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Patient-reported outcomes and experiences in a regional heart failure care network in northern Germany: a mixed-methods study

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Patient-reported outcomes and experiences in a regional heart failure care network in northern Germany: a mixed-methods study

1 Abstract

Background: Chronic heart failure (HF) is associated with high morbidity and mortality, necessitating well-coordinated, guideline-based care. In XXX, Germany, a regional HF care network based on cross-sector collaboration between a university heart centre, general practitioners, cardiologists, and hospitals was implemented. This study examined patient-reported outcomes and experiences within the network.

Methods: A non-interventional, exploratory pre-post study was conducted as part of routine care. HF-Patients referred from network partners to the university heart centre were invited to participate. Participants completed the Kansas City Cardiomyopathy Questionnaire (KCCQ-23) at baseline (T1) and after 6 months (T2). At T2, a brief, self-developed questionnaire assessed the perceived network-effects on care coordination. In addition, semi-structured telephone interviews were conducted with a subsample of patients. Quantitative data were analysed descriptively and using paired t-tests, while interviews were analysed using qualitative content analysis.

Results: Seventy-five patients (74.7% male, mean age 65 years) were enrolled, of whom 72 completed the KCCQ at T1 and 40 at T2. Mean scores across all KCCQ domains indicated a moderate to good health-related quality of life at both time points, with small, non-significant improvements observed over six months (e.g., mean clinical summary score T1: 63.69, SD: 25.08, n=72; T2: 71.15, SD: 23.79, n=40, p=0.16). Higher NYHA class and older age were associated with poorer KCCQ scores. Women reported more symptoms and a worse clinical status at baseline. Most respondents at T2 perceived the care process as well coordinated. Ten qualitative interviews revealed high acceptance of the network, perceived benefits of having a direct contact person, and better information, but also some burdens. Most patients considered the role of HF nurses as central contacts valuable.

Conclusions: In this regional HF network, health-related quality of life remained stable at a moderate to good level over six months, while patients reported high satisfaction and perceived improvements in coordination and information flow. These results suggest that a cross-sectoral HF network is acceptable and useful from a patient perspective. However, there is a need to strengthen communication about the network, clarify responsibilities, and incorporate patient-specific needs, such as more flexible appointment times, to further enhance patient-centred care.

2 Keywords

Heart Failure; Care Network; Health Services Research; Patient-Reported Outcomes; Health-Related Quality Of Life; Quantitative Evaluation; Qualitative Research

3 Background

Chronic heart failure (HF) is one of the most prevalent chronic conditions in industrialised countries and is associated with high morbidity, mortality and health-care costs (1, 2). Frequent hospitalisations and progressive functional limitations have a substantial negative impact on patients' health-related quality of life (HRQoL), representing a considerable burden on health systems (3, 4). Timely, guideline-directed medical therapy, as well as structured follow-up, are essential to prevent deterioration and avoidable hospital admissions (1, 5). To provide the best possible care based on international and German guidelines, the German Society of Cardiology (DGK) has developed a framework for the design and certification of specialised heart failure units (6). However, provision of HF care in Germany is challenged by geographical distances, an uneven distribution of specialists, and fragmented responsibilities between sectors. In rural regions such as XXX in the XXX part of Germany, patients often receive care from multiple providers, who may have limited opportunities to coordinate treatment. This can result in inconsistent recommendations and cause uncertainty for patients (7).

To address these challenges, a regional HF care network for XXX was implemented (8). The network is based on digital, cross-sector collaboration between a university heart centre, general practitioners, cardiologists, and hospitals. Patients with HF are referred to the university heart centre for specialised assessment and optimisation of guideline-directed therapy. Information from these visits is fed back to referring physicians. A HF nurse supports the coordination of care, patient education, and follow-up.

Previous studies have suggested that structured HF networks can improve adherence to guideline-directed therapy and may positively influence clinical outcomes (9, 10). However, there is limited evidence regarding patients' experiences of such regional, digitally supported care networks in routine practice, and their perceptions of the networks' impact on HRQoL and care coordination.

This mixed-methods health services study was designed to investigate the effects of the network on HRQoL, perceived coordination and quality of care, as well as patients' acceptance of, and perceived benefits from, the network in a real-world care provision context.

