Moreover, education is often tailored and individualized to fit patients characteristics and beliefs.¹⁹ 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.^{20,21} 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 region 3 at the time of this study. This may have influenced the results.

Lastly, 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, dietitian, 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.

Declaration of Competing Interest

Non declared for Baldewijns, Boyne, Rhode, De Maesschalck, Devillé, Brandenburg, De Bleser, Derickx.

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