4 Methods

4.1 Study design

This mixed-methods study was conducted as a non-interventional, exploratory health services study using a single-group pre-post design in routine care. Patients with HF who were referred to the university heart centre by participating network partners, such as general practitioners, cardiologists and other hospitals, were invited to take part in the evaluation.

The qualitative components of the study were conducted and reported in line with the Standards for Reporting Qualitative Research (SRQR) and the Consolidated Criteria for Reporting Qualitative Research (COREQ).

4.2 Ethics

The study was conducted in accordance with the principles of the Declaration of Helsinki. Ethical approval was obtained from the Ethics Committee of the XXX (reference number: 2023-567). All participants provided written informed consent prior to participating in the study.

4.3 Participants and recruitment

Patients were eligible for inclusion if they had a confirmed diagnosis of HF (ICD-10: I50), were at least 18 years old, had an expected life expectancy of over one year, could read and complete the study questionnaires, and provided written informed consent. No further exclusion criteria were defined. Eligible patients were identified either when attending the university heart centre as part of their routine care, or after being referred by a network partner. The clinic staff checked eligibility, provided written and oral information about the study, and obtained written informed consent.

4.4 Data collection

Sociodemographic and clinical data, including age, sex, New York Heart Association (NYHA) functional class, and distance from the patient's home to the university heart centre, were collected at baseline.

Questionnaires were completed on paper at the clinic at baseline (T1) and returned to the clinic staff in sealed envelopes. Six months after inclusion (T2), follow-up questionnaires were sent by mail to the participating patients, with a prepaid return envelope. As this was a study conducted in the context of everyday care, patients were generally not invited to attend a second interview at the university heart centre. The aim was to minimise disruption to everyday care as much as possible. Approximately six months after study inclusion, a purposive subsample of patients who had consented to be contacted for an interview were invited to take part in a qualitative telephone interview. Recruitment for the quantitative study took place between September 2023 and February 2024. Interviews were conducted between March 2024 and August 2024.

4.5 Questionnaires

Health-related quality of life was assessed at T1 and T2 using the Kansas City Cardiomyopathy Questionnaire (KCCQ-23). This is a disease-specific instrument with 23 items that cover multiple domains, including physical limitations, symptom frequency, symptom burden, symptom stability, self-efficacy, social limitations, and quality of life. It also provides a clinical summary score and an overall summary score (11). Item responses are converted to a 0–100 scale, with higher scores indicating better HRQoL.

To assess how patients perceived the effect of the network on the coordination of their medical care, a brief four-item questionnaire on network aspects of care was developed based on key findings from Schoen, et al. (12) and administered at T2. Using a 5-point Likert scale ranging from 1 (‘almost never’) to 5 (‘almost always’), patients were asked to rate the frequency of contradictory information and treatment recommendations from different healthcare providers, as well as how well collaboration and information transfer between providers had worked during the past six months.

4.6 Semi-structured interviews

Telephone interviews were conducted by an experienced qualitative researcher (AN) using a semi-structured interview guide. Although the intervention did not primarily evaluate the acceptance of digital communication pathways within the network, the Unified Theory of Acceptance and Use of Technology (UTAUT) framework was used to examine the acceptance of the new, digitally supported care process introduced by the regional heart failure network (13). In line with UTAUT, questions addressed (1) perceived benefits of the new care pathway (performance expectancy), (2) perceived effort and practicability of participation-related activities (effort expectancy), (3) perceived support and expectations from relevant others (social influence), as well as (4) structural/organizational enablers and barriers such as coordination, accessibility, and availability of contact persons (facilitating conditions). In addition, items on overall satisfaction, recommendation, and willingness to continue participation captured elements of post-adoption evaluation and continuance intention. This aligns with comparable applications of UTAUT in workflow-support and process-oriented implementations

in healthcare (14). With consent, interviews were audio-recorded, transcribed verbatim using an open-source transcription tool (aTrain 1.1.0, in combination with Whisper large-v2), and pseudonymised. The quality of transcripts was reviewed by a health information manager of the foundation, who compared the audio files directly with the transcripts. In the process, the transcripts were anonymised and occurring errors were corrected.

4.7 Data analysis

Quantitative questionnaire data were analysed using descriptive statistics (means, standard deviations and frequencies). Paired t-tests for dependent samples were used to examine changes in KCCQ scale and summary scores between T1 and T2. Where appropriate, multivariate analyses of variance were conducted to explore potential effects of sex and NYHA class. Correlation analyses were performed to investigate associations between KCCQ scales, age, and NYHA class. The significance level was set at $p < 0.05$, and effect sizes were calculated to support interpretation of clinical relevance.

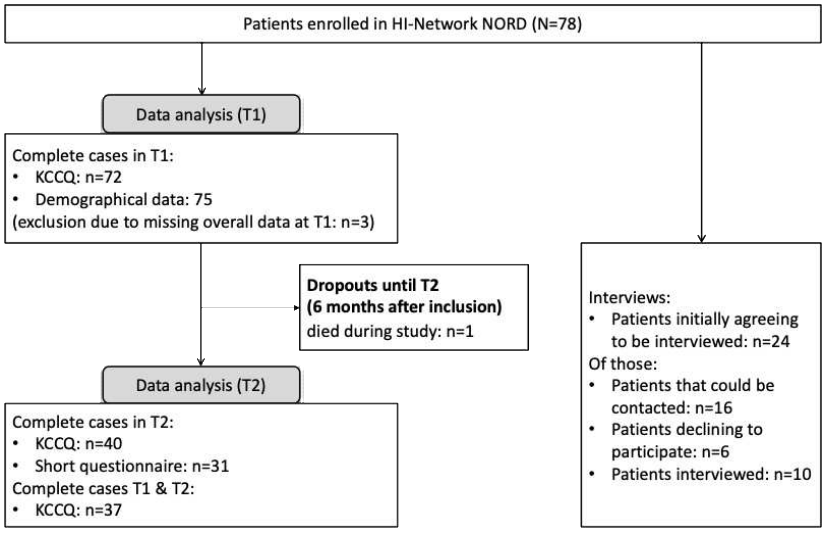
The qualitative interview data were analysed using qualitative content analysis following a combined deductive-inductive approach. An initial category system was developed based on the interview guide (deductive categories) and iteratively refined using emerging themes from the transcripts (inductive categories). Two researchers (AN, BS) coded the material using MAXQDA 24, discussed coding decisions with a third researcher (BZS) and resolved disagreements by consensus. The analysis aimed to provide a concise, well-structured summary of key themes regarding patients' experiences with and perceptions of the HF network.

5 Results

5.1 Participant characteristics

A total of 75 patients with HF were enrolled in the study. Figure 1 provides an overview of the participants and the availability of analysis datasets.

Figure 1: Participant flow and availability of analysis datasets in the study



Of the 75 patients for whom demographical data were available, 74.7% were male and 25.3% were female (Table 1). Their ages ranged from 25 to 97 years (mean 65.3 years, SD 14.6). At baseline, 12% of patients were classified as NYHA class I or I-II, 36% as NYHA class II or II-III, and 27% as NYHA class III or above, indicating predominantly moderate to severe symptoms. Most participants (46.7%) lived between 10 and 50 km from the university heart centre, while about one fifth lived between 51 and 100 km away. Data from KCCQ were available for 72 patients at T1 and 40 patients at T2, corresponding to a follow-up postal response rate of around 56%. No significant differences were found in age, sex or NYHA class when comparing patients with complete KCCQ data and those lost to follow-up.

Table 1: Patients characteristics

Patients	n	%
Gender		
Male	56	74.7
Female	19	25.3
Age		
18-49	10	13.3
50-59	11	14.7
60-69	24	32.0
70-79	18	24.0
80-89	10	13.3
90-100	2	2.7

HF severity		
NYHA I / I-II	12	16
NYHA II / II-III	36	48
NYHA III / III-IV	26	34.7
NYHA IV	1	1.3
Distance to university heart centre		
Less than 5 km	8	10,7
6-10 km	13	17,3
11-50 km	35	46,7
51-100 km	16	21,3
More than 100 km	3	4,0

Approximately 6 months after enrolment, 24 patients who had agreed to be interviewed were randomly selected and contacted to schedule a telephone interview. Eight of the 24 patients contacted could not be reached repeatedly, and six declined to participate in the interview without giving a reason. Ultimately, ten patients participated in a telephone interview. Of these, eight were male (80%) and two were female (20%). Most interviewees were aged between 60 and 69, were classified as NYHA class II at baseline, and lived approximately 11–50 km from the university heart centre. The interviews lasted around 35 minutes on average.

5.2 Health-related quality of life

As described above, KCCQ scores ranged from 0 to 100. Using 25-point ranges, the scores represent HRQoL and can be interpreted as follows: 0 to 24: very poor to poor; 25 to 49: poor to fair; 50 to 74: fair to good; and 75 to 100: good to excellent (11). For all KCCQ domains, the mean scores at both measurement points were within the range that is usually interpreted as indicating a moderate to good health status. This also applied for the total symptom summary score (T1: mean: 66.93, SD: 25.20, n=72; T2: mean: 74.74, SD: 22.55, n=40), the clinical summary score (T1: mean: 63.69, SD: 25.08, n=72; T2: mean: 71.15, SD: 23.79, n=40) and the overall summary score (T1: mean: 59.36, SD: 25.32, n=72; T2: mean: 66.11, SD: 25.46, n=40). While the quality of life domain in T1 scored lowest (mean: 54.28 on the 0–100 scale, SD: 29.04, n=72), indicating a fair quality of life, the symptom burden domain in T1 was rated higher (mean: 68.23, SD: 25.94, n=72), indicating less impairment due to symptoms and

a health status ranging from fair to good. The mean scores for other domains, such as physical limitations, symptom frequency and social limitations, ranged from 55.72 (social limitations: SD: 31.48, n=67) to 67.78 (self-efficacy: SD: 22.23, n=71) on the 0-100 scale. In T2, the quality of life domain was higher but still rated lowest (mean: 59.48, SD: 31.39, n=40). Symptom burden was also rated higher with a mean of 74.38 (SD: 22,75, n=40). Hence, from T1 to T2, small mean improvements were observed in most KCCQ domains, including the clinical summary score (mean difference between T1 and T2: 3.12, p=0.157, n=37) and overall summary score (mean difference between T1 and T2: 4.06, p=0.145, n=37). However, none of these changes reached statistical significance in paired t-tests. The appendix contains the descriptive analysis of the KCCQ domains and summary scores in T1 and T2 (tables S1 and S2), as well as the T-tests (table S3).

Correlation analyses (see appendix, table S4) revealed that higher NYHA class at baseline was associated with lower scores in several KCCQ domains, including physical limitations, symptom frequency and total symptom score, as well as lower clinical and overall summary scores. Older age was likewise associated with greater physical and social limitations and a poorer clinical summary score. At baseline, women reported more frequent and burdensome HF symptoms (symptom frequency: mean difference between man and woman: -16.63, p=0.018, n=69; total symptom score: mean difference between man and woman: -14.19, p=0.038, n=70) and a worse clinical summary score (mean difference between man and woman: -14.53, p=0.032, n=70) than men, indicating gender-related differences in perceived health status.

5.3 Perceived network aspects of care

Thirty to thirty-one patients completed the short questionnaire on network aspects of care at T2. Most respondents indicated that they ‘almost never’ or ‘mostly not’ received contradictory information (83.4%, n=25, N=30) or conflicting treatment recommendations from different providers (76.7%, n=23, N=30) during the past six months. In contrast, a substantial majority rated collaboration between providers (80.0%, n=24, N=30) and the transfer of information about their health status and treatment

(71.0%, n=22, N=31) as functioning ‘mostly’ or ‘almost always’ well. Only a small minority reported that collaboration or information transfer worked rarely or ‘mostly not’ (9.7%, n=3, N=31).

5.4 Qualitative findings on acceptance and perceived benefits

Analysis of the interviews yielded several overarching themes: (1) expectations and motivation to participate, (1) experiences of being enrolled in the network, (3) influence on everyday life and self-management, (4) the role of the HF nurse, (5) communication and coordination, (6) perceived benefits and burdens, and (7) overall satisfaction and potential for improvement.

5.4.1 Expectations and motivation to participate

Around half of the interviewees reported having no specific expectations when they joined the HF network. Others hoped for better coordination between healthcare providers and more comprehensive information about their condition.

> “In fact, the expectations are that communication between them will improve and that it will become more centralised. Now you rush from your GP to the cardiologist, who don't really know about each other. Then you rush to the [university heart centre], who don't know what the GP said, and so on [...]." (male, 50-59 years old)

Motivation to participate was often altruistic, driven by a wish to help other patients and to contribute to improving HF care structures.

5.4.2 Experiences of being enrolled in the network

Experiences of enrolment and care within the network were generally positive. Most patients described the admission and information process at the university heart centre as good or very good. Many also appreciated having direct contact persons and short waiting times for appointments.

> “Very good, they were always very courteous and there was always someone available to talk to. Whenever I had any difficulties or questions, I always received clear answers.” (male, 60-69 years old)

Some participants, however, would have preferred a clearer overall treatment plan and a single, consistent physician in charge.

> “[...] an overall plan would have been nice, but you can't really say in advance exactly what's going to happen or explain that we'll do a CT scan first, then an MRI, and then decide what needs to be done. So somehow, I missed an overall plan." (male, 60-69 years old)

Moreover, one patient was unaware that they were being treated within a HF care network.

5.4.3 Influence on everyday life and self-management

All patients reported that they received recommendations on medication, five patients on diet and six patients on physical activity. Everyone agreed that those recommendations were usually clear and, in the case of medication, could be easily incorporated into everyday life. However, one person noted that taking the medication since being diagnosed had been burdensome.

> "I'm afraid that with so many pills, there will be side effects or something, that it will affect the kidneys or something else in the body. And also, the fact that there was nothing before and suddenly there are eight tablets a day, the mind has to get used to it first." (male, 60-69 years)

Integrating dietary advice and exercise into daily routines was sometimes challenging, especially when away from home or when other life circumstances limited energy and time. Some patients described periods of low motivation or psychological strain following diagnosis. Although lifestyle changes and maintaining them over the long term required effort, the medication recommendations were always consistently implemented. One patient described that the advice of the university heart centre helped to accept and implement the necessary recommendations better into everyday life.

> "Yes, motivation needs a little input every now and then. Because it's taking so long [...] to put it in pictures, it's one step forward, two steps back. That's how it's been since the operation. There are always phases where you feel like you've broken through the barrier and you're back on track to your old level. And then it all comes crashing down and you're back where you thought you'd never have to be again. And that requires a high degree of self-motivation and

a certain amount of attention to detail not to give up. I have to be honest about that, because it's very frustrating." (male, 18-49 years old)

While most patients found the exercise recommendations clear, one patient would have preferred more specific wording regarding physical activity.

"I'm allowed to exercise, but I should do so in moderation. Well, what does that mean?" (female, 60–69 years old)

5.4.4 The role of the HF nurse

The role of the HF nurse within the HF network was perceived in different ways. About half of the interviewees mainly interacted with the HF nurse for appointment scheduling. A few patients reported having had no contact with the HF nurse and were unaware of the role. However, some patients described the HF nurse as an important contact person and intermediary between patients and physicians, providing advice and support.

"I see Ms [name HI-Nurse] as a bit of an interface between the patient and the doctor. As a point of contact when things are difficult and you don't know what to do. As an advisor and initiator for follow-up measures." (male, 18-49 years old)

5.4.5 Communication and coordination

Although most patients were unsure whether communication between healthcare professionals had changed, and two patients were unsure whether their general practitioner had been informed about their treatment, four respondents reported improved communication since receiving treatment at the university heart centre. One person also highlighted the good communication between their general practitioner and the university heart centre.

"Yes, I definitely feel that things have improved. [...] I mean the communication between the individual doctors, who now know about each other. They then sent me on to [place name], for example. But then everyone knows about it and it just works." (male, 50-59 years old)

However, communication between patients and professionals at the university heart centre was consistently described as respectful, attentive and responsive. Patients felt that their questions were taken seriously and that sufficient time was available during consultations. Many reported feeling seen as individuals rather than just cases, and several noted that the care they received gave them a strong sense of security and of being well looked after.

5.4.6 Perceived Benefits and burdens

Almost all interviewees perceived clear personal benefits from participating in the HF network. Many highlighted the availability of direct contact persons for questions and concerns, as well as prompt appointment suggestions. Some patients also appreciated the close care provided by the university heart centre, the monitoring of their health status, and the perceived ‘feel-good factor’ combined with the impression of being seen ‘as a person’.

> "No one likes to say it. But when I walk into the heart centre for my routine check-ups, it sometimes feels a bit like coming home. It's a bit silly. But you are addressed personally. Doctors, nurses, etc. rush past you in the corridor, saying, “Good morning, [name].” You are perceived as a human being. You're not just a patient or a number or an object.” (male, 18-49 years old)

Some patients reported that improved communication and information sharing between healthcare providers was a major advantage. For some, the network also contributed to more knowledge about their disease and reduced fear.

> “Well, I think it's good that there is such a network, because I think it's good that all doctors can always access it and then also know what's going on with the respective patients, not just with me, but also with others.” (female, 60-69 years old)

Furthermore, single patients noted an increased sense of security since HF treatment, and the online portal of the university heart centre as advantages. One person also cited as positive that their own

health had improved since participating in the study, that the qualitative interview had been conducted, and that patient feedback and experiences were being shared.

Four patients reported that they had not gained new insights from participating in the HF network, as they had been ill for many years, had already informed themselves in advance, or already had basic knowledge due to their profession. In contrast, four respondents described an increase in knowledge thanks to the extensive disease-specific information provided by the university heart centre. In addition, one patient mentioned that gaining knowledge had alleviated her fear of the disease.

> “Well, I don't know if it's just something to do with the network. Basically, I'm not so afraid of the disease anymore. I was really scared at the beginning.” (female, 60-69 years old)

Disadvantages or burdens were not immediately apparent to the patients. Few reported burdens including long travel distances and associated parking / taxi. Single responses included difficulties reaching the centre by phone, appointment times during regular working hours and, discomfort with wearing digital devices, such as a smartwatch.

> "[...] So, the appointments I have, I don't know if it's necessarily a networking issue or something. They're always at a time when normal people are working. So, getting an appointment in the mid to late afternoon is impossible. That means that because of this close integration, which I really appreciate, I always have an extreme disruption to my working hours, given that I only work part-time anyway, from 8 a.m. to 2 p.m." (male, 18-49 years old)

In summary, half of the respondents stated that the effort required war comparatively low and the benefits were high.

5.4.7 Overall satisfaction and potential for improvement

Overall satisfaction with care in the network was high: all interviewees described themselves as satisfied or very satisfied and expressed that they would recommend the network to other patients with HF.

> “Overall, it's just perfect. I can't put it any other way. I particularly like the contact person system, the fact that I now have a designated contact person. Communication is excellent. Not only between me and the doctors, but also among the doctors themselves. You feel much, much safer than you did before.” (male, 50-59 years old)

The majority wanted the current care arrangement to continue beyond the study period. The few suggested improvements included stronger integration with other hospitals, easier access to psychological support, clearer communication of treatment plans and shorter waiting times for certain procedures.

> “Yes and no. After my last hospital stay, or rather during my last hospital stay, I had a conversation with a psychologist, which I found very helpful. But of course, this is an area that I understand cannot be covered in the same way as the medical side of things. [...] But for me personally, that would definitely have been something that would have made the whole thing even better. That not only the medical side is covered, but that you are also supported on that level somewhere." (male, 18-49 years old)

6 Discussion

This mixed-methods study examined patient-reported outcomes and experiences within a regional HF care network in northern Germany. Overall, HRQoL measured with the KCCQ remained stable at a moderate to good level over six months. While patients reported high satisfaction with care, few contradictory recommendations and largely well-functioning collaboration and information transfer between providers. Qualitative interviews underlined a generally high acceptance of the HF care network and highlighted the perceived benefits of close follow-up, direct contact persons and improved coordination.

As described, KCCQ was used to measure the patient’s HRQoL. The absence of statistically significant changes in KCCQ scores over six months may appear disappointing. However, given the progressive

nature of HF and the relatively high baseline scores, maintaining stable HRQoL can be interpreted as a positive outcome, particularly in a sample with predominantly NYHA class II–III. Although in many studies, a difference of 5 points or more is described as a clinically relevant improvement or deterioration (11) other studies reported significant improvements from the patients' perspective with a difference of as little as 3.6 points (15). The small, insignificant improvements observed in several domains of the KCCQ (4.06 points in the overall summary score) could indicate stabilisation or slight progress. However, these changes could not be recognised as statistically significant due to the small number of patients who participated in the second round of KCCQ responses.

The quantitative analyses confirmed expected associations between functional status, age and HRQoL: higher NYHA class and older age were linked to lower KCCQ scores (11, 16). Furthermore, women reported more symptoms and a poorer clinical status than men at baseline, echoing findings from other HF populations (17). These differences underline the importance of gender- and age-sensitive approaches in HF care and suggest that regional networks should pay particular attention to underrepresented subgroups.

The short questionnaire on the network aspects of care, along with the qualitative interviews, provided converging evidence that the HF network helped avoid contradictory information and treatment recommendations, supporting coherent care processes. Patients valued the perception that their providers ‘knew each other’ and shared information. Such experiences are crucial for building trust in the healthcare system.

At the same time, the interviews revealed heterogeneity in how strongly the network structure was visible to patients. While some clearly perceived the benefits of improved coordination, others were unaware of being treated within a specific network or were unsure about the roles and responsibilities of different actors, including the HF nurse. Strengthening communication about the network, clarifying contact persons and making care pathways more transparent could further enhance patients’ sense of security and involvement.

Patients also perceived some structural burdens related to participation in the network, including travel distance, appointment times during working hours and difficulties reaching the centre by phone. Addressing these barriers, for example, by offering more flexible appointment times, improving telephone availability and exploring telemedicine options, could support long-term sustainability and equity of access, especially for patients with limited mobility or employment-related constraints.

6.1 Strength and limitations

A key strength of this study is its mixed-methods design, which combines standardised patient-reported outcome measures with an in-depth qualitative exploration of experiences in routine care. The integration of quantitative and qualitative data allows a nuanced understanding of how patients perceive the benefits and challenges of a regional HF care network.

However, several limitations must be considered. First, the study used a single-group pre-post design without a control group, so changes over time cannot be causally attributed to the network. Second, the response rate to the KCCQ follow-up was moderate, the qualitative sample was small and not intended to be representative, and selection bias cannot be ruled out. However, this limitation was taken into account when planning the study, as the study aimed to collect data from real-life practice without interfering with care processes. As patients were only invited to the university heart centre for a second examination if it was medically necessary, the second KCCQ questionnaire had to be sent by mail. Third, the study was conducted in a single federal state and within one particular network structure, which may limit generalisability to other settings. Finally, the short questionnaire on network aspects of care was self-developed and has not been validated.

Despite these limitations, the findings provide valuable patient-centred insights into the implementation of a regional HF network in routine care. They suggest that cross-sectoral collaboration can be implemented in a way that is acceptable and meaningful for patients and that helps to reduce fragmentation of care.

7 Conclusions

The HF network in XXX demonstrates a promising model for regional, cross-sectoral HF care. It is both highly acceptable to patients and perceived as beneficial in terms of coordination, information flow, and providing an overall sense of security. In this mixed-methods health services study, HRQoL remained stable at a moderate to good level over six months, while patients expressed consistently high satisfaction with the care received. The findings highlight the importance of patient-centred communication within the network and about the network, the need to strengthen clearly identifiable contact persons such as HF nurses, and the value of reducing structural burdens wherever possible. While this study focused on patient outcomes and experiences, future research should also consider the perspectives and requirements of healthcare professionals involved in the network in order to optimise structures and processes further. Overall, the results underscore the potential of regional HF networks to support high-quality, coordinated chronic care — particularly in health systems facing demographic shifts and uneven regional access to specialist services.

List of abbrivations

XX	University Hospital XX
DZHK	German Center for Cardiovascular Research
HF	heart failure
KCCQ-23	Kansas City Cardiomyopathy Questionnaire
n	number
SD	standard deviation
NYHA	New York Heart Association
HRQoL	health-related quality of life
DGK	German Society of Cardiology
SRQR	Standards for Reporting Qualitative Research

COREQ Consolidated Criteria for Reporting Qualitative Research

ICD International Classification of Diseases

UTAUT Unified Theory of Acceptance and Use of Technology

GP General Practitioner

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